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Holding a Vision: An Investigation of a Rights-Based Social Supports Infrastructure for Children/Young Persons with an Intellectual Disability in Ireland

**A Thesis Submitted for the Degree of PhD to
National University of Ireland, Galway**

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Abstract

The overall aim of the research is to assess the realities of the current social supports infrastructure as it applies children/young persons with an intellectual disability against the components of a rights paradigm. A case study approach was used to gather the data necessary to address the overall aim and related objectives of the study. The research target group are children/young persons who have been assessed as having an intellectual disability and, as a result, are in receipt of additional services and supports from the State.

The thesis takes as its starting point the fact that people with an intellectual disability are widely regarded as one of the most marginalised groups in society. While there has been a significant increase in the knowledge base, research literature, and targeted policies in the areas of both rights and social support, the linkages between the two discourses have not been well developed, particularly in relation to children/young persons with an intellectual disability. This study aims to address this gap by providing an insight into the social realities of this group of children/young persons from a rights perspective.

Two theoretical areas are examined in detail – a rights approach and social support. The research puts forward a rights paradigm consisting of seven key components – social inclusion, recognition, agency, voice, capabilities, equality and self-realisation – which are applied to the social supports infrastructure. The social supports infrastructure considered and analysed in the study is that reported by of a sample of parents/guardians, a sample of young persons with an intellectual disability and a sample of professional service delivery personnel consulted during the research.

The study findings show that the social support infrastructure exhibits some aspects which can be said to reflect a rights paradigm. However, it was found to fall short on a number of important dimensions. On the one hand, social attitudes are generally regarded as positive and inclusive while, on the other, separatist service provision and an absence of a clear social infrastructure to integrate children/young persons with an intellectual disability into mainstream society maintain, and may even reinforce a form of exclusion. Limited goal-setting, few progression options for those with an intellectual disability after second level education and only limited outlets for expression and creative social engagement emerged as significant deficits.

The study demonstrates that there is a clear mismatch between the rhetoric of the rights of children/young persons with an intellectual disability and the reality as experienced. There continues to be in place a set of institutional, cultural, legal and administrative processes which run counter to the underlying ethos of a rights paradigm and the development of a social supports infrastructure accordingly.

The research points to the need to develop a new narrative which would reflect and create a stronger context for the developing and embedding a rights-based social supports infrastructure for children/young persons with an intellectual disability in Ireland. Seven areas for further research relating to this narrative are identified.

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What for me was a new and challenging process could not have been completed without the support, assistance and encouragement of many people. The research depended primarily on the goodwill and co-operation of those who participated in it. The study was undertaken in close collaboration with one service provider which, for reasons of confidentiality, must remain anonymous. I wish to express my utmost gratitude to those who completed the survey questionnaire and to the parents/guardians, young persons, staff and other professionals who participated in interviews. They were generous, open and honest in their engagement and for this I am most grateful.

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Chapter One

Introduction

Introduction

People with an intellectual disability are widely regarded as one of the most marginalised groups in Western society (Foundation for People with Learning Disabilities 2001; Hall 2005; Pitonyak 2007; Verdonschot *et al.* 2009). Hall (2005) notes that documenting the everyday experiences of people with an intellectual disability in mainstream society reveals a complex geography of exclusion and inclusion which for many results in “marginalisation into ‘small action spaces’ on the ‘outer fringes of the daily round’... while for some, spaces of acceptance are found” (Hall 2005:108). Hall also posits the view that:

many people with learning disabilities are in a ‘double-bind’ of marginalisation, experiencing exclusion *from* and abjection and discrimination *within* the very social spaces that are the key markers of social inclusion policy (Hall 2005:110).

Despite the attention to community participation of people with disabilities, little is yet known about their community participation in different life domains and about problems and successes they experience in their community lives (Verdonschot *et al.* 2009). Many people with disabilities live lives of extreme loneliness and isolation and depend almost exclusively on their families for companionship (Pitonyak 2007). Others rely exclusively on people who are paid to be with them for their social support. “Although paid staff can be friendly and supportive, they frequently change jobs or take on new responsibilities. The resulting instability can be devastating to someone who is fundamentally alone” (Pitonyak 2007:4). Abbott and McConkey (2006) refer to the extensive evidence for the social exclusion of people with disabilities in general and, in particular, for those with an intellectual disability.

A 2011 national survey of public attitudes to disability in Ireland (National Disability Authority 2011) found that more than half (59%) of respondents believed that people with an intellectual disability or autism are not able to participate fully in life. People with an intellectual disability are considerably more at risk of mental illness than the general population (Moss *et al.* 2000).

The particular health needs of children with an intellectual disability have been identified (World Health Organization 2011) and children with an intellectual disability are at greater risk of experiencing poverty than non-intellectually disabled children which is likely to have adverse effects on the health and well-being of the children and their families (Emerson 2004). It is likely that the additional financial and social costs associated with bringing up a child with an intellectual disability will increase the chances of a family descending into poverty and its concomitant difficulties and reduce the chances of them escaping from poverty (Emerson 2004). Given that children with an intellectual disability are likely to have reduced

personal and social capital, their experience of poverty is likely to have a greater impact than it would on children who do not have an intellectual disability.

A human rights-based approach focuses on the inherent dignity of the human being.

It places the individual centre stage in all decisions affecting him/her and, most importantly, locates the main “problem” outside the person and in society (Quinn and Degener 2002:9–10).

The principle of equal rights gives equal importance to the needs of each individual and thus requires that societal resources be employed in such a way as to ensure that every individual has equal opportunities for participation, including the right to remain within their local communities and to be included in the ordinary structures of education, health, employment and social services (United Nations 1993).

A rights-based approach sees people with disabilities as subjects rather than objects and as equal citizens and stakeholders in society. It challenges the “social impulse to rank people in terms of their usefulness and to screen out those with significant differences” (Quinn and Degener 2002:10). This means giving them access to the benefits and freedoms that most people take for granted and doing so in a way that respects and accommodates difference. It means abandoning the tendency to perceive people with disabilities as problems and viewing them instead in terms of their rights as equal citizens.

A critical question is how the social supports infrastructure supports a rights approach as it applies in people’s social life domains – domestic life, interpersonal life (including formal relationships as well as informal social relationships, family relationships and intimate relationships), major life activities consisting of education (informal, vocational training and higher education) and employment (remunerative and non-remunerative) and community, civic and social life (including religion, politics, recreation and leisure, hobbies, socialising, sports, arts and culture) (Verdonschot *et al.* 2009).

While there has been a significant increase in the knowledge base, research literature, and policy in the areas of rights and social support (including family support), the linkages between the two discourses have not been well developed, particularly in relation to children/young persons with an intellectual disability. This study aims to address this gap by providing an insight into the social realities of this group of children/young persons based on the perspectives of a sample of parents/guardians, a sample of young persons with an intellectual disability and a sample of professional service delivery personnel.

The chapter is divided into four sections. Firstly, the rationale for and background to the study are described and the population being studied (children/young persons with an intellectual disability in Ireland) is

identified and defined. The research aim and objectives are then described. This is followed by a synthesis of the key theoretical underpinnings. The fourth section outlines the structure of the thesis.

1.1 Background to the study

The position of children/young persons with an intellectual disability in Ireland can be usefully critiqued by relating it to human rights principles generally and specifically to the relevant components of two UN Conventions on Rights – the *Convention on the Rights of the Child* (United Nations 1989) and the *Convention on the Rights of Persons with Disabilities* (United Nations 2006b). In Ireland, during the past decade, the rights of people with disabilities have become more centre stage politically, legally and socially with the emergence of human rights, equality and social inclusion as key underlying concepts in policy discourse. The issue of rights-based services was a key aspect of the Report of the Commission on the Status of People with Disabilities (Commission on the Status of People with Disabilities 1996). However, it is not at all clear whether or not the rights as set out in the UN Conventions are protected in respect of children/young persons with an intellectual disability or whether they are adequately reflected in policies and practice. The mismatch between the policy aspirations in Ireland for people with an intellectual disability and the lived experiences of people has been previously noted (National Federation of Voluntary Bodies 2009; Merriman and Canavan 2007; United Nations 2006a; Children's Rights Alliance 2006).

The concept of social solidarity is centrally relevant to a rights-based approach to people with disabilities and implies the presence of a social supports infrastructure which affirms and supports mutual ties and obligations that exist between people by virtue of their shared membership of society generally and, specifically, as members of a particular community. This often means buttressing the system of basic freedoms by substantive and additional social and economic supports (Quinn and Degener 2002). Social support, broadly defined, refers to the interface between people which helps them to cope with the stresses of daily living (McGrath *et al.* 2012). Four main types of support have been identified (Cutrona 2000) – 'concrete' (practical acts of assistance between people); 'emotional' (acts of empathy, listening and generally 'being there' for someone when needed); 'advice' (going beyond the advice itself to the reassurance that goes with it); 'esteem' (how one person rates and informs another of their personal worth).

The researcher's interest in the question of a rights-based social supports infrastructure has emerged over a number of years. During the 1970s and 1980s, he worked with unattached and homeless young people when he became very aware of the dearth of support services for this group, some of whom had an intellectual disability and/or mental health difficulties. He also worked as a researcher with the National Council on Ageing and Older People during the late 1980s and during this period became interested in the rights of older people and, particularly, the rights of those with reduced capacity as a result of dementia. In 2002, he was a member

of a research team that compiled a social policy report on the topic of supporting carers which highlighted significant gaps in the social supports infrastructure in Ireland for family carers of people with disabilities and dependent older persons. As a Board member of The Carer's Association (a national service providing and advocacy organisation for carers in Ireland) for a number of years, he became more acutely aware of gaps in the social supports infrastructure in respect of both carers and those being cared for. During the course of his research on meeting the accommodation needs of people with disabilities in 2008, he came to realise that people with disabilities in Ireland and, particularly, people with an intellectual disability, were treated very differently to other citizens in relation to the provision of public housing and viewed this difference of treatment as a significant rights issue. At a personal level, important insights to the social supports infrastructure for children/young persons with an intellectual disability were gleaned over the years from the experiences of extended family members who had a child with an intellectual disability. Finally, the PhD fellowship opportunity offered by the UNESCO Child and Family Research Centre, NUI Galway in 2009 presented a timely and valued opportunity for the researcher to bring together a range of interests and to apply these in a developmental way in the context of the present research.

1.2 Defining 'intellectual disability'

Under the International Classification of Functioning, Disability and Health (ICF) established by the World Health Organization (WHO) in 2001, disability is conceived as the outcome of the interaction between impairments and negative environmental impacts.¹ The World Health Organization emphasises that most people will experience some degree of disability at some point in their lives. Accordingly, the ICF classification focuses on a child's abilities and strengths and not just impairments and limitations. It also grades functioning on a scale from no impairment to complete impairment. The term 'impairment' has been used to refer to the loss or limitation of physical, mental or sensory function on a long-term or permanent basis while 'disability', on the other hand, has been used to describe the condition whereby physical and/or social barriers prevent a person with an impairment from taking part in the normal life of the community on an equal footing with others. The UN Convention on the Rights of Persons with Disabilities (United Nations 2006b) states that persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (Article 1) (United Nations 2006b). The Committee on the Rights of the Child (United Nations 2006a) emphasises that the barrier to inclusion of children with disabilities is not the disability itself but rather a combination of social, cultural, attitudinal and physical obstacles which children with disabilities encounter in their daily lives. The

¹ See the International Classification, www.who.int/icidh, for more information.

strategy for promoting their rights is, therefore, to take the necessary action to remove those barriers.

The term 'persons with disabilities', used in the title of the UN Convention on the Rights of Persons with Disabilities (United Nations 2006b) reflects a major shift in terminology in recent years. The move from 'disabled persons' to 'people with disabilities' is based on the premise that persons with disabilities are people first and that disability is secondary to their human citizenship (People First of Spokane Washington 2002). This principle is regarded as particularly important in relation to the target group of this study. The term 'children/young persons with an intellectual disability' is the term used throughout the thesis and refers to those aged under 24 in receipt of services from the agency involved in the case study. Various terms have been used in legislative and policy discourse over the years to describe people with an intellectual disability. 'Retarded', 'handicapped', 'mentally disordered', 'infirm' and 'disabled' are some of the terms used historically.² In recent decades, these terms have come to be regarded as inappropriate mainly because they reflected a medical or individualist conception of 'disability' which labelled and addressed people based on their individual impairment rather than as an outcome of the limitations of the social and physical environment which was designed to cater for the needs of the majority.

Historically, four broad approaches to the definition and classification of intellectual disability have been used (Schalock *et al.* 2007) – social, clinical, intellectual, and dual-criterion. According to the social approach, persons were defined or identified as having mental retardation because they failed to adapt socially to their environment. The clinical approach, based on the medical model, shifted the focus to a person's symptoms, including "an increase in the relative role of organicity, heredity, and pathology" (Schalock *et al.* 2007:119). The intellectual approach resulted in an emphasis on intellectual functioning as measured by an intelligence test and reflected in an IQ score. The dual-criterion approach systematically combined intellectual functioning and adaptive behaviour (Schalock *et al.* 2007).

The following five assumptions have been identified (Schalock *et al.* 2007) as essential to the application of the definition of intellectual disability:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.

² For example, Article 45 of the Irish Constitution refers to the need to safeguard the economic interests of the weaker sections of the community including "the infirm" (Article 45.4.1°, (Bunreacht na hÉireann 1937).

5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve. (Schalock *et al.* 2007:118).

Goodley (2001) challenges pervasive assumptions in relation to 'learning difficulties' and argues for a more inclusive epistemological discourse which would:

- Expose the social nature of diagnostic criteria and destabilising naturalised notions of 'learning difficulties'
- Include the accounts of people with 'learning difficulties' that locate impairment in, and as, personal and social narratives
- Highlight emergent resilient cultures of people with 'learning difficulties' that re-culturise impairment
- Ground the analysis by focusing attention to the ways in which assumptions about the origins of 'learning difficulties' impact upon the treatment of people so labelled (Goodley 2001).

An awareness and acceptance of their external origins invites us to destabilise taken-for-granted embodied notions of 'impairment' and pushes us towards an understanding of people with 'learning difficulties' that recognises their resilience in the face of arbitrary 'scientific' categorisations that have historically denied their humanity altogether (Goodley 2001:213).

Persons with an intellectual disability in Ireland

In 2011 there were 27,324 people registered on the National Intellectual Disability Database (NIDD) (Health Research Board 2012) in Ireland, representing a prevalence rate of 5.96 per 1,000 of the population. Almost two-thirds of those recorded on the NIDD in 2011 were categorised as having a moderate, severe or profound intellectual disability with one-third in the mild disability category. There were more males than females at all levels of intellectual disability, with an overall ratio of 1.35 to 1. The majority (almost two-thirds) of those with an intellectual disability lived at home with parents, relatives, or foster parents. This majority is larger for children under 19 years of age. In addition, there are those in the mild intellectual disability category living at home/independently without supports or services. Four thousand of those diagnosed with a moderate, or severe or profound disability were aged less than 19 years. People with an intellectual disability in residential care settings (community group homes and larger congregated settings) are predominantly in the older age groups and have higher levels of disability (Health Research Board 2012).

1.3 Aim and objectives of the study

The overall aim of the thesis is to assess the realities of the current Irish social support infrastructure as it applies to children/young persons with an intellectual disability against a rights paradigm. There are four related objectives:

- (i) To map the contours of a rights approach (and related Irish social policy aspirations) to social supports
- (ii) To ascertain the perspectives of key stakeholders in the delivery of social supports to children/young persons with an intellectual disability (parents/guardians, young persons and service professionals)
- (iii) To identify and analyse the current social support infrastructure for children with an intellectual disability and their families
- (iv) To critically assess this social supports infrastructure *vis à vis* the components of a rights paradigm

Four research questions are addressed relating to the research objectives.

- (i) What are the components of a rights paradigm applicable to a social support infrastructure for children/young persons with an intellectual disability and their families?
- (ii) What are the social support dimensions applicable in enhancing a rights paradigm in respect of children/young persons with an intellectual disability and how are these reflected in practice?
- (iii) What are the strengths and deficits from a rights perspective of the current social support infrastructure as it applies to children/young persons with an intellectual disability and their families?
- (iv) Is there evidence of a rights paradigm in the current social support infrastructure for children/young persons with an intellectual disability in Ireland?

In order to answer these objectives and related research questions, a case study was carried out in collaboration with one service provider in the West of Ireland. This obtained the views and perspectives of key informants – parents/guardians, young persons (over 16) and personnel involved professionally in the delivery of support services. The research engagement was built around key concepts gleaned from an analysis of the literature relating to both rights and social supports.

1.4 Key theoretical underpinnings

1.4.1 Underlying assumptions

This thesis takes the view that an approach based on the concept of universalism is more relevant to a rights paradigm than one based on minority rights or the rights of particular identity groups (Bickenbach 1999). Thus, while there is a requirement for specific supports to be made available to people with disabilities in order to assist them to exercise their rights, this should not undermine the proposition that the rights accorded to people with disabilities are substantively the same as those enjoyed by

all human persons (Rioux 1994). The provision of additional rights-based social supports is not based on the premise of special rights applying to people with disabilities as a group but rather on the principle that in order to achieve substantive equality for all human persons, additional supports for existing rights are required.

Following O'Brien and O'Brien (2000), the thesis adopts two core assumptions:

- (i) All people, with and without disabilities, share the same basic needs – the need for autonomy and independence; individuality; love and acceptance through presence and participation within a family and community; stability and continuity; continuous growth and learning; community status; security with respect to personal finances as well as protection of legal and human rights.
- (ii) The 'label'/description of 'disability' is relevant only to the extent that the disabling condition complicates the fulfilment of the above needs – people with a disability differ from others only in so far as they do not have the independent ability and means to create conditions, situations, and experiences in their lives to meet some or all of their basic human needs.

1.4.2 The social construction of disability

The first premise of the 'social construct' model is that human difference is not innate but something socially constructed and applied through labels such as 'the disabled' (Quinn and Degener 2002).

Society has ignored or discounted the difference of disability in regulating the terms of entry into and participation in the mainstream, thus excluding – or effectively excluding – 10 per cent of any given population" (Quinn and Degener 2002:10).

Thus, disability can be thought of as the outcome of an interaction between impairments or conditions and the behavioural or performance expectations of socially defined roles (Aron and Loprest 2007). "A child impaired or limited in one environment may not be limited when elements of that environment change" (Aron and Loprest 2007:11).

There has been extensive discussion of the social model of disability in recent years in academic texts, in expressions of disability culture in the media and the arts, in the independent living movement and the self-advocacy movement (Carlson and Kittay 2010; Oliver 2004; Dowling and Dolan 2001). Kayess and French (2008) highlight the dual purposes of the social model of disability – as a theory of disability and as a disability rights manifesto. The social model is central to the analysis of rights-based social supports outlined in this thesis. Carlson and Kittay (2010) suggest that much of the work about the social model is about physical disability and that more needs to be said about the social model and cognitive disability. The social model of disability, views 'disability' as separate from "impairment". 'Impairment' is the term used to describe the medical

condition affecting a particular individual, whereas 'disability' is the term given by sociologists to the societal disadvantage experienced by people with physical or mental impairments. The term 'disability' applies solely to the type of disadvantage suffered specifically by people with impairments. People with disabilities can, of course, suffer multiple types of societal disadvantage due to other factors such as poverty, gender, race, sexual orientation. In essence, there is a particular type of societal disadvantage that affects individuals who have impairments and this disadvantage must be acknowledged and addressed at a societal as well as at an individual level (Carlson and Kittay 2010; Oliver and Barnes 1998). It has been argued that the term 'people with impairments' would be more accurate than 'people with disabilities' (Kayess and French 2008).

Oliver (2004) suggests that the social model of disability switches the focus away from the functional limitations of individuals with an impairment to the problems caused by disabling environments, barriers and cultures, including education. However, he also makes the crucial point that

endorsement of the social model does not mean that individually based interventions in the lives of disabled people, whether they be medically, rehabilitative, educational or employment based, are of no use or always counterproductive (Oliver 2004:18–19).

Quinn and Degener (2002) argue that the social construct of disability is used not only to set people apart but also to keep people apart.

All points of access to the structures of everyday life – the world of education, of work, of the family or social interaction are established by reference to the dominant norm ...the communications environment generally assumes a capacity to listen and to speak. The education environment makes little allowance for different ways of learning (Quinn and Degener 2002:10).

People with disabilities are thus defined primarily in terms of what they cannot do. Quinn and Degener (2002) suggest that there is a powerful link between the 'social construct' model of disability and the human rights perspective on disability. "The individual is being disabled, not by their impairment, but by the failure of society to take account of and organise around difference" (Dowling and Dolan 2001:24). Emphasis is on *difference* because of disability and the person is defined in terms of what they cannot do because of the disability.

Dowling and Dolan (2001) suggest that the 'care burden', on families of children with a disability is a direct result of the social construction of disability. It is assumed that it is the impairment of the child *per se* that causes distress and hardship for the family, rather than the structures, systems, policies and attitudes of society towards the family.

Kilkelly (2002) expresses the view that perceptions of people with a disability "as inferior, less capable or less worthy individuals ... create a glass barrier to their involvement, which is compounded by the failure of society to secure their participation and to listen to their views" (Kilkelly 2002:121).

There has been some questioning of the major emphasis on the notion of people being disabled primarily by society. For example, Shakespeare and Watson (2002) suggests that it sounds much better to say 'people are disabled by society, not by their bodies' than to say 'people are disabled by society as well as by their bodies'.

We are not just disabled people, we are also people with impairments, and to pretend otherwise is to ignore a major part of our biographies (Shakespeare and Watson 2002:11).

Shakespeare and Watson (2002) further suggest that, analytically, it is clear that different impairments impinge in different ways. Not only do they have different implications for health and individual capacity, but also generate different responses from the broader cultural and social milieu. "Congenital impairments have different implications for self-identity than acquired impairments (Shakespeare and Watson 2002:12). The social model may underestimate the importance of such obvious differences.

1.5 The human rights approach

1.5.1 The emergence of rights discourse

The idea of human rights has been interpreted (Nussbaum 2006) as implying an essential moral principle, viz., that there is a minimum threshold of capabilities of human beings that should be protected. What humans are capable of doing is a matter not only of their internal and basic capabilities but is also related to external conditions which can be modified or improved by political and public action. A rights perspective exposes and draws critical attention to the social construct concept as it relates to people with disabilities.

The strong emergence of rights-based legislative and policy discourse internationally reflected in the United Nations *Universal Declaration of Human Rights* in 1948 (United Nations 1948) was specifically applied to people with disabilities in 2006 with the signing of the United Nations *Convention on the Rights of Persons with Disabilities* (UNCRPD) (United Nations 2006b). The 1975 United Nations *Declaration on the Rights of Disabled Persons* had already recognised the social problems which stem from impairment and the right of people with disabilities to social services (United Nations 1975: Section6)³ and led to the formation of the UN *World Program of Action on Disability* in 1982. Equalisation of opportunities was defined therein as "the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all (United Nations 1982: Para.12).⁴ This programme of action in turn led to the adoption of the UN *Standard Rules*

³ Section 6, Declaration on the Rights of Disabled Persons, proclaimed by United Nations General Assembly resolution 3447 (XXX) 9 December 1975.

⁴ United Nations General Assembly Resolution 37/52, 3 December 1982, A/RES/37/51, Supp. No. 51, para. 12.

on the *Equalization of Opportunities for Persons with Disabilities* in 1993 (United Nations 1993) which included the statement that:

[t]he principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation (United Nations 1993:Par. 25).⁵

However, the *Standard Rules* continued to adopt a definition of disability based on medical impairment which viewed disability as a medical condition, an impairment, which resulted in the impaired person's lack of ability to participate in society as a full citizen. Under the medical model, the services provided to people with disabilities were primarily concerned with curing or treating their impairment, rather than facilitating societal participation.

The *Madrid Declaration* (European Union 2002) explicitly made disability a human rights' issue. "The old approaches based largely on pity and perceived helplessness of disabled people are now considered unacceptable" (European Union 2002:2) and advocates a social model of disability and the necessary changes in society. Four underlying premises of a rights approach are outlined:

- (i) Away from people with disabilities as patients... and Towards people with disabilities as independent citizens and consumers;
- (ii) Away from professionals taking decisions on behalf of disabled people... and Towards independent decision making and taking responsibilities by disabled people and their organisations on issues which concern them;
- (iii) Away from unnecessary segregation in education, employment and other spheres of life... and towards integration of disabled people into the mainstream".
- (iv) "Nothing about disabled people without disabled people", which emphasises the need for person-centredness in all decisions" (European Union 2002:7)

The UNCRPD provides for the rights of all people with all disabilities to information, access to the physical environment and to the same range, quality and standard of healthcare as people who do not have a disability. All states that have signed the convention are requested to submit periodic reports of their compliance. The Council of Europe developed a Disability Action Plan (2006–2015) (Council of Europe 2006) that provides a framework for policy makers in member states to use when designing, implementing and evaluating disability policies and strategies.

The new policy and legislative framework that emerged in Ireland during the 1990s was marked by a more socially inclusive approach to disability which was reflected in new concepts in policy discourse, including, in particular:

⁵ United Nations General Assembly Resolution 48/96, 20 December 1993, A/RES/48/96, Supp No. 49, Annex at 202^11.

- Move from a medical to a social model of disability
- Recognition of 'voice' and self-advocacy
- All people with a disability having the same choice, control and freedom as any other citizen – at home, at work and as members of the community
- Mainstreaming of service provision
- Needs-based person centred planning
- Independent living
- A life-cycle approach to meeting the needs of people with a disability

(Commission on the Status of People with Disabilities 1996).

1.5.2 Human Rights and the Irish Constitution

The Irish Constitution was adopted in 1937 and predates both the United Nations and the Council of Europe. The Preamble to the Constitution (Bunreacht na hÉireann 1937) commits the State to the pursuit of a number of goals, including the promotion of the common good, the protection of the dignity and freedom of the individual, and the attainment of 'true social order'. Article 2 sets out the entitlement of every person born on the island of Ireland to Irish citizenship.

While the term 'human rights' is not used in the Constitution, Articles 40 to 44 provide for 'Fundamental Rights' which can be said to be, in effect, human rights principles by a different name (Irish Human Rights Commission n/d). These rights include the personal rights of citizens (Article 40), the right to family life (Article 41), the right to education (Article 42), the right to private property (Article 43) and the right to freedom of religious expression (Article 44).

Article 40 (1) states that all citizens shall, as human persons, be held equal before the law. According to Article 40(3) 1°, the State guarantees in its laws to respect, and, as far as practicable, by its law to defend and vindicate the personal rights of the citizen. Article 40 also makes provision for the vindication of the life, person, liberty, good name and property rights of every citizen. It also includes provision for the free expression of convictions and opinions and for the right of citizens to form associations and unions. The Irish Courts have interpreted Article 40.3.1 as a guarantee of certain rights not laid out in the Constitution, including right to bodily integrity; right to health; the right to earn a livelihood; and right to privacy (Irish Human Rights Commission n/d). Article 41(1) 1° identifies the family as a fundamental unit in society and Article 41 (3) 1° protects the institution of marriage.

Article 42 deals with the right to education. Although the State is obliged to provide for free primary education, Article 42 also acknowledges the primacy of the family as an educational provider. This Article was relied on in relation to claims by children with disabilities that the State was making inadequate provision for their educational welfare. The utility of this right was, however, arguably limited by the refusal of the Supreme Court in *Sinnott*⁶ and *T.D.*⁷ to compel legislative and executive expenditure on the enforcement of this entitlement.

Children and the Irish Constitution

An amendment to the Irish Constitution in November 2012 introduced a new article (Article 42A) which made provisions for a general recognition and affirmation of the rights of children:

- State intervention in certain cases to protect a child where his/her parents fail to do so
- Ensuring that the law treats all children equally in law, whether or not their parents are married, including in relation to the law on adoption
- A requirement that the best interests of children be regarded as the paramount consideration in the resolution of proceedings affecting children
- A requirement that the views of children be ascertained and given due weight according to their age and maturity in proceedings affecting them

1.6 Social supports

Based on the ethic of solidarity, human rights values presuppose

an elaborate social support structure designed to liberate people in their own lives and not to imprison them in gilded cages” (Quinn and Degener 2002:14).

Social supports should thus be designed and delivered to enhance each person’s capacity for growth and to convey the conviction that each person can participate in some valued role in the community. This goal is valid regardless of the type of disability or problems presented or the extent to which the disability complicates service provision (O’Brien and O’Brien 2000).

Viewing people with disabilities as individuals first and the difficulties they encounter as a result of disability as secondary issues means focusing on ordinary human needs and the multitude potential forms of support to help meet those needs. These include natural unpaid support networks (families, friends, neighbours, peers) as well as the support provided by formal services. While the literature includes many definitions of social

⁶ *Sinnott v. Minister for Education* [2001] 2 I.R. 545.

⁷ *T.D. v. Minister for Education* [2001] 4 I.R. 259.

support and while there is not a full consensus on a theoretical or empirical definition, most researchers agree that social support refers to the assistance and help that one receives from others (Findler 2000).

Incorporated in most definitions of social support is the exchange of one or more of three main types of support – emotional, informational, and instrumental – that people receive in times of need (Ellison 2006; Findler 2000). Emotional support involves the expression of empathy, reassurance, and positive regard, and is believed to enhance well-being by promoting self-esteem, reducing distress, and providing an emotional context for positive coping efforts. Informational support involves the provision of guidance, advice, or other information that can reduce confusion, increase perceptions of self-efficacy, and form the basis for positive coping strategies. Instrumental support refers to the provision of money, goods, and services that can be used in coping and problem solving. Additionally, some theories of social support highlight the importance of social integration – a sense of belonging – and the role of companionship and participation in social and leisure activities (Ireys and Sakwa 2006).

The subjective perception of support by recipients is another key dimension noted by several authors (Finfgeld-Connett 2005; Cutrona 2000; Lakey and Cohen 2000). The kind of support, who provides the support, and contextual issues all play a role in determining whether support is perceived as beneficial (Hogan *et al.* 2002). The importance of developing skills that allow people to ask for and receive the support that they need is a critical component of social support as are opportunities to reciprocate support. In general, support that communicates genuine caring, yet encourages the individual to solve his or own problems is most effective (Cutrona 2000).

How a child's relations with parents, grandparents, siblings, friends and others are weaved into a cohesive network that provides support to the child is an important dimension of children's lives and a crucial area of inquiry for social support research (Ellison 2006). To the extent that children enjoy good relationships with their social support systems, they are likely to share their preoccupations and worries and that, once these preoccupations have been discussed with peers or parents, solutions are likely to be generated. A key consideration in all the discourse on social supports is that "it is not easy to change the nature of a person's social network" (Cutrona 2000:104).

1.7 Outline of thesis

This introductory chapter has described the rationale for and background to the study and has set out the research aim and objectives. The key theoretical underpinnings have been summarised. The thesis contains eight further chapters.

Chapter Two sets out key historical and conceptual aspects of the rights approach as relevant to people with a disability with particular reference to

children/young people with an intellectual disability. The key components of a human rights approach generally are discussed with specific reference to rights provisions for people with disabilities and children under UN conventions and declarations. The rights approach as it applies to children/young persons with an intellectual disability is considered. The chapter identifies and discusses the main challenges to the rights approach.

Chapter Three discusses the concept of social support (and related family and community support concepts) in order to identify a context for considering and applying a rights-based paradigm to children/young persons with an intellectual disability. The concept of social support is defined and its theoretical underpinnings discussed. The different types and dimensions of social supports are described, including family support and community capacity. Challenges to the conceptualisation of social support theory are identified and discussed. Finally, the chapter looks at social support in the context of children/young persons with an intellectual disability.

Chapter Four traces the development of Irish social policy in order to identify the context within which the development of a rights-based social supports infrastructure for children/young persons with an intellectual disability is explored in the present thesis. The chapter describes the values underpinning Irish social policy and its main influencing factors and focuses in particular on a paradigm shift from welfare-based to rights-based legal provisions affecting people with disabilities generally that occurred during the 1990s. Relevant developments in children's policy from a rights perspective in the last three decades are considered. In particular, the question of how the core provisions of the UN Convention on the Rights of the Child as they relate directly or indirectly to children/young persons with an intellectual disability are reflected in Government policy is considered.

Chapter Five outlines the methodology used in order to address the objectives of this research which is carried out for the purposes of a doctoral thesis. Firstly, the chapter describes the context, rationale and objectives of the study. Secondly, the theoretical perspectives underpinning the study are considered. The research design is then outlined which also includes a detailed discussion of the Case Study approach used. Relevant ethical considerations are discussed as are some of the limitations of the methodology used. Finally, the process of implementing the research is outlined and the research challenges encountered are identified.

Chapter Six presents the outcomes of the analysis of a survey of parents/guardians and the analysis of interviews with a sample of parents/guardians and a sample of children/young persons. The survey findings are set out under the headings: sources of social support; access to services; needs assessment; access to information; perceptions of social attitudes to children/young persons with an intellectual disability and perceptions of a rights approach. The interview findings are set out under

a number of themes and sub-themes identified through the Framework approach (Ritchie and Spencer 1994) which was used to analyse the data and which reflect both the content of responses to questions and emerging themes not covered within the interview topic guide. The themes relating to parents/guardians are: their experiences of social supports; access to services; impact on families of having a child with an intellectual disability; perceptions of social attitudes to disability; perceptions of a rights based approach; and information and advocacy support. For young persons, the themes are: their current situation; their experiences of social support; social activities and hobbies; choice in their lives; their aspirations and plans for the future. This chapter also presents the outcomes of a Likert-type summation rating measures which were used by the researcher to systematically establish the views of parents/guardians and service provider staff on the extent to which rights-based principles were implemented.

Chapter Seven presents the findings of interviews with a sample of service provider staff and other professionals under a series of themes and sub-themes which reflect both the content of responses to questions and themes not covered in the interview topic guide. These are: the support services available to children/young persons with an intellectual disability and their families; availability of and access to services; needs assessment; personal outcomes planning; inclusive education; a rights-based approach; and access to information and advocacy support.

Chapter Eight analyses the study findings against seven components of a right-based paradigm deemed applicable to the social support infrastructure. Firstly, it addresses the research question relating to the strengths and deficits of the current social support infrastructure from a rights perspective. Secondly, the research question as to whether or not the social supports infrastructure reflects the components of a rights paradigm is addressed. The chapter then examines the extent to which the data does or does not reflect evidence of a rights approach and draws some conclusions accordingly. Finally, the chapter re-iterates the purpose of the research, provides a synthesis of the main findings and suggests a framework for further analysis and discussion of the study findings.

Chapter summary

The role of social supports in enhancing the coping capacity and quality of life of people has been widely acknowledged and discussed. Much of the discourse on disability in the past three decades has revolved around the concept of rights in the context of a shift from the medical model to the social model of disability. The concept of children's rights has also received particular attention including some focus on the rights of children with disabilities. Although there has been a significant shift in policy in recent years which reflects this new discourse, there are important questions relating to the links between policy aspirations and social realities as they apply to children/young persons with an intellectual disability. There is also a gap in the application of a rights paradigm to the social supports infrastructure as it applies to this group of citizens. This

study aims to address this gap by providing an insight into existing social realities and juxtaposing these with the components of a rights paradigm relevant to the social supports infrastructure.

This chapter has set the scene for the study, including the background, objectives and theoretical underpinnings. The structure of the thesis was also presented. The next chapter, Chapter Two, will examine the rights approach and Chapter Three will explore the concept of social supports.

Chapter Two

People with Disabilities and a Rights-Based Perspective

Introduction

The overall objective of the thesis is to develop a rights-based policy paradigm for the enhancement of social support systems for children and young people with an intellectual disability and their families in Ireland. This chapter sets out key historical and conceptual aspects of the rights approach as relevant to people with a disability with particular reference to children/young people with an intellectual disability.

The chapter is divided into two parts:

Part One: The Human Rights Approach

Part Two: Human Rights and Children/Young Persons with an Intellectual Disability

Part One: The Human Rights Approach

Part One of the chapter contains five sections:

- (i) Defining and understanding human rights
- (ii) Human rights charters and conventions
- (iii) Children's rights
- (iv) Citizenship, equality and social solidarity and the rights perspective
- (v) Enhancing the rights approach

2.1 Defining and understanding 'human rights'

The human rights approach places the individual centre stage in all decisions affecting him/her. A rights-based approach is particularly relevant to people with disabilities in that it views people as subjects rather than objects and as equal citizens and stakeholders in society and challenges the "social impulse to rank people in terms of their usefulness and to screen out those with significant differences" (Quinn and Degener 2002:10).

The rights approach rejects the long-established idea that obstacles to the participation of people with disabilities arise primarily from their impairment and focuses instead on environmental barriers. These include

- Prevailing attitudes and preconceptions, leading to underestimation

- The policies, practices and procedures of local and national government
- The structure of health, welfare and education systems
- Lack of access to buildings, transport and to the whole range of community resources available to the rest of the population
- The impact of poverty and deprivation on the community as a whole and more specifically on persons with disabilities and their families (UNICEF 2007).

Human rights are essentially the rights one has as a human being (Ishay 2008).

Human rights are rights held by individuals simply because they are part of the human species. They are rights shared equally by everyone regardless of sex, race, nationality, and economic background. They are universal in content (Ishay 2008:3).

Donnelly (2003), following Dworkin (1977), states that 'right' has two central moral and political senses – rectitude and entitlement.

In the sense of rectitude, we speak of 'the right thing to do', of something being right (or wrong). In the narrower sense of entitlement, we typically speak of someone *having* a right... Claims of rectitude ... focus on a standard of conduct and draw attention to the duty-bearer's obligation under that standard. Rights claims, by contrast, focus on the right-holder and draw the duty-bearer's attention to the right holder's special title to enjoy her right (Donnelly 2003:7).

Rights in the latter sense can be referred to as subjective rights in that they have as their focus a particular subject (the person who holds them) in contrast to an objective standard to be followed or a state of affairs to be maintained. This subjective approach emphasises irreducible moral worth and dignity independent of the social groups to which they belong and the social roles they occupy (Donnelly 2003:27). Carlson and Kittay (2010:17) make the point that personhood grants us special moral standing.

Donnelly (2003) identifies three special features of human rights:

- (a) Human rights are *equal* rights – one either is or is not a human being, and therefore has the same rights as everyone else (or none at all)
- (b) Human rights are *inalienable* rights – one cannot stop being human, no matter how badly one behaves or how barbarously one is treated
- (c) Human rights are *universal* rights – in the sense that we consider all members of the species *Homo sapiens* 'human beings' and thus holders of human rights (Donnelly 2003:10).

Human rights, while, historically, having religious and natural law foundations, transcend religious and ideological differences.

Across the centuries, conflicting political traditions have elaborated different components of human rights or differed over which elements had priority (Ishay 2008:3)

Ishay (2008) refers to the process of historical continuity and change through which rights are carried over from one era to another. However, she notes that while “each major stride forward was followed by severe setbacks” (Ishay 2008:4) and that, while there were inconsistencies and contradictions, various rights movements and discourses over the centuries “also moved the history of human rights forward” (Ishay 2008:5)

In relation to persons with disabilities, a rights approach means “abandoning the tendency to perceive people with disabilities as problems and viewing them instead in terms of their rights” (Quinn and Degener 2002:9).

2.2 Different types of rights

While there is some debate over which rights are human rights and about the precise nature, content and appropriate legal status of those rights, rights and freedoms which have come to be commonly thought of as human rights include:

- Civil and political rights
- Economic, social and cultural rights

Civil and political rights include the right to life, freedom of religion, freedom of assembly, electoral rights and rights to due process and a fair trial. Economic, social and cultural rights include the right to work, to own property; to adequate standards of living, to access to education, to respect and protection of the family, to social and medical assistance, to adequate nutrition, to social welfare benefits, to the enjoyment of scientific advancement, to protection of health and to protection of morals. Quinn and Degener (2002) suggest that economic, social and cultural rights are much misunderstood and that, in practice, they underpin the system of basic freedoms promoted by civil and political rights and that they give tangible expression to the ethic of solidarity. The connections between civil and political rights on the one hand and economic, social and cultural rights on the other become

tangible in the context of disability since the removal of barriers through civil rights and non-discrimination law is clearly not enough” (Quinn and Degener 2002:12).

Donnelly (2003) draws attention to the fact that the Universal Declaration of Human Rights (the focal point for subsequent international human rights discourse and discussed below in 2.3) is based on and recognises the indivisibility of rights and argues for the need to move beyond the conventional dichotomy between civil and political rights and economic, social and cultural rights.

Our lives – and the rights we need to live them with dignity—do not fall into largely separate political and socioeconomic spheres. Economic and social rights usually are violated by or with the collusion of elite-controlled political mechanisms of exclusion and domination (Donnelly 2003:32–33).

Moyn (2010) suggests that while the initial focus on human rights in the 1970s was primarily on political and civil rights and that

their social and economic cousins were regarded as ‘second-generation’ principles...unlike most civil and political protections, concern for inequality and socio-economic deprivation appears in the Bible and other antique expressions of human culture around the world (Moyn 2010:17).

2.3 Human rights charters and conventions

Contemporary international conceptions of human rights can be traced to the foundation of the United Nations. The Charter of the United Nations recognises the existence of human rights and calls for their promotion and respect. Article 1(3) of the Charter states one of the purposes of the UN as to

...achieve international cooperation in solving international problems of an economic, social, cultural, or humanitarian character, and in promoting and encouraging respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion (United Nations 1945: Article 1(3)).

Article 1(4) refers to the United Nations as being “a centre for harmonizing the actions of nations in the attainment of these common ends”.

The rights espoused in the UN Charter are codified in the International Bill of Human Rights, composing the Universal Declaration of Human Rights and two treaties – (a)) the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESR).

Universal Declaration of Human Rights 1948

The Universal Declaration of Human Rights (UDHR) is widely regarded as a milestone document in the history of human rights. Drafted by representatives with different legal and cultural backgrounds from all regions of the world, the Declaration was proclaimed by the United Nations General Assembly in Paris on 10 December 1948 as a common standard of achievements for all peoples and all nations. It set out, for the first time, fundamental human rights to be universally protected. It emphasises the indivisibility, interdependence, interrelation and equal importance of all human rights (civil, cultural, economic, political and social). The rights formulated in the Universal Declaration were comprehensive and ranged from classical political liberties to areas relating to work, social security, rest, education, and an adequate standard of living (Moyn 2010). Article 25 stipulates that each person has a right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his/her control (Ishay 2008).

The Universal Declaration of Human Rights was given expression in 1976 in the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The ICCPR provides protection for a range of civil and political rights. It seeks to underpin the freedom of the individual and to ensure that s/he is enabled to exert influence over political life. It commits its parties to respect the civil and political rights of individuals, including the right to life, freedom of religion, freedom of assembly, electoral rights and rights to due process and a fair trial. The ICESCR seeks to ensure that freedom is buttressed by appropriate social rights and social provision.

The European Convention on Human Rights (ECHR) (*Convention for the Protection of Human Rights and Fundamental Freedoms*) built on the Universal Declaration to provide an international treaty to protect human rights and fundamental freedoms in Europe. Drafted in 1950 by the then newly established Council of Europe, the Convention entered into force on 3 September 1953.⁸ All Council of Europe member states are party to the Convention and new members are expected to ratify the convention at the earliest opportunity.

The European Social Charter (Council of Europe 1996) is a Council of Europe treaty guaranteeing basic social and economic rights which concern all individuals. Adopted in 1961 and revised in 1996, the European Social Charter sets out rights and freedoms and establishes a supervisory mechanism guaranteeing their respect by the States Parties. The right to work and to a fair remuneration, the right to social security, the right to protection against poverty and social exclusion and the right to housing are particularly significant. The Treaty provides for a mechanism to monitor its implementation by which States submit annual reports showing how they implement the treaty in practice.

2.4 Children's rights

Children's rights have been central to international human rights documents since the establishment of the United Nations in 1945. The 1948 Universal Declaration of Human Rights (UDHR) mentions children in Articles 25 and 26. Article 25 states that motherhood and childhood are entitled to special care and assistance and that all children, regardless of whether they are born in or out of wedlock, shall enjoy the same social protection. Article 26 entitles everyone to equal access to education and allows parents the right to choose the kind of education given to their child. The need to extend particular care to the child stated in the UDHR had already been stated in the Geneva Declaration of the Rights of the Child of 1924. It was restated in the Declaration of the Rights of the Child adopted by the UN General Assembly on 20 November 1959 and in the International Covenant on Civil and Political Rights (in particular in Articles 23 and 24), in the International Covenant on Economic, Social and Cultural Rights (in particular in Article 10).

⁸ The text of the Convention was subsequently amended in 1971, 1994, 1998 and 2010.

While children's rights are articulated generally in the Universal Declaration of Human Rights (1948) and in the ICCPR and ICESR which came into force in 1976, the UN Convention on the Rights of the Child (UNCRC) (1989) provides a detailed formulation of children's rights. The provisions of the UNCRC are also reflected in the 1993 UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the Convention on the Rights of Persons with Disabilities (United Nations 2006b).

UN Convention on the Rights of the Child

The 1989 UN Convention on the Rights of the Child (UNCRC) (United Nations 1989) lays the foundation for and provides an over-arching framework for children's rights generally and makes special mention of children with disabilities in Articles 2 and 23. The UNCRC marks an important shift in thinking towards a rights-based approach by holding governments legally accountable for failing to meet the needs of children. It creates a new vision of children as bearers of rights and responsibilities appropriate to their age. Children's rights, as set out in the UNCRC, cover four main aspects of a child's life (including children with disabilities): the right to survive, the right to develop, the right to participate, the right to be protected from harm. The UNCRC provides children with the rights to special protection measures and assistance; access to education and health services; right to develop their personalities, abilities and talents to the fullest potential; the right to grow up in an environment of happiness, love and understanding; and the right to be informed about and to participate in achieving their rights.

The explicit mention of disability as a prohibited ground for discrimination in Article 2 is unique and explicitly recognises the fact that children with disabilities belong to one of the most vulnerable groups of children. While Article 2(1) and Article 23 contain specific reference to children with disabilities, a key aspect of the UNCRC is that every article that refers to "the child" applies also to a child with disabilities (Kilkelly 2002). For example, Article 31 which has general application may have particular relevance to children with disabilities.

Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts... and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity (UNCRC Article 31).

Kilkelly (2002) notes that in contrast to other human rights treaties, the application of general rights provisions to children with disabilities is vital "as it dramatically expands protection for the rights of children with disabilities in a whole range of areas" (Kilkelly 2002:120). (See 2.7 below for a fuller elaboration of the provisions of the UNCRC in respect of children with disabilities).

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations 1993), adopted by the UN General Assembly in 1993, provides detailed rights implementation guidance.⁹ These Rules are regarded as having had a major influence on the development of disability legislation, the level and provision of services for persons with disabilities and, above all, on attitudes towards disability issues (UNICEF 2007). The Rules address all aspects of the lives of persons with disabilities and indicate how governments can make social, political and legal changes to ensure that persons with disabilities are treated as full citizens of their country. The Rules cover four main areas:

- (i) Preconditions for equal participation (awareness raising, medical care, rehabilitation, support services and accessibility)
- (ii) Target areas for equal participation (accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, religion)
- (iii) Implementation measures, including information and research, policy-making and planning, legislation and economic policies
- (iv) Monitoring mechanisms – the monitoring of the implementation of the Rules by the UN Special Rapporteur on Disability (United Nations 1993).

The Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD), which came into being in 2007, is seen by the UNICEF Research Centre as reflecting a 'paradigm shift' in attitudes and approaches to persons with disabilities, in the direction of the social model of disability.

It represents the culmination of the process initiated over two decades ago by the United Nations of moving from the treatment of persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as 'subjects' with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as well as being active members of society (UNICEF 2007:10).

Provisions for children in the UNCRPD

Article 7 of the UNCRPD makes provision for measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. The UNCRPD re-iterates the provisions of the UNCRC in relation the best interests of the child principle and the right of children with disabilities to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other

⁹ The Committee on the Rights of the Child (United Nations 2007) recommended that the two documents (the UNCRC and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities) be used as complementary tools in promoting the rights of children with disabilities.

children, and to be provided with disability and age-appropriate assistance to realise that right. There is a general obligation on States parties to consult with children with disabilities when developing and implementing legislation and policies (United Nations 2006b).

All of the provisions in the Convention apply to children with disabilities as well as to adults. In recognition of children's specific situation, some articles make explicit reference to their rights. The Preamble recognises that children with disabilities have full enjoyment of all human rights on an equal basis with others. A particularly important principle (Article 3h) in the context of the present study is respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Education

Article 24 of the UNCRPD is particularly relevant to children in that it reflects a clear commitment to the principle of inclusive education as a goal. It also addresses the specific needs of children with severe and complex sensory impairments for access to specific supports to learning such as sign language, Braille and low vision aids. Other children with disabilities may also need modifications to the curriculum, to styles of teaching and to the organisation of the classroom. Support to all children with disabilities has to be individually tailored and resourced both in terms of time and staffing. Parents and the children themselves have to be partners in deciding the nature and intensity of such support and ways in which it can be reduced as both child and teacher become more confident and competent.

2.5 Citizenship, Equality and Social Solidarity and the Human Rights Perspective

2.5.1 Citizenship and social solidarity

Citizenship is a key consideration in understanding the human rights approach. Moyn (2010:38) refers to the "umbilical connection between rights and citizenship" as a central feature of the history of rights. Citizenship encompasses the right of individuals "to share to the full in the social heritage and to live the life of a civilised being according to the standards prevailing in society" (Marshall 1950:11). As Donnelly (2003) states, even where citizens do not have a particularly sophisticated sense of what a commitment to human rights means, "they respond to the general idea that they and their fellow citizens are equally entitled to certain basic goods, services and protections" (Donnelly 2003:39).

O'Ferrall (2008), in exploring the concept of citizenship in the Republic of Ireland in relation to our healthcare system, refers to active citizenship as encompassing "a 'much richer' consideration of the human person than one who simply 'consumes' health services (O'Ferrall 2008:12). He identifies five key components of citizenship in relation to the healthcare system:

- (i) The person as a citizen who engages in healthcare in a multi-dimensional fashion
- (ii) The person as a citizen who requires that taxes are spent appropriately
- (iii) The person as a citizen with an interest in issues of equity and fairness
- (iv) The person as a co-producer of the outcomes of health services
- (v) The person as a participant in governing health care organisations and as an active voice in health policy formulation at various levels (O’Ferrall 2008).

If we cannot participate in society because of the lack of support to meet our social needs and to mitigate physical disability or illness, we may also be excluded from taking a real part in the democratic processes of society or from exercising our legal rights. Thus, rights to health, housing and cultural expression should be protected “not just because they enable people to lead active and productive lives (value of autonomy) but also “because of the obligations of solidarity that exist within society” (Quinn and Degener 2002:14). Citizenship rights

encompass not only the core civil and political rights and obligations but also social, economic and cultural rights and obligations that underpin equality of opportunity and policies on access to education, employment, health, housing and social services (Department of Social, Community and Family Affairs 2002:20).

The concept of rights based on citizenship confers a social and economic status independent of the market and seeks to redress imbalances in market outcomes. The concept of human rights is underpinned by the equality principle:

The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunities for participation (United Nations 1993: Paras 24–25).

Donnelly (2003) makes the point that people have the same human rights whether or not they discharge their duties to society. “One is a human being, and thus has the same human rights as any other human being, whether or not one is a good citizen or even a contributing member of society” (Donnelly 2003:25). Tawney, in his classic discourse on equality (originally published in 1931) noted that the concept of equality may assert that while people may differ profoundly in capacity, character and intelligence,

they are equally entitled as human beings to consideration and respect, so that the wellbeing of a society is likely to be increased if it so plans its organization that, whether their powers are great or small, all its members may be equally enabled to make the best of such powers as they possess (Tawney 1964:46–47).

Quinn and Degener (2002) suggest that “one of the main unarticulated premises of the philosophy of ‘equality of opportunity’, in general and in the context of disability, is that every human being has something to contribute to humanity and that social structures should be built inclusively with human empowerment as a key goal” (Quinn and Degener 2002:12).

2.5.2 Citizenship rights and social justice

Rawls’ (1971), *A Theory of Justice*, provides a significant focal point for subsequent discussion of citizenship rights and social justice. Rawls’ theory is based on the concept of the social contract between free and equal individuals as being at the heart of social order and where social unity is understood by starting with the conception of society as a system of co-operation between free and equal persons. Rawls devises an abstract political theory of citizenship and social justice. He hypothesises a situation in which people assume a ‘veil of ignorance’ in which they do not know the true nature of their position in an inevitably unequal society. On this basis, Rawls develops his theory of social justice, a ‘social contract’ based on two principles:

First: each person is to have an equal right to the most extensive basic liberty compatible with a similar liberty for others.

Second: social and economic inequalities are to be arranged so that they are both (a) reasonably expected to be to everyone’s advantage; and (b) attached to positions open to all (Rawls 1971:60).

Rawls’ theory also stipulates that the first principle must take priority over the second principle so as to ensure that the basic liberties of all are safeguarded. The second principle is based on the notion of difference in the context of a meritocratic society where there is equal opportunity for people to be unequal provided that the resulting inequalities are to the advantage of the least advantaged members of society.

Central to Rawls’ theory is the idea of ‘justice as fairness’ (Beckett 2006). It rests on his notion of the reasonable individual who takes into account the need for co-operation without making excessive demands. Rawls’ view that rational individuals will co-operate on the basis of mutual respect has been criticised (Beckett 2006) (a problem, according to Beckett, acknowledged by Rawls himself in his later work). Beckett (2006) also suggests that Rawls’ reliance on the notion of competency presents significant difficulties, in particular the assumption that persons as citizens have all the capabilities that enable them to be normal and fully co-operating members of society.

Nussbaum (2006) has questioned the ability of dominant theories of justice to include people with disabilities. In her important work, *Frontiers of Justice* (Nussbaum 2006), Nussbaum, building on previous work of disability theorists, argues that contractarian theories such as those of Rawls fail as a conception of justice for animals, people in poor distant lands, and people with disabilities, especially cognitive disabilities. She proposes the capability theory, with an enumeration of ten central

capabilities (see Figure 2.1) that all governments should guarantee all citizens, including those with cognitive disabilities, as an important corrective to Rawls's theory.

Nussbaum (2006) classifies capabilities into three types – basic capabilities; internal capabilities; and combined capabilities. *Basic capabilities* are the innate equipment of individuals, that is, the necessary basis for developing more advanced capabilities. *Internal capabilities* build on pre-existing basic capabilities by interfacing with external conditions, including education. Most adults have the internal capabilities of use of speech, capabilities that would not exist without the informal education that occurs along with socialisation. Many internal capabilities require a more structured educational environment. *Combined capabilities* are defined by Nussbaum as internal capabilities plus the external conditions that make the exercise of a function a live option. For Nussbaum, the aim of public policy is the promotion of combined capabilities through the development of internal capabilities through socialisation and education (Nussbaum 2006).

Nussbaum (2010) in subsequent work identifies the various requirements in order to guarantee that people with cognitive disabilities are treated as citizens with equal dignity. These include access to medical care and education but on the basis of a capability theory, should also, Nussbaum argues, extend to their political participation in voting and jury duty. She suggests that, either through direct participation or via a guardian, each individual with cognitive disabilities, no matter how severe or extensive, should have a vote in that this is essential to being fully included within society. Be'rube' (2010) is in broad agreement with Nussbaum but for him the notion of surrogacy (using a guardian or advocate) poses a challenge to disability studies because of the disability community's insistence that there be 'nothing about us, without us' (Charlton 1998). The latter concept, Be'rube' suggests, leaves out those who cannot communicate effectively and those with reduced cognitive ability. Stark (2010) argues that in trying to accommodate the requirements of justice for those left out by the contractual approach, Nussbaum fails to respect the dignity of rational agents adequately while Wong (2010) looks for a way to preserve the central insights and the contractual structure of Rawls's theory of justice. She argues that we cannot presume an unalterable moral incompetence on the part of any given human being and that, therefore, society has an obligation to provide what she calls "the enabling conditions" (Wong 2010:133).

Figure 2.1: Synthesis of Nussbaum's ten capabilities

1.	<i>Life.</i> Being able to live to the end of a human life of normal length...; not dying prematurely...
2.	<i>Bodily health...</i> Being able to have good health, including reproductive health; being adequately nourished...; being able to have adequate shelter...
3.	<i>Bodily integrity.</i> Being able to move freely from place to place; being able to be secure against violent assault, including sexual assault...; having opportunities for sexual satisfaction and for choice in matters of reproduction
4.	<i>Senses, imagination, thought.</i> Being able to use the senses; being able to imagine, to think, and to reason—and to do these things in... a way informed and cultivated by an adequate education...; being able to use imagination and thought in connection with experiencing, and producing expressive works and events of one's own choice...; being able to use one's mind in ways protected by guarantees of freedom of expression...freedom of religious exercise; being able to have pleasurable experiences...
5.	<i>Emotions.</i> Being able to have attachments to things and persons outside ourselves; being able to love those who love and care for us; being able to grieve at their absence, to experience longing, gratitude, and justified anger; not having one's emotional developing blighted by fear or anxiety....
6.	<i>Practical reason.</i> Being able to form a conception of the good and to engage in critical reflection about the planning of one's own life...
7.	<i>Affiliation.</i> Being able to live for and in relation to others, to recognise and show concern for other human beings, to engage in various forms of social interaction; being able to imagine the situation of another and to have compassion for that situation...Being able to be treated as a dignified being whose worth is equal to that of others.
8.	<i>Other species.</i> Being able to live with concern for and in relation to animals, plants, and the world of nature.
9.	<i>Play.</i> Being able to laugh, to play, to enjoy recreational activities.
10.	<i>Control over one's environment.</i> (A) <i>Political:</i> being able to participate effectively in political choices that govern one's life... (B) <i>Material:</i> being able to hold property (both land and movable goods); having the right to seek employment on an equal basis with others... (Nussbaum 2006:76–77).

2.6 Enhancing the rights approach

While the process of ensuring that people with disabilities enjoy their human rights is slow and uneven internationally it is, according to Quinn and Degener (2002) taking place in all economic and social systems. Minow (1990) suggests that rights analysis by itself cannot remedy the exclusion of people defined as different “by experts and majorities in society” (Minow 1990:147). The human rights approach has been challenged in terms of its adequacy to include individuals across a wide spectrum of personal and social circumstances. Some authors have identified the need for a broader understanding of social realities, social relations and individual biography than that which is provided for under the human rights approach. The need for some enhancement of the rights

approach has been articulated by a number of authors and theorists (Beckett 2006; Nussbaum 2006; Gatens 2004; Fineman 2008; Honneth 1995, 2003; Fraser 2003; James 2003). The section which follows provides a synthesis of three inter-related critical perspectives centrally relevant to a rights approach – the concept of recognition, the concept of the social imaginary and the universality of vulnerability.

2.6.1 The concept of ‘recognition’

Honneth (1995, 2003) locates rights within a social justice framework which implies an innate set of human rights that incorporates the key principle of ‘recognition’ of any person (Dolan 2010). Honneth (2003) distinguishes three spheres of recognition – (i) primary relationships of positive regard; (ii) legal recognition involving rights and duties; and (iii) a community of solidarity. He also identifies three distinct forms of social relations through which members of society can count on reciprocal recognition – intimate relationships marked by practices of mutual affection and concern; legal relations through which people learn to understand themselves as legal persons owed the same autonomy as all other members of society; and, finally, in loose-knit social relations where people learn to understand themselves as subjects possessing abilities and talents that are valuable for society (Honneth 2003).

Primary relationships of positive regard

Honneth’s (1995) first sphere of recognition refers to people’s emotional needs being satisfied through relationships forged out of love, respect and understanding.

Because the normative self-image of each and every individual human being – his or her ‘me’...is dependent on the possibility of being continually backed up by others, the experience of being disrespected carries with it the danger of an injury that can bring the identity of the person as a whole to the point of collapse (Honneth 1995:131–132).

Legal recognition involving rights

Honneth’s (2003) second sphere of recognition refers to the legal recognition of personal rights through institutionalised protection of universal respect for the autonomy and dignity of persons. The legal recognition of the individual – his or her recognised status as a member of society protected by certain rights – was, according to Honneth (2003), traditionally directly connected to the social esteem s/he enjoyed by reason of origin, age or function. The scope of the rights legitimately at a person’s disposal arose in a sense directly from the “honor” or status conferred on him or her by all other members of society within the framework of an established prestige order” (Honneth 2003:139–140). The part of the ‘honor’ assured by hierarchy was, Honneth suggests, in a sense democratised by according all members of society equal respect for their dignity and autonomy as legal persons, while the other part was in a sense meritocratised: each was to enjoy social esteem according to his or her achievement as a “productive citizen” (Honneth 2003:141).

Community of solidarity

Honneth's (2003) third sphere of recognition refers to the esteem derived from being valued as a contributor to society. Within this sphere, Honneth suggests that a person's self-esteem rises when they achieve culturally defined goals and subsequently have their accomplishments recognised (Dolan 2010). Honneth (1995) argues that human beings "...always need – over and above the experience of affectionable care and legal recognition – a form of social esteem that allows them to relate positively to their concrete traits and abilities" (Honneth 1995:121). He makes the point that "the experience of being socially esteemed is accompanied by a felt confidence that one's achievements or abilities will be recognised as 'valuable' by other members of society" (Honneth 1995:128).

Honneth (1995) uses the term 'solidarity' to refer to the cultural climate in which the acquisition of self-esteem has become broadly possible. Honneth's view is that one can properly speak of solidarity only in cases where some shared, concern, interest, or value is in play.

To the extent to which every member of a society is in a position to esteem himself or herself, one can speak of a state of societal solidarity (Honneth 1995:129).

By situating esteem not in the division of labour but in the domain of recognition across multiple axes in a particular culture, Honneth opens up a conceptual framework within which social solidarity can be interpreted to recognise a number of spheres of human living and to incorporate multi-faceted social relations. However, Honneth (2003) points to the selective interpretation of 'achievement', the third sphere of social relations.

For the extent to which something counts as "achievement", as a co-operative contribution, is defined against a value standard whose normative reference point is the economic activity of the middle-class male bourgeois (Honneth 2003:141).

Honneth (1995) emphasises the point that the normative self-image of each and every individual human being – his or her 'me' "is dependent on the possibility of being continually backed up by others" (Honneth 1995:131). There is, for Honneth (1995), a categorical difference between the "blatant degradation involved in the denial of basic human rights, on the one hand, and the subtle humiliation that accompanies a public allusion to a person's failings, on the other (Honneth 1995:132).

Recognition or redistribution

Fraser (2003) refers to a "massive resurgence of the politics of status... [with] a corresponding decline in the politics of class ... [where] the centre of gravity has shifted from redistribution to recognition" (Fraser 2003:89). Honneth (2003) conceives recognition as the fundamental, overarching moral category in his understanding of justice. Somewhat in contrast to Honneth, but agreeing with his fundamental starting point, Fraser (2003) proposes a two-dimensional conception of justice that encompasses redistribution as well as recognition as core and equally valid components of justice. In arguing for the need for a two-dimensional conception of justice, Fraser (2003) makes a distinction between affirmation and

transformation strategies. She refers to the concept of 'mainstream multiculturalism'¹⁰ as an example of an affirmative strategy.

This approach proposes to redress disrespect by revaluing unjustly devalued group identities, while leaving intact both the contents of those identities and the group differentiations that underlie them (Fraser 2003:75).

Gatens (2004) in referring to the concept of group or cultural rights suggests that group rights by taking the group as their focus may override the rights of individuals. Fraser (2003) identifies two major drawbacks with affirmative strategies. Firstly, she states that by valorising group identity along a single axis, such strategies significantly simplify people's self-understandings, "denying the complexity of their lives, the multiplicity of their identifications, and the cross-pulls of their various affiliations" (Fraser 2003:76). She also states that such approaches can have the effect of pressurising individuals to conform to a group type thus discouraging dissidence or disaffection with the group identity.

Far from promoting interaction across differences, then, affirmative strategies for addressing misrecognition lend themselves all too easily to separatism and repressive communitarianism ((Fraser 2003:77).

A second reason why affirmative remedies prove problematic identified by Fraser (2003) is that they may provoke misrecognition in relation to a particular identity group.

In the liberal welfare state, for example, public assistance programs channel aid to the poor, while leaving intact the deep structures that generate poverty (Fraser 2003:76).

Fraser (2003) contrasts affirmative strategies with transformation strategies which "...would redress status subordination by deconstructing the symbolic oppositions that underlie currently institutionalised patterns of cultural value. Far from simply raising the self-esteem of the misrecognised, it would destabilise existing status differentiations and change *everyone's* self-identity" (Fraser 2003:75).

For Fraser (2003), transformative strategies largely escape the difficulties that she identifies with affirmative strategies:

Applied to misrecognition, deconstructive remedies ... aim to destabilize invidious status distinctions...When successful, such reforms discourage the *en bloc* conformism that often accompanies mainstream interculturalism. And far from promoting separatism and repressive communitarianism, they foster interaction across differences (Fraser 2003:77).

While Fraser sees the potential of the universalism of transformative approaches to "reduce inequality without creating stigmatised classes perceived as beneficiaries of special largesse" (Fraser 2003:77), she also acknowledges that transformative strategies are not altogether without

¹⁰ Fraser acknowledges that not all versions of multiculturalism fit the model she uses but that it represents the majority understanding and is the version that is usually debated in mainstream public spheres.

difficulties in that they may be longer-term and, therefore, removed from the immediate concerns of people experiencing misrecognition. She further suggests that in a general way transformative strategies are highly vulnerable to collective action problems.

In their pure form, at least, they become feasible only under unusual circumstances, when events conspire to wean many people simultaneously from current constructions of their interests and identities (Fraser 2003:78).

Honneth and Fraser find much common ground. Fraser (2003) argues that "... to pose an either/or choice between the politics of redistribution and the politics of recognition is to posit a false antithesis. On the contrary, justice today requires both" (Fraser 2003:93). Honneth (2003) is in broad agreement with Fraser when he emphasises the primacy of recognition as the key determinant of justice and social solidarity. He argues that since injustice is regularly associated with withheld recognition, it is more plausible that the experiences of injustice be conceived along a continuum of forms of withheld recognition rather than on the basis of cultural identities. "It makes a fundamental difference whether the culturally defined groups are demanding a kind of social appreciation or the legal recognition of their collective identity..." (Honneth 2003:135–136).

2.6.2 *Rights as aspirations*

Gatens (2004) refers to the fact that some theorists have drawn attention to the difference between rights 'talk' and rights 'action'. She cites O'Neill (1996) as referring to cases where it is unclear who or what – if anyone or anything – is under an obligation to enforce a rights claim. Rights that are not enforceable are regarded by Gatens (2004) as

worse than empty rhetoric since they provide false security or offer vain hope to those who are most in need of protection or assistance (Gatens 2004:281).

James (2003) argues that unless rights are claimable, they are no more than rhetorical gestures which mock the poor and needy. She poses the key question as to what makes a right claimable and argues that, if rights are to avoid the charge of emptiness, they must be effectively enforceable.

To possess a right one must be able to claim it (for example by successfully demanding that other agents fulfil correlative obligations, or by simply taking advantage of the fact that they are already doing so) or have it claimed in one's name (for example by one's representatives) (James 2003:133).

She suggests that when the institutions which create and allocate obligations based on rights work efficiently and reliably we are able to claim our rights with relative ease, even if the procedures for doing so are lengthy and complicated (James 2003). However, she suggests that the conditions in which appeals to rights are useful are more limited than many contemporary theorists allow and that the non-availability of rights enforcement mechanisms may in fact compound disadvantage or exclusion.

When governments or international organisations allocate rights of education, free speech or holidays to people who have no likelihood of gaining these things, their efforts are merely rhetorical gestures which display a lack of political and philosophical understanding (James 2003:133).

For O'Neill (1996), rights are only real rights to the extent that they are matched by corresponding obligations on others.

Unless obligation-bearers are identifiable by right-holders, claims to have rights amount only to rhetoric: nothing can be claimed, waived or enforced if it is indeterminate where the claim should be lodged, for whom it may be waived or on whom it could be enforced (O'Neill 1996:129).

Gatens (2004), following O'Neill (1996) and James (2003), sets out the complex conditions on which the view of rights as effectively enforceable claims depends:

- Rights depend on robust institutions capable of identifying and allocating the relevant rights and duties and then of effectively enforcing them;
- The effectiveness of even the best designed institutions relies upon the skills, dispositions and resources of the agents who animate them;
- The notion of rights as enforceable claims assumes the existence of persons capable of claiming rights – persons who have access to the requisite resources and who possess the appropriate knowledge and attitudinal dispositions;
- Institutions, duty holders and rights bearers will function harmoniously only when they are supported by a broadly shared moral consensus about their correctness (Gatens 2004).

For example, women's right to be free from domestic violence becomes viable only when husbands and fathers recognize their obligations... and only when effective institutions are in place to respond appropriately if the right is transgressed (Gatens 2004:281).

Gatens (2004) suggests that the ways in which a community governs and imagines itself become embedded, over time, in institutions and in the social norms that constrain action and determine meaning independent of the wishes of individuals. She posits the concept of the 'social imaginary', understood in terms of the always present backdrop within which meaningful social action can take place, as one within which the interface between rights claimants and existing cultural norms and patterns can be negotiated. For Gatens (2004) the social imaginary concept embraces the aspirational aspects of rights discourse, "*what could or should be*" (Gatens 2004:282

Since meaning is always ambiguous and open to re-interpretation and contestation, Gatens argues for the need to push such ambiguities to their limit through the reinvention or reinterpretation of aspects of those

imaginaries (Gatens 2004). Following this line of argument, she posits a view of human rights

as an international imaginary that aims to challenge national and cultural imaginaries: a set of second-order norms that encourage reflection on the taken for granted – possibly unexamined—first-order norms (Gatens 2004:288).

For Gatens (2004), social imaginaries are sites of multiple, complex, even contradictory social meanings which offers a “possible site of negotiation between human rights and cultural norms” (Gatens 2004:288). Thus, she suggests that the human rights approach should not be exalted to the status of a ‘master discourse’. Rather

The aspirational dimension of human rights may lie in their ability to act as ‘second order’ norms, that is, reflectively endorsed norms through which the various social imaginaries that help structure the clustering of first order norms may be challenged (Gatens 2004:293).

2.6.3 *The concept of universal vulnerability*

Gatens (2004) notes that difference – especially cultural difference – has come to occupy centre stage in the case of human rights discourse. The emphasis on cultural identity, Honneth (2003) argues, falls short because “it cannot be neatly translated back into the already established principles” (Honneth 2003:161) since “it requires social recognition not of the singular needy subject (love), the autonomous legal person (law), or the co-operative member of society (esteem), but of members of a cultural group” (Honneth 2003:161). Fineman (2008) posits the vulnerability approach as an alternative to traditional equal protection approaches. “This approach has the potential to move us beyond the stifling confines of current discrimination-based models toward a more substantive vision of equality” (Fineman 2008:1).

Fineman's (2008) theory of universal vulnerability has four premises:

- (i) Vulnerability is universal and constant;
- (ii) Vulnerability is not situated in the body alone, that is, it may be the product of economic, institutional, and other social harm;
- (iii) Disadvantage (including discrimination) that results from vulnerability is best addressed by moving past identity categories, including protected classes;
- (iv) Both state and private actors must address vulnerability.

Fineman's concept of vulnerability is that it is a universal, inevitable and enduring aspect of the human condition and that all individuals are vulnerable, in the sense that they have the potential to become dependent through impairment of one kind or another. Beckett (2006) uses the term ‘vulnerability’ to describe the fragile and contingent nature of personhood. “Thus, we are all ‘vulnerable’ in some respect and most people are

potentially, or actually 'vulnerable' with regard to a wide range of 'risks' and new forms of social exclusion" (Beckett 2006:3).

The essence of Fineman's vulnerability theory is that vulnerability transcends identity group categories and that, therefore, an inclusive approach to inequality must be based on universalism rather than on a focus on specific social or cultural groups.

The promise of equality must not be conditioned upon belonging to any identity category, nor should it be confined to only certain spaces and institutions, be they deemed public or private (Fineman 2008:23).

Fineman (2008) argues that our current understanding of equality, shaped in part by the twentieth-century history of the use of the equal protection doctrine as a tool to fight blatant forms of discrimination focused on race, sex, and ethnicity, is limited. Indeed, Fineman suggests that "equality," reduced to sameness of treatment or a prohibition on discrimination, has proven an inadequate tool to resist or upset persistent forms of subordination and domination.

Similar to Fraser's (2003) distinction between affirmative and transformative strategies, for Fineman (2008), the formal equality model based on group identity not only fails to take into account existing inequality of circumstances but also fails to disrupt persistent forms of inequality since such inequality transcends group boundaries. This view is broadly reflective of Fraser's (2003) distinction between affirmative and transformative strategies of social intervention.

The general tendency under a sameness of treatment equality framework is to focus on individuals and individual actions...Inequalities are produced and reproduced by society and its institutions. Because neither inequalities nor the systems that produce them are inevitable, they can also be objects of reform (Fineman 2008:4–5).

Fineman's (2008) universal vulnerability theory questions the idea of a liberal subject by suggesting that the vulnerable subject is a more accurate and complete universal figure to place at the heart of social policy. She argues that the dominant political and legal theories built around a universal human subject defined in the liberal tradition as a competent social actor capable of playing multiple and concurrent societal roles fail to give due cognisance to the concept of interdependence and related dependency. She posits the view that because dependency is episodic and individual for most people, mainstream political and social theorists can and often do conveniently ignore it as being of no theoretical interest. "Thus largely rendered invisible within the family, dependency is comfortably and mistakenly assumed to be adequately managed for the vast majority of people (Fineman 2008:11). In contrast, under Fineman's universal vulnerability theory, dependency and vulnerability cannot be hidden since it is ever-present and enduring in that the human experience encompasses a wide range of differing and interdependent abilities over the span of a lifetime.

On an individual level, the concept of vulnerability (unlike that of liberal autonomy) captures this present potential for each of us to become dependent

based upon our persistent susceptibility to misfortune and catastrophe” (Fineman 2008:12).

For Fineman (2008), the universal nature of vulnerability draws in the whole of society (not just specific minorities) and, in so doing, focuses attention not only on individuals, but also on institutions – the structures and arrangements that can almost invisibly produce or exacerbate existing inequality. A key question for Fineman is “whether the state, in fashioning its institutions, acts with equal regard for the shared vulnerability of all its legal subjects” (Fineman 2008:23).

Vulnerability theory and people with disabilities

Fineman's universal vulnerability theory has been applied by Satz (2008) to the disability domain, both in terms of thinking about people with disabilities and the State's response. Satz (2008) sets out five key considerations relevant to the theory of universal vulnerability as applied to people with disabilities:

- (i) A vulnerable subject may become a disabled subject. Vulnerability to disability (and other impairments) is universal and constant – “we are all one curb step away from disability” (Satz 2008:530);
- (ii) We are all susceptible to disability as part of the human condition;
- (iii) The vulnerable subject exists within a spectrum of possible abilities and disabilities;
- (iv) An individual becomes disabled when certain vulnerabilities are realised;
- (v) An individual with a disability remains vulnerable to further disability and may experience particular vulnerabilities more acutely than those who do not have a disability (Satz 2008).

Satz (2008) (following Fineman 2008) argues that the rights approach to disability discrimination is inherently limited because it requires viewing disability as an identity category. People with disabilities bear a unique burden under the rights paradigm, in the sense that they must prove that they qualify for membership of the ‘protected class’. The outcome of this is people having to prove their disability to get basic rights – income, housing, supported education, transport. The growing phenomenon (internationally and in Ireland) of advocacy by and for people with disabilities reflects this focus on membership of a specific identity group.

The vulnerability approach, posited as an alternative to a traditional equality and rights-based analysis, concentrates on the structures our society has and will establish to manage our common vulnerabilities.

This approach has the potential to move us beyond the stifling confines of current discrimination-based models toward a more substantive vision of equality (Fineman 2008:1).

2.6.4 Self-realisation

According to Anderson (1995), for Honneth (1995), self-confidence, self-respect and self-esteem and related self-identity

can only be acquired and maintained intersubjectively, through being granted recognition by others whom one also recognizes" (Anderson 1995:xi).

This means in effect that the conditions for self-realisation become dependent on the establishment of relationships of mutual recognition which must be established and expanded through social struggles.

To the extent to which every member of a society is in a position to esteem himself or herself, one can speak of a state of societal solidarity (Honneth 1995:129).

For Honneth (2003), relationships go beyond close relations of love and friendship to include legally institutionalised relations of universal respect for the autonomy and dignity of persons, and networks of solidarity and shared values within which the particular worth of individual members of a community can be acknowledged. Thus, self-confidence, self-respect and self-esteem represent three distinct species of 'practical relation-to-self'.

These involve a dynamic process in which individuals come to experience themselves as having a certain status, be it as a focus of concern, a responsible agent, or a valued contributor to shared projects" (Anderson 1995:xii).

Anderson (1995) states that for Honneth a society in which individuals have a real opportunity for full self-realisation, would be a society in which the common values would match the concerns of individuals in such a way that no member of the society would be denied the opportunity to earn esteem for his/her or contribution to the common good.

Self-realisation involves an understanding of life as involving the harmonious development of the person both as an individual and as a member of the wider collective. It rejects a view of the human person as static or one-dimensional. Central to the concept of self-realisation is people coming to think of themselves as unique individuals with chosen rather than prescribed or standard identities (Markley and Harman 1982). For Prout (2000) modernity embraces the notion of self-realisation, "the belief that a world increasingly subject to rational control creates the conditions in which people can shape their own lives through the formation and exercise of self-consciousness, creativity and agency" (Prout 2000:307). Prout (2000) argues for a stronger focus on the present well-being of children in order to ensure their participation in social life and to provide opportunities for human self-realisation and suggests that the

logic of individualisation requires new kinds of institutions in which authority, and allegiance, must be constantly renegotiated, re-established and earned" (Prout 2000:307)

Prout (2000) cites Beck (1998) in suggesting that the trend towards people coming to think of themselves as unique individuals with chosen rather than prescribed or standard identities requires not fewer but different sources of social interdependency “because although such individuals are produced through collectivities (such as family, locality and class), they are not bound by them in traditional ways” (Prout 2000:307). Prout refers to the emergence of a pattern in which public institutions are more and more concerned with the control of children, whilst the private sphere is constituted as the place where children are more allowed to express choice, exercise autonomy and work at their individual self-realisation (Prout 2000:311).

How to make organisations better attuned to participation, how to engage children in serious dialogue and how to make participation practices appropriate and effective are key questions to be addressed in the context of achieving a balance between social control and self-realisation (Prout 2000). This raises a key question about how the components of self-realisation are to be fulfilled for children/young persons with an intellectual disability who frequently need more involvement by public institutions in their socialisation and development than that required by other children/young persons. It also raises important and interesting questions about how formal family support interventions might be conceptualised to enhance the concept of self-realisation for children/young persons with an intellectual disability.

Part Two: Human Rights and Children/Young Persons with an Intellectual Disability

The section focuses specifically on rights provisions for children with disabilities with particular reference to children/young persons with an intellectual disability. Firstly, it sets out the relevant provisions in three specific human rights instruments. Secondly, some of the limitations identified are summarised. Thirdly, the core components of implementing a rights-based approach to children with disabilities are identified. Fourthly, the implications of applying rights-based principles to children/young persons with an intellectual disability are discussed.

The rights of children/young persons with an intellectual disability are located within the overall domain of children's rights and the rights of persons with disabilities which in turn evolve out of the general universal human rights approach which has been outlined in the first part of this chapter.

Part Two contains five sections:

- (i) Human rights instruments and children with disabilities
- (ii) Implementing the rights of children in respect of children with disabilities: core components
- (iii) An enhanced view of children's rights
- (iv) Children/young persons with an intellectual disability
- (v) A rights paradigm for a social supports infrastructure

2.7 Human rights instruments and children with disabilities

The human rights approach to disability has led to a shift in focus from a child's limitations arising from impairments to the barriers within society that prevent the child from having access to basic social services and developing to the fullest potential. Such an approach is regarded as "the essence of the social model of disability" (UNICEF 2007:5).

Provisions for protecting the rights of children with disabilities are included in the Convention of the Rights of the Child, the Convention on the Rights of Persons with Disabilities and in The Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The rights of children with disabilities are also dealt with comprehensively in the deliberations and recommendations of the Committee on the Rights of the Child (United Nations 2006a, 2007). The UNICEF Research Centre Report (UNICEF 2007) states that human rights have provided both the inspiration and the foundation for the movement towards inclusion for children with disabilities.

2.7.1 UN Convention on the Rights of the Child¹¹

The UN Convention on the Rights of the Child (UNCRC) provides an overarching framework for children's rights and makes special mention of children with disabilities in Articles 2 and 23. This inclusion marks an important shift in thinking towards a "rights-based approach," holding governments legally accountable for failing to meet the needs of all children.

Article 2 of the UNCRC requires that the rights of all children be protected without discrimination of any kind, irrespective of race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status. Article 23 of the UNCRC focuses specifically on children with disabilities and stipulates that a child with a mental or physical disability should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. While all articles in the UNCRC have relevance to all children, there are some specific provisions that have more particular relevance to children/young persons with an intellectual disability. Article 3(1) refers to promoting the best interests of the child, Article 12(1) refers to the right of the child to express his/her views freely on all matters affecting him/her; Article 13(1) refers to the right to freedom of expression, including freedom to seek, receive and impart information; and Article 31 refers to the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.

The stipulation in Article 3 that the best interests of the child shall be a primary consideration in all actions taken concerning children emphasises the principle that the "best interests of children with disabilities be a core consideration in decision-making concerning them" (Kilkelly 2002:121). Kilkelly (2002) also points out that the right to survival and development (Article 6) is also of significance for children with disabilities "since neglect of such children can cause death or institutionalisation resulting in an extremely poor quality of life" (Kilkelly 2002:121). Given that children with disabilities are even more marginalised and silent than children in general, the recognition of their equal right to be heard and to participate is hugely significant, according to Kilkelly. She identifies the barriers that impede the participation of children with disabilities in society and at school as including physical barriers and the absence of a means of expression.

Four shortcomings to the UNCRC as it applies to children with disabilities have been identified (Kilkelly 2002):

- (i) While Article 23 (1) refers to States parties recognising that children with disabilities should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and

¹¹ Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 and entry into force on 2nd September 1990.

facilitate the child's active participation in the community, it does not recognise or seek to guarantee this for children with disabilities as a matter of right. It places no obligations on State parties to take measures to achieve that end.

- (ii) Article 23(2), while referring to States parties recognising the right of children with disabilities to special care, stops short of specifying how this right is to be secured. The reference to "subject to available resources" undermines the right (Kilkelly 2002:120).
- (iii) The stipulation in Article 23(3) that assistance to children with disabilities should be provided free of charge, wherever possible and taking into account the financial resources of the parents or others caring for the child undermines the basic right to assistance (Kilkelly 2002).

Kilkelly (2002) notes, however, that positive elements are discernible in Article 23(3) which stipulates that assistance provided under Article 23(2) should be designed to:

ensure effective access to and receipt of education, training, health care and rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to achieving the fullest possible integration and individual development (Kilkelly 2002:120).

However, she suggests that "there is no clear need-based entitlement to have access to or to benefit from such services" (Kilkelly 2002:120).

2.7.2 UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) includes specific provisions in relation to children with disabilities and re-iterates in the provisions of the UNCRC in respect of such children. Article 7 (3)) of the UNCRPD reiterates the provision of Article 12 (1) of the UNCRC in respect of children with disabilities. The provisions of Article 19 of the UNCRPD, while not specifically referring to children/young persons with disabilities, are centrally relevant to their inclusion in society in that they emphasise the right of all persons with disabilities to live in the community, with choices equal to others.

2.7.3 The Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Specific rights of children with disabilities and their families are addressed in The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations 1993).

Rule 2 states that infants and children should especially have access to the same level of medical care that others have. Rule 6 states that general education authorities are responsible for the education of people with disabilities in integrated settings and encourages the active involvement of

parent groups and organisations in the education process. Special attention is to be given to very young children with disabilities and populations at risk for double discrimination. Rule 9 states that persons with disabilities should be enabled to live with their families and that States should encourage the inclusion in family counselling of appropriate modules regarding disability and its effects on family life as well as providing respite-care and attendant-care services to families of persons with disabilities

2.7.4 UN General Assembly Document: ‘A World Fit for Children’

The UN Document, *A World Fit for Children* (United Nations 2002), makes clear reference to the rights of children with disabilities, including, in particular, protection from discrimination, access to services and access to adequate treatments and care. It also makes reference to the promotion of family-based care and the provision of appropriate support structures for families. It includes a commitment to take all measures to ensure the full and equal enjoyment of all human rights and fundamental freedoms, including equal access to health, education and recreational services, by children with disabilities (United Nations 2002:5–6).

2.8 Implementing the Convention on the Rights of the Child in respect of children with disabilities: core components

2.8.1 Focus on children with disabilities

Acknowledging the importance of Articles 2 and 23 of the UNCRC, the Committee on the Rights of the Child (CRC) (United Nations 2006a) takes the view that, as already stated, the implementation of the Convention with regard to children with disabilities should not be limited to these articles. The CRC has paid sustained and particular attention to identifying and addressing disability-based discrimination. The Committee has pointed to the necessity of paying particular attention to and including explicitly children with disabilities within the framework of general measures for the implementation of the Convention on the Rights of the Child.

UNICEF (2007) examined the rights of children with disabilities around the world and focused in particular on the implications of the Convention on the Rights of the Child (UNCRC), the Convention on the Rights of Persons with Disabilities (UNCRPD) and the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Ten actions were identified by UNICEF as being necessary at national level in order to implement the articles of the UNCRPD as these apply to children with disabilities.

1. A comprehensive review of all legislation in order to ensure its conformity with the standards, in particular the inclusion of children and adults with disabilities
2. Provision for effective remedies in case of violations of the rights of children with disabilities

3. A national plan of action that integrates the relevant provisions of all applicable international instruments
4. A focal point for disability in each relevant department, as well as a high-level multisectoral co-ordinating committee
5. Independent monitoring mechanisms, such as an Ombudsperson or Children's Commissioner
6. Concerted efforts to ensure that the necessary resources are allocated to and for children with disabilities and their families (including free primary and secondary education in accessible buildings, training of teachers and other professionals, financial support and social security, appropriate individual support and assistive technologies)
7. Programmes for the deinstitutionalisation of children with disabilities
8. Awareness-raising and educational campaigns for the public, as well as specific groups of professionals, with the aim of preventing and addressing the de facto discrimination of children with disabilities
9. A system of community services and support for children with disabilities
10. Consultation with organisations of persons with disabilities
(UNICEF 2007)

2.8.2 *Children with disabilities: implications of UNCRC provisions*

The CRC (United Nations 2007) has drawn particular attention to the implications of a number of rights statements included in the UNCRC in relation to children with disabilities:

- Best interests of the child
- Respect for the views of the child
- Social inclusion and children with disabilities
- Inclusive education
- Recreation and cultural activities
- Access to appropriate information and mass media
- Children with disabilities in institutions
- Right to the highest possible standard of health
- Early identification of disability and intervention
- Multidisciplinary support and care
(United Nations 2007:9ff.)

Best interests of the child

The CRC recommended that Article 3(1) of the UNCRC, viz. 'In all actions concerning children...the best interests of the child shall be a primary consideration', should be the basis on which programmes and policies are set and that this provision should be duly taken into account in every service provided for children with disabilities and any other action affecting them. The Committee notes that the best interest of the child provision is of particular relevance in institutions and other facilities that provide services for children with disabilities

as they are expected to conform to standards and regulations and should have the safety, protection and care of children as their primary consideration, and this consideration should outweigh any other and under all circumstances, for example, when allocating budgets" (United Nations 2007:9).

Respect for the views of the child

The CRC notes that more often than not, adults with and without disabilities make policies and decisions related to children with disabilities while children themselves are left out of the process. It is essential, the Committee states, that children with disabilities are heard in all procedures affecting them and that their views are respected in accordance with their evolving capacities. This includes providing children with whatever mode of communication they need to facilitate expressing their views and supporting training for families and professionals on promoting and respecting the evolving capacities of children to take increasing responsibilities for decision-making in their own lives (United Nations 2007).

Social inclusion and children with disabilities¹²

Inclusion requires the recognition of all children as full members of society and the respect of all of their rights, regardless of age, gender, ethnicity, language, poverty or impairment. This involves the removal of barriers that might prevent the enjoyment of these rights, the creation of appropriate supportive and protective environments and "changing the attitudes and practices of individuals, organisations and associations so that they can fully and equally participate in and contribute to the life of their community and culture" (UNICEF 2007:1).

Paragraph 1 of Article 23 of the UNCRC, viz., that States parties recognise that a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community, is identified by the CRC as the leading principle for the implementation of the Convention with respect to children with disabilities. The CRC notes that in practice the spiritual, emotional and cultural development and well-being of children with disabilities are frequently overlooked.

¹² There are an estimated 200 million children with disabilities in the world. Around 80 percent of them live in developing countries. (Source: UNICEF 2007).

Their participation in events and activities catering to these essential aspects of any child's life is either totally lacking or minimal. Furthermore, when their participation is invited, it is often limited to activities specifically designed for and targeted at children with disabilities. This practice only leads to further marginalization of children with disabilities and increases their feelings of isolation. Programmes and activities designed for the child's cultural development and spiritual well-being should involve and cater to both children with and without disabilities in an integrated and participatory fashion (United Nations 2007:10).

Inclusive education

The CRC reiterates the provisions in the UNCRC (Articles 28 and 29) that children with disabilities have the same right to education as all other children and that they should enjoy this right without any discrimination and on the basis of equal opportunity to promote the development of the child's personality, talents and mental and physical abilities to their fullest potential.

The Committee notes the explicit commitment towards the goal of inclusive education contained in the Convention on the Rights of Persons with Disabilities (Article 18) and the obligation for States to ensure that persons, including children with disabilities, are not excluded from the general education system on the basis of disability and that they receive the support required, within the general education system, to facilitate their effective education.

Inclusive education means attending the age appropriate class of the child's local school, with individually tailored support and a curriculum that is differentiated to ensure access to a wide range of children and that reflects all the needs and interests of children in the local community (UNICEF 2007). The need for modification to school practices and for training of regular teachers to prepare them to teach children with diverse abilities and ensure that they achieve positive educational outcomes referred to in the UNCRC is noted by the CRC.

As children with disabilities are very different from each other, parents, teachers and other specialized professionals have to help each individual child to develop his or her ways and skills of communication, language, interaction, orientation and problem-solving which best fit the potential of this child (United Nations 2007:17).

The CRC has stated that all schools should be without communicational barriers as well as physical barriers impeding the access of children with reduced mobility and that higher education, accessible on the basis of capacities, should be accessible for qualified adolescents with disabilities. The need for many children to have additional supports to facilitate educational participation has been highlighted by the Committee, in particular,

teachers trained in methodology and techniques, including appropriate languages, and other forms of communication, for teaching children with a diverse range of abilities (United Nations 2007:18).

As part of an inclusive education model, the CRC sees education for career development and transition as imperative.

Developing career awareness and vocational skills as early as possible...It begins with students choosing goals according to their evolving capacities in the early years" ((United Nations 2007:19).

The need to provide measures to meet the diversity of pupil needs, including, in particular, those with special educational needs, in both jurisdictions on the island of Ireland has been noted recently (Children and Youth Programme 2012). This report made the salient observation that "inappropriate or limited classroom support constitutes a denial of educational opportunities to enable pupils to reach their full potential" (Children and Youth Programme 2012:40).

Recreation and cultural activities

The CRC highlights the importance of both play and participation in cultural and arts activities as important sources of learning various skills, including social skills.

The attainment of full inclusion of children with disabilities in the society is realized when children are given the opportunity, places, and time to play with each other (children with disabilities and no disabilities) (United Nations 2007:19).

Access to appropriate information and mass media

The CRC (United Nations 2007) highlights the role of access to information and means of communication, including information and communication technologies and systems, in enabling children with disabilities to live independently and participate fully in all aspects of life. This includes access to information concerning their disability and access to the appropriate technology and other sources of information including all forms of media¹³ (United Nations 2007).

Right to the highest possible standard of health

The CRC (United Nations 2007) notes that children with disabilities often fail to get appropriate access to quality healthcare because of multiple challenges, including discrimination, inaccessibility due to the lack of information and/or financial resources, transportation, geographic distribution and physical access to health care facilities. Another factor identified by the CRC is the absence of targeted health care programmes that address the specific needs of children with disabilities.

Adolescent health and development are identified by the CRC as particularly important for children with disabilities in the area of establishing relationships with peers and reproductive health. The Committee recommends that States parties provide adolescents with

¹³ The CRC points out that States parties are required to protect all children, including children with disabilities from harmful information, especially pornographic material and material that promotes xenophobia or any other form of discrimination and could potentially reinforce prejudices.

disabilities with adequate, and where appropriate, disability specific information, guidance and counselling taking into account the provisions of the UNCRC.

2.9 An enhanced view of children's rights

Woodhouse (2000) states that in order to embrace the complex nature of children's situations, rights must be revisualised to include a more child-centred perspective which would encompass not only capacity based rights, recognising children's emerging autonomy, but also needs based rights, recognising children's essential dependence on adults to provide nurture and protection. This vision of children's rights is particularly useful in discussing the rights of children/young persons with an intellectual disability which is the subject of the present thesis.

Woodhouse (2000) suggests that the difficulty of integrating children into our theories about justice and into our legal system exposes underlying tensions between the child's initial helplessness and his/her emerging capacities, between children as individuals, as family members, and as citizens of states and nations. (Woodhouse 2000:1)

For Woodhouse (2000), children's "needs-based rights" reflect children's essential dependency at birth but also leave room to honour their inherent capacity for growth to maturity.

Children's 'needs-based rights' would include rights to nurture, education, food, medical care, shelter, and other positive goods without which children cannot grow into autonomous adults and productive citizens. Children's "needs-based rights" would also reflect their need to grow – and to test the wings of their increasing autonomy (Woodhouse 2000:3).

The notion of children's "dignity rights" is identified by Woodhouse (2000) as acting as a necessary complement to the notion of needs based rights "because it acknowledges that children are individual persons with the same claims to dignity as autonomous adults (Woodhouse 2000:3). Recognising children's dignity rights and assigning the protection of these rights to parents is regarded by Woodhouse as one route to acknowledging that childhood is a journey to autonomy (Woodhouse 2000). This approach requires that we work harder to integrate children's needs with their capacities, acknowledging that dependency and autonomy are two sides of the same coin.

Woodhouse (2000) proposes five 'principles' which, she states, are different from but bear a strong relation to the five legal frameworks articulated by Minow (1990)¹⁴: (1) the equality principle; (2) the individual dignity principle; (3) the privacy principle; (4) the protection principle and

¹⁴ Minow (1990) has identified five legal frameworks children's advocates used in thinking and talking about children. These five are child protection, child liberation, children as potential adults, children in need of traditional authority, and children as recipients of social resource redistribution.

(5) the empowerment principle. Each of these principles represents a basic value that ordinary people as well as judges would agree ought to be reflected in the scheme of human rights.

According to Woodhouse's (2000) *equality* principle, there is a need to create an environment for both the individual child and for children as a class that supports their capacities for growth.

Equality for children in society as in family life begins with meeting their basic needs and continues by recognizing and supporting their individual capacities (Woodhouse 2000:15).

Woodhouse's (2000) second principle, *individual dignity*, the right to be treated as a unique person, requires government to treat all persons as individuals with claims to human dignity. This principle is in broad concurrence with the 'best interest of the child' provision in the UNCRC.

Treating children with the dignity owed to individual persons requires an assessment of the child's needs, even if the child has no autonomous views to articulate. It also suggests a careful listening to discern the child's perspective even before the child is capable of articulating it, and to consider that perspective seriously once the child is capable of articulating it (Woodhouse 2000:16).

Woodhouse's third principle, *empowerment*, is based on the notion that each member of a society ought to have the right to participate in collective decision-making and especially the right to a voice in critical decisions affecting his/her own life. This requires that "children must be treated as rights-bearing individuals, regardless of their 'capacity' or developmental stage" (Woodhouse 2000:17).

The *protection* principle is for Woodhouse the very essence of 'law and order' based on the understanding that "rights and responsibilities must replace raw power as the means of ordering social interactions" (Woodhouse 2000:18).

Children have the right to "law and order" in the places where they live, their own homes, families, and neighbourhoods (Woodhouse 2000:19).

Woodhouse's (2000) fifth principle, *privacy*, refers to the protection of an individual's most intimate personal choices from state regulation and intrusion. Woodhouse notes that, while family privacy holds serious risks for the less powerful members of the family system,

...persons who cannot make their own decisions must have the right to have those decisions made privately, within the family, rather than publicly, by a bureaucracy of strangers (Woodhouse 2000:20).

Woodhouse (2000) thus notes the challenge of articulating a scheme of children's rights that reflects their dependency as well as their capacity.

2.10 Children/Young persons with an intellectual disability

The general rights discourse on children and people with disabilities provide an essential context for a consideration of the rights of

children/young persons with an intellectual disability. Koh (2004) states that “a genuine commitment to human rights for all requires that people with intellectual [ly] disabilities be treated as different but equal” (Koh 2004:19).

Children with intellectual disabilities have the same needs and wishes as any other children: they want to interact with their peers, play and laugh, learn and develop into a respected adult member of society (Inclusion Europe 2008:1).

The rights of children/young persons with an intellectual disability are thus essentially those of children generally as well as those of people with disabilities. While this principle may be obvious in many respects, its implementation presents significant challenges. How to address such challenges is a key consideration of the present thesis.

People with an intellectual disability are widely regarded as one of the most marginalised groups in Western society (Foundation of People with Learning Disabilities 2001). Hall (2005) notes that documenting the everyday experiences of people with an intellectual disability in mainstream society reveals a complex geography of exclusion and inclusion which for many results in “marginalisation into ‘small action spaces’ on the ‘outer fringes of the daily round’... while for some, spaces of acceptance are found” (Hall 2005:108). Koh (2004) echoes these views:

From a human rights perspective, the intellectually disabled rank among the world’s most vulnerable and at-risk populations, both because they are different and because their disability renders them less able either to assert their rights or to protect themselves against blatant discrimination (Koh 2004:7–8).

The need to frame the concerns of people with intellectual disabilities not simply as a social problem but as a human rights imperative has been argued cogently by Koh (2004):

Treating intellectual disability as a human rights issue directly addresses, and seeks to readjust, the power relationships that shape the unequal treatment of the disabled (Koh 2004:9).

The concept of agency

The core elements of a rights approach to people with an intellectual disability have been identified by Koh (2004) as including access to tools for exercising individual agency, participation and inclusion in critical decisions that affect their lives and future and freedom to exercise proactively their rights both personally and through agents (Koh 2004).

The concept of agency is regarded by some authors as central to an effective rights-based approach to people with an intellectual disability. For example, Carlson and Kittay (2010) suggest that there is a need for a more collaborative conception of agency, one that is, in reality, appropriate to all, but especially useful in relation to people with an intellectual disability. Lindemann (2010) suggests that not only those who care for people with an intellectual disability discharge obligations but also that people with this disability are involved in a form of moral engagement that

holding another in personhood involves. Carlson and Kittay (2010) point out that “the ability to empathize is a capacity that is unimpaired in many with cognitive disabilities” (Carlson and Kittay 2010:12). These authors suggest that those with mild cognitive disabilities exhibit unquestionable signs of agency, even if they are not fully capable of understanding the consequences of their actions. They also acknowledge that “those whose impairments are more pronounced are less easily viewed as agents, especially when agency is thought to require the capacity to conceive of one’s own good and to act on it oneself” (Carlson and Kittay 2010:12).

Other authors (Nelson 2010; Francis and Silvers 2010) have developed conceptions of agency that are not dependent on the autonomous actions of a singular individual, but rather are more social and relational.¹⁵ Carlson and Kittay (2010:13) suggest that such conceptions may implicitly call into question what in philosophy has been known as the “internalist theory of mind” – namely, that our terms and our thoughts are individuated by us alone, independent of the social understanding of these terms.

Nelson (2010) argues that if the beliefs we hold are ‘not in our heads’ and if what constitutes the human mind is more than the sum of the cognitive and psychological capacities of our brains, then there is an important sense in which the limitations of cognitive capacities are not as determinative of the meaning we attribute to the words, actions, and beliefs of those with these disabilities. Francis and Silvers (2010) suggest that the conception of the good, if it is to be meaningful for people with cognitive impairment, rather than being formed and maintained by the individuals themselves, should be formulated, validated, and maintained in a collaborative fashion. Carlson and Kittay (2010) argue for the need for a more collaborative conception of agency, one that is appropriate to all, but especially useful in facilitating the voice of people with an intellectual disability. Such a conception of agency would support the contention that its attributes are not all located within the limits of an individual body.

2.11 A rights paradigm for children/young persons with an intellectual disability: seven components identified

The focus of this thesis is on a rights-based social supports infrastructure applicable to children/young persons with an intellectual disability. This approach is based on the view that a rights paradigm offers a useful way to consider the social supports infrastructure. The first of four research questions addressed in the thesis, therefore, refers to identifying the components of a relevant rights paradigm. Drawing on the human rights literature and related discourse, the researcher identified seven inter-related components of a rights-based paradigm relevant to the social supports infrastructure for children/young persons with an intellectual disability. Arriving at this seven-point conceptual framework involved a five-stage analytical pathway.

¹⁵ Carlson and Kittay (2010) suggest that authors using concepts of trusteeship, surrogacy, and guardianship, e.g., Nussbaum, Jennings and Wolff implicitly invoke such relational models.

The first stage involved distilling the main components of a rights approach set out in the literature and discussed earlier in the chapter with particular reference to the key underlying concepts of a rights approach (equality, citizenship and social solidarity) and to the provisions of international human rights conventions. This stage also involved factoring in critiques of the rights approach discussed in 2.6 above, including, in particular, the limitations of the identity group concept that underpins many rights' statements (Fineman 2008; Fraser 2003; Gatens 2004), the ineffectiveness of articulating rights that are not enforceable (Gatens 2004; James 2003; O'Neill 1996) and, in the case of Ireland, a heavy reliance on Government discretion in respect of the provision of 'rights-based' services (Flynn 2010). This process enabled the researcher to develop and set out an enhanced understanding of the rights perspective and the need to develop a fuller and more inclusive rights discourse accordingly.

The second stage involved looking more specifically at the rights approach as it applied to children/young persons with an intellectual disability. This drew on the provisions of the UN Convention on the Rights of the Child (UNCRC) (United Nations 1989) and on its specific provisions relating to children with disabilities as well as on the provisions of the UN Convention on the Rights of Persons with Disabilities which reflects the provisions of the UNCRC in respect of children with disabilities. This stage also drew on Nussbaum's (2006) capability theory (which enunciated ten capabilities which all governments should guarantee to all citizens), Honneth's (2003; 1995) concept of recognition, Woodhouse's (2000) five principles relevant to children's rights (equality; dignity; privacy; protection; and empowerment) and on the work of a number of authors in the area of rights of people with an intellectual disability (Koh 2004; Carlson and Kittay 2010; Francis and Silvers 2010; Nussbaum 2010).

The third stage involved the development of a set of categories and related sub-categories based on the analysis carried out in Stage One and Stage Two. Through a detailed and repeated process of allocation and re-allocation of the various aspects of the discourse and through re-visiting the literature, these categories and sub-categories were defined and re-defined so as to: (a) ensure that all of the relevant factors were included; (b) that each relevant factor was included in the most appropriate category; and (c) that each category was conceptually separate from the others. This resulted in the identification of seven categories which were identified by the researcher as reflective of all of the key components of an enhanced rights paradigm relevant to the social supports infrastructure relating to children/young persons with an intellectual disability.

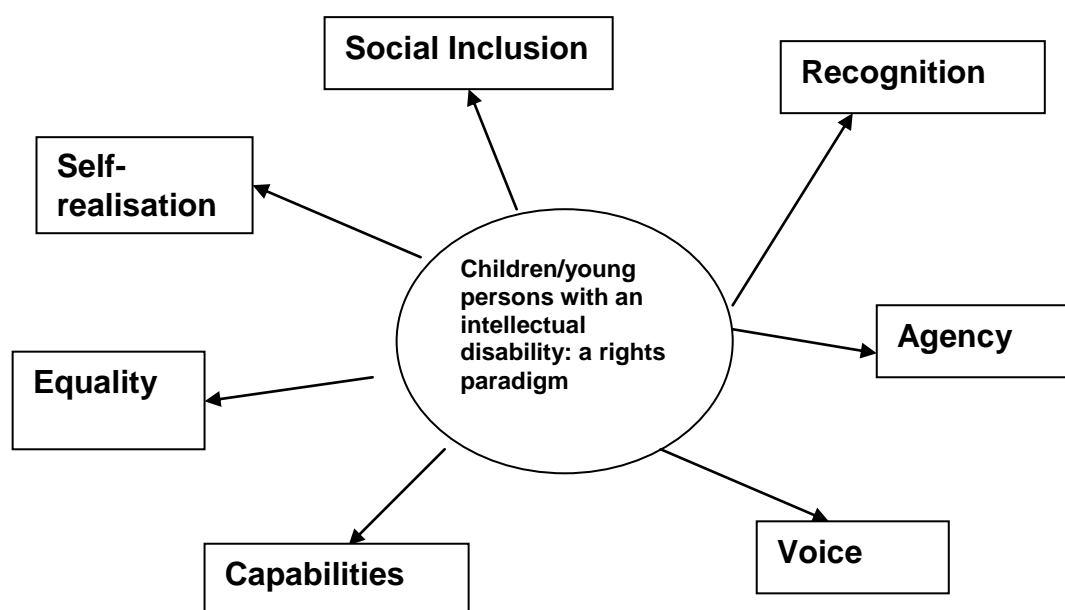
The fourth stage was a presentation of these categories by the researcher to his in-college PhD Committee and to two other academics for critical appraisal. The ensuing discussion and feedback resulted in some amendments being made to the category labels and some refinement of their description in order to provide as much clarity as possible about the content and distinctive nature of each category.

The fifth stage involved the researcher tracking back through the literature review to ensure that: (a) all relevant aspects of the rights discourse were captured in the list of categories; (b) the final category labels were reflective, as far as possible, of the points to be included and referenced in that category; and (c) each category was conceptually distinct and exclusive of the other categories.

The result of this five-stage process was the seven-point conceptual framework set out in Figure 2.2 and used as the main data analytical tool in the thesis. The components of this framework are social inclusion; recognition; agency; voice; capabilities; equality; and self-realisation.

For children/young persons with an intellectual disability, *social inclusion* means, on the one hand, equal treatment with other children to basic goods, services and protections, and, on the other, a positive affirmation of their shared citizenship at all points of engagement with societal structures and institutions (United Nations 2007). *Recognition* (Honneth 1995) refers to the esteem that one feels based on the respect that is afforded by

Figure 2.2: Seven components of a rights paradigm



others. A child/young person with an intellectual disability thus needs to be able to observe and feel that s/he has a recognised identity, experiences a sense of belonging and is given due regard by others. *Agency* refers to the ability of a person to act, make choices and decisions and express views (Carlson and Kittay 2010). For children/young persons with an intellectual disability, agency may need to be exercised in a more social, relational and supported context as distinct from engaging in individual autonomous actions. The concept of *voice* (Woodhouse 2000) is based on the right of a child/young person with an intellectual disability to express his/her views freely in all matters affecting him/her with the views of the child being given due weight in accordance with the age and maturity of the child

(United Nations 1989). The concept of *capabilities* (Nussbaum 2006) builds on the concepts of recognition and voice and includes being able to be treated as a dignified being whose worth is equal to that of others; being able to have attachments and to engage in critical reflection about the planning of one's own life. The concept of *equality*, in the context of children/young persons with an intellectual disability, means acknowledging that each individual, while differing in capacity, character and intelligence, is equally enabled to maximise his/her potential and has something to contribute to humanity. Related to capabilities, *self-realisation* refers to the development of the human person in all his/her dimensions. Self-realisation involves an understanding of life as involving the harmonious development of the person both as an individual and as a member of the wider collective (Markley and Harman 1982). It is based on the belief that a world increasingly subject to rational control creates the conditions in which people can shape their own lives (Prout 2006).

These seven components are used as a framework for an assessment of the social supports infrastructure carried out in Chapter Eight of the thesis.

Chapter summary

Part One of this chapter has set out the basic tenets and underlying principles of the human rights approach. It has provided an overview of the key UN treaties and conventions deemed relevant to children/young persons with an intellectual disability. The overall values that underpin human rights – citizenship and social solidarity, social justice and the inherent equality of all regardless of difference – have been described. The challenges to the rights perspective have been outlined and ways in which the rights approach could be enhanced have been discussed. In particular, the particular contributions of the concepts of recognition, the social imaginary and universal vulnerability have been identified.

Part Two focused more specifically on the rights of children with disabilities with particular reference to children/young persons with an intellectual disability. It set out the provisions for children with disabilities set out in UN rights conventions and protocols. Some of the limitations of these provisions have been outlined and discussed. The core components of an implementation framework for the rights of children with disabilities have been described drawing on the recommendations and proposals for action identified by the United Nations Committee on the Rights of the Child and by UNICEF. The need for more of a focus on needs-based rights in respect of children with disabilities and the need for a stronger integration between children's needs and children's capacities, as articulated by Woodhouse (2000), has been discussed. Her five principles of children's rights – the equality principle, the individual dignity principle, the privacy principle, the protection principle and the empowerment principle – have been enunciated. It has been suggested that this vision of children's rights is particularly useful in discussing the rights of children/young persons with an intellectual disability, the subject of the present thesis. The particular challenges of applying a rights-based paradigm to people with an intellectual disability have been discussed. Finally, drawing on the analysis

of the literature, seven key components of a rights paradigm applicable to the social supports infrastructure for children/young persons with an intellectual disability have been identified.

The chapter which follows will outline and discuss social support theory and in so doing will explore further the role of the social supports infrastructure in implementing a rights approach to children/young persons with an intellectual disability.

Chapter Three

Social Support: Definition, Theoretical Underpinnings and Conceptual Challenges

Introduction

The previous chapter has explored various dimensions of a rights-based approach and their relevance to addressing the needs of children/young persons with an intellectual disability. This chapter discusses the concept of social support (and related family and community support concepts) in order to identify a context for considering and applying a rights-based paradigm to children/young persons with an intellectual disability.

The chapter contains five sections:

- i. Defining social support
- ii. Theoretical underpinnings
- iii. Social support interventions
 - The different dimensions of social support
 - Family support
 - Community capacity
- iv. Challenges to the conceptualisation of social support theory
- v. Social support and children/young persons with an intellectual disability

3.1 Defining social support

Based on the ethic of solidarity, human rights values presuppose “an elaborate social support structure designed to liberate people in their own lives and not to imprison them in gilded cages” (Quinn and Degener 2002:15). While the literature includes many definitions of social support, there is not a consensus on a theoretical or empirical definition (House *et al.* 1988). Most researchers agree that social support refers to the assistance and help that one receives from others. McGrath *et al.* (2012) state that there is consensus among many researchers that a full understanding of what constitutes social support remains elusive in the professional and academic literature. Incorporated in most definitions is the exchange of one or more of three main types of support – emotional, informational, and instrumental – that people receive in times of need (Findler 2000). Emotional support involves the expression of empathy, reassurance, and positive regard, and is believed to enhance well-being by promoting self-esteem, reducing distress, and providing an emotional context for positive coping efforts. Informational support involves the provision of guidance, advice, or other information that can reduce

confusion, increase perceptions of self-efficacy, and form the basis for positive coping strategies. Instrumental support refers to the provision of money, goods, and services that can be used in coping and problem solving (Ellison 2006).

Additionally, some theories of social support highlight the importance of social integration – a sense of belonging – and the role of companionship and participation in social and leisure activities (House *et al.* 1988). Ireys and Sakwa (2006:10) (following Hobbs 1976) refer to social support as “information leading people to believe they are esteemed and valued and that they belong to a network of mutual obligations”. The need for increased efforts to differentiate social support from concepts such as caring has been emphasised by Finfgeld-Connett (2005). The subjective perception of support by recipients is another key dimension noted by several authors (Finfgeld-Connett 2005; Cutrona 2000; Lakey and Cohen 2000).

The kind of support, who provides the support, and contextual issues all play a role in determining whether support is perceived as beneficial (Hogan *et al.* 2002:428). House *et al.* (1988) suggest that the term social support and related terms (social networks and social integration) are often used interchangeably as general rubrics for a broad range of phenomena, generally dealing with consequences of social relationships for individual health and well-being. Finfgeld-Connett (2005) states that effective social support is context specific and involves an exchange of information

Social support appears to be most effectively delivered when all parties have a common context in which to anticipate, interpret and respond to each others' needs” (Finfgeld-Connett 2005:7).

Support can emerge from both natural and more formal support systems. Natural (informal) support systems encompass family (including grandparents, uncles, aunts and cousins), friendship networks and neighbours. Formal support is that provided by professionals or agencies either through direct service provision or through stimulating and enhancing the potential of informal support systems. Many sources of support, however, do not fall neatly within one or the other category (Dolan *et al.* 2006). For example, support offered through service delivery organisations or community support organisations may combine the two categories of support.

The importance of social support as a vital resource for individuals and families who are dealing and coping with stressful situations has been highlighted in the literature (Hogan *et al.* 2002). People who are involved in supportive social relationships experience benefits in terms of their health, morale and coping. Conversely, low levels of social support have been repeatedly linked to poor physical and mental health outcomes (Hogan *et al.* 2002). Ellison (2006), from her review of the literature, concluded that social networks and the social support that they provide buffer the adverse psychological impacts of exposure to stress by

promoting well-being and enhancing the use of coping processes. She cites Cohen and Wills (1985), Dunst *et al.* (1994), Thoits (1986) and Blankfeld and Holahan (1996) in support of her conclusion that “relationships with others, especially spouses, friends, and family members, can help individuals maintain emotional health during stressful life events and ongoing life strains” (Ellison 2006:13). The role of social support for families with a child with a disability has been emphasised (Ellison 2006; Findler 2000; Dunst *et al.* 1994).

While the basic assumption in much of the literature is that the provision of support is beneficial to people, Hogan *et al.* (2002:428) state that there is a growing body of research that suggests that the presence of ‘negative support’ (support that does not meet the needs of the recipient or behaviour that is perceived as harmful, critical or hostile) can be counterproductive.

3.2 Social support: theoretical underpinnings

For Hogan *et al.* (2002), “how support is conceptualized and operationalised within an intervention may be critical in determining the ultimate success of that intervention” (Hogan *et al.* 2002:383). Consideration of the theoretical traditions within social support research is thus regarded by Lakey and Cohen (2000) as crucially important:

Any statement about social support mechanisms must be qualified by the fact that many different interpersonal processes and constructs have been included under the rubric of social support ... For example, perceptions of available support, actual help received, seeking support and network characteristics ... are at best moderately correlated and appear to represent different constructs (Lakey and Cohen 2000:29–30).

Lakey and Cohen (2000) identify three theoretical perspectives used in social support research which, they argue, need to be differentiated conceptually:

- (i) The stress and coping perspective (including supportive actions and appraisal)
- (ii) The social constructionist perspective (including social cognition and symbolic interactionism)
- (iii) The relationship perspective

3.2.1 The stress and coping perspective

This perspective hypothesises that supportive actions reduce the effects of stressful life events on health because the supportive actions of others enhance the coping ability of the stressed. The related hypothesis is that “social support will be effective in promoting coping and reducing the effects of a stressor” (Lakey and Cohen 2000:31). An alternative stress and coping perspective postulated by Lakey and Cohen is that support protects people from the effects of stress by leading them to interpret

stressful situations less negatively. “How people interpret situations (i.e., appraisals) is very important in determining an event’s stressfulness” (Lakey and Cohen 2000:34). Lakey and Cohen describe two types of appraisals – primary and secondary.

Primary appraisals involve judgements of whether the event is a threat or not. Secondary appraisals involve evaluations of the ability to cope with the event ...More negative appraisals are hypothesised to lead to greater emotional distress (Lakey and Cohen 2000:34).

3.2.2 *The social constructionist perspective*

The social constructionist perspective on social support draws on social-cognitive theories and symbolic interactionism (Lakey and Cohen 2000). The basic assumptions of the social-cognitive view is that good social relations are essential for emotional wellbeing and, conversely, that negative thought about social relations leads to negative thought about the self, which in turn, leads to emotional distress.

The second theoretical perspective identified by Lakey and Cohen (2000) under the social constructionist perspective is symbolic interactionism. Meaning and identity are derived, in part, from the roles we occupy and create within a social context. The evaluation of one’s performance is seen as being rooted in social interactions and, perhaps, direct feedback from others. According to the symbolic interactionist perspective, social support directly promotes health and well-being by providing the individual with a way of making sense of the self and the world. Social support operates by helping create and sustain identity and self-esteem.¹⁶

3.2.3 *The relationship perspective*

The third perspective identified by Lakey and Cohen (2000) conceptualises support as part of a more generic relationship process. This perspective hypothesises that the impacts of support come from other aspects of relationship – companionship, attachment, guidance. Support may thus primarily reflect relationship satisfaction and intimacy understood as “the bonded, connected and close feelings that people have towards each other” (Barnes and Sternberg 1997 quoted in Lakey and Cohen 2000).

Levitt *et al.* (1993) posit what they term the ‘convoy’ model as an alternative to traditional approaches to social support in that it allows us to capture the complexity of social relationships across time and context. The social convoy is viewed as a network of relationships that moves with a person throughout his/her lifetime, changing in structure but providing continuity in the exchange of support. The convoy is represented as a series of concentric circles surrounding an individual. Inclusion of persons in the convoy is thought to be jointly determined by the individual’s emotional attachment to the person and by the role of the person in

¹⁶ This can be related to Honneth’s (2003) concept of ‘recognition’ which has been discussed in 2.6.1 above.

relation to the individual. Persons who are strongly linked to the individual, such as close family members, are likely to occupy the inner circle and to provide relatively high levels of support. Those who are less close, e.g., those who are linked primarily through role status, extended kinship, neighbourhood or friendships, are likely to occupy the outer regions and to provide less support. The latter relations are also likely to be less stable over time. Changes in the convoy are hypothesised to occur across normative life transitions, in response to non-normative events, or as a result of individual maturation (Levitt *et al.* 1993).

The Canadian Policy Research Networks Inc. (CPRN) (Valentine 2001) developed the 'nest' metaphor ((see Figure 3.1) to illustrate the interconnected nature of policy actors and how they support families with children (it applies equally well to individuals and families without children)

[C]hildren are "nested" in multiple environments...Each of these distinct spatial and political environments are also social nests in which children and, in turn, families are nurtured (Valentine 2001:v).

Figure 3.1: The Societal Nest



Source: Valentine (2001:v)

The concept of the 'cupped model' of family support developed by Dolan *et al.* (2006) is broadly similar to the CPRN nest. This places the child/young person and his/her nuclear family in the top cup, the wider family/friends in the second cup, the school/neighbourhood in the third cup, community/voluntary and statutory service providing agencies in the fourth cup and national policy/legislation in the bottom cup.

Lahey and Cohen (2000) suggest that there is a need for social support research to take cognisance of a number of key questions, including

whether measures of supportive actions adequately reflect the amount and quality of the social support received and whether the effects of support are stronger if support is matched to the demands of the stressor. Greater cognisance is also required, they argue, of how support is related to coping, which personal characteristics of supporters influence judgements of support and what categories people naturally use in thinking about support and social relations. Also, important is how beliefs in the availability of different types of support (tangible, belonging, esteem support) relate to primary and secondary appraisals.

3.3 Categorisation of social support interventions

House *et al.* (1988) distinguish between two elements of social relationship structure:

- (i) Social integration (which refers to the existence or quantity of social relationships; and
- (ii) Social network structure (which refers to the structural properties that characterise a set of relationships) (House *et al.* 1988:293).

Dolan *et al.* (2006), drawing on the literature, identify four types of social support:

- (i) Concrete support (practical acts of assistance);
- (ii) Emotional support (acts of empathy, 'being there' for someone when needed);
- (iii) Advice support; and
- (iv) Esteem support (how one person relates to another in terms of personal worth).

They further identify three qualities of social support – closeness; reciprocity (exchange of help); and durability (levels and rates of contact and length of time people are known to each other. Cutrona (2000) refers to three kinds of support providers – the 'expert' who can speak with authority about the problem, the 'veteran' who has been through the experience him/herself and fellow participants who are going through the same experience.

Findler (2000) identified three social support analytical axes:

- (i) Formal vs. informal
- (ii) Received vs. perceived
- (iii) Structural vs. functional

3.3.1 Formal vs. informal

The first axis distinguishes between informal support provided by family members, friends and by peers (other persons with similar difficulties) and formal support provided by a professionals (e.g., medical professional, psychologist, nurse, social worker or care worker). The main distinction between informal and formal sources of social support is the individual's or family's relationship with that individual or group. Informal support networks are comprised of individuals such as family members and friends as well as social and community groups. Formal services are organised to provide assistance and to assist individuals with specific needs (Dunst *et al.* 1988; Findler 2000). Support offered through the natural network is more likely to be culturally appropriate, and may be easier to accept than professional help (Walker and Sage 2006:5). Cutrona (2000) highlights the role of nurturant support (expressions of caring, empathy and concern) in cases where instrumental support cannot have an impact and suggests that in times of duress, the most meaningful support is that which we receive from the people closest to us and that the importance of friendship for well being persists across the life course (Cutrona 2000).

For Walker and Sage (2006), interventions that are intended to improve the quality of relationships within an existing network typically focus on strengthening a family's connections to natural support systems and to community organisations such as clubs, religious organisations and peer-run support organisations. Hogan *et al.* (2002) suggested that while, presumably, natural support networks are a more enduring source of support and while other forms of support may be more transient "whether one or the other is a superior source of support is not clear" (Hogan *et al.* 2002:383). Dolan *et al.* (2006) noted that when natural support is deemed to be weak, non-existent or incapable of offering the help required, a person is more likely to turn to formal sources of support. Formal support interventions may or may not work to increase the support received or perceived in the person's own natural environment.

One of the strengths of formal supports is that an organisation has the potential to provide a stable source of support over time.

This can help guard against 'burning out' individual support givers, or over-reliance on a particular relationship, since support can come from multiple sources (Walker and Sage 2006:5).

Dolan *et al.* (2006) noted that both the informal and formal have advantages and disadvantages:

Whereas informal support is non-stigmatising, cheap and available outside of 'nine to five', there are forms and degrees of need where professional help is clearly required ...families can also be the main source of strife, including abuse. In such cases direct intervention from professionals is certainly necessitated (Dolan *et al.* 2006:13–14).

Hogan *et al.* (2002), from their review of the research, concluded that social support interventions would likely be more effective if greater

attention were paid to matching a person's support needs with potential sources of support and that matching specific forms of support interventions to specific populations may be a particularly useful avenue for further research.

3.3.2 Received vs. perceived social support

A second analytical axis of social support interventions refers to received versus perceived social support. Conceptualising social support in terms of individuals' perception of social support is the most important aspect of the social support process (Vaux and Harrison 1985). Received social support is defined in terms of behaviours that assist the individual in accomplishing a goal (Findler 2000; Vaux and Harrison 1985). On the other hand, perceived social support refers to the recipients' understanding regarding the support provided by others. Here the recipient simply interprets the behaviours and intentions of others as being helpful (Findler 2000).

For Cohen and Syme (1985), feeling as though one has the right amount of social support in one's circumstances leads to a well-balanced life. Sandler and Barrera (1984) found that information regarding an individual's evaluation of his/her support system is more important than knowledge of the quantity of resources or support available to the individual. For example, in a study of parents of children with developmental disabilities, Dunst *et al.* (1994) found that parental views of the nature of support provided by others were related to satisfaction with support rather than the amount of support received. Results further indicated that parental perception of support was directly related to the well-being and functioning of the family. Hogan *et al.* (2002) noted that interventions that emphasised reciprocal support (e.g., both giving and receiving support) demonstrated more encouraging results, suggesting that merely receiving support may not be as potent as mutual exchanges of support" (Hogan *et al.* 2002:425).

3.3.3 Structural vs. functional social support

A third analytical axis of social support refers to the structural and functional measures of social support networks. Structural measures include characteristics such as the size, range, and interconnectedness of the social support networks (Ferrari and Sussman 1987). Structural social support measures are considered to be objective and generally define the existence or lack of fundamental social relationships and ties. Functional measures of social support refer to the emotional, informational, and instrumental qualities of the social support network (Findler 2000). Emotional support is characterised by behaviours such as an expression of love, care and solidarity, and fulfilment of personal needs. It involves verbal and nonverbal communication of caring and concern and is believed to reduce distress by restoring self-esteem and permitting the expression of feelings. It is about being available as a 'listening ear' for people and validating their feelings (Hogan *et al.* 2002).

Informational support is defined by education, training and other resources that empower individuals and increase their knowledge to enable them to improve their current situation (Thoits 1986). Informational support includes advice and knowledge, both formal advice from professionals and informal advice from others who have experienced similar situations. Technological advances in recent decades enhance significantly the delivery of informational support (Drentea and Moren-Cross 2005). Hogan *et al.* (2002) pointed to the growing use of on-line support through social media outlets and suggested that its usefulness needed to be further examined. They stated that on-line support groups “provide an opportunity for persons whose disability impairs mobility, for rural and other isolated populations, as well as for those who desire anonymity... the Internet can also be used to provide referral links and informational support” (Hogan *et al.* 2002:432).

Instrumental support is a tangible action that enables another person to carry out his/her personal responsibilities (House 1981). The instrumental qualities of social support include assistance such as goods, services, money, and helping with practical tasks. Instrumental support helps individuals with daily living needs and includes elements of physical help such as cooking, house-cleaning, personal care and transport.

Hogan *et al.* (2002) have identified two further classifications of social support interventions:

- (i) Group vs. individual
- (ii) Direct vs. enhancing the natural support system

3.3.4 Group vs. Individual

Interventions clearly differ in whether a group or individual format is used. Depending on the individual and on the existing social context, a group or individual support intervention may be the most effective. Also, a key consideration is that group formats tend to be more cost-effective which may be a key factor in the implementation of formal support programmes. Both group and individual interventions may involve the provision of support through family and/or friends, peers, professionals and, also, may have a skills enhancement component.

From their review of research, Hogan *et al.* (2002) identified four aspects of group supports – group interventions that provide support through family and/or friends, through peers (self-help groups), through support groups and through skills training group interventions. Similarly, individual interventions identified included support through family and/or friends, support through peers, support through professionals and individual skills training. Hogan *et al.* concluded from their review that “unfortunately, results of these studies do little to clarify the comparative efficacy of group and individual interventions” (Hogan *et al.* 2002:424).

3.3.5 Direct Support vs. Enhancing Natural Support System

This distinction refers to whether a given intervention is targeted at directly providing support (e.g., providing emotional, informational, or instrumental support, or increasing enacted support) or whether it is targeted at producing lasting changes in the naturally occurring support environment (e.g., developing or improving social skills or making changes in social networks).

These two different approaches have different conceptual underpinnings. Support provided by others is believed to strengthen coping resources, render a sense of being supported, and ultimately lead to a reduction in psychological or general health symptoms (Lakey and Lutz 1996). Interventions targeted at enhancing social skills or improving the naturally occurring social environment are based on the belief that people can create and maintain support systems (or their perception of the support received from these systems) if they acquire the necessary skills. The resulting improvements in support are assumed to improve health and well-being.

Cutrona and Cole (2000) suggested that the role of professionals “is to motivate and educate family, friends and neighbours to maximise the quality of care they provide to one another” (2000:280).

3.4 Persons with low levels of social support

A major challenge identified in the literature is that those that most need social support are least likely to have the social network to provide it (Tracy and Whittaker 1990; Gardner 2003). Davison *et al.* (2000), in exploring why people have low social support in the first instance, suggest the following as possible reasons:

- Persons low in social support may differ in whether they possess social skills or do not possess such skills;
- They may differ in whether their lack of social support is transient or enduring; and
- They may differ in whether their low level of social support is involuntary (and thus associated with a desire to increase social support) or voluntary (not associated with a desire to increase social support).

Hogan *et al.* (2002) suggest that some people lack social skills that would enable them to either:

- foster relationships that could provide them with the support they need,
- ask for support when needed, or

- perceive existing enacted support as available and helpful.

While some persons may lack assertiveness or conflict resolution skills, others may have trouble initiating and developing new relationships or nurturing existing ones.

... persons may suffer from low social support because they have personality disorders, some of which are associated with very limited or almost nonexistent social networks (e.g., avoidant personality disorder and schizoid personality disorder), while others experience very volatile interactions with their family members or friends (e.g., borderline personality disorder) (Hogan *et al.* 2002:430).

Some people, particularly those who are highly introverted or independent, may not desire additional support, even if their networks are relatively small (Walker and Sage 2006:8). While skills training may be of assistance to some people with skills deficits and low levels of enacted support from their social networks, "it is likely that the personality disorder itself must be addressed before meaningful and lasting changes in social support can occur" (Hogan *et al.* 2002:430).

A sub-group of people with low support levels identified by Hogan *et al.* (2002), from their review of research, are those who have lost their primary source of social support. This may be because of the death of a person close to them, a move of house, or after an event that has caused alienation from loved ones. Hogan *et al.* (2002) identified three other groups who may experience low levels of social support:

- (i) those who under normal circumstances have adequate levels of support but, in a time of crisis or increased stress, need an increase in support or a different kind of support;
- (ii) those whose relationships lack reciprocity (they have a desire to receive social support but do not provide social support to others and this imbalance leads to the withdrawal of support by others); and
- (iii) persons who genuinely do not want support from others.

3.5 The importance of reciprocity

Cutrona (2000) states that an important consideration when trying to build support resources for families is that people do not like to receive supports without the opportunity to repay or reciprocate in some way the help that they receive. She refers to research findings that show that support from a friend or spouse was valued more highly if it was given spontaneously rather than after a request. Finfgeld-Connett (2005) concludes that shared experiences coexist with mutual relationships in which reciprocity is the norm for both parties. For Hogan *et al.* (2002), "interventions that emphasized reciprocal support (e.g., both giving and receiving support) demonstrated more encouraging results, suggesting that merely receiving support may not be as potent as mutual exchanges of support" (Hogan *et al.* 2002:425).

3.6 Family support

Social support theory has been applied to the concept of family support (Dolan *et al.* 2006). At the top of Dolan *et al.*'s (2006) cupped model of family support are the child and the nuclear family. These are supported by the wider family and by friends which are in turn surrounded by the school and neighbourhood and then by community, voluntary, and statutory agencies, services, and organisations.

Family support is recognised as both a style of work and a set of activities that reinforce positive informal social networks through integrated programmes. These programmes combine statutory, voluntary/community and private services and are generally provided to families within their own homes and communities (Dolan *et al.* 2006:16).

Dunst *et al.* (2000) defined social support within the context of a family systems approach in which the family's social network system is instrumental in providing the resources needed for everyday living, in carrying out parenting responsibilities, and in supporting child learning and development. Support is often provided by family members and friends and by community agencies and organisations. These members of the family's social network provide a range of environmental experiences that will ultimately influence the development and behaviour of the child and the entire family. Pinkerton and Dolan (2007) posit the view that better mental health is associated with perceived support from the family. Dunst *et al.* (2000) suggest that experiences of social support strengthen the family by instilling feelings of competence and promoting new skills that are instrumental in helping families deal with children with disabilities (Dunst *et al.* 2000).

Frost and Dolan (2012) suggest that despite its complexity, difficulty of definition and ambiguity, family support has a central and crucial role within child welfare. Because family support is multilevel and multifaceted, in order to fully comprehend its complexity, there is a need to

draw on wider social theories (around equality and social change), mid-range social theories around communities and social resilience, and micro-theories concerned with bringing about change in individual families through one-to-one or therapeutic approaches (Frost and Dolan 2012:49).

Understanding family support, therefore, requires an examination of theories about the 'family' as a social construction and theories around the idea of 'support'. For Chaskin (2006), family support, as a field of practice, has been characterised by "the development and delivery of a diverse set of services provided by a broad range of practitioners and organizations (voluntary and statutory) in local communities" (Chaskin 2006:42).

Cutrona (2000) suggests that, while family support can be a critical resource for children who are striving to overcome adverse circumstances, supportive interventions are not always effective because of a number of factors, including, in particular, the source of support. "Support is most effective from those with whom we share close emotional bonds" (Cutrona

2000:120). For Gilligan (2000), family support is about mobilising that support in all contexts in which children live their lives – family, school, peer group and sports activities. In Ireland, the Commission on the Family highlighted the importance of family support as a preventive strategy through empowering of individuals, building on family strengths, enhancing self-esteem and engendering a sense of being able to influence one's situation (Commission on the Family 1998).

Dunst *et al.* (1993) identified family support principles as competency-enhancing as opposed to protectionistic; empowering as opposed to usurping and strengths-building as opposed to dependency forming. These principles underpin a sense of control which is a fundamental tenet of family support requiring resources commensurate with maximising their control and decision-making power regarding the services they receive (Dunst *et al.* 1993).

Frost and Dolan (2012) suggest a threefold classification of family support programmes – statewide initiatives (e.g., anti-child poverty programmes); community-based or neighbourhood initiatives (e.g., local community development programmes and building community capacity) and family-focused initiatives (e.g., partnership with parents to enhance coping capacity). They also (following Hardiker *et al.* 1991) suggest that family support can be understood in terms of the intentions or levels of intervention – primary prevention (universal programmes often area-based); secondary programmes (generally aimed at families with challenges) and tertiary prevention (focus on issues such as alcohol/drug abuse, child protection or domestic violence).

Principles of family support practice identified by Dolan *et al.* (2006) emphasise a partnership approach between children, families, professionals and communities which adopt a needs-led and strengths-based (including informal networks) intervention model and take clear account of the wishes, feelings, safety and well-being of children. Frost and Dolan (2012) conclude that because family support exists at the complex interface between the state and the family, “family support practice can be both political and controversial” (Frost and Dolan 2012:49).

3.6.1 Family support and children with disabilities

The Committee on the Rights of the Child (United Nations 2007) states that children with disabilities are best cared for and nurtured within their own family environment provided that the family is adequately provided for in all aspects. Most families of children with disabilities want their family member to live at home and believe that they can cope if given sufficient support services (Quin and Redmond 2005).

However problems occur when the basic services are inadequate and when mothers become exhausted from heavy burdens of physical care (Quin and Redmond 2005:148).

Appropriate family support is thus a central component in enabling families to carry out both their own wishes and in reflecting the widely held view that, for the most part, children are best cared for in their own family environment.

Providing families with well-designed support services must be done so that they do not experience restricted and diminished lives just because they have chosen to care for their family member with disability (Quin and Redmond 2005:148).

Support to families is identified by the UN Committee on the Rights of the Child (United Nations 2007) as including education of parent/s and siblings, not only on the disability and its causes but also on each child's unique physical and mental requirements; psychological support that is sensitive to the stress and difficulties imposed on families of children with disabilities; education on the family's common language, for example, sign language, so that parents and siblings can communicate with family members with disabilities; material support in the form of special allowances as well as consumable supplies and necessary equipment, such as special furniture and mobility devices that is deemed necessary for the child with a disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community. The UN Committee on the Rights of the Child (CRC) (United Nations 2007) also emphasises the role of the extended family, "which is still a main pillar of childcare in many communities and is considered one of the best alternatives for childcare" (United Nations 2007:13). The CRC states that this role should be strengthened and empowered to support the child and his/her parents or others taking care of the child.

3.7 Community capacity

Social support has been linked to the concepts of social ecology and social capital (Dolan 2008; Pinkerton and Dolan 2007). Community development is central to social ecology development (Bronfenbrenner 1979; Dolan 2008). This approach moves away from a focus on family function to a more holistic, broader view of how the environment influences outcomes for children and families. Social ecology theory focuses on how individuals and families, their communities and wider society mutually influence each other. Bronfenbrenner (1979), cited by Chaskin 2006:66) identified four types of systems which influence the development of each child:

- The microsystem (family, school, peer group, neighbourhood, and childcare environments)
- The meso-system (connections between immediate environments such as the child's home and school)
- The exo-system (external environments such as parent's workplace which indirectly affect development), and

- The macrosystem (the larger cultural context such as the national economy, public policy, culture, etc.).

According to ecological theory, if relationships in the immediate microsystem break down, the child will not have the tools to explore other parts of his/her environment. The ecology perspective is closely linked to social capital. The better connected a family is across the eco-system the greater the sources of social capital that will be available to them (Chaskin 2006). Building social capital involves empowerment, participation and engagement to reduce vulnerability and increase well-being for the individuals involved (Jack 2006). The concept of social capital focuses attention on the resources available within the family and in the community that can assist people in adversity. Having positive, available social capital allows people to build strong lasting social relationships.

3.7.1 Enhancing community capacity

Chaskin (2006) states that the community focus underpinning social support and family support interventions is based on the “importance of the community in the lives of families and its potential as an organizing principle for informing practice” (Chaskin 2006:43). This results in an emphasis on the goal of “strengthening the *capacity* of communities to identify priorities and opportunities, effectively support and provide for the individuals and families who live there, and work to foster and sustain positive community change” (Chaskin 2006:43). Dunst *et al.* (1993) suggested that a sense of community promotes the exchange of resources and supports that “constitute the range of aid and assistance necessary for enhancing individual, family, and community well-being” (Dunst *et al.* 1993:4).

The notion of community capacity building is identified by Chaskin (2001) as a key element in the rhetoric, missions, and activities of a broad range of contemporary community development efforts. The neighbourhood as a social unit and as a nexus of networks of relationship provides a context for fostering the development of interpersonal networks among neighbours and, through them, neighbourhood attachment and social participation. Chaskin (2001) suggests that although relational networks (and particularly “intimate” ties) among individuals are often dispersed beyond the neighbourhood, instrumental relationships among neighbours remain common, providing mechanisms through which information and support may be exchanged and links to systems beyond the neighbourhood may be fostered.

Chaskin (2001) points out that neighbourhoods are experienced differently by different populations and in different cultures. He suggests that people most integrated into the larger society tend to have larger, more dispersed, more casual neighbour networks and that those less integrated into the larger society tend to have smaller, more intense, and more frequently engaged relationships in the neighbourhood. Also, people living in particularly depleted neighbourhoods may have fewer intense, frequently engaged relationships within the neighbourhood. Chaskin also observes

that neighbourhoods are used differently by different populations. Neighbourhoods that are reasonably homogeneous, low-income, and have a fairly high percentage of young people may be the most likely areas for concentrated local use if the necessary facilities, services, and institutions are available. He also suggests that populations at both the very high and the very low ends of the socioeconomic spectrum may be less likely to concentrate their activities within their neighbourhoods.

3.8 Challenges to social support conceptualisation

Hogan *et al.* (2002), from their analysis of 100 studies¹⁷, concluded that the results of the research reviewed very tentatively suggested that support provided by friends and/or family members and by peers is beneficial and that social support skills training may be especially useful. “These findings hold across both individual and group interventions and for peer- and professionally-directed protocols” (Hogan *et al.* 2002:424). They concluded, however, that their analysis was “of limited use because many different types of interventions, delivery formats, and populations get lumped together” (Hogan *et al.* 2002:424). For these authors, “conceptual and methodological problems further prevent much confidence in simplistic reporting of results” (Hogan *et al.* 2002:425). Similarly, Walker and Sage (2006) concluded that methodological, analytical, and conceptual difficulties make it difficult to draw firm conclusions from the existing literature on social support interventions.

For Hogan *et al.* (2002), the most salient problem facing social support theory is that

most of the studies examining efficacy of support interventions failed to include a *measure* of social support. This is particularly striking because investigators usually posit that improved support is their hypothesized reason for otherwise observed benefits. Hence, underlying models cannot be tested (Hogan *et al.* 2002:425, added).¹⁸

Walker and Sage (2006) concluded that, despite conceptual and methodological issues,

the literature does point to some particular challenges that should be acknowledged – and some promising strategies that can be incorporated – in the design, implementation, and evaluation of future social support interventions in children’s mental health (Walker and Sage 2006:4).

A need for the study of social support to have greater sociological input to complement dominant psychological and biological orientations was identified by House *et al.* (1988). They argued that the impact of

¹⁷ Of the 100 studies examined by Hogan *et al.* (2002), 39 reported that supportive interventions were superior to no-treatment or standard care controls, 12 reported that interventions were superior or equivalent to alternate (also successful) treatments, 22 suggested partial benefits of support interventions, 17 suggested no benefit, and in two studies treated participants got worse. In eight studies, there were no controls that allowed comparison.

¹⁸ In the 100 studies reviewed by Hogan *et al.*. 30 different measures of social support were identified “many lacking in definitional specificity” (Hogan *et al.* 2002: 425).

macrosocial structures on social integration and social support needed to be better understood and posited the view that sociology and sociologists have much to contribute to the study of “structures and processes of social relationships and support” (House *et al.* 1988:315).

The interchangeable use of terms such as social support, social networks, social integration or isolation and social relationships in theoretical discussions and their application to almost identical, empirical phenomena and measures presented a difficulty for House *et al.* (1988). They suggested that previous literature on social relationships has focused primarily on the more microsocial or psychological level, largely ignoring the existence of important macrosocial determinants of levels and content of social relationships. Hogan *et al.* (2002) concluded that, despite a massive literature on the benefits of social support, there was surprisingly little hard evidence about how, and how well, social support interventions work.

The almost exclusive focus in the literature on social support (and on its related concepts, social networks or social integration) on social support as an independent, mediating or moderating variable was identified by House *et al.* (1988) as unsatisfactory. They argued that, for both scientific and practical or policy reasons, social support, social networks, and social integration must be viewed as *dependent* variables and that “more attention must be paid to the macrosocial structures and processes” (House *et al.* 1988:301). The need to distinguish between social integration and support both conceptually and empirically was seen by House *et al.* (1988) as reflecting Durkheim's conception of social integration as providing a sense of meaning and purpose in life and by creating a set of constraints or controls on individual behaviour. They suggested that only studies which simultaneously assess and study the interrelationships among multiple social, psychological, behavioural, and biological processes and mechanisms can advance our understanding of these issues.

To actualize this potential requires knowledge of the more macrosocial as well as the psychological or biological structures and processes that determine the nature and level of social relationships and their structure and content (House *et al.* 1988:309).

For House *et al.* (1988), failure to take account of macrosocial determinants of social relationship structure and content can lead to an overemphasis on policies that focus on changing individuals which may incorrectly and unfairly blame the victim and ultimately be ineffective. While accepting that it was highly plausible that various skills and dispositions of individuals affected their ability to establish and maintain social relationships, thus affecting the levels of social relationships they experience, House *et al.* challenged any assumption that the structure and content of social relationships may be due more to the dispositional characteristics of the person than to the nature of the social environment.

Three main issues relating to social support research were identified by Hogan *et al.* (2002). Firstly, they stated that it was still unclear whether support interventions were consistently effective modes of intervention and suggested that more randomised, controlled trials were necessary. Secondly, they stated that additional reliable and valid measures of social support were needed. Thirdly, they concluded that there was a need for more exploration of why people lack support in order to provide important clues as to how their support needs can best be met.

3.9 Social supports and children/young persons with an intellectual disability

Enhancing the community and family support system for children/young persons with an intellectual disability is essentially about realising the potential of existing support systems. Dunst *et al.* (1993) viewed family support programmes for people with disabilities as a social action movement aimed at supporting and strengthening family functioning.

As such, family support programs for persons with disabilities are considered a 'special case' of a broader-based set of initiatives that recognise the importance of providing resources and supports to families in a competency-enhancing manner ... (Dunst *et al.* 1993:1).

McConkey *et al.* (2013) refer to the particular expertise required to provide effective support services to families of children with disabilities who have complex needs and to the need to do this in the context of "a complex package of service inputs from differing agencies" (McConkey *et al.* 2013:5). Chadwick *et al.* (2013) identify a number of strategies as to how services can better support family carers in Ireland in their role, including:

families being provided with flexible and timely support... at critical times; being offered services, support, entitlements and information without having to fight for them; knowing that their family member with intellectual disabilities is well cared for, listened to and provided with opportunities to develop and be part of the community; and carers being shown respect, listened to and involved in decisions (Chadwick *et al.* 2013:119).

McConkey *et al.* (2013) conclude that an appropriate response requires a careful judgement by social workers and services in consultation with parents "as to when intensive support services might be offered to families, the amount of support that is provided and how this is adjusted over time and in response to competing demands from other families" (McConkey *et al.* 2013:6). Chadwick *et al.* (2013) refer to families being unique in their "personalities, structures, dynamics and propensity for adaptation" (Chadwick *et al.* 2013:130)

Policy makers, service providers and the wider community in Ireland and internationally should work more closely with families to address these needs to enable people with intellectual disabilities and their families to feel supported, empowered, included and afforded their basic human rights (Chadwick *et al.* 2013:130).

Parents of children with disabilities face extra demands and are vulnerable to stress. Social, emotional and material resources have been shown to aid family adjustment and parental coping and close familial support has been found to be particularly important (Mitchell 2007). The importance of closeness of personal relationships in the context of successful respite care has been noted by McConkey *et al.* (2013). While research on grandparent support in families with children with disabilities has been patchy and underdeveloped, the studies that exist “demonstrate that grandparents’ support, both practical (providing respite care and domestic help) and emotional (non-judgemental advice, a ‘listening ear’), is generally valued” (Mitchell 2007:97). However, for example, the provision of informal childcare by grandparents may lead to different or additional practical, emotional and financial costs for grandparents of disabled children compared with grandparents of non-disabled children (Mitchell 2007). Mitchell (2007) suggests that there is a need for professionals, when considering how best to support families of a child with disabilities, to recognise the support that grandparents provide and the support needs of grandparents themselves.

There is clear evidence for the social exclusion of people with disabilities generally and people with an intellectual disability in particular (Abbott and McConkey 2006). The Innocenti Digest (UNICEF 2007) emphasised a number of principles for advancing inclusion of children with disabilities which can be related to the concept of social support – consulting and listening to children with disabilities and their families; adopting a life-cycle and integrated approach that responds to the evolving capacities of the child, and working with parents, other family members, peers and communities. Promoting social inclusion for children with disabilities requires

mobilizing and increasing the capacity of those key individuals most influential and supportive for this process – especially the extended family, teachers, community members, health staff and other carers” (UNICEF 2007:38).

The Convention on the Rights of Persons with Disabilities, building on the provisions of the earlier Convention on the Rights of the Child as well as on the strong emergence in policy discourse of the social model of disability, laid the foundations for a more inclusive approach to social supports for children with disabilities and their families. Of particular relevance in this regard was the acknowledgement that disability cannot be considered in isolation but cuts across all aspects of a child’s life and can have very different implications at different stages in a child’s development. The emphasis on children with disabilities, like all other children, being supported in making their voices heard was a key consideration in rights-based statements and is centrally relevant to the concept of social support and the related need for governments and communities to make provisions accordingly.

As already stated in 2.4 above, Article 23 of the UNCRC refers to the obligations of States parties to ensure that a child with mental or physical disabilities is entitled to enjoy a full and decent life, in conditions that

ensure dignity, promote self-reliance and facilitate the child's active participation in the community. Requirements for the best interests of the child to be protected and for the participation of children themselves in decision-making are particularly important for children with disabilities, "whose interests and voices are all too frequently overlooked and undervalued" (UNICEF 2007:11). Specific reference is made in the Innocenti Digest (UNICEF 2007) to the Portage Model for Early Intervention¹⁹ which emphasises the provision of home-based services to children with disabilities and their families. The Portage Model provides well-structured assessment and learning procedures and an individualised curriculum based on the child's current level of development and the family's own priorities and resources (Rodgers 1998).

3.9.1 Friendship and peer support

Reference has been made to the important mutual support role that can be played by peers and friends in the lives of children with disabilities.

Children with different strengths can support each other in a number of ways, introduce different experiences and break down prejudices and preconceptions (UNICEF 2007:24).

While emphasising the importance of friendships and the rewards that come from having a network of friends, McConkey (2005) also notes that "people with disabilities have few close friends, whatever their age or wherever they live" (McConkey 2005:329). Abbott and McConkey (2006) identify key barriers to social inclusion of people with an intellectual disability as a lack of knowledge and skills to access community facilities, restrictive staff and service practices, transport access difficulties, the availability of community amenities and the attitudes of the public. Emerson and McVilly (2004) found that the service setting system restricted friendship more significantly than individual characteristics.

Encouraging children with disabilities to take part in sport and recreational activities in company with all their peers wherever possible is regarded as of critical importance. To this end the UNCRPD includes a specific clause requiring States parties to ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system (Article 30 5(d)). In this regard, the Innocenti Digest noted that:

Many simple and creative initiatives to support children with disabilities do not require new infrastructure or investment, but can simply build on community strengths and pre-existing facilities (UNICEF 2007:25).

McConkey (2005) cites Newton *et al.*'s (1994) framework for addressing the friendship needs of people with an intellectual disability. This overarching framework has four main components – social support, social

¹⁹ The Portage Model for Early Intervention, which originated in Portage, Wisconsin, USA, was developed in response to the growing need to provide services at home to young children with disabilities living in rural communities (Rodgers 1998).

interactions, social networks and social stability. This framework emphasises the importance of a range of supports with all stakeholders providing support rather than relying on a single programme or group of paid staff. Social interaction based on the provision of communication supports as required is vital in developing and maintaining friendships. The expansion of social networks is identified as a key requirement in the lives of people with an intellectual disability as is maintaining social stability in their lives through, for example, minimising the effects of regular service provider staff turnover.

O'Regan *et al.* (2009) applied Newton *et al.*'s framework in evaluating a 'Best Buddies' programme in the West of Ireland. They suggested that the Best Buddies Programme can offer people with intellectual disability the opportunity to increase their social support through the addition of an arranged relationship with their peer buddy and through related informal networks. Involvement in social activities and community based hobbies was found to be a vital aspect of providing people with opportunities to develop friendships in an age appropriate and least restrictive environment. It was noted that the programme has the potential to expand participants' social networks and, thereby, create conditions which may over time lead to additional friendships. On the social stability component, it was noted that there was some potential to build on connections made through the programme and, thereby, help to buffer some of the negative effects of disruptions to social networks when services are altered, modified or discontinued (O'Regan *et al.* 2009).

Siperstein *et al.* (1997) explored the nature and quality of preadolescent friendships between children with and without learning difficulties. They found that, unlike friendships between children without disabilities, friendships between children with and without learning problems were marked by limited collaboration and shared decision-making, a low level of co-operative play and an asymmetrical, hierarchical division of roles. Wenz-Gross and Siperstein (1997) suggested that our view of the social world of children with learning problems has been dominated by the negative reactions of others towards the child and that children with developmental delay or learning disabilities have been shown to have lower social status and to be perceived negatively by their nondisabled peers as well as their teachers (Wenz-Gross and Siperstein 1998). Thus, these authors highlighted the importance of examining the social ecology of children with learning problems from the child's own perspective, including the number and types of relationships that make up their social networks; their perceptions of to whom they can turn for social support (e.g., emotional support, problem-solving support, and companionship); the quality of their friendships; and the influence of social support on the way they adjust to school (Wenz-Gross and Siperstein 1997).

It has been argued (Wenz-Gross and Siperstein 1997) that the perspective of children with the disability should be a key consideration in looking at the whole domain of social supports. Included in this perspective should be how the child with disabilities envisions his/her social world. In this

regard, they cite two studies which suggested that children with mild disabilities do not differ from children without disabilities in the number of people they name in their network or in its composition. Wenz-Gross and Siperstein (1997) also suggest from their review of the limited research available that children with learning problems may use their networks for support differently than those without disabilities. Wenz-Gross and Siperstein (1997) suggest that their findings in relation to peer support may reflect a difference in the quality of students with learning problems' friendships. They also suggest that interventions aimed at strengthening and maintaining parental support and involvement, while important for all students, may be particularly important for students with learning problems, to supplement or compensate for poorer peer relationships (Wenz-Gross and Siperstein 1997).

Cairns *et al.* (1998) concluded that individuals cannot be understood outside of the social contexts in which they exist. Peer and friendship relationships are thus an important component of the social support infrastructure of all children/young persons (McGrath *et al.* 2012).

Friendships are contexts in which children can acquire or elaborate basic social skills like social communication and co-operation. Second, they provide children with self-knowledge as well as knowledge about other people and about the world. Third, they give children emotional support in the face of stress. Fourth, they are the forerunners of subsequent relationships (romantic, marital and parental) in that they provide experience of handling intimacy and mutual regulation (McGrath *et al.* 2012:3).

Gifford-Smith and Brownell (2003), from their analysis of relevant research on friendships and children, concluded that children's friendship choices appear to be important to their continuing adjustment and that "children with mutual friends are generally better adjusted and more socially competent than are children without friends" (Gifford-Smith and Brownell 2003:255). Gifford-Smith and Brownell (2003) make the point that friendships vary along many dimensions involving both positive and supportive interactions as well as conflictual and stressful interactions and that "who a child chooses as friends is as important as whether a child has friends or not" (Gifford-Smith and Brownell 2003:259). The importance of locating children's friendships and peer group social status in a larger social network of peer relationships and experiences is highlighted by Gifford-Smith and Brownell (2003).

One consequence of the emphasis on the individual or dyad as the primary unit of analysis in the study of peer relations has been the relative neglect of group level factors that shape children's social experience (Gifford-Smith and Brownell 2003:260).

Chapter summary

This chapter has drawn on the research literature to explore the concept and domains of social support and to identify the challenges to the theoretical underpinnings of social support research. The related concepts of family support and community capacity have been discussed and reference has been made to the concepts of social ecology and social

capital. Selected aspects of the application of social support concepts to children/young persons with an intellectual disability and their families have been considered. The role of peer relations among children/young persons and related social networks has also been explored.

The literature suggests that, while there is no single theoretical framework for social support that has been accepted by everybody, there is a consensus that both the psychological sense of support and expressions of support both play critical roles in maintaining health and well-being. Social support, however manifested, is important for physical and mental functioning. The kind of support, who provides the support, and contextual issues all play a role in determining whether support is perceived as beneficial. While the theory and measurement of social support have been expanding in recent years, a number of authors have suggested that there is surprisingly little hard evidence about how, and how well, social support interventions work. The literature also points to difficulties in translating social support research into effective interventions. Key questions arising from the research identified as requiring further consideration are whether or not effects are maintained over the long term and the reasons for intervention success and failure.

The importance of developing skills that allow people to ask for and receive the support that they need is a critical component of social support as are opportunities to reciprocate support. In general, support that communicates genuine caring, yet encourages the individual to solve his or own problems is most effective (Cutrona 2000). How a child's relations with parents, grandparents, siblings, friends and others are weaved into a cohesive network that provides support to the child is an important dimension of children's lives and a crucial area of inquiry for social support research in relation to children with disabilities (Ellison 2006). To the extent that children enjoy good relationships with their social support systems, they are likely to share their preoccupations and worries and that, once these preoccupations have been discussed with peers or parents, solutions are likely to be generated. A key consideration in all the discourse on social supports is that "it is not easy to change the nature of a person's social network" (Cutrona 2000:104).

Chapter Four

Irish Social Policy and Disability

Introduction

This chapter traces the development of Irish social policy in order to identify the context within which the development of a rights-based social supports infrastructure for children/young persons with an intellectual disability is explored in the present thesis. The chapter focuses in particular on a paradigm shift from welfare-based to rights-based legal provisions affecting people with disabilities generally that occurred during the 1990s. It also discusses relevant development in children's policy from a rights perspective in the last three decades.

The chapter is divided into three parts.

Part One describes the values underpinning Irish social policy and its main influencing factors. It traces the evolution of Irish social policy generally from the poor law system to welfare state provisions. The impact of the social inclusion principle is described as is the shift of responsibility for the provision of supports to people with disabilities from charitable organisations to the state and the public sector.

Part Two describes the impact on Irish social policy of the global paradigm shift from welfare to rights-based provisions. It describes the contribution of international human rights developments with particular reference to the rights of children and the rights of persons with disabilities. It locates these developments in the emergence of the social model of disability to replace the traditional medical model.

Part Three explores the concept of children's rights in Ireland and how these have been implemented in policy and practice. In particular, it looks at how the core provisions of the United Nations Convention on the Rights of the Child, as they relate directly or indirectly to children/young persons with an intellectual disability, are reflected in Government policy.

Part One: Irish Social Policy in Perspective

4.1 Irish social policy: underlying principles

In a seminal National Economic and Social Council (NESC) Report (NESC1975), Donnison defined social policy as:

Those actions of government which deliberately or accidentally affect the distribution of resources, status, opportunities and life chances among social groups and categories of people within the country and thus help to shape the general character and equity of its social relations (NESC 1975:30).

While this definition implies that virtually all government policies have a social component, some (income maintenance, housing, education and health) have been traditionally regarded as the main constituent elements of social policy “since they are the most visible instruments of achieving the distributive aims of government” (Curry 2005:1).

Four factors have been identified (NESC 1981) as triggering a social policy response from government:

- (i) A socially acceptable distribution of income and other resources that could not be guaranteed by a market economy
- (ii) A socially desirable level of provision of some particular goods and services (e.g., education and health)
- (iii) The community as a whole sharing the burden of dependency that arises from factors such as unemployment or illness and
- (iv) The concept of citizenship and social solidarity that confers rights to participation in the community, including social services

O'Mahony (1985), following Room (1979), identifies three models²⁰ of welfare provision in western capitalist societies, each associated with particular economic and political theories. Firstly, the *residual model* of welfare provision, based on neo-classical economic theory, emphasises the market system as the most rational basis for social organisation. According to this model, the market system is the best means of distributing life chances. It includes a strong focus on self-help and individuals purchasing privately produced services with the role of the State limited to the provision of a minimum subsistence standard of living for those in need with little focus on people's rights to basic services and supports from the State.

The second model, the *market liberal* model, shares many of the assumptions of the first model but sees an important role for social

²⁰ “The use of the ‘model’ as a conceptual tool for understanding complex social processes is well established in the discipline of sociology ... The model does not correspond precisely to social realities but rather to an abstract representation which isolates and describes the central characteristics of complex social phenomena” (O'Mahony 1985:16).

services as a mechanism to temper the harshness of the economic market, to protect the labour force from periodic economic downturns and to promote integration and social solidarity. While state help is to be limited to those individuals who are shown to be the most in need, the model advocates a reasonable standard of living for those dependent on the State. However, there is an emphasis on ensuring that increased public expenditure on services must be conditional on economic growth and that better provision for the poor depends on a larger national income rather than on changing the existing distribution of wealth (O'Mahony 1985). The third model, the *institutional redistribution* model differs fundamentally from the first two. This model challenges the free market system on the grounds that it facilitates the pursuit of self-interest to the exclusion of collective social goals. As a result, some western societies are characterised by poverty and social exclusion and an uneven pattern of public services to deal with such issues.

The institutional redistribution model (which sees a central role for the State in all areas and particularly in the area of income redistribution) emphasises collective State welfare provision to cater for all contingencies. According to this model, social rights are publicly defined and guaranteed rights for citizens that provide for equal access to a range of opportunities and experiences, in particular, those distributed through social policies and related services – health, education, housing and social welfare. Social rights under the institutional redistribution model guarantee an individual's free access to a fair share of society's resources. It thus becomes the responsibility of the State to ensure equal opportunity of access to a wide range of activities and opportunities through the provision of high quality, universally available social services as a matter of right to all citizens (O'Mahony 1985). The institutional redistribution model is identified in this thesis as the context required for a rights-based approach to flourish.

The predominant ethos of social service provision in Ireland would appear to broadly reflect the basic tenets of the market liberal model. The role of the State is to regulate the economic and social environment while simultaneously making provision for those deemed to be in need. Means tests are regularly used to establish eligibility for services. Service cutbacks (associated with economic downturns) in the 1970s and 1980s and, more recently, in the last five years (2009–2013) are clearly related to a basic tenet of the market liberal model that adequate levels of provision depend on economic growth. While the development of the welfare state in Ireland from the Poor Law system has brought about a gradual transformation, many of the original paternalistic overtones have survived (Cousins 2002). The market liberal model can also be said to be reflected in the mixed economy of welfare provision (public, voluntary and private) which is a strong feature of service provision in Ireland.

A structure for Ireland's welfare state proposed by NESC in 2005 (National Economic and Social Council 2005) (and subsequently incorporated in the ten-year social partnership agreement, *Towards 2016* (Department of the

Taoiseach 2006)) contains three overlapping areas of welfare state activity – “services, income supports and activist or innovative measures” (National Economic and Social Council 2005:xviii) – which embrace a life-cycle approach. For Murphy and Millar (2007), this approach largely “reinforces the presumption of social inclusion as being grounded in participation in the labour force and education” (Murphy and Millar 2007:84). In essence, the approach proposed favours redistributing opportunities through education, training and paid employment, the latter being the basic pathway to promoting equality and social inclusion. The primary role accorded government is

as regulator or guarantor of a diversified, high quality and equitable regime... [which requires] ... harnessing the characteristic contributions of direct public provision, non-profit organisations and the commercial sector (NESC 2005:170)

While reference is made to rights related expectations of, and demand for, a wider range of and better quality supports for disadvantaged groups, the focus is primarily on the role of the labour market as the core integrative mechanism. Murphy and Millar (2007) suggest that, while the NESC model has some plausible attributes, for example, in respect of mainstreaming public services and supports across the life-cycle, there has been an under-emphasis on need from a citizen perspective. Significantly, from the point of view of this thesis, the NESC document makes little reference to people with disabilities. While reference is made to the need for people with disabilities to have greater access to mainstream services, their right to enjoy the autonomy of which they are capable in order “to reflect our stronger contemporary awareness of the worth of each human person” (NESC 2005:199), there is no discourse on how this is to happen within the welfare state model proposed.

4.2 Factors influencing the development of Irish social policy

The shape of social policies and the type and level of services provided in any country are determined by a number of inter-related factors – socio-demographic, economic and ideological (Curry 2005). Fanning (2004) argues that the Catholic Church “was central... to the modernisation of Irish society within mass education, culture and politics” (Fanning 2004:12). “The ideological role of the Church with regard to social and sexual reproduction was complemented by its institutional contributions to nation-building” (Fanning 2004:12). Curry (2005) refers to the pre-eminence of Catholic social teaching until relatively recently which emphasised the principle of subsidiarity, *viz.*, that the state should not undertake functions that could be fulfilled by individuals on their own or by the local community, and that the state’s role should be to supplement and not supplant the role of the family and the local community. This was reflected in all levels of society, including a strong emphasis on a ‘Catholic sociology’ approach in Irish universities well into the second half of the 20th century (Fanning 2004).

More recently, the Catholic Church, in Ireland as well as internationally, has been highlighting issues of poverty and social exclusion and

emphasising inadequacies in social policies and services based on social justice arguments (Fanning 2004). This shift was accompanied by the emergence of a stronger involvement by civil society generally in social policy formulation.

In recent years voluntary sector groups and new social movements relating to gender, ethnicity, disability and sexuality have campaigned for rights-based approaches to social policy in opposition to strong resistance from successive centre-right ... governments (Fanning 2004:15)

The emergence in the 1990s of a neo-liberal narrative emphasised individualism and agency at the expense of an emphasis on structural barriers and inequalities (Fanning 2004). Fanning quotes Galbraith (1992) as suggesting that neo-liberalism has resuscitated the old Poor Law emphasis on poverty as a moral problem of individual failing. Allen's (2003) critique of the inequalities in 'Celtic Tiger' Ireland posits the view that social partnership mechanisms reflect a neo-liberal hegemony. Murphy-Lawless and Quin (2004) state that a significant feature in the 1980s and 1990s was a shift from the Keynesian model of welfare, grounded in egalitarian and collectivist values, "to the dominance of economic models of welfare which emphasised the values of pluralism, individualism and self-reliance" (Murphy-Lawless and Quin 2004:131). Peillon (2001) concludes that while Irish social policy has been shaped by a number of interconnected social forces, the project of the state is strongly influenced by the interests of the economic elite whose interests relate primarily to the promotion of economic development based on the concept of private enterprise. The role of social policy in reproducing social inequalities has been emphasised, in the area of education (Smyth 1999) and in maintaining existing differential access generally (UNICEF 2010).

4.3 The evolution of disability policy in Ireland

The policy response to disability was initially based on the perception of disability as a medical problem. State responses were either focused on medical treatment or financial compensation for what was regarded as a "personal tragedy" (Oliver 1990). This approach reflected to some extent the residual model of social welfare, kept people with disabilities institutionalised and emphasised provision by charitable groups with minimal input by the state. Historically, families of people with intellectual disabilities were encouraged to place them in an institution (Quin 2003). Gradually, services, based on a medical model of disability were introduced. While this approach was instrumental in the provision of services, the emphasis on the medical aspects of disability distracted from other areas like education, employment, transport and social relationships (Quin 2003).

Quin and Redmond (2005) note that by the 1950s major problems created by custodial institutional care for those with disabilities were being identified. They cite Goffman's seminal work, *Asylums* (Goffman 1961), which argued that the institution robbed people of their individuality. In

Ireland, Raftery and O'Sullivan's (1999) research highlighted the systematic abuse of children, some with physical and intellectual disability, in the reformatory school system from the foundation of the state to the mid-1970s. The growing disquiet with conditions of care for those with disabilities was reflected in pressure to move services for people with disabilities out of institutions and into smaller, community settings. "Such moves were not only in response to the demands for better quality care, but they were also related to the escalating costs of running large institutions and the belief that services could be provided at less cost within the community" (Quin and Redmond 2005:143).

The shift from institutional care services to community-based supports both reflected and gave impetus to the emerging paradigm shift from welfare to rights which will be discussed in Part Two of this chapter.

4.4 The impact of the 'social inclusion' principle

In recent decades, the notion has emerged that the welfare state should take more proactive measures beyond financial compensation for disability to ensure a decent standard of living for all citizens, including people with disabilities. This includes accessible housing and transport and supports for independent living in the community. In Ireland, the concepts of citizenship and social inclusion emerged strongly during the 1990s in the context of promoting a more participatory and egalitarian society. Social inclusion became a key goal of many policies and programmes introduced during the 1990s, particularly in the areas of welfare and health. Since 1997, Ireland has developed national policies to tackle poverty and social exclusion. These policies have sought to address poverty in a strategic and co-ordinated manner, based on an integrated framework of economic and social development. The national policies have been complimented by biennial national action plans and national strategies for social protection and social inclusion. During the 1990s new thinking emerged as a result of influences from the USA and Europe which introduced the concept of a rights-based approach to services, particularly in respect of people with disabilities (Lundstrom *et al.* 2000).

The current National Action Plan (*National Action Plan for Social Inclusion 2007–2016*) identifies a wide range of targets and interventions as well as a number of high level strategic goals in certain key priority areas in order to achieve the overall objective of reducing consistent poverty. The adoption of the lifecycle approach referred to above was seen as offering a comprehensive framework for implementing a streamlined, cross-cutting and visible approach to tackling poverty and social exclusion. This was reflected in the social partnership agreement, *Towards 2016* (Department of the Taoiseach 2006), which set out a strategic framework agreed by Government and the social partners to meet the economic and social challenges during the decade to 2016. The focus was on placing "the individual at the centre of policy development and delivery" (Department of the Taoiseach 2006:6) The vision for people with disabilities, as set out in *Towards 2016*, is one where they have, to the greatest extent possible, the opportunity to live a full life with their families and as part of their local

community, free from discrimination. Four lifecycle stages are identified: children, those of working age, older people, and people with disabilities. The following goals were set out in respect of people with disabilities:

- Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living;
- Every person with a disability would, in conformity with his/her needs and abilities, have access to appropriate care, health, education, employment and training and social services;
- Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing;
- Every person with a disability would be supported to enable him/her, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise his/her potential. (Department of the Taoiseach 2006:).

4.5 A changing disability policy and legislative context in Ireland

The 1990s were a period of profound change in policy, legislation and, to a lesser extent, service provision in respect of people with disabilities. New thinking emerged as a result of influences from the USA and Europe which challenged the perceived wisdom of the medical model of disability which had been dominant during the previous decades (Commission on the Status of People with Disabilities 1996).

The emerging paradigm shift from welfare to rights has been described by Banks and Kayess (1998) as a shift from a model dominated by service-providers to one in which self-determination for people with disabilities is theoretically paramount.

The belief that people with disabilities are best placed to define their own support needs and lifestyle choices represents a call by people with disabilities for independence, to have a voice, to have the right to make choices and to have control over actions that affect their lives (Banks and Kayess 1998:155).

On a more general level, the medical model of disability began to be challenged from the 1970s onwards with the emergence of Wolfensberger's (1972;1983) theories of normalisation and social role valorisation in the United States and the critique of the 'personal tragedy' definition of disability as highlighted by Oliver in the UK (Campbell and Oliver 1996). The principle of normalisation suggests that legal regulation affecting people with disabilities should be designed to ensure that patterns of life and conditions of everyday living are as close as possible to the regular circumstances and ways of life or society (Nirje 1969). Oliver's (2004) social model of disability postulated the theory that impairment was something that society could do something about rather than merely view it as a personal tragedy for individuals and that there was a need for steps to re-balance the system.

These emerging theories led to what Bellamy (1998) terms 'the braid of progress' in service provision to people with disabilities. He argues that disability services in the 1960s were based on a model of protection, which favoured the segregation of people with disabilities, both to protect them from society and to protect society from them. However, in the 1970s, with the increasing popularity of Wolfensberger's theories, the model for service provision moved more towards accommodating the diverse needs of people with disabilities and a cultural shift towards the right of people with disabilities to independence, including community living, supported employment and personal future planning. People with disabilities began to claim rights to appropriate services, initially for rehabilitation and subsequently for services which allow them to participate more fully in society (National Disability Authority 2003).

The paradigm shift from welfare to rights-based legal provision in Ireland occurred in the context of greater acceptance of the social model of disability and the recognition of disability as a human rights issue. The basis of this shift from welfare to rights-based provisions has been described by Quinn and Degener (2002) as the perception of people with disabilities as rights-bearers, rather than passive objects of welfare, charity and health programs. In 2000, the UN Special Rapporteur with responsibility for disability strongly articulated the view that disability is a human rights issue and that people with disabilities must be able to claim equal rights on the basis of equal value (Lindqvist 2000).

Summary of Part One

The values underpinning Irish social policy and its main influencing factors have been described. Historically, social supports for people with disabilities were provided by charitable and religious organisations. These organisations had complete discretion in the distribution of resources to vulnerable individuals, including people with disabilities (Clapton 1997). The shift of responsibility for the provision of services for people with disabilities to the state and the public sector occurred only slowly. The emergence of social inclusion as a key underlying policy principle was reflected in disability policies and children's policies. A paradigm shift occurred during the 1990s by which policies moved beyond viewing disability as a purely healthcare-related and medical phenomenon requiring financial compensation towards acknowledging people with disabilities as rights-bearing citizens. The next part will look at key developments in disability policy in Ireland during the period 1990 to 2010.

Part Two: Disability Policy in Ireland – Shift in Paradigm

4.6 Disability Policy in Ireland: Key Developments 1990–2012

4.6.1 *Report of the Commission on the Status of People with Disabilities (1996)*

The main trigger for change during the 1990s was, as already stated, the changing discourse emanating from a new approach to disability internationally. This led to the establishment of the Commission on the Status of Disabilities in 1993 and the publication of its seminal report in 1996. This was followed by the introduction of a series of new legislative provisions and the adoption by Government of the National Disability Strategy (Government of Ireland 2004). The Commission on the Status of People with Disabilities is generally acknowledged as a watershed and a key catalyst in shaping new thinking (Lundstrom *et al.* 2000). The Commission was tasked with the responsibility to record and document what contemporary life in Ireland was like for people with disabilities. Various mechanisms including submissions, consultations, interviews and focus groups were used to collect information. People with disabilities drew attention to their experience of being excluded from “every aspect of economic, social, political and economic life” (Commission on the Status of People with Disabilities 1996:4). They called for equality of opportunity which was at that time hindered by the lack of access to basic services such as transport, housing, employment, education and training and health. Information about services was not available in accessible formats which was identified as a further mechanism of exclusion of people with disabilities. The starting point of the Commission’s deliberations was that public attitudes towards disability were still based on charity rather than on rights. The Commission presented a number of recommendations on the basis of 3 guiding principles – equity, maximising participation and enabling independence and choice – which were seen as facilitating the full and equal participation of people with disabilities in Irish society. Such participation was regarded as essential in order to enable them to achieve their full potential, and to exercise their right to quality services that address their needs at all stages of the life-cycle. The Commission highlighted the principle that people with disabilities should be afforded the right to experience the same degree of fulfilment from relationships and sexuality as any other person in society.

4.6.2 *The National Disability Strategy*

The National Disability Strategy (Government of Ireland 2004) built on the emerging rights paradigm and the related need for equality of provisions and the need to prohibit discrimination against people with disabilities in employment and in the provision of goods and services. The National Disability Strategy aims to put in place an effective combination of legislation, policy, and services to support equal participation for people with disabilities. It aims to co-ordinate actions across Government Departments to deliver on the agenda of including people with disabilities in mainstream Irish life and provides for improvements in the accessibility

of health services and public services generally to people with disabilities (Government of Ireland 2004).

Equality and disability legislation

The first important step in the recognition of people with disabilities as full citizens in Ireland was the legal prohibition of discrimination on the ground of disability in both the private and the public spheres. Equality legislation was enacted to prohibit discrimination in the provision of goods and services, on a number of grounds, including disability, in the Employment Equality Acts 1998 and 2004 (Flynn 2010).

The Employment Equality Acts 1998 and 2004 prohibits discrimination across nine grounds (including disability). The Acts make provision for appropriate measures for people with disabilities in relation to access, participation and training in employment. The Equal Status Act 2000 obliges anyone providing a service to accommodate the needs of people with disabilities provided that to do so does not incur more than a 'nominal cost'. The Act requires a person providing goods or services to do all that is reasonable to accommodate the needs of a person with a disability by providing special facilities or treatment.²¹

A number of key legislative reforms were introduced as part of the National Disability Strategy – the Education for Persons with Special Educational Needs Act 2004, the Disability Act 2005 and the Citizens Information Act 2007 (which included provision for the establishment of a Personal Advocacy Service). Structures and a reporting framework were put in place to oversee the implementation of the National Disability Strategy. The Office for Disability and Mental Health, headed by a Minister of State, was established with a specific remit to develop cross-sectoral engagement across government departments.

Education for Persons with Special Educational Needs Act 2004

Following the launch of the National Disability Strategy in 2004, the first significant piece of 'rights-based' disability legislation which attempted to go beyond generic anti-discrimination provisions was the Education for Persons with Special Educational Needs Act 2004. This Act builds on the state's constitutional requirements to provide for free primary education for all persons under the age of 18, regardless of severity of disability and in a manner which is appropriate for the child's needs. The Act acknowledges that children with disabilities have a right to be educated in an inclusive environment²² and in a manner which is appropriate for their particular disability.²³

²¹ In 2004 the Act was amended, enacting 3 European directives on race, gender and employment into Irish Law.

²² Section 2, Education for Persons with Special Educational Needs Act 2004.

²³ *Ibid.* section 3(5).

The Disability Act 2005

The Disability Act 2005 is the central piece of legislation in the National Disability Strategy. It has as its main focus the advancement of participation by people with disabilities in everyday life. The Act defines disability as “a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment”.²⁴ This definition shifted the discourse from the focus on impairments included in the Employment Equality Acts (1998 and 2004) and the Equal Status (2000) (Flynn 2010). Part 3 of the Disability Act 2005 sets out the legal obligations of public bodies to provide integrated and accessible public services to people with disabilities, to provide assistance to people with disabilities to access services, to provide accessible information, and to engage in procurement of accessible goods and services.

Assessment of needs

A core provision of the Disability Act 2005 is the provision of an individual's right to an independent assessment of need for people with disabilities,²⁵ and a subsequent right to receive necessary social services on the basis of a service statement.²⁶ Standards for this needs assessment process have been developed through national consultation by the Health Information and Quality Authority. The standards seek to ensure that effective links with other services are established and stipulate that "where assessment of need reports indicate a requirement for referral beyond the health and education sectors, guidelines and pathways for such referrals are in place" (Health Information and Quality Authority 2007).

Citizens Information Act 2007

The final legislative component of the *National Disability Strategy* is the Citizens Information Act 2007, which makes provision for the establishment of a Personal Advocacy Service (PAS) as an independent state body to advocate for and on behalf of people with disabilities. The Personal Advocacy Service has not been established because of its relatively significant exchequer resources implications. The National Advocacy Service (NAS)²⁷ was set up in 2011 under the auspices of the Citizens Information Board to provide independent, representative advocacy services for people with disabilities. The National Advocacy Service is essentially different from the Personal Advocacy Service envisaged in the Citizens Information Act 2007 in that it does not have an independent statutory remit or a basis in legislative provision.

²⁴ Section 2(1), Disability Act 2005.

²⁵ Sections 8–9, Disability Act 2005.

²⁶ *Ibid.* section 11.

²⁷ The NAS has five regional teams who provide a service to people with all types of disability across the country. Each regional team is managed by a particular Citizens Information Service's Board.

The new policy and legislative framework that emerged was marked by a more socially inclusive approach to disability which was reflected in new concepts in policy discourse, including, in particular, the social model of disability, the recognition of 'voice' and self-advocacy ('nothing for us without us'), people with disabilities having the same choice, control and freedom as any other citizen (at home, at work and as members of the community) and the mainstreaming of service provision across the life-cycle. However, the issue of resources is centrally relevant in that if the end-product services are not actually available because of resource constraints, the legislative provisions and more inclusive policy discourse are in effect meaningless (Flynn 2010).

4.7 People with an intellectual disability: the move to a community support infrastructure

Policy developments for people with an intellectual disability from the 1990s onwards were shaped by three key policy documents – the *Report of the Commission of Inquiry on Mental Handicap* (Commission of Inquiry 1965), the 1984 policy document *Towards a Full Life* (Department of Health 1984) and the *Needs and Abilities* report (Review Group on Mental Handicap Services 1991). These were aimed at addressing the growing numbers of those with an intellectual disability in need of both better day services and residential care. The *Report of the Commission of Enquiry on Mental Handicap* specifically favoured the provision of these services through religious orders and voluntary bodies (Robins 1992), a policy decision which still has considerable impact on Irish service provision to the present day (Quin and Redmond 2005). *Towards a Full Life* (Department of Health 1984) supported joint statutory/voluntary involvement in service provision, favouring the enabling rather than the mandatory approach to service provision (Quin and Redmond 2005:143). The *Needs and Abilities* report supported the move from accommodation in large buildings on campus settings to the development of domestic-style houses clustered together on campuses and the provision of residential services in group houses in the community. The latter has gathered pace more recently with the concept of independent community living being actively promoted (Health Service Executive 2011). This recent trend towards deinstitutionalisation clearly reflects a social model of disability and an approach based on maximising the capacity of the individual in accordance with the provisions of the UNCRPD. It also reflected a growing view that people with an intellectual disability could live a full, inclusive life nurtured by those around them (Health Service Executive 2011). A report published by a HSE Working Group on Congregated Settings (Health Service Executive 2011) recommended a new model of support in the community. Under this model, people living in congregated settings would move to dispersed forms of housing in local communities provided in the main by housing authorities.

4.8 Changing the discourse: recent developments

Three specific manifestations of a new policy perspective on disability have emerged in more recent years. These are:

- The updating of mental capacity legislation
- The development of a new model of service delivery generally
- The establishment of new structures for delivering early childhood services and school-age supports to children with disabilities

4.8.1 *Updating Irish mental capacity legislation*

A widely acknowledged deficit in implementing a rights approach in Ireland has been the deficit in legislation relating to people with reduced capacity (National Disability Authority 2009). In order to address this deficit, the Government published the Mental Capacity Scheme of Bill in 2008. The Bill, which has not as yet been processed through the legislative machinery, would, if enacted, have important implications for protecting the rights of those with cognitive and mental health impairments who may lack capacity to consent. The proposed legislation is an important step in the process towards Ireland's ratification of the UN Convention on the Rights of Persons with Disabilities. Article 12 of the Convention states that people with disabilities shall enjoy legal capacity on an equal basis with others in all aspects of life and State Parties to the Convention shall take appropriate measures to provide access by people with disabilities to the support they may require in exercising their legal capacity.

A core provision in the proposed legislation is the provision for supported decision-making. The reference to assistance to the individual to enable decision-making offers significant potential for the development and enhancement of supported decision-making which is provided for in Article 12 (3) of the UNCRPD. A view was expressed, however, (Citizens Information Board 2010) that the Scheme of Mental Capacity Bill does not place sufficient emphasis on the concept of supported decision-making especially since people with different degrees of capacity will need to be assisted.

The presumption of legal capacity should, therefore, be reflected in a major emphasis in legislation on the concept of supported as distinct from substitute decision-making – the latter should be exceptional and should only be used when all avenues in supported decision-making have been exhausted (Citizens Information Board 2010).

4.8.2 *Reframing of disability policy*

The Value for Money (VFM) Review (Department of Health 2012) involved an evaluation of the efficiency and effectiveness of HSE spending under its Disability Services Programme as well as a review of the policy objectives behind the Programme in order to ensure that the system would meet the needs of the service users in the future in the most efficient and effective way possible. The Review proposed a fundamental change in approach to the governance, funding and focus of the Disability Services Programme, with the migration from an approach that is predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports. This was seen as requiring

more effective methods of assessing need, allocating resources and monitoring resource use as well as the articulation of a set of realistic, meaningful and quantifiable objectives to achieve measurable outcomes and quality for service users at the most economically viable cost.

The following vision statement is set out as the one which should underpin and reflect a revitalised and re-orientated Disability Services Programme:

To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being (Department of Health 2012:164).

The VFM Review (Department of Health 2012) noted that people with disabilities and their families are looking for more choice in disability services and control over how they access them. The Review identifies changed expectations of service users and families and a related need for flexible services that meet their individual needs and for systems which vest more control in the service user (and families, as appropriate).

A person-centred model is put forward in the Review as the basis of the future direction of disability policy. It is noted that this model has many facets and may be implemented in a number of ways.

Further work should be undertaken by the HSE and the Department of Health to identify the precise features of the model proposed, taking into account that the model will be multi-form and multi-faceted, in order that it may be fully appraised and costed" (Department of Health 2012:175).

Underpinning a new policy vision for people with disabilities and their families is the person with a disability as a self-determining citizen and a reframing of current disability service provision (Expert Reference Group (ERG) on Disability Policy 2011).

The shift in discourse referred to the wider needs of the person and the contributions s/he can make and focused on a system of individually tailored supports to ensure that the person with a disability gets the support s/he needs to live a full life. The new policy discourse around individualised supports was identified as requiring an approach to needs assessment that is driven by the person and family (as appropriate) and one which covers the important domains in a person's life. (Expert Reference Group (ERG) on Disability Policy 2011).

Individualised supports are conceptualised as individually-tailored personal and flexible supports which include a range of assistance and interventions required to enable an individual to live a fully included life in the community. The key characteristics of the individualised support concept are identified as:

- Determined by the person (in collaboration with their family/advocate as required and in consultation with an independent assessor) not the service provider or other ‘experts’;
- Directed by the person (with their family/advocate as required);
- Provided on a one-to-one basis to the person and not in group settings (unless that is the specific choice of the person and a ‘natural’ group activity, such as a team sport);
- Flexible and responsive, adapting to the person’s changing needs and wishes;
- Encompassing a wide range of sources and types of support so that very specific needs and wishes can be met;
- Not limited by what a single service provider can provide
- Having a high degree of specificity

(Expert Reference Group (ERG) on Disability Policy 2011:15).

(See Chapter Three above for a more detailed discussion of social supports generally.)

The VFM Review makes a number of recommendations relating to a reconfigured governance and accountability framework which refer to the administrative, funding and resource allocation framework (including pay and non-pay costs). It sets out guidelines for National Quality Framework to address standards, quality assurance, person-centred planning and outcome measurement. Choice, control, independence and community inclusion are identified as the keys to an effective person-centred service. The need to facilitate access to mainstream services in the areas of education, employment, housing, transport, healthcare and community inclusion is stated as is the need to provide personal assistance supports for adults who live in the community and therapy supports for children attending school. It is suggested that, where appropriate, clinical and therapy supports should be provided in a mainstream setting, i.e. provided by non-disability specific providers. “The precursor to this should be the establishment of the primary care network” (Department of Health 2012:176).

The Review states that all funding should be allocated on the basis of a standardised assessment of individual need, which should be linked to the resource allocation methodology. “Since it will not be feasible for all assessed needs to be met in full by the HSE in the context of competing resources, the protocols for prioritising need, and deciding which needs are met and which are not, should be transparent, fair and equitable” (Department of Health 2012:176).

The VFM Review has been criticised (Disability Federation of Ireland 2012). The underlying focus in the Review on cost savings as applied to existing models of service delivery was seen as limiting its ability to examine in sufficient depth how community-based disability specific and mainstream services could facilitate the transition to the new model proposed (Disability Federation of Ireland 2012). A further significant gap identified was the failure to give due consideration to many of the activities that facilitate people sustaining their lives in families and communities, such as peer group and family support, disability self-management, communication of information and pioneering work to make mainstream services accessible.

The Review was unable to analyse the efficiency or effectiveness of multidisciplinary services for children, PAs, the provision of aids, appliances and home support services, much less the enabling type supports..... the Review did not take into account the role of the social infrastructure in underpinning supports for people with disabilities (Disability Federation of Ireland 2012:4).

4.8.3 Restructuring of support services for children with disabilities

A need identified for a more equitable and consistent model of service delivery to children with disabilities resulted in two new integrative mechanisms being established in recent years – early intervention services and school age services.

Early intervention services

Early intervention services have long been recognised internationally as an important component in the development of children with disabilities as well as other groups of at-risk children (Office of Educational Research and Improvement 1996). In Ireland, Early Intervention Service Teams have been developed as a support service for children from birth to age six with childhood developmental delay or disabilities. In some areas, the service is provided directly by the HSE and in others by NGOs. The Team is made up of different professionals, including medical personnel, psychologists, speech and language therapists, physiotherapists, occupational therapists (OTs), social workers, nurses and educationalists. The Early Intervention Team works in partnership with parents and referral to the service is made by a paediatrician, a GP or a public health nurse or by direct contact by parents.²⁸ The team screens, assesses and identifies children's needs²⁹ and in consultation with the parents develops a plan of action for providing services in accordance with available resources. This plan may include individual therapy, group therapy and skills development, as well as supports for parents. The approach adopted is based on the concept of collaboration with families and maximising their input through the putting in place of partnership mechanisms (Muldoon 2009).

²⁸ The support of other specialists and relevant voluntary sector service providers may also be available to the team, if required.

²⁹ This assessment is different from the assessment of need under the Disability Act 2005 which has been discussed above.

Early childhood intervention services have usually been defined in terms of services to children with disabilities and their families (Moore 2010). This emphasis on service provision as the essence of early childhood intervention has been challenged by Dunst and Trivette (2009) who propose an alternative definition:

Early childhood intervention and family support are defined as the provision or mobilisation of supports and resources to families of young children from informal and formal social network members that either directly or indirectly influence and improve parent, family, and child behaviour and functioning (Dunst and Trivette 2009:126).

Moore (2010) notes that this definition differs from most other definitions by its inclusion of informal experiences and opportunities as 'interventions' contributing to improved functioning, and by its focus on parent and family capacity building as the principle means of supporting and strengthening child functioning. While the Irish model of early childhood intervention services includes reference to family involvement, it falls short of the more integrative model proposed by Dunst and Trivette (2009) and supported by Moore (2010).

School age programme

A national programme to integrate services and supports for school age children was launched in 2012. This programme is based on the recommendations of the Report of the National Reference Group on Multidisciplinary Services for Children Aged 5–18 Years (National Reference Group 2009) produced by representatives of the professions and management involved in delivering multi-disciplinary services to children.³⁰

The new model of service delivery is based on the premise of primary care teams meeting the general needs of children with disabilities. Children who require more complex supports and services would be supported by specialist early intervention and school age disability teams. It also builds on the premise of having one clear pathway for all children with disabilities. "This means health professionals and parents will know where a child should be referred and how to do this" (Health Service Executive 2012:1). This includes looking at what is currently available for children with disabilities, planning how best to use these resources and making sure throughout that there is good consultation and communication.

The Report of the National Reference Group on Multidisciplinary Services for Children aged 5–18 (National Reference Group 2009) concluded that health related services should be provided according to the biopsychosocial model which recognises disability as an interaction between the individual's impairment and the environment. Therefore, all services should address both the child's individual functioning and the needs of the family. It is recognised that the family provides the environment for the nurturing of the child and the achievement of best possible outcomes.

³⁰This group is comprised of representatives from a range of statutory agencies and NGOs.

The report called for clear referral pathways across health and education in each Local Health Office area for all children who require assessment and intervention. It further stated that children should receive their health services as close to their home as possible and that the initial intervention should be at mainstream primary care level with referral to specialist services when necessary. This was seen as requiring the availability of physiotherapists, occupational therapists, speech and language therapists, psychologists with paediatric training and expertise to work with children as part of the primary care infrastructure, with children with more complex needs being referred to a specialist school age network interdisciplinary teams. The National Reference Group recommended that further studies should be undertaken to inform planning, including mapping of current resources, prevalence of disability and related service requirements by each Local Health Office (National Reference Group 2009).

Summary of Part Two

The way in which people with disabilities are viewed, treated and included in society changed radically in Ireland as elsewhere during the last two decades. The social model of disability and the new discourse on rights-based provisions have resulted in fundamental changes in legislation, policies and practices. The National Disability Strategy sets out a blueprint for improving services. Recent developments and initiatives in the field of disability policy generally and in relation to children with disabilities have been described.

Part Three: Children's Rights in Ireland

4.9 Children's rights

This section sets out the evolution of policy discourse on children's rights in Ireland since the 1990s and identifies how this references and supports the rights of children/young persons with an intellectual disability.

The State's requirement to uphold the rights of children as specified in the 1990 United Nations Convention on the Rights of the Child (UNCRC) (ratified by Ireland in 1992) provides the context for a significant shift in policy over the past 20 years around the rights of children. The 1993 Report on the Kilkenny Incest Case (McGuinness 1993) and the more recent Report of the All-Party Oireachtas Committee on the Constitution (Government of Ireland 2006) (which identified the need for an amendment to the Irish Constitution to explicitly provide for children's rights) were also significant triggers for change. Dolan (2010) suggests that, while up to now children's rights have not always been explicitly protected or upheld, there has been a significant focus on meeting the needs of children, albeit sometimes driven by tragic events in the lives of families and outcries from concerned individuals (Dolan 2010). This position was perhaps rectified in 2012 with the passing of an amendment to the Irish Constitution which provided for specific rights for children (see 4.10 below).

4.9.1 *The National Children's Strategy and children/young persons with an intellectual disability*

The National Children's Strategy, *Our Children Their Lives* (Government of Ireland 2000), introduced as a ten-year Government Plan, in its broad thrust, aimed to support and underpin the UNCRC.

The 'whole child' perspective allows those working with or supporting children to focus on their particular interest and responsibility while, at the same time, recognising the multi-dimensional aspect of children's lives. It identifies the capacity of children to shape their own lives as they grow, while also being shaped and supported by the world around them (Government of Ireland 2000:24).

The Strategy, which was seen as a blueprint for improving the lives of children, had three main goals:

- Children would have a voice in matters which affect them and their views would be given due weight in accordance with their age and maturity.
- Children's lives would be better understood; their lives would benefit from evaluation, research and information on their needs, rights and the effectiveness of services.
- Children would receive quality supports and services to promote all aspects of their development (Government of Ireland 2000).

The strategy was seen as reflecting a widely acknowledged consensus that a more rounded view of children's needs was required as a basis for more effective policy development and service delivery. There was also an emerging recognition of children as citizens whose rights needed to be strengthened in legislation, policies and practices and whose voices needed to be heard. The strategy was based on the principle that the empowerment and support of families and communities was the most effective way of supporting children. Reflecting the provisions of the UNCRC, the main areas of children's concerns and needs were identified as health and wellbeing; learning and education; play, leisure and cultural opportunities; children in crisis; child poverty and youth homelessness; discrimination in children's lives; supporting children with disabilities; and responding to and harnessing children's concern for the environment (Government of Ireland 2000).

Children with disabilities were listed along with Traveller children and children from ethnic minority communities as having special needs which had to be considered and addressed both collectively and individually. Objective J of the strategy stated that "children with a disability will be entitled to the services they need to achieve their full potential". The promotion of participation at third-level by students with disabilities was also identified as an important strategic component (Government of Ireland 2000).

The *Agenda for Children's Services* (Government of Ireland 2007) sets out the strategic direction and key goals of public policy in relation to children's health and social services in Ireland. It draws together the various types of outcomes found in contemporary children's policy and presents them as a single list of seven National Service Outcomes for Children in Ireland:

- Healthy, both physically and mentally
- Supported in active learning
- Safe from accidental and intentional harm
- Economically secure
- Secure in the immediate and wider physical environment
- Part of positive networks of family, friends, neighbours and the community
- Included and participating in society

(Government of Ireland 2007).

This provided a single framework for the relevant Government Departments and agencies in all policy considerations and services related to children and families. In addition to these seven outcomes, the *Agenda for Children's Services* included a set of ten practice principles as

a common underpinning of a shared style of working for everyone contributing to achieving the outcomes:

- Working in partnership with children, families, professionals and communities
- Needs-led and striving for the minimum intervention required
- A clear focus on the wishes, feelings, safety and well-being of children
- A strengths-based/resilience perspective
- Strengthening informal support networks
- Accessible and flexible, incorporating both child protection and out-of-home care
- Facilitating self-referral and multi-access referral paths
- Involving service users and front-line providers in the planning, delivery and evaluation of services
- Promoting social inclusion, addressing issues of ethnicity, disability and rural/urban communities
- Measures of success routinely built into provision so as to facilitate evaluation (Government of Ireland 2007).

These principles were seen by Government as having currency at individual and agency level, and across front-line management and policy contexts (Government of Ireland 2007). The Agenda emphasised the point that outcomes are about both what is happening now in children's lives and what may happen for them in the future.

Outcomes address both the 'being' and the 'becoming' of childhood. Although there is considerable consensus about the types of outcomes that are desirable for children across the various dimensions of their lives and considerable understanding about how to achieve them, there continues to be many different ways in which these outcomes are described ((Government of Ireland 2007:12).

The Agenda was regarded as "a way of ensuring a common language of outcomes within children's services" ((Government of Ireland 2007:12).

The National Children's Strategy (Government of Ireland 2000) included a number of specific provisions for children with disabilities:

- More effective early intervention and respite services for children with disabilities

- An increase in the number of residential and associated day places (to enable all children have access to a residential place based on need)
- The development of quality training and placement to facilitate young people with disabilities to access employment
- The provision of suitable transport and aids/appliances where their absence is a barrier to participation in education or training
- An examination of the feasibility of introducing a cost-of-disability payment (Government of Ireland 2000).

A number of shortcomings have been identified in relation to the implementation of the strategy in the context of the children with disabilities (Children's Rights Alliance 2011). Specifically, the failure to implement the provisions of Part 2 of the Disability Act 2005 which gives people with disabilities an entitlement to an independent assessment of health and education needs and a service statement accordingly (other than for under five-year olds introduced in 2007) was noted. The terms used to frame standards for early intervention services ('develop more effective' and 'increase the number') were regarded as difficult to measure and, therefore, not suitable for a ten year strategy (Children's Rights Alliance 2011).

The provision in the Strategy for an increase in the number of residential places soon became redundant as the underlying philosophy in relation to residential places changed with residential places now seen as a last resort. However, a core issue remained in relation to residential centres for children with disabilities relating to inspection and standards (Children's Rights Alliance 2011). A process to address this matter was put in place in October 2012 with the publication of Draft Standards for Residential Centres for People with Disabilities which included a separate section for children (Health Information and Quality Authority 2012). However, provision for the establishment of these standards on a statutory basis subject to regulatory inspection has not yet been made.

Mechanisms for the transfer of resources for children with disabilities at transition points in education (pre-school to school, primary to second-level, second-level to university) were identified as unsatisfactory.

The present system is not child-centred and requires re-assessments at transition points, which can leave children waiting a number of months for necessary supports" (Children's Rights Alliance 2011:29).

The exploration of the feasibility of introducing a cost-of-disability payment, provided for in the Strategy, was undertaken by the National Disability Authority (NDA). An NDA Report (National Disability Authority and Indecon 2004) report recommended the introduction of a cost of disability payment but no such measure was introduced.

The Children's Rights Alliance (2011) concluded that overall the needs of children with disabilities remain unmet, noting that "accessing aids and appliances to support children's learning remains bureaucratic and complex" (Children's Rights Alliance 2011:29).

4.9.2 *Implementing the provisions of the UN Convention on the Rights of the Child*

As already discussed in Chapter Two, the guiding principles of the United Nations Convention on the Rights of the Child (UNCRC) are:

- a) That all children should be entitled to basic rights without discrimination
- b) The best interests of the child should be the primary concern of decision-making
- c) Children have the right to life, survival and development and
- d) The views of children must be taken into account in matters affecting them

The Irish government signed the United Nations Convention on the Rights of the Child (UNCRC) on 30 September 1990 and ratified it on 28 September 1992. The UN Committee on the Rights of the Child, a body of 18 internationally elected independent experts on children's rights, monitors progress towards implementing these rights. As a 'State Party' to the UNCRC, Ireland is required to submit periodic reports describing progress towards implementing the UNCRC in Ireland. Submissions (Shadow Reports) are also made by non-governmental organisations (NGOs) (in the case of Ireland, the Children's Rights Alliance³¹) and independent human rights bodies. Following a plenary hearing, the UN Committee issues its Concluding Observations and Recommendations.

In 2005, in accordance with protocol, Ireland submitted its Second Report to the UN Committee on the implementation of the UNCRC (Government of Ireland 2005) and the Children's Rights Alliance submitted its second shadow report (Children's Rights Alliance 2006).

Children with disabilities

The Second Shadow Report (Children's Rights Alliance 2006) acknowledged that there had been some significant advances in relation to the issue of disability since 1998, including the establishment of the National Disability Authority, an improvement in the provision of services for children with disabilities and legislative developments, with the enactment of the Equal Status Act 1998; the Education of Persons with Special Educational Needs Act 2004 and the Disability Act 2005. However, as already stated, neither the Education of Persons with Special

³¹ The Children's Rights Alliance is a coalition of over 100 non-governmental organisations (NGOs) working to secure the rights of children in Ireland, by campaigning for the full implementation of the UN Convention on the Rights of the Child.

Educational Needs Act 2004 nor the Disability Act 2005 was fully rights based. "There is no comprehensive legislation to ensure that children with disabilities have the right to access to a full range of health, social and educational services" (Children's Rights Alliance 2006: 41). Referring to young children (under 4 years) with severe developmental delay, the Second Shadow Report stated that Government support for these children had historically been low on the basis that they may not live much beyond early childhood. The point was made, for example, that while, in theory, all young children with severe developmental delay qualify for a medical card on the basis of medical need, in practice, however, these children can be and have been refused a medical card if their parents do not meet the income eligibility criteria. In addition, children with a severe developmental delay were seen as falling into the gap between acute hospital services and the services for those with a learning disability.

The Committee on the Rights of the Child in its Concluding Observations and Recommendations for Ireland (United Nations 2006a)³² welcomed the measures introduced by Ireland to date, including the establishment of the National Children's Office and the National Children's Advisory Council in 2001, the appointment of an Ombudsman for Children in 2004, and the establishment of the Office of Minister for Children in 2005. However, the Committee expressed regret that matters relating to the status of the child as a rights-holder and the adoption of a child rights-based approach in legislation, policies and practices had not been addressed satisfactorily. The Committee welcomed the creation of the National Children's Strategy as the main instrument for the improvement of the lives of children and for the enhancement of the protection their rights. The Committee also noted the over-arching principles guiding the actions and the goals set out in the Strategy and the broad-based co-operation and public consultations undertaken in its development, including with NGOs and academics. The Committee noted that, while steps had been taken in some areas to ensure respect for the best interests of the child, the principle was still insufficiently addressed (United Nations 2006a).

The Committee urged Ireland to further strengthen its efforts to ensure that the provisions of the UNCRC are widely known and understood by both adults and children, including through periodic and nation-wide public awareness-raising campaigns that include child-friendly material, and through targeted campaigns and necessary training for professionals working with children, in particular within schools and health and social services.

While welcoming legislative and policy developments such as the Disability Act 2005 and the National Disability Strategy of 2004, the Committee expressed concern that the legal framework inadequately addresses the specific needs of children with disabilities as well as their

³² The formal examination of the Second National Report of Ireland took place in Geneva on 20 September 2006 and the UN Committee issued its Concluding Observations and Recommendations for Ireland on 29 September 2006.

access to necessary health services and educational facilities. The Committee recommended that Ireland:

- a) Adopt an inclusive and rights-based legal framework that addresses the specific needs of children with disabilities and implement all relevant provisions of existing legislation related to children with disabilities; and
- b) Undertake awareness-raising campaigns with the involvement of children which focus on prevention and inclusion and combating negative societal attitudes towards children with disabilities

The Committee urged Ireland to review existing policies and practices in relation to children with disabilities, giving due attention to the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations 1993) and the recommendations adopted by the Committee.

The Second Shadow Report (Children's Rights Alliance 2006), referring to second-level education for children with disabilities, stated that, even though the Education for Persons with Special Educational Needs Act 2004 provides for co-ordination between the Health Service Executive and the Department of Education and Science (now the Department of Education and Skills), in practice co-ordination is problematic. Under the Act, there is no guaranteed entitlement to therapy or supports within schools for children with disabilities. Since special needs equipment belongs to the school rather than to the child, children moving from primary to second-level schools have to re-apply for their supports (Children's Rights Alliance 2006).

The incidence of early school leaving among children with disabilities was also highlighted in the Second Shadow report as being significantly higher than the average. More recent research shows that school-leavers with disabilities are four times less likely to progress to higher education (Heelan 2012). CSO figures indicate that people with disabilities are three times more likely to leave school before they are 15 and that adults with disabilities are twice as likely to be unemployed as adults who do not have a disability (Heelan 2012).

The Committee on the Rights of the Child recommended that Ireland should continue to undertake measures to create an educational environment where the special needs of the child are taken into consideration, including, *inter alia*, undertaking appropriate professional assessment of the specific needs of children, providing technical and material support for children with special needs, ensuring children in schools have the right to be heard in all matters concerning their well-being, and by continuing efforts to reduce overall class sizes to provide education to all children on an equal footing.

While the principle of inclusion is now much more widely accepted, the physical infrastructure to make this real is inadequate (Children's Rights

Alliance 2006). The main barrier for children with disabilities as well as those with specific learning difficulties has been identified as relating to the fact that the education system was never designed to include them.

It is a traditional system that has not changed in spite of the introduction of a policy of inclusion and mainstreaming. Instead it has opted for a sticking-plaster approach of adding compensatory supports (Heelan 2012).

The provision of compensatory supports and the application process for getting additional supports is identified by Heelan (2012) as administratively convoluted and highly complex. The under-provision of appropriate education services is highlighted by the fact that in recent years over one hundred families have begun court proceedings against the Department of Education and Science, “in an effort to secure appropriate educational services for their children” (Children’s Rights Alliance 2006:63). The fact that decisions are made within the context of constrained resources and inadequate therapeutic services, delays in the provision of specialised equipment and supports which have been deemed necessary to enable a child to reach his/her full potential was regarded as having an overall negative impact on the implementation of the UNCRC in respect of children with disabilities (Children’s Rights Alliance 2006).

The principle of respecting and facilitating the voice of the child as provided for in the UNCRC is particularly important in respect of children/young persons with an intellectual disability. Article 12 of the UNCRC stipulates that States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. It is Irish Government policy that children will have a voice in matters which affect them and that their views will be given due weight in accordance with their age and maturity (Government of Ireland 2000).

It is accepted that some progress has been made on facilitating the voice of children in public policy-making through the establishment of new mechanisms at national and local level for young people to express their views (Comhairle na nÓg, Dáil na nÓg and Coiste na dTeachtaí) (Department of Children and Youth Affairs (2010). The publication in 2005 of guidelines on children’s participation (Young Voices: Guidelines on how to Involve Children and Young People in your Work) was an important development in this regard. *Children First* includes a core principle of best practice in child protection the right of children to be heard, listened to and to be taken seriously. (Department of Children and Youth Affairs 2011).

The Children’s Rights Alliance has suggested that the practice of hearing young voices is still at an early stage of development in Ireland. “Until it is widely accepted that children have a right to speak for themselves, opportunities for children to speak on their own behalf will remain sporadic” (Children’s Rights Alliance 2006:21). The Committee on the Rights of the Child (United Nations 2006a) noted the measures undertaken to promote the respect for the views of the child, including

through the Children and Youth Parliaments, and the progress made to establish effective student councils in post-primary schools. The Committee, however, expressed concern about the high number of the complaints received by the Ombudsman for Children relating to a lack of respect for the views of the child (United Nations 2006a).

4.10 The rights of children/young persons with and intellectual disability: the current situation in Ireland

Dolan (2010) makes the point that ongoing invigoration of the rights of children through collective action by the state services (including the legal profession), civic society and children's own voices is vital to realising their rights. The need for a Constitutional Amendment was long argued for in order to protect children's rights and as a necessary step towards Ireland's full implementation of the UN Convention on the Rights of the Child. Such an amendment to the Irish Constitution was approved by the people in November 2012 and made provisions for a general recognition and affirmation of the rights of children:

- State intervention in certain cases to protect a child where his/her parents fail to do so
- Ensuring that the law treats all children equally in law, whether or not their parents are married, including in relation to the law on adoption
- A requirement that the best interests of children be regarded as the paramount consideration in the resolution of proceedings affecting children
- A requirement that the views of children be ascertained and given due weight according to their age and maturity in proceedings affecting them.

The amendment is seen by many as addressing the situation that existed up to now where constitutionally, and in practice, children's rights were not always explicitly protected or upheld (Dolan 2010). Kilkelly (2012) states that the amendment (Article 42A.1) commits the State to recognising and affirming the natural and imprescriptible rights of all children and, as far as practicable, by its laws protect and vindicate these rights. She makes the point that the amendment will act as a change to the threshold for State intervention in the family where the welfare of the child is affected and to make the best interests of the child paramount and the child's views heard in certain judicial proceedings.

Kilkelly (2012) suggests that in other countries constitutional protection of children's rights has been linked to the creation of a children's rights culture that can have positive effects on the way services are provided to children and the extent to which children enjoy their rights in practice. "It can lead to legislation that advances the rights of children in the areas of health, education, child protection, youth justice and immigration ... by

investing in education and training, decision-making across children's lives can be more effectively informed by regard for their rights and their views" (Kilkelly 2012).

The key change brought about by the Amendment is, in Kilkelly's view, that the Constitution will state that upholding children's rights becomes the State's responsibility, rather than something that falls within the private confines of the family. Article 42A.1 offers the potential of constitutional protection for a wider array of children's rights. It could, if the courts so decide, explicitly recognise the child's right to health, to identity, to protection from all forms of exploitation, to play and to know and be cared for by one's parents (Kilkelly 2012).

Other views on the constitutional amendment reflected a perspective that the amendment would make no effective change. For example, Sinnott (2012) argued that the existing Constitution contained adequate provision for the protection of children with disabilities and that the real issue was that the State would continue to circumvent the Constitution by the way legislation was framed, in particular, limiting the State's responsibilities on the basis of exchequer requirements. This had been the case in both the Education for Persons with Special Educational Needs Act 2004 and the Disability Act 2005 as discussed above.

The Children's Rights Alliance has noted that the amendment sets down a legal minimum standard which will have to be built upon in legislation, policy and practice. The following set of additional requirements has been identified (Children's Rights Alliance 2012):

- The timely introduction of specific legislation to give effect to the constitutional provisions
- The introduction of a comprehensive Children's Bill to address outstanding gaps, including the child's right to know his or her identity and reform of the law on guardianship
- Resources to support the implementation of the amendment
- A reliance by the judiciary and Oireachtas on the UN Convention on the Rights of the Child in its interpretation of the amendment, in particular when identifying 'natural and imprescriptible rights' for children (Article 42.A.1)

(Children's Rights Alliance 2012).

Ireland and rights enforcement

On the general area of rights enforcement, the United Nations has established a Universal Periodic Review (UPR) process whereby each country provides a progress report on its implementation of international rights provisions and Ireland has submitted its report accordingly (United Nations 2011). This report noted Ireland's commitment to the promotion and protection of human rights as an underlying principle of policy in all

spheres and stated the Government's overall goal of achieving full respect for human rights by building on the legal framework in the Irish Constitution and domestic legislation, as well as the international treaties and conventions to which Ireland is a party. *Your Rights Right Now* (a coalition of Irish civil society organisations working on a broad range of human rights issues), while welcoming Ireland's positive engagement with the UPR process, expressed concern about Ireland's outright failure to act on a number of rights components, including the judgment of the European Court of Human Rights on access to abortion, putting an end to ongoing religious discrimination in access to schools and recognising Irish Travellers as an official ethnic minority group. The group called for words to be translated into deeds and urged the timely ratification by Ireland of all core UN human rights instruments, especially the UNCRPD (International Federation of Human Rights Leagues/ *Your Rights Right Now* 2012).

Ireland has not yet ratified the UN Convention on the Rights of Persons with Disabilities. Flynn (2012) makes the point that, although the civil and political rights of people with disabilities in Ireland are protected in various ways and while many significant advances have been made in promoting their human rights, people with disabilities still experience serious difficulties with accessing social services and supports required to ensure equality. The system for allocating resources as outlined in the Disability Act 2005 relies heavily on governmental discretion and cannot be judicially challenged by a person who has an entitlement to services. Thus, despite these empowering elements of reform at international and national levels, the Irish legislation does not fulfil in practice many of the Convention's aspirations and thus cannot be said to be truly rights-based (Flynn 2010).

On the question of the implementation of children's rights, Ireland's last progress report to the UN Committee on the Rights of the Child was in 2005. A substantial progress report (the combined third and fourth reports) covering the period 2006 to 2011 is to be submitted to the UN Committee on the Rights of the Child in 2013. The Children's Rights Alliance Report Card 2013 (Children's Rights Alliance 2013) gave a 'D' grade to Government in respect of its response to children with special educational needs (including children with disabilities). While the National Children's Strategy (Government of Ireland 2000) takes it lead from the UNCRC and while the Strategy reflects support for a rights-based approach, the Strategy is not a rights-based document (National Children's Advisory Council n/d).

Summary of Part Three

Part Three has explored the concept of children's rights in Ireland and how these have been implemented in policy and practice. In particular, it has looked at how the core provisions of the United Convention on the Rights of the Child, as they relate directly or indirectly to children/young persons with an intellectual disability, are reflected in Government policy. The picture that emerges is of a growing recognition in policy discourse of children's rights since Ireland ratified the Convention in 1992. This

culminated in the amendment to the Irish Constitution in November 2012 which commits the State to recognising and affirming the natural and imprescriptible rights of all children. Despite these important developments, the failure to implement the provisions of the Disability Act 2005 referring to assessment of need, the shortfall in appropriate education services, the underdevelopment of provisions for facilitating the voice of children/young persons generally and, most importantly, the 'resource dependent' clause in various pieces of legislation contribute to a significant undermining of the rights of children with disabilities. Some progress has been made in the area of children's rights but much more needs to be done in the areas of education, awareness-raising and training in relation to implementing Article 12 of the UNCRC which emphasises the right of children to express their views freely in all matters affecting them. Affording due weight to the voice of children with an intellectual disability has rarely appeared to date in Irish social policy discourse. On the education front, children with disabilities continue to lose out despite the policy of inclusion and mainstreaming. The logical progression from the amendment to the Irish Constitution will be the enactment of comprehensive, rights-based legislation to address the rights of children generally and specifically the rights of children with disabilities and for the provision of resources commensurate with the implementation of such legislation.

Chapter summary

This chapter has traced the development of Irish social policy as it applies directly or indirectly to children/young persons with an intellectual disability. The chapter has focused in particular on a paradigm shift from welfare-based to rights-based legal provisions affecting people with disabilities generally that occurred during the 1990s and also discusses relevant development in children's policy from a rights perspective in the last three decades.

The need to secure the rights and entitlements of people with disabilities to participate fully and equally in society emerged as a major policy issue during the 1990s. The recommendations of the Commission on the Status of People with Disabilities (1996) became a central plank of disability policy resulting in the National Disability Strategy. Side by side with the new thinking on the rights of people with disabilities, the growing emphasis on the concept of social inclusion generally contributed to the new discourse around people with disabilities. The stronger focus on children's rights generally (triggered by the United Nations Conventions on the Rights of the Child and the need to create better child protection mechanisms) and on the development of integrated children's services created a climate and a policy context within which the specific needs of children with an intellectual disability could be explored.

Irish social policy generally retains a relatively large amount of discretion in the provision of services and resources. This is balanced by some legislative entitlements for people with disabilities which reflect an increasing acceptance of a rights-based approach in Ireland. However,

recurring problems include challenges encountered by disability service providers in adapting to a rights-based model of provision in the context of a gap between aspirations, legislative provisions and resources. Ensuring that children/young persons with an intellectual disability have the range of supports they and their families need and the opportunity to participate equally and effectively in education, employment and social life continues to present a significant challenge. The more recent policy emphasis on tailoring services and supports to meet the needs of individual citizens through a partnership model of social supports involving service users, their families and the non-statutory service providers remains to be tested. The Constitutional provisions for the rights of children will require a strong legislative, policy implementation and resource allocation infrastructure if these are to be meaningful for children generally, and, as a matter of equality, to meet the additional needs of children/young persons with an intellectual disability.

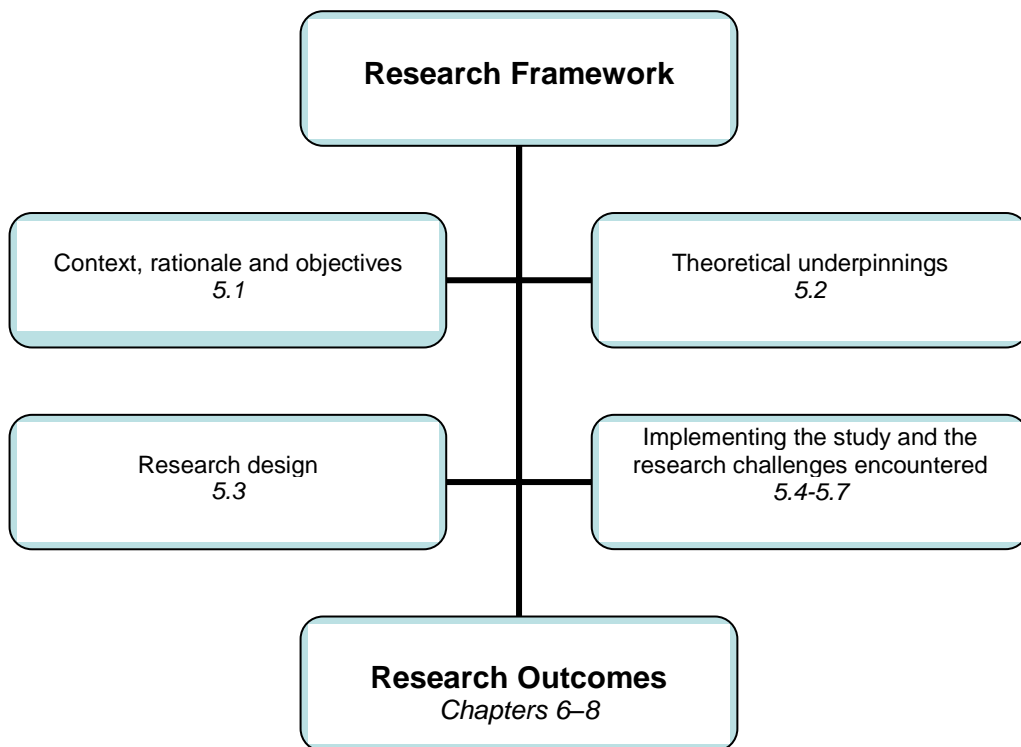
Chapter Five

Research Design and Methodology

Introduction

This chapter outlines the methodology used in order to address the objectives of this research. The chapter is divided into four sections. Section 5.1 describes the context, rationale and objectives of the study (Figure 5.1). Section 5.2 considers the theoretical perspectives underpinning the study. The research design is considered in Section 5.3 which also includes a detailed discussion of the Case Study approach used. In addition, it discusses relevant ethical considerations and identifies some of the limitations of the methodology used. Finally, the process of implementing the research is outlined in Section 5.4 and the research challenges encountered are identified.

Figure 5.1: Research design



5.1 Context, rationale and research objectives

The thesis takes as its starting point the view that there may be a deficit between rights-based principles³³ relating to children/young persons with

³³ These principles are gleaned from the literature on human rights and specifically reflect the provisions of both the UN Convention on the Rights of the Child (United Nations 1989) and the UN Convention on the Rights of Persons with Disabilities (United Nations 2006b).

an intellectual disability and social reality. The research focuses on children/young people with an intellectual disability in Ireland and specifically on the social support infrastructure in place to deliver outcomes in keeping with the components of a rights paradigm. It uses a case study approach to capture and analyse the experiences and perspectives of a sample of parents/guardians, a sample of children/young persons (aged over 16), a sample of service provider staff and a sample of other professionals involved with children/ young persons with an intellectual disability.

The overall aim of the research is:

To assess the realities of the current Irish social support infrastructure as it applies to children/young persons with an intellectual disability against a rights paradigm.

There are four related objectives:

- (i) To map the contours of a rights approach (and related Irish social policy aspirations) to social supports
- (ii) To ascertain the perspectives of key stakeholders in the delivery of social supports to children/young persons with an intellectual disability (parents/guardians, young persons and service professionals)
- (iii) To identify and analyse the current social support infrastructure for children with an intellectual disability and their families
- (iv) To critically assess this social supports infrastructure *vis à vis* the components of a rights paradigm

The main research task is to examine the existing social support infrastructure for children/young persons with an intellectual disability in Ireland in light of a rights-based paradigm and four main research questions are identified accordingly.

- (i) What are the components of a rights paradigm applicable to a social support infrastructure for children/young persons with an intellectual disability and their families?
- (ii) What are the social support dimensions applicable in enhancing a rights paradigm in respect of children/young persons with an intellectual disability and how are these reflected in practice?
- (iii) What are the strengths and deficits of the current social support infrastructure as it applies to children/young persons with an intellectual disability and their families?
- (iv) To what extent is a rights paradigm reflected in the current social support infrastructure for children/young persons with an intellectual disability in Ireland?

5.2 Theoretical underpinnings

The main theoretical considerations taken into account in designing a methodology appropriate for addressing the research objectives and related research questions are discussed in this section. Firstly, some general theoretical considerations are discussed and their methodological implications are considered. Secondly, the two main underlying theoretical concepts used to inform the study – a rights approach (discussed in Chapter Two) and social support theory (discussed in Chapter Three) are described briefly.

5.2.1 Theoretical basis

The theoretical basis of the research design informs both the way the research evolves and how the empirical data is analysed. Crotty (1998) makes the point that “justification of choice and particular use of methodology and methods is something that reaches into the assumptions about reality that we bring to our work” (Crotty 1998:2). The researcher’s beliefs on the nature of the reality being studied, his/her way of understanding *what is* (ontology) and his/her understanding of how knowledge is gained (epistemology) informs the way the researcher approaches his/her subject and the choice of methodology and the interpretations presented. Crotty (1998) suggests that ontological issues and epistemological issues tend to merge together “...to talk of the construction of meaning is to talk of the construction of meaningful reality” (Crotty 1998:10). Following Crotty, four aspects of the research design process are thus identified as relevant to this study and discussed below – epistemology, theoretical considerations and methodologies (including methods).

Epistemology refers to the theory of knowledge and deals with “the nature of knowledge, its possibility, scope and general basis” (Hamlyn 1995 quoted in Crotty 1998:8). The epistemological underpinnings of research refer to what is regarded as an acceptable form of knowledge within a particular discipline (Bryman 2012). Mason (2001) posits the view that the researcher’s epistemology informs the principles by which decisions about whether and how social phenomena can be known and how knowledge can be demonstrated are taken. The influence of personal experiences and culture is noted by Creswell (2007). This requires the researcher to establish an epistemological position at the outset *vis-à-vis* a particular study.

A central epistemological question is whether the natural and social sciences can be studied according to the same principles, procedures and ethos. Crotty (1998) addresses this question when he identifies three core epistemologies – objectivism, constructionism and subjectivism. Objectivist epistemology holds that meaning exists apart from the operation of any consciousness. Thus the objective truth relating to both things and people can be understood if we approach the phenomenon in the right way. An objectivist epistemology which is dominant in the natural sciences reflects a positivist approach which holds that knowledge is arrived at through the

gathering of facts (based largely on quantitative data) in a value free objective manner. Causality is established through testing hypotheses and demonstrating empirical regularities (Bryman 2012; Robson 2002). Purely positivistic approaches have been criticised on the basis that the characteristics and perspectives of the researcher come into play even within the natural sciences (Robson 2002). Post-positivism, recognising this criticism, accepted that the theories, hypothesis, background, knowledge and values of the researcher can influence what is being researched. While there is recognition of the likely effects of these biases, post-positivists continue to believe in the notion of objective reality and hold the view that it is the researcher's job to discover this reality (Reichardt and Rallis 1994; Robson 2002).

Constructionism (also known as 'constructivism' and 'interpretivism') rejects the objectivist view of human knowledge as reflected in positivism and post-positivism and offers a contrasting epistemological position. According to the constructionist perspective, there is no objective truth waiting to be discovered. "Truth or meaning, comes into existence in and out of our engagement with the realities in our world" (Crotty 1998:8). Thus, according to the constructionist approach, different people may construct meaning in different ways, even in relation to the same phenomenon. Essentially, the constructionist approach is based on the view that the study of the social world requires a different logic to that in the natural sciences.

In the third epistemological stance identified by Crotty, subjectivism, which "comes to the fore in structuralist, post-structuralist and postmodernist forms of thought" (Crotty 1998:9), meaning does not come out of an interplay between subject and object but is imposed on the object by the subject and the object as such makes no contribution to the generation of meaning. However, "Even in subjectivism we make meaning out of something. We import meaning from somewhere else" (Crotty 1998:9).

Similar to Crotty's (1998) three core epistemologies, Ritchie and Lewis (2003) refer to three broad stances:

- (i) Realism, which claims that there is an external reality which exists independently of people's understanding
- (ii) Materialism, which acknowledges that there is a real world but that this reality is held only in material manifestations such as physical space and
- (iii) Idealism, which posits a view of reality as known through the human mind and socially constructed meanings

This research adopts a broad constructionist approach based on the view that all meaningful reality is

contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context (Crotty 1998:42).

In the constructionist approach, the researcher works to a large extent from the 'bottom up' and uses the participants' perspectives to shape his/her own perspectives on the research objectives and questions. In this approach, the researcher and object of investigation are assumed to be linked, so that the findings are created rather than theories or hypotheses being proven or falsified.

The task of the researcher using a constructionist approach is to understand the multiple social constructions of meaning and knowledge. The need to distinguish between different types of knowledge and understanding has been noted by Mayer and Greenwood (1980) – value assumptions, presuppositions, empirical generalisations and hypotheses. Value assumptions are assertions about the way things ought to be and, as such, are not subject to empirical verification. However, because they are implicit in every research task, "such valuations need to be made explicit early in the [research] process" (Mayer and Greenwood 1980:27). Presuppositions are assumptions of a general nature that are assumed to be true within a given context but not necessarily known to be true. "Unlike value assumptions, they are potentially subject to empirical verification" (Mayer and Greenwood 1980:26). Empirical generalisations are propositions enunciating observable uniformities about persons or relations. They are true by virtue of the fact that they are empirically affirmed. Generalisations are formulated through the process of induction. "[They] conform to the canons of science – they are communicable, replicable, and verifiable" (Mayer and Greenwood 1980:27). Hypotheses are conjectures about uniformities because they have not yet been verified by observations. They are derived from some set of propositions which are known to be true or accepted as true and "have a theoretical or deductive basis but do not yet have an empirical basis" (Mayer and Greenwood 1980:27). In practice, hypotheses often grow out of personal experiences.

Being consistently constructionist requires researchers to put all their understandings, scientific and non-scientific alike, on the very same footing. They are all constructions. None is objective or absolute or truly generalisable (Crotty 1998:16). Patton (2002:51) suggests that the debate on objectivity or subjectivity is best avoided, aiming instead for "balance, fairness and completeness" in the research study. Crotty (1998) summarises this approach succinctly:

The long journey we are embarking upon arises out of an awareness on our part that, at every point in our research ...we inject a host of assumptions...Without unpacking these assumptions and clarifying them, no one (including ourselves!) can really divine what our research has been or what it is now saying (Crotty 1998:17).

5.2.2 Main underlying concepts

The research uses two main concepts to investigate the social realities of children/young persons with an intellectual disability and their families – a rights-based approach (discussed extensively in Chapter Two) and social supports (discussed extensively in Chapter Three). A starting point for the present study is that there may be a mismatch between the existing social

supports infrastructure as it applies to children/young persons with an intellectual disability and their families in Ireland and the requirements of a rights paradigm. The social support infrastructure as reported is thus juxtaposed with key components of a rights paradigm as generally understood and specifically as set out in two UN Conventions on Rights – the *Convention on the Rights of the Child* and the *Convention on the Rights of Persons with Disabilities*.

A rights-based approach sees people with a disability as subjects rather than objects and as equal citizens and stakeholders in society. There are four core values which underpin human rights:

- The inestimable dignity of each and every human being
- The concept of autonomy or self-determination that demands that the person be placed at the centre of all decisions affecting him/her
- The inherent equality of all regardless of difference
- The ethic of solidarity that requires society to sustain the freedom of the person with appropriate social supports (Quinn and Degener 2002).

This approach challenges the “social impulse to rank people in terms of their usefulness and to screen out those with significant differences” (Quinn and Dgener 2002:10). This means

giving them access to the full benefits of basic freedoms that most people take for granted and doing so in a way that is respectful and accommodating of their difference. It means abandoning the tendency to perceive people with disabilities as problems and viewing them instead in terms of their rights (Quinn and Degener 2002:9).

The UN *Convention on the Rights of the Child* (United Nations 1989) gives children and young persons a comprehensive set of rights, including the right to special protection measures and assistance, access to services such as education and health care and the right to develop their personalities, abilities and talents to the fullest potential. Article 7 of the UN *Convention on the Rights of Persons with Disabilities* (United Nations 2006b) requires States Parties to take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

For purposes of this research seven components of a rights paradigm relevant to a social support infrastructure for children/young persons with an intellectual disability have been identified – social inclusion, recognition, agency, voice, capabilities, equality and self-realisation.

Social support (discussed extensively in Chapter Three) is generally understood as an integral component for coping with the stresses of everyday life. Four main types of support have been identified by Cutrona (2000) – ‘concrete’ support (practical acts of assistance between people);

'emotional' (acts of empathy, listening and generally 'being there' for someone); 'advice' support (includes reassurance as well as advice); and 'esteem' support (how one person rates and informs another of their personal worth). The nature and extent of social support available to young persons is shaped by context, culture and other factors unique to local life (McGrath *et al.* 2012). Social support can emerge from both the natural (family, community/neighbourhood and friendship networks) and the more formal support systems.

5.3 The research design

This section describes the research design and the research approach selected. It discusses the relative strengths and weaknesses of the approach, and considers the ethical issues involved.

5.3.1 The methodological approach

The research methodology used in any study determines to a large extent the fit of the research design. Qualitative methodologies are generally regarded as supporting the constructionist approach to research in that they facilitate the acquisition of knowledge through a collaborative process between the population being studied and the researcher (Robson 2002). Denzin and Lincoln (2000) state that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them" (Denzin and Lincoln 2000:3). For Robson (2002), qualitative approaches show substantial flexibility in their research design, "typically anticipating that the design will emerge and develop during data collection" (Robson 2002:164). By contrast, quantitative approaches call for a tight pre-specification of the design prior to data collection.³⁴ Quantitative methods are described as methods which emphasise quantification in collection and analysis of data with a deductive approach to the relationship between theory and research (Bryman 2012).

This research, based as it is on a constructionist approach, seeks an in-depth understanding of the social supports infrastructure as it applies to children/young persons with an intellectual disability and their families. It also seeks to establish the extent to which this infrastructure reflects or does not reflect a rights paradigm. Thus qualitative research methods are regarded as offering a rich source of relevant data. Because this researcher wanted to get the individual and personal views and perspectives of the participants, a qualitative approach to data collection was deemed most appropriate in this study. The approach used thus entailed hearing, documenting and analysing the views and personal accounts of the main stakeholders – parents/guardians, children/young persons and those centrally involved in developing, managing and delivering social supports. The end product of qualitative research is a

³⁴ Robson (2002) uses the terms 'flexible' and 'fixed' designs rather than 'qualitative' and 'quantitative' approaches.

report characterised by comprehensive, holistic, expansive and rich description (Merriam 2009).

'Good' qualitative research design includes a number of characteristics (Robson 2002). Rigorous data collection, analysis and reporting procedures are required which typically involve multiple data collection techniques. The study needs to be framed within the assumptions of the qualitative approach, including "an evolving design, the presentation of multiple realities, the researcher as an instrument of data collection and a focus on participants' views" (Robson 2002:166). The need for the research to be open to using different traditions of enquiry is identified as is the need for the researcher to start with a single idea or problem that s/he seeks to understand. Merriam (2009) identifies four key characteristics of conducting qualitative research:

- (i) Focus on process, understanding and meaning
- (ii) The researcher as the primary instrument of data collection and analysis
- (iii) The research as an inductive process and
- (iv) The outcomes of the research as richly descriptive

The overall purpose of qualitative research is to achieve an understanding of how people make sense of their lives, delineate the process of meaning-making and how they interpret their experiences. For Patton (2002), a qualitative research design is naturalistic in that observations take place in real world settings and people are interviewed with open-ended questions in places which are familiar and comfortable to them. Accordingly, a wide range of interconnected methods are employed in order to: "get a better fix on the subject matter at hand" (Denzin and Lincoln 2000:2). This approach also provides an opportunity to explore unusual or unanticipated responses. In this study, completed parent/guardian survey questionnaires were used to identify, inform and refine emerging themes to pursue further in follow up interviews.

The present study seeks to expand the researcher's understanding of the social supports infrastructure. This understanding to date is informed primarily by his involvement in policy research relating to housing for people with disabilities.³⁵ This research pointed to a deficit between policy aspirations in relation to housing and related supports for people with disabilities and the supports put in place to facilitate independent living in the community. Patton (2002) notes that qualitative inquiry is: "particularly orientated towards exploration, discovery and inductive logic" (Patton 2002:55). Researchers should strive to gain an overall view of the issues

³⁵ See, for example, Browne, M. (2009), *The Right Living Space*, Citizens Information Board, www.citizensinformationboard.ie and Cotter, N., Browne, M. and Silke, D. (2011), *Review of Good Practice Models in the Provision of Housing and Related Supports for People with a Disability*, Housing Policy Discussion Series, Housing Agency, <http://www.housing.ie>

and context and to represent the range of realities of participants (Lincoln and Guba 1985) and the findings should be “believable and realistic, accurately reflecting the complexities of real life” (Robson 2002:166). The case study model adopted in this study allows for this.

Triangulation

Triangulation refers to the process whereby the researcher attempts to strengthen the validity of his/her observations by using more than one data collection method. Broadly defined, it is the process of “building checks and balances into a design through multiple data collecting strategies” (Patton 1987:60). As part of the case study and as an adjunct to the qualitative approach, two quantitative methods were used. First, a survey of parents/guardians of children/young persons using case study provider services was carried out (see Appendix Five). Second, Likert-type summation rating measures were used by the researcher to systematically establish the views of parents/guardians and service provider staff on a rights-based approach. Likert scales consist of statements which respondents are asked to rate from one to five. Five denotes the highest level of agreement with the statement.

In Likert scales the respondent is not asked to decide just whether he agrees or disagrees with an item, but rather to choose between several response categories, indicating various strengths of agreement and disagreement (Moser and Kalton 1975:361–362).

The Likert scale approach was deemed by the researcher to be a useful way of capturing the essence of research participants’ perceptions on a rights approach and as a way of checking and validating the perspectives gleaned from the survey and the semi-structured interviews.

5.3.2 The case study as a method of social inquiry

A key consideration in this research is to get an insight into the perspectives and experiences of those centrally involved in the social support infrastructure as it relates to children/young persons with an intellectual disability. A case study approach is adopted as a way of purposefully and efficiently getting those perspectives. The case study was carried out in collaboration with an NGO providing supports and services to people with an intellectual disability (including children/young persons). The case study involved a research engagement with a sample of parents/guardians, a sample of children/young persons and a sample of service provider staff and other professionals.

The case study as a research approach involves the observation of a single group or setting at point in time, in this case an agency providing services to people with an intellectual disability (Patton 1990; Robson, 2002). Robson (2002), following Yin (1981;1994), adopts the following definition of Case Study:

Case study is a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence (Robson 2002:178).

Robson (2002) notes that until relatively recently, case study was considered in methodology texts as something of a 'soft' research option possibly admissible as an exploratory precursor to some experiment or survey or as a complement to such approaches but of dubious value by itself. One of the standard criticisms of the case study is that findings deriving from it cannot be generalised and that the evidence derived from a case study has restricted external validity. Quantitative and survey researchers are concerned with being able to generalise their findings to larger populations and random sampling is frequently used to enhance the representativeness of the sample and, therefore, the external validity of their findings. In contrast, case study researchers argue that it is not the purpose of their research design to generalise to other cases or to populations beyond the case. Rather, the case study seeks to engage in a single examination of a single case in relation to which they then engage in a theoretical analysis (Bryman 2012). A crucial point is that a case study research design "*is not a flawed experimental design; it is fundamentally a different research strategy with its own designs*" (Robson 2002:180, *Italics in original*).

A major concern in case study research, as in other research designs, is the quality of the theoretical reasoning in which the researcher engages. "The crucial question is not whether the findings can be generalised to a wider universe but how well the researcher generates theory out of the findings" (Bryman 2012:71). Flyvbjerg (2006) identifies five common misunderstandings about case-study research which he explains and corrects, *viz.*

- (i) That theoretical (context-independent) knowledge is more valuable than concrete, practical (context-dependent) knowledge;
- (ii) That one cannot generalise from a single case and, that, therefore, the single case-study cannot contribute to scientific development;
- (iii) The case study is most useful for generating hypotheses, whereas other methods are more suitable for hypotheses testing and theory building;
- (iv) The case study contains a bias towards verification, i.e., a tendency to confirm the researcher's preconceived notions; and,
- (v) It is often difficult to summarise and develop general propositions on the basis of specific case studies.

Flyvbjerg (2006) posits five corrections to the five misunderstandings about case-study research that he identifies. First of all, he states that predictive theories and universals cannot be found in the study of human affairs and that, therefore, concrete, context-dependent knowledge is "more valuable than the vain search for predictive theories and universals" (Flyvbjerg 2006:224). Secondly, he argues that it is possible to generalise

on the basis of a single case and, more specifically, that the case study may act as a supplement or alternative to other methods. “But formal generalization is overvalued as a source of scientific development, whereas ‘the force of example’ is underestimated” (Flyvbjerg 2006:228). Thirdly, Flyvbjerg claims, “the case study is useful for both generating and testing of hypotheses but is not limited to these research activities alone” (Flyvbjerg 2006:229). He also argues that the case study contains no greater bias toward verification of the researcher’s preconceived notions than other methods of inquiry.

On the contrary, experience indicates that the case study contains a greater bias toward falsification of preconceived notions than toward verification (Flyvbjerg 2006:237).

Finally, Flyvbjerg (2006) acknowledges that summarising case studies is often difficult, but suggests that the problems in summarizing case studies “are due more often to the properties of the reality studied than to the case study as a research method” (Flyvbjerg 2006:241). Indeed, he suggests that it is often not desirable to summarize and generalize case studies but rather that “good studies should be read as narratives in their entirety” (Flyvbjerg 2006:241).

Bryman (2012), following Yin (2009), distinguishes five types of case.

- (i) The critical case is where the researcher has a well-developed theory and a case is chosen on the basis that it will provide a better understanding of the circumstances in which the hypothesis will and will not hold.
- (ii) The extreme or unique case refers to studies that focus on a particular context deemed to have characteristics not replicated elsewhere, e.g. a particular tribe or an event that holds an intrinsic interest at a particular point in time that makes it unique.
- (iii) The representative or typical or exemplifying case seeks to capture the circumstances and conditions of an everyday or commonplace situation. “The notion of exemplification implies that cases are often chosen not because they are extreme or unusual in some way but because they epitomize a broader category of cases or they will provide a suitable context for certain research questions to be answered” (Bryman 2012:70).
- (iv) The fourth type, the revelatory case has as its basis an opportunity to observe and analyse a phenomenon previously inaccessible to scientific research.
- (v) Finally, a longitudinal case may be chosen because it affords the opportunity to be investigated at two or more junctures.

Using Bryman’s typology, the present study is posited as a *representative* or *typical* or *exemplifying* case.

One of the strengths of the case study is that the researcher is in touch with the research process at all stages which allows him/her to develop a holistic picture of service users' experiences of particular programmes and interventions. Through the use of a case study, a wide range of information can be captured and analysed to identify patterns and themes in the data. In arguing for the merits of the case study, Flyvbjerg (2006) emphasises the importance of the closeness of the case study researcher to real life situations which allows for the development of a nuanced view of reality and the enhancement of the researcher's own learning processes.

Notwithstanding the many advantages of the case study approach, it presents methodological problems that must be fully acknowledged. These refer to questions about both internal and external validity. Internal validity refers to the validity of the research findings. How, for example, does the researcher know with certainty that his/her perceptions of the social processes observed are valid when dependent and explanatory variables are not quantified and measured? Clearly within the case study approach, this is not possible. Rather, the case study approach operates on the basis of marshalling a variety of pieces of evidence based on the principle of triangulation.

The second set of problems relates to the question of external validity. In survey-type research, problems of generalisation (extrapolation of findings to the population as a whole) are dealt with by means of sampling. The case study presents the data in terms of a single case and the question arises as to how representative this is. While no clear claims for generalisation can be applied to this approach, it can be suggested intuitively that the findings described may apply to other similar areas of the social support infrastructure for children/young persons with an intellectual disability in Ireland.

5.3.3 *Implementing the case study*

Selecting the case

In selecting the case, the researcher wanted to find a service provider with an underlying philosophy, ethos and modus operandi that broadly reflected the principles of a rights approach. The researcher looked at a number of NGOs and consulted with the National Federation of Voluntary Bodies (an umbrella Organisation for NGOs providing services to people with an intellectual disability in Ireland) and other key informants. Contact was made with sixteen NGOs and preliminary discussions took place with three who had indicated a willingness to consider the matter further. The case selected was based on five inter-related factors:

- (i) The presence of a rights approach to people with an intellectual disability in its mission statement and underlying principles
- (ii) A long tradition of providing services to people with an intellectual disability in Ireland

- (iii) The use of the Personal Outcomes model of service delivery for service users
- (iv) A willingness to participate in the study and an active interest in the research findings
- (v) Geographical location (in the West of Ireland where the researcher was based)

The mission statement of the case study service provider selected and its related principles fitted with the general principles of a rights approach. These focused on supporting people as persons to make individual choices about their lives rather than choices based on membership of a group and included the following as the core principles of service delivery:

- Community-based with an emphasis on mainstreaming, independence, and community involvement
- A person-centred approach whereby the needs of individuals are assessed and where individual plans are put in place for the provision of services and supports accordingly

Another relevant consideration from a rights perspective in the selection of the case was the fact the service provider has in place a Rights Committee with the aim of ensuring due process for individuals. The Committee membership includes staff, people receiving services, family representatives and community representatives.

A key factor in the selection of the case study service provider was its use of the Personal Outcomes approach which broadly reflected a rights approach. The Personal Outcomes model is the main approach to needs assessment and individual planning used by the case study service provider. It was developed in the USA by the Council on Quality and Leadership in Supports for People with Disabilities. The model has been in operation in the agency since 1997. The Personal Outcomes approach references 23 personal outcomes covering all aspects of a person's life – from safety and protection to the best possible health outcomes, having choices, achieving personal goals, connecting to families, having friends and relationships, living in the community and taking an active role in it and being able to assert one's rights.

The Personal Outcomes model is regarded as a way of ensuring that the services provided address need in an optimum manner and in a way that is responsive to the wishes of service users and their families. Thus measuring the quality of life for individual service users and the quality of the service that supports them in achieving their desired quality of life are key considerations (The Council on Quality and Leadership in Supports 2012). The interests, hopes, aspirations and skills of each individual are assessed and identified and supports and options are provided accordingly. In essence, Personal Outcomes are what people expect from

the supports and services they receive across key areas of living. They focus on expectations and issues that matter to each individual.

The case study service provider

The case study service provider has been involved in service delivery to people with an intellectual disability in the catchment area for over thirty-five years. There are currently 387 service users in total (24 in Early Childhood Services, 148 in School Age Services and 215 in Adult Services). There are 125 in residential accommodation supported by the service provider. The service provider does not have any large residential congregated setting.

The percentage breakdown of children/young persons receiving case study service provider services in different types of schools is mainstream school (63%); special school (16%); special class in mainstream school (13%) and Autism Specific Unit (9%). At pre-school stage, 35% are in mainstream services, 22% in special resource centres and 43% combining mainstream and resource centre (e.g., 2 days in one and 3 in the other). Support services provided include multi-disciplinary services (speech and language therapy, occupational therapy, physiotherapy, positive behaviour support, social work), respite services, residential services and rehabilitative training and day services.

5.4 Ethical considerations

Ethical considerations are integral to all research and include matters such as right to privacy, protection from harm and informed consent. Prior to the commencement of the case study, in accordance with NUIG requirements, ethics approval for the research proposal was sought from the NUIG Research Ethics Committee and this approval was granted in December 2010. Approval was also sought from and granted by the case study service provider's own research ethics committee.

A key ethical issue in the study is that of ensuring confidentiality and protecting the anonymity of all participants. Although all participation was anonymous, because the case study is based in a particular service and involves a relatively small number of families, it was important to ensure that information is disguised or omitted in order to protect the identities of children/young people, their families, staff members and other professionals. Confidentiality was guaranteed to all participants unless a child protection concern arose. Care was taken to ensure as high a degree of anonymity as possible. Names and contact details of participants were recorded only on the consent form. For further reference, each participant was given a reference number which was the only means of identification throughout the research documentation. While no names are used in the report and every effort is made to ensure that comments are not directly attributable to any identified individual, in some cases, it may be possible to infer that comments have been made by a particular individual where the participant group is very small. All participants were informed that,

although no names will be given, anonymity could not be absolutely guaranteed.

A central consideration in the case study is that every care and effort is made to make sure that absolutely no harm is done to the participants during or after their participation in the study. Some of the parents/guardians involved in the case study may experience stress associated with living with the reality of having a child/young person with an intellectual disability, coping with the day-to-day challenges and experiencing difficulties in accessing appropriate services. Thus it was essential that every effort was made to minimise any discomfort or distress that may arise for the participants in discussing their situation. Care was taken to ensure that prior to involvement each participant was fully informed about the nature of the study and the areas to be explored. The voluntary nature of the participation was emphasised and the fact that participants could withdraw at any time was made explicit.

In drawing up the various research instruments (information sheets, research consent form, questionnaire and interview schedule), the researcher drew on Patton's (2002:408) Ethics Checklist to help him ensure that best ethical practice was adhered to in the way the research was implemented.

1. Explaining purpose – how is the study explained, what language will make sense, what details are critical to share, what can be left out?
2. Promises and reciprocity – what is in it for the interviewee, why should the interviewee participate, can I keep all promises made?
3. Risk assessment – in there any way in which conducting the interview will put the person at risk?
4. Confidentiality – will names or locations be required, do participants have the option of being identified, what information will be anonymous, where will the data be stored, how long for, who will see it?
5. Informed consent – what kind of informed consent is necessary, what needs to be covered to ensure adequate information?
6. Advice – who will act as an advisor to the researcher in the event of a difficulty?
7. Ethical/value base – what ethical stance and value base informs your work, what is the code of conduct which will guide you as a researcher?

Because of the particular vulnerability of children/young persons with an intellectual disability, three criteria were applied in selecting the sample of children/young persons to be interviewed:

- (i) Aged over 16 years
- (ii) Consent by the child/young person and his/her parent/guardian
- (iii) Consensus involving the child/young person, his/her parent/guardian and key support staff that the young person had the capacity to understand the purpose of the interview and to give his/her consent and that participation in the study would have no harmful effects.

Each young person was informed prior to the interview that s/he could have a key support worker present if s/he so wished. Existing published Guidelines³⁶ were used in developing and implementing the research protocols. Protocols in line with *Children First* National Guidelines and the UNESCO Child and Family Research Centre NUIG, *Child Protection Policy* were put in place for conducting the interviews with young persons. The UNESCO NUIG Child and Family Research Centre *Protocol for Interviewing Children* included in its *Child Protection Policy* was observed (see Appendix One). To support the children/young persons to participate in the research and to help to ensure that they understand what is involved, information sheets, consent forms and interview schedules contained symbols and pictorial representations, where possible and appropriate.

Consent to participate in the study was sought from all participants. Materials were developed to provide information to and to seek consent from parents/guardians (see Appendix Two), children/young persons (see Appendix Three), service provider staff and other key informant professionals identified during the course of the study (see Appendix Four). Before an interview or focus group discussion, all participants were asked for their consent to have the interviews audio-recorded – if a participant was not willing to give his/her consent for this, audio-recording was not used and was replaced by the researcher making detailed written notes. (The latter happened in the case of one interviewee.)

5.5 Validating the case study findings

Both Patton (1990) and Sandalowski (2004) argue that the understanding and descriptive reporting of what is happening in a particular setting is a valued end in itself. As already stated, the literature suggests that by using triangulation of methods researchers can be assured that the picture they present of reality of a situation is clear and true.

The case study approach adopted in the research is based on the process of building checks and balances into a design through multiple data collection strategies (Patton 1987). Four sources of data are used:

³⁶ National Federation of Voluntary Bodies (2005), *Consent in Research*; Brothers of Charity, *National Guidelines for Research*; National Disability Authority (2002), *Guidelines for Including People with Disabilities in Research*; National Federation of Voluntary Bodies (2005), *Guidelines for Interviewing People with an Intellectual Disability*.

- (i) A postal survey of parents/guardians
- (ii) Semi-structured interviews with a sample of parents/guardians, a sample of young persons and a sample of service provider staff and professionals
- (iii) Likert-type scale ratings by parents/guardians and staff of rights-based statements
- (iv) Documentary analysis and
- (v) Validation of emerging findings through a focus group with personnel from other agencies providing services to children/young persons with an intellectual disability

The semi-structured qualitative interviews with a sample of parents/guardians focused on specific aspects of the social support infrastructure (as identified in the survey questionnaires) and the way it is perceived. The interviews sought to get an elaboration on the views and perceptions of parents/guardians on core aspects of a rights-based social supports infrastructure. The semi-structured interviews with a sample of young persons (aged over 16 years) sought to get their views and perspectives on the same aspects of the social support infrastructure and the semi-structured interviews with a sample of service provider staff and professionals did likewise.

5.6 Methodological challenges and limitations

A number of methodological challenges emerged as the study progressed. Since the focus of the study is on the social support infrastructure as it applies to children/young persons with an intellectual disability, it was considered essential to have input by the group themselves to ensure that their perspectives and experiences are taken into account as well as those of their parents/guardians and the providers of services. Finding ways to support the ‘voice’ and ‘experience’ of children/young persons in the study, an approach in keeping with the “rights” emphasis of disability theory, intervention and research (Quinn and Degener 2002) was an important consideration. A key question identified early on by the researcher and one raised by the NUIG Research Ethics Committee was how to implement this part of the research taking into account the fact that some children/young persons may not have the capacity to understand the nature of the study and to consent to participate in an interview with the researcher accordingly. Following a review of the literature on the matter and following discussions with personnel working in the field, the researcher decided that only those aged over 16 would be interviewed and that additional specific protocols would be put in place for selecting the sample prior to approaching the young person. The specific approach used is outlined in the next section.

While the approach adopted was pragmatic and worked effectively, an important shortcoming of the sampling procedure adopted was that it was

not fully inclusive of some young people, *viz.*, those deemed by service provider support staff and parents/guardians not to have the capacity to consent. McVilly and Dalton (2006) make the salient point that excluding people on the basis of limited or lack of decisional capacity may reflect a view that they do not have a contribution to make to scientific knowledge and “so further diminishes the perceived value of these individuals who are members of a population that is already marginalised by society” (McVilly and Dalton 2006:187). They question the validity of relying on surrogates to satisfy what they regard as the increasingly stringent requirements of Research Ethics Committees and suggest that “reliance on surrogate consent could be at odds with one of the major aims of contemporary social policy, namely that opportunities for people with disability to exercise choice and self determination should be maximised” (McVilly and Dalton 2006:187).

A further limitation in the methodology used is potential biases in the case selected, in the sample of respondents within the case and in the way the data was analysed. As already stated, the case was selected primarily on the basis that its overall approach to service provision and *modus operandi* reflected key aspects of a rights approach. While initial and emerging findings were validated through a focus group with additional NGOs providing services and supports to children/young persons with an intellectual disability in Ireland, it cannot be claimed that the case is representative of all service providers. Rather, it is suggested that the case study provides a snapshot of social reality as experienced by significant stakeholders in the current social supports infrastructure and that the findings may reasonably be applied to other similar areas.

Three potential biases in the sample of respondents are identified. First, parent/guardian interviewees (n=20) were a self-selected group of survey respondents, *viz.*, those who indicated in the survey that they would be willing to be interviewed, and thus may not be fully representative of all parents/guardians. Second, the young people interviewees (n=10) were selected according to specific criteria relating to their capacity to understand what the research was about and to give their consent accordingly as perceived by parents/guardians and by staff. This excluded those who were deemed not to have such capacity which meant that young person interviewees were not representative of the group of young persons as a whole. This, as already stated, was a notable limitation and one which would need to be addressed in future studies of this nature. Third, while it was made explicit to research participants at the outset that the research was not an evaluation of the social supports infrastructure where the case study service provider is a central player, it may be that there was some bias towards protecting a valued service provider in the responses of some of the parent/guardian interviewees. Similarly, it may be the case that staff respondents (n=18) had an intuitive bias towards providing responses which were affirmative of a valued employer and respected NGO in the community.

Based on the commonly held view that reliability assessments improve the rigor of qualitative research (Cook 2011), the fact that inter-rater reliability was not used in the analysis could have resulted in some bias. However, the researcher took the view that because the analysis of the data was content related and because the Framework approach provided a transparent pathway between the content of the interview transcriptions and the themes and sub-themes that emerged, potential bias was minimised. It was also the case that the analysis and write up was overseen throughout by the thesis supervisor.

Another methodological limitation is that the researcher in this instance is an 'outsider'. Oliver (1992) makes the point that frequently researchers have assumed the role of 'experts' over the research subjects and, thus, reinforced the dominant power structure of society (Oliver 1992). Thus in order to shift the balance of power from the researcher to the researched, the need for greater involvement of research participants at every level of the research process has been identified, for example, in the choice of topic for investigation as well as the uses to which the findings should be put. While this was an attractive aspiration at the outset, it remained an aspiration, especially in relation to the children/young persons. Therefore, the research cannot be said to be emancipatory in Oliver's (1992) sense of shifting the control from the researcher to the researched and thus changing the social relations of research production.

The fact that the research was for a PhD was made explicit to all participants and their agreement to participate was on that basis. While no specific undertakings could be or were given about the impact of the research in the longer term, participation was generally on the basis that the outcomes might help to promote a better social support infrastructure for children/younger persons in the longer term. The researcher undertook to make the findings available to the case study agency in due course.

5.7 Implementing the study

This section describes and examines the process of implementing the study – the data collection process and the methods used to analyse the data. *Phase One* of the research drew on the literature to develop key concepts relevant to a rights-based approach to the provision of social supports to children/young persons with an intellectual disability and their families. This involved defining and engaging with key theoretical concepts including those relating to a rights paradigm (Chapter Two) and those relating to social supports (including family support) (Chapter Three). It also involved examining the existing Irish social policy context as it applies directly or indirectly to children/young persons with an intellectual disability (Chapter Four). *Phase Two* implemented the case study and is described below.

5.7.1 Implementing the case study

The case study used a combination of data collection mechanisms – a postal survey, semi-structured interviews (face-to-face and telephone),

documentary analysis and non-participant observation. A review of internal documentation regarding policies, protocols and practice was conducted. This included a review of the Personal Outcomes plans (anonymised) of six children/young persons. Research instruments (survey questionnaire and interview schedules and observation record) were developed to implement each of the above components.

Forty parents/guardians completed the postal survey and twenty of these participated in interviews. Ten young persons participated in interviews, eighteen service provider staff and four other professionals (see Table 5.1).

Table 5.1: Case Study Respondents

	Postal Survey*	Interviews
Parents/Guardians	40	20
Young Persons	-	10
Staff	-	18
Other Professionals		4
Total	40	52

* The survey response rate was 19%.

5.7.2 Survey of parents/guardians³⁷

The Survey sought to capture the experiences and perspectives of parents/guardians on the social support infrastructure as it refers to children/young persons with an intellectual disability (see Appendix Five).

Survey of parents/guardians

Given that this area of social inquiry was relatively new to the researcher, he decided at the outset that a survey of parents/guardians would provide him with a sharper insight into the social realities of families of a child with an intellectual disability prior to undertaking the more qualitative part of the study.

The survey of parents/guardians thus had four main purposes:

- (i) To provide the researcher with an overview of the experience and perspectives of parents/guardians in relation to:
 - (a) the social supports infrastructure as it related to their child with an intellectual disability
 - (b) Their awareness and experience of a rights-based approach
- (ii) To assist the researcher in identifying the topic guide headings for semi-structured interviews with parents/guardians, young persons and staff/other professionals

³⁷ The Survey Data was analysed using SPSS software.

- (iii) To provide a benchmark against which the findings of the qualitative research could be checked
- (iv) To provide parents/guardians with a clearer insight into what the study was about (in addition to the information sheets provided) and, having completed the survey, to enable them to decide whether or not they wished to participate in the interview

The survey data provided valuable assistance to the researcher in respect of (i) to (iii) above and 62.5% of survey respondents indicated a willingness to be interviewed. In this sense, the survey played a centrally important role in the research. In addition, the data provided a number of important insights which the researcher believes could be analysed in greater depth in further studies. These areas are:

- The relatively high ratings given to supports from the specialist service provider (Table 6.4)
- The relatively low ratings given to supports from the local community (Table 6.4)
- The low ratings given to State support for families of a child with an intellectual disability (Table 6.7)
- The relatively low ratings given to the extent to which the rights of children/young persons with an intellectual disability are protected (Table 6.11)
- The ratings by parents/guardians of rights components (Figure 6.1).

Designing the questionnaire

The survey questionnaire was developed in consultation with a number of personnel involved in the provision of services to children/young persons with an intellectual disability and with personnel working in the National Federation of Voluntary Bodies (NFVB) (an umbrella body in Ireland for NGOs providing services to people with an intellectual disability). The questionnaire was structured into seven distinct sections:

- Current services to children/young persons and families
- Needs assessment
- Social supports
- Information and advocacy support
- The system of service delivery
- Rights of children/young persons with an intellectual disability

- Household socio-economic characteristics

Piloting the questionnaire

The questionnaire was piloted with five parents/guardians of children/young persons receiving services from a separate agency to that involved in the case study. Minor amendments were made to the wording of some questions on the basis of the feedback from the pilot group. The time taken to complete the questionnaire was approximately 25 minutes which was deemed by the researcher to be an acceptable length of time to ask respondents to allocate.

Administering the postal survey

All parents/guardians of children/young persons using services provided by the case study agency were invited to participate in the postal survey. This was done in three stages. Firstly, all parents/guardians of children/young persons who were service users were sent an information sheet by the service provider about the study and a consent form which they were asked to sign and send directly to the researcher in a stamped addressed envelope (SAE) if they were willing to participate in the survey. Secondly, the anonymous questionnaire was sent by the researcher to those who indicated a willingness to participate in the survey. Enclosed with this questionnaire was a separate document asking respondents to indicate whether or not they would be willing to participate in a follow-up interview and, if so, to provide contact details. They were asked to return the completed questionnaire and the interview follow-up document directly to the researcher in an SAE.

5.7.3 Semi-structured interviews

Interviews with parents/guardians (n=20)

Twenty-five of the parents/guardians who completed the postal survey indicated that they were willing to participate in a follow-up interview and provided telephone contact details to the researcher. Interviews were carried out with twenty of these³⁸ (15 face-to-face and 5 by telephone). Of the face-to-face interviews, ten were conducted in the person's own home and five in the offices of the service provider. All were offered a choice between face-to-face and telephone interviews and, for those who opted for face-to-face interviews, a choice between their own home and the office of the service provider. All interviews were audio-taped with the interviewee's permission.

The interview themes for parents/guardians (see Appendix Six) reflected the core components of the study – social supports (informal and formal), access to services and perceptions of how the rights of children/young persons with an intellectual disability are recognised and implemented (see Figure 5.2).

³⁸ The other five were not interviewed due to different reasons – their child was no longer receiving services; they had a change of mind or could not be contacted by the researcher.

Interviews with young persons (n=10)

Interviews were carried out with a sample of ten young persons aged over 16 years. Three criteria were applied in selecting the sample of children/young persons – (i) aged over 16 years; (ii) consent by the child/young person and his/her parent/guardian; (iii) consensus involving the child/young person, his/her parent/guardian and key support staff that participation in the study would have no harmful effects. All of the interviews were conducted face-to-face – six in the service provider office and four in their home. Before the young person was contacted by the researcher, the study was explained to him/her by either a parent/guardian or a service provider staff member on the basis of written information provided by the researcher and each young person had indicated to a parent/guardian or staff member a willingness to participate. Prior to the interview, each young person was given a copy of the information sheet about the study which the researcher went through in detail. The researcher also went through the Consent Form with the young person before asking him/her to sign it. In cases where the young person was under 18 years (4), the parent/guardian was asked to countersign the Consent Form before the interview began. Nine of the interviews were audio-taped with the interviewee's permission. (One interviewee expressed a preference not to have the interview audio-taped and detailed written notes of the interview were taken by the researcher in this instance). The interviews with young persons (see Appendix Seven) referred to their current situation, their experience of social supports and their future aspirations (see Figure 5.2).

Interviews with service provider staff (n=18)

A stratified sample of service provider staff was interviewed. Stratification refers to a system of controlling elements of the population included in the research (Creswell 2007). All service provider staff were listed and a sequence of stratification was adopted taking into account the respective numbers of support workers, multi-disciplinary staff and administrative staff. The researcher wanted to give similar weight to each category of staff. A sample of 20 staff was drawn who were invited to participate. Eighteen agreed and were interviewed. The interviews took place in the offices of the case study agency and all interviews were audio-taped with the interviewee's permission.

The interview themes for service provider staff (see Appendix 8) reflected the core components of the study – social supports (informal and formal), access to services and therapies and perceptions of how the rights of children/young persons with an intellectual disability are recognised and implemented (see Figure 5.2).

Figure 5.2: Interview themes by interview group

Interview Group	Interview Themes
<i>Parents/Guardians (n=20)</i>	<ul style="list-style-type: none"> • Social supports (informal and formal) • Accessing services and therapies needed by the child/young person • Experience of integrated (mainstream) education • Child/young person's needs assessment and related planning • Impact on family of having a child/young person with a disability • Perceptions of social attitudes to children/young persons with an intellectual disability • Perceptions of how the rights of children/young persons with an intellectual disability are recognised and implemented
<i>Young persons (n=10)</i>	<ul style="list-style-type: none"> • Their current situation <ul style="list-style-type: none"> ○ Experience of school/training programme ○ Social activities ○ Leisure interests/hobbies • Social supports <ul style="list-style-type: none"> ○ Immediate family ○ Extended family ○ Service provider ○ Friends/peers ○ Local community/neighbourhood ○ Future aspirations
<i>Service provider staff (n=18)</i>	<ul style="list-style-type: none"> • Accessing services and therapies needed by the child/young person • Social supports (informal and formal) • Experience of integrated (mainstream) education • Child/young person's needs assessment and related planning • Perceptions of social attitudes to children/young persons with an intellectual disability • Perceptions of how the rights of children/young persons with an intellectual disability are recognised and implemented • Model/s of service delivery and social supports
<i>Other professionals (n=4)</i>	<ul style="list-style-type: none"> • Delivering integrated (mainstream) education • Access to supports and therapies needed by the child/young person • Child/young person's needs assessment and related planning • Perceptions of social attitudes to children/young persons with an intellectual disability • Perceptions of how the rights of children/young persons with an intellectual disability are recognised and implemented

Interviews with other professionals (n=4)

Four professionals (not service provider staff) working with children/young persons with an intellectual disability in the area who were identified during the course of the case study as key informants were interviewed. The interviews took place at each participant's place of work and all interviews were audio-taped with the interviewee's permission. The interviews with the other professionals (see Appendix 8) referred to their perceptions of integrated (mainstream) education and their perceptions of how the rights

of children/young persons with an intellectual disability are recognised and implemented in mainstream services (see Figure 5.2).

5.7.4 Focus group discussions

Two focus groups were organised as part of the research – one with young persons and one with staff from other service providing agencies. There were four participants (three of whom had already been interviewed) in the focus group discussion with young persons. The focus group was organised around four themes about which the researcher wanted to get a sharper insight and covered three main areas of living – their current situation, their social supports infrastructure and their future aspirations (see Figure 6.4).

A focus group discussion was held with staff from service providing agencies not involved in the case study in collaboration with a national umbrella organisation in the field of intellectual disability. There were five participants in the focus group. Ten emerging propositions arising from an initial analysis of the data were presented by the researcher as discussion points. There was broad concurrence among focus group participants with the propositions as presented. Some minor amendments were made by the researcher to the way the findings were presented following the focus group.

5.7.5 Likert scales

As part of the Parents/guardians Survey, Likert-type scales were included by which respondents were asked to rate ten rights-based statements drawn up by the researcher on the basis of the provisions of the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities Thirty-eight (out of forty survey respondents) did so. Subsequent to their interview, service provider staff interviewees were sent the same ten statements and asked to submit their ratings to the researcher in an SAE. Eleven (out of eighteen interviewees did so). These ratings by parents/guardians and by staff are presented in Chapter Six (Figure 6.1).

Limitations of the Likert Scale approach

The advantage of the Likert Scale is that it is easily understood and that the responses are easily quantifiable. Since it does not require the participant to provide a simple 'yes' or 'no' answer, participants are not forced to take a stand on a particular topic but allowed to respond in a degree of agreement. Also, the responses accommodate neutral or undecided feelings of participants.

On the downside, attitudes in reality exist on a vast, multi-dimensional continuum and the Likert Scale, since it is one-dimensional, gives only limited options of choice, and the space between each choice cannot possibly be equidistant (Baron 1996). Therefore, it fails to measure the true attitudes of respondents. Also, it may be the case that peoples' answers will be influenced by previous questions, or will heavily

concentrate on one response side (agree/disagree). When using a Likert scale respondents can distort responses away from true scores, consciously or unconsciously (Baron 1996).

Responses are subject to central tendency biases, where respondents avoid using extreme response categories; acquiescence responding, where subjects show a tendency to agree with statements as presented; and social desirability responding, where respondents try to portray themselves in a more positive manner (Baron 1996:52).

The Likert-type scale is used in the present study as part of a triangulation research approach (see 5.3.1 above). Its purpose is to provide a backdrop against which the more qualitative findings of the semi-structured interviews with parents/guardians and staff can be measured. The Likert-type scale ratings provide a useful and important reference point which the research could use to validate in a general way the qualitative findings. The inherent limitations of the Likert Scale approach, as summarised above, are acknowledged and an alternative approach based on scenario writing and the use of vignettes would, perhaps, have provided a sharper insight into social realities.

The vignette technique is a method that can elicit perceptions, opinions, beliefs and attitudes from responses or comments to stories depicting scenarios and situations (Barter and Renold 1999:1).

This latter approach would provide a potentially richer data source than the Likert-type scales and would allow for a more thorough engagement with participants' life situations. Such an approach would be particularly useful in directly engaging children/young persons with an intellectual disability in the research process and, in hindsight, is one that the researcher might have used in the present study. Such an approach could be usefully used, the researcher believes, in future multi-method studies of this nature. The advantages of this approach would be to provide a social reality context within which respondents' views and perceptions could be explored and which would allow participants to define their situation in their own terms (Barter and Renold 1999).

5.7.6 Documentary analysis

The documentary analysis aspect of the case study had two components:

- A review of internal service provider documentation regarding policies, protocols and practice
- A review of 6 children/young persons Individual Care/support Plans³⁹ randomly selected (and anonymised by service provider staff prior to review by the researcher)

³⁹ These plans refer to the Personal Outcomes model of support used by the case study service provider which has been referred to in 5.3.3 above.

Review of internal documentation

The review of internal documentation was carried out to provide the researcher with an insight into the range of services provided by the agency, its underlying philosophy and *modus operandi* and, in particular, how the Personal Outcomes model (which is the key organising framework for the provision of supports and services) was implemented.

The review showed that policy and practice documents were underpinned by the following key considerations:

- Individuals control their own lives and are the authors of their own vision for their life;
- Support is individually tailored to ensure that people have a good life;
- Money is close to the individual (concept of individualised funding);
- Family and friends have a vital role to play;
- Support is designed by and with the individuals;
- Individuals live ordinary lives doing ordinary things in an inclusive community;
- Supports and experience are best delivered by an individual's natural support networks to keep them connected to and within their family and local community;
- People with disabilities have the same rights as all other citizens – with assistance people can and will exercise these rights.

Key areas of support set out in policy documents are:

- Supporting families when an initial awareness of a intellectual disability is made
- Working with families to help them make decisions around their child's needs
- Acting in a supporting and advocacy role to families and schools when children attend school in their local communities
- Supporting adults to live inclusive lives in their communities by supporting them and advocating with them to seek appropriate supports in relation to housing and social welfare rights

- Helping to ensure that service users are encouraged and enabled to express their views and exercise their rights through self-advocacy

The Personal Outcomes model is set out in the policy documents as a way of ensuring that services are provided in an optimum manner and in a way which is responsive to the wishes of service users and their families. Thus, measuring the quality of life for individual service users and the quality of the service that supports them in achieving their desired quality of life are key considerations.

In summary, the policy documentation reviewed emphasises that Personal Outcomes are what people expect from the supports and services they receive and focus on expectations and issues that matter most to people in their lives across three key areas – *My Self, My World, My Dreams* – each with its own set of indicators.

Review of individual plans

Six individual plans were reviewed as part of the research. These were randomly selected (three from children involved in school-age services and three from children involved in early childhood intervention services). The purpose of these reviews was to provide the researcher with a sharper insight into the content of and processes involved in an individual plan which was highlighted by service provider staff as a key organising concept in the provision of services and supports. The review showed that the individual plans included a synthesis of the assessment of needs that had been carried out, the personnel involved in this assessment, the procedures in place to respond to these needs, the ongoing review process and changes made as a result of these reviews. What emerged from the review was confirmation for the researcher that individual plans were in place, that there were ongoing reviews of these plans and that changes to the plans were made on the basis of these reviews. While the extent to which these plans mirrored reality was not measured in the study, the documentary analysis exercise provided the researcher with an insight into how the process of individual planning and the related personal outcomes process was conceptualised and the tracking mechanisms put in place to monitor progress.

5.8 Analysing the data

The tasks of defining, categorising, theorising, exploring are all part of the qualitative data analysis process (Ritchie and Spencer 1994). This includes: defining and understanding concepts; mapping the range, nature and dynamics of phenomena; creating typologies and finding associations.

The case study lends itself to a thematic analysis approach in that it can potentially provide a rich, detailed and complex account of the data (Caelli *et al.* 2003; Braun and Clarke 2006). This involves looking for patterns based on experiences, meanings and the reality as perceived by the study

participants. In a thematic analysis, themes within the data are identified in an inductive way which is consistent with qualitative research (Merriam 2009). In this study, the researcher wanted to capture the range of experiences relating to the social supports infrastructure and how these related to the components of a rights paradigm.

The first data source used in the present study was the Survey of Parents/Guardians. The survey was analysed using an SPSS software programme and data was generated accordingly. The survey findings are reported and discussed in Chapter Six (6.1).

The second data source is the semi-structured interviews and the researcher drew on the 'Framework' model (Ritchie and Spencer 1994) as the analytical tool for the present study.

'Framework' is an analytical process which involves a number of distinct but interconnected stages in qualitative data analysis. The key features of 'Framework' have been identified (Ritchie and Spencer 1994).

- (i) It is heavily based in, and driven by, the original accounts and observations of the research population.
- (ii) It is open to change, addition and amendment throughout the analytic process.
- (iii) It allows a full, and not a partial or selective, review of the data.
- (iv) It allows access to, and retrieval of, the original textual material.
- (v) It enables within-case analysis.
- (vi) The analytic process is accessible to others

The Framework approach was adopted in the present study because it enabled the researcher to explore the data in depth while simultaneously maintaining an effective and transparent audit trail (Ritchie and Lewis 2003).

Three types of methods for undertaking qualitative data analysis can be identified (Smith and Firth 2011): (i) sociolinguistic methods (discourse and conversation analysis that explore the use and meaning of language); (ii) methods typified by grounded theory that focus on developing theory; and (iii) methods, such as content and thematic analysis, that describe and interpret participants' views. The Framework approach, which was developed in the 1980s by social policy researchers at the National Centre for Social Research as a method to manage and analyse qualitative data in applied social research, belongs to the third of these types of methods. Essentially, this involves the researcher working with structured topic guides to elicit and manage data (Smith and Firth 2011).

This approach contrasts with entirely inductive approaches, such as grounded theory, where the research is an iterative process and develops in response to the data obtained and ongoing analysis (Smith and Firth 2011:52).

The Framework model provided the researcher with an approach which enabled him to systematically engage with a series of interconnected stages that guided the analytical process and provided for an integrated analysis of the data. The Framework approach is similar to but somewhat different from thematic analysis which has been criticised for lacking depth and as resulting in data fragmentation and the danger of data being misinterpreted. “As a consequence findings are subjective and lacking transparency in how themes are developed” (Smith and Firth 2011: 54). Central to the analytical processes in the Framework approach is a series of interconnected stages that enables the researcher to move back and forth across the data until a coherent account emerges (Ritchie and Lewis 2003).

There were four main reasons for choosing the Framework approach for the present study. First, it allowed the researcher to capture and analyse the different aspects of richly descriptive data from different sources (parent/guardians, young persons and staff/professionals) and to interpret them in a manner that was logical and meaningful. Second, it allowed for an analysis where both the participants’ views and perspectives and the researcher’s interpretations of these views and perceptions are fully transparent (Ritchie and Lewis 2003). Third, it allowed the researcher to move systematically from the data management and interpretation stage to the stage of developing the analysis sufficiently to address the research questions in a logical and coherent manner. Fourth, it allowed for the application of the different dimensions of a rights-based social supports infrastructure to the data.

The interview topic guide⁴⁰ enabled the researcher to explore participants’ perceptions of social reality. The data management stage (becoming familiar with the data, identifying initial themes/categories, developing a coding matrix and assigning data to the themes and categories in the coding matrix) created a platform which not only allowed for the ‘whole picture’ to emerge but also allowed for ongoing refinement. This provided the basis for developing associations/patterns and for subsequently addressing one of the main research questions: What are the strengths and deficits from a rights perspective of the current social support infrastructure as it applies to children/young persons with an intellectual disability and their families?

The core strength of the Framework approach as applied in the present study was that it enabled the researcher to remain true to participants’ descriptions while developing more abstract concepts. The forward and

⁴⁰ Some of the initial categories became themes or sub-themes, e.g., provision for the additional support needs of families; inclusive social attitudes.

backward movement between participants' accounts and emerging themes provided a transparent trail to the emergence of the final categories and the development of the final conceptual framework.

This iterative process resonates with the central tenet of the framework approach that the interconnected stages are not linear, but a scaffold that guides the analysis ((Smith and Firth 2011:60).

The approach enabled the researcher to track decisions at different junctures, which ensured that links between the original data and findings are maintained and transparent. This was seen as adding to the rigour of the research process and enhancing the validity of the findings.

The five interconnected stages of analysis involved in 'Framework', as identified by Ritchie and Spencer (1994) are: familiarisation; identifying a thematic framework; indexing; charting; and mapping and interpretation. (See also Braun and Clark 2006). These stages are described in Figure 5.3.

Familiarisation involves immersion in the data – listening to audio-tapes, reading transcripts and studying fieldwork observational notes. During the familiarisation stage, key ideas and recurrent themes are identified in order to get an overview of the richness, depth and diversity of the data and to begin the process of abstraction and conceptualisation. This also involves recording the range of responses to questions asked by the researcher and identifying the points that emerge as important to respondents themselves. The next stage involves the researcher drawing out the main issues and concepts in order to identify the *thematic framework* within which the material can be sorted and categorised.

When identifying and constructing this framework or index, the researcher will be drawing upon a priori issues (those informed by the original research aims and introduced into the interviews via the topic guide), emergent issues raised by the respondents themselves and analytical themes arising from the recurrence or patterning of particular views or experiences (Ritchie and Spencer 1994:179–180).

Indexing refers to the process whereby the thematic framework is systematically applied to the data in its textual form and all of the data is annotated according to this thematic framework. This involves taking into account the fact that single passages of text often contain a number of different themes, each of which needs to be referenced. "Multiple indexing of this kind can often begin to highlight patterns of association within the data" (Ritchie and Spencer 1994:182).

Charting involves taking the data from their original context (interview transcripts) and rearranging them according to headings and sub-headings under the relevant thematic reference. The final stage in the 'Framework' approach, *mapping and interpretation*, involves the researcher applying the themes and associations which have emerged from the data themselves to his/her original research questions. A case

study narrative is developed which integrates and summarises key information around the focus of the case study.

The *Framework* model as applied in the present study is set out in Figure 5.3. The *familiarisation* phase initially involved a reading the interview transcripts and checking these against the original written and audio accounts to ensure accuracy. Once the researcher was confident that the transcribed material was accurate, the transcripts were re-read engaging in what Fuller and Petch (1995:85) describe as: 'immersion in the data'. Initial notes were made of the main themes, concepts and issues emerging and the transcripts were re-read to ensure the accuracy of the data being imported. This was followed by a process of identifying and drawing out the ideas and patterns emerging from the data, applying codes, noting the emerging themes and creating the *thematic framework*. The third phase involved *indexing* and *charting* by which the thematic framework is applied to the data. Charts were drawn up for each key thematic area setting out the various sub-themes and entries were made as appropriate for several respondents on each chart. The themes were refined, redeveloped and merged where appropriate. The themes and sub-themes that emerged in respect of parent/guardian interviews (n=20) and young person interviews (n=10) are set out in Chapter Six (Figure 6.2 and Figure 6.3 respectively and those relating to staff/professionals (n=22) are set out in Chapter Seven (Figure 7.1). The next phase of analysis was the *mapping and interpretation* one. This involved reviewing the whole data in terms of the themes identified in order to consider the validity of individual themes in relation to the raw data. It also included a process of evaluating whether or not the identified themes reflected the meaning evident in the data taking into account the theoretical and analytical approach adopted in the study. This also involved distilling a set of generalisations that reflected the consistencies discerned in the data (Miles and Huberman 1994). General categories were identified based on the main themes identified (n=21) and sub-themes (n=75). A number of direct quotes from respondents were extrapolated in order to illustrate or substantiate points relating to each sub-theme where appropriate.

In summary, the process of qualitative data analysis used in this study reflects Miles and Huberman's (1994) view that data analysis in qualitative research follows a series of sequential stages: giving codes to the different pieces of information (where possible); going through the information and identifying patterns, themes and relationships; gradually distilling a small set of generalisations that cover the consistencies discerned in the data.

Chapter summary

This chapter has described the methodology designed and implemented to address the objectives of the study. The rationale and objectives of the study were outlined and the related research questions. This was followed by discussion on the main theoretical underpinnings. The research design and methodology were then discussed with particular reference to the case study approach used. The main research challenges and limitations were identified and the ethical considerations were discussed. The

implementation of the research process was then described in detail including the data collection and analysis processes used.

The case study approach used in this research and described in this chapter provided a rich data source (both qualitative and quantitative) which enabled the researcher to address the research questions and provided a valuable insight into the social support infrastructure as it applied to the research target group.

Figure 5.3: The 'Framework' model applied to the interviews data

	Parents (n=20)	Young persons (n=11)	Service provider staff and other professionals (n=22)
Familiarisation	Transcripts reviewed and validated and key points noted	Transcripts reviewed and evaluated and key points noted	Transcripts reviewed and validated and key points noted
Thematic framework	9 themes: <i>Social supports available; Access to formal services; Individual needs assessment; Person-centred planning; Inclusive and integrated education; Perceptions of social attitudes; Impact on family; Perceptions of rights enforcement; Access to information and advocacy support</i> (see Fig. 6.2 for list of sub-themes)	4 themes: <i>Their lives at present; Their social supports; Social activities; Future aspirations</i> (see Fig. 6.3 for list of sub-themes)	8 themes: <i>Social supports availability; Access to formal services; Needs assessment; Person-centred planning; Integrated and inclusive education; Perceptions of social attitudes; Rights enforcement; Access to information and advocacy support</i> (see Fig. 7.1 for list of sub-themes)
Indexing	Transcripts colour-coded according to the 9 themes identified.	Transcripts colour-coded according to the 4 themes identified.	Transcripts colour-coded according to the 8 themes identified.
Charting	Data from each interview transcript re-arranged under each of the 9 themes identified	Data from each interview transcript re-arranged under each of the 4 themes identified	Data from each interview transcript re-arranged under each of the 8 themes identified
Mapping (1)	Data arranged under 35 sub-themes identified	Data arranged under 11 sub-themes identified	Data arranged under 29 sub-themes identified
Mapping (2)	Themes applied to the research questions: (a) 7 components of a rights paradigm (b) 24 social support goals	Themes applied to the research questions (a) 7 components of a rights paradigm (b) 24 social support goals	Themes applied to the research questions (a) 7 components of a rights paradigm (b) 24 social support goals
Interpretation	The data analysed <i>vis-à-vis</i> a rights-based social supports infrastructure	The data analysed <i>vis-à-vis</i> a rights-based social supports infrastructure	The data analysed <i>vis-à-vis</i> a rights-based social supports infrastructure

Chapter Six

The Perspectives of Parents/Guardians and Young Persons: The Study Findings

Introduction

The Case Study was carried out during 2011–2012 in collaboration with a non-governmental organisation (NGO) in the West of Ireland providing services to children/young persons with an intellectual disability. The study involved a research engagement with parents, children/young persons, staff and other professionals involved in service delivery. The purpose of this engagement was to ascertain their experiences and perspectives on social supports generally and on the extent to which their experience of social supports reflected and promoted rights based principles. While social support is defined by varying terms in the literature, it is generally agreed that the concept broadly refers to the assistance and help that one receives from others (see Chapter Three). It includes formal and informal supports, support provided to an individual and support provided to groups, support provided directly to the individual and support aimed at enhancing informal family and community-based support systems.

- Part One: Survey of parents/guardians
- Part Two: The views and perspectives of parent/guardian interviewees
- Part Three: The views and perspectives of young person interviewees

6.1 Survey of parents/guardians

The research with parents/guardians included both a postal survey of parents/guardians. All parents/guardians of children/young persons aged less than 24 years who were in receipt of services from the case study specialist service provider were invited to participate in the survey. There were 40 parent/guardian postal survey respondents (a 19% response rate). This section presents the findings of the survey.

6.1.1 Age and type of disability of survey respondents' children with an intellectual disability

The focus of the study was on children/young persons with an intellectual disability and survey respondents were thus asked to describe the type of disability and age of their child/young person. Almost half (47.5%) of parents categorised their child's disability as 'intellectual disability', a quarter categorised the disability as 'other' while the remainder (37.5%) categorised the child's disability as having an autism component (Table 6.1). The age categories of the children/young persons reported by the parents/guardians indicated a broad age range spectrum (Table 6.2). Almost two-thirds (65%) were in the 6–12 years and 13–18 years categories.

Table 6.1: Type of child/young person's disability reported by parents/guardians

Type of Disability of Child/Young Person	%
Intellectual disability	47.5
Autism spectrum	12.5
Autism and intellectual disability	15.0
Other	25.0
Total	100.0

N = 40

Table 6.2: Type of child/young person's disability reported by parents/guardians

Age of Child	%
5 years or under	20.0
6–12 years	37.5
13–18 years	27.5
19–24 years	15.0
Total	100.0

N = 40

6.1.2 Sources of social support identified: survey findings (N=40)

The Survey of Parents/Guardians asked respondents to indicate whether or not they received specific listed supports. The supports listed included formal supports from service providers (in-home supports, out-of-home supports, school supports and supports from multi-disciplinary professionals) and informal supports from extended family, community and friends. Table 6.3 shows that almost all (97.5%) reported receiving support services. Over three-quarters (77.5%) reported receiving support from their immediate family, 42.5% from friends, 37.5% from neighbours and 27.5% from the extended family. A smaller proportion (10%) reported receiving support from local community groups. Over two-thirds (67.5%) reported that they had the support of a key worker/advocate.

Table 6.3: Percentages of respondents who identified different sources of support

Source of support	%
Specialist service provider	97.5
Immediate family	77.5
Key worker/advocate	67.5
Friends	42.5
Neighbours	37.5
Extended family	27.5
Local community groups	10.0
Key worker/advocate	67.5
Other sources	10.0

N = 40

6.1.2.1 Parent/guardians rating of different sources of social support

Survey respondents were asked to rate three different sources of support – support from family, support from the local community and support from the specialist service provider. Table 6.4 shows that over 82% of respondents rated supports from the specialist service provider as ‘very beneficial’ or ‘beneficial’; 70% rated support from family similarly and less than half (43.2%) gave a ‘beneficial’ or ‘very beneficial’ rating to support from the local community. Almost one-fifth (18.9%) rated support from family as of little benefit or of no benefit and over one-third (35.1%) rated supports from the local community similarly.

Table 6.4: Rating of social supports by survey respondents

	Support from family	Support from local community	Support from specialist service provider
	%	%	%
Very beneficial	51.4	21.6	51.3
Beneficial	18.9	21.6	30.8
Of some benefit	10.8	21.6	15.4
Of little benefit	2.7	8.1	2.6
Of no benefit	16.2	27.0	-
	N=37	N=37	N=39

6.1.2.2 Frequency and main source of social support

Table 6.5 shows that three-quarters of survey respondents indicated that they had support ‘usually’ or ‘always’. Almost one-fifth stated that they had support ‘rarely’ or ‘never’. For one-third of respondents, the main support person was a family member and for almost a quarter it was a service provider. Almost 17% listed a friend as their main support person while 13% listed a family member and friend (Table 6.6).

Table 6.5: Survey respondents’ perceptions of support availability from any source

Frequency of support availability %	
Always	36.1
Usually	38.9
Sometimes	5.6
Rarely	8.3
Never	11.1

N=36

Table 6.6: Survey respondents’ relationship to main support person/s

Relationship to parent	%
Family member	36.7
Service Provider	23.3
Service provider and family member	3.3
Friend	16.7
Family member and friend	13.3
Other	6.7
Total	100.0

N=30

6.1.3 Access to services required: survey findings (N=40)

Table 6.7 below presents survey respondents' assessment of some aspects of service provision to children/young persons with an intellectual disability and their families. More than three-quarters of respondents rated services in the county as 'excellent' or 'good' with almost 70% rating interagency collaboration similarly. Only 30% of respondents rated State support to families of children/young persons with an intellectual disability as 'excellent' or good', with 40% rating the State contribution as 'poor' or 'very poor'.

Table 6.7: Parents' assessment of selected aspects of service provision

Rating	Services in the county	Inter-agency collaboration	State support to families of children with an intellectual disability
	%	%	%
Excellent	48.7	29.7	5.0
Good	30.8	40.5	25.0
Adequate	15.4	13.5	30.0
Poor	5.1	16.2	22.5
Very poor	-	-	17.5
	N = 39	N = 37	N = 40

6.1.4 Individual needs assessment

Table 6.8 shows that almost three-quarters (72.5%) of survey respondents reported that an assessment of the child/young person's needs had been carried out. Where a service statement was required by a law (for children under 5 years under the Disability Act 2005), most stated that such was not provided or that they didn't know or were not sure.

Table 6.8: Parents/guardians' views on assessment of need protocols

Needs assessment and planning components	Yes	No	Not sure/don't know	
	%	%	%	
Assessment of child/young person's needs	72.5	17.5	10.0	N= 40
Individual plan put in place	66.7	15.4	17.9	N=39
Service statement provided (where required by law)	28.6	28.6	42.9	N= 6

Table 6.9 shows that most (86.2%) of survey respondents reported that they were 'involved' or 'very involved' in the assessment of need. The relatively low response rate to this question may suggest some lack of awareness of what needs assessment and individual planning entailed.

Table 6.9: Parents/guardians' perceptions of involvement in assessment of need and implementation of plan

Level of involvement of parents	Assessment of need	Drawing up individual plan	Review of plan (parents' involvement)	Review of plan (children/young persons' involvement)
	%	%	%	%
Very involved	41.4	37.5	45.5	9.1
Involved	44.8	41.7	36.4	22.7
Slightly involved	3.4	8.3	4.5	4.5
Not involved	10.3	12.5	13.6	50.0
Excluded				13.6
	N=29	N=24	N=22	N=22

6.1.5 Person-centred planning

Two-thirds (66.7%) of respondents reported that an individual plan had been put in place for their child/young person by the service provider (Table 6.8). Over three-quarters (79.2%) of parents/guardians were 'involved' or 'very involved' or in drawing up an individual plan and 82% were 'very involved' or 'involved' in reviewing the plan. (Table 6.9) Over one-third (36.3%) reported that their child/young person was involved in reviewing the plan (Table 6.9).

6.1.6 Perceptions of social attitudes to children/young persons with an intellectual disability

In the Survey of Parents/Guardians, respondents were asked to rate social attitudes to children/young persons with an intellectual disability on a scale of 1–5. Table 6.10 shows that less than a half (42.5%) of the survey respondents rated social attitudes to children/young persons with an intellectual disability as 'positive' or 'very positive' with a similar percentage rating them as 'neither positive or negative' and 15% as 'negative'.

Table 6.10: Parents' perceptions of social attitudes to children with an intellectual disability

Parents' Perceptions	%
Very positive	2.5
Positive	40.0
Neither positive or negative	42.5
Negative	15.0
Very negative	–
Total	100.0

N=40

6.1.7 The implementation of a rights-based approach

Since the focus of the research is on rights-based social supports for children and young persons with an intellectual disability, the survey

sought to get the views of parents/guardians on whether and how rights-based principles informed the availability and delivery of support services. Table 6.11 shows that over half (52.8%) of the survey respondents considered that the rights of children/young persons with an intellectual disability were ‘always’ (16.7%) or ‘usually’ (36.1%) protected. Almost 14% considered that these rights were ‘rarely’ or not at all protected. This finding that almost 14% of respondents considered that their child’s rights were rarely or not at all protected and that one-third considered that they were only sometimes protected is a significant finding for exploring the concept of a rights-based social supports infrastructure and a point that will be developed further in subsequent chapters.

Table 6.11: Parents’ rating of how rights of children/young persons with an intellectual disability are protected

Rating	%
<i>Not at all protected</i>	2.8
<i>Rarely protected</i>	11.1
<i>Sometimes protected</i>	33.3
<i>Usually protected</i>	36.1
<i>Always protected</i>	16.7
<i>Total</i>	100.0

N=36

Ratings of rights-based statements

Drawing on the provisions of the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child and on discussions with key informants, nine statements were identified in the course of the research as representing the core of a rights-based approach to children/young persons with an intellectual disability. In order to estimate the perceptions of parents/guardians’ and those of service provider staff of the extent to which rights-based principles were present in the social supports infrastructure, Likert-type summation rating measures were used by the researcher in relation to each of the nine rights statements (see 5.7.5 above). The findings are presented in Figure 6.1.

As can be seen from Figure 6.1, overall rating by parents/guardians of rights based components averaged 3.5 out of a maximum score of 5. In the case of staff, the overall rating was lower at 2.6. Staff ratings were lower than those of parents/guardians across all of the nine statements. The highest rating by both parents/guardians (3.9) and by staff (3.5) related to the statement ‘*children/young persons with an intellectual disability are supported to enjoy a full and decent life*’. In the case of parent/guardians, the lowest rating (3.0) was given to the statement: ‘*the best interests of children/young persons with ID are the primary consideration in all actions by the State affecting them*’. The relevant staff rating was 2.5. The lowest rating by staff (2.4) was given to the statement: ‘*children/young persons with ID enjoy fully all human rights and basic freedoms on an equal basis with other children/young persons*’. The relevant parent/guardian rating was 3.4.

Three key findings emerge from the Likert-type scale ratings. Firstly, there was a perception by both parents/guardians and by service provider staff of deficits in the rights approach. Secondly, these deficits were perceived as higher by staff than by parents/guardians. Thirdly, the highest ratings by both parents/guardians and by staff (children/young persons with an intellectual disability being supported to enjoy a full and decent life), when contrasted with the lowest rating by both groups (the best interests of children/young persons being a primary consideration by the State), suggests a perception of a lack of adequate State support for community and family efforts.

Figure 6.1: Rating of selected rights statements by parents/guardians and by service provider staff

<i>Rights Component</i>	<i>Rating by parents $\overline{(X)}^*$</i>	<i>Rating by staff $\overline{(X)}^*$</i>
Children/young persons with an intellectual disability are supported to enjoy a full and decent life	3.9	3.5
Children/young persons with an intellectual disability are enabled to participate actively in the community	3.6	3.4
Children/young persons with an intellectual disability are provided with equal opportunities for cultural, recreational and leisure activity	3.4	2.7
Children/young persons with ID enjoy fully all human rights and basic freedoms on an equal basis with other children/young persons	3.4	2.4
The best interests of children/young persons with ID are the primary consideration in all actions by the State affecting them	3.0	2.5
Children/young persons with ID are allowed to express their views freely on all matters affecting them	3.6	2.7
The views of children/young persons with an ID are given due weight in accordance with their age and maturity and on an equal basis with other children/young persons	3.4	2.5
Children/young persons with ID are provided with appropriate assistance to enable them express their views freely	3.5	2.8
The State ensures that children/young persons with ID are given access to the support they may require to exercise their legal capacity	3.5	2.5
<i>Overall average</i>	3.5	2.6

*The arithmetic mean (average) score for each component.

6.1.8 Information and advocacy support

Access to information and advocacy support was identified by the researcher as an important component in a rights-based social supports infrastructure. Table 6.3 above has shown that just over two-thirds of parents/guardians stated that they had the support of key worker/advocate. Over half of the respondents (55.2%) rated the information available as 'excellent' or 'good' at first indication of the child's disability (Table 6.12). This proportion was 63.1% at early intervention stage, 58.8% at school-going age and 78.6% at second level school stage. The respective figures for a 'poor' or 'very poor' rating at each of the four stages were 31.6%, 23.7%, 29.4% and 14.3%.

The percentages of those who rated information availability as 'poor' or 'very poor' at each of the four transition points identified (ranging from 31.6% to 14.3%) points to an important deficit in one or both the availability of information or people's ability to comprehend the information provided. This confirms the findings of the qualitative interviews described in Chapter Six above and analysed further in the next chapter.

Table 6.12: Parents' assessment of information available at various transition stages

Rating	At first indication of child's disability	At early intervention stage	At school-going age	At 2 nd level school stage
	%	%	%	%
Excellent	26.3	28.9	29.4	28.6
Good	28.9	34.2	29.4	50.0
Adequate	13.2	13.2	11.8	7.1
Poor	15.8	13.2	20.6	14.3
Very poor	15.8	10.5	8.8	-
	N=38	N=38	N=34	N=14

Summary of section

While three-quarters of parents/guardians report that they 'usually' or 'always' have support available, almost one-fifth state support is available 'rarely' or 'never'. Parents/guardians feel that they are not always supported by their local community – over one-third stated that support from the local community was of 'little' or 'no' benefit. Parents/guardians do not always get support from their family – almost one-fifth stated that support from the family was of 'little' or 'no' benefit.

Over half of the parent/guardians considered that the rights of children/young persons with an intellectual disability were 'always' or 'usually' protected. One-third considered that they were only sometimes protected and almost 14% considered that these rights were 'rarely' or not at all protected. Overall rating by parents/guardians of rights based components averaged 3.5 out of a maximum score of 5 and the overall rating by staff was lower at 2.6. The deficits in the rights approach identified is a crucial finding in relation to exploring the concept of a rights-based social supports infrastructure which is the main purpose of this study.

6.2 The views and perspectives of parent/guardian interviewees

The parent/guardian interviewees (n=20) were a self-selected group of survey respondents, viz., those who indicated in the survey that they would be willing to be interviewed. The interview data was analysed using the Framework model (Ritchie and Spencer 1994) discussed in 5.8. Its application in the current study has been set out in detail in Figure 5.3. The themes and sub-themes that emerged from the Framework analysis of the interviews with parents/guardians are set out in Figure 6.2 and are discussed in this section of the chapter. Nine main themes emerged from the Framework analysis of parent/guardian interviews and thirty-five sub-themes.

Figure 6.2: Interviews with parents/guardians: themes and sub-themes identified

Themes	Sub-themes
Social supports available	Supports from specialist service provider; support from family; neighbourhood/local community supports; friendship networks;
Access to formal services	Pathway and access to services; respite services; availability of therapies; impact of budgetary cutbacks
Individual needs assessment	The child/young person's individual needs; statutory needs assessment; assessment of family support needs
Person-centred planning	Awareness of Personal Outcomes approach; planning for transition; parents/guardians' concerns about the future
Inclusive and integrated education	Choosing the 'right' school; experience of mainstream schools; putting the required school supports in place
Perceptions of social attitudes	The emergence of more positive social attitudes; experience of negative attitudes; perceived mixed attitudes of children/young persons' peers; attitudes dependent on type of intellectual disability
Impact on family	The need for constant attendance to the needs of the child; Additional demands on the family; maintaining a 'normal' family life; positive impact on family; negative impact on family; impact on siblings
Perceptions of rights enforcement	Awareness of a rights-based approach; perceptions of equality of access to services; access to services and supports; choice by children/young persons as appropriate to their age; maximising individual potential
Access to information and advocacy support	Access to information at various transition points; specific gaps in information; need for and availability of key worker/advocacy support

6.2.1 Availability of social supports

Social support, broadly defined, refers to the help that one receives from others (see Chapter Three above). The sources of social support may be informal (family, friends, neighbours, peers, local community, special

interest support group) or formal (statutory, NGO service provider, professional).

Four sub-themes were identified in regard to social supports:

- (i) Supports from service providers
- (ii) Support from extended family
- (iii) Local community/neighbourhood supports
- (iv) Friendship networks

6.2.1.1 Supports from service providers

Overall, parent/guardian interviewees expressed relative satisfaction with the support available from the specialist service provider and emphasised the significant role played by the specialist service provider in their lives and that of their children/young persons.

“The [specialist service provider] have been good to me ...and I’ve no problem. I think they’re great really” (Parent 15).

Parents/guardians identified a number of instances where they had to engage in sustained efforts in order to get the services that they deemed necessary for their child/young person. These for the most part were services not available directly from the specialist provider (e.g., school supports) or services that were available but not at the level deemed necessary by parents/guardians (e.g., therapies). Resource constraints and budgetary cutbacks were seen as impacting on service availability commensurate with need.

The experience of having to ‘fight for’ services was reported repeatedly, as was the stress associated with this.

“Well earlier on we would have tried and fought more for speech therapy and physiotherapy ... Trying to get an ear test for [child] we had to go and ask a question in the Dáil because we would be waiting a year and a half or something like that” (Parent 7).

“But you are always battling, a total battle – looking for this and looking for that ... it’s very, very stressful” (Parent 3).

“There should have been extra support there ... it was very hard with her growing up ... I suppose at the end of the day it’s probably down to funding” (Parent 1).

This experience reflects the findings of other research (Chadwick *et al.* 2013) in relation to the impact that having to fight for services has upon families – they refer to “frustration, anger, resignation, exhaustion and household stress amongst family members (Chadwick *et al.* 2013:125). On the other hand, positive outcomes of fighting and advocating identified included “getting the changes and additional services desired and benefiting other people because previous successful fighting set some sort of precedent within the organization” (Chadwick *et al.* 2013:126).

The difficulties that arise from regular turnover in and part-time working by service provider staff was highlighted by parents/guardians.

"We find that every time someone leaves a position... The case seems to drop ... when the previous person goes there seems to be no sort of follow-up" (Parent 4).

6.2.1.2 Support from extended family

Williams et al. (2010) found that an important part of the support system to parents in Ireland is grandparents and that contact with grandparents seems to be relatively high. They suggested that this was probably due to the small size of the country and low levels of mobility and, perhaps, also because of the value placed on the extended family.

Two contrasting perspectives emerged in respect of parents/guardians' experience of support from their families. On the one hand, there were those who stated that they had good levels of family support while, on the other hand, there were those who stated that they had little or no support from families

Those who reported good family support stated that it came from a variety of sources, including spouse, parents, siblings, and, in some instances, the extended family. The following statements by parents/guardians are typical of those who stated that they had good support from their extended family.

"I have extended family alright. [husband's] mother and father will take him and mind him and I have two brothers and they'll help mind him and my daughter looks after him as well ...usually we do get someone we're not too bad (Parent 4).

"My sister is very good ...she lives about 3 miles away – if I want t anything or anything done she's very supportive. My family are great really" (Parent 6).

"My mum is just down the road from where we are. She would have been a great help as he [child] was growing up" (Parent 9).

For some, support from the extended family meant that they did not need additional support from the specialist service provider.

"I had, I suppose, a good family network ...they [service provider] would have offered me home sharing and that... but we didn't need it ...if we were going anywhere there was always an auntie who would have her" (Parent 12).

The availability of regular support from family members was identified as a valuable contribution.

"She [interviewee's sister] comes home every weekend, almost every weekend to help... she stays on the Saturday night" (Parent 7).

Some parents/guardians regarded support from their extended family as useful even if they lived some distance away.

"The family is a good support even though some are far away ... We see them when we can ... and there is a lot of support there" (Parent 10).

The fact that extended family included the child with the intellectual disability in the same way as they did children who did not have a disability was affirmative for parents/guardians.

"[Husband's sister] would take the four of them... there would be no distinction made, and she would always say, 'if you're going, I'll take the lads' ... It would be the four of them" (Parent 16).

In contrast, other interviewees stated that they had little or no family support. This was because they had no family living in the area or because their own parents were of advanced years.

"I wouldn't really have help from the family now at all because my two sisters are away and my mother I suppose to be brutally honest she never really took to [child] and her disability" (Parent 1).

"There wouldn't be much [support from family] ... he [child] would be difficult I suppose and [husband's] family don't know what's wrong with him and mine are away ... so there is nobody around really" (Parent 5).

"There's not a lot of support within the family ... I don't have family as a crutch to lean on basically" (Parent 3).

One interviewee stated starkly:

"I don't have any support [from family] – it's just me" (Parent 11).

Some interviewees commented that it was somewhat unrealistic, perhaps, to expect much support from members of their extended family because people are busy and have their own family responsibilities.

"Once they [siblings] have children of their own they are not really a help. Talking to other people, it's the same because everybody thinks they are very busy" (Parent 7).

"There wasn't really any supports... because everybody was so caught up in their own lives" (Parent 15).

6.2.1.3 Neighbourhood/local community supports

Contrasting perspectives emerged in relation to support from the local community/neighbourhood. Most parent/guardian interviewees referred to relatively little engagement with neighbours or with the local community while a smaller proportion referred to the local community/neighbourhood as a positive source of support. Some families had little or no contact with neighbours because the neighbours worked during the day. Others had only recently moved into the area and others were happier relying on their family rather than on neighbours for support.

"Well the neighbours now, I wouldn't have any neighbours help...all we get [from local community/neighbours] is sympathy ...nothing really" (Parent 4).

"You're on your own because nobody really understands but yourself you know" (Parent 5).

"There wouldn't be anybody [neighbour/friend] that would be available. Most people are working" (Parent 1).

"I suppose since I moved to [name of village] ...I wouldn't have very close friends...realistically I would stick to family really... I'd call them to see if someone was available" (Parent 6).

"We are in a quiet rural area...we are far away from other people" (Parent 9).

A positive and supportive local community/neighbourhood was reported by some parents/guardians.

"The people here are very friendly ...the landlord lives a bit away but he has introduced me to people ... it's a good network here now I would say... I think people look after one another better in a small place like this than they do in town" (Parent 10).

6.2.1.4 Friendship networks

Only a small number of parent/guardian interviewees saw friends as a significant source of support. Some stated that they felt that the nature of the child's disability and his/her care requirements meant that they could not ask friends to care for the child.

"With the [child's] breathing difficulties ...you couldn't ask anybody to be responsible for that. They would be there for us in other ways ... if [other child] had to be picked up from school in a hurry or something...We go out with this couple ...and that's what you need as well" (Parent 7).

"When he was younger he had so many problems it was very difficult to leave him with anyone. Now he is much more independent whereas I wouldn't have been able to leave him before" (Parent 9).

One interviewee put a strong emphasis on the friendship support network available to her child who has the intellectual disability:

"... they bring her off nearly every day the summer period... they go up to the park, and they go to [café] ... that's where all the teenagers hang out, and she goes there, and she loves that, and it breaks up the summer ..." (Parent 15).

6.2.2 Access to formal services

Parent/guardian interviewees were asked about their general experience of accessing formal services and negotiating the relevant pathways. Four themes emerged from the Framework analysis:

- (i) Pathways and access to formal services
- (ii) Respite services
- (iii) Availability of therapies
- (iv) Impact of budgetary cutbacks

6.2.2.1 Pathways and access to formal services

There was a range of responses with most interviewees stating that once they were referred to the specialist service provider, accessing the support services required became somewhat easier.

"I'm happy with the services that have been put in place when we needed them...everything we needed has been put in place" (Parent 10).

"I don't have a problem...I always got what I wanted really and they [specialist service provider] were good ...I mean what more can the State do...you have to be realistic" (Parent 15).

"They [specialist service provider] are a great service...they do have the best interests of the person" (Parent 16).

"I couldn't be happier with where he is now and with what the [specialist service provider] have done, and it's down to the style and type of service that they provide" (Parent 17).

Some parents/guardians reported mixed experiences in accessing formal services and highlighted long waiting times for essential services.

"Sometimes I think it has been quite difficult. Other times I think it has been quite positive. The most difficult has been the timescale, waiting for things" (Parent 9).

6.2.2.2 Respite services

There is a broad consensus in the literature that both service users and carers should benefit from the respite. Research indicates that the benefits for the carer are mainly related to health and well-being, family functioning and practical supports. For service users, social development and independence are identified as the main benefits. In a general way, the rationale for respite care has moved from maintaining carers in their roles towards improving their caring capacity and providing benefits for service users (McConkey *et al.* 2011; Merriman and Canavan 2007). The vital contribution that specialist short break services can make to retaining children within their families has been noted by McConkey *et al.* (2013) provided that some important conditions are met. These conditions are the management of complexity, the formation of trusted relationships and the creation of tangible benefits for the family and for the child. These authors also make the point that short break services need to be "embedded within a co-ordinated, multiagency support network for children and families embracing education as well as health and social services (McConkey *et al.* 2013:11). McConkey *et al.* (2013) also note that "if the quantum of services is spread too thinly across families, then it may be insufficient to help families cope and could trigger the child's removal from the family" (McConkey *et al.* 2013:12).

Many of the parent/guardian interviewees emphasised the importance of respite, whether out of home or in-home. Some respondents stated that they did not like out of home respite, some stated that they would like more while others stated that they did not require respite at this point in time.

"It [respite care] gives you a bit of space... you would have somebody here in the house some days and then he'd go to another woman on say Monday evening, Tuesday evening and Friday" (Parent 5).

"It [respite] has been great for me... there is in-home service. I'm also on my own too, a lone parent so it's been hard" (Parent 6).

“Respite makes it easier. If I didn’t get respite I couldn’t go on. I have to say that”
(Parent 1).

The pressure on the family generated by the suspension of some services during holiday periods was noted as was the related need for additional respite.

“The month of August is coming and she doesn’t have any day service and that is a massive issue ...the fact that she doesn’t have the day service means you end up having her longer ” (Parent 1).

While parents/guardians generally acknowledged the fact that respite and outreach support are very resource intensive, some stated explicitly that they needed more respite care support.

“When he is here at weekends, there could be more support ... you’d be talking more outings, more transport, more staff because he needs two with him at all times, you need back up” (Parent 5).

6.2.2.3 Availability of therapies

Access to a range of therapies on the basis of assessed needs is set out as the guiding principle of service delivery by the specialist provider. This provision is governed by resource availability with resultant necessary rationing.

While the experience of the therapies provided to the child/young person when they are available was generally positive, some parents/guardians reported having to ‘fight for’ additional therapies on occasions and stated that they felt that the availability of therapies is not always commensurate with the needs of individual children/young persons. Others referred to having to pay privately for some therapies because they feel that the State-funded provision for some therapies needed by their child/young person is inadequate. The uncertainty about the availability of therapies commensurate with the child/young person’s needs resulted in parental anxiety and stress about the ongoing availability of therapies and supports.

The need for additional therapies for their child was referred to by a small number of respondents:

“I would like if he got more speech therapy...he gets a bit of Occupational Therapy but I would like more of that too” (Parent 4).

Some parents/guardians expressed the view that the provision of therapies is prioritised by the service provider on the basis of whichever parents are most demanding.

“If we hadn’t made that phone call, someone else would have got in ahead of him for the appointment [for speech and language therapy]” (Parent 4)

6.2.2.4 Impact of budgetary cutbacks

Resource constraints generally and budget cutbacks in recent years were identified as an ongoing issue which required additional efforts on the part

of parents/guardians to ensure that support services were provided. Having to engage with service providers in this way was stated by some parents to cause additional stress in their lives over and above the normal stress of caring for and supporting a child/young person with an intellectual disability.

"I suppose at the end of the day it's probably down to funding as well but the reality is that she needs it [respite care] and that is that" (Parent 1).

While parents understood budgetary constraints as a general difficulty for government, and acknowledged that services such as outreach, respite care and school supports are resource intensive, they felt that such services were vital in enabling the family to manage and in enabling the child/young person to continue to have as full a life as possible and to continue to expand his/her horizons. Parents/guardians were thus very anxious that their child would continue to get the supports that s/he needed and that service cutbacks would not have a detrimental effect on the child's development. They noted that even minimum service cutbacks added to the difficulties of parents of a child/young person with an intellectual disability and undermined the coping capacity of the family. Some stated that they were fearful in this regard.

"They [specialist service provider] know her well and they know what suits her. But you see it's all whether there's enough money to do it now" (Parent 15).

Reductions in social welfare payments relevant to children/young persons with an intellectual disability were reported as having a negative impact on families, in particular reductions to Disability Allowance (payable to those aged over 16) and Carer's Allowance (a means-tested payment to those providing full-time care to another person).⁴¹

The challenges facing the mainstream school system, if it is to cater adequately for the needs of children with an intellectual disability, were highlighted. The withdrawal of school resources due to current budgetary constraints resulting in additional difficulty in getting special needs assistant (SNA) and resource teacher support was identified as problematic by parent/guardian interviewees.

"I think it's too bad that they're thinking about pulling SNAs... That would be one thing you'd be really angry about" (Parent 12).

6.2.3 Individual needs assessment

There is a strong emphasis in legislation and in policy discourse on the importance of needs assessment in relation to the provision of services

⁴¹ In addition to basic income supports, additional supports provided by the State to families of children/young persons with an intellectual disability include Domiciliary Care Allowance, Respite Care Grant, Mobility Allowance, Motorised Transport Grant, Free Travel, Transport-related Tax Concessions and Housing Grant for Persons with Disabilities and Carer's Allowance.

and supports to persons with disabilities. The Disability Act 2005 in Ireland provides for a right to a needs assessment for people with disabilities.

Parents/guardian interviewees were asked to give their perspectives on needs assessment based on their own experience.

Three sub-themes emerged from the Framework analysis:

- (i) The child/young person's individual needs
- (ii) Statutory needs assessment
- (iii) Assessment of family support needs

6.2.3.1 The child/young person's individual needs

There was a range of perspectives among parent/guardian interviewees as to whether, how and to what extent the child/young person's needs were assessed. Some were clear that an assessment had been carried out while others were somewhat unsure as to whether or not there had been a needs assessment and others felt that no needs assessment took place.

"I don't think it [needs assessment] was done" (Parent 1).

"Well it must have been done... it must have... we've had about 3 or 4 people from the [specialist service provider] ...It's done on a year to year basis" (Parent 8).

"It wasn't until she was, I'd say, until she was near enough to going into first year. Because she was let slip through the net" (Parent 13)

There was a perception of discussion about needs being part of the ongoing support available from the specialist service provider.

"They probably were assessing her all along... they used to bring her in, she used to have speech therapy and physiotherapy ...they'd have regular meetings ... she'd have been discussed at those meetings" (Parent 15).

"We sat down around the table ... and pretty much everything that was needed to be put in place was done ... we were involved in absolutely everything because I personally need to be involved in his care" (Parent 17).

The crucial importance of needs assessment was noted.

"It wasn't really until there was an assessment done that we realised what his needs were...we didn't know that he had a mild learning disability... Once that was established the [specialist service provider] stepped in" (Parent 3).

6.2.3.2 Statutory needs assessment

Under the Disability Act 2005, all children with disabilities in Ireland are required by law to have an assessment of need carried out and a service statement provided accordingly (see 4.6.2 above). (This has been limited to date to those aged less than five years).

There was a lack of clarity among parents/guardians about statutory needs assessment and whether or not it was carried out in accordance with the legislation in cases where a child was legally entitled to have such an assessment carried out.

"I never heard of that [statutory assessment of need for child]. I've read about it at the Doctors surgery" (Parent 9).

6.2.3 3 Assessment of family support needs

Parent/guardian interviewees were also asked as to whether there was an assessment of their support needs as parents of a child with an intellectual disability. Again, there were mixed perspectives. The majority stated that no such specific assessment was carried out.

"I don't have any recollection of being asked about that [our needs as a family]" (Parent 17).

"No, nobody never came near us at that time ...It's like as if nobody knew" (Parent 11).

"The [assessment] is all about [child] – we haven't been asked a question about our needs ... we should have been" (Parent 4).

Some parents/guardians felt that an assessment of their own support needs as parents of a child with an intellectual disability would have been incorporated to some extent in the overall assessment of the child's needs.

"We would have met the social worker a couple of times a year ... and I suppose maybe they probably did in their way ask [what we needed]..." (Parent 12).

"No there hasn't been any assessment as such but they would have asked us, 'are you doing alright' " (Parent 10).

6.2.4 Person-centred planning

'Person-centred planning' has been defined as "a systematic way to generate an actionable understanding of a person with a developmental disability as a contributing community member" (O'Brien and O'Brien 2000:2). Person-centred planning and related individual care and support plans details people's needs and outlines the supports required to maximise their personal development, in accordance with their wishes.

The Personal Outcomes model is, as already stated (see 5.3.3), the main approach to needs assessment and individual planning used by the case study service provider. The Personal Outcomes approach covers all aspects of a person's life – from safety and protection to the best possible health outcomes, having choices, achieving personal goals, connecting to families, having friends and relationships, living in the community and taking an active role in it and being able to assert one's rights.

Three sub-themes emerged from the Framework analysis:

- (iv) Level of awareness of the Personal Outcomes approach

- (v) Planning for transition
- (vi) Parents/guardians' concerns about the future

6.2.4.1 Level of awareness of Personal Outcomes approach

Parent/guardian interviewees were for the most only somewhat aware of the Personal Outcomes model.

"I know the [service provider] brought in something a few years ago, it was an American thing where they would come once a year and look at their needs ... and they would also talk to us as a family... I think they have stopped it in the last couple of years" (Parent 7).

Some, however, referred to forward planning which involved themselves as parents/guardians.

"There was a social worker from [service provider] and in the beginning she would have been asking what we needed ... like a kind of individualised care planning for [child] but it involved the parents as well" (Parent 16).

6.2.4.2 Planning for transition

Parent/guardian interviewees were asked as to whether or not there was specific person-centred planning at key transition points in the child's life. For the most part parents focused on two aspects of person-centred planning at key transition points – planning for Special Needs Assistants (SNAs) at school going age and planning for supports when transitioning out of second-level education. Their perception generally was that there was a significant lack of meaningful future planning and that this uncertainty added to their concerns.

"I remember [child] was starting [school] in September and not knowing in June what kind of supports he'd have. And I remember being on the phone trying to get through and, you know, that was a horrible time..." (Parent 16).

"Now I don't know what's happening now ... I've applied for another year, so I don't know what's happening there... The only thing I do know is that I have to have a service because I wouldn't be able to manage at home" (Parent 1).

"I think, where I am at that at the moment is full of the unknown, because I don't know where [young person] will go, or what lies ahead for her after she leaves the secondary school ... She has one year left there, but I don't know what lies ahead for her" (Parent 15)

Concern was expressed by some parents/guardians about what they perceived as a lack of more long-term planning.

"He can stay on there [in special school] until he is 18 but I don't know what will happen then" (Parent 4).

"We would like to know where he will be when he is 15 ...I'd like to speak to someone – 'Ok what we can expect from [child] as a teenager or as an adult?' It's a critical age now" (Parent 8).

One parent/guardian interviewee expressed the hope that the specialist service provider would draw up a transition plan for the child/young person at the end of second level schooling.

"I'm sure there is [planning at end of second level]. You know you'd usually do it from 16 to 18. ..They usually have a parent teacher meeting in September. They do jobs placement" (Parent 5).

6.2.4.3 Parents/guardians' concerns about the future

Parents/guardians almost universally expressed uncertainty about their child/young person's future and many stated that they were fearful and anxious about the future held in the longer-term.

How the child/young person would cope in social situations was a concern for some parents/guardians.

"That would probably be the one thing that would worry me. He is very trusting ... but would he know the difference between somebody that is going to be good for him or is not going to be a good friend and lead him astray" (Parent 9).

"And then we don't know if people would short-change her. You don't know if that would happen ... for a girl in particular it's dangerous" (Parent 12).

"Well sometimes I worry a little bit about when they get older and how somebody will treat them when we're not with them" (Parent 8).

Exploitation by irresponsible employers was a concern for some parents/guardians.

"She [young person] could be working somewhere and that person could have her doing overtime and [young person] wouldn't think to ask 'well am I going to get paid for this overtime' " (Parent 13).

One parent/guardian referred to the fact that their child (who was now a young adult) had expressed an interest in living independently and indicated that they were somewhat apprehensive about this prospect.

"She has it in her head about living on her ownI wouldn't be mad about it. I'm thinking you know like 'well, [young person], you'll get lonely now ...I think she's kind of seeing that too" (Parent 12).

Some parents/guardians stated that they were very concerned as to what would happen when they were no longer around or able to provide the care and support required. Such an eventuality was perceived as being potentially traumatic for the child/young person with some expressing concern about whether society would fully protect and care for their child in their absence.

"The biggest worry I'd have is her [young person's] dependency on us to be there, and God forbid something should happen to us, you know, I don't know how she'd handle that...she really wouldn't know how to cope with that I'd say, and that would worry me " (Parent 15).

"That would be a main worry for me... That would be a big thing you know, down the road if I wasn't able... if something would happen to me, that's the only thing I would worry about" (Parent 6).

Some stated that they could not, or did not wish to, look too far ahead because of fear and uncertainty about how the child would cope in the longer term and whether the necessary supports would be in place to meet the child's needs on an ongoing basis.

"At the end of the day I don't like looking ahead for [child]. I suppose a lot comes back on us, what we're able to do for him ...no matter what legislation is out there, if the jobs aren't out there for any of them, he [child] isn't going to get a job (Parent 16).

"I don't know how far we're looking...I'm always hoping that if we could get him to communicate a bit more that would be a help ... I don't want to look too far ahead because his [child's] health needs would be huge... any day he is good is a good day" (Parent 7).

Preoccupation with the child's future was seen by some parents/guardians as taking the focus of living in and enjoying the present.

"Well it's frightening because you're always wary of your child growing up and you're thinking ahead, where really you should be thinking of what's going on now at the minute..." (Parent 13)

6.2.5 Inclusive and integrated education

Integrated (mainstream) education for all children is an underlying policy principle which reflects the provisions of the UN Convention on the Rights of the Child (United Nations 1989) (see 2.8.2 above). The research sought to get the views of parents/guardians on how the concept of inclusive or integrated education⁴² operates in respect of their children. It also sought to get their views on any difficulties they experienced in accessing appropriate education for their child.

Three sub-themes emerged from the Framework analysis:

- (i) Choosing the 'right' school
- (ii) Experience of mainstream schools
- (iii) Putting the required school supports in place

6.2.5.1 Choosing the 'right' school

Parent/guardian interviewees reported that engaging with the education system was a challenging and sometimes difficult experience mainly related to choosing the 'right' school for their child whether mainstream or special and maintaining vigilance that their child's needs were being

⁴² UNESCO's *Guidelines for Inclusion: Ensuring Access to Education for All* (UNESCO 2005) defines inclusive education as a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education.

catered for. All parent/guardian interviewees reported that they felt their child did get into the right school even if for some this did not happen at the initial stage.

The search for the 'right' school for their child was reported by parents/guardians as a significant feature in their lives at and around the starting school time.

"I might have gone the special [school] route but we went up to [local] school and the principal says 'why wouldn't you send her here – the bus is passing your door, and she would know most of the children in the corridor' ...it worked very well" (Parent 12).

"I was reading an article in the local paper and I saw a school which was only four miles away from where we live, they had a few special needs children and they had a Resource Teacher and they had Special Needs Assistants and all of that. So I enquired into that and I got her in there the following September and it was a real turning point for her... because she loved it" (Parent 15).

Those parent/guardians who had a child in a special school expressed the view that this was the best option for their child. Attendance at the special school was based on professional advice in one instance, an intuitive sense of what was best in another and on a negative experience of mainstream schooling in another.

"We were told that it [local school] wasn't an option because there was nothing in the school for him because he needed a classroom with no more than 6 ... now I'm talking 10 years ago ... or a special classroom in the school and we didn't have that here ...he needs one to one in [special school] ...they have programs specific for him" (Parent 5).

"We first sent him to [mainstream] school; there was a big push at the time when [child] started school about this social integration. All kids to be integrated into mainstream and all that. ...If anything we were slightly influenced that it was the best way to go... it didn't suit him" (Parent 4).

6.2.5.2 The experience of mainstream schools

Most of the interviewees who had children in mainstream schools referred to a supportive school ethos as being a key factor in their choice of school. The experience of mainstream schools was generally positive.

"I have to say it is a fantastic school ...we've never had a problem with [child] and [principal] would have always made it as easy as possible, I could bring him in at 2.30 for a half hour ...it's huge for us now to have that support and have [child] as part of the school" (Parent 7).

"The school tries to get her to do things ... she gets training on interaction. She's out playing in the schoolyard everyday and she has a lot of friends from school over at the house and things like that" (Parent 10).

Some difficulties with the mainstream school were reported, in particular, the failure of the school to understand the sometimes complex learning needs of a child with an intellectual disability.

"Some of the teachers don't have a full understanding of the capabilities or the lack of capability. I found situations where, because [child] looked normal they

treated him as if he was fully normal ...they knew he had an intellectual disability but yet somehow they were expecting that maybe he could do things that wasn't within his capability" (Parent 3).

The crucial importance of adequate supports in mainstream schools in order for the child to survive and to flourish was emphasised. This was seen as necessary because of the demands on teachers who have responsibility to teach all the children in the classroom, all of whom are special in their own way.

"[Child] cannot sit still, so if he can't sit still because he's got this sensory thing, if there isn't someone to take him out of the classroom and to do, let's say, occupational therapy stuff with him, he's not going to learn. If he's not learning, he's going to get disruptive" (Parent 16)

A significant difficulty with mainstream schools reported referred to getting the necessary school supports put in place.

"I would say it was at least two years until he got the proper support he needed, as in a SNA, as in a more speech therapy, OT and all the supports he needed ...There are still a lot of things he can't do but mainly he has improved 100% from those years when he started school" (Parent 9).

The experience of the mainstream school for one parent/guardian was very negative.

"I would not advise anyone to put a special needs child into a mainstream school up to a certain level of need" (Parent 4).

6.2.5.3 Putting the necessary school supports in place

Putting the necessary school supports in place in mainstream schools presented difficulties for many parents/guardians. In particular, uncertainty about resource teacher and Special Needs Assistant (SNA) support.

"Well he has had an SNA for the last year which has really helped him because otherwise I don't think he would have reached the milestones. He has done very well but as far as I know that SNA support won't be available now because of the cutbacks" (Parent 9).

6.2.6 Perceptions of social attitudes to children/young persons with an intellectual disability

Social inclusion and positive recognition of children/young persons with an intellectual disability are regarded as key aspects of a rights-based approach (Honneth 1995; Dolan 2010; Nussbaum 2006; Carlson and Kittay 2010). In order to more fully apprehend the day-to-day experiences of families that have a child with an intellectual disability, parents/guardians were asked for their views on social attitudes to children/young persons with an intellectual disability.

Four sub-themes emerged from the Framework analysis of the parent/guardian interviews:

- (i) The emergence of more positive social attitudes

- (ii) Experience of negative attitudes
- (iii) Perceived mixed attitudes of children/young persons' peers
- (iv) Attitudes dependent on type of intellectual disability

6.2.6.1 *The emergence of more positive social attitudes*

The overall perception of parents/guardians was that social attitudes towards children/young persons with an intellectual disability are becoming increasingly more inclusive and are generally positive. This was seen as being reflected in people with an intellectual disability being publicly visible and actively participating in various life domains. It was also seen as being reflected in children/young persons attending mainstream schools and participating in some community-based activities.

"I'd say they [social attitudes] would be mainly positive" (Parent 4).

"I think society has definitely changed, even in the last 10 years ...everybody accepts people with disabilities in society now" (Parent 9).

"I absolutely think they [attitudes] have improved fantastically, and I think that the thing of mainstreaming children ... and them going out and other children with them is great..." (Parent 12).

The attitudes of other children in schools to the child with the intellectual disability were generally regarded as positive.

"The other kids in school are very positive. The other children are very good to [child]. And the parents are very positive and I haven't found anything negative really" (Parent 10).

6.2.6.2 *Experience of negative attitudes*

Outdated attitudes among some people were reported by some parent/guardians while others referred to experiences of members of the public looking at or staring at their child.

"I still find people turn around and look... and especially children" (Parent 1).

"There is an awful lot of people that just stop and stare at her" (Parent 15).

Other instances were identified of people in public venues expressing discomfiture with what they perceived as anti-social behaviours of the child/young person and, as a result, avoided such situations.

"I wasn't comfortable with the way people were looking at us [at a children's show] and even one of them [performers] they said to me 'can you stop them making noise' so I wouldn't even go into those situations anymore" (Parent 7).

Perceptions of attitudes that reflected uncertainty rather than negativity were reported by some parent/guardian interviewees.

"It doesn't have to be a negative thing just a natural reaction. Like 'everybody should be healthy and happy and have all the options and the chances' but the world isn't like that... after a while people see past that and I'm always glad when people talk directly to him" (Parent 7).

"People might sometimes be unsure – when she was smaller, she might go up and hug somebody in the supermarket and things like that because she didn't know, she had no boundaries ...but they weren't really negative either" (Parent 10).

Some interviewees stated that people who did not have direct experience of a child/young person with an intellectual disability did not fully comprehend the reality and that attitudes that might appear to be negative may arise as a result of this lack of insight.

"I don't think anybody understands and I mean I wouldn't have either until we had [child] ...with behaviour [difficulties], I don't think anyone understands" (Parent 5).

"I think people who haven't an involvement with a person with a disability ... they don't have the same feeling for them as they would for a normal, whatever normal is, person ... I don't think it's that they feel that they shouldn't be there or anything ... I think it's just 'I don't know how to deal with that'" (Parent 1).

The initial response of people who had no direct experience of a child with an intellectual disability was viewed as being sometimes one of pity.

"When people meet [child] at the beginning, there's a mask and you'd get pity ... and I can understand, if I wasn't the mother I probably would feel exactly like that... It's a natural reaction. I would see a child with Down Syndrome and I would feel pity for the parent as well" (Parent 7).

"People think 'God help that poor person' and might stare at them for a minute, which isn't right to be doing but they are drawn into it" (Parent 12).

6.2.6.3 Perceptions of attitudes of children/young persons' peers

Parent/guardian interviewees reported generally positive attitudes towards their children with an intellectual disability by their peers.

"No different with his friends and they are very good, you know they never see him as anything different...in any way that I have noticed" (Parent 6).

The point was made repeatedly that once other children/young persons got to know the child/young person on an individual basis, the response was generally positive and inclusive to some extent.

"Before, when we would go out the town, you'd see her age group looking at her, whereas now you go out and it's 'Hiya! and Hi! ... they all know her, which is great" (Parent 15).

The experience of peers and classmates being protective of the child/young with the intellectual disability was reported by some parents/guardians.

"The lads would actually be protective of him, which is great ... They all include him the same, even the youth-club" (Parent 16).

The importance of a child/young person with an intellectual disability developing coping skills in their interactions with their peers was noted.

"When [child] was small, he had a lot of problems ... as he got older and he's got more independent, he's more accepting [of his situation]. He stands up for

himself now at 12 whereas when he was younger he couldn't because he didn't understand that he had those problems at the time" (Parent 9).

"In the winter time, some of them would throw snowballs at her because she's too quiet... And you'd be thinking, oh well you don't want your daughter going through that but then she has to have an experience of that, what life's really like" (Parent 13).

Some parents/guardians reported experience of what they perceived to be somewhat exploitative behaviours by the child/young person's peers.

"It's the sort of stuff that isn't obvious, not seen ... they [other young persons] say 'you go and do that or we'll beat you up' or whatever and he feels he has to go into a shop and steal something or whatever and I know that he has done that" (Parent 3).

Reference was made by one parent/guardian to her child being the subject of ridicule because he could not read the time correctly.

He [child] might say 10 o'clock and it might be 2 o'clock and it was a great joke to them ... There's just little things, little subtle things" (Parent 6).

Another referred to other young persons failing to take the young persons with the intellectual disability seriously.

"And even like [young person's] friends now – I'd see some of them like laughing at her when she says something ... she'd be serious and they'd start laughing" (Parent 11).

6.2.6.4 Attitudes dependent on type of intellectual disability

A number of parent/guardian interviewees were of the view that social attitudes were to some extent shaped by the type of the child/young person's intellectual disability, in particular, whether the disability was visible or not and whether the child manifests behavioural difficulties.

"Well I suppose if you say to someone 'oh they have an intellectual disability', they're looking at, they might think, 'well what, it doesn't look like she has a disability'" (Parent 13).

"People know straight away by looking at him that [child] is Down Syndrome ... they [children with Down Syndrome] can be more affectionate so people will respond better to somebody being more affectionate to them than if somebody would box you" (Parent 4).

"I find that people don't seem to understand – he looks normal. One woman said he needs a good crack of the wooden spoon ..." (Parent 5).

6.2.7 Impact on families of having a child with an intellectual disability

Families of children with disabilities face unique challenges associated with their child's condition (Ellison 2006). The presence of the disability or chronic condition affects the entire family as an interactive unit; that is, if something affects or influences one member in the family, all members of the system can be affected. Experiences vary, however with a number of studies reporting that parental adjustment to caring for a child with a

disability varies from parents who experience psychological distress to those who successfully adapt (Ellison 2006).

Parent/guardian interviewees were asked to describe the impact on family life of having a child with an intellectual disability on how the family coped on a day to day basis. Six sub-themes emerged from the Framework analysis:

- (i) The need for constant attendance to the needs of the child
- (ii) Additional demands on the family
- (iii) Maintaining a 'normal' family life
- (iv) Positive impact on family
- (v) Negative impact on family
- (vi) Impact on siblings

6.2.7.1 Need for constant attendance to the needs of the child

All of the interviewees identified the need for constant attendance to the needs of the child with the intellectual disability as being a core component of daily life.

The significant demands on time and the need for parents/guardians to be ever-present was reported as a current feature of their lives

"It's like having a baby really. He just can't be left on his own ... somebody has to be with him the whole time ... it's the total dependence really ... everything has to revolve around [child] ..." (Parent 4).

"You just have to be with her all the time when she's at home, you' can't leave her ... I find it hard work now, mentally and physically ... you can't communicate, you can't say to her, 'well what's wrong' it gets harder now as she gets older ... you'd be worn out when you get to wherever you were going [with her] and you need two people" (Parent 1).

Having to plan ahead was an important part of family life for most parent/guardians.

"You have to plan no matter what...like if you get an invite or if you're going anywhere even something like getting your hair cut, you have to plan. 'Will he be home, will he be gone [to respite]'" (Parent 5).

The need for constant vigilance, both inside the home or in public spaces, was reported as a recurring aspect of family life.

"You can't turn your back, you have to know where she is, if you go out, you have to watch her all the time" (Parent 15).

"You have to watch her constantly because she'll leave hair straighteners on, she'll leave the chipper on, she leaves things like knives down in front of the kids [younger children in family] ... you have to keep an eye on her" (Parent 11).

"It is still difficult to walk about anywhere outside the house because you always have to keep an eye on her" (Parent 10).

6.2.7.2 Additional demands on the family

The huge demand on time and energy was a recurring theme for the interviewees. Caring for the child with the intellectual disability was frequently reported as hard going and very labour intensive. It was particularly difficult in situations where there was only one parent.

"It is hugely labour intensive ... You are all the time on the road, and the cost of petrol... the amount of appointments. And then working as well, I find it hard ... and you need two people to go with him (Parent 4).

"And I mean he could be up at 7 o'clock in the morning, he might not go to bed until 2 o'clock at night... and I'm on the go all day and you still have to cook a dinner, you still have to shop and [younger sibling] is bored ... you're trying to keep everyone happy" (Parent 5).

"Well it's hard going, I find it tough because I am on my own" (Parent 6).

"You might be called 4 or 5 times a night. If you are, then it's very hard to cope the next day" (Parent 7).

"It's tiring sometimes because she talks a lot and if you don't answer she will repeat it, gets louder and louder until you answer her, we are trying to deal with that" (Parent 10).

Dealing with the day to day reality of the situation without getting too preoccupied with the additional needs of the child with the intellectual disability was seen as necessary in order to manage on a day-to-day basis.

"I think we would just get on with it... we have to make the most of it or whatever... there would have been a lot of other things going on as well in life, I don't know whether it's good or bad, but it's the way we do it" (Parent 16)

Living with and caring for a child with an intellectual disability was reported as impacting on the social lives of parents/guardians. A number made reference to not being able to do things as a family such as going out as a couple and bringing the child with an intellectual disability on a family holiday.

"That's now one thing that I'd be lacking. – we are rarely seen out together, myself and [husband] as a couple because we can never do that" (Parent 15).

"When I go on holidays, [young person] goes into respite because I found that bringing her is a nightmare – when she was small we did" (Parent 1).

"When [child] was younger we didn't go abroad on holidays and we still haven't gone because of the sensory thing and because of just wondering how it would affect him" (Parent 16).

The need to have more than one person accompanying the child/young person in some instances was identified as an additional demand on the family.

"I would have often tried to take him swimming ...but I would always have to bring the [other] two boys with me for added support" (Parent 17).

Having to always take care of the child/young persons in social situations was part of the life experience of some parents/guardians:

"She'd always sort of sit beside me...very clingy. If we went out to the local pub maybe on a Sunday afternoon, she'd have to sit beside me, she wouldn't go off with kideens [other children]" (Parent 13).

Additional costs incurred by the family in respect of transport to services and appointments were reported by some parents/guardians.

"You always have to have fuel in your car because you don't know when you'd have to head for the doctor or hospital" (Parent 1).

"I had to drive to [local town] twice a day when he was going to school in [town] then I used to have to take him to the speech and language and then he used to go to occupational therapy as well and he seemed to have an awful lot of dental, orthodontic appointments" (Parent 3).

"There are costs with going up and down to the hospital and I'm in and out to the school constantly" (Parent 11).

"That was an additional cost, going to [town] , we went sometimes every two weeks so that was quite a long way ...and even going to the Doctor who is in [town] or going to the dentist in [town]" (Parent 10).

6.2.7.3 Maintaining a 'normal' family life

Maintaining as 'normal' a family life as possible was a feature in the lives of many of parents/guardians.

"There would be so many things on of an evening that I love doing. And, I suppose, it hasn't stopped us doing that... [child] was involved in the local football, he'd come along, he would have been involved in the community games" (Parent 16).

"She did everything that the other two were doing. Went on holidays, everything, you know ... but the noise she just couldn't tolerate so we would have nearly stopped going to the [football] matches because of that" (Parent 12).

Integrating the child with the intellectual disability into regular family life was seen as necessary in order to cope with daily living was reported by some parents/guardians:

"It was very normal that way, she would have been as normal as the others she came and went the same way as everyone else, you know, because she had to, because I was working, and she had to fall in" (Parent 15).

Having to make special efforts to maintain a regular family life was a feature in the lives of some parents/guardians.

"There were times when I said 'God, I just hate going to it [social occasion] because you had to be constantly at her [child's] beck-and-call and every time you think 'I'll make an excuse, and I won't go' " (Parent 12).

6.2.7.4 Positive impact on family life

Parent/guardian interviewees were asked to describe the experience for the family of having a child with an intellectual disability. Notwithstanding the challenges presented by interviewees by the demands of daily living, many of the interviewees referred to the positive aspects of the experience.

"I'd say it has been a positive experience, we have met some great people. It brings out the best in people and everybody that meet [child] they all seem to take to him" (Parent 7).

"Well it has been mostly positive I would say but very difficult at times as well" (Parent 18).

The belief that their child with the intellectual disability is more caring, affectionate and sociable than many children was articulated by a number of parents/guardians.

"He's a very affectionate child. He'll have loads of kisses and hugs the whole time and he's a very lovable kid... and anybody who comes into contact with him says the same thing and that's nice" (Parent 4).

Reference was made to the positive impact of a child with an intellectual disability on other children in the family.

"If children grow up with a child with a disability of some sort, I think they're far more caring children" (Parent 12).

Different reactions by the two parents were highlighted by one parent/guardian. One was able to adapt to the situation and deal with the child's disability whereas the other took some time to come to terms with the fact that the child had a significant disability and to respond in a positive way to the child.

"From the very minute I heard she had Down Syndrome I have to say it never really bothered me, now her father got an awful shock I have to say. I couldn't really talk about it to him for a long time but having said that like he was brilliant with her" (Parent 1).

Another interviewee referred to the complex feelings experienced.

"You get strength, you have to get strength; you just have to be ready for the good and the bad. But there was a lot of crying done ... but I would keep going back to the fact that she was healthy, that was just such an advantage" (Parent 12).

6.2.7.5 Negative impact on family life

Difficulties were noted which were regarded as having a negative impact on family life, including, as already stated, not being able to go places as a family and not being able to plan ahead.

"Not being able to go anywhere as a family, that would be the biggest thing looking back ...when the kids were small, like the other two,... we could never go for a day with them...if we went to the zoo she'd kick up... she would be exhausted, she'd say 'no' " (Parent 15).

"You're curtailed with everything. You can't just go anywhere... We don't get upset if we miss something" (Parent 14).

"We have a wedding on Friday and we have to try and get support in here and I'm still a bit iffy about going" (Parent 5).

Not being able to have visitors in the home was reported as a feature in the lives of some families.

"People calling to the house upsets [child] ...when they see him in action. they don't come back ...we would have very few that would actually come ...Just to get the house painted now we have to get it done when he is gone [to respite] because you couldn't have somebody painting when he is here" (Parent 5).

6.2.7.6 Impact on siblings

Interviewees were asked to describe the impact that having a child with an intellectual disability in the home had on their other children. In general, while the parents/guardians saw their other children as positively integrating their sibling with an intellectual disability, regret was expressed by some that their other children lost out.

"It has been quite hard for [sibling] ...she [sibling] is the one that spends the most time with [child with the intellectual disability] and I think that can be very overwhelming because it is tiring sometimes" (Parent 10).

"There were times when it was extremely difficult, particularly for the other two children ...they needed to have some sort of a quality of life that they just didn't have, because a lot of time was taken up trying to manage him" (Parent 17).

"I say it would have impacted a lot on her [other child's] life because it was always to do with [child with the intellectual disability] or I had to go somewhere with [child with the intellectual disability]...and I suppose she had to always come along or had to go to somebody else's house. She [other child] said to me once 'where am I here – it's all her' " (Parent 1).

Not being able to bring friends home because of the negative impact on the child with the disability was identified as an aspect of some siblings' lives.

"Even to have friends around for them you couldn't really, you would really need to have him in respite before you could invite somebody along" (Parent 17).

"It's not fair on [younger sibling]... trying to keep things quiet. Although he has improved a lot she wouldn't bring friends home now when he is here" (Parent 5).

Some referred to continually trying to compensate the other children.

"I actually take her out now sometimes and take her places on her own and she appreciates that ... you have to think of her [other daughter's] needs as well" (Parent 10).

6.2.8 The Implementation of a rights-based approach

Since the focus of the research is on rights-based social supports for children and young persons with an intellectual disability, the study sought

to get the views of parents/guardians on whether and how rights-based principles informed the availability and delivery of support services.

Parent/guardian interviewees were asked about their awareness of a rights-based approach, their views on how rights based principles were implemented and whether the support services in place supported such an approach.

Five sub-themes emerged from the Framework analysis of the parent/guardian interviewee data on a rights approach:

- (i) Awareness of a rights-based approach
- (ii) Equality of access to services
- (iii) Access to services and supports
- (iv) Choice by children/young persons as appropriate to their age
- (v) Maximising individual potential

6.2.8.1 Awareness of a rights-based approach

Parent interviewees stated that for the most part they did not explicitly refer to the rights of children/young persons with an intellectual disability in their negotiation for services. Some stated that they were unaware of what rights of the children/young persons with an intellectual disability have.

"I wouldn't [be aware of rights] no. I wouldn't know what rights are there" (Parent 5).

"I wouldn't know anything about that [a rights approach] ... I don't know enough to be honest" (Parent 19).

Parents/guardians generally stated that they felt that the approach of the specialist service provider was underpinned by rights-based principles.

"Well I think they [child/young person's rights] are respected ...there is a huge emphasis on it, but I wouldn't really be that aware of them myself" (Parent 17).

"I think they [rights] are ok...it really depends, doesn't it, on how severe the disability is" (Parent 4).

One parent/guardian stated that she was aware of the UN Convention on the Rights of Persons with Disabilities.

"I would be aware of it [the UN Convention on the Rights of Persons with Disabilities] but I think the level of the disability that [child] has is going to restrict him a lot" (Parent 7).

6.2.8.2 Equality of access to services

The overall perception of the parent/guardian interviewees was that, at some level, there was equality of access to services and that additional resources were put in place by the State for this purpose.

"I think they have [equality]... the resources are put in place... The State is probably doing what they can with the way the budget is at the minute" (Parent 10).

"I think they get the extra help that they need – more than normal children" (Parent 11).

However, there were also perceptions of lack of equality generally for people with disabilities.

"It's a contradiction, I can't get my head around this contradiction because at one level there is a tolerance or acceptance of people... but yet when it comes to doing something that ensures that equality is there, people do the opposite ... they take the [disability car parking] spaces" (Parent 7).

The absence of supports commensurate with ensuring that there is equality was an issue for many parents/guardians.

"That's what's so hard – you really do have to fight for the child to have all these things put in place ... There must be other parents out there that have the same problem that aren't aware [of their rights]" (Parent 9).

"There is a lot of things being done....but I don't believe there is the same choice [as for other children]" (Parent 3).

6.2.8.3 Access to services and supports

Many of the interviewees made a clear link between the implementation of a rights-based approach and access to support services. This was regarded as particularly relevant in what was perceived as significant service retrenchment arising from current budgetary constraints. One interviewee summarised this perspective succinctly:

"Leave the health services alone; let the people that have SNAs keep them; let the people coming in [to school] have them; let the support workers be there...because if they keep cutting the service a little bit at each time, and if they keep gnawing at it, eventually there's going to be nothing of that service left" (Parent 13).

Another interviewee pointed to the inherent inequality in the specialist service provider, because of budgetary constraints, having to prioritise services to those deemed to be most in need.

"Somebody might need more supports and all the funding might go there because he needs respite more than you do and then you are way down the line again, you know starting off again... they will always tell you it's down to funding" (Parent 5).

6.2.8.4 Choice by children/young persons as appropriate to their age

The researcher identified 'choice' as a component of a rights-based approach and how the voice of the child/young person was facilitated in practice. Interviewees were asked for their views on how this concept manifested itself in their experience of accessing social supports.

Some interviewees were somewhat unclear as to whether and how this concept operated in practice in the lives of their child/young person with an intellectual disability.

"I suppose we don't know ourselves what [child's] voice is but were always trying to find out... what direction he is going in, how we can accommodate him" (Parent 7).

"I don't know how you could answer for somebody like [young person], somebody with his level of disability ...how he'd show, how you would know that the decision was really what he wanted to do...I genuinely don't know how ...I don't see or don't know how you could be sure" (Parent 17).

Parents/guardians referred to working with their child from an early stage around the area of choice – giving the child realistic choices and asking him/her to express a preference. For many children, this involved by necessity relatively small choices about daily living, e.g., a choice between two times for going to bed, some choice in food and treats.

"We give him loads of choices but it has to be just one thing or the other – the one that you really need him to do and the one that you know he is not going to do. ...I suppose we are kind of controlling it" (Parent 5).

A number of interviewees referred to difficulties around food in terms of having to deny access to food because of overeating and obesity and the implications of that for concepts such as choice.

"Now we can't give him access to food because he would eat and eat and eat, so we restrict ... It is a huge challenge...there are rights and there is a need to be cautious and sensible about things... I don't know how you do these things to be honest" (Parent 17).

6.2.8.5 Maximising individual potential

Maximising individual potential was identified by the researcher as an important rights component. The predominant view of parent/guardian interviewees was that the potential of their child/young person was maximised.

"Even though to an outsider it might be kind of limited but to [child] it wouldn't be limited because it's going as far as he can... They have cookery class [in the school] and trying to make him as independent as they can and showing him how to put on his shoes ... and how to dress himself" (Parent 4).

"Everything that can be done is done" (Parent 5).

"We do what we can for [child] within his ability" (Parent 7).

Others were less sure that the maximising potential principle always operated.

"It maybe doesn't happen all the time ...people with disabilities don't get the same chances" (Parent 13).

6.2.9 Information and advocacy support

It is now widely accepted that information is an essential prerequisite for active citizen involvement. Without good quality, accessible information, it is not possible for citizens to vindicate their rights. Good quality and easily understood information is necessary to enable people to have control over their lives and to make appropriate choices.

Three sub-themes emerged from the Framework analysis:

- (i) Access to information at various transition points
- (ii) Specific gaps in information
- (iii) Need for and availability of key worker/advocacy support

6.2.9.1 Access to information at various transition points in the child/young person's life

Almost all of the interviewees reported that they got the information they needed when they needed it and some stated that they were relatively happy with the information they had received.

However, some referred to having to search for information.

"I feel pretty much that you're left to your own devices. I feel that you have to do an awful lot of prowling yourself to get a lot of information" (Parent 3).

"There was good communication... but there was also this feeling that you had to fight for everything... That really to get anything you had to know about it and to shout for it" (Parent 16).

6.2.9.2 Specific gaps in information

Specific areas were identified where parents/guardians felt there were information deficits. One parent/guardian referred to hearing by chance about a support available to the child.

"If we hadn't been at that meeting [about the child's needs] we wouldn't have known about the service [special provision for July] because the Department wasn't going to tell us ...we should have been told about it" (Parent 4).

Another stated that she did not know about her entitlement to Carer's Benefit (a social insurance based payment available to people who take time off paid employment to provide full-time care to a family member).

"For years I didn't realise this Carer's Benefit was there and I used to take the time off work without pay" (Parent 15).

Getting information about third-level education options was identified by one parent/guardian as a concern.

"Getting more information on things like third level education [for young person] would bother me – I wouldn't have a clue about it you know and I was trying to figure out where I would go to get it" (Parent 6).

6.2.9.3 Need for and availability of key worker/advocacy support

All of the parents/guardians referred to the fact that their child needed an advocate/support person to help him/her to articulate his/her needs in public forums, particularly in the school setting.

"She is a quiet-natured a child and I don't think as an adult it'll even change...If she doesn't have a voice to speak up for herself, someone will have to be an advocate for her" (Parent 13).

The majority of interviewees stated that they had access to key worker and advocacy support from the specialist service provider.

"If we have a problem we'd ring them [specialist service provider] and we have a good social worker...you are always told that, I mean we have [phone] numbers...you would never feel intimidated to ring them" (Parent 6).

Some stated that they would not have a named individual as a support person but felt that they could contact the specialist service provider if and when needed.

"There wouldn't have been anybody [individual support worker] there; it was mainly if you wanted to know something you had to phone up" (Parent 9).

One interviewee emphasised the importance of parents/guardians being able to negotiate on behalf of their child/young person.

"I can talk to people here [specialist service provider] but I don't feel it's necessary any more ... at the end of the day you have to do your own thing" (Parent 1)

Summary of section

Eight main themes and related sub-themes emerged from the analysis of parent/guardian interviews – social supports available to children/young persons and their families, access to formal services, individual needs assessment, person-centred planning, inclusive and integrated education, social attitudes to children/young persons with an intellectual disability and impact on families of having a child with an intellectual disability. The implementation of a rights-based approach and the role of information and advocacy support also emerged.

The analysis reflected a complex picture across all themes with a range of views and perspectives emerging. There were significant variations in parent/guardians experience of family support, local community/neighbourhood connections and friendship networks. There was a consensus among parents/guardians that mainstream social outlets do not cater adequately for children/young people with an intellectual disability who may be vulnerable.

For the most part formal services were perceived as useful and beneficial when available. However, there was the perception of having to 'fight for' services, particularly at this time of budgetary retrenchment. The 'voice of the child' principle was regarded by parents/guardians as an important one

which they recognised but one which was sometimes undermined by the absence of commensurate resources, particularly in respect of these with more complex disabilities.

Parents/guardians believe that social attitudes to children/young persons with an intellectual disability are becoming more positive. However, some report having some negative experiences. Once the 'right' school was found, parents/guardians felt that their child was adequately catered for educationally. While many parents/guardians stated that that their child/young person is being provided with opportunities to maximise his/her potential, there is a widespread uncertainty, fear and apprehension about what the future holds.

6.3 The perceptions of young persons

This section of the chapter sets out the experience and perspectives of a sample of young persons in receipt of supports from the case study service provider. It is based on one-to-one interviews with ten young persons aged over 16 years and a Focus Group involving four young persons (three of whom had participated in the one-to-one interviews). The focus group was organised around four themes about which the researcher wanted to get a sharper insight.

Seven of the young people were attending education/training programmes. These interviewees had completed their schooling (six in mainstream and one in a special school). They were engaging in different training and employment support programmes co-ordinated by the case study service provider. Four of the interviewees were currently attending a post-primary school.

The interview schedule used simple open-ended questions with additional prompt questions to explore further their views and perceptions (see Appendix Seven). The interviews covered the main areas of living relating to their current situation, their social supports, their activities and their future aspirations.

Four main themes and eleven sub-themes emerged from the Framework analysis of the young person interviews. These are set out in Figure 6.3.

6.3.1 *Young persons: their lives at present*

Two sub-themes emerged from the Framework analysis relating to young persons' lives at present:

- (i) Their current situation
- (ii) Having their voice heard

Figure 6.3: Interviews with young persons: themes and sub-themes identified

Their lives at present	Their current situation; having their voice heard
Social supports	Families; support from service provider; local neighbourhood connections; friendship networks
Social activities	Social outings; hobbies
Future aspirations	Work aspirations; education/training; future living arrangements

6.3.1.1 *Their current situation*

All young person interviewees felt that they had some good things in their lives at present. In particular, their music, time with their friends and home life were stated as positive experiences. Ten reported that they are happy with their current situation (school or education/training programme).

“Everything is good ... I get to go out to different places ...and get to do different things” (Young Person 8).

Two of the interviewees attending the education/training programme stated that they left school at the end of fifth year. While one was quite clear that she left because she found doing exams too difficult, the other was less sure why he left, stating the he found the school “good enough” (Young Person 2).

Four of the six interviewees attending the training/education programmes were involved in work placements – one in a department store, one in a mini-market/filling station, one in a hairdressers and one in a printers shop. All of the interviewees stated that they liked these placements. One of them, however, stated that she had a difficulty with her activity placements in that she did not get paid:

“I know it’s hard for me to say this but, the thing iswe’re volunteers in [a community-based service} ... I don’t really get paid, to be honest... it’s kind of difficult” (Young Person 5).

One interviewee who was training for the Special Olympics was very excited about the prospect of qualifying.

“Hopefully to get through to the Olympics...And go to different places and go swimming everywhere else” (Young Person 2).

When asked if there were any problems with the training programme, one interviewee stated that he missed his friends from school.

One of the young people in school stated that he was not happy and wanted to leave school. When asked by the researcher what might be

done to remedy the difficulty he had in school, he stated that he had heard about a computer programme that would help somebody like him.

"It would be nice, do you know how there is a CD for the computer now ... To help you type on your computerthere would be CDs for English, maths and maybe business. That would help other people and me in to the future" (Young Person 1)

6.3.1.2 Having their voice heard

Interviewees were asked whether they could give their opinion on things that were important to them and whether they were listened to. Nine stated that they could give their opinion on things and eight said that they were listened to 'always' or 'sometimes'. In one case, it was not clear to the researcher what the interviewee's response was to either of the questions.

In general, the young people stated that they were listened to by parents, teachers and other support staff involved with them. However, some stated that they felt that they were not always listened to by parents.

"Sometimes I could tell my mum and dad things but they wouldn't listen" (Young Person 6).

Support staff not listening because they are busy was regarded by one interviewee as resulting in him becoming bored.

"They [staff] don't listen to me when they're busy at something...[then] I'd be bored" (Young Person 2).

6.3.2 Young persons: their social supports

Four sub-themes emerged from the Framework analysis relating to young persons' social supports:

- (i) Family support
- (ii) Support from service provider
- (iii) Community/neighbourhood connections
- (iv) Friendship networks

6.3.2.1 Family support

All of the interviewees reported good relationships with their parents and mostly with their siblings. When asked who the most important person in their lives was, seven stated that it was parents or parents and siblings and two stated that it was family and friends. One interviewee stated that she was a bit unsure about the question. Nine of the ten interviewees stated that they had an extended family network and reported varying levels of contact with extended family members.

"She [mother] gives me a good lot of help around; even when I come home with my homework she would help me ...I've a load of cousins ... I would get on fine with them ...You would get better memories if you were with your family than if you were with your friends" (Young Person 1).

"I get on very well with my sister... I've loads of cousins" (Young Person 6).

"I get on fine at home...though sometimes, I have fights with my brothers" (Young Person 8).

"I get on well with them [parents]...and then, you know we have our moments ...I get on with [one brother] fine. I don't get on with [other brother]" (Young Person 10).

Two interviewees stated that they were godmother to a niece and both expressed a strong sense of satisfaction with that.

6.3.2.2 Supports from service providers

The interviewees in the training programmes centres stated that they got enough help. All six of them stated that they were happy coming into the centre. They were involved in various employment support programmes, computer training programmes and leisure/fitness activities, including swimming, bowling and horse-riding. Three were preparing for their Driving Theory Test. One of the interviewees stated that she presents a weekly programme on Community Radio where she reviews the local weekly newspaper.

The young person interviewees were asked if they had any specific difficulties with the supports available to them. Eight stated that they were happy with the supports they had. However two identified specific gaps in respect of school support.

One young person highlighted the fact that additional support in the school was intermittent in that it was available in some years but not in others.

"It's been ok but in 1st year I didn't get as much resource as in 2nd year, 3rd year and then in 4th year I got none at all... I liked the teachers but in first year I didn't have a clue what to do ...It's very hard to work by myself. I need someone there to help me in some classes ... in 2nd year I got on ok, 3rd year I got on even better ...I am not getting any [learning support] in 4th year " (Young Person 1).

Another young person attending school stated that there was insufficient support in some classes.

"Well, if I could get more help with maths like, because I'm really bad at maths ... I would be sitting there, and I could be saying 'come on bell ring!' in my own mind. I think just if someone sat beside me and just explained it to me a bit more, I might be able to do it" (Young Person 6).

Three of the four interviewees who were in school stated that they had outreach support from the agency. This mostly involved a support worker bringing them out at week-ends. All of them stated that they were very happy with this support, got on well with the support worker and had a say in the activities that they did.

"I have somebody [service provider support person] who comes at the week-end and I'd go out shopping and we could go to the cinema like. It's great help really" (Young Person 6).

All three of them also stated that they would not talk to their friends and classmates about this support with two of them stating that their classmates would not be aware of it. Two of them explicitly stated that they did not tell their classmates about the specialist agency outreach week-end support. The fourth interviewee attending school stated that he did not get outreach support but did get speech therapy and physiotherapy assistance.

6.3.2.3 Community/neighbourhood connections

Interviewees were asked about their links with their neighbourhood and local community. Eight stated that they had some links with neighbours and their local community. Two stated that they did not have any contact with neighbours.

"I get on with my neighbours fine...I'd call into [neighbour]...she's really nice" (Young Person 10).

"Good, I get on with [names of neighbouring families] but if I went to [nearest village] – not too good" (Young Person 1).

"I know them [neighbours] fairly well" (Young Person 2).

"There isn't really much neighbours, now, but I get on well with the neighbours as well" (Young Person 6).

One interviewee stated that she knew no neighbours and another reported that she had no contact with neighbours.

6.3.2.4 Friendship networks

All of the interviewees attending the training/education programmes identified their fellow attendees as their friends. Three stated that they had friends outside the centres who they met from time to time. Two of these reported having "loads of friends". Two of those attending school stated that they had friends both in the school and outside the school. One stated that she did not have any friends outside of the school and one reported that he no longer has friends from either inside or outside the school because he avoids them due to persistent bullying.

"I have loads of friends now actually ...I have friends in school and then I've friends that are not in school" (Young Person 6)

"I've got loads and loads of friends around me so that's how I became popular.... I like hanging around with my friends, and my family, cause it's really important, you know...well I've got friends up the road, in my road, where I'm from, which is in [name of village]" (Young Person 5)

"I used to have friends but now I don't have much friends ...it's mostly the neighbours around here that are basically good friends ...they would be a lot younger than me" (Young Person 1).

Three of the interviewees stated that they had friends on Facebook.

"So my friends they're on Facebook ...we'd be contacting each other, so it's good to have it actually" (Young Person 5).

"I go on Facebook – I have 583 friends there" (Young Person 7).

While four of the six interviewees attending the training/education programmes stated that their friends were primarily from the centre, the other two stated that they had friends outside the centre. Three interviewees referred to having "loads of friends" (Young Person 5), "three or four friends" (Young Person 7) and "a good few" (Young Person 8).

"I've made loads of friends in there [community drop-in centre] and I just love helping out doing the teas and coffees and that" (Young Person 10)

One young person expressed regret that he no longer met his friends from school.

"Before I left school I had a few friends at school like...I was supposed to go up and see them some day like...they stayed on another year in school" (Young Person 2).

6.3.3 Social activities and hobbies

Two sub-themes emerged from the Framework analysis relating to young persons' social activities:

- (i) Social outings
- (ii) Activities and hobbies

6.3.3.1 Social outings

Young person interviewees reported different experiences in respect of social activities. Three stated that they were very active socially, four engaged in some level of social activity and four reported limited or no social involvement outside of their school or training/education centre.

"I would sometimes go out ...probably go to [name] night club ...I'd probably go to a restaurant ... with friends" (Young Person 8)

"I would go out ...with my parents [at the week-end]...just going for a drink in a pub" (Young Person 9)

"I used to go out before ...I don't go out that often at all. I just go to work and come home... I enjoy going, if the lads weren't fighting with me I would love to go to the discos. And I would love to go bowling, it's a nice thing and go carting. Go carting is a nice thing as well" (Young Person 1).

A particular feature of their lives reported by some of the interviewees was not going out at week-ends.

"I never went to any discos or anything" (Young Person 2).

"I used to go to junior discos – I got too old and don't go now" (Young Person 3).

"I wouldn't be out really at all [at the week-end]" (Young Person 7).

One interviewee stated that she wasn't allowed out and had nothing to do at the week-end. She did, however, state that she looked at TV and listened to her music.

Almost all of the young persons indicated that they would like to be involved in other areas of social activity that they are not involved in at present – this referred primarily to going out more, including, in particular, going to discos.

6.3.3.2 Activities and hobbies

The interviewees reported being involved to varying degrees in a range of activities and hobbies. Music was a strong component in the lives of all interviewees and most stated that they had favourite singers or groups ranging from Rap and pop to country and western. Four interviewees referred to downloading music from the Internet.

Engaging in multiple hobbies was a feature of the lives of some of the young persons.

"To be honest, I've got loads of hobbies ...I do bowling sometimes ...and swimming is my thing" (Young Person 5)

"I like watching TV ... and music ...I like going on to the computer but I wouldn't go on it a lot of the time, just some of the time ... I like going out for a walk ...I love cooking and baking.. I love reading magazines ..." (Young Person 6)

"I like singing and dancing ...sometimes I do cooking ... I play with [friend] on the Wii ...sometimes I go out to my friend's house down the road ... and I go out with mum and dad ... horse riding ...I do it every Thursday...I'm doing voluntary work ... I like doing coffee mornings just to raise money for [voluntary organisation]" (Young Person 10)

"I would watch TV, play games, I would do a bit of cooking now and againswimming, football...sometimes basketball...when I come here [training centre], I usually go on the computer...on the Internet ...because I like listening to all my songs, music" (Young Person 2).

"I kind of have football and stuff ...and swimming sometimes..."I swim in my school with my mother ... I've a heap of DVDs ...a whole lot of them ... Westlife because I'm going to see them" (Young Person 9).

One young person stated that he had tried to play sport (football) but had to opt out because of lack of appropriate support.

"When I was playing [football] I wouldn't be able to kick a ball. It's very hard for me like, the manager who knows I have that disability. He would help me. But now he doesn't do that anymore so that's why I don't play" (Young Person 1).

Pets were an important feature in the lives of the young persons with six of the ten interviewees reporting that they had pets and/or liked working with animals.

"I've two dogs and one cat" (Young Person 6)

"We have cats and dogs... three dogs and four or five cats" (Young Person 8).

"I have three dogs and horses and donkeys" (Young Person 10).

6.3.4 Their future aspirations and plans

The young person interviewees were asked about their plans and hopes for the future in respect of life generally, the work they would like to do and with whom they would like to live in the longer-term. They were also asked whether or not they thought they would be able to achieve what they wanted.

Three sub-themes emerged from the Framework analysis relating to the theme of future aspirations and plans:

- (i) Work aspirations
- (ii) Further education and training
- (iii) Future living arrangements

6.3.4.1 Work aspirations

On the question of future work aspirations, all of the interviewees expressed a desire to engage in some kind of work and all identified a particular area or area where they would like to work.

Working as a cook/chef was identified as an aspiration by some.

"I would love to be a chef ... it could work out because how I got a B in the Junior Cert for cooking I could go on to college for a year or two for that. That's the only thing for work and for the future I would do ... (Young Person 1).

Another interviewee stated that she would probably go into baking and cooking and stated that she felt that she would be able to do it:

"Well I'd give it a go and see how I get on...I haven't been looking at any courses about it yet" (Young Person 6).

One interviewee stated that if the cooking did not work out, he would like to work in the area of social care.

"If my cheffing didn't go too well I would love to work with elderly or disability" (Young Person 1)

Hair-dressing and beautician work was identified by others.

"I would like to do hair and beauty – I hope that I can go on a course when I finish school and get a job" (Young Person 3).

"I would probably get a job as a hair-dresser... I'm doing work experience in [a hair salon] at the moment, every Tuesday... folding towels and that..." (Young Person 8)

One interviewee stated that she would like to have a job in the store where she works voluntarily at present but was very unsure as to whether this would be possible, or, indeed, whether any approach had been made to the store in this regard.

Another interviewee appeared to feel somewhat trapped with the lack of a clear pathway to paid work.

"It's a long story, to be honest with you because I have been on supported employment for a while and I'm not sure...I've been doing what is called 'job shadow' in [name of store] Well, hopefully, please God. I really want this so badly... and to get paid as well ... to get longer hours as well in there" (Young Person 5).

One of the interviewees had a number of work aspirations but it was not clear from what he said that any mechanisms were being put in place to explore these in a meaningful way.

"I'll probably work likein the market selling stuff like in the ... clocks, carvings ... I like woodwork...Probably...like a job in a swimming pool, like a life-guard or something...I have two jobs that I'd like to be able to get...probably a life-guard or be a chef in a kitchen ...I love cooking" (Young Person 2).

Another interviewee stated that she did not know what she was going to do when she finished the supported employment programme in which she was currently involved. While she described the work in the store she was in at present as 'grand' and hoped that she would be able to continue to work there, she stated that she did not know if this would happen. This left her unsure about what the future held.

"I did the job shadow for a while. I'm not too sure if I would [get job]... there could be interviews, and I don't know" (Young Person 5).

6.3.4.2 Further education and training

On a specific question posed by the researcher about further education, one interviewee stated that going to a third-level college was not something she wanted.

"Well that's [college] not my thing... some people likes to do college but not me" (Young Person 5).

Another said that he would like to go to a college but did not have any knowledge or information about it.

"I would like to go to a college like...I heard about them before but I don't know where though ...go to college, get a job" (Young Person 2).

A third interviewee was unsure about going to college but felt that he probably would prefer to "go working somewhere" (Young Person 7) and would like "kitchen work".

Another interviewee stated that she would like to join a drama group

"I've done one in [name of town] when I was younger with the boys...my brothers... so hopefully" (Young Person 10).

6.3.4.3 Future living arrangements

On the question of future living arrangements, interviewees were asked whether they would like to live with parents, family, with friends, or, on their

own. A clear preference to continue living with family or parents was expressed by some.

I probably will be a home bird” (Young Person 6).

“I’m not sure...probably live with my family or parents...I’m very sure [that I could do that” (Young Person 1).

One interviewee (Young Person 4) stated succinctly that she would like to live with her Dad and that she thought that she would be able to do this.

Some of the young persons expressed an aspiration to live with friends.

“I would probably like to live with friends for a while ... I don’t know if I will be able to do it” (Young Person 3).

“Yeah, with friends” (Young Person 7).

“Probably with friends” (Young Person 8).

One interviewee stated that she would like to live with her boyfriend. When asked by the researcher as to whether she thought this would be possible, she stated that her parents were somewhat fearful but that it might be possible

“Maybe...but not just now” (Young Person 10).

Another interviewee hoped that he would be able to share a house with his girlfriend.

“I would like to share....probably with my girlfriend ... I don’t know [if that will be possible] ... [I would like to] try and get my own house if I’ve enough money” (Young Person 2).

Two interviewees who were part of an independent living programme being implemented by the agency stated that they were happy to be part of this programme but also somewhat apprehensive about living on their own and one reported that she was getting help with cooking “and all that stuff” (Young Person 9). One interviewee had already begun staying overnight in her new apartment.

One referred to her parents being somewhat fearful for her well-being when she moved out of home and into her own accommodation.

“My mam, she was scared” (Young Person 9).

The other young person stated that she was somewhat scared about the prospect of moving out of the family home.

“I’m probably a bit scared and think about it...” (Young Person 8).

6.3.5 Focus group with young persons

A focus group involving four young persons (three of whom had already been interviewed) was organised by the researcher in order to get a

sharper insight into the themes emerging from the interviews. The focus group was organised around four themes around which the researcher wanted to get a sharper insight and covered three main areas of living – their current situation, their social supports infrastructure and their future aspirations. The focus group participants were asked to choose from three options in respect of 17 areas of living and these are presented in Figure 6.4.

The focus group broadly confirmed the findings that emerged from the interviews. All felt that they had some good things in their lives at present and most felt that they could do with more help than they have at present. All would like to be involved in other areas of activity that they are not involved in at present. Some of those involved in the training unit do not have friends outside the unit and some of those attending school do not link up with their school-friends at week-ends. Most would like to go out more both during the week and at week-ends, some would not. While some are happy with their current friendship networks, most would like to have more friends and most would like to have more hobbies. There is a heavy reliance on their families for companionship. While generally the young people do not see themselves as any different from other young people in their school/community, there appeared to be some reluctance to talk to others about the fact that they get additional services/supports that others do not get.

Most would like to have a job that they get paid for; to have more friends and to have a boyfriend/girlfriend in the longer-term. Most expressed a desire to live independently of their parents at some stage in the future – some were unsure as to whether they would be able to do this. Most were rather unsure as to where they would be a year from now. Most felt that broadly speaking they had the same choices as other young people their own age and that they could do what they wanted to do (as appropriate to their age). A minority felt that they could not. All were aware of their Personal Outcomes plan.

Summary of section

Four main themes emerged from the analysis of interviews and the focus group with young persons – their lives at present, their social supports, their social activities and hobbies and their future aspirations and plans. Eleven sub-themes were identified relating to their current situation; having their voice heard; family support; support from service provider; local neighbourhood connections; and friendship networks. Social outings and hobbies, work aspirations; education/training options and future living arrangements also emerged as sub-themes.

All the young persons felt that they had some good things in their lives at present and most were happy with their current situation (whether in school or a training programme). Many of the young persons in the training programmes appeared to be reliant on fellow trainees for friends. Those attending school appeared to be somewhat isolated at week-ends. Music and an interest in pets emerged as key features in their lives.

Figure 6.4: Focus Group with young persons (N=4): views on selected topics

Topic/Question	Participants' Response
The training programme	<i>'I like it a lot here' (3)</i> <i>'I like it a bit here' (1)</i> <i>'I'd like to be able to move somewhere else' (0)</i>
'The help that I get'	<i>'I have all the help that I need' (1)</i> <i>'I could do with a little more help' (1)</i> <i>'I could do with a lot more help' (2)</i>
'Thinking about my life'	<i>'I have lots of good things' (1)</i> <i>'I have a few good things' (3)</i> <i>'I don't have any good things' (0)</i>
'Going out more at the weekend'	<i>'Yes I want to' (3) 'I kind of want to' (0) 'I don't want to' (1)</i>
'Go out more during the week'	<i>'Yes I want to' (2) 'I kind of want to' (2) 'I don't want to' (0)</i>
'Have more hobbies'	<i>'Yes I want to' (3) 'I kind of want to' (1) 'I don't want to' (0)</i>
'Have more friends'	<i>'Yes I want to' (4) 'I kind of want to' (0) 'I don't want to' (0)</i>
'Have a boyfriend/ girlfriend'	<i>'Yes I want to' (3) 'I kind of want to' (1) 'I don't want to' (0)</i>
'Continue to live at home'	<i>'Yes I want to' (2) 'I kind of want to' (2) 'I don't want to' (0)</i>
'Live on my own in the future'	<i>'Yes I want to' (1) 'I kind of want to' (2) 'I don't want to' (1)</i>
'Live with one person who is <u>not</u> my family'	<i>'Yes I want to' (3) 'I kind of want to' (0) 'I don't want to' (1)</i>
'Live with two or three other persons (who are <u>not</u> my family)'	<i>'Yes I want to' (3) 'I kind of want to' (1) 'I don't want to' (0)</i>
'Be able to have a job that I get paid for'	<i>'Yes I want to' (3) 'I kind of want to' (0) 'I don't want to' (1)</i>
'Do other things that I don't do now'	<i>'Yes I want to' (4) 'I kind of want to' (0) 'I don't want to' (0)</i>
'Being able to do what I want to do'	<i>'Yes I can' (2) 'I kind of can' (1) 'I can't' (1)</i>
'I have the same choices as other young people of my age'	<i>'Yes I have' (2) 'I kind of have' (2) 'I don't have' (0)</i>
Personal Outcomes Plan	<i>'Yes I have one' (4) 'I don't know' (0) 'I don't have one' (0)</i>

Strong family support was reported, including in some instances good links with their extended family. There was some community involvement by some of the young persons while for others this was non-existent. All had aspirations to have a job and most were unsure as to whether they would be able to realise this aspiration. Some indicated that they would like to continue living in the family home while others would like to live independently (mostly with friends) in the longer-term.

Generally, the young persons felt that their opinion on matters important to them was listened to by the adults in their lives. Most felt that they had the same choices as other young persons their own age. Most would like to have more friends and to have more social activities in their lives.

Chapter summary

This chapter has set out the findings of a survey of parents/guardians, interviews with a sample of parents/guardians and interviews and a focus group with young persons. The findings of Likert-type summation rating scales used with both parents/guardians and service provider staff were also presented.

While three-quarters of parents/guardians reported that they 'usually' or 'always' have support available, almost one-fifth stated that support is available 'rarely' or 'never'. Parents/guardians stated that they felt that they are not always supported by their local community – over one-third stated that support from the local community was of 'little' or 'no' benefit. Parents/guardians do not always get support from their family – almost one-fifth stated that support from the family was of 'little' or 'no' benefit.

Over half of the parent/guardians considered that the rights of children/young persons with an intellectual disability were 'always' or 'usually' protected. One-third considered that they were only sometimes protected and almost 14% considered that these rights were 'rarely' or not at all protected. Based on ratings of nine rights-based statements, there was a perception by both parents/guardians and by service provider staff of significant deficits in the social supports infrastructure from a rights perspective.

The picture that emerged from the parents/guardians' and young persons' perspectives is a complex one. There is a general sense of a social supports infrastructure that is responsive to the needs of children/young persons with an intellectual disability in a general way. However, there also emerged a clear picture of significant deficits from a rights perspective across a range of areas. These referred to inequitable access to education, uncertainty about getting formal services commensurate with individual needs, underdeveloped local community/neighbourhood connections in some instances and some children/young persons having weak friendship networks. While the young person interviewees for the most part stated that they were happy with their current situation, they would like to have more options for social activities and, very importantly, they were very unsure as to what the future held for them. In summary, the

social supports infrastructure, while perceived as having many positive aspects and as being some way along a rights-based continuum, was also perceived as falling short in a number of key domains.

Chapter Seven

The Perspectives of Service Provider Staff and Other Professionals: The Study Findings

Introduction

As part of the case study, interviews were carried out with a sample of staff working in the case study service provider. Those interviewed were selected on the basis of reflecting in a broadly proportionate manner the various disciplines and services provided by the agency. Eighteen staff members were interviewed drawn from multi-disciplinary staff, direct support workers and administrative staff. Four other professionals involved in service delivery to children/young persons identified during the course of the study as key informants were also interviewed.

The interviews with service provider staff and other professionals (see Appendix Eight) sought their views on a range of topics related directly or indirectly to rights-based social supports – the social supports available to children/young persons and their families; access to services; needs assessment; person-centred planning; educational options; perceptions of social attitudes; a rights-based approach; and access to information and advocacy support.

Eight main themes emerged from the Framework⁴³ analysis of these interviews and twenty-nine sub-themes. These are set out in Figure 7.1.

7.1 The social supports available to children/young persons and their families

Social support is defined by varying terms in the literature and is generally taken to refer broadly to the assistance and help that one receives from others (see Chapter Three).

Five sub-themes emerged from the Framework analysis of interviews with service provider staff and other professionals relating to social supports available to children/young persons and their families:

- (i) Adequacy of formal support services
- (ii) Role of support workers
- (iii) Supports for families
- (iv) Role of extended family
- (v) Community integration of children/young persons with an intellectual disability

⁴³ The Framework model is drawn from Ritchie and Spencer (1994) and has been outlined in 5.7 above.

Figure 7.1: Interviews with service provider staff and other professionals: themes and sub-themes identified

Social supports availability	Formal support services; role of support workers; supports for families; role of extended families; local community/neighbourhood integration
Access to services	Pathway to formal support services; resource availability and service gaps; impact of budgetary cutbacks; inter-agency collaboration
Individual needs assessment	Statutory needs assessment; ongoing assessment of needs
Person-centred planning	Personal outcomes model; implementing Personal Outcomes plans; perceptions of divergent views of parents/guardians and staff
Integrated and inclusive education	Accessing the best educational option for each child; suitability of mainstream schools; supports for child/young person at school transition stages
Perceptions of social attitudes	Changing public attitudes; perceptions of difficulties members of the public have in relating to children/young persons with an intellectual disability; impact of specialist model of service delivery
Rights enforcement	A rights ethos in the specialist service provider; equality of access to services; equality of status; how the concept of 'choice' is implemented; promoting the 'best interests of the child' principle; specific rights deficits identified; enhancing a rights-based approach
Access to information and advocacy support	Information dissemination; central role of support workers in the lives of the children/young persons and their families

7.1.1 Adequacy of formal support services

The consensus view among service provider staff interviewees was that the services and supports available to children/young persons, most of which were provided by their own agency, were generally of good quality.

"I think that the children that come here [specialist service provider] get a very good service" (Staff 7).

"If the child is at home the support is there, if the child is in preschool the support is there, if the child is in school support is there... We try to keep it consistent" (Staff 9).

"I think the early childhood services are very good ... children are being noticed very early – from the time they are born, there's multi-disciplinary services put in place ... which is having a positive knock on effect for the transition into school age" (Staff 2).

The difficulty in providing an equally good quality service to school age children as that provided to pre-school children was noted by a number of interviewees. This was related to higher numbers at school-going age, resource rationalisation and increasing levels of demand arising from expanding expectations.

"We do not have as many resources at school-age and I think in an ideal world if we had more resources we would happily use them at school-age"(Staff 9).

"I think that we provide a good service to the younger children...as they get older it's difficult to give them the time probably that they need ...when you look at the amount of school age kids that would be in the service and the amount of staff" (Staff 1).

7.1.2 Role of support workers

Staff interviewees emphasised the importance of support workers, particularly at transition times. The role of transition support workers in ensuring that all of the relevant supports are in place was emphasised by several staff interviewees.

"One of the best developments we have had over the last few years has been the transition worker – somebody who supports the child in their transition from early childhood services through their first year in school" (Staff 9).

It was pointed out by some interviewees that, while at second level school stage there would not be a specific transition support worker as such, there would still be a comprehensive assessment of needs and support available from different staff members as required. This would usually relate to the specific needs of an individual child.

"It's not necessarily one identifiable person ...but the person who has the strongest relationship with the family" (Staff 9).

"There would be a key worker assigned...they would have the school age team for the kids that are going to school. They would have a member of the school age co-ordination team ... they would know who to pick up the phone to if there was a problem or if they needed help" (Staff 1).

"We work with them when they are in national school and continue when they are in secondary school ... there is a person who is common to both schools, so it is not such a dramatic change for a child" (Staff 6).

The availability of a transition co-ordinator at the end of second level education was regarded as beneficial.

"The transition [at end of secondary school] is very good because they know they have their place and they will come even before they finish secondary school" (Staff 14).

7.1.3 Supports for families

Family support was identified as a core component of service delivery. While there was a general perception among staff interviewees that families were well supported by social workers, outreach workers and behaviour support staff, there was also an acknowledgement that additional support, while not absolutely essential, would be beneficial to some families. Such supports were identified mainly as inputs that would enhance the coping capacity of the family.

"I think we are supporting families to the best of our abilities but there probably needs to be more improvement but we're getting there – some families are very

well supported... but for others there is probably more work to be done on it" (Staff 2).

"Parents have become quite good for asking for support and they would get that support and parents that we think wouldn't be proactive or would have difficulty [in asking] we would actually offer" (Staff 4).

There was a perception of family support not being as extensive or applied as would be desirable and beneficial to families. There was also a view of support provided being determined to some extent by the ability of parents/guardians to seek out specific support.

"There is a little bit of room for things to be more snugly fit around the family ... they kind of feel a bit lost at times" (Staff 3).

"I think that some families get a lot more than other families ...some people...would advocate more for their child and then other people would be happy with whatever they get" (Staff 5).

The importance of not undermining families' own competencies and ability to deal with the challenges arising from meeting the child's needs on an ongoing basis was noted.

"You don't want to take away that person's skill or you don't want to undermine somebody ... because sometimes parents want to get involved at that level even though it takes a lot of work because they want to feel as if they are doing something" (Staff 16).

7.1.4 Role of extended families

Staff interviewees reported that in their experience, the role of extended families varied enormously. Some children were perceived as having a strong and supportive extended family network while, for others, this was very marginal or even non-existent.

"Some parents would have great extended family links ...Other families can be very disconnected... they might not have family living here ... and we would have single parents as well who would have no real support... So it's so mixed" (Staff 7).

"Grandmothers and grandfathers are huge for many families" (Staff 8).

"There are a few families that don't seem to get extended family support. They don't think the extended family understand their situation" (Staff 5).

"We would have a lot of families that do not have extended family support" (Staff 9).

One interviewee emphasised the importance of agency support staff proactively engaging the extended family as part of a more organic support infrastructure:

"The extended family need the information, need to be educated, need to feel confident, need to know the child. ...It's fantastic where the extended family is involved because the child is part of it, normally there are other kids around, other cousins or whatever" (Staff 1).

7.1.5 Community/neighbourhood integration of children/young persons with an intellectual disability

The UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child stipulate that children/young persons with an intellectual disability should be provided with equal opportunities for cultural, recreational and leisure activity and that they should be enabled to participate actively in the community. The research, therefore, sought to get service provider staff views on both the extent to which community participation was a reality and on any blockages that existed to such participation.

All staff interviewees acknowledged the crucial importance of community involvement by children/young persons with an intellectual disability and all pointed to what they perceived as significant efforts by the agency to improve such involvement. The crucial role of the specialist service provider in integrating people with an intellectual disability into 'normal' community life was emphasised.

"It is not just about us providing a service, it is about how the person is in the community... we should be the conduit to help them live ordinary lives in ordinary communities, doing ordinary things" (Staff 4).

"Involvement of the family in the community is encouraged. We would encourage families to use their local services if they suit the needs of the child – their local swimming pool, the local mother and toddler groups and all of that" (Staff 1).

Community integration initiatives reported included identifying and putting in place circles of support for individual young persons, especially at school leaving stage.

"There would be circle support identified around each potential school leaver" (Staff 4).

Enhancing community linkages was identified as being given greater priority in recent years.

"We are looking at that model much more in the last couple of years ...we are bringing in volunteers and the community and the relatives" (Staff 2).

The differences in communities and the different ways that families engage with their local communities were identified as an important feature of the social supports infrastructure. Some families had good neighbourhood/local community connections

"There are some fantastic communities...They have all sorts of stuff for all age groups. They have quite a few special needs kids attending school, they have some projects that the kids get involved with... the community sees a need and develops something around it" (Staff 9).

Some families live in wonderful communities and there is great support around an individual (Staff 14).

"In some areas it's very positive ...there would be no issues, they would just be treated exactly the same [as other children]" (Staff 7).

For others community linkages were seen as weak and/or underdeveloped. Understanding these differences was regarded as central to dealing with the challenge of improved community integration for children/young persons with an intellectual disability.

"Some families wouldn't be as lucky as other families ... in some communities these children are taken wherever the rest of the family go and they are naturally part of it" (Staff 3).

"Communities are very different [from each other]. Some of that would depend on whether the family originates from the area and are very familiar with everyone around them...but then we have a lot of families now that have moved from other countries and they might know nobody around, they might not speak the same language" (Staff 16).

The role of families themselves in proactively involving their child in community activities was identified as significant.

"Very often the families work hard to make sure that [community involvement] happens. They are bringing the child to football and they are bringing them off to this that and the other – all of the stuff that happens outside of school... So the families have worked hard to create their own networks" (Staff 9).

Difference between the way children/young persons with an intellectual disability were integrated into communities were identified as arising not only from the extent of families' organic links with their local communities but also from the nature and extent of community integration.

"Some communities would be made up of people who work fulltime, so they don't know each other well ...or they moved into an area, they wouldn't really have the opportunity to get to know one another. Then there are other communities where people have been in the area for years, and even if someone new moves in they make the effort to get to know them and offer help" ((Staff 7).

Social attitudes to children/young persons with an intellectual disability, while becoming more positive, were identified as an ongoing barrier to community integration.

"I think there is a lot of work going on to make sure that integration happens...it's the attitudes maybe of people that still need to change. I think maybe now that children are going in to mainstream schools and that they are more in the community.... So I think the attitudes are changing slowly ... it's very mixed" (Staff 7).

The potential for social inclusion and neighbourhood integration was emphasised but realising this potential was seen as requiring a fundamental change in community attitudes to children/young persons with an intellectual disability.

"I think anything is possible if you try ...what we need to look at is how can we make it happen instead of saying we can't do this because it might be hard ... we can't say that it is not possible, we should say that we have to make it possible" (Staff 4).

"But I think we have a lot of work to do on community" (Staff 9)

The fact that there had been a growing presence and visibility of people with an intellectual disability in the community in recent years was seen as gradually bringing about the change in attitude required.

“As people are going into the community more it will become more normal that people are just out in the community all the time....you don’t have a white bus pulling up with 10 people with learning disabilities getting off and being segregated again in their own little group” (Staff 6).

A number of interviewees referred to the active involvement of service users in community initiatives in the local town, including a community-based drop-in centre/coffee shop:

“[Local town] would be very welcoming, and lot of people would use everything in the community, the swimming pool, the arts centre, the (community drop-in centre) (Staff 6).

However, there was also a perception of a lack of connectedness to local communities.

“An awful lot of the young people seem to be isolated, you know isolated from peers their own age and from activities for themselves. I think that the more formal supports are excellent, but it’s the more informal supports, like community integration and that sort of thing that is lacking” (Staff 10).

Some parents/guardians of a child with an intellectual disability were identified as being somewhat isolated in their communities because of what these parents/guardians perceive as a reluctance on the part of other people to engage with children/young persons who require a lot of care and attention.

“I think parents probably feel a sense of isolation when they have a child with a disability and they don’t think that anyone would be willing to spend time with them unless they are being paid...I suppose they think they are very hard work and why would anyone want to get involved unless they were being paid for it” (Staff 6).

The particular difficulties people in neighbourhoods/local communities may have in engaging with children/young persons with challenging behaviour was noted.

“Where there is more challenging behaviour, I think there is not as much understanding of how to include that person in their community, give them the same status. I think there is not enough education around that” (Staff 10).

7.2 Access to services

Access to services (therapies, social work, psychological support, respite care and outreach support) is key to ensuring that children/young persons with an intellectual disability are cared for and supported in a way that maximises their individual potential and supports families to this end. Four sub-themes emerged from the Framework analysis of service provider staff and other professional interviewees relating to social supports available to children/young persons and their families:

- (i) Pathways to formal support services
- (ii) Resource availability and service gaps
- (iii) Impact of budgetary cutbacks
- (iv) Inter-agency collaboration

7.2.1 Pathways to formal support services

The pathway to formal support services is a key determinant in shaping the quality and fit of the service to the needs of families. Staff interviewees pointed to the fact that the pathways to support services were at times difficult for families. This was particularly the case in respect of school-related supports such as Special Needs Assistants (SNAs).

“At [primary]school age level, children very much depend on resources from the Department of Education, either resource teaching hours or special needs assistant hours, and that creates huge paperwork... when the child is transitioning from primary school to second level, it comes into play again because there isn’t an automatic transferral of resources” (Staff 4).

All of the staff interviewees referred to parents/guardians experiencing stress relating to negotiating the pathways to support services. This arises because of delays in accessing required services, uncertainty about whether the child will get adequate supports (e.g., speech and language therapy or occupational therapy) and having to wait for decisions to be made, for example, in relation to the provision of SNA support in school.

“It [the process of accessing supports] causes huge stress, absolutely huge stress for parentseven at preschool stage they are talking maybe to parents that are in the school system and they are already projecting what might happen” (Staff 3).

“I think a lot of parents find it traumatic being put off and being put off ... when the need is identified ...if the corresponding services aren’t available immediately, as is frequently the case, it puts them in to a tailspin” (Staff 8).

Anxiety about whether or not their child would get a particular service and when was seen by staff as impacting negatively on parents/guardians ability to live in the present.

“They can’t even live in the moment and do what they have to deal with...they are trying to look forward and see how they will manage the situation when the child actually comes to school age” (Staff 3).

The experience of parents/guardians of having ‘to fight’ for services and supports referred to in Section 6.2.1.1 above was echoed in the perceptions of some staff interviewees.

“Parents have said they have to argue and fight for everything... they might get what they want but they have to threaten something ... Then there are some parents that don’t seem to bother ... and their child loses out” (Staff 5).

There was also a perception that some families may lose out because they lack the same level of assertiveness as other families and a related need for the service provider to address this issue.

"Sometimes I think that families don't want to rock the boat in case they end up with no service ... they don't want to take on a whole agency. There is more work to be done on how to deal with this under our current structures" (Staff 2).

Another staff perspective was that while, generally speaking, support services were available up to a certain level, in some instances families may not be ready to become involved with specialist disability services because of their concerns about assigning a label of intellectual disability to their child.

"We need to educate all the parents at whatever level people are comfortable with" (Staff 9).

7.2.2 Resource availability and service gaps

Difficulty with resource availability commensurate with need was a recurring theme among the staff interviewees. While there was an acknowledgement that some services are more stretched than others, the overall view was that supports for children/young persons and their families were generally good but that all services could do with additional resources. In particular, it was noted that because the school day is only part of the child's life all of the resources cannot be put into the school setting.

"Obviously there needs to be more [services]... there is a waiting list for some services" (Staff 5)

"We would certainly need more OT and more speech and language... We would also need more physio[therapy]" (Staff 9).

"At the moment there is a great problem with physiotherapy, they have a huge backlog and speech and language therapy as well, so it's not adequate, And there is a dietician but she only comes, I think, one day a month for everybody ... There is a need for more respite as well" (Staff 6).

"I think OT could probably do with more staff and more hours" (Staff 7).

"Speech and language and social work are two areas where we need more" (Staff 2).

The lack of additional supports over and above the formal supports available from the specialist service provider was noted.

"I think the formal supports are quite good, day services, trainings services ...access to physiotherapy, outreach ... the early childhood services, the school age services, the training workshops and that sort of thing, ... but it's after that, outside all of those hours, there doesn't seem to be that much" (Staff 6).

On the positive side, it was noted that many staff adopt a very flexible approach to their working hours.

"All our multi-D[isciplinary] would be very flexible in the way they work so they can go and do the sessions in schools ... they can go to the homes and work with the families ... because of the flexibility they are able to put their hours to the best use" (Staff 7).

An alternative perspective expressed referred to the way current resources were being used and a view that they were not being used to optimum effect:

"There are enough resources but it's how they are used... it is about the delivery. We need to be careful that we are teaching the teachers and parents how to do them [different therapies] rather than doing them ... we will never be able to give enough hours ..." (Staff 8).

What was perceived as a significant gap in the services provided by the agency was identified, viz., the absence of a counselling service. Such a service was regarded as vital by some interviewees because some parents have complex personal feelings around the child's disability which require a more professional counselling intervention than can be provided by the current support staff.

"Counselling is not given [by the specialist service provider]. There is a need there for counselling...and it is needed full-time" (Staff 8).

7.2.3 Impact of budgetary cutbacks

The impact of the economic downturn on the extent and quality of the support services that could be provided was referred to by several staff interviewees as was the case with parent/guardian interviewees (see Section 6.2.2.4 above). A key point referred to here was that budgetary cutbacks resulted in a significant retrenchment in vital support services.

"I think we are on the way to having a very good service ... we are going to go back probably 10 steps" (Staff 2).

"I think recently as services are getting more and more stretched and we seem to be getting a lot more children ... it is more difficult to provide a good service within our resources" (Staff 7).

The specific difficulties for parents/guardians arising out of the current service retrenchment were noted, particularly the difficulties identified in getting SNA and resource teacher support in schools.

"This [additional support] is very relevant for the children going to school ... The State has said that it [mainstream school] is a right that that they are entitled to access whatever education they think is best. But now they [the State] are putting a lot of limitations on the resources available, on the SNA support" (Staff 14).

The uncertainty for parents/guardians arising out of current budgetary constraints was identified as having a significant negative impact on their well-being.

"It's become more a fear [for parents] recently, over the last 12 months to 2 years, because it is becoming so much more difficult to pin down the availability of a Special Needs Assistant and to get resource hours for your child" (Staff 3).

The fact of not knowing until the 'last minute' as to whether or not the child would get the required support to enable him/her to attend mainstream school was identified as a significant difficulty.

"Even if they get them [the additional school supports], they [the State] are not making it easy on the families – they have to wait until the last minute and the schools are very reluctant to say they will definitely take the child without having the information [about support availability]" (Staff 7).

7.2.4 Inter-agency collaboration

A key aspect of service delivery is how the different agencies involved interact with each other. Interviewees pointed to a somewhat complex scenario. The complex and fragmented service delivery system was seen as making it difficult for children/young persons with an intellectual disability and families to access the supports they need at different times and at different transition points.

There were diverse views among staff interviewees as to how well the inherent blockages arising from the involvement of multiple agencies were dealt with. Some were of the view that inter-agency working was satisfactory.

"I think the communication is quite good I do know the [service provider] is always linking with the HSE and linking with the staff ... our Multi D[isciplinary] staff are always going to be going into the schools and I think between the schools and the HSE and say our service there is continuous communication there " (Staff 2).

Other staff experienced deficiencies in the liaison between the specialist service provider, the HSE and the educational system.

"I think they [services] are very segmented ... they are not seamless by any means. I think there is a lot of duplication in terms of parents needing to get things, doing the same thing in many places, rather than being clear about the way through ... as a worker I would say it is very hard to negotiate the system" (Staff 4).

The situation was regarded by some as particularly problematic at early childhood stage where the service provision is primarily the direct responsibility of the HSE.

"In the early childhood services it's quite complicated at the moment because there are a few different teams catering for the same age groups. That is confusing and it is confusing for parents as well" (Staff 1).

7.3 Individual needs assessment

Comprehensive and inclusive needs assessment is widely regarded as a core component in service provision to people with disabilities. This involves in the first instance assessing an individual's nature and level of disability and his/her related support needs and putting in place a package of services accordingly. Secondly, it involves establishing goals for the child. For younger children, this will obviously take cognisance of the

parents' aspirations for the child and, as children get older, it takes into account the child/young person's own views and aspirations.

Two sub-themes emerged from the Framework analysis of service provider staff and other professional interviewees relating to individual needs assessment:

- (i) Statutory assessment of need
- (ii) Ongoing needs assessment

7.3.1 Statutory assessment of need

Under current Irish legislation, each child with a disability aged under 5 years is entitled to an assessment of need and the drawing up a service statement based on this assessment. Interviewees for the most part questioned the validity and value of this approach and, particularly, the relevance of the service statement which was conditional on resource availability. Also noted, was the absence of clarity as to how and where the required services and supports identified were to be sourced. This was seen as leaving parents/guardians at a severe disadvantage.

"They [children] have a service statement written up but the service statement can be very vague... So we find that children that have come through the assessment of need are supposed to be receiving supports, but are not getting them because the resources just aren't there" (Staff 7).

"I don't know how much further ahead the parents are in relation to getting what they want. And there is that perception that if I get that assessment then I am going to get more input which is not quite true... the resources may not be there" (Staff 4).

7.3.2 Ongoing needs assessment

The limitations of once-off needs assessment were highlighted.

"While you are guaranteed by law to get your assessment [statutory needs assessment for children under 5 years] within a certain time frame, it might not work out because the child is assessed too early and the child's development is not taken into account" (Staff 13).

While the assessment may be accurate at the time it was carried out, this did not necessarily carry through as the child got older.

"They could be assessed at age 1 [under the statutory needs assessment] but that wouldn't be looking towards school age unless it [assessment of need] is reviewed annually and especially coming up to school age" (Staff 3).

This gap was perceived as being filled to some extent by the specialist service provider when the child is at school-age.

We [specialist service provider] would be doing psychological assessments the year before school. That would then highlight the need for assistance of whatever kind required" (Staff 3).

"We genuinely do try to look at what the person's outcomes are. What their vision would be at each point in their life" (Staff 4).

The importance of involving families in the ongoing needs assessment process was highlighted.

"We look at the whole family unit not just the child's development need...what they want as a family and what ways we can support them" (Staff 3).

A gap in the needs assessment carried out by the specialist service provider was identified which referred to a failure to identify the specific services and interventions required to implement the developmental goals identified.

"It [assessment] is looking at things in terms of passions, likes, interests from an outcomes framework" (Staff 4).

The sometimes different perspectives of staff and parents/guardians were identified as presenting significant challenges in respect of developmental needs assessment.

"Sometimes it [what staff are recommending] comes into conflict with what the parents want...It can be hard to get the balance right ... when the children are coming up to 18 there are a lot of things that they might need to be doing but the parents might not want to push them, they don't want to let go sometimes" (Staff 5).

The difficulty of implementing a truly developmental approach for some children/young persons was noted by some interviewees.

"We would have kids who are high dependency... they are going to always need [support]over and above what others would need ... and the goal here would be to make supports more and more individualised around the person" (Staff 4).

7.4 Person-centred planning

Person-centred planning based on needs assessment was identified by the researcher as a key component in the development and implementation of rights-based social supports. The views of staff interviewees on their experience of how this was operationalised are described in this section.

As already stated in 5.3.3 above, the Personal Outcomes model is the main approach to needs assessment and individual planning used by the specialist service provider.

Three sub-themes emerged from the Framework analysis of service provider staff and other professional interviewees relating to person-centred planning:

- (i) The Personal Outcomes model
- (ii) Implementing Personal Outcomes plans

- (iii) Perceptions of divergent views of staff and parents/guardians

7.4.1 The Personal Outcomes model

Staff interviewees universally endorsed the Personal Outcomes model and its advantages were emphasised. The challenges facing its implementation were identified. Most acknowledged that, even though there are major challenges in implementing the model in a truly meaningful manner, significant progress was being made.

“We use Personal Outcomes to assess what we’re doing and we are very much looking at the individual’s desires and needs ... we are finding out what people want to do, what their interest is, what talents they have and trying to then support them in doing what they want” (Staff 3).

“It [Personal Outcomes model] is effective. It makes you look outside the box a bit ... hear what parents would have to say , it would like make you think in a different way ... we can problem solve together and come up with solutions that make a difference to somebody’s lives (Staff 1).

One of the clear advantages of the Personal Outcomes approach identified was that it created goals and targets set out in writing for each individual which could be referred to by staff on an ongoing basis in relation to assessing progress.

“It is written down in paper so you have it there as a reminder that you have this to achieve and you said you have signed up for that” (Staff 5).

“It [the Personal Outcomes approach] has kind of stretched us a little bit but I think it’s mainly got us to put things into a different framework” (Staff 3).

The importance of involving the family in the Personal Outcomes process was noted by a number of interviewees. In particular, this was seen as allowing for the different needs of both children and families to emerge and for supports to be put in place accordingly.

“I think the fact that we do Personal Outcomes is a great benefit, it means that we really do look at the whole family... We try to take everything into account and develop the relationship with the parents and make sure that they are included in deciding which goals to put in place for the child” (Staff 7).

“It [Personal Outcomes model] is a very good way of going out to ask families what they want...it is an opportunity to sit down and ask them what their goals are and what they would like to achieve...Their goals could be totally different to what you might have expected” (Staff 5).

The potential of the Personal Outcomes model in enhancing social capital was identified by one interviewee.

“One of the parts of the Personal Outcomes approach would be social capital, looking at what the child can do for the community and their status in the community” (Staff 7).

7.4.2 Implementing Personal Outcomes plans

Difficulties with implementing the Personal Outcomes model were identified by some interviewees. It was pointed that sometimes planning ahead was not sufficiently long-term, particularly for those finishing in second level schools.

"In my experience, sometimes the planning can be very last minute" (Staff 6).

The challenge of putting in place the structures to achieve the goals set out was noted:

"Each year you'd have a meeting where the goals would be set but it might take a while [to deliver them] ... some people would be given them as an action point so that it wouldn't be let sit ... but even with that it can sometimes take awhile... It's probably a resource thing" (Staff 1).

Some of the implementation difficulties identified referred to resource constraints which would be exacerbated with budgetary cutbacks.

"I think as resources get less and less... and we don't have that extra funding... I think that's where the follow up will start to fall off" (Staff 7).

Implementing the Personal Outcomes approach in respect of people with more profound difficulties was seen as being particularly challenging.

"For the more profoundly disabled people I think it is not as useful...I personally find it very difficult to do personal outcomes with people who are profoundly disabled" (Staff 6).

Reference was made by some staff interviewees to the danger of the Personal Outcomes approach becoming predominantly a paper exercise which did not reflect the social reality for some children/young persons.

"I find the [Personal Outcomes] categories excellent...but I would see that there is a danger there where it becomes a tick the box exercise and there will not be any meaningful engagement ... there could be a spectacular folder for the service user which means nothing in reality" (Staff 8).

One interviewee referred to a danger of an over pre-occupation in the Personal Outcomes approach to what people want or would like to do in the short-term as distinct from what would be really beneficial to them in the medium to long-term.

"I think sometimes people get overly obsessed with personal outcomes – everything has to fit in with personal outcomes ... You don't want to make it happen for them just for the reason that they want to do it, you have to be thinking how this fits into their lives" (Staff 6).

The attitudes of some staff based on more traditional approaches to people with an intellectual disability were seen by one staff interviewee as a barrier to the full and integrated implementation of the Personal Outcomes approach.

“There is a massive amount of work to be done with all our staff yet around how you support personal outcomes ... It is a challenge for the staff who grew up in a more medical model, a more care model” (Staff 9).

7.4.3 Perceptions of divergent views of staff and parents/guardians

Some staff interviewees identified as a key challenge in implementing the Personal Outcomes model the fact that sometimes staff and parents/guardians have different perspectives as to what was best for the child/young person. While the person-centred planning approach and the focus on personal outcomes was seen as involving significant engagement with families, a difficulty sometimes arose because of what were seen as different perceptions and expectations on the part of service provider staff and parents/guardians.

“You often get two very different perspectives. So there is a lot of work to mediate between them and make sure the young person is still respected, that they still have a choice. It’s hard to work with the parents around that as well because you don’t want to disrespect their views” (Staff 7).

“The family might want one thing and you might have to highlight the pros and cons to certain approaches or certain ideas” (Staff 3).

“If the child can’t speak for themselves, they [the family] let us know what their goals are as a family for the child ... but these can be different [to staff goals] ... I might be working on goals that the child becomes independent, their goal might be that their child can go horse riding” (Staff 1).

“The parent’s main idea might be that they need to be safe all the time” (Staff 13).

Some staff interviewees expressed the view that young people in their late teens or early 20s were still regarded as children by their parents/guardians.

“Sometimes it [what staff member is recommending] comes into conflict with what the parents want...It can be hard to get the balance right... the parents might not want to push them, they don’t want to let go sometimes” (Staff 5).

This divergence of view was seen as raising serious issues about basic rights and freedoms in respect of young adults and created difficulties for staff.

A lot of people, say in their late teens or early 20s, would still be viewed by the parents as children, whereas the staff would view them very much as young adults and are trying to get them to move on... When someone becomes 18, we are supposed to take their views into consideration, not the parents’ views and this can be very difficult” (Staff 6).

7.5 Integrated and inclusive education

The UN Convention on the Rights of the Child stipulates that children with disabilities have the same right to education as all other children and should enjoy this right without any discrimination and on the basis of equal opportunity. The Convention also stipulates that inclusive education should be the goal of educating children with disabilities. The research

sought to get service provider staff and other professionals' views on the extent to, and manner in which, the concept of inclusive or integrated education operates in respect of their service users. It also sought to get their views on any difficulties facing the integrated approach and how these might be addressed.

Three sub-themes emerged from the Framework analysis of service provider staff and other professional interviewees relating to integrated and inclusive education for children/young persons with an intellectual disability:

- (i) Accessing the best educational option for each child/young person
- (ii) Suitability of mainstream schools
- (iii) Supports for children/young persons at school transition stages

7.5.1 Accessing the best educational option for each child/young person

Interviewees in general were of the view that the best educational options were assessed for each child. For some this was a mainstream school, for others it was a special class or unit in a mainstream school and for some it was in a special school (see Section 5.3.3 above). The particular educational needs of each child were, according to the interviewees, looked at in the broader context of their individual needs and the Personal Outcomes approach and an ongoing dialogue with parents.

"It's never black and white – it might be family circumstances or family attitudes to a particular school. Somebody might feel that mainstream school is the absolute best option for a child but they may find that the staff [in the local school] really struggle with having a child with additional needs" (Staff 9).

"One of the biggest decisions [for parents] would be what school is right for the child... I would say that most of the time if not all of the time the decision that the parents make in the end is the right one for the child (Staff 7).

The availability of a number of educational models was regarded as important so that there were options and choices for individual children.

"Some [children] may need to be in a special class receiving individualised education and would benefit from joining their age equivalent class for drama or singing and to socialise with kids of their own age. Then there is the other scenario where kids with high needs do very well attending the regular class in their local school" (Staff 1).

The lack of availability of a suitable school locally for some children was noted by one interviewee.

"If a parent wants a special school or a special class, there may not be one nearby and they may have to get transport to a school further away and this makes it more difficult" (Staff 1).

7.5.2 Suitability of mainstream schools

The concept of inclusive education was regarded by interviewees as the ideal to be aimed at.

"I think it's vital that children with an intellectual disability have access to mainstream environments. There is a lot to learn both ways. There is a lot that other children can learn from having a child with an intellectual disability in the school" (Staff 7).

Parents/guardians were perceived by staff interviewees as favouring sending their child to a mainstream school where this was possible.

"We are finding in recent years parents want their children to go to mainstream school, I suppose purely for the integration and the social aspect of it" (Staff 7).

Interviewees stated that for the most part children were being adequately catered for in terms of choice of schools.

"The mainstream [approach] has come on a long way in comparison to the past ... they [children] are being assessed and they are getting into school if they can get the support services identified by the professionals" (Staff 12).

Some shortcomings of current practice were identified. These were the lack of supports in mainstream schools commensurate with children's needs; inadequately trained teachers; different attitudes by different schools; lack of adequate time and resources to cater for the sometimes additional complex needs of children with an intellectual disability.

"Teachers here do not have a special needs qualification" (Other Professional 1).

"The State is not doing anything to ensure mainstream teachers are equipped" (Other Professional 3).

The point was made repeatedly that, if the additional supports are not there and if the teachers don't have the appropriate training, the inclusive education concept becomes meaningless. In this regard a significant difference between schools was noted.

We can see a huge difference in schools, some would really embrace a child with an intellectual disability and they would really put a lot of effort in and they'd go and do training courses and they would be very good at educating the other children as to what the needs of the child are... And then there would be other schools where there isn't as much" (Staff 10).

The emphasis on the mainstream educational curriculum at second level was regarded as making it very difficult to integrate pupils with an intellectual disability.

"We try our very best in the school to do that but we have a monster sitting there at the end of it ...the Leaving Certificate. And it colours everything ... the euphoria of the high points person" (Other Professional 1).

Both staff interviewees and the other professionals interviewed referred to the huge challenges facing the mainstream school system in order to be

truly inclusive of children/young persons with an intellectual disability. Such inclusion was perceived as requiring an approach which acknowledged the clear need for an inclusive curriculum and pedagogy which was not always available.

“Children with an intellectual disability take so much time to do things. And it takes so much effort to put into place valid modules for them to progress to. In a busy school environment, where really there is no kudos in that, they are not being included” (Other Professional 1).

The particular importance of having high levels of support at transition to school stage to lessen the fears and apprehension of parents/guardians was emphasised by many of the interviewees.

“There is a lot of stress for families around school and a lot of concern and they need a lot of support” (Staff 7).

“They [parents] have a lot of fears about it [child going to school] – it is such a big change” (Staff 15).

“There is so much going on around school and that worry starts early. It would start a year or two before their ever going to cross that bridge” (Staff 3).

“It is an awful big thing for parents to send their child to school because they are not sure whether the school will be suitable for their child ... we [specialist service provider] provide emotional and practical support in the transition to national school ... we can give an opinion on different schools” (Staff 5).

The provision of support at transition from second level school stage was perceived as being undermined by the lack of meaningful and accessible post-school options to cater for the particular needs, skills sets and aspirations of some young persons.

“We would have kids that are leaving [school] that would never fit the groove, they are high dependency, they are going to need over and above what the traditional funding offers” (Staff 4).

The reported current withdrawal of school resources due to budgetary constraints was identified as a key concern.

“What we are seeing now is that children are going into school with less support because financially everything is being pulled back” (Staff 17).

“If all children are in the one classroom, extra resources are required for that, particularly if there is a child with challenging behaviour in the class... That is one area [the State] is cutting back on and that's the area where the whole integration will fall down if that [support] isn't there” (Staff 1).

“Our resource allocation for resource hours next year is under serious question... it would have an absolutely chaotic effect on services that we have for the students with an intellectual disability” (Other Professional 1).

“The Occupational Therapist just cannot fit in enough of time [for the school]” (Other Professional 3).

The lack of appropriate educational options for some children after primary school was noted and identified as a major concern for the parents of the children involved.

“But it is a pity to see everything that was good [in current school] being just dropped. They have to leave here in 6th class ... the parents are disappointed ...I contacted some secondary schools, nobody wants to know” (Other Professional 2).

7.6 Perceptions of social attitudes to children/young persons with an intellectual disability

Three sub-themes emerged from the Framework analysis of service provider staff and other professional interviewees relating to their perceptions of social attitudes to children/young persons with an intellectual disability:

- (i) Changing public attitudes
- (ii) Perceptions of difficulties members of the public have in relating to children/young persons with an intellectual disability
- (iii) Impact of specialist model of service delivery

7.6.1 Changing public attitudes

Staff interviewees referred to changes in social attitudes that had been taking place in recent years which were manifested in a more inclusive response generally to children and young persons with an intellectual disability. Younger age cohorts were perceived as having more inclusive attitudes to intellectual disability generally. Families were seen as for the most part taking a proactive approach to strongly affirming the child with the intellectual disability and including him/her as far as possible in all the activities of daily living.

“The younger people coming through now, it seems as though the attitudes are changing, their parents are much more willing to allow the child to live as full a life as possible ...the families are much more open” (Staff 7).

Integrated education was seen as having the potential to help change public attitudes.

“I’m hoping the children in the school who have got used to learning with children with an intellectual disability, when they become employers in the future that they would be more tolerant, that they would be more welcoming of people with disabilities” (Other Professional 3)

The ‘Special Olympics’ was seen as contributing significantly to promoting more inclusive and more positive attitudes to people with an intellectual disability.

“The Special Olympics is great way to put these people forward and let people see them as the people they are rather than these people with this label. That still kind of goes on, [in relation to] the ones with Down Syndrome” (Staff 3).

What was regarded as a somewhat negative attitude on the part of the public was also identified.

“Some people would be like you know ‘oh God love them’... This kind of charity attitude or ‘feeling sorry them’ attitude still happens” (Staff 5).

Different responses of the public to different types of intellectual disability were identified as reflecting less than fully positive public attitudes. There was a perception that responses varied from positive to negative depending on the type of intellectual disability a child has.

“People have great time for Down Syndrome and that person is received very well into the community... But then you might have someone with autism and severe challenging behaviour... For two people with an intellectual disability the experience [of community] could be very different” (Staff 7).

7.6.2 Perceptions of difficulties members of the public have in relating to children/young persons with an intellectual disability

A point made by several staff interviewees was that people who are not directly involved with children/young persons with an intellectual disability would tend to focus on the fact that they are different from and separate to other children/young persons.

“Say someone who has a disability is going to have a Special Needs Assistant which is fantastic, but straight away they are set apart from others then... it’s very difficult for them to break into the mainstream, with their peers and that sort of thing” (Staff 6).

The fact that members of the public can sometimes be quite nervous and frightened of people with an intellectual disability because they do not know how to communicate with and react to them was noted. The need for further public visibility of people with an intellectual disability as individuals was highlighted.

“This town is a great example because no matter what day of the week you are here, you see so many people with disabilities out, walking up and down the street, in the supermarkets, in restaurants, that people don’t really bat an eyelid” (Staff 14).

7.6.3 Impact of specialist model of service delivery

The specialist service delivery model was seen as setting children with an intellectual disability apart and excluding them from their general peer groups and reinforcing stereotypical images of intellectual disability.

“It makes them special and different and not part of the bigger group – the more that people with disabilities are seen in everyday situations the better” (Staff 11).

“I think people have stereotypical images ... People are becoming more aware than they were years ago, but I still think there is a long way to go (Staff 7).

The inclusion of children with an intellectual disability in mainstream schools was generally seen by staff interviewees as helping to bring about

attitudinal change in society. However, the need to be cautious about overemphasising the role of education was also noted:

"I think it is a bit simplistic to say that it is about education really because we are constantly chipping away at that all the time and I think that is going to take a generation to change" (Staff 9).

Other staff perceptions were that social attitudes had, perhaps, not changed as much as might be generally perceived.

"I saw some heading that some adult with Down Syndrome had got their driving license and it's such a novelty....Something like that is a novelty where really in this day and age it shouldn't be" (Staff 1).

7.7 A rights-based ethos of service delivery

The research sought to get service provider staff views on the implementation of a rights approach generally, the extent to which a rights-based approach was reflected in the ethos and *modus operandi* of their own agency, how it was being implemented in practice and on the challenges and difficulties being faced in this regard. As shown in 6.1.7 and Figure 6.1 above, based on Likert-type summation rating measures of nine rights statements used by the researcher, the overall rating by staff averaged 2.6 out of a maximum score of 5. This was lower than the rating by parents/guardians (3.5).

Seven sub-themes emerged from the Framework analysis of service provider staff and other professional interviewees relating to a rights-based approach to children/young persons with an intellectual disability:

- (i) A rights ethos in the specialist service provider
- (ii) Equality of access to services
- (iii) Equality of status
- (iv) How the concept of 'choice' is implemented
- (v) Promoting the 'best interests of the child' principle
- (vi) Specific rights deficits identified
- (vii) Enhancing a rights-based approach

7.7.1 A rights ethos in the specialist service provider

There was a broad consensus among service provider staff interviewees that a rights ethos pervaded the work of the agency and that this provided the backdrop for the development of support services. This ethos was stated to be strongly embedded in the Personal Outcomes model referred to above.

"The whole way we work is to promote the rights of a child with a disability... basically any child you are working with is seen as having the same rights as anybody else ..." (Staff 1).

"This organisation is definitely guided by those [rights] principles, we have the Rights Committee here... It's hard to explain to other organisations that it is people's right to have a council house if they want" (Staff 6).

"Personally and professionally I would be aware of the importance of every child's rights and the rights of children with disabilities and the rights of the family" (Staff 3).

"I think with our services the rights are always there. There is a lot of work done with the service users around rights, we have the advocacy and all of that...It's getting there" (Staff 7).

Reference was made to engaging families around the rights of their child.

"From our earliest working with the family we would be ensuring that families would be aware of what rights the child had and ensuring that they all their entitlements" (Staff 12).

"We do support our families [around rights] ...we give a lot of information, written information on rights, we do evenings on rights and try to make sure that parents are aware of all the rights" (Staff 3).

Some interviewees commented that that, while intuitively they felt that they were reflecting a rights-based ethos in their work, this would not be based on any systematic consideration of international or national human rights documents.

"I would say if I am being truthful that I have never gone through the UN Convention on the Rights of the Child ..." (Staff 4).

Others commented that, while the principle of equal rights was there at some level and, while efforts were made to ensure that people are aware of their rights as far as possible, there is a lot of work that still needed to be done to get people to internalise the concept in a meaningful way.

"I am aware that all of the rights of children under the age of 18 may not be exercised as yet and there is more work to be done on that" (Staff 2).

"A lot of our service users still would not know anything about rights ... so while people are starting to get a grasp of it they have not really internalised it" (Staff 9).

7.7.2 Equality of access to services

Staff interviewees reported that in their experience children/young persons with an intellectual disability had equality of access to health services, whether routine or specialist.

"If you are a child [with an intellectual disability] going to the doctor, going into the hospital, you would have the same equality as anyone else from a health service point of view" (Staff 2).

"I think children with an intellectual disability can access the health side as easily as children without a disability" (Staff 7).

Interviewees were mostly of the view that there was not equality of access to education for children with an intellectual disability mainly because the additional supports required were not available to the extent required to enable equality of access.

"I would say with education, it [equality of access] is not necessarily there because the supports aren't put in place... they are not being treated in an equal way" (Staff 3).

"Education is a big one at the minute...I don't think that they [children with an intellectual disability] are able to access it as easily as other children because the supports aren't being made readily available" (Staff 16).

A significant indicator of inequality of access to education identified was the fact that there were different entrance criteria for children with an intellectual disability in that a separate application had to be made for the additional educational resources required and that schools will only allocate a place when the additional resources have been approved by the State.

"That doesn't happen for any other child as part of an entry requirement" (Staff 16).

The fact of parents/guardians sometimes having to engage in appeals and redress mechanisms in order to get the additional school supports required was identified as indicative of inequality in the educational system.

"We have had several children here who have had to go through appeals – they have eventually got into the school because they are entitled to go but those obstacles have been there. So different entrance criteria are used for the child with a disability – in that sense, you have an equal right to education but not in practice ...even if it works out in the end" (Staff 4).

7.7.3 Equality of status

On the question of equality of status, staff interviewees stated that, while there were significant improvements in recent years, there were still situations, both in society generally and in specific instances where equality of status was not afforded to children/young persons with an intellectual disability. Separate service provision, having to apply for specialist assistance and people not getting paid properly for work they were doing were all regarded as undermining equality of status.

"People who aren't involved in the service would look at people who are involved in the service and think they are a very separate entity ... Someone who has a disability is going to have a Special Needs Assistant [in school], which is fantastic, but straight away they are set apart" (Staff 6).

"Now I know that we have Special Needs Assistants in schools but if you are special you're in a separate category aren't you" (Staff 3).

"I think definitely they [children/young persons with an intellectual disability] are seen as lesser... It is so ingrained even in the young kids. The kids that don't have the skills to participate in what the others are doing are not seen as being equal" (Staff 8).

Equality of status for children/young persons with an intellectual disability was perceived by staff as taking place at a microlevel – in families and to some extent in local communities and in public amenities.

"The places I would go to, where all the young people would like to go, like swimming or the cinema, bowling, shops, a local shop and that, generally everybody is fine, and would treat them with respect" (Staff 5).

However, evidence of a lack of equality of status was reported by some staff interviewees.

"I worked with a young woman who was doing part-time work on a voluntary basis...it came about through her Personal Outcomes review that because she was not getting paid, it [her work] was not a real or valued social role So they approached the employer to see if he was willing to pay her but he wasn't..." (Staff 6).

"You might go into a shop with someone and they might give the change to you rather than the person [who had paid]" (Staff 5).

7.7.4 How the concept of 'choice' is implemented

The concept of choice is an important one from a rights-based perspective and one that has been highlighted in both the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. Staff interviewees were asked for their views on how the concept of choice was reflected in the engagement by the agency with children/young persons and their families.

Staff interviewees stated that choice was a core component of the way the agency worked. This applied in particular to the Personal Outcomes model which was central to the *modus operandi* of the agency.

"You would always help young people to make choices for themselves – they might be very minor choices ...in a lot of cases the choice is 'you have this service or you don't have it' that is the choice" (Staff 6).

Some staff interviewees pointed to limitations to the concept of choice and in relation to supports and services.

"You have no choice as to who your support staff are... In so far as possible they are given choices but I think they are superficial choices" (Staff 12).

The absence of choice in career/work options for young people leaving school was identified as a major limitation.

"I think that these kids are let down too when they want to move into the workforce there should be choice not just go to A, B or C centre so that's where I think we need to continue to progress and develop" (Staff 3).

Giving young persons more control over their own money was identified as an important and pragmatic and feasible way of enabling them to exercise choice.

"We are very much trying to have our service users, all of them, in control of their own money... but there is a bit more work to be done on that" (Staff 2).

The sometimes different perspectives of parents/guardians and service provider staff was identified as an important factor in respect of developing a strong and meaningful application of the concept of choice.

"We would have a lot of discussion around the child or young person wanting to do one thing and parents having a different idea. The most common one would be alcohol. You would definitely see there that parents of young people with disability – they wouldn't give them as much freedom as their siblings have" (Staff 7).

The importance of enabling people to make choices and have the experience of having to deal with the consequences of poor choices was highlighted.

"If someone wants to go and spend all their money in the shop in one day [they need to learn] that for every action there is a consequence" (Staff 11).

The particular difficulty of giving a voice to those who do not verbalise was highlighted and the fact that in such situations the parent's voice would be the dominant one.

"I think in a lot of situations the main voice is the parents' voice – even though it's not supposed to be" (Staff 6).

"If you take somebody who can't speak, their parents are going to have a bigger voice than them" (Staff 17).

"Some people don't verbalise – so we are relying a lot on behaviour, on others – you are wondering then is that their view or the parent's view" (Staff 4).

7.7.5 Promoting the 'best interests of the child/young person' principle

One of the underlying themes of a children's rights-based perspective is that the best interests of the child/young person is always a basic criterion for the provision of support services. Staff interviewees stated that the best interest factor would always be a key principle in their *modus operandi* but that this was sometimes difficult to realise.

"I think the aim would be for it [best interest of child] to be the primary consideration – but sometimes resources might be an issue" (Staff 9).

"The best interests of the child are the primary consideration, I suppose, the majority of the time, but then sometimes, it's down to resources and supports ... sometimes, organisational circumstances would take precedence" (Staff 6).

The Personal Outcomes model used was seen as strongly reflecting the 'best interests' principle.

"I think the Personal Outcomes [model] would be very mindful of that [the best interests of the child/young person]... Obviously the best interest of the child when they are so young, 3–6 years, would be decided by the family" (Staff 7).

Implementing the best interest principle in practice was seen as sometimes compromised by resource constraints and having to fit the best interests of a number of children/young persons into the resources available at any given time.

"It [the best interests of the child] may not always happen in practice ...you might be looking at the resource available and you'd be putting a group of children into that resource rather than looking at the individual child" (Staff 2).

It was pointed out that while individual staff generally adopted a best interest approach to their work with individual children/young persons, the potential of this approach was limited by broader budgeting factors.

"I think on an individual basis the decisions they [staff] make about their everyday work would be very much based on the best interest of the child... On a more global scale then, financially and politically, the child isn't at the centre of what goes on with budgeting and things like that, definitely not" (Staff 3).

While the initial response to each child/young person's needs was seen as being based on a positive and inclusive vision based on his/her best interests, this is sometimes lost in the day to day realities of service delivery.

"I would actually say that in terms of the best interest of the child ...I think we start off with a vision or an aspiration, a vision which is inspirational in itself We do actually genuinely try to find what is in the best interest of this young person...then we have to work in reality because their best interest might cost half a million" (Staff 14).

7.7.6 Specific rights deficits identified

Staff interviewees identified a number of factors that impacted negatively on the full implementation of a rights-based approach. These included an absence of rights-based services, young persons (over 18) not having control over their own money, an underdeveloped engagement with supporting people in developing and maintaining intimate relationships and general accessibility issues.

Access to rights-based services by people with an intellectual disability generally was seen as problematic.

"I suppose the trouble with rights, is very early on, we have very little rights in the whole area of learning disability. You have a right to an assessment of needs but you have no right or entitlements to an intervention that assessment identifies" (Staff 9).

Control of an individual young person's money by parents/guardians, which happened in some instances, was seen as an infringement of an individual's rights.

“Some people in the service wouldn’t have access to their own money. The parents would control the money. I don’t know where that fits in now with rights” (Staff 6).

“They [families] don’t see the rights part of it – that this is the person’s money to do with it what they wish...So it’s almost like people somehow feel that the person with the intellectual disability cannot go through those natural learning experiences that we go through (Staff 15).

On the question of sexuality and the development of personal relationships by young persons, all staff reported that efforts were being made in this regard but that these efforts fell somewhat short of what would be ideal. This latter point was stated succinctly by one interviewee who highlighted the significant challenges to be addressed in order to address this issue in an inclusive and meaningful manner:

“We probably aren’t great in dealing with sexuality and relationships ... we would be trying to do sexual education programs appropriate for a person with an intellectual disability. Sometimes the staff are uneasy about it, the families are uneasy about it – so I think we have an awful lot of work to still do about that” (Staff 9).

7.7.7 Enhancing a rights-based approach

As discussed in 6.1.7 above, there was a perception by both parents/guardians and by service provider staff of deficits in the social supports infrastructure from a rights perspective. This deficit was perceived as higher by staff than by parents/guardians (see Figure 6.1).

A point made by a number of staff interviewees was that during the next few years there is likely to emerge a greater public awareness and understanding of rights. Families that have come through what are regarded as more progressive childhood services in the last two years were perceived by staff as having a much firmer grounding in a social model of disability and related rights principles where the focus is on maximising independence and giving the child/young person with the intellectual disability the same status and rights as their peers and siblings who do not have a disability. Older families that have been socialised into the more traditional medical model of disability were perceived as perhaps not having the same perspective and thus struggle with the idea of this person has the same rights as others of their age.

A need to engage all families in the developmental life journey where the child’s potential is maximised and where all of his/her rights are realised as far as is realistically possible was identified. This was seen as requiring families to be educated around citizenship and rights very early on so that all stakeholders could walk that journey together.

One interviewee referred to a significant difficulty arising in respect of a rights-based approach when families have not had an early education about and engagement with rights.

“I think there is more education needed with families so families’ perceptions and mindset change around what they want for their children” (Staff 2).

The need for a stronger and more proactive engagement with a rights approach throughout their own agency was highlighted by some staff interviewees. This was regarded as particularly important in the case of those with more complex disabilities.

“There is a massive amount of work to be done yet with all our staff around supporting personal choice, particularly people with really significant needs. If you cannot choose what to eat for your breakfast how can you choose where you should live or who you live with... it is the challenge for managers and it is a challenge for the staff who grew up in a more medical model, a more care model” (Staff 9).

“We are taking steps but I suppose not quickly enough really...there are still old-fashioned ideas out there which need to be challenged” (Staff 3).

7.8 Access to information and advocacy support

Information is widely regarded as a critical building block in enabling people to have control over their lives and to exercise choice. (Browne 1999). Accurate and up to date information is essential if support services are to be tailored to individual needs. Two sub-themes emerged relating to information and advocacy support:

- (i) Information dissemination
- (ii) Central role of support workers in the lives of the children/young persons and their families

7.8.1 Information dissemination

Staff interviewees acknowledged the crucial importance of providing comprehensive information to families.

“We give a lot of information but we also follow that up by checking with families is it enough or is there anything specific that they require ... the social workers who go out and speak to families” (Staff 7).

“We would have a strong emphasis on information... because even when we cannot give people what they really want, they are clear why we cannot” (Staff 9).

Generally there was a perception of there being good information flow between the service provider and families.

“I think that we are very good with communicating with the families with our own multi-disciplinary team staff, with our social workers and our direct link support workers to the family” (Staff 2).

“There is a genuine proactive giving of information in a wide variety of areas ... If the child has a specific syndrome... we offer information in as easy a format as we can” (Staff 4).

The need to be continuously vigilant about ensuring that not only was information provided but that it was also well understood by families and that there was regular follow-up was noted by some interviewees.

"I think that they [parents] do have a lot of information but then some of the time they do have to go to great pains to find out...there could be a lot of work done really in the area" (Staff 16).

A need for families to be facilitated in self-accessing information was identified.

"We are getting to the point that they [families] have access to all the information that they need... but some families need to become more educated and more familiar with accessing information... Some might be brilliant on the Internet sourcing information, others aren't" (Staff 2).

The fact that the policy, service delivery and social supports environment was always changing was seen as requiring an approach where information is updated on an ongoing basis and proactively disseminated to families .

"I think it [information] is an area that needs to be constantly looked at ... because things are always changing and within the area of health and education and, especially, when you have a child with a disability who is going into the educational system" (Staff 3).

The danger of information overload was highlighted.

"We would have a strong emphasis on information for families ... but I heard one mother say 'if I am brought into one more meeting...!' – it was information overload" (Staff 9).

"Parents are at different levels ... it sounds a little bit disrespectful but I think parents sometimes can only take so much in at any one particular time" (Staff 4).

7.8.2 Central role of support workers in the lives of the children/young persons and their families

Staff interviewees referred to the central role of support workers. The role of support workers in ensuring that all of the relevant services were in place for the child/young person was emphasised by several staff interviewees.

"Every child would have a key worker and that's the person they would meet with annually for information and personal outcomes and they would also be the link person for the families" (Staff 7).

The importance of the availability of support workers to facilitate the transition to school and between schools was highlighted.

"We work with them when they are in national school and continue when they are in secondary school ... so there is a person who is common to both schools ...it is not such a dramatic change for a child" (Staff 6).

"I think one of the best developments we have had over the last few years has been the transition worker – somebody who supports the child in their transition from early childhood services through their first year in school" (Staff 9).

Chapter summary

This chapter has described the perspectives of staff and other professionals on the social supports infrastructure and on the extent to which a rights approach is or is not embedded in the service delivery system.

Service provider staff and other professionals interviewed were generally of the view that the best educational option was accessed for each child. The availability of a number of educational models was regarded as important. The availability of adequate support services in mainstream schools was regarded by many staff interviewees as problematic. Three shortcomings of current practice were identified: teachers not adequately trained to teach children/young persons with cognitive impairment; some children spending a lot of time outside the school classroom being cared for and 'taught' by his/her SNA; therapies not being available to the child at optimum level.

Community and neighbourhood supports were viewed by staff as generally positive notwithstanding the fact that there was a huge variation in the levels of integration, depending not only on the individual child/young person but also on the parents/guardians' links to the community and the particular type of community where people lived. The crucial importance of community involvement by children/young persons with an intellectual disability was highlighted as was what was reported as significant efforts by the agency to improve such involvement.

The general consensus among staff interviewees was that families are now much more proactive than in previous decades in enabling the child/young person with an intellectual disability to live as full a life as possible and in seeking to provide the child, as far as possible, with equal opportunities for education and social interaction. Staff interviewees reported that, in their experience, the role of and support from extended families varied enormously.

Service provider staff and professionals stated that, while intuitively they felt that they are reflecting a rights-based ethos in their work, this was not based on any systematic reference to international human rights provisions or of any systematic consideration of rights-based legislation. Their rating of rights based statements relating to children/young persons with an intellectual disability suggests a significant deficit in the rights approach.

A perception of there being equality of access to general health services by children/young persons with an intellectual disability was reflected in the Case Study data. Where health inequalities exist, these are deemed to relate to factors that affect all children and families, e.g., geographical location and whether, or not the family has private health insurance. On the deficit side, the complex and fragmented service delivery system that exists in Ireland makes it difficult for children/young persons with an

intellectual disability to access the supports required at different transition points in their lives.

Service provider staff interviewees stated that choice was a core component of the way their agency worked. This applied in particular to the Personal Outcomes model which was central to the *modus operandi* of the agency.

Service provider staff stated that there was a good information flow between the agency and the families using their services. The need to be continuously vigilant about ensuring that not only was information provided but that it was also well understood by families and that there was regular follow-up was identified. The central role of service provider support staff in ensuring that children/young persons were able to access supports commensurate with assessed need was noted.

While much progress on identifying and implementing a rights approach had been made in recent years, the main conclusion that emerged from the interviews with staff and other professionals was that there remains a lot of work to be done to put a social supports infrastructure in place that would reflect a society where the rights of children/young persons with an intellectual disability are fully protected.

Chapter Eight

The Case Study Data Analysed and Main Conclusions

Introduction

The overall aim of the thesis is to assess the realities of the current Irish social support infrastructure as it applies to children/young persons with an intellectual disability against a rights paradigm. In order to meet this objective, a case study approach involving one service provider was adopted. Evidence was gathered from a sample of parents/guardians (survey and interviews), a sample of children/young persons (interviews and focus group), a sample of staff from the service providing agency (interviews) and selected other professionals who are involved in service provision to the research target group (interviews). The previous two chapters have outlined the main research findings. This chapter will analyse the case study data and assess the social supports infrastructure from a rights perspective.

The chapter contains three parts.

Part One analyses the study findings against seven components of a right-based paradigm deemed applicable to the social support infrastructure. It addresses the research question relating to the positives and deficits of the current social support infrastructure from a rights perspective.

Part Two addresses the research question as to how far the social supports infrastructure reflects the components of a rights paradigm. It seeks to establish the extent to which the data does or does not reflect evidence of a rights approach and draws some conclusions accordingly.

Part Three draws together the different strands of the study. Firstly, it summarises the background to and rationale for the study. It also summarises the theoretical underpinnings and the research methods used. It then synthesises the findings under the seven rights components identified as applicable to the social supports infrastructure as it pertains to children/young persons with an intellectual disability in Ireland. Finally, some areas for further inquiry and debate arising from this study are identified.

Part One: The Study Findings Analysed

8.1 The analytical framework

8.1.1 *The dimensions of social support identified*

The second research question addressed in the thesis referred to the social support dimensions applicable in enhancing a rights paradigm in respect of children/young persons with an intellectual disability. Social support, broadly defined, refers to the assistance and help that one receives from others – both formal services and informal support (see Chapter Three). Quinn and Degener (2002) make the crucial point that people with disabilities are entitled to social support regardless of the utility of their potential contribution to society. Drawing on the social supports literature, a number of relevant social support dimensions were identified using an analytical pathway similar to that used in developing the seven-point rights conceptual framework which had already been developed (see Figure 2.2).

The first stage of identifying the relevant dimensions of social support involved distilling the main components of social support as set out in the literature with particular reference to children and families. The overarching dimensions of social support across five different axes were identified – formal vs. informal support; direct support vs. enhancing natural support networks (family, community/neighbourhood and peer/friendship); structural support vs. functional support; individual support vs. group support and perceived vs. received social support (Dolan *et al.* 2006; Walker and Sage 2006; Millar 2006; Hogan *et al.* 2002).

The second stage involved looking more specifically at the dimensions of social support applicable to children/young persons with an intellectual disability across the five axes identified in Stage One. This stage took into account six key considerations identified from the literature (UNICEF 2007; United Nations 2007; Ellison 2006; McConkey 2005; Dunst *et al.* 1993).

- (i) Integrating children/young persons with an intellectual disability in their family and local community/neighbourhood is of paramount importance;
- (ii) Access to formal support services is of vital importance both for the children/young persons and for their parents/guardians;
- (iii) Supporting children/young persons with an intellectual disability to access appropriate education is central to their well-being and development;
- (iv) The way services and supports are delivered (e.g., whether mainstream or specialist) is likely to have a bearing on the way children/young persons with an intellectual disability are integrated into mainstream society and on the status and

recognition they are afforded;

- (v) Friendship and peer networks have significant potential to enhance the quality of life of children/young persons with an intellectual disability;
- (vi) The social supports infrastructure should make provision for developing meaningful future aspirations and related implementation mechanisms in respect of children/young persons with an intellectual disability

The third stage involved the development of an inventory of social support dimensions based on the analysis carried out in Stage One and Stage Two. This stage took into account the need to include all relevant dimensions of social support and to apply and prioritise these in relation to the particular needs of children/young persons with an intellectual disability.

Stage Four involved the researcher re-appraising the literature review to ensure that: (a) all relevant aspects of the social supports discourse were captured in the inventory of social support dimensions; (b) the dimensions were relevant to meeting the support needs of children/young persons with an intellectual disability when approached from a rights perspective; and (c) the dimensions were, as far as possible, conceptually distinct. This stage resulted in some refinement of the initial inventory. The outcome of Stage Four was the identification of 24 social support dimensions relevant to children/young persons with an intellectual disability (see Figure 8.1).

8.1.2 Applying the Analytical Framework

The application of the analytical framework involved assigning each of the 24 dimensions of social support identified to the relevant component in the seven-point rights-based analytical framework which had already been developed and each of the social support dimensions listed was linked to one of the seven rights components accordingly. While there is some similarity and cross-over between the different interfaces, as far as possible, each dimension of social support is linked to the rights component to which, in the view of the researcher, it is most closely related. The seven rights components – social inclusion, recognition, agency, voice, capabilities, equality, self-realisation – are posited as an integrated and complementary set of requirements for developing an inclusive and rights-based social supports infrastructure applicable to children/young persons with an intellectual disability. The dimensions of social support listed are those identified as relevant to a rights-based social supports infrastructure. The juxtaposition of rights components and social support dimensions is presented in Figure 8.1 and provides the analytical framework used in the study.

Figure 8.1: Rights components and dimensions of the social supports infrastructure juxtaposed

Rights component	Social support dimensions
Social inclusion	<i>Integrated education</i> <i>Family support</i> <i>Community/neighbourhood integration</i> <i>Friendship/peer networks</i>
Recognition	<i>Inclusive social attitudes</i> <i>Family and social integration of child/young person</i> <i>Provision for the additional support needs of families</i> <i>Promoting the best interests of the child</i>
Agency	<i>Affirmation of child/young person</i> <i>Effective and meaningful communication with child/young person</i> <i>Optimising control by young persons over their lives</i> <i>Access to therapies as required by child/young person</i>
Voice	<i>Provision as appropriate for choice by children/young persons</i> <i>Due weight to the voice of children/young persons</i> <i>Access to information and advocacy support</i>
Capabilities	<i>Holistic, integrated and inclusive needs assessment</i> <i>Personal outcomes planning</i> <i>Envisioning the future</i>
Equality	<i>Promoting equality of status</i> <i>Equality of access to social, educational and health services</i> <i>Protecting support services to children/young persons with an intellectual disability in a climate of budgetary cutbacks</i>
Self-realisation	<i>Positive engagement by children/young persons with their current situation</i> <i>Expanding the boundaries for children/young persons with an intellectual disability</i> <i>Maximising individual potential</i>

8.2 'Social inclusion' and the social supports infrastructure

8.2.1 Social inclusion and children/young persons with an intellectual disability

For children/young persons with an intellectual disability, *social inclusion* means, on the one hand, equal treatment with other children to basic goods, services and protections, and, on the other, a positive affirmation of their shared citizenship at all points of engagement with societal structures and institutions. Valentine (2001) suggests that, despite all the policy attention being given to children in recent years, many children with disabilities and their parents do not yet enjoy full citizenship rights. Hall

(2005) notes that many people with an intellectual disability are confined to 'small action spaces' on the margins of society.

8.2.2 Social inclusion: the research findings

Parent/guardian survey respondents gave a score of 3.6 (out of a maximum of 5) and service provider staff interviewees gave a score of 3.4 based on a Likert-type summation rating in respect of their agreement or disagreement with the following rights statement (see 6.1.7 and Figure 6.1 above).

'Children/young persons with an intellectual disability are enabled to participate actively in the community.'

Four dimensions of the social supports infrastructure are identified as relevant to the rights component 'social inclusion': (i) integrated education; (ii) family support; (iii) community/neighbourhood integration; and (iv) peer/friendship networks. Figure 8.2 outlines the positives and deficits in relation to each of these dimensions.

8.2.2.1 Integrated education

Integrated (mainstream) education for all children is an underlying policy principle which reflects the provisions of the UN Convention on the Rights of the Child (United Nations 1989). This principle is reflected in Irish educational policy (National Council for Special Education 2011) and the *modus operandi* of the service provider involved in the present Case Study. Huck *et al.* (2010) found from their study on children with an intellectual disability in general education classrooms that these children perceived their cognitive and physical competence and their peer acceptance very positively. On a more negative note, a Children and Youth Programme (2012) report noted that effective inclusion in education in both Ireland and Northern Ireland has been constrained by "ambiguous interpretation of the role of classroom assistance" (Children and Youth Programme 2012:40). It can also be argued that having to place children in a 'special school' may be indicative of a lack of truly inclusive education.

The present study indicates that children with an intellectual disability are placed in mainstream schools where appropriate and feasible. Additional supports, resource teachers, Special Needs Assistants (SNA) are provided to cater for the additional needs of such children. A minority of children are placed in a special school⁴⁴ where such is deemed by parents/guardians and professionals to be the most appropriate for the child. The overall perception of parents/guardians and service provider staff is that children are placed in the 'right' school for them even though, in some cases, this did not happen in the first instance. All except one of the young person interviewees had or were attending mainstream schools and those who

⁴⁴ Special schools in Ireland are designated as primary schools catering for a particular category of disability and operate under the Rules for National Schools (National Council for Special Education 2011).

were currently attending school (all in mainstream schools) reported relatively positive experiences.

Parent/guardian interviewees reported that engaging with the education system was a challenging and sometimes difficult experience mainly related to choosing the 'right' school for their child whether mainstream or special. Maintaining vigilance that their child's needs were being catered for in whatever school s/he attended was an ongoing feature of their lives. Those whose child was in a mainstream school referred to a supportive school ethos as being a key factor in their choice of school. The one to one and inclusive teaching in the special schools was a key factor in parents/guardians choosing such a school for their child. The possible negative impact on other children in the class was identified by some parents/guardians as a factor in some mainstream schools being reluctant to accommodate a child with an intellectual disability. While appreciating this perspective, parents/guardians for the most part did not necessarily agree with it.

Three positive aspects of the school experience were identified by parents/guardians. The fact that their child was actually accepted by the local school was regarded as significant by some while for others their child actually 'surviving' in whatever school s/he attended was the important aspect. Others highlighted the fact that their child/young person was having a positive and affirmative school experience. Some parents/guardians referred to feedback from teachers stating that the presence in a school of a child/young person with an intellectual disability enhanced both the school generally as well as the specific class attended by the child. On the negative side, the fact that a child is a slower learner than others in a class was seen as marginalising the child and, in one instance, resulting in the child refusing to go to school.

The availability of a number of educational models⁴⁵ was regarded as important by staff interviewees so that there were options and choices for individual children. Staff interviewees stated that for the most part children were being adequately catered for in terms of choice of schools. However, while the concept of inclusive education was regarded as the ideal to be aimed at, the current mainstream educational model for children with disabilities based on the provision of additional educational supports in accordance with assessed needs was regarded as less than satisfactory because of its inherent potential to be a target for funding cutbacks. Any retrenchment in such provisions was seen as almost certain to result in a serious undermining of the inclusive education approach and a negative impact on the ongoing development of more positive and inclusive social attitudes generally. Significantly, the fact that most of the teachers in mainstream schools are not trained to deal with children with an intellectual disability was seen by some staff and professionals as presenting difficulties in terms of maximising the child's learning potential.

⁴⁵ Mainstream school; special school; special class in mainstream school; autism unit.

A particular issue relating to mainstream education at second level identified refers to the fact that the primary focus in second-level schools is academic with a focus on Leaving Certificate points and access to third-level education. This focus was perceived by some interviewees (across the three categories of parents/guardians, staff and other professionals) as not appropriate for some students with an intellectual disability. While there is provision for FETAC⁴⁶ accreditation in second level schools, this was perceived as marginal and of a significantly lower status and, therefore, as effectively undermining the concept of integrated education. The lack of further education/career options and paths for young people with an intellectual disability who do not sit the Leaving Certificate was also identified as a significant deficit. This lack of after-school options in Ireland has been previously highlighted by Haase and Byrne (2005).

8.2.2.2 Family support

The concept of family support is a central one in children's policy in Ireland (Millar 2006) and an underlying principle of service delivery (Department of Health and Children 2007). Frost and Dolan (2012) suggest that despite its complexity, difficulty of definition and ambiguity, family support has a central and crucial role within child welfare. The Committee on the Rights of the Child (United Nations 2007) states that children with disabilities are best cared for and nurtured within their own family environment provided that the family is adequately provided for in all aspects.

Two contrasting pictures emerged in relation to family support – some families have good support depending on their extended family networks, their friendship networks and their local community/neighbourhood connections while others have weak or underdeveloped linkages with their extended family and their local community. There was evidence reported by parents/guardians and young persons of strong immediate family and sibling support. Most young persons and some parents/guardians reported good support from their extended families. There was a perception on the part of some of the service provider staff that the potential support role of the extended family is somewhat underdeveloped.

Those parents/guardians who reported good family support stated that it came from a variety of sources, including spouse, parents, siblings, and, in some instances, the extended family. Those who had little or no family support stated that this was because they had no family living in the area or because their own parents were of advanced years.

The most important person/s in their lives identified by young persons were parents, parents and siblings or family and friends. An extended family network and reported varying levels of contact with extended family members were a significant feature in most of the young persons' lives

⁴⁶The Further Education and Training Awards Council (FETAC) was the statutory awarding body for further education and training in Ireland until the establishment in November 2012 of the Quality and Qualifications Ireland (QQI) www.qqi.ie as a new integrated awards agency.

with specific relationships (godparents to nieces/nephews) identified by some young persons as very significant in their lives.

Family support deficits identified by parents/guardians included insufficient cognisance by service providers of the different coping capacities of individual families and their related support needs (e.g. the need for respite care). The fact that the formal supports for families of children with an intellectual disability are provided by the specialist service as distinct from being provided through mainstream family support initiatives is identified by the researcher as a significant deficit from a social inclusion perspective in that it may add to a sense of difference and separateness for families and children/young persons.

8.2.2.3 Local community/neighbourhood integration

The community focus underpinning social support and family support interventions is based on the importance of the community in the lives of families (Chaskin 2006). The limited access that people with intellectual disabilities have to community amenities has been noted (McConkey 2007). Milner and Kelly (2009) found that community participation and inclusion which was supported from service settings tended to be steered towards public spaces rather than the private social contexts “where people were more likely to experience a sense of psychological safety and interpersonal intimacy antecedent to a sense of belonging (Milner and Kelly 2009:58). Abbott and McConkey (2006) found from their research with a sample of people with intellectual disabilities that for them social inclusion meant meeting other people in ordinary settings and being treated similarly and that participants recounted both positive and negative experiences in this regard.

The principle of greater local community/neighbourhood participation by children/young persons with an intellectual disability as central to a socially inclusive approach is acknowledged by the specialist service provider. All staff interviewees acknowledged the crucial importance of community involvement by children/young persons with an intellectual disability and all pointed to what they perceived as significant efforts by the agency to improve such involvement.

Linkages with neighbours and their local community were reported by some of the young person interviewees with a minority stating that they did not have any contact with neighbours and/or that they knew no neighbours. The active involvement of some young persons with an intellectual disability in local voluntary community initiatives was reported by parents/guardians, staff and some of the young persons. However, such involvement was not the norm and a lack of organic connectedness to local communities emerged as a key factor.

Figure 8.2: Social Inclusion: social support infrastructure strengths and deficits identified

Social support dimension	Social Supports Infrastructure <i>Positives</i>	Social Supports Infrastructure <i>Deficits</i>
<i>Integrated education</i>	<ul style="list-style-type: none"> • Integrated (mainstream) education an underlying policy principle; • Children placed in mainstream schools where appropriate and feasible; • A minority of children placed in special schools where deemed most appropriate; • Some additional resources and supports in place in mainstream schools; • Perception of each child being in the 'right school' • Some provision for FETAC accreditation in second level schools 	<ul style="list-style-type: none"> • Most teachers not trained to deal with children with an intellectual disability; • Difficulties in getting additional supports required by individual children; • Therapies available to individual children not commensurate with need; • Primary focus in second-level schools on Leaving Cert. points not appropriate for some students; • Lack of further education/career options and paths on completing second-level education
<i>Family support</i>	<ul style="list-style-type: none"> • Family support an underlying principle of service delivery; • Enhancing coping capacity of families a key goal of support intervention by service provider; • A perception of some families having good family support; • Immediate family very supportive of child/young person; • Some support from extended families; • Evidence of resilience among families 	<ul style="list-style-type: none"> • Insufficient cognisance of different coping capacities of individual families and related support needs; • Support role of extended family underdeveloped; • Separate (not mainstream) support for families of children with an intellectual disability; • Availability of family support workers not commensurate with need;
<i>Community/ neighbourhood integration</i>	<ul style="list-style-type: none"> • A policy focus on greater local community/neighbourhood participation by children/young persons with an intellectual disability; • Good local community/neighbourhood integration by some families; • A minority of children/young persons with good local community/neighbourhood connections. • Some innovative programmes in stimulating local community involvement by young persons with an intellectual disability. 	<ul style="list-style-type: none"> • A supportive local community dependent on family linkages with local community; • Some families poorly integrated in their local community; • Some children/young persons socially isolated; • Poor provision by mainstream sports and cultural activities for children/young persons with an intellectual disability
<i>Friendship/ peer networks</i>	<ul style="list-style-type: none"> • Some children/young persons have good friendship networks; • Some parents have good friendship networks; • Some innovations in enhancing networks; 	<ul style="list-style-type: none"> • Some children/young persons with no peer/friendship networks outside of school or training programme; • Underdeveloped organic peer/friendship networks; • Decline in friendships as children grow older.

More than one-third (35.1%) of parent/guardian survey respondents stated that they found support from the local community as 'of no benefit' or 'of little benefit' (see Table 6.4). Most parent/guardian interviewees reported relatively little engagement with neighbours or with the local community while a smaller group referred to the local community/neighbourhood as a positive source of support. Community and neighbourhood supports were viewed by staff as generally positive notwithstanding the fact that there was a huge variation in the levels of integration, depending not only on the individual child/young person but also on the parents' links to the community and the particular type of community where people lived.

A difficulty with the community integration of children/young persons with an intellectual disability identified by staff referred to fear and apprehension on the part of some parents/guardians about letting their child/young person with an intellectual disability out around the local neighbourhood or allowing them to participate in generic community sports and leisure activities. Another difficulty identified by both parents/guardians and staff referred to the fact that a support staff person or family member or trusted adult is not always available to accompany the child/young person. Some parents/guardians referred to particular environments (e.g., noise levels at sports events) which their child could not tolerate. This effectively excluded both the child/young person and the parents/guardians from such events. This view of some parents/guardians was echoed by some staff interviewees who stated that community integration was difficult for some families because minding the child/young person in a social/public setting entailed additional effort by the parents/guardians which added to an already stressful daily routine. Some parents/guardians stated that they would not be able to cope with the additional demands involved in having the child/young person participating more in community-based social activities.

The general picture that emerged was that children/young persons with an intellectual disability could be more involved at a local community level and that, while there were some initiatives in place, much more work needs to be done in that regard. The main deficit identified refers, perhaps not surprisingly, to the fact that a supportive local community appears to be entirely dependent on the family's linkages with the local community.

The research indicates that there is a minority of children/young persons with good local community/neighbourhood connections. Some innovative programmes in stimulating local community involvement by young persons with an intellectual disability are reported as are initiatives by the main service provider in this regard. The study also points to some children/young persons with an intellectual disability being socially isolated. In the view of the researcher, some of this isolation may relate to the fact that there is poor provision by mainstream social, sports and cultural activities for children/young persons with an intellectual disability.

Differences in communities, different ways that families engage with their local communities and the different types of intellectual disability emerged as key factors in determining the extent to which the children/young

persons are integrated. Understanding these differences is, in the view of the researcher, central to dealing with the challenge of improved community integration for children/young persons with an intellectual disability.

8.2.2.4 *Friendship/peer networks*

Peer and friendship relationships are an important component of the social support infrastructure of all children/young persons (McGrath *et al.* 2012). Children's friendship choices appear to be important to their continuing adjustment (Gifford-Smith and Brownell 2003). Emerson and McVilly (2004) make the point that despite there being considerable evidence to suggest that friendships are central to health and well-being, relatively little attention had been paid to the friendships of people with intellectual disabilities.

Smyth and McConkey (2003) found that eighty-five per cent of students with intellectual disability would like to have more friends. O'Regan *et al.* (2009) noted that people with an intellectual disability can experience disruptions to their social networks when services are altered, modified or discontinued without considering the impacts on their sources of support. A dearth of acquaintances and friendships among people with intellectual disabilities has been noted (McConkey 2007). Gregory *et al.* (2001) found that increased satisfaction with friendships and relationships was associated with users having both more and a greater proportion of people with an intellectual disability in their social networks. These authors noted that few people with an intellectual disability in residential care have meaningful relationships with people who do not have an intellectual disability, are not a member of their family and are not paid to be with them.

All of the young person interviewees attending education/training programmes identified their fellow trainees as their friends. Some stated that they had friends outside the centres whom they met from time to time with some reporting that they had 'loads of friends'. Having friends on Facebook was a feature in some of their lives. Some of those attending school stated that they had friends in the school and some stated that they had friends outside of school. Some of the young persons stated that they have no peer/friendship networks outside of their school or training programme. The main service provider and some schools are involved in developing and maintaining friendship networks involving children/young persons with an intellectual disability.

On the question of friendship supports for their child with an intellectual disability, parents/guardians generally referred to their child having friends in or associated with the school or in the training/education programme they attended. A minority referred to their child having friends in the neighbourhood who were attending a different school while some also referred to the child/young person having friends calling to the house or, in a minority of cases, the child/young person visiting his/her friends' houses. Some parents/guardians referred to their child/young person with

an intellectual disability being isolated when s/he is not at school. Other children were reported by their parents/guardians as being quite self-contained and happy to be alone or, in some cases, having difficulty generally in being in the company of other people. The difficulty their child/young person had in relating to other people generally (including those of similar age) was a feature in the lives of some families and, as a result, friends calling to the house would not be the norm. Some parents/guardians referred to the fact that other children might be afraid of their child because of particular styles of behaviour that would not be seen as normative, something they understood very well.

The absence of a friendship network in the lives of some children/young persons with an intellectual disability appears to be related to one or other of two factors – the nature, severity and complexity of the disability or the fact that the child/young person preferred to be on his/her own and did not, for the most part, wish to interact. Some parents/guardians reported a decline in the child's friendship network over the years as s/he grew older. This was perceived as being related to the fact that their child's cognitive, personal and social development was slower than that of other children of the same age. The point was made that it was probably easier for younger children to have and maintain friendships irrespective of whether or not some of them had an intellectual disability.

Good friendship networks in their own lives were reported by some parents/guardians. The importance of different types of networks/relationships with people in their own lives was identified – those that help with the caring/support tasks, those that they themselves can socialise with and those that relate to the parent as an individual in his/her own right and not just as a parent of a child with an intellectual disability. In a small number of instances, friends were seen as a significant source of support in caring for their child/young person.

Summary of section

Integrated (mainstream) education is an underlying policy principle and children for the most part are perceived as being placed in the 'right' school. Most teachers in mainstream schools are not trained to deal with children with an intellectual disability. There are difficulties in getting additional learning and therapy supports. The primary academic focus in second-level schools is not appropriate for some students and other educational and curricular models are underdeveloped. There is a shortage of appropriate further education/career options and paths.

Enhancing the coping capacity of families is a key goal of support intervention. Some families have good support from their extended families as do some children/young persons. There is good local community/neighbourhood integration by some families and consequently by their children. Some families are poorly integrated in their local community and some children/young persons are socially isolated and some have no peer/friendship networks outside of their school or training programme.

There are some innovative programmes in stimulating local community involvement by young persons with an intellectual disability and some children/young persons have good friendship networks. Poor provision by mainstream sports and cultural activities and underdeveloped organic peer/friendship networks were reported.

8.3 'Recognition' and the social supports infrastructure

8.3.1 *Recognition and children/young persons with an intellectual disability*

Recognition refers to the esteem that one feels based on the respect that is afforded by others. A child/young person with an intellectual disability thus needs to be able to observe and feel that s/he has a recognised identity, experiences a sense of belonging and is given due regard by others. Honneth (2003) distinguishes three spheres of recognition and three distinct forms of social relations through which members of society can count on reciprocal recognition. For Honneth, relationships go beyond close relations of love and friendship to include legally institutionalised relations of universal respect for the autonomy and dignity of persons, and networks of solidarity and shared values within which the particular worth of individual members of a community can be acknowledged.

The Committee on the Rights of the Child (United Nations 2007) refers to the strengthening of positive self-awareness, making sure that the child feels s/he is respected by others as a human being without any limitation of dignity as a crucial aspect of education. McConkey (2007), following Burchardt *et al.* (2002), identified the need for an understanding of social inclusion that would encompass four dimensions which can be said to strongly reflect the concept of recognition. These are consumption (the capacity to purchase goods and services, i.e. income); production (participation in economically or socially valuable activities such as employment, child-rearing or voluntary work); political activity (involvement in local or national decision making through voting or membership of a campaigning organisation), and social engagement (with family, friends, and community). Where the principle of recognition is upheld, a child can foster 'felt concern' for others and their values which is a central function of positive civic engagement (Dolan 2010). Conversely, for a child where such a sense of 'community' is not present, they may see themselves as devalued and thus value others less.

8.3.2 *Recognition: The research findings*

Parent/guardian survey respondents gave a score of 3.9 (out of a maximum of 5) and service provider staff interviewees gave a score of 3.5 based on a Likert-type summation rating in respect of their agreement or disagreement with the following rights statement (see 6.1.7 and Figure 6.1 above):

'Children/young persons with an intellectual disability are supported to enjoy a full and decent life'.

Four dimensions of the social supports infrastructure are identified as relating to the rights paradigm component recognition – (i) fostering positive and inclusive social attitudes; (ii) family and social acceptance and integration of child/young person with an intellectual disability; (iii) recognising and providing for the additional support needs of the family; and (iv) promoting the best interests of the child/young person. Figure 8.3 outlines the positives and deficits in relation to each of these dimensions.

8.3.2.1 Fostering positive and inclusive social attitudes

A 2011 national survey of public attitudes to disability in Ireland (National Disability Authority 2011) found that more than half (59%) of respondents believed that people with an intellectual disability or autism are not able to participate fully in life. A 2009 national inclusive research project conducted in Ireland and involving people with intellectual disabilities as co-researchers found that people with an intellectual disability wanted to be the same as the rest of society in respect of core domains of living – paid employment, accommodation, communication, money management, partners in relationships – and generally to be respected citizens (National Institute for Intellectual Disability 2009).

Chadwick *et al.* (2013) reported both a lack of societal awareness of disabilities and the challenges families face supporting a family member with an intellectual disability. “This was particularly evident when their family member did not have any physical signs that they had intellectual disabilities and were viewed as unruly or difficult, resulting in people thinking carers had poor parenting skills” (Chadwick *et al.* 2013:127). Despite the negative aspects of life reported by families, findings regarding the positive aspects of having a family member with an intellectual disability were also reported by Chadwick *et al.* (2013).

Positive attitudes towards their child with an intellectual disability by their own family, by friends and by the child/young person’s peers were reported in the present study. Social attitudes towards children/young persons with an intellectual disability were perceived as becoming increasingly more inclusive in recent years. This change was seen by staff interviewees as being manifested in a more inclusive public response to children/young persons with an intellectual disability. It was also reflected in people with an intellectual disability being publicly visible and actively participating in various life domains. It is also reflected in children/young persons attending mainstream schools and participating in some community-based activities and the positive attitude reported by some schools to including and integrating children/young persons with an intellectual disability. A perceived positive impact on other children in a school was reported as was the fact that participation by children with an intellectual disability in mainstream schools provides other children with an opportunity to engage with and respect the notion of difference. The Special Olympics was regarded as having a major impact on public perceptions of people with an intellectual disability (notwithstanding the fact that it was not a mainstream activity).

Figure 8.3: Recognition: Social Support infrastructure strengths and deficits identified

Social Support Dimension	Social Supports Infrastructure Positives	Social Supports Infrastructure Deficits
<i>Inclusive social attitudes</i>	<ul style="list-style-type: none"> • Perception of social attitudes becoming more inclusive; • Public responses to children/young persons with an intellectual disability generally positive; • Perception that a child with an intellectual disability is treated the same as every other child. • Positive attitudes by some schools. 	<ul style="list-style-type: none"> • Policy focus on assigning children/young persons with an intellectual disability to a 'special' (separate) group/category; • Label 'intellectual disability' masking the individuality and particular needs of each child/young person; • Different public responses to different types of intellectual disability; • Nature of child's disability sometimes shaping public attitudes; • Separatist provision for sports and cultural activities (e.g. Special Olympics).
<i>Family and social integration of child/young person</i>	<ul style="list-style-type: none"> • Positive and inclusive integration by families of children/young persons with an intellectual disability; • Strong sibling support of child/young person; • Focus by service provider on enhancing the coping capacity of the family; • 	<ul style="list-style-type: none"> • Parents feeling alone in providing for the sometimes significant care needs of the child/young person; • Parents having difficulty in coping with the challenging behaviour characteristics of some children; • Inclusion of children and support from extended families underdeveloped; •
<i>Provision for the additional support needs of families</i>	<ul style="list-style-type: none"> • A perception by parents of good support from service provider; • Respite care and outreach support provided to families; • Professional support personnel working with families in developing • inclusive ways of responding to child's needs • 	<ul style="list-style-type: none"> • Separate (specialist) provision of services may contribute to marginalisation; • Parents having to 'fight for' to get and to retain the supports and services required by the child/young person; • Additional costs incurred in attending appointments
<i>Promoting the best interests of the child</i>	<ul style="list-style-type: none"> • Acceptance by parents/guardians of the of the 'best interests' principle; • Acknowledgement by service provider and schools of the 'best interests' principle; • Adjustment by families of daily living arrangements to facilitate the needs of the child/young person; • Seeking the 'right' school for the child; 	<ul style="list-style-type: none"> • The needs of the school/community as a whole sometimes having to take precedence over 'the best interests of the child' principle; • Local community initiatives may not be fully cognisant of the 'best interests' principle • Resources available not always commensurate with supporting the 'best interests' principle

People who did not have direct experience of a child/young person with an intellectual disability were perceived as not being able to fully comprehend the notion of difference and/or non-normative behaviour. A number of parent/guardian interviewees were of the view that social attitudes were to some extent shaped by the type of the child/young person's intellectual disability, in particular, whether the disability was visible or not. Different public responses to different types of intellectual disability were reported. The perception was that public attitudes were likely to be much more positive to a child/young person with, for example, Down Syndrome, than to a child/young person on the autism spectrum who displayed behavioural difficulties. Some parent/guardians had experience of what they perceived to be exploitative behaviours by the child/young person's peers, e.g., getting them to spend money; encouraging them to steal or to engage in other antisocial behaviour.

The reality that a child/young person with an intellectual disability was different to other children/young persons who did not have such a disability could not be ignored, according to some parents/guardians. The fact was that many of them could not do what children who did not have an intellectual disability could do. For those with more profound disability, the priority was on accepting their limitations and providing for their care needs as well as possible rather than focusing too much on whether or not they were different.

Some parents/guardians stated that they found the practice of people (friends and acquaintances) regularly focusing on and asking about the child with the intellectual disability somewhat disconcerting. A possible public perception of families of a child with an intellectual disability as being downtrodden and oppressed and having no other dimensions to their lives other than caring for the child/young person with the disability was posited by some parent/guardian interviewees. Living full and socially integrated lives was more difficult for some parents/guardians. Such difficulty was associated to some extent with weak or underdeveloped extended family, friendship and community support networks as well as to the nature of the child's disability.

8.3.2.2 Family and social acceptance and integration of the child with an intellectual disability

Ellison (2006) concludes from her analysis of the research literature that, while the presence of a disability affects the entire family as an interactive unit, parental adjustment to caring for a child with a disability varies from parents who experience psychological distress to those who successfully adapt.

Parents/guardians in the present study described the experience of having a child with an intellectual disability as challenging for the family in terms of daily living. Notwithstanding this, positive aspects of the experience were noted. These included the belief that the child with the intellectual disability can sometimes be more caring, affectionate and sociable than those who do not have an intellectual disability. On the negative side,

some difficulties were reported, including, in particular, not being able to go places as a family, not being able to plan ahead and not being able to have visitors in the home.

The parent/guardian interviewees described the impact that having a child with an intellectual disability in the home has on other children in the household. Some parents/guardians expressed regret that their other children lost out while others referred to continually trying to compensate the other children. According to parents, having to be always careful about where they left their personal belongings was an adjustment some siblings had to make. Also, not being able to bring friends home because of the negative impact on the child with the intellectual disability was identified as an aspect of some siblings' lives.

Parents/guardians for the most part reported quickly coming to terms with the fact (following a specific medical and/or psychological diagnosis) that their child had an intellectual disability. For the most part they stated that the main difficulty arose from their experience of having to negotiate for the support services required by the child. While the care and support requirements were sometimes substantial, families universally sought to ensure that the child with the intellectual disability was included in the family the very same as their other children. In a minority of instances, parents stated that one parent took more time than the other to come to terms with the diagnosis and with the daily challenges of providing the additional support required.

While there was a strong sense of parents/guardians being very aware of wanting to protect their child, there were some who expressed the view that children/young persons with the intellectual disability should not be over protected and should be treated in the same way as other children with the same boundaries established as for other children and the same expectations in accordance with their capabilities. This entailed the parents/guardians taking reasonable risks and encouraging others involved with the child/young person to do likewise.

The research findings suggest a positive and inclusive integration by families of children/young persons with an intellectual disability. Strong parental and sibling support emerged as a significant factor. On the deficit side, some parents/guardians reported feeling alone and isolated in providing for the sometimes significant care, support and attention needs of their child/young person. The challenging behaviour of some children/young persons presented additional difficulties for some families. An underlying concern reported by all parents/guardians was their need to be continuously vigilant in providing for the care and support needs of their child/young person and in ensuring that s/he gets the supports and services needed.

8.3.2.3 Recognising and providing for the additional support needs of the family

Valentine (2001) suggests that the particular needs of parents caring for children with disabilities have also been overlooked. The huge demand on

their time and energy was a recurring theme for parent/guardian interviewees and a number referred to the fact that caring for the child/young person with the intellectual disability was hard going and very labour intensive. All of the parent interviewees identified the need for constant attendance to the needs of the child with the intellectual disability as being a core component of daily life. While this varied depending on the child/young person's needs, the weekly routine of attending appointments and the necessity of having to accompany the child/young person wherever s/he went were recurring themes. As part of the constant attendance role, some parents/guardians referred to the challenge of always having to find something to keep the child/young person occupied. This was seen as putting significant demands on the family. For the most part, families just dealt with the day to day reality of the situation without getting too preoccupied with the additional needs of the child with the intellectual disability.

There were three specific aspects of support around which parents/guardians experienced apprehension and anxiety – getting Special Needs Assistants (SNA) at school going age, getting supports when transitioning out of second-level education and the provision for the longer term care and support needs of the child/young person if and when they themselves are not in a position to do so. On the latter point, their own non-availability as the core providers of care and support was an eventuality that most preferred not to contemplate. There was a view among some parents/guardians that it was unrealistic to expect that the same level of care and support would be provided by paid staff as that provided by themselves. For the researcher, this raises a crucial question about the extent to which the ethic of social solidarity prevails.

The provision of additional family support was identified by service provider staff as part of the ethos of the agency and a core component of service delivery. There was a perception among staff interviewees that families were well supported by social workers, outreach workers and behaviour support staff. There was also a perception that children/young persons were generally provided with the essential therapies that they required. However, there was also an acknowledgement that some children/young persons and some families needed a counselling service which was not currently available from the main service provider.

The consensus view of parents/guardians was that there is good support from the main service provider in terms of meeting the child/young person's and their own needs. Many pointed to a significant change in their lives and that of their child once they had been referred to the specialist provider. The specific focus of the specialist service provider was regarded as enabling them to articulate their needs in what they perceived as an understanding and responsive environment.

While the contribution of the specialist service provider was acknowledged as very significant, this co-existed with a perception on the part of some parents/guardians of having to 'fight' to get and to retain some of the

supports and services required by the family and the therapies required by the child/young person. The additional costs incurred in attending frequent appointments with or on behalf of the child/young person was a concern for some families while other parents/guardians referred to having to pay privately for some therapies because they felt that the State-funded provision for some therapies needed by their child/young person was inadequate. These factors were seen as to some extent undermining the family efforts at affirmation and integration of the child/young person.

8.3.2.4 Promoting the 'best Interests of the child'

One of the underlying themes of a children's rights-based perspective is that the best interests of the child/young person is always a basic criterion for the provision of support services. This is referenced in Article 3 of the UN Convention on the Rights of the Child (United Nations 1989) and has recently (November 2012) been provided for in the Irish Constitution. Parents/guardians gave a score of 3.0 (out of a maximum of 5) and service provider staff interviewees gave a score of 2.5 based on a Likert-type summation rating in respect of their agreement or disagreement with the following rights statement(see 6.1.7 and Figure 6.1 above):

'The best interests of children/young persons with ID are the primary consideration in all actions by the State affecting them.'

These ratings reflect a perception among parents/guardians and, to a greater extent among service provider staff, of a somewhat underdeveloped application of the 'best interests of the child' concept.

The Case Study data indicates acknowledgement of and acceptance by parents/guardians, by service provider staff and by schools of the 'best interests of the child' principle. The study points to significant adjustment by families in their daily living arrangements to facilitate and cater for the needs of their child/young person. Such adjustment applies to the child/young person's siblings as well as to his/her parents/guardians. The strong focus on finding the 'right' school for the child reflects a strong awareness of the 'best interests' principle.

On the deficit side, there is a perceived significant difficulty in implementing the 'best interests of the child' principle. In particular, the needs of the whole family, the needs of the community as a whole or the overall needs of the school sometimes have to take precedence over 'the best interests of the child' principle. Health and safety factors were identified in this regard as were factors relating to resource availability in schools where significant additional supports that would benefit the child's learning and development are simply not affordable within existing budgets. The fact that local community, sports and leisure initiatives may not always be fully cognisant of the 'best interests' principle (in that there is little or no provision for including children/young people with an intellectual disability) also emerged as a factor.

Summary of section

A positive attitude by some schools to including children/young persons with an intellectual disability is reported. Families engage in positive affirmation of their child/young person and strong sibling support is reported. There is a perception among parents/guardians of good support from the specialist service provider in the form of multidisciplinary support, respite care and outreach support in response to the child's needs. Different public responses to different types of intellectual disability are seen by the researcher as reflecting an undermining of the notion of universal recognition and positive regard. Parents/guardians sometimes feel isolated in providing for the sometimes significant care needs of their child/young person and some have difficulty in dealing with perceived public misunderstanding and negative social attitudes to challenging behaviour. There is an acknowledgement by parents/guardians and by service provider staff and other professionals of the importance of the 'best interests' principle. The needs of family unit, the school or the local community as a whole sometimes have to take precedence over 'the best interests of the child' principle.

8.4 'Agency' and the social supports infrastructure

8.4.1 *Agency and children/young persons with an intellectual disability*

The concept of *agency* as used in the present study refers to the ability of a person to act, make choices and decisions and express views. For children/young persons with an intellectual disability, agency may need to be exercised in a more social, relational and supported context as distinct from engaging in individual autonomous actions. Carlson and Kittay (2010) argue for the need for a more collaborative conception of agency, one that is, in reality, appropriate to all, but especially useful in relation to people with an intellectual disability. Francis and Silvers (2010) argue that, for people with serious cognitive impairments, the formulation and articulation of desires and understandings of one's own good may require the assistance of others which, they suggest, is in fact congruent with the way we all form our conceptions of the good. They thus make the case for including conceptions of the good that are formulated, validated, and maintained in a collaborative fashion. This view offers a rich context for expanding horizons in relation to the way children/young persons with an intellectual disability are to be engaged in decision-making and choices and, in so doing, to change the focus of debate from a deficit to a developmental paradigm in relation to agency.

8.4.2 *The research findings*

Parents/guardian survey respondents gave a score of 3.5 (out of a maximum of 5) and service provider staff interviewees gave a score of 2.8 based on a Likert-type summation rating in respect of their agreement or disagreement with the following rights statement (see 6.1.7 and Figure 6.1 above):

'Children/young persons with an intellectual disability are provided with appropriate assistance to enable them express their views freely'.

Four dimensions of the social supports infrastructure are identified relating to the rights component 'agency': (i) affirmative support for the child/young person; (ii) effective and meaningful communication with child/young person; (iii) optimising self-management by young persons of their own affairs; and (iv) access to therapies as required by the child/young person. Figure 8.4 outlines the positives and deficits in relation to each of these dimensions.

8.4.2.1 Affirmative support for the child/young person

Parent/guardian interviewees emphasised the importance of affirmation wherever possible in enhancing their child's own sense of well-being and empowerment in relation to daily living. Encouraging the child/young person to carry out daily living tasks as far as was practicable and possible and affirming him/her accordingly was seen as necessary to enhance coping capacity and independence and to give the child/young person a sense of self-worth. While in some instances this required patience and a concerted and ongoing effort by parents/guardians, the outcome was considered worth the additional effort. Positively affirming the child/young person in any success that s/he had in school (e.g. completing the Junior Certificate) was seen as a buffer against any sense of inadequacy arising from feeling different in a mainstream educational setting.

The affirmation of the child/young person with an intellectual disability by his/her siblings was reported by both parents/guardians and young persons as a strong feature in their lives. In some instances affirmation within the school system and by their local community was reported. The perceived positive impact on other children in schools, as noted above, acts indirectly as a positive affirmation of children/young persons with an intellectual disability.

The lack of accreditation for educational achievement was identified as a factor in the lives of young persons who had spent a period of time in second level education without having completed any formal examination. The absence of any accreditation for achievement by some children/young persons in accordance with their ability emerged as an issue. This lack of accreditation to some extent undermined the efforts of the child/young person, the efforts of parents/guardians, teachers and other support personnel. Not all parents/guardians saw this lack of accreditation as an issue and focused instead on the merits of their child/young person actually attending mainstream school and participating in school-based activities.

A picture emerged of an under recognition of the interests and aptitudes of children/young persons with an intellectual disability in mainstream school and local community contexts because frequently they do not fit with normative expectations in relation to educational achievement, social roles or sports and leisure activities.

Figure 8.4: Agency: Social Support infrastructure strengths and deficits identified

Social Support Goals	Social Supports Infrastructure Positives	Social Supports Infrastructure Deficits
<i>Affirmation of children/young persons</i>	<ul style="list-style-type: none"> • Parents fully cognisant of the need to affirm their child in all the domains of living; • Affirmation of child/young person by his/her siblings; • Some affirmation of children/young persons with an intellectual disability within the school system; • Some local community affirmation; • Positive impact on other children in school 	<ul style="list-style-type: none"> • Underdeveloped engagement with children/young persons with more severe disabilities; • Affirmation not always inclusive of child/young persons interests and aptitudes; • Local communities responses not always positively affirmative; •
<i>Effective and meaningful communication with children/young persons</i>	<ul style="list-style-type: none"> • A policy emphasis on enhancing communication for each individual child; • Some use of assistive communications technology; • Access by young persons to a key support worker (from service provider); 	<ul style="list-style-type: none"> • Underdeveloped communication techniques for children/young persons who cannot verbalise; • Schools lacking in facilities; • Non-availability of specialised communications technology due to cost factors; • Availability of therapies not commensurate with the needs of individuals
<i>Optimising self-management by young persons of their own affairs</i>	<ul style="list-style-type: none"> • Optimising self-management included as part of Personal Outcomes planning; • Young persons experience of having choices; • Parents working with child/young person to develop skills in carrying out daily living tasks; • Some parents proactively working to enhance the money management skills of the young person; • Additional independent living programme options being explored by main service provider. 	<ul style="list-style-type: none"> • Learning goals not sufficiently developmental; • Lack of transition options after primary school for children in autism specific unit; • Some parents having unrealistic and unrealisable aspirations for their child; • The mainstream school environment not sufficiently inclusive of children/young persons with very different and specific learning needs
<i>Access to therapies as required by the child/young person</i>	<ul style="list-style-type: none"> • A range o therapies provided to the child/young person on the basis of needs • Therapies provided in the home, in the school and in service provider centres • Parents assisted to acquire the skills to do the various therapies under the guidance of the relevant professional 	<ul style="list-style-type: none"> • The availability of therapies is not always commensurate with the child/young person's assessed needs. • Parents at times have to fight for additional therapies • Special Needs Assistants may be asked to do some of the therapies in school settings under guidance from the professional

A point made by both some parents/guardians and some young persons was that there were instances where the young person was involved in work or job sampling but felt undermined by the fact that there was no specific additional payment for the work. This was seen as exploitative, disrespectful to the young person and, as such, can be regarded as a fundamental undermining of personal agency.

A central deficit relating to affirmation is what appears to the researcher to be a significantly underdeveloped engagement with children/young persons with more severe disabilities in terms of enabling them to act, make choices and decisions and express views (key components of agency identified by Carlson and Kittay (2010)). The exercise of agency in the more social, relational and supported context as distinct from an individual engaging in individual autonomous actions appears to be largely undeveloped.

8.4.2.2 Effective and meaningful communication with the child/young person

There is an emphasis in the provisions of the UN Convention on the Rights of Persons with Disabilities (United Nations 2007) on enhancing communication for each individual child/young person. This is reflected by the case study service provider in the reported substantial provision of speech and language therapy and the provision of assistive communications technology in school and in the home. Purcell *et al.* (2000) noted that interventions to improve the language and communication of children with intellectual disabilities were increasingly centred around interactive approaches in naturally occurring contexts. They concluded from their analysis of a staff communication training programme that the central issue was no longer identifying communication deficits in clients or training staff in communication but rather in creating service environments in which communicators have equal status and are seeking mutually important outcomes.

How people communicate with or 'treat' their child was experienced as a real difficulty by some parents/guardians. This difficulty manifested itself in two ways – people being over-friendly (and somewhat patronising) or people maintaining an unnecessary distance from the child/young person because, perhaps, they feel they cannot relate adequately to the child/young person. Some parents/guardians expressed frustration at the fact that an effective means of communication was not available to their child because s/he doesn't speak. While some children/young persons who did not verbalise could communicate with family members through other means (touching, tapping or making sounds), this method of communication was frequently not understood or appreciated by outsiders (both adults and the child/young person's peers) and, as a result, they did not really engage with the child/young person. In contrast, other parents referred to the child not wanting social interaction and/or wanting his/her own space and/or not seeking or responding to physical contact or touch.

The ability of children/young persons with an intellectual disability to understand and comprehend much more than might appear obvious was a recurring theme in the interviews with parents/guardians. The style of communication used by people who do not know or encounter children/young persons with an intellectual disability on a regular basis was perceived as failing to take account of a child/young person's different understanding of and use of language.

A key aspect of communication noted was that in order to communicate with some children/young persons, *viz.* those with mobility or standing difficulties, that it was necessary to actually get down to their level, whether on the floor or on a low seat or wheelchair and that many people do not understand the need to or do not feel able to do that. The difficulty of engaging in communication, even over a short period of time, with children/young persons with low attention spans was seen as presenting difficulties for some people, both adults and peers. Communicating with and systematically engaging children/young people who need to have a clear and instant response to their needs presented a difficulty for some parents/guardians who were unsure as to how they could more effectively deal with that reality. Children/young persons who have difficulty in giving meaningful feedback that can be interpreted and understood by those who are not in daily contact with them was seen as acting as a barrier to social inclusion, *e.g.*, in the extended family, in peer/friendship networks or in neighbourhood networks. Communication by the child/young person was also seen as being enhanced by the availability of a key support worker (from the main service provider).

Deficits in the communications support infrastructure identified were a shortfall in the availability of speech and language therapy and the non-availability of adequate specialised communications technology for those who cannot verbalise or who have difficulty in so doing. This was seen in the school settings as due primarily to cost factors. The fact that the availability of therapies is sometimes not fully commensurate with the needs of individual children/young persons undermines the maximising communication principle. The requirements of implementing the regular curricular programmes in mainstream schools may not always be conducive to ensuring that the additional communication needs of some children/young persons are met. A further deficit identified is what appears to the researcher to be the significant under-application of techniques to enhance the communication ability of children/ young persons with significantly diminished capacity to verbalise.

8.4.2.3 Facilitating appropriate control by young persons over their affairs

Recent research involving young people with disabilities in the UK (VIPER 2012) concluded that it still appeared that young people with disabilities were being denied opportunities to participate in decision-making. The reasons given were that relevant staff lack the skills and knowledge to facilitate participation by children with disabilities, including skills associated with addressing accessibility issues such as making

information accessible or removing barriers faced by young people with communication needs.

Optimising self-management by young persons is included as part of Personal Outcomes model of planning used by the case study service provider. Many of the young persons stated that they have choice in managing their own affairs in at least some of the domains of daily living, e.g., money matters. Parents/guardians reported working with their child/young person to develop skills in carrying out daily living tasks, with some engaging in this process in a detailed and sustained manner. Some parents/guardians work proactively to enhance the money management skills of the child/young person. Some referred to their exercising some control over the young person's Disability Allowance payment.⁴⁷ Achieving a balance between exercising responsible control and facilitating the young person's independence, choice and agency was a core concern for parents/guardians.

In order to optimise self-management by young persons in accordance with their abilities, additional independent living programme options are being explored by the main service provider and some of the young persons interviewed as part of the Case Study are exploring such options.

8.4.2.4 Access to therapies as required by the child/young person

Lindemann and Lindemann (1987) refer to the need to broaden health care to embrace the total life experience of children and their families. They make the point that special assistance is sometimes required from occupational therapists, physiotherapists, nurses or physicians, in order to determine the limits of independent functioning for an individual and to enable him/her to learn adaptive procedures and to use adaptive devices that may be necessary where there are motor, sensory, or cognitive limitations.

Access to a range of therapies on the basis of assessed needs is set out as the guiding principle of service delivery. This provision is governed by resource availability with resultant necessary rationing. The rationing is reported by service provider staff to be primarily on the basis of the prioritisation of needs based on the child/young person's requirements at different stages and on the parents' ability to do some of the therapy once the process has been shown to them by a professional. While in a general way children/young persons were reported as getting the therapies they needed, the experience of having to 'fight for' what they perceived as essential therapies, e.g., speech and language, was reported by many parents/guardians. The point was also made that the onus was on the parents/guardians to maintain vigilance to ensure that therapies were provided on an ongoing basis and with a frequency commensurate with

⁴⁷ In some instances a parents/guardian would be registered with the Department of Social Protection as an agent for receipt of the Disability Allowance on the young person's behalf.

need.

The provision of therapies was seen by some parents/guardians as being prioritised by the service provider based on whichever parents are most demanding rather than on a prioritisation of needs. Having to pay privately for additional therapy, which they felt was necessary, was a feature in the lives of some parents/guardians with additional pressure on the household budget as a result.

Summary of section

Overall, the study findings suggest that the social supports infrastructure, formal and informal, while to some extent affirming children/young persons with an intellectual disability, may not always be sufficiently developmental or innovative in terms of embracing a broader and more inclusive understanding of agency. This is regarded as applying in both the school setting and in the application of the Personal Outcomes model and, to some extent, in the family context. Some of this related to the academic bias of schools while some of it was also seen as reflecting the limited view of society as a whole as to how people with an intellectual disability are to be integrated. A related deficit identified was the fact that the mainstream school environment is not geared to being sufficiently inclusive of children/young persons with very different and specific learning needs and to providing learning opportunities accordingly. The availability of therapies being contingent primarily on resource availability as distinct from assessed needs undermines individual agency.

8.5 'Voice' and the social supports infrastructure

8.5.1 *Voice and children/young persons with an intellectual disability*

The concept of *voice* as used in the present study refers to the right of a child/young person with an intellectual disability to express his/her views freely in all matters affecting him/her. The concept of the 'voice of the child/young person' is explicitly referenced in the UN Convention on the Rights of the Child (UNCRC) (United Nations 1989). Article 12 (1) provides a child who is capable of forming his/her own views the right to express those views freely in all matters affecting him/her, the views of the child being given due weight in accordance with the age and maturity of the child. Article 13 (1) provides that a child shall have the right to freedom of expression, including freedom to seek, receive and impart information and share ideas through media of choice. The UN Convention on the Rights of Persons with Disabilities (United Nations 2007) (Article 7 (3)) reiterates the provision of Article 12 (1) of the UNCRC in respect of children with disabilities and adds that such provisions should be on an equal basis with other children and that disability and age-appropriate assistance to realise that right should be provided. The *Ladder of Participation* concept has been developed by a number of writers, including Arnstein (1969) and Hart (1992). Both of these identify an 8-rung ladder of participation ranging

from a tokenistic or non-participation rung at the bottom to a social inclusion/citizenship rung at the top.

The Committee on the Rights of the Child (United Nations 2007) notes that more often than not, adults with and without disabilities make policies and decisions related to children with disabilities while children themselves are left out of the process. The Committee emphasises the need for children with disabilities to be heard in all procedures affecting them and that their views be respected in accordance with their evolving capacities.

8.5.2 Voice: The research findings

Parent/guardian survey respondents gave a score of 3.6 (out of a maximum of 5) and service provider staff interviewees gave a score of 2.7 based on a Likert-type summation rating in respect of their agreement or disagreement with the following rights statement.

'Children/young persons with an intellectual disability are allowed to express their views freely on all matters affecting them'

Both parents/guardians and service provider staff interviewees gave lower scores (3.4 and 2.5 respectively) in respect of the rights statement.

'The views of children/young persons with an intellectual disability are given due weight in accordance with their age and maturity and on an equal basis with other children/young persons'.

Three dimensions of the social supports infrastructure are identified relating to the concept of 'voice': (i) provision for choice by children/young persons as appropriate; (ii) including the voice of the child/young person in tandem with the voices of parents and service provider staff/professionals; (iii) access to relevant, comprehensible and transparent information and advocacy support. Figure 8.5 outlines the positives and deficits identified in relation to each of these dimensions.

8.5.2.1 Provision for choice by children/young persons as appropriate

Provision for choice in accordance with age and maturity is a component of facilitating the voice of children/young persons is a key provision in both the UN Convention on the Rights of the Child (United Nations 1989) and the UN Convention on the Rights of Persons with Disabilities (United Nations 2006b).

A 2009 national inclusive research project conducted in Ireland and involving people with intellectual disabilities as co-researchers found that people with intellectual disabilities in Ireland wanted, among other things, to have choice in their lives (National Institute for Intellectual Disability 2009). McCormack and Farrell (2010) found from their study of adults with intellectual disabilities that the personal outcomes least often present were: choosing where and with whom you live; exercising personal rights and choosing services such as hairdresser, dentist or doctor. McClimens and Hyde (2012) suggest that current trends towards the commercialisation of health and social care services has significant

implications for equal choice by persons with an intellectual disability because they do not have equality as consumers.

Service provider staff interviewees stated that choice was a core component of the *modus operandi* of the agency. While almost all of the young persons interviewed stated that they had, to some extent at least, the same choices as other young people their own age, there was a minority who felt that they did not. In response to a question from the researcher as to whether they felt that they could do what they wanted to do (as appropriate to their age), most felt that they could but a minority felt that they could not. Both those involved in the training programmes and those attending school perceived themselves as having opportunities to express preferences.

Giving their child/young person realistic and meaningful choices around daily routines in the home was important for parents/guardians. For many children/young persons, this involved by necessity relatively small choices about daily living and routines. Reference was made to the difficulty in offering food choices to some children/young persons because of concerns about their health. Some parents/guardians, for example, reported having to lock food presses and the fridge to deal with this problem and, while somewhat uncomfortable with this, felt that the primary consideration was protecting the young person's health.

While there was an acknowledgement by both parents/guardians and staff that choice operated within limited parameters for some children/young persons, the notion of choice was seen as more ambivalent in the case of others, e.g., those who could not verbalise and/or could not clearly indicate a preference. Also, limitations to the concept of choice for some young persons in situations where the parents took responsibility for making decisions in a way that may not be the case if the young person did not have an intellectual disability were identified by staff.

A centrally important deficit identified by the researcher is the absence of meaningful choice in service provider. There is only one specialist service provider in the area and all children/young persons with an intellectual disability in the area are necessarily referred to that service provider which in a general way reflects a clear lack of choice. A related factor is that there is relatively little choice of therapist or support worker in that generally the child/young person and the family do not have the option of seeking an alternative person. Parents/guardians did not report any significant difficulty with the multi-disciplinary and support personnel allocated and some stated that they had to be realistic in terms of what level of choice is possible within a relatively small staff cohort.

8.5.2.2 Including the voice of the child/young person in tandem to the voice of parents/guardians and the voice of staff/ professionals

Woodhouse (2000) argues for the right of each member of a society to participate in collective decision-making and especially the right to a voice

Figure 8.5: Voice: Social Support infrastructure positives and deficits identified

Social Support Goals	Social Support Infrastructure Positives	Social Supports Infrastructure Deficits
<i>Provision as appropriate for choice by children/young persons</i>	<ul style="list-style-type: none"> • Consultation with children/young persons part of the needs assessment and goal-setting process; • Consultation with parents part of the needs assessment process; • Some consultation with individual children/young person in implementation of school-based and other support programmes; • Parents providing realistic and meaningful choices to child/young person around daily routines 	<ul style="list-style-type: none"> • Absence of meaningful choice in service provider; • Limited choice in respect of therapists and support workers;
<i>Due weight to the voice of children/young persons</i>	<ul style="list-style-type: none"> • Strong parental awareness of the concept of giving due weight to the voice of the child; • A policy focus by the main service provider on catering for the voice of the child/young person; • A perception by young persons that their voice on matters that affect them is generally heard 	<ul style="list-style-type: none"> • 'Voice' of children who are in a minority lost in mainstream school system; • Decisions sometimes made by parents and/or professionals without full engagement with child/young person involved; • Parents of children with an intellectual disability reluctant to be seen as 'over-demanding' on schools and support services; • Some schools concerned about being viewed by the community generally as a 'special needs' school; • Absence for the most part of an independent advocate to articulate the voice of children/young persons with severe disabilities and reduced capacity to articulate.
<i>Access to information and advocacy support</i>	<ul style="list-style-type: none"> • Extensive information provided to parents; • Young people perceive themselves as having access to all the information that they need; • Children/young persons have access to a key support worker; • Parents have access to a support worker; 	<ul style="list-style-type: none"> • Some parents not having relevant information at the time that they need it; • Information overload at some transition points rendering it difficult for parents to comprehend; • Focus on sometimes divergent views of parents and service provider staff and little reference to views of child/young person; • Parents having to act as advocates for their child; • Little evidence of children/young persons having access to an independent advocate

in critical decisions affecting his/her own life. This requires that children must be treated as rights-bearing individuals, regardless of their capacity or developmental stage. She states that children's inclusion in decision making plays a crucial role in educating them for independence. Thomas (2010) posits the view, based on his own and other research, that there is little sign of children and young people generally really participating in the processes that actually produce important political decisions, or in contributing to defining the terms of the policy debate despite the fact that so many big current issues in public policy are to do with children and young people, e.g., their education, their leisure and their health and well-being. Thomas's (2010) conclusion is, in the researcher's view, particularly pertinent to children/young persons with an intellectual disability.

Young person interviewees were asked two questions relating to 'voice', i.e., whether they could give their opinion on things and whether they were listened to. All except one stated that they could give their opinion on matters that affected them and that they were listened to 'always' or 'sometimes'. Occasions when they were not listened were identified but these did not present any major difficulty for the young persons. In general, the young persons felt that they were mostly listened to by parents, teachers and other support staff involved with them.

All parents/guardians referred to the fact that their child/young person needed an advocate/support person to help him/her to articulate his/her needs in public forums, particularly in the school setting. Most parents/guardians were of the view that such support was usually available. The SNA was seen as sometimes fulfilling this role in the school setting. The fact that many children/young persons with an intellectual disability tend by nature not to be assertive was seen as pointing to a clear need for them to have an independent advocate to ensure that their voice is heard.

An issue identified by both service provider staff and parents/guardians was, as already stated, that most teachers are not trained to deal with children with diminished cognitive ability in the classroom and, therefore, may not give sufficient cognisance to facilitating the voice of children/young persons with an intellectual disability. This was acknowledged by interviewees involved in the school system. A related perspective from some professionals was that the 'voice' of the minority, individually and collectively, tends to get lost in the mainstream school system.

8.5.2.3 Access to relevant, comprehensible and transparent information and advocacy support

Information is an essential prerequisite for active citizen involvement and access to information is an essential component in accessing the wide and disparate range of Government services and myriad of social provisions. It is now widely accepted that information is an essential prerequisite for active citizen involvement (Cotter et al. 2010). Without good quality, accessible information, it is not possible for citizens to vindicate their

rights. Good quality and easily understood information is necessary to enable people to have control over their lives and to make appropriate choices. It is also recognised that access to information is broader than physical access to buildings, publications and databases, important as these are in themselves (Browne 1999). The concept of information capability has been used (Harris 1992) to focus attention on people's capacity to access and use information. Information provision thus becomes an exchange or an interactive process of development as distinct from a once-off response to a perceived deprivation.

The present study indicates that information is made available to parents/guardians by the service provider at various transition points in the child/young person's life. In the Survey of Parents/Guardians, more than two-thirds of respondents rated the information available at each of four transition points in the child/young person's life as either 'excellent' 'good' or 'adequate' (see Table 6.12). Almost all of the parent/guardian interviewees reported that they got all of the information they needed when they needed it while a minority stated that they were not made aware of what supports the child/young person and family were entitled to at different transition stages. The young persons reported that generally they had access to all the information that they needed and stated that they have access to a key support worker. This positive perception of service provider support co-existed with the proactive and sustained involvement in negotiating access to support services as a feature in the lives of many parents/guardians.

Service provider staff stated that there was a good information flow between the agency and the families using their services. The need to be continuously vigilant about ensuring that not only was information provided but that it was also well understood by families was identified as a key consideration. A point also made by staff was the need to avoid an information overload where people become overwhelmed with information which they are unable to decipher and apply to their own situation.

People with disabilities and their families frequently need advocacy support – a 'champion' who accompanies them through needs assessment and provision to ensure an appropriate service access outcome (Cotter *et al.*) 2010). Flynn (2010) refers to the unique role of advocacy in bridging the gap between traditional models of welfare provision and an emerging paradigm of rights-based legal provision for people with disabilities and its related role as a rights-enforcement mechanism.

Parents/guardians frequently act as advocates for their child/young person at different points of interface with the service delivery system as do key support workers. There was no evidence of children/young persons having access to an independent advocate in their own right, i.e., someone who is not a parent/guardian or a service provider staff member. This is seen by the researcher as a significant deficit, especially in the context of those with reduced capacity to understand what is being discussed and planned and being able to give their consent accordingly.

Summary of section

There appeared to be strong parental awareness of the concept of giving due weight to the voice of the child and this is reflected in the approach of the service provider. There was a perception on the part of young persons that their voice is generally taken into account on matters that affect them. Parents/guardians strive to give their child/young person voice around matters of daily living. On the deficit side, there is a sense that decisions are sometimes made by parents and/or professionals without full engagement with the child/young person involved. The fact of a child/young person being perceived to have reduced capacity and, as a result, a lesser engagement in decision-making than might be the case in relation to children/young persons who do not have an intellectual disability may significantly undermine the concept of 'voice'. The reported absence for the most part of an independent advocate to articulate the voice of children/young persons with severe disabilities and reduced capacity to articulate is seen as a significant deficit in giving due weight to the voice of the child/young person. The impression gleaned by the researcher was that a focus by service provider staff on sometimes divergent views between parents and service provider staff as to what was in the best interest of the child/young person may result in insufficient weight being afforded to the voice of child/young person.

8.6 'Capabilities' and the social supports infrastructure

8.6.1 *Capabilities and children/young persons with an intellectual disability*

The concept of *capabilities* (Nussbaum 2006) builds on the concepts of recognition and voice and includes being able to be treated as a dignified being whose worth is equal to that of others; being able to have attachments and to engage in critical reflection about the planning of one's own life. The concept of capabilities as used in the present context draws on Nussbaum's (2006) capability theory which refers to a number of core capabilities which should be guaranteed by society to each individual. Nussbaum's (2006) capability theory enumerates ten central capabilities that all governments should guarantee all citizens, including those with an intellectual disability. She posits this capability theory as an 'important corrective' to Rawls's Theory of Justice.

While clearly all of Nussbaum's ten capabilities refer to all citizens (see 2.5.2 above), six are identified here as having particular relevance to children/young persons with an intellectual disability in the context of the current research. These are: Capability 4 (being able to use the senses and being able to imagine, to think and to reason and being able to have pleasurable experiences); Capability 5 (being able to have attachments to things and persons outside ourselves and to love those who love and care for us); Capability 6 (being able to form a conception of the good and to engage in critical reflection about the planning of one's own life); Capability 7 (being able to live for and in relation to others and to engage in various forms of social interaction); Capability 9 (being able to laugh, to

play, to enjoy recreational activities); and, finally, Capability 10 (being able to participate effectively in political life and society, being able to hold property and having the right to seek employment on an equal basis with others).

8.6.2 Capabilities: The research findings

Parents gave a score of 3.5 (out of a maximum of 5) and service provider staff interviewees gave a score of 2.5 based on a Likert-type summation rating in respect of their agreement or disagreement with the following rights statement (see 6.1.7 and Figure 6.1 above):

'The State ensures that children/young persons with an intellectual disability are given access to the support they may require in exercising their legal capacity'.

Three dimensions of the social supports infrastructure are identified relating to the concept of 'capabilities': (i) holistic, integrated and inclusive needs assessment; (ii) personal outcomes planning; (iii) envisioning the future. Figure 8.6 outlines the positives and deficits identified in relation to each of these dimensions.

8.6.2.1 Holistic, integrated and inclusive needs assessment

Needs assessment is widely regarded as a core component of an adequate social supports infrastructure (Cotter et al. 2010; and of person-centred planning (O'Brien and O'Brien 2000). There is a strong emphasis in legislation and in policy discourse in Ireland on the importance of needs assessment in relation to the provision of services and supports to persons with disabilities and provision for needs assessment has been made in the Disability Act 2005⁴⁸ (see 4.6.2 above).

Effective citizen participation requires the active involvement of people in shaping and influencing the social policies that affect their lives. However, a distinction needs to be made between user friendly approaches where the user remains external to the service and participatory approaches which imply user involvement in the definition of need and in the planning, management and delivery of services accordingly (O'Mahony-Browne 2002). Factors that come into play in determining how need is defined and understood include need being frequently defined in terms of the predominant social and cultural values of the time and, by the State, in terms of demand for existing services and supports (O'Mahony-Browne 2002).

The practice as reported in the present study is that a needs assessment is carried out for all children/young persons referred to the specialist service provider and that supports were put in place based on such assessments. Almost three-quarters of respondents in the Survey of

⁴⁸While people with disabilities have a legislative right to have a needs assessment carried out and a service statement provided accordingly, this is only currently applied in the case of children below the age of five.

Figure 8.6: Capabilities: Social Support infrastructure positives and deficits identified

Social Support Dimension	Social Support Infrastructure Positives	Social Supports Infrastructure Deficits
<i>Holistic, integrated and inclusive needs assessment</i>	<ul style="list-style-type: none"> • A strong emphasis in policy discourse, by the State and by service provider on the central importance of needs assessment; • Needs assessment carried out for all children/young persons referred to service provider; • Parents consulted by service provider as part of the needs assessment process; • Legal right for each child with a disability under 5 years to have a statutory assessment of need and a service statement accordingly. 	<ul style="list-style-type: none"> • A gap between needs assessment, personal outcome targets and the lived realities of children/young persons with an intellectual disability; • No right in law to have service statement implemented.
<i>Personal outcomes planning</i>	<ul style="list-style-type: none"> • The Personal Outcomes model adopted by the service provider as a central component of service delivery; • Some young people very aware of their Personal Outcomes plan and involved in ongoing reviews; • A Personal Outcomes plan drawn up for each child/young person; • Some involvement of parents in Personal Outcomes planning and monitoring; 	<ul style="list-style-type: none"> • Personal outcomes plan not always commensurate with support services and implementation mechanisms put in place; • Personal Outcomes plan and school-based Individual Education Plan not always fully integrated; • Parents not always fully engaged in developing and implementing the Personal Outcomes plan
<i>Envisioning the future</i>	<ul style="list-style-type: none"> • Envisioning future included as part of the personal outcomes planning; • Young persons having positive aspirations for the future; • Some education programmes around sexuality and relationships • Some supported independent living options 	<ul style="list-style-type: none"> • Lack of opportunities for meaningful social roles; • Education not always sufficiently focused on envisioning a meaningful future for each child/young person; • Few career/work options on leaving second-level education; • Young persons feeling that they may not be able to realise their aspirations; • Parental fear and apprehension about relationships and future living arrangements

Parents/Guardians reported that an assessment of the child/young person's needs had been carried out. Most (86.2%) reported that they were 'very involved' or 'involved' in the needs assessment process. The needs of the family as the primary support provider were reported by service provider staff as being routinely assessed as part of that process. The majority of parents/guardians interviewees stated that no specific assessment of their needs as parents of a child with an intellectual disability was carried out while others felt that it would have been incorporated to some extent in the overall assessment of the child's needs.

While there was an overall perception that the needs of each children/young person were identified in a general way, it is unclear whether this is always done in a coherent, systematic and applied manner. The process was seen by some parents/guardians as being related to some extent on parents/guardians pushing to ensure that all the child's needs were identified and supports put in place accordingly.

The research suggests a gap between needs assessment, personal outcome targets and the lived realities of children/young persons with an intellectual disability. While the needs of children/young persons are identified in terms of developmental goals within a personal outcomes framework, there appears to be less emphasis on assessing and identifying the specific supports and therapies needed to achieve those goals/targets. A key issue is that there is no right in law to have the statutory needs assessment service statement implemented since such a requirement in the legislation is contingent on resource availability.

8.6.2.2 Personal outcomes planning

Needs based person-centred planning and the putting in place of related individual care and support plans was identified as an integral part of the Personal Outcomes model adopted by the case study service provider (see 5.3.3 above). This involves in the first instance an assessment of a child's level of disability and his/her related support needs and putting in place a package of support services accordingly. Secondly, it involves establishing goals for the child/young person – for younger children, this takes cognisance of the parents' aspirations for the child and, as children got older, it takes into account the child/young person's own views and aspirations. McCormack and Farrell (2010) refer to the challenge of moving from a focus on groups of people, to thinking about what each individual wants and trying to respond, which is at the core of the Personal Outcomes model.

Two-thirds of respondents in the Survey of Parents/Guardians stated that an Individual Plan was put in place for their child/young person (see Table 6.8 above). The remainder were unsure or were unaware of a plan having been put in place. Some of the young persons interviewed stated that they had a Personal Outcomes Plan, were aware of its contents and felt that they had a meaningful input into its content. However, some were quite unsure as to whether or not they had a Personal Outcomes Plan.

Service provider staff interviewees universally endorsed the Personal Outcomes model and highlighted the importance of one of its basic tenets – person-centred planning. All staff interviewees referred to the advantages of the Personal Outcomes model and to the fact that progress was being made in implementing it. Some of the challenges faced in implementing the model in a truly meaningful manner were identified, including mainly resource constraints and the absence of implementation structures but, also, barriers arising out an underdeveloped approach to maximising potential and capacity on the part of some parents/guardians and some professionals.

8.6.2.3 *Envisioning the future*

Being able to envision the future is a key component of maximising capability. An image of the future is a vision of things to come which encourages and stimulates creative exploration and self-development. The realisation of the full potential of the human person requires the presence in thought and in action of such an image (Polak 1973). Smyth and McConkey (2003) found that many of the young people with severe learning disabilities in their study were able to articulate their future needs and that parents were, perhaps, less certain, often wanting to support their ambitions but yet afraid that these may not be realisable. Taggart *et al.* (2012) make the point that carers may not make plans as a result of denial about the inevitability of their own mortality and having to come to terms with the fact that they will not be able to provide care indefinitely. McConkey *et al.* (2013) referred to the chasm that existed between children and adult service systems in both health and social services and concluded that creating a clearer pathway for families through the transition to adulthood will require concerted efforts from all partners.

Adult service planners should learn from the new models of family support services that will be required for a future generation of young adults (McConkey *et al.* 2013:12)

Parent/guardian interviewees in the present study universally expressed uncertainty about their child/young person's future with many having significant concerns as to what the future held. Their perception generally was that there is a lack of future planning, particularly for the longer term and that this uncertainty added to their concerns. Not being able to, or not wanting to, look too far ahead because of fear and uncertainty about how the child/young person would cope in the longer term and whether the necessary supports would be in place to meet his/her needs on an ongoing basis were recurring concerns in the lives of parents/guardians. One commonly held view was that it was probably unrealistic to think that anyone would provide the same level and quality of care and attention to the needs of the child/young person in the longer term as that currently provided by parents/guardians. Uncertainty about the future was manifested in parents/guardians concerns about matters such as where the child/long person would live in the longer-term, who would provide for their care and support needs, and who would look out for them. These were all roles that parents/guardians provided at this point in time. In cases where the child/young person had siblings, the consensus view was

that there should not be an expectation that they should take responsibility for looking after their sibling with an intellectual disability in the longer term even if they felt an obligation to do so.

Dealing with the unknown was a central and ongoing concern for parents/guardians. This was their experience from the time the child was diagnosed with an intellectual disability and carried through at different transition points – pre-school, primary school, second-level school and completion of second-level schooling. Parents/guardians acknowledged that there was much about their child's future that they could not anticipate and many stated that they did not plan too far ahead. Preoccupation with the child's future was seen by some as taking the focus of living in and enjoying the present. For some, the primary concern was to get assurance from the service provider about the availability of respite and day support services in the immediate future. Despite their apprehension about the future, some parents/guardians expressed a degree of optimism and all expressed the hope that their child/young person would get the help that s/he needed with learning and life-skills acquisition appropriate to his/her potential. There was a perception among the young persons in the present study of their parents/guardians being somewhat fearful for their well-being if and when they moved out of home and into their own accommodation

On the question of future living arrangements, young person interviewees were asked by the researcher with whom they thought they would like to live in the longer term – with parents, family, with friends, or on their own. Most stated that they would probably want to continue living with family or parents and thought that that they would be able to do this. Living with friends was identified as an option for some and living with a boyfriend/girlfriend was an aspiration for a minority of interviewees. Interviewees who were participating in an independent living project stated that they were happy to be part of this programme but also somewhat apprehensive about living on their own. These findings are broadly similar to those of Smyth and McConkey (2003) who found that the majority of young people envisaged continuing to live with their parents and also reflect the findings of the National Institute for Intellectual Disability (2009) study where most people saw themselves as single, some people hoped for a relationship in the future and some said they were satisfied the way they were.

On the question of sexuality and relationships, reference was made by both parents/guardians and staff to some education programmes being provided around sexuality and relationships specifically geared towards young persons with an intellectual disability. Despite such provision, parents/guardians are somewhat fearful about the young persons embarking on personal and intimate relationships. In some instances, they expressed the hope that their son/daughter would be able to form relationships and be equipped to deal with the challenges of intimate relationships. Two aspects of relationship formation raised issues for some parents/guardians in the present study – (a) how others might perceive

such relationships and (b) the fact some of the children/young persons who were teenagers did not see themselves as having a relationship (boyfriend, girlfriend).

With regard to future work, all of the young persons interviewed expressed a desire to engage in some kind of work and all identified a particular area or areas where they would like to work. This is similar to Smyth and McConkey's (2003) finding that the young people in their study mainly wanted purposeful day-time activities such as paid work. The future work options identified by the young persons in the present study included, in particular, work in beauty and hair salons, working with animals, cooking and farm work. However, it was not at all clear if and how these aspirations could be realised. Some young persons appeared to feel somewhat trapped with the lack of a clear pathway to paid work. While current work placements were generally enjoyed by the young persons, the absence of any clear mechanisms to consolidate such placements in terms of real jobs was a matter of regret for those involved and for their parents/guardians.

A specific question posed by the researcher to the young persons interviewed referred to further education/training options after they finish school or their current training programme. While the idea of 'going to college' had attractions for some, none saw it as a realistic option. Some had identified follow-on courses which they hoped they would be able to get while others had a general idea of courses they would like to do but were not at all sure that this would be possible.

Other future aspirations identified included being able to drive (at the time of interview, some were preparing for their Driving Theory Test), participation in the Special Olympics and joining a drama group. One parent/guardian referred to an aspiration their child had to do something quite different from what was available locally but was unsure as to how this could be realised.

Envisioning the future is included as part of the personal outcomes planning process. All of the young persons consulted have positive aspirations for the future relating to work, social and leisure activities. The reality as reported, however, is that there are few career/work options on leaving second-level education. This makes it difficult for young persons to identify ways of being and engaging in society. The fact that the education system is not always sufficiently focused on envisioning a meaningful future for children/young persons with an intellectual disability is a considerable deficit in the system. This resulted in young persons stating that they may not be able to realise their clear aspirations for their future. It also results in parental fear and apprehension about how their child/young person will negotiate a meaningful and secure life pathway.

Summary of section

There is a strong emphasis on the concept of individual needs assessment and related person-centred planning. All children with a

disability under five years have a legal right to a statutory assessment of need and the provision of a service statement accordingly. The young persons interviewed are aware of their Personal Outcomes plan and some are involved in ongoing reviews. Envisioning the future is part of the Personal Outcomes planning and most of the young person interviewees have positive aspirations for the future. Some specialised education programmes around sexuality and relationships are in place. There are gaps between needs assessment, personal outcome targets, implementation strategies and lived realities. There is no right in law to have a statutory service statement provided implemented. There is a lack of opportunities for meaningful social roles and career paths and the education system does not cater adequately for diversity of learning need. The young person interviewees feel that they may not be able to realise their aspirations. Accreditation systems for non-academic skills and aptitudes are underdeveloped. Parental fear and apprehension about relationships and future living arrangements are very prevalent.

8.7 ‘Equality’ and the social supports infrastructure

8.7.1 *Equality and children/young persons with an intellectual disability*

The concept of *equality* as understood in the present study refers to the notion that all members of a society are equally enabled to maximise their potential. This requires that the general social infrastructure (physical economic, social and cultural) is made accessible to all (United Nations 1982). In the context of children/young persons with an intellectual disability, it means acknowledging that each child/young person has something to contribute to humanity and that the goal of social supports should be to maximise this contribution. Tawney (1964), in his classic discourse on equality (originally published in 1931), noted that the concept of equality may assert that, while people may differ profoundly in capacity, character and intelligence, they are equally entitled as human beings to consideration and respect and that when that happens, the wellbeing of a society is likely to be increased. Quinn and Degener (20002) suggest that equality of opportunity in the context of disability means “acknowledging that every human being has something to contribute to humanity and that social structures should be built inclusively with human empowerment as a key goal” (Quinn and Degener 2002:12). The notion of human rights as equal rights is underpinned by the principles set out in the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations 1993) which emphasised the needs of each and every individual as being of equal importance and the need for choices and appropriate supports to be provided accordingly within the mainstream social supports infrastructure.

Carlson and Kittay (2010) suggest that the history of people with cognitive disabilities is that they have suffered more than most in terms of claims to just treatment. For Valentine (2001), the full implementation of the Convention on the Rights of the Child requires more than formal equality of treatment. “It may also necessitate differential treatment in order to

allow children with disabilities to achieve their full potential” (Valentine 2001:iv).

Power’s (2008) study of carers’ experiences of learning disability services in Ireland found that there was limited flexibility, choice and availability in meeting the preferences of service-users. Services were characterised as “being non-supportive interactions on the ground” (Power 2008:92). Such non-supportive interactions were identified as: (a) a lack of clear engagement with carers or people with disabilities in terms of offering information, advice about available services; and (b) a mismatch between occupational training services and the needs of young adults with an intellectual disability. Power’s (2008) research further referred to carers’ perceptions of services geared towards supporting care in the community being lacking both in availability and quality.

The continual presence of non-supportive interactions, despite increased expenditure in disability service provision, proves that supportive attitudes and flexibility are still crucial in meeting user’s requirements at the level of delivery (Power 2008:97).

Shortfalls in the service delivery system from an equality perspective are reflected in a belief amongst many family carers of people with an intellectual disability in Ireland reported by Chadwick *et al.* (2013) that no one else would fight for supports for them or their families and so they had to do it themselves. “Yet they felt that they shouldn’t have to fight for basic rights for their children: services should be provided based on equity and need” (Chadwick *et al.* 2013:125). These authors also found feelings of being thankful for what you have among the family carers in their study and a belief that one shouldn’t complain which led to some family carers not looking for more supports.

Others didn’t advocate because they feared that fighting for services and complaining about services may lead to service loss or to negative repercussions for their family member. Some focus group participants spoke specifically about older families not wishing to rock the boat having accepted the status quo of service provision as it currently stood (Chadwick *et al.* 2013:125).

8.7.2 Equality: The research findings

Parents/guardians gave a score of 3.4 (out of a maximum of 5) and service provider staff interviewees gave a score of 2.4 based on a Likert-type summation rating in respect of their agreement or disagreement with the following rights statement (see 6.1.7 and Figure 6.1 above):

‘Children/young persons with an intellectual disability enjoy fully all human rights and basic freedoms on an equal basis with other children/young persons’.

These ratings suggest a perception by parents/guardians, and, more strongly, by service provider staff that there are deficits in the application of the equality principle in respect of children/young persons with an intellectual disability.

Three dimensions of the social supports infrastructure are identified relating to the concept of 'equality' – (i) promoting equality of status; (ii) equality of access to social, educational and health services; and (iii) protecting support services for children/young persons with an intellectual disability in a climate of budgetary cutbacks. Figure 8.7 outlines the positives and deficits identified in relation to each of these goals.

8.7.2.1 Promoting equality of status

Ensuring equality of status of all children/young persons emerged as a core concern, in other words, focusing as far as possible on sameness rather than difference. For parents/guardians, this meant treating the child with the intellectual disability in the same way as they did their other children and rearing their child in a manner as close as possible to the rest of their children. This was manifested in the child attending the local school (with additional support) where feasible, being in relatively regular contact with neighbours and the local community and being acknowledged as a valued member of that community. The extent to which equality of status could be realised was perceived to be closely related to the parents' organic links with the local community. It was also associated with the nature of the child/young person's disability in that it was perceived that people generally found it easier to integrate children/young persons with some types of intellectual disability (e.g., those with Down Syndrome) than others into the community. Those whose intellectual disability was manifested in behavioural problems and those who had severe or profound disabilities were less likely to have equality of status in the local community. Community status also seemed to relate to the way parents/guardians themselves approached the situation. In other words, once the family acknowledged and integrated the child's intellectual disability into their own lives without focusing too much on it (something that was acknowledged as being difficult for many parents/guardians), an ethos of social inclusion and community acceptance of the child/young person emerged somewhat spontaneously. This was seen as resulting in the child/young person with an intellectual disability integrating almost seamlessly into the local neighbourhood/community in the same way as children/young persons who did not have an intellectual disability did.

Significant improvements in recent years were noted in respect of equality of status. However, instances were reported where equality of status was not afforded to children/young persons with an intellectual disability. An example of such instances reported was the fact that some stores did not deal directly with young persons with an intellectual disability when they were transacting business and making purchases at the counter, referring instead to an accompanying adult.

Figure 8.7: Equality: Social Support infrastructure positives and deficits identified

<i>Social Support Dimension</i>	<i>Social Supports Infrastructure Positives</i>	<i>Social Supports Infrastructure Deficits</i>
<i>Promote equality of status</i>	<ul style="list-style-type: none"> • Additional income provided by the State to meet the additional costs of child's disability; • Access to mainstream schools provided for some; • Educational supports provided 	<ul style="list-style-type: none"> • Service delivery through specialist rather than mainstream services may contribute to marginalisation; • Parents having to separately apply for additional educational resources for their child; • Underdeveloped accreditation systems for non-academic skills and aptitudes
<i>Equality of access to social, educational and health services</i>	<ul style="list-style-type: none"> • Equality of access to general health services; • Additional assistance provided with transport; • Essential therapies provided to child/young person; • Access to mainstream schools facilitated as far as possible 	<ul style="list-style-type: none"> • Complex and fragmented service delivery system makes it difficult to access the supports required at different transition points; • Parents experiencing continually having to fight for services; • Families having to pay privately for services putting a significant drain on the household budget
<i>Protecting support services in a climate of budgetary cutbacks</i>	<ul style="list-style-type: none"> • Specialist service providers keeping a focus in policy discourse on the particular service and support needs of persons with an intellectual disability; • Lobby groups keeping issue of supports for persons with an intellectual disability on the policy agenda 	<ul style="list-style-type: none"> • Negative impact on children/young persons arising from cutbacks in services arising from budgetary retrenchment; • Parental anxiety and stress arising from uncertainty about the availability of therapies and supports; • Additional pressures on families

Through its income support provisions for families that have a child with an intellectual disability, the State seeks to ensure that such families are not worse off financially than those who do not have a child with an intellectual disability. The provision of additional supports to children/young persons with an intellectual disability to enable them to participate in mainstream education is also identified as promoting equality of status as is the focus on individual planning and the Personal Outcomes approach. A significant negative impact on the promotion of equality of status identified is the fact that service delivery for the most part takes place through specialist rather than generalist services. This almost certainly, in the view of the researcher, contributes to a lessening of status and related marginalisation from mainstream society. While access to mainstream schools is facilitated as far as possible, the fact that a separate application has to be made for additional school supports in order to enable a child with an intellectual disability to attend school undermines the principle of equality of status. Underdeveloped accreditation systems for non-academic skills and aptitudes also negatively affect equality of status.

8.7.2.2 Equality of access to social, educational and health services

Positive experiences in accessing a range of services and supports – a learning support teacher, the Special Needs Assistant, school-age nurse, psychologist, public health nurse, respite care services and GP support – were reported by parent/guardian interviewees. Equality of access to services was perceived as operating in some areas. Children/young persons with an intellectual disability were reported as generally having equality of access to health services, whether routine or specialist. However, there was not equality of access to education. Three main reasons were cited for this: (i) the fact that most teachers were not trained to teach children/young persons with an intellectual disability; (ii) the fact that therapies, such as Speech and Language, were not always available at an optimum level to maximise the child's participation and learning; and (iii) that mainstream school curricula and pedagogy were not always fully inclusive of the learning needs and aspirations of those with an intellectual disability.

The lack of equality generally in society was seen as being reflected in the absence of supports commensurate with ensuring that each child/young person with an intellectual disability can reach his/her full potential. This general lack of equality of access was seen as being exacerbated by the current retrenchment in support services arising from budgetary cutbacks. Having to prioritise services to those deemed to be most in need was seen as inevitably impacting on those deemed to be 'less in need' but who may in reality need the supports to have a reasonable quality of life and/or to maximise potential for agency and development of capability and, as such, to have equality of opportunity. The experience of parents/guardians of having to be ever-vigilant in ensuring that services and supports were provided and maintained at a level commensurate with their child's needs can be said to be a significant undermining of the equality principle.

Referral of the child/young person to the specialist service provider (where the case study took place) facilitated access to services. However, waiting times for some essential therapies, additional costs incurred by the family in respect of attending services and appointments and having to pay privately for services not available through the specialist service provider, e.g., counselling, all impacted negatively on the equality of access principle. While services available from the specialist agency were generally regarded as of good quality, there were difficulties in maintaining consistency of provision as children grew older and, indeed, as expectations expanded. A specific aspect of the services/supports system identified as impacting on equality of access arose from a perceived pressure to exaggerate the child's additional care needs in application documentation in order to enhance the chances of the child getting a support deemed essential, for example, to enable the child to attend a mainstream school. Such practice, while perhaps understandable, demonstrates not only a lack of equality of access but, also, and more importantly, an unnecessary assignment of some children to a marginalised identity group. This is a crucial consideration from an equality perspective.

Another factor impacting negatively on equality of access identified was the difficulty arising from a logistical requirement to have two adults present when involving some children/young persons in social activities and/or family outings. This not only presented challenges for the families involved but also inevitably resulted in a lessening of involvement in such social activities. The obvious resource implications of providing such support were acknowledged by both parents/guardians and service provider staff. Specialised equipment which some children/young persons with an intellectual disability required to enhance their communication and functioning was reported as difficult to access because of cost factors. A general accessibility issue for children/young persons with an intellectual disability with mobility problems identified was the fact that some facilities are not fully wheelchair accessible and/or amenable to use by a child/young person who has mobility or posture difficulties.

Finding the 'right' school, as already stated, sometimes presented difficulties. This was related to the child's learning needs, distance from specialised educational services, the shortage of resources and a perceived low level of interest by some schools in accommodating children/young persons with an intellectual disability. Finding the 'right' school was frequently particularly problematic at second-level stage.

The actual pathway to support services is a key indicator of the equality of access principle. The reality as reported was that the pathways to support services were at times difficult for families. This was particularly the case in respect of school-related supports, in particular, Special Needs Assistants (SNAs). The stress that negotiating the pathways to support services put on parents/guardians is fundamentally at variance with the equality of access principle. A related point is that some children/young

persons may lose out on support services because the parents/guardians lack the assertiveness and tenacity of other parents/guardians.

8.7.2.3 Protecting support services for children/young persons with an intellectual disability in a climate of budgetary cutbacks

Resource constraints generally and, specifically, budget cutbacks in recent years have the effect of undermining the equality principle. This arises for three reasons. Firstly, cutbacks to essential supports and therapies put children/young persons who require such services at a further disadvantage. Secondly, the additional efforts required by parents/guardians to ensure that support services are provided and/or maintained at a level commensurate with need adds to their experience of difference. Thirdly, having to engage with service providers in this way was reported as causing additional stress in the lives of families over and above the normal stress of daily caring and supporting. While budgetary constraints are clearly a general difficulty for government and while support services such as outreach and respite care are resource intensive, the vital role of such services in enabling the family to cope and in enabling the child/young person to continue to have as full a life as possible and to continue to expand his/her horizons are perhaps more important considerations from an equality perspective.

The backdrop of budgetary cutbacks in the current economic climate clearly shaped the perceptions of parents/guardians, service provider staff and other professionals consulted. Reduction in staff numbers impact on the provision of support services and therapies to optimum effect. The overall view was that additional resources (rather than less) were required across the board in order to ensure equality of access.

There was some consensus that services and supports for children/young persons with an intellectual disability may be spared from the worst effects of current budgetary cutbacks. This view was associated with a sense of their being some level of political sensitivity about appearing to cut services to the 'most vulnerable' as well as significant lobbying of Government by advocacy and support groups. However, the reality as reported was that non-recruitment of staff, even over a short period, will have an incremental negative impact on service availability. McConkey *et al.* (2013) referred to the issue of resource availability during times of austerity and concluded that the failure to provide adequate resources "may result in a much higher cost in the longer term" (McConkey *et al.* 2013:12).

Uncertainty about service availability results in additional parental anxiety and stress. The potential negative impact on the equality principle as it applies to children/young persons with an intellectual disability arising from cutbacks in services is a major concern for parents/guardians, agency staff and other service delivery personnel.

Summary of section

A perception of there being equality of access to general health services by children/young persons with an intellectual disability was reflected in the Case Study data. Where health inequalities exist, these are deemed to relate to factors that affect all children and families, e.g. geographical location and whether, or not the family has private health insurance. It was noted that some of the potential barriers to inequality are lessened through the provision of additional income supports as referred to above, the provision of medical cards and the provision of assistance with transport to and from schools. The provision of therapies is also seen as enhancing equality of access. On the deficit side, the complex and fragmented service delivery system that exists in Ireland makes it difficult for children/young persons with an intellectual disability to access the supports required at different transition points in their lives. Having to pay privately for services that might be reasonably expected from the State puts a significant drain on the household budget of some families. The experience of some parents/guardians of having continually to 'fight' for services and supports for their child/young person is clearly at odds with the equality principle.

8.8 'Self-realisation' and the social supports infrastructure

8.8.1 *Self-realisation and children/young persons with an intellectual disability*

Related to capabilities (discussed in 8.6 above), *self-realisation* refers to the development of the human person in all his/her dimensions. Self-realisation involves an understanding of life as involving the harmonious development of the person both as an individual and as a member of the wider collective. It rejects a view of the human person as static or one-dimensional. Central to the concept of self-realisation is people coming to think of themselves as unique individuals with chosen rather than prescribed or standard identities (Markley and Harman 1982). For Prout (2006) modernity embraces the notion of self-realisation by which people can shape their own lives through the formation and exercise of self-consciousness, creativity and agency. Prout (2006) argues for a stronger focus on the present well-being of children in order to ensure their participation in social life and to provide opportunities for human self-realisation. This raises a key question about how the components of self-realisation are to be fulfilled for children/young persons with an intellectual disability who frequently need more involvement by public institutions in their socialisation and development than that required by other children/young persons. It also raises important and interesting questions about how formal family support interventions might be conceptualised to enhance the concept of self-realisation for children/young persons with an intellectual disability.

8.8.2 Self-realisation: The research findings

Parents gave a score of 3.4 (out of a maximum of 5) and service provider staff interviewees gave a score of 2.7 based on a Likert-type summation rating in respect of their agreement or disagreement with the following rights statement (see 6.1.7 and Figure 6.1 above):

'Children/young persons with an intellectual disability are provided with equal opportunities for cultural, recreational and leisure activity'.

Four dimensions of the social supports infrastructure are identified relating to the concept of 'self-realisation': (i) positive engagement of children/young persons with their current situation; (ii) expanding the boundaries for children/young persons; (iii) the special group identity requirement; and (iv) maximising individual potential. Figure 8.8 outlines the positives and deficits identified in relation to each of these goals.

8.8.2.1 Positive engagement by children/young persons with an intellectual disability with their current situation

All of the young persons interviewed (7 in a training/employment support programme and 4 in school) stated that they had some good things in their lives at present. In particular, their music, time with their friends and home life were stated as positive experiences. All except one reported that they were happy with their current situation (school or training programme). The young person interviewees reported being involved to varying degrees in a range of activities and hobbies. Music was a strong component in the lives of all and some reported having multiple hobbies. Pets/animals were a feature in many of their lives and some reported an interest in cooking.

Getting out more both during the week and at week-ends was an aspiration for most of the young persons. In this regard, some parents/guardians were somewhat apprehensive about encouraging the young person to become more actively involved in social activities on the basis that his/her vulnerability would be exploited by others. Others referred to a reluctance by the young person to engage in activities that the parent/guardian considered should be part of the learning and growing up process, e.g., going to discos. The contemporary social context for young persons was seen as presenting additional challenges for those with an intellectual disability. In particular, the pressure to succeed and to conform and the dangers of a permissive alcohol and drugs culture were cited.

The fact that their child/young person lived at home in a familiar and supportive family environment where his/her care and support needs were met and where there the parent was there to negotiate access to the support services and therapies that the child/young person needed was a significant re-assuring factor for parents/guardians.

The young persons consulted mostly had a positive view of their current situation. All reported a positive and affirming family environment. Good

friendship networks were a feature in the lives of some. However, there were some who have weak friendship networks. Based on the perceptions of the young person interviewees and that of parents/guardians and service provider staff, local community/neighbourhood integration is weak for some children/young persons with an intellectual disability. Some of this disconnect can be related to the personal characteristics of the individual child/young person and to the fact that some families do not have strong local community or neighbourhood connections. Some of it also relates to the absence of meaningful opportunities for local community engagement by children/young persons with an intellectual disability.

8.8.2.2 *Expanding the boundaries for children/young persons*

Gillan and Coughlan (2010), in their study of parents' perspectives on the transition from special education into post-school services for young adults with intellectual disability, found that there were considerable gaps between policy and service provision in Ireland regarding transition planning and post-school services for this group of people. Barriers to successful transition identified included a lack of information about available options; a lack of meaningful alternatives to the specialist vocational training provider; waiting lists for available services; lack of person-centred practices in vocational training services and a lack of co-ordination between child and adult services (Gillan and Coughlan 2010).

The young persons in the present study were asked about their plans and hopes for the future in respect of life generally, the work they would like to do and with whom they would like to live in the longer-term. They were also asked whether or not they thought they would be able to achieve what they wanted.

Most indicated that they would like to be involved in other areas of activity that they are not involved in at present – this referred primarily to going out more, including in particular, going to discos. In general, the young persons stated that they would like to have a job that they get paid for. Most would like to have more friends and most wanted to have a boyfriend/girlfriend but were quite unsure as to whether or not they would be able to realise this. A common theme in parent/guardian interviews was a fear of 'letting go' in relation to their teenage child with an intellectual disability.

The Personal Outcomes approach focuses attention on the putting in place of appropriate goals and on the related exploration of different possibilities for the child/young person taking cognisance of an emerging understanding of the need to ensure that people with an intellectual disability are not limited to living within the confined physical, emotional and intellectual spaces traditionally assigned to this group (Hall 2005). Thus, the concept of expanding the boundaries is an underlying aspect of individual and personal planning and some training programmes. It is also reflected in an initiative where the main service provider is a partner aimed at developing options for independent living in the community.

Figure 8.8: Self-realisation: Social support infrastructure strengths and deficits identified

Social Support Dimension	Social Supports Infrastructure Positives	Social Supports Infrastructure Deficits
<i>Positive engagement by children/young persons with current situation</i>	<ul style="list-style-type: none"> • Young persons consulted mostly had a positive view of their current 	<ul style="list-style-type: none"> • An absence of a clear image of the future relating to children/young persons with an intellectual disability; • Implementation mechanisms to achieve some of the young persons' hopes and aspirations lacking; • Few progression options after second level education
<i>Expanding the boundaries</i>	<ul style="list-style-type: none"> • Additional options for independent living being developed; • Some mainstream voluntary community involvement by young people; • Some skills training ongoing; • Some options for third-level education developed 	<ul style="list-style-type: none"> • Parents' apprehension about their child in the future; • Limited options for post second-level education • Limited outlets for expression of positive aspects of the lives of children/young persons with an intellectual disability; • Parents fear of risk-taking in respect of the child/young person
<i>The special group identity requirement</i>	<ul style="list-style-type: none"> • Young persons feel that they have the support that they need; • Service provider has an ethos of person-centred planning; • The Personal Outcomes model used focuses on individual choice and goal-setting accordingly 	<ul style="list-style-type: none"> • The 'intellectual disability' label masks the individuality and uniqueness of each child/young person; • Separatist model of provision highlights difference; • The development potential of a child/young person might not be fully realised in the broader society if s/he has a 'special needs' identity
<i>Maximising individual potential</i>	<ul style="list-style-type: none"> • An underlying policy principle of the specialist service provider • Included as part of the Personal Outcomes discourse and planning • Young persons in after-school programmes pursuing specific learning goals 	<ul style="list-style-type: none"> • Underdeveloped public perceptions of the capabilities of children/young persons ; • Parents setting somewhat limited goals ; • Divergence of views between service provider staff and parents as to the options to be pursued ; • Schools not resourced to work in a sustained and fully developmental way with individual children; • Limited outlets for individuals to explore their potential

While there is some mainstream local community involvement by young persons on a voluntary basis, this does not extend to those with poorly developed social skills and/or significantly reduced capacity. The concept of 'pushing out the boundaries', while a central aspect of the 'new' discourse around the social integration and support of people with an intellectual disability, is inhibited by the continuing absence of a clear social role for people with an intellectual disability who do not fit conventional and normative patterns of economical productive work or socially useful engagement.

While there are some options for third-level education and some ongoing training initiatives in place, the overall picture is that there are few meaningful progression options after second level education for most young persons with an intellectual disability. This deficit is further manifested to some extent in the lack of effective implementation mechanisms to achieve some of hopes and aspirations of the young persons and only limited outlets for expression of positive aspects of their lives, e.g., music, dance, visual art, craft work and interest in animals. Not surprisingly, perhaps, parents/guardians have high levels of apprehension about their child's future role and place in society. There is also a significant fear on the part of many parents/guardians in relation to pushing out boundaries that entail any aspect of risk-taking.

8.8.2.3 The special group identity requirement

Both Fineman (2008) and Satz (2008) argue that assigning special identity status to people with disabilities undermines the equality principle. Challenges to the identity group concept have also been posited by Gatens (2004); James (2003); and Fraser (2003). A question relating to the special group identity concept identified by the researcher and included in the research was whether and how the children/young persons being assigned to a specific identity group relating to their intellectual disability impacted on their well-being.

The more inclusive terminology that has emerged in recent years associated with the social model of disability and a rights-based perspective was regarded overall by parents/guardians, staff and other professionals as a positive development. However, occasional reference to usage of terms such as 'retarded' and 'handicapped' by some people were reported by parents/guardians. Concern about the impact of labels such as 'intellectual disability', 'learning disability', 'autism spectrum' or, indeed, the label attached to attending a 'special' school, and/or going to respite care was expressed by some parents/guardians. On the question of whether there should be any label, some parents/guardians stated that they were happy with the term 'special needs' while others favoured 'additional needs'. The point made in this regard was that the children clearly had special or additional needs which had to be acknowledged and addressed. However, there was also an awareness that, while the label 'special needs child' or 'a child with additional needs' might be a positive thing for some, it might have negative connotations for others. Labels such as 'intellectual disability', 'autism spectrum' were regarded by some

parents/guardians as not helpful in that they tended to mask the individuality and uniqueness of each child. While children/young persons were perceived as receiving relatively good support from the specialist service provider, some concern was expressed about the impact of this separatist model of provision. For example, the development potential of a child might not be fully realised in the broader society if s/he had a specific group identity associated with 'special' services, 'special' identity and 'special' needs. The young persons attending work/training programmes for the most part expressed satisfaction with the programme. The young person interviewees attending mainstream schools stated that they did not talk to their friends and classmates about the additional support that they received from the specialist provider. This, for the researcher, suggests a desire on their part not to appear as different and/or to be labelled as 'special' by their peers.

8.8.2.4 Maximising individual potential

An underlying policy principle of disability support services is the maximisation of individual potential and this is a central component of the Personal Outcomes discourse and planning. It is also reflected in specific learning programmes being put in place in schools for some children/young persons.

The dominant view of parent/guardian interviewees was that the potential of their child/young person was being maximised. Some noted that, while it might not be obvious to an outsider, their child/young person was achieving significantly relative to his/her ability. However, despite the embedded aspirations relating to maximising potential, the reality as identified was that it was extremely difficult in the mainstream school setting to maximise individual potential for children/young persons with an intellectual disability, particularly those within the moderate to severe disability spectrum who required a sustained and extensive engagement in relation to developing their communication skills and enhancing their capacity accordingly. A key factor here is the dominant emphasis in mainstream schools on academic achievement and passing exams coupled with the absence of meaningful career or social inclusion paths/options on finishing school. The lack of adequate second level provision for those attending autism specific units at primary level was also identified as an issue.

Summary of section

The underdeveloped perceptions in society generally of the capabilities of people with an intellectual disability may contribute to an under-identification of individual potential and the promotion of self-realisation accordingly. As a result, parents/guardians, schools and young people themselves may set somewhat limited goals. A key deficit identified in relation to self-realisation, and one that is seen by the researcher as centrally important, is the fact that mainstream schools at both primary and second-level are not resourced to work in a sustained and fully developmental way with individual children with significant learning

disabilities and that, consequently, options for pursuing more realistic and meaningful learning goals for the child at critical junctures and for promoting self-realisation accordingly remain underdeveloped.

Summary of Part One

Part One of the chapter has examined the main research findings as these relate to the research aim and related research objectives. The analysis is based on the perspectives (separately articulated) of a sample of parents/guardians, a sample of young persons (aged over 16), of a sample of service provider staff and selected other professionals. Using the case study data, the positives and deficits of the social support infrastructure have been identified on the basis of seven components of a rights paradigm deemed by the researcher to be applicable to children/young persons with an intellectual disability.

The principle that children with disabilities are best cared for and nurtured within their own family environment (United Nations 2007) underpins the concept of maximising the family's coping and support capacity so as to enhance the child's care, development and social integration. The analysis in this chapter, while distinguishing as far as possible between the supports provided to the child/young person and that which aims to enhance the support role of the family, has regarded both dimensions of support as interlinked and complementary. The linkages between enhancing the family support role as a way of supporting the individual child and providing direct supports to the child/young person are related to the notion that support is most effective when it comes from those with whom we share close emotional bonds (Cutrona 2000).

The social support infrastructure when assessed against the components of a rights paradigm reflects a complex discourse permeated to some extent by a rights ethos. This is manifested in the way services are delivered, the focus on integrated education, the emphasis on enhancing the coping capacity of families and a concern with maximising individual potential. The use of the Personal Outcomes model provides a valuable framework within which the rights approach can be developed and monitored. The fact that the social supports infrastructure, while reflecting to some extent a rights approach, is not explicitly underpinned by rights principles emerged as an important factor which will be explored further in the next section of this chapter.

Part Two: Evidence of a rights paradigm in the social supports infrastructure

The previous section has discussed the positives and deficits of the social support infrastructure when assessed against seven components of a rights paradigm. This section addresses the research question relating to whether or not there is evidence of a rights paradigm in the social supports infrastructure as it applies to children/young persons with an intellectual disability.

8.9 The social supports infrastructure: The rights components reflected

The case study data point to the social supports infrastructure developed around children/young persons with an intellectual disability as reflecting some positive aspects in relation to each of the seven components of a rights paradigm as identified by the researcher but also, and, very significantly, substantial deficits in respect of each component (see Figure 8.9).

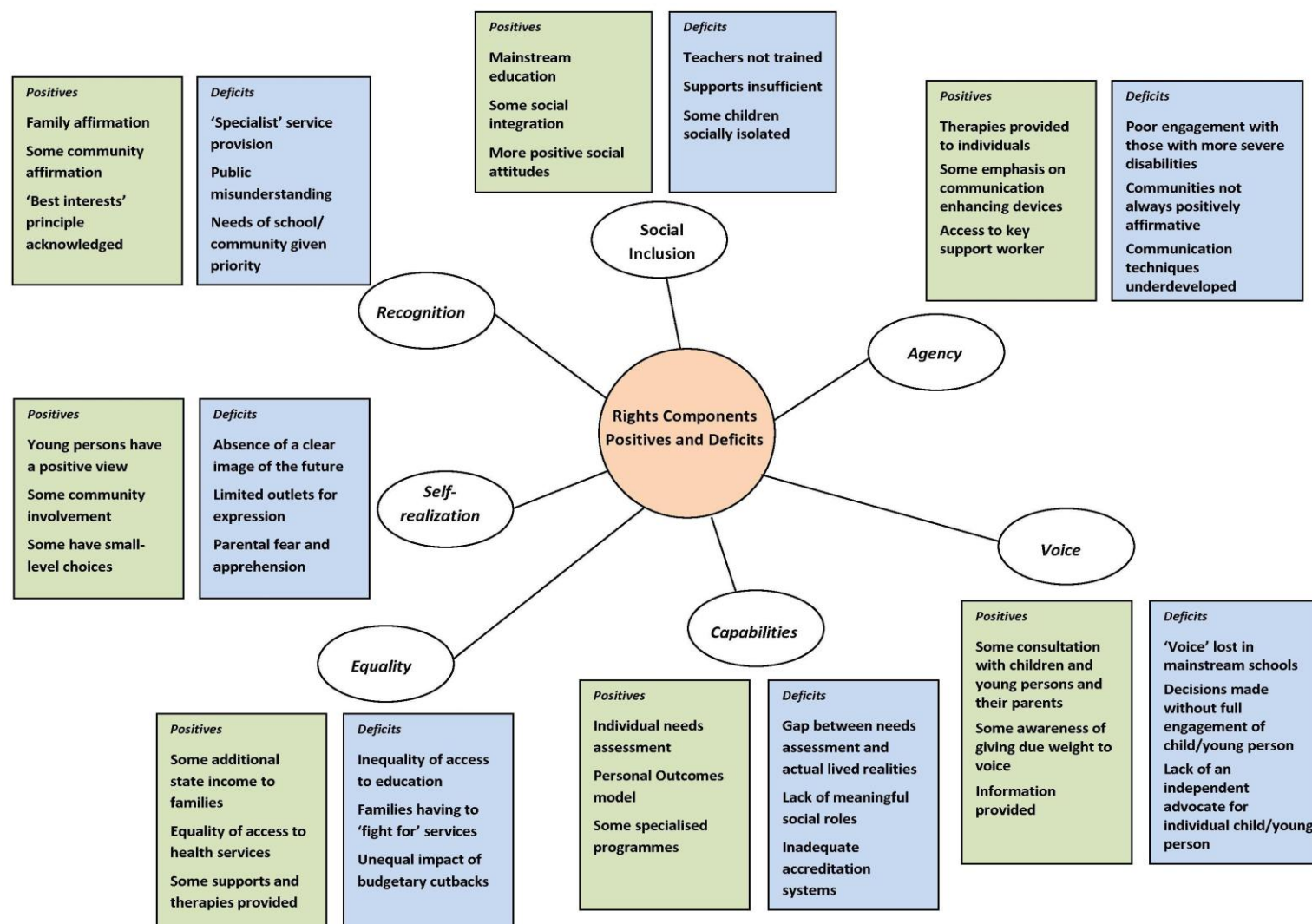
8.9.1 *Social inclusion*

Four social support goals were identified by the researcher as relevant to the rights component 'social inclusion' – integrated education; family support, community/neighbourhood integration and peer/friendship networks.

The principle of integrated (mainstream) education for children/ young persons with an intellectual disability is generally applied and children are placed in mainstream schools where appropriate and feasible. A minority of children are placed in special schools where this is deemed by parents/guardians and professionals as the most appropriate way of providing for their individual learning needs and in the best interests of the child. Despite integrated (mainstream) education being a key underlying policy principle, as it currently operates, it falls short across four key dimensions – resources, teacher training, inclusive curriculum, and meaningful further education/training and career paths and life choices on completion of second level education.

While some additional resources and supports are in place in mainstream schools, these do not appear to be commensurate with need and thus fall short in terms of maximising participation and inclusion. This, in the view of the researcher, is indicative of a conflict between providing an inclusive curriculum and pedagogy that meets the additional needs of children/young persons with an intellectual disability and allocating resources accordingly and providing the more academic learning environment required by most. While this dilemma is one that is not easily resolved, the sense is that any further reductions in funding for resource teachers, therapies and specialised equipment would make it extremely difficult for mainstream schools to deliver even a minimum level of

Figure 8.9: Synthesis of research findings: positives and deficits in the social supports infrastructure from a rights perspective



integrated education. Most teachers in mainstream schools are not trained to deal with children with an intellectual disability. The primary academic focus, particularly in second-level schools, is not appropriate for some children and more inclusive educational and curricular models are underdeveloped. There is a shortage of appropriate further education/career options and paths for young people with an intellectual disability on completion of second-level education.

Good local community/neighbourhood integration is reported by some families and consequently by their children. There are some innovative programmes in stimulating local community involvement by young persons with an intellectual disability and some children/young persons have good friendship networks. In contrast, some families are poorly integrated into their local community, some children/young persons are socially isolated and some have no peer/friendship networks outside of their school or training programme. There is poor provision by mainstream sports and cultural activities and underdeveloped organic peer/friendship networks.

Family support is promoted as a key policy component in respect of services for children/young persons with an intellectual disability and is a key underlying component of current children's policy in Ireland (Department of Health and Children 2007). The findings of this research, indicate that the family support structures in place may not give sufficient cognisance to the different coping capacities of individual families and related support needs. The potential support role of extended families is underdeveloped. A key question arises as to whether or not the separate (not mainstream) support for families of children with an intellectual disability enhances the concept of social inclusion. The separatist provision focuses attention on difference and, while this may have the effect of targeting support services at a particular group (children/young persons with an intellectual disability and their families) and appear beneficial in the short-term, it may also, in the view of the researcher, serve to reinforce difference and social exclusion.

There is a policy focus on greater local community/neighbourhood participation by children/young persons with an intellectual disability. Some families are well integrated into their local community/neighbourhood. A minority of children/young persons with an intellectual disability have good local community/neighbourhood connections. There are some innovative programmes aimed at stimulating local community involvement by young persons with an intellectual disability. In spite of the attention to community participation of children/young persons with an intellectual disability in policy discourse, the actual experience of belonging by children/young persons with an intellectual disability in mainstream community life (including in recreation and leisure activities, sports, arts and culture) is underdeveloped. Some children/young persons with an intellectual disability are socially isolated in their own community. The separatist provision for sports and cultural activities (e.g., Special Olympics), while widely welcomed as affirmative of

individuals, may run counter to the concept of mainstreaming and social inclusion.

Some children/young persons have good friendship and peer networks (as reported by themselves and by their parents/guardians) and some of the parents/guardians themselves have good friendship networks. While there are some initiatives in place to enhance peer/friendship networks for young persons, there are some who do not have peer/friendship networks outside of their school or training programme. This suggests an underdevelopment of organic peer/friendship networks for this group of children/young persons. A key point that emerged from the case study is that friendships involving children/young persons with an intellectual disability were perceived as lessening and dissipating as children grow older.

The picture that emerges is a dualistic one. While there is provision (sometimes considerable) in the social supports infrastructure relating to social inclusion, there are significant deficits in the continuum. This picture also emerges from the results of the Likert-type scale presented in relation to social inclusion referred to in Section 8.2.2 above.

8.9.2 Recognition

Four social support goals were identified by the researcher as relevant to the rights component 'recognition' – inclusive social attitudes; family and social integration of child/young person; provision for the additional support needs of families; and promoting the best interests of the child

While attitudes to children/young persons with an intellectual disability are regarded as generally positive, there is a perception that this exists side by side with a residue of traditional misconceptions and ignorance which, while having lessened significantly in recent decades, still permeate the way people with an intellectual disability are understood. While concepts such as equality, dignity, choice and social solidarity are dominant in the policy discourse, this does not always translate into commensurate actions that enhance recognition. The terminology used ('disability'; 'additional needs') and the need for children/young persons with an intellectual disability to be assigned a 'special' group/category status may undermine the core of recognition which is the esteem one holds based on the respect that is afforded by others.

There is a picture of positive and inclusive integration by families of children/young persons with an intellectual disability and strong parental and sibling support is a significant factor. Families make significant adjustments to their daily living arrangements in order to facilitate the specific needs of the child/young person with an intellectual disability. On the deficit side, some parents/guardians reported feeling alone and isolated in providing for the sometimes significant care, support and attention needs of their child/young person. The challenging behaviour of some children/young persons presents additional difficulties for some families.

On the matter of the provision of additional supports to families to help them to meet the additional needs of a child with an intellectual disability, parents/guardians value highly supports such as respite care and outreach support, the professional support personnel working with families in developing inclusive ways of responding to the child's needs and the provision of therapies (speech and language therapy, physiotherapy, occupational therapy and behaviour support therapy) to enhance the functional ability of the child. An underlying concern reported by all parents/guardians was their need to be continuously vigilant in providing for the care and support needs of their child/young person and in ensuring that s/he gets the supports and services needed.

There is a general consensus that the 'best interests of the child' principle is acknowledged with, for example, families putting immense effort into seeking and finding the 'right' school for their child. While the importance of the 'best interests of the child' principle is widely acknowledged, there are situations in the household, school and community contexts where it cannot be implemented because of priority of other factors, including the needs of other children/young persons and barriers created by social attitudes and exclusionary institutional and cultural practices

There are clearly some aspects of the social supports infrastructure that promote the concept of recognition. Such provision exists side by side with significant deficits. This picture also emerges from the results of the Likert-type scale in relation to recognition referred to in 8.3.2 above.

8.9.3 Agency

Four social support goals were identified by the researcher as relevant to the rights component 'agency' – affirmative support for the child/young person; effective and meaningful communication; optimising self-management of their own affairs; and access to therapies as required.

Parents/guardians affirm their child in all the domains of living and there is positive affirmation of the child/young person by his/her siblings. There is some affirmation of children/young persons with an intellectual disability within the school system and some have positive affirmation in their local community. However, there is an underdeveloped engagement with children/young persons with more severe disabilities. Also, affirmation is not always inclusive of the child/young person's interests and aptitudes and the response of local communities, while not perceived as negative, is not always positively affirmative.

There is a policy emphasis on enhancing communication for each individual child and some assistive communications technology is made available. Access by young persons to a key support worker is seen as helping to enhance individual agency. Optimising self-management is included as part of Personal Outcomes planning. Communication techniques for children/young persons who cannot verbalise are underdeveloped and schools may not have (due to resource constraints)

the facilities required to support and enhance communication by children with complex communication difficulties.

The mainstream school environment is not sufficiently inclusive of children/young persons with very different and specific learning needs. While there is a clear policy emphasis underpinned by the UN Conventions on enhancing communication for each individual child and on the use of assistive communications technology to achieve this, the nature and level of engagement with children/young persons with a more severe intellectual disability suggests a significant deficit in this area. In other words, it may be the case that some individuals who appear to have reduced capacity and/or cannot verbalise are not afforded maximum support in terms of techniques and technologies that would optimise their communication capacity.

Overall, the data suggests that goals may not always be sufficiently developmental or innovative in terms of self-management. This is related to fear of risk-taking on the part of some parents/guardians, underdeveloped support mechanisms for those with more severe disabilities and the absence of a targeted school curriculum and pedagogy to achieve such goals.

Access to a range of therapies on the basis of assessed needs is set out as the guiding principle of service delivery and therapies are provided on the basis of assessed needs governed by resource availability with resultant necessary rationing. Parents/guardians reported having to 'fight for' what they perceived as essential therapies, e.g., speech and language. There was a perception that parents/guardians who are assertive in their demands were likely to get priority in the allocation of rationed therapies. The view of the researcher is that any allocation of therapies by the service provider based on sustained advocacy by parents/guardians as distinct from prioritisation of needs undermines the concept of enhancing personal agency and, while understandable, is clearly at odds with both the best interests of each child principle and the rights of individual children/young persons.

The current social supports infrastructure to some extent promotes the concept of agency. However, agency is also largely underdeveloped, particularly for those with more severe disabilities. This picture also emerges from the results of the Likert-type scale in relation to agency referred to in 8.4.2 above.

8.9.4 Voice

Three social support goals were identified by the researcher as relevant to the rights component 'voice' – provision as appropriate for choice by children/young persons; due weight to the voice of children/young persons; and access to information and advocacy support.

Consultation with children/young persons is part of the needs assessment and goal-setting process involved in the Personal Outcomes model as is

consultation with parents/guardians. There is some consultation with individual children/young persons in the implementation of school-based and other support programmes. Parents/guardians work towards providing realistic and meaningful choices around daily routines. The young persons interviewed mostly stated that they have the same choices as other young people of their own age – a small number stated that they do not. Many parents/guardians engage in sustained efforts in order to provide realistic and meaningful choices to their child/young person around daily routines.

There is some parental awareness of the concept of giving due weight to the voice of the child and a policy focus by the main service provider on facilitating the voice of the child/young person. There is a perception by young persons that their voice on matters that affect them is generally heard. There are some limitations in the way the concept of 'voice' is applied. Decisions appear to be sometimes made by parents/guardians (in conjunction with service provider staff and/or or professionals) without full engagement (appropriate to age and/or capacity) with the child/young person involved. The 'voice' of children who are in a minority is frequently lost in the mainstream school system. The absence for the most part of an independent advocate (other than a parent or a member of the specialist service provider staff) to articulate the voice of children/young persons undermines the concept of 'voice'.

The availability of appropriate information at various transition points in the child/young person's life (at initial diagnosis, at school-going stage, at second level school stage and on completion of second-level education) to enable informed decision-making is acknowledged. The young persons interviewed perceived themselves as mostly having access to all the information that they need and having access to a key support worker as do parents/guardians. Some gaps in the information provision continuum were reported.

Under the current model of service delivery, there are few meaningful options to exercise 'voice' in respect of the services and supports required and available to children/young persons with an intellectual disability. At a very basic level, there is an absence of choice of service provider since there is only one specialist service provider in the area. All state funding for services and supports to people with an intellectual disability are channelled through that service provider. There is also a limited choice in respect of therapists and support workers. Parents/guardians frequently have to act as advocates for their child/young person in order to get supports. While, as already stated, there is a strong sense of parents/guardians acting in the best interests of their child, there is also the possibility that in the absence of an independent advocate, the perspective of the child/young person is not given due cognisance.

While parents/guardians are generally satisfied with the supports available to their children and themselves, it can be reasonably suggested that since this is the only option available they have to work with it. Some parents/guardians refer to their reluctance to appear to be 'always

complaining' about services or to be making what might be perceived as excessive demands.

While this is clearly a complex area of discussion and debate, the conclusion reached by the researcher is that the fact of a child/young person having an intellectual disability may result in less deference being afforded to his/her voice than would happen in the case of a child/young person who did not have an intellectual disability.

The rights component 'voice' is reflected to some extent in the current social supports infrastructure. However, it falls short on a number of fronts, particularly in relation to the availability of meaningful choices. This picture also emerges from the results of the Likert-type scale in relation to voice referred to in 8.5.2 above.

8.9.5 Capabilities

Three social support goals were identified by the researcher as relevant to the rights component 'capabilities' – holistic, integrated and inclusive needs assessment; personal outcomes planning; and envisioning the future.

There is a strong emphasis on the concept of individual needs assessment and related person-centred planning. All children with a disability under five years have a legal right to a statutory assessment of need and the provision of a service statement accordingly. The young persons interviewed are aware of their Personal Outcomes plan and some are involved in ongoing reviews. There are gaps between needs assessment, personal outcome targets, implementation strategies and lived realities. There is no right in law to have a statutory service statement provided implemented.

The Personal Outcomes model is adopted by the service provider as a central component of service delivery and a Personal Outcomes plan is drawn up for each child/young person. The support services and implementation mechanisms put in place, however, may not always be commensurate with the Personal Outcomes plan.

While envisioning the future is included as part of the Personal Outcomes planning process and young persons have positive aspirations for the future, these are hampered by weak implementation structures and lack of opportunities for meaningful social roles. Since the school system is not always sufficiently focused on envisioning a meaningful future for each child/young person with an intellectual disability and since there are few career/work options on leaving second-level education, young persons may not be able to realise their aspirations. Parental fear and apprehension about future living arrangements and the challenges of intimate relationships are also key factors.

There is an absence of a clear image of the future relating to children/young persons with an intellectual disability and this almost

certainly contributes to parents' apprehension about the future. There are limited outlets for expression of positive aspects of their lives, e.g., artistic expression; music/dance; alternative educational curricula and appropriate accreditation. Also, the sense of belonging by young persons which is an integral part of community and social integration and solidarity remains underdeveloped. This makes it difficult for the young persons to envision a meaningful future.

Provision is made in the current social supports infrastructure for the development of capabilities. However, capability development across a continuum of life domains is hampered by limited outlets for engagement and expression, in particular for those with more severe disabilities and those who have weak social and friendship networks. This picture also emerges from the results of the Likert-type scales presented in relation to capabilities referred to in 8.6.2 above.

8.9.6 *Equality*

Four social support goals were identified by the researcher as relevant to the rights component 'equality' – promoting equality of status; equality of access to social, educational and health services; and protecting support services to children/young persons with an intellectual disability in a climate of budgetary cutbacks.

Where a child is assessed as requiring significant additional care, some additional income is provided to the family by the State. Access to mainstream schools is facilitated and some educational supports are provided to facilitate this. There is a perceived equality of access to general health services and some additional assistance provided with transport. Essential therapies are provided to the child/young person as resources permit. Service delivery through a specialist agency may contribute to marginalisation and related lessening of status. The research shows that sometimes parents/guardians have difficulties in getting the additional learning and therapy supports required to enable full and purposeful participation in schools. Parents/guardians' having to apply separately for additional educational supports is a manifestation of difference and inequality of access to education. The need for persistent efforts by lobby groups regionally and nationally to keep the issue of supports for persons with an intellectual disability to the forefront of the social policy and political agendas is indicative of a core deficit from an equality perspective and suggests that services and supports required for optimum functioning and related ability to participate in society on an equal basis with others are dependent on the vagaries of budgetary arithmetic rather than on a basic underlying equality principle. Parents/guardians are generally cognisant of the pressure on service provider resources, particularly at the current juncture of significant budgetary cutbacks and, in the view of the researcher, accept that this is the way things are and, therefore, not amenable to change. This reflects some acceptance of the inevitability of inequality in the social supports infrastructure.

All of these factors suggest that the social supports infrastructure falls short on a number of equality fronts which combine to reflect a lower status for children/young persons with an intellectual disability. A similar picture emerges from the results of the Likert-type scale in relation to equality referred to in 8.7.2 above.

8.9.7 Self-realisation

Three social support goals were identified by the researcher as relevant to the rights component 'self-realisation' – positive engagement by children/young persons with their current situation; pushing out the boundaries and maximising individual potential.

The young persons consulted mostly have a positive view of their current situation. Future planning and supported decision-making are included as a core component of the Personal Outcomes discourse. There is some mainstream voluntary community involvement by some of the young persons and some additional options for independent living are being developed. Young persons feel that they have the support that they need and many parents/guardians work with children/young persons to enable them to make choices on daily living matters.

There is, however, a lack of opportunities for meaningful social roles and career paths for young persons with an intellectual disability and the education system does not cater adequately for diversity of learning need. The young person interviewees feel that they may not be able to realise their aspirations. Accreditation systems for non-academic skills and aptitudes are underdeveloped and mechanisms to achieve some of the young persons' hopes and aspirations are lacking. There are limited outlets for expression of positive and creative aspects of their lives. There are few progression options after second level education.

Parents/guardians are for the most part apprehensive about what the future holds and are fearful about risk-taking and pushing out the boundaries. There is an under-identification of individual potential generally and underdeveloped public perceptions of capabilities which results in somewhat limited goals. Supported decision-making is underdeveloped. There is a mismatch between the 'best interests' principle and resource allocation.

The concept of 'pushing out the boundaries', while a central aspect of the 'new' discourse around the social integration and support of people with an intellectual disability, is inhibited by the continuing absence of a clear social role for people with an intellectual disability who do not fit conventional and normative patterns of economical productive work or socially useful engagement. As a result, parents/guardians, schools and young people themselves may set somewhat limited goals. A centrally important lack in the self-realisation domain is the fact that mainstream schools at both primary and second-level are not resourced to work in a sustained and fully developmental way with individual children with significant learning disabilities. Also, while there is some mainstream local community involvement by young persons on a voluntary basis, this does

not extend to those with poorly developed social skills and/or significantly reduced capacity. If self-realisation is to be meaningful for children/young persons with an intellectual disability, a more dynamic, developmental and respectful engagement is required with individuals and a further engagement with how families of children with an intellectual disability can be supported in the process.

The current social supports infrastructure to some extent promotes the concept of self-realisation. However, self-realisation is also largely underdeveloped due to the absence of fully inclusive educational, social and cultural environments. This picture also emerges from the results of the Likert-type scale in relation to self-realisation referred to in 8.8.2 above.

8.10 Evidence of a rights paradigm in the social supports infrastructure

In addressing the research question as to the extent to which the social supports infrastructure reflects the components of a rights paradigm, the picture that emerges is a complex one. The findings of the research show that the continuum along which the social supports infrastructure operates reflects some aspects of a rights paradigm along each of the components analysed while at the same time showing significant deficits from a rights perspective. Supports for inclusive education, community/neighbourhood integration and ensuring equality of access to services make an important contribution to the rights paradigm. The recognition concept has the potential to transform the way children/young persons with an intellectual disability are regarded by and integrated into society. The focus on promoting the best interests of the child, maximising individual capacity and facilitating choice as far as possible reflect a rights approach. Side by side with these positive rights aspects of the infrastructure, there are clear deficits reflected across each of the seven rights components used in the analysis. In the main, these are underdeveloped social integration structures, an under-valuing of the concept of recognition in respect of people with an intellectual disability generally, underdeveloped opportunities for choice, voice and developing capabilities and an absence of mechanisms and structures within which young persons with an intellectual disability can realise and validate their aspirations and envision a meaningful future. The perceived different public responses to different types of intellectual disability and the perception that public attitudes to a child/young person with an intellectual disability are to some extent related to the nature of the disability raise issues about the extent to which recognition is truly engrained in the social psyche.

The policy focus on assigning children/young persons with an intellectual disability to a 'special' (separate) group/category in order to have support services allocated has clear implications for social inclusion, equality and recognition. A key question arises as to whether the label 'intellectual disability' promotes or hinders the implementation of a rights paradigm. A related question is whether and how such a generic label undermines

individual agency by masking the individuality and particular support needs of each child/young person as an individual.

The research shows that there are strong elements of a rights approach present in the discourse and in the way social supports are configured and that this is reflected to some extent in the social supports infrastructure. The research also shows clearly that the social supports infrastructure continuum falls short on a number of fronts when analysed using the core components of a rights paradigm. This is reflected in the fact that the legitimate and important hopes and aspirations of young persons (and frequently those of the parents/guardians in relation to the young person) cannot be realised because the key concepts of inclusion, recognition, agency, voice, capabilities, equality and self-realisation are often weakly reflected in the existing social support infrastructure.

Part Two: Summary

The analysis demonstrates a complex and multi-faceted system of social supports all of which are related directly or indirectly to the advancement of a rights paradigm. The social support infrastructure identified exhibits some aspects which can be said to reflect a rights paradigm. However, it falls short on a number of important dimensions. On the one hand, social attitudes are generally regarded as positive and inclusive while, on the other, separatist service provision and an absence of a clear social infrastructure to integrate children/young persons with an intellectual disability into mainstream society maintain, and may even reinforce a form of exclusion. Such exclusion is manifested in children/young persons with an intellectual disability continuing to be regarded as 'special' and their families regarded as different for no reason other than they have a child with an intellectual disability. This is reflected in limited goal-setting and is exemplified in the fact that there are few progression options for those with an intellectual disability after second level education and that there are only limited outlets for expression and creative social engagement.

Part Three: Conclusions

8.11 Background to the study and theoretical underpinnings

A rights-based approach is relatively new in Ireland generally and specifically in relation to both children and people with disabilities. While there is an ongoing debate regarding what constitutes social support, there is relatively little research on the role of the social support infrastructure in enhancing the implementation of a rights paradigm. In order to add to the body of knowledge on the linkages between rights and social supports, this study reviewed the literature on both rights and social supports. Seven key components of a rights paradigm relevant to a social supports infrastructure applicable to children/young persons with an intellectual disability were identified. The evolution of Irish social policy and legislation as it applies to both children and to people with disabilities was also described and analysed. This provided a contextual framework for considering the current status of the social supports infrastructure *vis a vis* a rights paradigm. Dimensions of the social supports infrastructure relevant to each of the seven rights components were identified and these were juxtaposed with the relevant rights component in order to analyse the study findings.

Two theoretical areas were examined in detail (a rights approach in Chapter Two and social supports in Chapter Three). The key components of a human rights approach generally were discussed with specific reference to rights provisions for people with disabilities and children under UN conventions and declarations. The concept of social support was defined and its theoretical underpinnings discussed, including family support and building community capacity. The literature refers to the kind of support provided, who provides the support and other contextual issues as all playing a role in determining whether or not support is perceived as beneficial. The broad goals of social support were identified as enhancing the health, well-being and coping capacity of the individual child through the direct provision of services, therapies and other supports while simultaneously enhancing the capacity of the family to provide such supports. Seven core components of a rights approach were identified as relevant to a social supports infrastructure for children/young persons with an intellectual disability. These are: social inclusion, recognition, agency, voice, capabilities, equality and self-realisation. The social supports infrastructure was assessed against these seven components and the positives and deficits of current practice were identified accordingly. Challenges to the rights approach and to the conceptualisation of social support were identified and discussed. It was noted that in discussing rights-based social supports, it is not always easy to distinguish between the supports provided to the child/young person as an individual and those provided to the family as the unit or locus of support and care.

8.12 Research methodology

A case study approach was used in this research to gather the data necessary to address the overall aim and objectives of the study. As Denzin and Lincoln (2000) state, a wide range of interconnected methods are necessary in order to get “a better fix” on the subject matter at hand (2000:2). As a prelude to the case study, key informants in the area of services for children/young persons with an intellectual disability were consulted. The outcomes of this consultation were reflected in the design of the Parents/Guardians Survey Questionnaire and in the development of themes for the semi-structured interviews with parents/guardians, young persons, service provider staff and other professionals. Finally, a focus group was held with service provider staff from agencies other than the one involved in the case study to validate the preliminary findings. The survey questionnaire obtained data on the experience and perceptions of parent/guardians of children/young persons with an intellectual disability. The interviews obtained data on the respective experiences and perspectives of parents/guardians, young persons, service provider staff and other professionals of the social supports infrastructure and on a rights-based approach.

The research approach adopted has a number of strengths. Firstly, it captures the views and perspectives of those centrally involved at the interface between children/young persons and the formal and informal social supports infrastructure. Secondly, the research is located in a specific geographical area and community where all the service users have access to specific support in a specific context and all the service provider respondents are fully *au fait* with the specific social supports infrastructure. Thirdly, the views and perspectives of study participants are located and considered within a rights paradigm which, it is suggested, offers a rich analytical context in that it moves the discourse significantly from an individual deficit model to one which affirms and supports mutual ties and obligations that exist between people by virtue of their shared membership of society. Fourthly, the study assesses the strengths and deficits of the current social supports infrastructure by juxtaposing existing social realities with seven components of a rights paradigm identified. Fifthly, the study applies the insights gained in addressing the question as to whether there is evidence of a rights paradigm in the current social support infrastructure for children/young persons with an intellectual disability in Ireland. Finally, an indicative framework for ongoing consideration of the outcomes of the research is identified.

As with any research study, there were a number of limitations to this study. While the study is concerned with the social support infrastructure as it applies to children/young persons with an intellectual disability, those with severe and more profound disabilities were not consulted in the study. The perspective in relation to such children/young persons is, therefore, that of parents/guardians, service provider staff and other professionals interviewed. It is acknowledged that future research to ascertain the

experience of those with a more severe intellectual disability will be required in order to provide a more complete picture.

The case study approach adopted in the research may mean that the findings are not representative of all parents/guardians, children/young persons and service providing agencies in Ireland. It is also the case that the parents/guardians interviewed were a self-selected group (i.e., those who indicated a willingness to be interviewed in their response to a survey of all parents/guardians). While this study does not claim to be fully representative, it does provide a snapshot of social reality as experienced by significant stakeholders in the current social supports infrastructure. Also, while it was made explicit to research participants at the outset that the research was not an evaluation of the social supports infrastructure where the case study service provider is a central player, it may be that there was some bias towards protecting a valued service provider in the responses of some of the case study participants. A wider sample of key stakeholders in this area would be needed to validate and enhance the findings from the present case study.

8.13 Key research findings

The overall aim of the thesis is to assess the realities of the current Irish social support infrastructure as it applies to children/young persons with an intellectual disability against a rights paradigm and to establish the extent to which there was evidence of a rights approach. The findings of the research show that the continuum along which the social supports infrastructure operates reflects some aspects of a rights paradigm along each of the components analysed while at the same time showing significant deficits from a rights perspective.

The core findings identified from the data generated by this study indicate that, while there are elements of a rights approach present in the discourse and in the way social supports are configured and delivered, the social supports infrastructure falls short on a number of fronts. There was a broad consensus between parent/guardians and staff/professionals on the positives and deficits in the social supports infrastructure. There was agreement that there are gaps in the implementation of core rights components with staff giving a lower rating to the presence of these components than parents/guardians. The young person interviewees also identified strengths and deficits in the social supports infrastructure from their perspective.

In relation to 'social inclusion', while there is an ongoing debate between the respective merits of specialist and mainstream services, the service delivery to children/young persons with an intellectual disability through specialist rather than mainstream services creates a separateness which contributes to marginalisation. The terminology used ('disability', 'additional needs') and the need for children/young persons with an intellectual disability to be assigned to a 'special' group/category may, in the researcher's view, add to the marginalisation and social exclusion of children/young persons with an intellectual disability. In spite of the great

attention to community participation of children/young persons with an intellectual disability, the research indicates that there is relatively little meaningful community participation in mainstream community, civic and social life (including recreation and leisure, hobbies, socialising, sports, arts and culture) by this group of children/young persons. There is good local community/neighbourhood integration by some families and consequently by their children. However, many children/young persons do not experience a strong sense of community belonging – as a result, their citizenship is somewhat diminished. The principle of integrated (mainstream) education is generally applied where appropriate and feasible. However, it falls short across four key dimensions – resources for the additional supports required, teacher training, inclusive curriculum and pedagogy and meaningful career/life choices and paths.

On the concept of 'recognition', there is a perception of social attitudes becoming more inclusive with public responses to children/young persons with an intellectual disability being generally regarded as positive. However, different public responses to different types of intellectual disability reflect an undermining of the notion of universal recognition and positive regard. There is an acknowledgement by parents/guardians and by service provider staff and other professionals of the importance of the 'best interests' principle. However, the needs of the school or the local community as a whole are seen as sometimes having to take precedence over 'the best interests of the child' principle.

In relation to 'agency', parents/guardians affirm their child in all the domains of living and there is positive affirmation of the child/young person by his/her siblings. Optimising self-management is included as part of Personal Outcomes planning process. There is some affirmation of children/young persons with an intellectual disability within the school system and local community affirmation for some. However, affirmation is not always inclusive of the child/young person's interests and aptitudes and the response of local communities, while not perceived as negative, is not always positively affirmative. Communication techniques for children/young persons who cannot verbalise are underdeveloped and schools may not have the facilities required to support and enhance communication by children with complex communication difficulties. The mainstream school environment is not sufficiently inclusive of children/young persons with very different and specific learning needs. While supportive therapies and assistive technologies are provided on the basis of assessed needs, these are governed by resource availability at any given time.

On the rights component 'voice', there is a perception by young persons who participated in the research that their voice on matters that affect them is generally heard. There is some parental awareness of the concept of giving due weight to the voice of the child and a policy focus by the main service provider on facilitating the voice of the child/young person. Consultation with children/young persons and their parents/guardians is part of the needs assessment and planning process. Parents/guardians

work towards providing realistic and meaningful choices around daily routines. The 'voice' of children who are in a minority is frequently lost in the mainstream school system. Decisions may sometimes be made by parents/guardians and staff without full engagement (appropriate to age) with the child/young person involved. While access by young persons to a key support worker from the specialist service provider is seen as helping to enhance individual voice, the absence for the most part of an independent advocate (other than a parent or a member of the specialist service provider staff) to support children/young persons undermines the concept of 'voice'. A concern articulated in the study (by both staff and parents/guardians) about the sometimes divergent views of parents/guardians and service provider staff in relation to what is best for a child/young person contributes, in the view of the researcher, in inadequate consideration of the voice of the child/young person.

On the question of 'capabilities' and related capacity-building, there is a strong emphasis on the concept of individual needs assessment and related person-centred planning. Envisioning the future is included as part of the Personal Outcomes planning process. Most of the young persons who participated in the research have positive aspirations for the future. However, there are gaps between needs assessment, personal outcome targets, implementation strategies and the lived realities of children/young persons. There is no right in law to have a statutory service statement provided implemented. There is a lack of opportunities for meaningful social roles and career paths and the education system does not cater adequately for diversity of learning needs. The young person interviewees feel that they may not be able to realise their aspirations. Accreditation systems for non-academic skills and aptitudes are underdeveloped. Parental fears and apprehension about relationships and future living arrangements for their child/young person are prevalent.

The rights component equality is reflected in the fact that, where a child is assessed as requiring significant additional care, some additional income is provided to the family by the State. Some additional educational supports are provided to facilitate access to mainstream schools. There is a perceived equality of access to general health services and some additional assistance provided with transport. While therapies and supportive technologies are provided to the child/young person, these are governed by resource constraints and related rationing. The experience of parents/guardians of having to 'fight for' services and apply for additional educational supports highlights difference.

On the rights component, 'self-realisation', the young persons who participated in the research mostly reported a positive view of their current situation. Future planning and supported decision-making are included as a core component of the Personal Outcomes discourse. There is some mainstream voluntary community involvement by some of the young persons and some additional options for independent living are being developed. Young persons feel that they have the support that they need and many parents/guardians work with children/young persons to enable

them to make choices on daily living matters. There is, however an absence of a clear image of the future for those with an intellectual disability. Mechanisms to achieve some of the young persons' hopes and aspirations are lacking. There are limited outlets for expression of positive and creative aspects of their lives. There are few progression options after second level education. Parents/guardians are for the most part apprehensive about what the future holds and are fearful about risk-taking and pushing out the boundaries. There are underdeveloped public perceptions of capabilities which results in somewhat limited goals. The concept of supported decision-making is not maximised. The balance between the 'best interests of the child' principle and the allocation of resources is not optimal.

8.14 Study findings: implications for further research

8.14.1 *The need for a transformative narrative*

The research points to the need to develop a new narrative which would reflect and create a stronger context for the development of a rights-based social supports infrastructure for children/young persons with an intellectual disability. Markley and Harman (1982) point to the power of images, i.e., those sets of fundamental assumptions about human nature and its potential, to shape all our social values and institutions. Fraser (2003) argues for the need for transformative (as distinct from affirmative) strategies which deconstruct currently institutionalised patterns of cultural value and destabilise existing status differentiations. Markley and Harman (1982) use the term 'transformation' to refer to the potential to bring about attitudinal and value changes in society which would lead to a balancing and co-ordinating of satisfactions along many dimensions rather than maximising concerns along one narrowly defined economic dimension (Markley and Harman 1982:119).

The researcher has identified a number of possible policy responses which, although they do not flow directly from the thesis findings, are regarded as necessary to bring about the type of transformation required to develop a stronger rights-based social supports infrastructure applicable to children/young persons with an intellectual disability in Ireland. Seven aspects of a transformative narrative are thus identified which would form the basis of further research and ongoing policy debate.

- (i) Changing the discourse
- (ii) Enhancing recognition in the social supports infrastructure
- (iii) Reconfiguring the social imaginary
- (iv) The uniqueness of the individual
- (v) Inclusive education
- (vi) Communities of solidarity

(vii) From benevolence to justice

The attributes of each of these seven aspects are summarised in Figure 8.10 which also identifies an indicative legal/institutional framework for realising these.

8.14.2 Key aspects of a transformative narrative identified

Changing the discourse

The study findings indicate a social supports infrastructure where supports are available on the basis of children/young persons as belonging to a special group category. This is particularly the case in relation to formal services and supports. Gatens (2004) suggests that the ways in which a community governs and imagines itself become embedded, over time, in institutions and in the social norms that constrain action and determine meaning independent of the wishes of individuals. She also suggests that “by questioning past practices and by revealing present practices, one causes a shift or tremor in the web” (Gatens 1995:53). This is a core consideration which has strong resonance in developing a stronger rights-based discourse relating to children/young persons with an intellectual disability. Further research is required in this important area.

Enhancing the recognition of each person as an individual through the social supports infrastructure

The research findings point to children/young persons with an intellectual disability being frequently at the lower rungs of Hart’s (1992) *Ladder of Participation* where participation is non-existent or tokenistic. This is particularly the situation for those with more severe disabilities. For children to grow in a socially constructive, positive environment or community, being valued positively by themselves and others, is important not just as a personal right but also in relation to how they behave and engage with wider society.

Where the principle of recognition is upheld, a child can foster ‘felt concern’ for others and their values which is a central function of positive civic engagement (Dolan 2010). The methodologies required to enhance the concept of recognition in respect of children/young persons with an intellectual disability is identified as an area requiring further research. How to fully include children/young persons in this process is a centrally important question.

Reconfiguring the social imaginary

The study findings point to an under-recognition of the concept of agency in respect of children/young persons with an intellectual disability and an under-development of a vision to achieve this. Carlson and Kittay (2010) argue for the need for a more collaborative conception of agency, one that is, in reality, appropriate to all, but especially useful in relation to people with an intellectual disability. Such a reconfiguration of how society refers to individuals and how they are included offers a useful corrective to the current situation where children/young persons with an intellectual

Figure 8.10: Components of a transformative narrative

Component	A transformative approach	Indicative legal/institutional framework
1. Changing the discourse	From separatist to fully inclusive services; From special group identity to individuals as equal citizens; From intolerance of difference to celebrating diversity; From paternalism to equality of status; From dichotomy to continuum	Stronger citizenship initiatives by the State; The state taking direct responsibility for delivering the formal social supports infrastructure (currently this is devolved to NGOs); Moving from disability as a central funding budgetary head
2. Enhancing the recognition of each person as an individual through the social supports infrastructure	Moving from a deficits based model of service delivery to an assets-based and life-enhancing social supports infrastructure; From a dependency-based approach to one of reciprocity and mutual exchange; Broadening the economic and cultural basis for social esteem; Enhancing the concept of 'voice'	A universal needs-based model of service provision; Individual needs assessment accompanied by mandatory service statements; Legal recognition of rights accompanied by a stronger recognition of corresponding duties of enforcement
3. Reconfiguring the social imaginary	Revisioning the potential contribution of people with an intellectual disability to society; Creating a social, economic and cultural milieu that creates space for multiple contributions	Reforming the economic and social processes by which people are categorised and labelled and are included and excluded accordingly
4. The uniqueness of the individual as central tenet/core value	A stronger focus on opportunities for self-realisation and development of capabilities (using Nussbaum's ten capabilities); Enhancing decision-making;	Updating mental capacity legislation to provide for supported decision-making; Clarifying and enhancing the role of independent advocates
5. From mainstream schools to inclusive education	Educational curricula inclusive of the interests, aptitudes and aspirations of children with an intellectual disability; Identifying limitations of the current system; Broader and more inclusive accreditation systems	Developing a fully integrated education system to cater for diversity; A broader approach to inclusive curricular development by the State
6. Communities of solidarity	A need for the public generally to become more accepting of difference as it applies to children/young persons with an intellectual disability; Creating networks of solidarity	Local government taking responsibility for putting the citizen at the centre and for building community structures inclusive of diversity
7. From benevolence to justice	Rights aspirations reflected in implementation structures that guarantee and proactively promote equality of status and equality of access; Protecting the 'best interests' principle	Making the enforceability of rights the responsibility of the State rather than individuals; Clarifying the respective responsibilities/duties of the State and the family

disability are under regarded in terms of their agency and in terms of their participation in the social contract. This requires revisioning the potential contribution of people with an intellectual disability to society, creating a social, economic and cultural milieu that makes space for multiple contributions and, most importantly, ensuring that the processes of social contract engagement are inclusive of all. This, it is suggested, is a rich area for further research.

The uniqueness of the individual as central tenet/core value

The research findings point to some deficits in relation to provision for Nussbaum's (2006) ten capabilities, in particular, to plan one's life and to enjoy recreational activities on an equal basis with others; being able to live for and in relation to others; and having the right to seek employment on an equal basis with others. This requires a fundamental dismantling of the label 'intellectual disability' and a focus on individuals as unique persons with hopes and dreams rather than people who just engage with the service delivery system. It also requires further exploration of how the authentic voice of children/young persons with an intellectual disability can be heard, including in research (Carpenter and McConkey 2012). How Nussbaum's (2006) capability theory can be more fully applied in the Irish context requires further consideration and related research.

From mainstream schools to inclusive education

The deficits in current educational provision identified in the research – inadequate curricular and pedagogical approaches; inadequately trained teachers; difficulties in accessing educational supports commensurate with need; and lack of meaningful post second-level education options – undermine the concept of inclusive education as understood by the Committee on the Rights of the Child as providing the child “with empowering experience of control, achievement, and success to the maximum extent possible for the child” (United Nations 2007: Par. 64). While the integration of learners with disabilities into mainstream educational settings has become more commonplace in Ireland, difficulties identified include lack of recognition for them as persons and inadequate institutional provisions for their needs (Lodge and Lynch 2004). Questions relating to how to better achieve truly inclusive education offers potential for further research.

Communities of solidarity

The research findings point to weak community engagement by many children/young persons with an intellectual disability and a dearth of relevant integrative structures and mechanisms. The lack of active community engagement and community connectivity undermines the experience of citizenship. The concept of social solidarity is one that is centrally relevant to a rights-based approach to children/young persons with an intellectual disability. The ethic of solidarity requires society to sustain the freedom of the person with appropriate social supports (Quinn and Degener 2002). Further research is required to explore how this concept might be developed and enhanced in the Irish context to fully integrate those with an intellectual disability.

From benevolence to justice

The study findings suggest that service delivery through specialist rather than mainstream services may reflect an outdated model of disability which at a basic level reflects some connotations of benevolence and a significant under-acknowledgement of the justice principle. This is clearly manifested in the fact that, for example, parents/guardians have to separately apply for additional educational supports for their child with an intellectual disability. The need to embrace the notion of moving from the treatment of persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as 'subjects' with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as well as being active members of society has been emphasised by UNICEF (UNICEF 2007). How to ensure that the principle of justice based on human rights as equal rights is applied to children/young persons with an intellectual disability requires further and ongoing research in the Irish context, in particular, how rights-based supports can be configured within the ordinary structures of education, health, employment, housing and social services.

8.14.3 Disseminating the findings

The researcher has identified four aspects of the study where he proposes to do further work in disseminating the findings and engaging in some additional research as required. These are:

- (i) *The components of a rights-based social supports infrastructure applicable to children/young persons with an intellectual disability* (Possible Journal Article – *Disability & Society*)
- (ii) *Developing and enhancing a rights-based social supports infrastructure for children with an intellectual disability: Implications for policy and practice in Ireland* (Possible Journal Article: *Administration*)
- (iii) *Changing the discourse and reconfiguring the social imaginary* (Possible Journal Article: *Social Policy and Society; Children & Society*)
- (iv) *Rights-based social supports for children/young persons with an intellectual disability: International comparisons* (Possible Journal Article: *Families in Society; Child and Family Social Work*)

In the first instance, a paper will be prepared, in consultation with the thesis supervisor on '*The components of a rights-based social supports infrastructure applicable to children/young persons with an intellectual disability*' for submission to an appropriate journal.

The researcher also intends to engage the National Federation of Voluntary Bodies (an umbrella organisation for NGOs providing services to people with an intellectual disability in Ireland which supported the research) in exploring ways of disseminating the findings, e.g. through a seminar or as part of a larger Conference or Symposium. It is also envisaged that the findings will be presented to the case study service provider stakeholders – parents/guardians, service users, staff and other professionals and the Board of Management.

Chapter summary

This chapter has identified seven components of a rights paradigm identified by the researcher as applicable to the social supports infrastructure as it relates to children/young persons with an intellectual disability. The case study data has been analysed by juxtaposing these seven rights components with a range of dimensions of social support. The positives and deficits of the existing social support infrastructure have been identified accordingly.

The chapter has shown that the concept of children and young persons with an intellectual disability having access to the same life opportunities and the same choices in everyday life as those who do not have a disability is widely acknowledged. That includes growing up in their families, being educated in a mainstream school in the local community, seeking employment in line with their education and skills and having equal access to the same public goods and services and, most importantly, being, as far as possible, in charge of their own lives.

The analysis shows that in a general way a rights ethos pervades the approach by families and by the state-funded specialist service provider referenced in the case study. This is seen as reflecting an explicit acknowledgement that children/young persons with an intellectual disability have the same rights as other children/young persons of their age. However, this is not based on any systematic engagement with either rights principles or rights-based legislation. Equality of access to health services, a focus on inclusion in mainstream schools and a generally more positive attitude by society are seen as strong indicators of a rights ethos. However, truly inclusive education in respect of children/young persons with an intellectual disability is significantly underdeveloped.

While the rights ethos underpins the overall approach to the provision of social supports, there was a clear acknowledgement that much needs to be done to make this a reality for all children/young persons with an intellectual disability. The development of a rights-based social supports infrastructure is posited as a developmental journey requiring an inclusive understanding of citizenship so that all stakeholders can walk this journey together.

The chapter shows that, while there are strong elements of a rights approach present in the discourse and in the way social supports are

configured and delivered, the social supports infrastructure continuum falls short on a number of fronts when analysed using the core components of a rights paradigm. While the rights components discussed underpin much of the social support infrastructure, the implementation mechanisms in place to achieve some of the related social support goals are inherently lacking.

The chapter has also summarised the background to the study, the aim and objectives of the research, its key theoretical underpinnings and the methodology used to collect the data necessary to answer the research questions. Finally, the implications for further research relevant to the development of a narrative commensurate with the enhancement of a rights-based social supports infrastructure for children/young persons with an intellectual disability in Ireland have been outlined.

This study, based on the perspectives of key actors – parents/guardians, young persons, service provider staff and professionals – involved with one service providing agency, describes the social reality as experienced. The picture that emerges, while multi-faceted and complex, is one of a significant mismatch between the rhetoric of the rights of children/young persons with an intellectual disability and the reality as experienced. There continues to be in place a set of institutional, cultural, legal and administrative processes which run counter to the underlying ethos of a rights paradigm and the development of a social supports infrastructure accordingly.

“To grant priority, not to survival, but to life and the poetry of the human being, is the only way to put an end to oppression”
(Vaneigem 2011:37).

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Appendix One

Protocol for the Implementation of Child Protection Guidelines

Protocols in line with *Children First* National Guidelines, the NUIG Child Protection Policy and the Child and Family Research Centre (CFRC) *Child Protection Policy* will be observed in conducting the interviews with children/young persons (confined to those aged over 16). The CFRC *Protocol for Interviewing Children* included in its *Child Protection Policy* will be observed.

- The consent of the parent/guardian as well as the child/young person will be sought
- The research will be explained fully to the child/young person and appropriate communication aids will be used for this purpose
- The researcher will not be alone with the child/young person
- The child/young person will be told that s/he can withdraw from the interview at any time
- The researcher will continuously look for any signs that the child/young person is distressed or in need of a break
- The interview will be stopped if the child/young person shows any signs of discomfort/distress

In the event of a child protection issue emerging during the course of the interview, any concerning information will be dealt with in accordance with the principles and procedures of *Children First*:

- (i) The matter will be reported to the Service Provider Designated Person who will be known to the researcher and to the Child and Family Research Centre Designated Person
- (ii) The Service Provider Designated Person and the Child and Family Research Centre Designated Person will liaise in relation to the concern and whether it is necessary to refer the matter to the HSE under *Children First* Guidelines.

This protocol will be agreed with the [Service Provider] staff prior to the commencement of the research.

Appendix Two

Information and Consent Form for Parents/Guardians

Title of Study

Holding a Vision: An Investigation of a Rights-Based Social Supports Infrastructure for Children/Young Persons with an Intellectual Disability in Ireland

What this study is about

The study seeks to get your views on the help and supports you and your child/ren receive. It is likely that you receive support from the following sources:

- The [case study service provider]
- The HSE
- Schools
- Department of Education
- Your extended family
- Your neighbours
- Your GP
- The Public Health Nurse
- Your friends
- Voluntary organisations (nationally and locally)

There may also be other people and organisations that give you support.

Who is doing the research?

The research is being done by Michael Browne from The Child and Family Research Centre (CFRC) at the National University of Ireland, Galway.

The [case study service provider] have agreed to help the researcher, first, by meeting and talking to him and, second, by providing information about the research both to the parents/guardians of children/young people who use their services and to children/young persons aged over 16 years.

Why do we need this research?

Research studies provide an opportunity to hear the views of all the people involved – in this case, the parents/guardians, children/young people (over 16), [case study service provider] staff and other professionals working with the children/young persons.

By looking at the help and support you and your child receive now and how this is for you, we can learn how the services and supports operate in practice. The study thus seeks to get your views on the help and support you receive so that this information can be used to highlight gaps and to make recommendations for change. Getting your views can help to identify strengths and weaknesses of current services and how these can be improved in the future.

The research is also seeking to get your views on how society generally could better ensure that children and young people with additional needs are treated the same as other children/young persons and are given the best possible life chances.

The views of parents/guardians are also being sought on what policy changes (in education, health, training, housing and social welfare) are required in Ireland to provide better supports to children/young persons with additional needs.

What are parents/guardians being asked to do?

Parents/guardians of children/young persons availing of services and supports from the [case study service provider] are being asked to do three things:

- (i) Complete a Survey Questionnaire

- (ii) Ten families will be invited to participate in meetings and discussions with the researcher – parents/guardians will be asked in the Survey Questionnaire if they would be willing to participate in this part of the research
- (iii) Consent, where appropriate, to your child (confined to those aged over 16) being interviewed by the researcher – this may be in either a group interview or in a one to one interview with the researcher in the presence of a [case study service provider]support worker.

Survey Questionnaire

All parents/guardians of children/young people availing of [case study service provider] support services will be asked to complete a Survey about the social supports and services available to yourself and to your son or daughter.

- The Survey Questionnaire will be circulated to you and you will be asked to return it directly to the researcher in a stamped addressed envelope provided.
- You will not be required to give your name on the Survey Questionnaire
- The Survey should take 30–40 minutes to complete.

Interviews with Parents/Guardians

The researcher would like to meet and carry out detailed conversations with ten families in order to get a detailed insight into:

- The experience of day to day living
- The experiences in accessing services and supports
- The supports provided by extended family, neighbours and friends
- The supports provided by [Service Provider]y, HSE, schools, Department of Education and others involved in the child's life
- How they experience the response of other people to the fact that the family has a child with additional needs.

How the Information You Provide Will Be Used

Any information that is collected about you during the course of the research will be kept strictly confidential and will not be shared with anyone else. The information collected in this research study will be stored in a way that protects your identity. The information provided will be reported in a manner which will not identify you in any way.

Consent by Parents/Guardians

If you, as a parent/guardian, are willing to take part in the research, you are requested to sign the Consent Form. Your participation is totally voluntary and you can of course refuse to take part and can change your mind at any point during the study and decide not to continue.

Children/Young Persons (Over 16)

Information about the study will be provided separately to your child if s/he is aged over 16. He/she will be asked to give her/his consent to be interviewed

If your child is aged over 16 and you are willing for him/her to take part in the research, the child /young person's consent form should be signed by you and by him/her.

The participation of your child/young person is totally voluntary and s/he is free to refuse or to withdraw at any time.

To support the children/young persons participating in the research, symbols and pictorial representations will be used in the information leaflet and on the consent form and on interview sheets where appropriate. A support worker from the [case study service provider] known to the child/young person will be available where required to help him/her to participate in the interview.

How the Information Provided by Child/Young Person Will Be Used

Any information that is collected about your child/young person during the course of the research will be kept strictly confidential and will not be shared with anyone else. The information collected in this research study will be stored in a way that protects his/her identity. The information provided will be reported in a manner that will not identify him/her in any way.

Further Information

The following documents will be available to parents/guardians:

- The survey questionnaire
- The list of areas to be covered in the discussions with 10 families
- The interview questions for children/young persons (aged over 16).

If you agree to take part, please sign the consent form.

If you agree to your son/daughter taking part, please countersign his/her consent form.

For further information, please feel free to contact Michael Browne at any time.

Tel.: 087 6479580/091 494050

Email: m.browne11@nuigalway.ie

Address: Child & Family Research Centre, School of Political Science & Sociology,
Science Engineering & Technology Building,
National University of Ireland, Galway
www.childandfamilyresearch.ie

Thank you for taking the time to read this information sheet.

Research Consent Form for Parents/Guardians

Title of Study

An Investigation of a Rights-Based Approach to Social Supports for Children and Young People with Additional Needs in Ireland

Name of Researcher: Michael Browne

DECLARATION:

Please Tick Boxes

1. I have read this consent form and the attached information sheet outlining the study.
☐
2. I have had the opportunity to ask questions.
☐
3. I understand the information given and my role in this research.
☐
4. I have had enough time to consider my participation in this research.
☐
5. I understand that my participation is entirely voluntary and that I am free to withdraw at any time.
☐
6. It has been explained to me that there will be no negative consequences should I choose not to participate in the study.
☐
7. I am aware that my participation in the study and the information I disclose will be treated in a confidential manner and that my name will not be used.
☐
8. It has been explained to me that any information gathered will be retained and stored securely for a period of five years.
☐
9. I am aware that any information disclosed of a child protection concern will be reported to the [Service Provider] designated person.
☐
10. I am aware that my child (if over 16) may be asked to participate in the study.
☐
11. I agree to take part in the study.
☐

Name of Parent/Guardian

Date

Signature

Researcher

Signature

Michael Browne

Appendix Three

Information and Consent Form for Young Persons

Information Sheet



Title of Study

'Getting by with a little Help from my Friends' – Who Helps You?



What the research is about.

The study is to get your views on the help that you get from:

The [Service Provider] Your family Your neighbours
Your school Your friends Other people you know



Why do we need the research?

By getting your views and opinions on the help you get from your family, your friends and the [case study service provider] and how this is for you, we hope to learn what the good things are and what things are not so good. This may help to get more of the good things done in the future and change what is not so good.



Who is doing the research?

The research is being done by Michael Browne from the Child and Family Research Centre at the National University of Ireland, Galway.



The [Service Provider] has agreed to help Michael with the research, first, by meeting and talking to him and, second, by providing information about the research to children/young persons aged over 16 years who use their services and to their parents.



What children/young people (over 16 years) are being asked to do?

About 10 children/young persons aged over 16 using [Service Provider] Services are being asked to talk to Michael Browne and to give their views and opinions. Michael will arrange to have someone you know from the [Service Provider] there to help you if you need. These meetings will last about 30 minutes.



Who else is involved in the study?

Michael will also ask your parents or, someone you live with (if you do not live with your parents) and [case study service provider] staff about what they think of the help and supports that you receive and listen to their ideas about how things could be improved.



How the information provided by child/young person will be used

The information you provide will not be given to anyone else.



The only thing we would have to tell someone about is if you said that you or someone else was being hurt or harmed in any way, because it's important that everyone is kept safe. That's the only thing that we might tell somebody else.



Results from the study will be included in a report in a manner that will not identify you in any way.



Your Consent

If you are aged over 16 and you are willing to take part in the research, you should sign the Consent Form and get your parent/guardian to sign it as well.

Your parent/guardian will also be asked to give consent to you becoming involved.

You are of course free to refuse to take part in the study and can change your mind at any point during the study and decide not to continue.

Further Information

A list of the questions that you will be asked will be available for you to see before the interview.

You will be given a copy of this information sheet and signed consent form to keep.

For further information, please feel free to contact Michael Browne at any time.

Tel.: 087 6479580 or 091 494050

Email: m.browne11@nuigalway.ie

Address: Child & Family Research Centre, School of Political Science & Sociology,
Science Engineering & Technology Building,
National University of Ireland, Galway
www.childandfamilyresearch.ie

Thank you for taking the time to read this leaflet.

Research Consent Form for Children/Young Persons (Over 16)

Title of Study

‘Getting by with a little Help from my Friends’ – Who Helps You?

Name of Researcher: Michael Browne

DECLARATION:

Please TICK Boxes



The study has been explained to me

☐


I have had enough time to think about it

☐


I understand what the study is about

☐


I know that I that I am free to withdraw at any time

☐


I know that my name will not be used in any report

☐


I understand that if I tell the researcher that I or someone else was being hurt or harmed in any way he will have to report this to _____ **Name of Designated Person**

☐


I will meet with and talk to the researcher

☐

Name Young Person

Date

Signature

Name of Parent/Guardian

Date

Signature

Researcher

Signature

Michael Browne

Appendix Four

Information and Consent Form for Staff and Other Professionals

Information Sheet for Service Provider Staff and Other Professionals

Title of Study

Holding a Vision: An Investigation of a Rights-Based Social Supports Infrastructure for Children/Young Persons with an Intellectual Disability in Ireland

What this study is about

The study seeks to develop a rights-based policy instrument for the enhancement of social support systems for children and young people with an intellectual disability and their families in Ireland. While social support is defined by varying terms in the literature, it is generally agreed that social support broadly refers to the assistance and help that one receives from others. The study aims to explore the difference between a rights approach (and related Irish social policy aspirations) and the lived realities of children and young people with an intellectual disability and their families. This requires getting the views of key stakeholders in respect of rights-based social supports – children/young people with an intellectual disability, their families and service providers.

What is the Role of the [Service Provider]

The [Service Provider] is being requested by the researcher to facilitate and collaborate in the carrying out of a Case Study which will involve a research engagement with families, children and young persons (over 16), staff and some other professionals involved. This Case Study will include:

- Review of internal documentation regarding policies, protocols and practice relating to social supports
- Review of 5 Individual Care/Support Plans with all Identifying Information removed)
- Survey of parents/guardians of children/young persons using [case study service provider] services
- In-depth consultation (interviews/focus groups with selected families and young persons (aged over 16)*)
- Interviews/focus groups with staff
- Interviews with other key informants identified during the course of the research

The co-operation of staff is requested in carrying out the Case Study. As part of the Case Study, the views of the staff around the various domains of social supports are being sought.

Why do we need this research?

While reference is frequently made to equality of access to supports and services for all children and to the rights of children with disabilities under various international Human Rights Conventions, it is not at all clear that appropriate supports are available in Ireland to enable children/young persons with an intellectual disability to avail of these rights. By carrying out an in-depth analysis of the services and supports available, it is hoped on the one hand to highlight the gap between aspirations and practice and, on the other, to identify a comprehensive range of components of rights-based social supports and a vision for children/young persons with an intellectual disability accordingly taking into account three key interfaces – the child with an intellectual disability and his/her family; the child with an intellectual disability/the family and the service providers; and the child with an intellectual disability/the family and the neighbourhood/community.

What staff are being asked to do?

The research is seeking to get staff views on the social supports available and on how society generally, social supports, social policy and legislative provision could better ensure that the rights of children and young people with an intellectual disability can be better protected.

Staff members are being asked to:

- (iv) Participate in preliminary discussions about operationalising the research
- (v) Participate in interviews and focus group discussions with the researcher
- (vi) Make available relevant [Service Provider] policy documents to the researcher

- (vii) Make available to the researcher 5 Individual Care/Support Plans (with all identifying information removed)

- (viii) Facilitate as far as possible liaison between the researcher and parents/guardians and children/young people (over 16)

- (ix) Assist and support as appropriate children/young persons (over 16) who have agreed to be interviewed

Who is doing the research?

The research is being done by Michael Browne from The Child and Family Research Centre (CFRC) at the National University of Ireland, Galway.

For further information, please feel free to contact Michael Browne at any time.

Tel.: 087 6479580/091 494050

Email: m.browne11@nuigalway.ie

Address: Child & Family Research Centre, School of Political Science & Sociology,
Science Engineering & Technology Building,
National University of Ireland, Galway
www.childandfamilyresearch.ie

Thank you for taking the time to read this leaflet. You will be given a copy of this information sheet and signed consent form to keep.

Research Consent Form for Staff and Professionals

Title of Study

Holding a Vision: An Investigation of a Rights-Based Social Supports Infrastructure for Children/Young Persons with an Intellectual Disability in Ireland

Name of Researcher: Michael Browne

DECLARATION:

Please Tick Boxes

1. I have read this consent form and the attached information sheet outlining the study.
☐
2. I have had the opportunity to ask questions.
☐
3. I understand the information given and my role in this research.
☐
4. I have had enough time to consider my participation in this research
☐
5. I understand that my participation is entirely voluntary and that I am free to withdraw at any time.
☐
6. It has being explained to me that any information gathered will be retained for a period of five years and only reported in an anonymous manner.
☐
7. I am aware that my participation in the study and the information that I disclose will be treated in a confidential manner.
☐
8. I understand that this study is about social supports generally and is not in any way an evaluation of the [Service Provider] services.
☐
9. I am aware that any information disclosed of a child protection concern will be reported to the [Service Provider] Designated Person
☐

Having read the above information I have carefully considered my participation in this study and I agree to take part in the study.

☐

Name of Staff Member/Professional

Date

Signature

Researcher

Signature

Michael Browne

Appendix Five

Survey Questionnaire for Parents/Guardians

Ref. No _____

The purpose of this Questionnaire is to get the views of parents/guardians of children/young persons (aged under 24 years) using (Service Provider] Services. The Questionnaire seeks to get your views on the supports and services available to your child/young person and to you as parents/guardians. It also seeks to get your views on how the rights of children/young persons with an intellectual disability are protected in Ireland.

The Questionnaire will take about 30 minutes to complete and your willingness to provide the information requested is much appreciated.

Please note that any information you give will be treated in strict confidence

Q.1 What is your relationship with the child/young person using the Services?

Parent ☐ 1 Guardian ☐ 2

Q.2 Please indicate which category best describes the situation of the child/young person using [Service Provider] Services

Child/young person with an intellectual disability ☐ 1
 Child/young person with autism ☐ 2
 Child/young person with autism and intellectual disability ☐ 3
 Other (Please specify) _____ ☐ 4

Q.3 What age is the child/young person using [case study service provider] Services? (Please ✓ one)

5 years or under ☐ 6–12 years ☐ 13–18 years ☐ 19–24 ☐ years

Q.4 Does the family live in? (Please ✓ one)

A town ☐ 1
 A village (with a group of houses and shops) ☐ 2
 A rural area ☐ 3

Section A

The Services the Child/Young Person Receives

Q.5 What services outside the home does the child/young person receive at present? (Please ✓ all that apply)

Specialised pre-school support	1 <input type="checkbox"/>	Mainstream School	2 <input type="checkbox"/>
Special Class	<input type="checkbox"/> 3	Special school	4 <input type="checkbox"/>
Autism specific unit	5 <input type="checkbox"/>	Physiotherapy	6 <input type="checkbox"/>
Social Work	<input type="checkbox"/> 7	Occupational Therapy	8 <input type="checkbox"/>
Speech and Language Therapy	9 <input type="checkbox"/>	Psychologist	10 <input type="checkbox"/>
Respite care	11 <input type="checkbox"/>	Rehab/Training Centre	12 <input type="checkbox"/>
Transition support	13 <input type="checkbox"/>	Supported Employment	14 <input type="checkbox"/>
Supported 3rd-level education	15 <input type="checkbox"/>		
Other	16 <input type="checkbox"/> Please state _____		

Q.5(a) Please indicate your overall assessment of the services your child receives **outside** the home. Please ✓ **one only** of the following:

Very beneficial	Of some benefit	Beneficial	Of little benefit	Of no benefit
5	4	3	2	1

Q.6 **What services are available within the home at present?**
(Please ✓ **all** that apply)

Community Nurse	<input type="checkbox"/> 1	Physiotherapy	<input type="checkbox"/> 2
Occupational Therapy	<input type="checkbox"/> 3	Social Work	<input type="checkbox"/> 4
Speech and Language Therapy	<input type="checkbox"/> 5	Respite	<input type="checkbox"/> 6
In-home Grant	<input type="checkbox"/> 7	Family Support Worker	<input type="checkbox"/> 8
Dep. Of Education Home Tuition	<input type="checkbox"/> 9	Behaviour support	<input type="checkbox"/> 10
Other	<input type="checkbox"/> 11 (Please specify) _____		

Q.6(a) Please indicate your overall assessment of the services your child receives **within** the home. Please ✓ **one only** of the following:

Very beneficial	Of some benefit	Beneficial	Of little benefit	Of no benefit
5	4	3	2	1

Section B Assessment of Need and Individual Plan

Q.7 **Was an assessment of the child's/young person's overall service and support needs carried out at any stage?**

Yes ☐ 1 No ☐ 2 Not sure/Don't know ☐ 3

Q.7(a) **If YES, were you involved in carrying out the assessment?**
(Please ✓ one)

Very involved	Involved	Token involvement	Not involved	Excluded
5	4	3	2	1

Q.8 **Was an individual plan for your child put in place?** (Please ✓ one)
Yes ☐ 1 No ☐ 2 Not sure/Don't know ☐ 3

If YES to Q.8, please answer the questions in the next BOX, otherwise please go to Q.9

Q. 8(a) **Were you involved in drawing up the plan?** (Please ✓ one)

Very involved	Involved	Token involvement	Not involved	Excluded
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Q. 8(b) **n your opinion, how well was the plan implemented?** (Please ✓ one)

Fully	Mostly	Partly	Not implemented	Totally disregarded
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Q. 8(c) **How often is the plan reviewed?** (Please ✓ one)

Every 6 months	Once a year	Every 2–3 years	More than 3 years	Never
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Q.8(d) Are you involved in reviewing the plan? (Please ✓ one)

Very involved ☐ 5 Involved ☐ 4 Slightly involved ☐ 3 Not involved ☐ 2 Excluded ☐ 1

Q. 8(e) Is your child/young person involved in reviewing the plan? (Please ✓ one)

Very involved ☐ 5 Involved ☐ 4 Slightly involved ☐ 3 Not involved ☐ 2 Excluded ☐ 1

Q.9 Was your child aged under 5 years on 1st June 2007? (Please ✓ one)

Yes ☐ 1 No ☐ 2

If YES to Q.9, please answer the questions in the next BOX, otherwise, please go to Q.10

Q.9(a) Did you your child receive a Service Statement from the HSE following the assessment of need? (Please ✓ one)

Yes ☐ 1 No ☐ 2 Not sure/Don't Know ☐ 3

Q. 9(b) If YES, How would you rate this Service Statement in helping you get the services/supports your child needs? (Please ✓ one)

Very helpful ☐ 5 Helpful ☐ 4 Not helpful ☐ 3 Unhelpful ☐ 2 Very helpful ☐ 1

Section C Supports for Parents/Guardians

Q.10 Which of the following services provide help to you as a parent/guardian in supporting your child? (Please ✓ all that apply)

[Case Study Service Provider] ☐ 1
HSE ☐ 2
School/teachers ☐ 3
National Educational Psychological Service (NEPS) ☐ 4
National Council for Special Education ☐ 5
GP ☐ 6
Other service provider (Please specify) _____ ☐ 7
Other (Please specify) _____ ☐ 8

Q.10(a) Please indicate your overall assessment of the support provided to you as a parent/guardian by services and professionals. (Please ✓ one)

Very beneficial ☐ 5 Of some benefit ☐ 4 Beneficial ☐ 3 Of little benefit ☐ 2 Of no benefit ☐ 1

Q.11 What family/community supports are available to you as a parent/guardian? (Please ✓ all that apply)

Immediate family ☐1 Neighbours ☐2 Extended family ☐3
 Friends ☐4 Local community groups ☐5 Clergy ☐6
 Parents support group ☐7 Other ☐8 (Please state) _____

Q.11(a) Please indicate your overall assessment of the support provided to you as a parent/guardian by your neighbours and local community. (Please ✓ one)

Very beneficial ☐5 Of some benefit ☐4 Beneficial ☐3 Of little benefit ☐2 Of no benefit ☐1

Q.11(b) Please indicate your overall assessment of the support provided to you as a parent/guardian by your family (immediate and extended) (Please ✓ one)

Very beneficial ☐5 Of some benefit ☐4 Beneficial ☐3 Of little benefit ☐2 Of no benefit ☐1

Q.12 Is there somebody that you can call on for support for yourself during times of uncertainty in meeting the needs of your child? (Please ✓ one)

Always ☐5 Usually ☐4 Sometimes ☐3 Rarely ☐2 Never ☐1

Q.12(a) Please state your relationship with the person/s that you mostly call on for support during these times?

Q.13 What family/community supports are available to your child/young person? (Please ✓ all that apply)

Immediate family ☐1 Neighbours ☐2 Extended family ☐3
 Friends ☐4 Local community groups ☐5 Club ☐6
 Parents support group ☐7 Other ☐8 (Please state) _____

Q.13(a) Please indicate your overall assessment of the support available to your child/young person from the extended family, neighbours and local community. (Please ✓ one)

Very beneficial ☐5 Of some benefit ☐4 Beneficial ☐3 Of little benefit ☐2 Of no benefit ☐1

Section D
Information and Advocacy Support

Q.14 *How would you describe the information about support services and options that you received at different stages of your child's development?*

(i)	At first indication that the child had additional needs (Please ✓ one)				
Excellent	Good	Adequate	Poor	Very poor	
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
(ii)	At Early Intervention Stage (Please ✓ one)				
Excellent	Good	Adequate	Poor	Very poor	
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
(iii)	At school-going age (Please ✓ one)				
Excellent	Good	Adequate	Poor	Very poor	
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
(iv)	At second-level school stage (Please ✓ one)				
Excellent	Good	Adequate	Poor	Very poor	
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
(v)	At completion of second level education (Please ✓ one)				
Excellent	Good	Adequate	Poor	Very poor	
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
(v)	At transition to training/work/3 rd level education (Please ✓ one)				
Excellent	Good	Adequate	Poor	Very poor	
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	

Q.14(a) If you would like to add any comments on your answers to the previous question, please do so in the space below

Q.15 Does the family have the support of an advocate or key worker to assist you in getting the supports your child/young person requires?
Yes ☐ 1 No ☐ 2

Q.15(a) If YES, how would you rate that support? **(Please ✓ one)**

Very beneficial	Of some benefit	Beneficial	Of little benefit	Of no benefit
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Q.16 Have you at any stage had cause to complain about the services/supports that your child/young person receives? **(Please ✓ one)**

Yes/very frequently	Yes/frequently	Yes/occasionally	Rarely	Never
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Q. 16(a) If YES, how would you describe the way your complaint was dealt with? **(Please ✓ one)**

Dealt with fully and efficiently	<input type="checkbox"/> 5
Dealt with after an inappropriate delay	<input type="checkbox"/> 4
Partly dealt with	<input type="checkbox"/> 3
Complaint noted but not addressed	<input type="checkbox"/> 2
Complaint ignored	<input type="checkbox"/> 1

Section E
General Service Availability and Delivery

Q.17 How would describe the services in [name of county] for children/young persons with needs such as your child?

(Please ✓ one)

Excellent	Good	Adequate	Poor	Very poor
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Q.17(a) If you would like to add any comment on your answer to the previous question, please do so in the space below

Q.18 How would you describe the co-operation between schools, health services and other professionals in responding to the needs of your child/young person?

(Please ✓ one)

Excellent	Good	Adequate	Poor	Very poor
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Q.18(a) If you would like to add any comment on your answer to the previous question, please do so in the space below

Q.19 How would you describe the contribution by the State to supporting the family in meeting the child's needs?

(Please ✓ one)

Excellent	Good	Adequate	Poor	Very poor
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Q.20 Have you experienced any change in the level of support provided by the State to your child/young person during the past 2 years?

Big increase	Small increase	No change	Small decrease	Big decrease
<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Q.20(a) If you would like to add any comment on your answer to the previous question (20), please do so in the space below

Q.21 Are there things that could be done differently by the State to make it easier for you as a family to get the support you need to ensure the best possible outcomes for your child?

Yes ☐ 1

No ☐ 2

Q.21(a) If YES, Please list in order of priority

1. _____

2. _____

3. _____

Section F
Rights and Children/Young Persons with an Intellectual Disability

Q.22 How would you rate the attitude of Irish society generally to children/young persons with an intellectual disability?

(Please ✓ one)

Very positive
☐ 5

Positive
☐ 4

Neither positive or negative
☐ 3

Negative
☐ 2

Very Negative
☐ 1

Q.23 Based on your experience, what is your assessment of how the rights of children/young persons with an intellectual disability in Ireland are protected by the State. (Please ✓ one)

Always
protected
☐ 5

Usually
protected
☐ 4

Sometimes
protected
☐ 3

Rarely
protected
☐ 2

Never
protected
☐ 1

Q. 24 Please indicate whether you agree or disagree with the following statements in relation to the rights of children/young persons with an intellectual disability in Ireland.

	Please ✓ one for each statement	<u>Strongly Agree</u>	<u>Agree</u>	<u>Neither Agree nor Disagree</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
1.	Children/young persons with an intellectual disability are supported and facilitated to enjoy a full and decent life.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
2.	Children/young persons with an intellectual disability are enabled to participate actively in the community.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
3.	Children/young persons with an intellectual disability are provided with equal opportunities for cultural, recreational and leisure activity.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
4.	Children/young persons with an intellectual disability enjoy fully all human rights and basic freedoms on an equal basis with other children/young persons.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
5.	The best interests of children/young persons with an intellectual disability are the primary consideration in all actions by the State affecting them.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
6.	Children/young persons with an intellectual disability are allowed to express their views freely on all matters affecting them.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
7.	The views of children/young persons with an intellectual disability are given due weight in accordance with their age and maturity on an equal basis with other children/ young/persons.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
8.	Children/young persons with an intellectual disability are provided with appropriate assistance to enable them to express their views freely.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
9.	The State ensures that children/young persons with an intellectual disability are given access to the support they may require in exercising their legal capacity.	<input type="radio"/> 5	<input type="radio"/> 4	<input type="radio"/> 3	<input type="radio"/> 2	<input type="radio"/> 1
10.	Children/young persons with an intellectual disability do not enjoy human rights and basic freedoms on an equal basis with other children/young persons.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

Q.24(a) If you would like to make any additional comments on your answers to Q.24 on the previous page, please do so in the space below.

Q.25 If there are any other things that you would like to say about the supports and services that your child/young person receives or about the supports that are available to you as a family, please do so in the space below

Section G
Information about Your Household

In addition to the questions about the supports that you and your child/young person receive that you have already answered, you are now asked to answer Questions 26–33 on the following pages as far as you can.

This information is requested in order to allow the researcher to make a comparison between families living in [name of county] who have a child/young person with an intellectual disability and the general population.

Q. 26 Which of the following best describes your present employment status?

(Please ✓ one)

- | | | |
|---|---|------------------------------------|
| At work <input type="checkbox"/> 1 | Looking for first regular job <input type="checkbox"/> 2 | Student <input type="checkbox"/> 3 |
| Looking after home/family <input type="checkbox"/> 4 | On a CE or similar-type scheme <input type="checkbox"/> 5 | Retired <input type="checkbox"/> 6 |
| Unemployed, having lost or given up previous job <input type="checkbox"/> 7 | | |
| Unable to work because of long-term illness/disability <input type="checkbox"/> 8 | | |
| Other (Please specify) _____ <input type="checkbox"/> 9 | | |

Q. 27 If you are or have been employed outside the home, please describe as accurately as you can your occupation in your current or last main job

Q.28 Please indicate the sources of your household income

(Please ✓ all that apply)

- | | |
|---|---|
| Employment (full-time) <input type="checkbox"/> 1 | Employment (part-time) <input type="checkbox"/> 2 |
| Self-employment <input type="checkbox"/> 3 | Unemployment Payment <input type="checkbox"/> 4 |
| One-parent Family Payment <input type="checkbox"/> 5 | Disability Payment <input type="checkbox"/> 6 |
| Carers' Allowance/Carers Benefit <input type="checkbox"/> 7 | Pension <input type="checkbox"/> 8 |
| Other (Please specify) _____ <input type="checkbox"/> 9 | |

Q.29 Please indicate the number of people normally resident in the household in the following age-ranges.

(Please write the number in each box)

- 0–14 years ☐ 1
15–24 years ☐ 2
25 –44 years ☐ 3
45–64 years ☐ 4
65 years and over ☐ 5

Q.30 Which of the following describes your household type?

(Please ☒ one)

- One person household ☐ 1
Couple without children ☐ 2
Couple with children (any age) ☐ 3
Couple without children but with other persons ☐ 4
Couple with children (any age) and other persons ☐ 5
Lone parent with children (any age) ☐ 6
Lone parent with children (any age) and other persons ☐ 7
Two or more family units ☐ 8
Non-family household ☐ 9

Q. 31 If in employment, does the family receive Family Income Supplement?

(Please ☐ one)

- Yes ☐ 1 No ☐ 2

Q. 32 Does the family have a Medical Card?

(Please ☐ one)

- Yes ☐ 1 No ☐ 2

Q. 33 Please indicate whether your house is owned or rented by ticking ☒ one of the following boxes

- Owner occupied with loan or mortgage ☐ 1
Owner occupied without loan or mortgage ☐ 2
Being purchased from a Local Authority ☐ 3
Rented from a Local Authority ☐ 4
Rented from a Voluntary Body ☐ 5
Private rented unfurnished ☐ 6
Private rented furnished or part furnished ☐ 7
Occupied free of rent ☐ 8
Other (Please state) _____ ☐ 9

**THANK YOU VERY MUCH FOR TAKING THE TIME
TO COMPLETE THIS QUESTIONNAIRE**

Appendix Six

Interviews with Parents/Guardians: Topic Guide Headings

1. General experience of social supports

(Social support refers to the assistance and help that one receives from others. It may be provided inside the home or outside the home and may come from the family, friends, the community, service providers, voluntary groups or paid professionals. The support may be provided to the child/young person directly or to the family or to both)

A. *Which of the following provides significant/meaningful support to you as parent/s/guardian/s*

Immediate family	Other children
Extended family	Neighbours
Friends	Parent support groups (local)
Parent support groups (national)	Local community groups
HSE	School/teachers
[Case study service provider]	Dep. of Education services
Professionals	Other Service Provider
Other	

B. *Which of the following provides significant/meaningful support to your child/young person*

Siblings	Extended family
Neighbours	Friends/peers
Local community groups	Local sports/recreation groups
HSE	Schools/Teachers/Special Needs Assistants
Home tuition	[Case study service provider]
Professionals	Other service provider
Other	

2. Involvement in Needs Assessment and Planning

- ***Assessment of child/young person's support needs***
 - Involvement of family
 - Involvement of child/young person
- ***Drawing up and implementing the Individual Support Plan***
 - Level of involvement of parent/guardian in implementation
 - Level of involvement of child/young person (where the age of the child/young person warrants such involvement)
- ***Overall experience of the Individual Support Plan Approach***

3. Accessing the Support Services required by the Child/Young Person

- How is the experience of *accessing* the required support services
 - In the home
 - Outside the home
- Any blocks/barriers encountered
- Any experience of having to 'fight for' the services required
 - Impact of this on parents/guardians
 - Impact on child/young person

- What role is played by advocates/key workers in getting access to services
- Any significant gaps in support services for your child/young person

4. Services/professionals involved with the child/young person and his/her family

- Number of professionals involved in supporting the child/young person
- Experience of having to deal with multiple services/professionals

5. Impact on Family of Having a Child with an Intellectual Disability

- Positive/negative
- Experience of daily living
- Things that assist/make it easier for the family to manage
- Things that make it difficult for the family to manage
- Challenges faced by the family at different stages of child's development and points of transition

Has there been an assessment carried out of the supports that you as parents/guardians need to manage over and above the supports provided to your child/young person?

6. Perceptions of Social Attitudes to Children with an Intellectual Disability

- Positive/negative?
- Inclusive or not?

7. Language/Terminology Used

Is the terminology used appropriate?

Do labels used have an impact?

- On the child/young person
- On the family

8. Relationship between families of a child with an intellectual disability/autism, the community and the State

What do you think is the right relationship?

- Is it being achieved?
- If not, why not?

9. Costs of having a child with an intellectual disability/autism?

Does the family incur any extra expenditure in accessing additional services/supports?

If so, what impact does this have on the family budget?

10. Rights of Children with an Intellectual Disability

The UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities gives specific rights to children/young persons with a disability. These include, in particular:

- *Right to participate in all decisions affecting him/her in an age-appropriate manner*
- *Right to individual choice, dignity, personhood*
- *Right to inclusive education*
- *Right to equality of access to services*
- *Right to equality of opportunity*
- *Right to equal citizenship*

- *Maximising the child/young person's capacity to make decisions*
- *Maximising the child/young person's developmental potential*
- How aware are you as a parent/guardian of these rights?
- How well are these rights implemented in practice in Ireland?
- What do you see as the blocks to implementing these rights?

11. Exercising Choice

- In your opinion, do children/young persons with an intellectual disability/autism have the same choices as children/young people who do not have these conditions?
- What factors impact on this group of children/young persons exercising choice?
- Negative
- Positive

12. Developing stronger rights-based social supports for children/young persons with an intellectual disability in Ireland

What actions would help?

- By society generally
- By service providers
- By Government

13. Other comments/suggestions that you would like to make

MANY THANKS FOR YOUR HELP

Appendix Seven

Interviews with Young Persons: Topic Guide Headings

Thank you very much for agreeing to talk to me. The reason for talking to you is to get your views on the help that you receive, to hear about the good things and the things that are not so good and to ask you about your hopes and plans. The interview will take about a half an hour. If you need to take a break at any stage please tell me.

I would like to record the interview to make sure that I am getting everything you tell me accurately. If you are not happy with this, I will not record it and will make written notes instead.

1. First of all can I ask you to tell be a bit about yourself

- Age
- Where you live
- Who you live with



2. Do you go to school or to a training centre or work?

3. Can you tell me about your school or training centre or work?

- What is good about it?
- What is not so good about it?

4. Can you tell me about the help that you receive from other people:

- Your parents
- Your brothers and sisters
- Aunts/Uncles
- Granny/Grandad
- Cousins
- Neighbours
- Your friends
- Other people that you know
- School
- [Service Provider]



5. Who are the most important people in your life?



6. Do you have any pets?

7. What are your favourite things to do when you are at home?

TV	DVDs	Radio	Music	Games
Cooking	Reading	Hobbies	Anything else	

8. What music/singer do you like? |||||

9. Can you tell me about when you go out?
- How often do you go out?
 - When (During the week? / On Saturday/Sunday?)
 - Please tell me about the different things that you do when you go out
 - Do you go with a group or with one or two other persons?
 - What do you enjoy doing most when you go out?
 - Do you go on holidays?
 - Do you go away for weekends?

9. Comparing yourself with your friends and with other people in your class, would you say that you go out
- As often as they do
 - More often
 - Less often

10. Do you play any sport?



11. What are the good things for you as a young person?

12. What are the difficult/hard things for you as a young person?

13. When you tell people what you want or ask for something, are you listened to?
- Always
 - Sometimes
 - Never

14. Are there any things that you would like to do that you have not been able to do or that you have not done yet?
If YES, *Please tell me about these*

15. Are you able to give your opinion/say what you want about things that are important for you/ say what you want?
- Always
 - Sometimes
 - Never

16. What would you like to do after you finish school?

17. Do you think that you will be able to do this?

18. What type of work would you like to do in the future?

19. Do you think that you will be able to do this?

20. With whom would you like to live for the future?
- Family
 - Friends
 - On your own



21. Do you think that you will be able to do this?

22. Is there anything else about the help and support that you receive that you think is important that you would like to talk about?

23. Is there anything else about help and support that you feel you need but **do not** receive that you would like to talk about?

Thank you for talking to me and for telling me about yourself and giving me your views

Appendix Eight

Interviews with Service Provider Staff and Professionals: Topic Guide Headings

1. Service delivery role
2. What is your general opinion of the support services available to children/young persons with an intellectual disability in Ireland?
3. How would you describe the supports available at each transitional stage of the child's development?
 - At first indication that child had a disability
 - Pre-school
 - At school-going age
 - At second-level stage
 - At completion of second level education
 - Transition to further education/work/training
4. Would you or would you not say that the best interest of the child/young person is the primary consideration in all decisions affecting the child/young person with an intellectual disability?
5. Do children/young persons with an intellectual disability and their families have access to adequate information concerning their disabilities to enable them to understand fully and manage their situation?
6. Generally, do you feel that the support services available in [name of county] for children/young persons with an intellectual disability are adequate to meet need?
7. Is the availability of professional support services commensurate with need?
8. How would you describe the levels of collaboration, cross-referral, integration between schools, health services, respite services, other support services and training services?
9. Would you say that families are or are not well supported in caring for a child/young person with an intellectual disability?
 - by the community/neighbourhood
 - by the extended family
 - by the State
 - by service providers
 - by advocates/key workers
10. How would you describe the contribution by the State to supporting the family in meeting the needs of children/young persons with an intellectual disability?
11. From your experience, how do the following concepts operate in implementation and practice?
 - Equality of access to health, education and support services
 - Assessment of need
 - Person-directed planning
 - Individual care/support plans
 - Mainstreaming

12. To what extent do you think that services and supports for children/young persons with an intellectual disability in Ireland are informed by the principles underpinning the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities?
13. How do the following rights-based principles underpin the way services for children/young persons with an intellectual disability are delivered in Ireland?
1. *Supported decision making*
 2. *Their views given due weight in all decisions affecting them*
 3. *Maximising individual choices and options*
 4. *Maximising the potential of each individual*
 5. *Active participation in the community*
 6. *Equal opportunities for cultural, recreational and leisure activity*
 7. *Citizenship*
 8. *Equality of opportunity*
14. What is the appropriate balance between the weight given to the views of parents/guardians and the views of children/young persons with an intellectual disability?
- Is the right balance achieved in practice?
15. How would you describe the attitude of society generally to children/young persons with an intellectual disability?
16. What additional support services are required to enhance citizenship for children/young persons with an intellectual disability?
17. Are there any additional comments/observations that you would like to make?

Thank You