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**Independent Living for People with  
Disability and High Dependency Needs -  
Why we need a P.A. Act and what it might  
look like in the Irish Context.**

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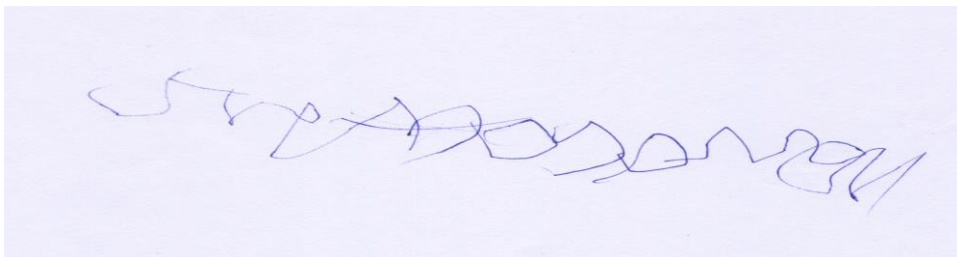
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## Declaration

I declare that this thesis was composed by myself, that the work contained herein is my own except where explicitly stated otherwise in the text, and that this work has not been submitted for any other degree or professional qualification.

A rectangular area containing a handwritten signature in blue ink. The signature is cursive and appears to be 'M. J. ...'.

## **Acknowledgements**

Completing this thesis is by far the most challenging task that I have undertaken in my life so far. It has kept me going during dark days and, equally, has caused me many dark days with the testing demands and almost insurmountable difficulties it has presented me with.

It is a task I could not have undertaken alone. I am, first and foremost, deeply indebted to my immediate family – my parents Rory and Patricia and my brother Eoin, who have been my encouragement and inspiration, not only during my PhD period, but throughout my whole life. Very special mention must go to my mum, Patricia, who has enabled me, by her belief, drive and determination, to push my horizons endlessly and to believe that all things are possible. She is my help, my rock and my inspiration and this work is particularly dedicated to her.

It is also dedicated to all those PWDs out there who have been conditioned by our society to believe that their potential is limited by their disability. I would hope to convince them that it is not. I would also hope that they might be inspired in some small way by my journey and to undertake journeys of their own in the belief that all things are possible.

Finally, I would also like to thank my supervisors Shivaun Quinlivan and Andrew Power (University of Southampton) and the staff at the Centre for Disability Law and Policy at National University of Galway.

## **Abstract**

This research examines the legislative context for Independent Living for people with disabilities and high dependency needs in Ireland. The CRPD provides the key platform for this and reaffirms the fundamental rights of people with disabilities for inclusion, independence and equality. It has the key role in articulating the vision of people with disabilities, and people advocating on their behalf, for an inclusive, dignified and independent life with the freedom to make their own choices. Following the principles of the CRPD, I believe we should go a step further by taking the principles of the Convention and make them legally binding in our country in the form of a P.A. Act.

The introduction gives the reader a ‘First-hand Account of Independent Living’ through my difficulties of coping with inadequate support leading to social exclusion and alienation, frequently experienced by people with disabilities. I speak candidly about my experiences, as a person with a disability and high dependency needs, throughout my life. The challenges I face on a daily basis are frustrating, depressing and degrading as they chip away at my hunger for independence, dignity and a quality of my life that most people take for granted. Many of these challenges could be avoided if I had sufficient Personal Assistance to allow me to live independently with freedom of choice as per the tenets of the CRPD.

After examining how the key aspects of the Irish disability legal and policy methods relate to the principles of the CRPD, I focus on Independent Living and the types of services needed for this to be realised. People with disabilities are the ‘experts’ on disability and high dependency needs and must be treated as such and involved with the ‘decision-makers’ in their support packages. This is clearly outlined in Article 4.3 of the CRPD.

Education empowers people with disabilities to be more confident, more educated, socially-skilled and more likely to gain employment. In addition,



the value of the sense of self-esteem that education brings, cannot be over-estimated in the lives of people with disabilities.

It is with mixed emotions that I conclude the research with recommendations for the Irish Government to provide a rights-based policy and person-centred practice which are progressive and comprehensive for people with disabilities and high dependency needs. We need to look forward and continue our active participation, criticism and advocacy for independence that make our world an inclusive, secure and supported community environment where our struggles will not be so profound. I have hope – optimism is the faith that leads to achievement.

## **List of Abbreviations**

AHC	Ad Hoc Committee
ANED	Academic Network of European Disability experts
ÁT	Áiseanna Tacaíochta
CAB	Citizens Advice Board (Ireland)
CD-P-RR	Committee on the Rehabilitation and Integration of People with Disabilities (Partial Agreement)
CD-P-SP	Public Health Committee (Partial Agreement)
CEB	CoE Development Bank
CEDAW	Convention on the Elimination of Discrimination of Women
CESCR	Committee on Economic, Social and Cultural Rights
CHO	Community Healthcare Organisation
CIB	Citizens Information Board
CIE	Committee of Independent Experts
CIL	Centre for Independent Living
CoE	Council of Europe
CPQ	Cerebral Palsy Quadriplegia
CRPD	Convention on the Rights of People with Disabilities
CSO	Central Statistics Office
DAP	Disability Action Plan
DELOC	De-institutionalisation & Community Living: Outcomes and Costs
DFI	Disability Federation Ireland
DLA	Disability Living Allowance
DPI	Disabled People's International
DRC	Disability Rights Commission

ECCL	European Coalition for Community Living
EC	European Commission
ECHR	European Convention on Human Rights
ECJ	European Court of Justice
ECSR	European Committee on Social Rights
ECtHR	European Court on Human Rights
EHR	European Human Rights Reports
ENIL	European Network on Independent Living
ESC	European Social Charter
ESF	European Social Fund
ESIF	European Structural and Investment Funds
ESW	Educational Support Worker
EU	European Union
EYPD	European Year of People with Disabilities
FLAC	Free Legal Advice Clinics/Centres
ICCL	Irish Council for Civil Liberties
FRA	European Union Agency for Fundamental Rights
GBP	British Pound Sterling
HEA	Higher Education Authority
HIQUA	Health Information and Quality Authority
HSE	Health Service Executive
ICF	International Classification of Functioning
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ILF	Independent Living Fund

IPFT	Irish Penal Reform Trust
IWA	Irish Wheelchair Association
NAP	National Action Plan
NAS	National Advocacy Service
NDA	National Disability Authority
NDS	National Disability Strategy
NDS	(Ireland's) National Disability Survey
NESC	National Economic and Social Council
NGO	Non-governmental Organisations
NIDD	National Intellectual Disability Database
NPSDD	National Physical and Sensory Disability Database
NSP	National Service Plan
NUI	National University of Ireland
OECD	Organisation for the Economic Co-operation and Development
OP	Optional Protocol
OT	Occupational Therapy
PA	Personal Assistance/Assistant
PACE	Parliamentary Assembly Council of Europe
PAS	Personal Advocacy Service
PAS	Personal Assistance Service
PDSP	Physically Disabled Students Program
PWD	Person/People with Disability/Disabilities
RAS	Resource Allocation System
SILC	Survey on Income and Living Conditions
SLA	Service Level Agreements

SNA	Special Needs Assistant/Assistance
UDHR	Universal Declaration of Human Rights
UN	United Nations
WHO	World Health Org

## **Chapter One**

### **Independent Living for People with Disabilities and High Dependency Needs**

#### **1.1 Introduction - A First-hand Account of Independent Living as a Person living with Disability and High Dependency Needs**

Grounded in my own experiences of independent living as a person with a disability and high dependency needs, this study critically examines international human rights law with a view to informing Irish legislation and disability policy that would support people with disabilities to live an independent life and participate in society as equal citizens. The focus of the study is the UN Convention on the Rights of People with Disabilities (CRPD), specifically how its underlying principles might ensure people with disabilities an independent life, free from poverty and disadvantage and a standard of living that is commensurate with the general population.

Before introducing key concepts underlying the study, this section turns briefly to my own experiences of everyday life as a disabled person living independently in my community. A source of data informing the present study on the circumstances and challenges of leading such a life in Ireland, the section focuses on how I interact with my physical and social environment and the barriers placed before me based on legal and policy frameworks and the resources and services available to me.

I was born in 1984, 11 weeks prematurely and have grown up with high dependency needs as I was diagnosed with Cerebral Palsy Quadriplegia (CPQ) when I was 9 months old. The outlook for me given to my parents about my future was bleak but from the outset they saw potential in me that others missed. They enrolled me in a course of Conductive Education run by the Peto Institute, renowned for its positive approach to children with CPQ, wishing to give me every chance to live as normal and independent a life as possible. They quickly passed on this determination to me – a wish to strive

in every respect to live a full and fulfilling life. When I was 3 years old I started 'kindergarten' in Rotterdam where my family was living at the time. There the regime required me to have at least a one-hour nap at a specific time each day. When I objected and created a scene, my 'cot' was wheeled into a store cupboard and there I spent the hour, so the other children could sleep in peace. In regular kindergarten centres it was a parent's choice whether their child needed a nap or not. I found the daily programme which consisted of songs, playing, sleeping and eating boring and unfulfilling. At the age of 4 I advanced to the adjoining school and was part of a class of about 6 or 7 disabled pupils of mixed ability. I was even more unfulfilled as the programme was very similar with no academic stimulation. This situation was to continue when my family moved to Southampton, in the U.K. I joined a class of about 8 disabled pupils in a 'Special' school where academia was not catered for. After a long struggle my parents were successful in their quest to enrol me in a mainstream school and so I woke up, started to learn, had numerous friends and went from strength to strength in my new environment. These early experiences of both segregation and integration tell us that unless a human being is accepted for who they are through complete integration, they will not develop and grow to their full potential. They also highlight characteristics and underlying views common to education systems across EU member states at that time - that 'Special' schools were needed for 'Special' children. They required special care and needed to be tucked away from 'normal' children lest the latter would mimic these 'special' children and behave in a similar way or worse still they might pick up something from them. I am glad to say those dark days are over and attitudes and facilities are at a more humane stage but are far from where they should be.

For as long as I recall I constantly strove to develop my own sense of identity. I have always wanted to be in charge of my life. From an early age, I expected that I would live independently in the community and contribute to the public purse. Realising this kind of an independent life-style was paramount for me as it represented the prospect of having privacy, personal choice and control over where, how and with whom to live. Up to the age of 19 I lived with my parents, handing over my weekly social welfare payments to my parents who

were the primary carers in the home. Luckily for me, they were fortunate enough to be able to put it into my bank account towards the cost of my further education. During this time, I also frequented state and voluntary respite care institutions where I availed of their services. Then, as is typical for young adults and post-secondary school students, I had a desire to move out of the family home which I did once I found a suitable place of my own and secured personal assistance hours and social housing supports. My decision, transition and ability to live independently for the past 14 years relied on a combination of factors. Not least was my sense of self and levels of clarity, confidence and determination to live my life how I wanted. For example, well before the age of 19 I was astute with managing most aspects of my life such as my own time and who I socialised with. I was also adept with managing my own finances as my parents made sure I had plenty of experience controlling and budgeting my pocket-money from an early age. There has also been the unrelenting support of my family who played a key role facilitating the start-up process and continue to enable independent living and my sense of independence, privacy and safety in my own place. Aware of my ability to cope with difficult and different situations on the one hand and the lack of services to support people with high dependency needs to live alone on the other, they were both delighted and apprehensive about the prospect of me living in this way.

Compared to living at home with my parents or in a state institution where I would have full-time residential care and such services as occupational therapy (OT) to hand - living in my own home gives me a lot more freedom to pursue my goals, do as I wish and organise and live my life as I please within the limits of my disability. I can structure my own day and manage my own money. I make decisions on a day-to-day basis i.e. about when to get up, what to eat, what to wear, what to buy, what TV and radio shows to watch/listen to and who to connect and share my life with. Exercising self-determination and weaving my own web of everyday life in a dignified way enhances my sense of self and makes me feel good. This freedom and practice of independent living however does not come without challenges. Not least are the difficulties of dealing with the everyday practicalities of managing to



survive, running my household, maintaining my health, lifestyle and privacy and engaging with a range of public and private services and formal supports to ensure my many and varied high dependency needs are met. Ensuring even the basics, such as a week's supply of nourishing food, water and prescription medication, paying my bills, scheduling and attending medical appointments or maintaining and keeping essential equipment such as my power-chair and hoist powered up requires an enormous amount of time, energy and planning. Furthermore, the adversity I deal with in a highly disabling social and physical environment characterised by bureaucracy, inaccessible buildings and negative attitudes is constant. Compounding this is adversity because of the current economic climate. I endure various levels of stress and strain meeting a combination of high routine and exceptional costs incurred not just by standard daily consumption but also my disability and high dependency.

Compounding the high cost of living with a disability is the insufficient personal assistance to hand, low levels of personal control over disability payments and formal supports, inadequately funded services and limited personal income based on absolute rather than graded disability benefits. Together these disabling aspects and restrictions on my everyday life require me to practise high levels of resilience, personal insight, reflection and flexibility. They demand endless hard work and a multitude of skills, from time management and planning to interpersonal and financial skills and an abundance of cognitive, emotional and physical energy to sustain high levels of perseverance and commitment. Whilst the study is limited in so far as it can reveal the full extent to which such restrictions impede my ability to practice a self-determined life in the community, it is nonetheless important to pay some attention to the manner in which inadequate personal assistance, limited funding and resources and absolutist disability payments shape my experiences of independent living with high dependency needs and my vulnerability to multiple forms of social exclusion, poverty and discrimination.

Let me first turn to personal assistance (PA) which I have been using since I was 19 for most aspects of daily life, from personal care and social life to attending university and completing third and fourth level education. After a

long hard-won battle fought by myself with the support of family and lecturers, I currently benefit from two personal assistance support programmes provided by established organisations. Funded by the HSE West, the larger of the two is administered by the Irish Wheelchair Association (IWA) a community-based voluntary group. The second is funded by the National University of Ireland, Galway (NUI Galway) and administered more recently by Servicesource, a private organisation specialising in the home care sector. Over the years I have found my relationships with my personal assistants and service operators to be highly complex, multifaceted and sensitive. As with any formal or informal inter-personal relationship, they are shaped by an array of gender, age and other intersecting power dynamics. Without exception, leaders such as myself should be supported to hold as much control as possible within any assisted transaction and be in-charge, whether of our finances, choice of physiotherapist, brand of coffee or TV show. Also vital for my health and autonomy is high quality, adequate, one-to-one personal assistance tailored to my specific needs and preferences. A distinctive feature of both programmes providing personal assistance however is the limited control I have over either. Over the years this has resulted in a lack of decisive influence on the way in which this service is designed, managed and delivered according to my specific needs, preferences, life choices and desire to participate and contribute to society. For example, I have limited involvement in the recruitment and training of my PAs often leading to counterproductive independent living practices. Whilst I agree with the need for basic provider-managed training of PAs, such as manual handling, I remain cautious about the extent to which FETAC certification Level 5 - a requirement which providers have introduced when recruiting PAs – represents an ideal form of training and preparation. The subject matter has not always suited my needs and I have found an understanding of the social model of disability and an appreciation of the ethos of independent living to be lacking such that what this type of life-style means in practice is not always taken on board by the PAs. Rather than a formal qualification based on a one-size-fits-all approach, much more important for my ability to live an independent life are the personal traits and inter-personal skills of my PAs, such as patience, empathy, flexibility, respect

for equality, diversity and the ethos of self-determination, an ability to listen and converse with ease – and not forgetting of course - a sense of humour.

Adolf Ratzka (a personal service user) has argued that the term ‘Personal Assistance’ cannot be truly applied where the service is controlled and delivered by community agencies or local government owing to the hierarchical nature of such organisations that place the service user at the bottom of such hierarchies.<sup>1</sup> His view is that “[s]ocial policy is rarely made by the people whose lives depend on it. For that reason we often see legislation, programs and practices that make people with disabilities more dependent rather than more independent.”<sup>2</sup>

Within this context of governance and unequal power relations, my ability to exercise any control over the quality, content and effectiveness of such services is limited by current forms of regulation and the system of budget allocation in Ireland where payments to personal assistants are not made directly by the disabled person. Instead of being a direct employer and manager of the personal supports I use daily, I am a passive recipient of an ‘in-kind’ payment for personal assistance with very little say and influence over the administration of funding and resources for recruitment, training and salaries of my PAs. Meanwhile most of the responsibility and hence control of the service lies with the two provider organisations. As well as the disempowering effects this has on myself as the service user, operating the PA service in this way generates additional monetary costs and unnecessary levels of bureaucracy, diverting already scarce funds away from service provision itself. Additionally, and as has been my experience, this threatens the pay and working conditions of my PAs, compromises service availability

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<sup>1</sup> Adolf Ratzka, “The Swedish Personal Assistance Act of 1994” (Independent Living Institute, 2004)

<<https://www.independentliving.org/docs6/ratzka20040623.html>> accessed 10 June 2016.

<sup>2</sup> Adolf Ratzka (ed.), “National Personal Assistance Policy” (European Centre for Excellence in Personal Assistance, 2010)

<<https://www.independentliving.org/docs6/ratzka200410a.pdf>> accessed 20 October 2018.

and quality and ultimately jeopardises even the most basic standards of independent living.

A further impediment to my ability to practice self-determination and enjoy independent living is the poorly funded PA service in Ireland and its vulnerability to erosion and serial cutbacks. Because of my high dependency needs, living an independent life to the degree I desire and am comfortable with, requires me to have continuous home-based coverage i.e. 24/7 cover. At present I receive inadequate levels of cover from the Health Service Executive (HSE) which leaves me alone for prolonged periods of isolation and immobility, without care or company. In other words, for about 6-7 hours of my waking day I am without human contact and I do not have any form of assistance. The support hours I receive from the Higher Education Authority (HEA) through National University of Ireland, Galway (NUI Galway) will cease when my education is finished. Being left without sufficient PA hours has made the transition and process of independent life very difficult, sometimes distinguishing between surviving and living a meaningful life. It has enormous repercussions on my ability to go about my daily life and on my well-being, not least my immediate and day-to-day physical and emotional health as I do not have the full array of special aids and domestic appliances installed in my house necessary for such basic activities as drinking, eating and so forth. I cannot get up or nourish or hydrate myself when I want. I cannot leave my home, go to college, go shopping, visit friends etc. without the support of a personal assistant. Insufficient PA hours thus curtails my already limited participation in everyday private and public life whether in my home, in education and during leisure time activities and other aspects of social life. It also increases my emotional and other forms of dependency on my friends and family. Adding to the day to day inconveniences and anxieties caused by insufficient care and assistance is the prospect of both remaining indefinitely on the HSE waiting list for an increase in PA hours and the reality of losing a substantial number of weekly hours as soon as I complete my Ph.D. No longer a student, I will not be entitled to the invaluable education related support I am currently in receipt of. Besides enhancing my potential to contribute to the exchequer and facilitating active

citizenship and productivity (albeit unpaid) such as disability research and advocacy, the hours have helped me avoid living in a residential care institution or with my parents. Aware of the multiple forms of poverty and social exclusion experienced by people with disabilities in my community and elsewhere in Ireland, I constantly worry about the consequences of losing these academic personal assistance hours. When I finish college I anticipate that I will be totally reliant on my current allowance of HSE hours (approximately 97 hours per week). I am deeply concerned about the effect this will have on my physical and mental health needs. Instead of looking forward to a new and exciting chapter in my life I am dreading it. My ability to exercise self-determination and generate an income of my own is beginning to seem 'out of reach' and unattainable under the present system. Foremost on my mind is my vulnerability to poverty and enforced institutionalised dependency, whether emotional or financial, on the state and on my family.

Whilst integral to independent living, a framework ensuring a secure and consumer-controlled service and fund - from which PWDs such as myself could get as many hours as we require - still does not exist in Ireland. As a result, my experiences of living with very diverse and high dependency needs in my own home have been marred by a combination of inadequate hours and my lack of influence and choice about the organisation of my PA service including the option of direct payment. I feel frustrated by my limited ability to direct a service so fundamental to my everyday life whilst the uncertainty I face about future provision, supports and transitioning from education to work compromises my ability to plan for and build an independent life. Managing the anxiety, fear and frustration associated with this demands high levels of emotional energy already needed simply to get on with life and meet the challenges faced by typical people without disabilities. In sum, whilst generating more work and a different set of challenges, I feel I would benefit more from a policy and system based on assessment of need, access to advocacy and direct payments, where I pay the wages, giving me more control as well as access to back-stopping and tailored supports where necessary.

Over the past 14 years, the quality of my health and well-being and my transition and ability to live according to how I choose have been profoundly shaped by limited public funding and resources essential for decent living conditions and standards of independent living. Furthermore, the absolutist nature of the current system in Ireland allocating PWDs their living allowance also has profound consequences for my standards of independent living, quality of life and vulnerability to poverty. In Ireland graded disability allowance, employment opportunities, tax allowances, or allocation of a lump sum, depending on severity of disability, for extra expenses incurred by people with disabilities and high dependency needs as they commence employment simply do not exist. My entitlement to the disability living allowance, extra social welfare benefits and supplementary welfare payments is not only similar to disabled people with medium and low dependency needs, but also resembles entitlements rightly afforded to non-disabled people who are in employment but are in receipt of benefits subsidised by the state to enhance their earnings. For example, people with severe disabilities, such as myself, should be allocated a higher allowance according to higher dependency needs and those with lower needs allocated a graded payment according to their needs. The system of allocating benefit payments to PWDs currently does not vary according to the degree of disability.

Since the age of 16 I have been in receipt of Disability Allowance which is a weekly allowance paid to PWDS. In 2016 and up to March 2017 the weekly maximum rate of Disability Allowance was €188.00. From March 2017, the rate is €193.00 and now currently stands at €198.00, an increment of €5.00 annually. I also get extra benefits associated with disability allowance. For example, I am entitled to travel free of charge on public transport (which I largely find inaccessible) and receive the Household Benefits Package that is to help me with the costs of running my household. It includes electricity and gas allowances; a Free Television Licence and the National Fuel Scheme provides me with an allowance to help towards my heating needs during certain times of the year. My circumstances also qualify me for social housing support which I receive through the Housing Assistance Payment. Meanwhile, to make the cost of health and medical care more affordable I

also receive benefits and services provided by the HSE West. For example, my medical card allows me to access GP services for free, and with the Drugs Payment Scheme I pay €134 each month for approved prescribed drugs.

Whilst the system goes some way towards recognising my vulnerability to income poverty caused by the high cost of living and my reduced earning capacity, it does not take into consideration the routine and exceptional costs of *independent living with high dependency needs*. For example, and as previously mentioned in the chapter, I face many difficulties meeting the material costs of living incurred by standard daily consumption and also my disability. Not least are the costs of my basic health care generated by prescription medication (€20.00) and regular physiotherapy (€200.00) to help control severe pain. There are also the costs of day-to-day maintenance alongside the heavy consumption of utilities due to my high dependency needs. Higher refuse charges (because of my personal care needs), greater electricity consumption (due to being at home most days), lighting, mainstream technology (electric hoisting, power chair, electric bed etc.), more frequent use of washing machine as well as recharging batteries for assistive devices all contribute to an above average monthly expenditure. As a person with very limited mobility I also need to keep my house warm at all times of the year due to my inactivity and inability to exercise. As I do not go out much and spend long periods at home, sometimes alone, I need access to internet and TV to keep me in touch with the outside world. Currently, and as has been in the past, my disability allowance and subsidies together, in no way cover all of my living costs, leaving me to depend on family for regular financial support. This flies in the face of the ethos of independent living and compromises my ability to practice dignified self-determination.

The vast majority of routine tasks in my home are human and technology assisted. To get on with life and perform most basic and routine tasks I am fully reliant on an array of formal supports beyond personal assistance including mainstream and assistive technologies, not least my hoist, power chair, TV and my mobile phone. Technology lessens my need to rely on formal and informal supports, giving me a sense of freedom, privacy and

control thus making it easier for me to live independently. Assistive technologies and devices for example are essential for simplifying my daily life and making a success out of independent living. With the aid of personal assistance, the hoist enables me to get out of bed, the power chair enables me to move about inside and outside my home with relative ease and independence whilst the environmental-controls (though limited – allows me to open front door and turn on TV) make me feel less isolated and more confident and safe, especially when I am on my own in the house for long periods. I also rely on my computer, the internet and mobile phone to access information, undertake research, complete my education and other productive activities such as disability advocacy. Finally, technology is vital for me to enjoy dignified self-determination as it helps me to, not just receive, but also reciprocate love, care, assistance and other forms of emotional support. It is essential for me to maintain one of most highly valued elements in my life; regular contact and companionship with family and friends most of whom do not live near me.

Having a disability for me means going about my daily life in a completely different way to others. My life is not defined by my disability and my high dependency needs, but it is greatly affected by it. Like all the other aspects of my personality, I have lived with them all my life and am apt at self-managing the challenges they bring to my life. For example, I take more time to get from place to place compared to a typical person without any physical disability or a person with a less severe or different type of disability. My biggest problems are moving about and accessing spaces such as streets, footpaths, sports stadiums, restaurants, buildings, hospitals and community welfare and health services as they are not often designed to accommodate my access needs.

## **1.2 Conceptualising Disability: The Nature of Disability**

Discussed in much greater detail in chapter two of the thesis, this section briefly sets out what the study understands by disability as this has important legal and policy implications for the broad range of characteristics of people



with a disability. The concept of disability underlying this study is the ‘bio-psycho-social model’ of disability advocated by the World Health Organisation (WHO). In this model disability is understood in terms of how the individual interacts with the physical and social environment. In other words, to understand what people can do, we need to take account of the resources available to them and the barriers placed before them in their environment as well as their own physical, mental and emotional resources.<sup>3</sup> Depending on the context therefore, the term disability can mean different things. How the study understands disability is grounded in constructivist and intersectional perspectives. For example, drawing on a social relations approach, including gender and lifecycle, the study recognises the links between disability and ageing. It also covers the significant role gender relations, including the wider gender regime, play in shaping the emergence of disability, in other words the multiple challenges women and men with disabilities encounter at different life cycle stages. The study understands the nature of disability to be multidimensional, encompassing the type of disability, the level of difficulty associated with disability and its impact on health, stamina and people’s ability to perform basic activities such as self-care. It extends to specific areas in which people are limited in their everyday activities, from education, paid work and living standards to the social and built environment. In terms of education and paid work, disability constitutes not just the extent to which PWDs are able to participate in these key areas of life; it also relates to the consequences this has for people’s living standards and vulnerability to income and other forms of poverty, as with all vulnerable groups, labour force participation is an important goal for people with disabilities, representing the primary route out of poverty and disadvantage<sup>4</sup>. Whilst not the focus of the study, it is important nonetheless to note the powerful influence prevailing gender relations, and its structures of power, cathexis and labour not least unpaid care have on the economic status and

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<sup>3</sup> Dorothy Watson and Brian Nolan, Department of Social Protection, *A Social Portrait of People with Disabilities in Ireland* (Dublin, 2011) xi.

<sup>4</sup> *Ibid.*, 21.

financial independence of women and men with disabilities.<sup>5</sup> The emergence of disability and PWDs' vulnerability to poverty is further exacerbated by the additional costs of disability itself which according to recent research amount to just under one third of the average household income.<sup>6</sup> This reduces those from low socio-economic backgrounds to even greater disadvantage and poverty. Other forces driving the social construction and emergence of disability are the social and physical environments of disability, as these shape what people can do and the level of difficulty they experience.

Briefly, the social environment pertains to marital status and living arrangements, informal supports, use of care services, the attitudes of other people, experiences of discrimination and participation in social activities. Indeed, the broad range of characteristics of people with a disability are particularly shaped by the reciprocal relationship between disadvantage and disability and the link between living arrangements and care or personal assistance. Meanwhile, the physical environment encompasses the level of difficulty people with disabilities have in carrying out routine daily activities in their home and in accessing services and participating in activities outside the home.<sup>7</sup>

### **1.3 Thesis' Rationale and Aims and Objectives of the Study**

As discussed briefly in the previous section of this chapter, a nexus exists between disability, educational disadvantage and economic activity. These reciprocal relationships emphasise informal and formal supports and flexible living and working arrangements as critical enabling factors for diminishing

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<sup>5</sup> Bettye Rose Connell and Jon A. Sanford, "Research Implications of Universal Design" in Edward Steinfeld and Gary Scott Danford (eds.), *Enabling Environments* (Springer 1999) 35-57.

<sup>6</sup> John Cullinan and Brenda Gannon, "Estimating the Extra Cost of Living for People with Disabilities" (2010) 20(5) *Home Economics* 582-99.

<sup>7</sup> Dorothy Watson and Brian Nolan, Department of Social Protection, *A Social Portrait of People with Disabilities in Ireland* (Dublin, 2011) xiv.

the risk of PWDs to poverty and increasing their meaningful participation in key areas of social life. Addressing areas of daily life where people are limited through their gender and other aspects of their life-course, demands the full implementation of the relevant international legal and policy instruments and State measures. Still absent in the Irish context which is elaborated on further in chapter six, these would go some way towards ensuring the availability of adequate funding and disability-adjusted resources. This line of argument underlies the rationale, aims and objectives of the study and represents its central thesis to which the current section now turns.

The crux of my thesis argument revolves around choice, control, funding and resources for independent living. With a view to informing Irish legislation and disability policy, the study critically examines international human rights law, namely the United Nations Convention on the Rights of People with Disability (CRPD). Elaborated on in greater detail in chapter four, the CRPD is an internationally recognised legal tool designed to guarantee PWDs their fundamental rights. According to recent research and providing justification for this study, PWDs living in Ireland are very disadvantaged in terms of educational achievement, participation in employment and living standards and are at a higher risk of experiencing poverty and social exclusion compared to the general population.<sup>8</sup> Despite availability of social science research and analysis about the impact of the lack of state measures to address the characteristics and grave circumstances of people with disability (PWD), Ireland has only recently ratified the CRPD (March 2018), a decade after signing it. This has consequences for the lack of relevant State measures that would ensure PWDs can live a life free from poverty and disadvantage and a standard of living that is consummate with the general population through education, paid work and enabling social and physical environments. The relatively recent genesis of the CRPD and the limited although growing body

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<sup>8</sup> The Economic and Social Research Institute, Dorothy Watson, Joanne Banks and Sean Lyons, *Education and Employment Experiences of People with a Disability in Ireland: An Analysis of the National Disability Survey, Final Report* (Research Series Number 41, 2015).

of legal research and academic publications related to it provides further justification for this study's timely examination of the CRPD.

Combining two epistemological approaches, autoethnography and standpoint and based on an analysis of statutory material, academic commentary, and secondary materials such as policy reports, media articles and advocacy group recommendations, this study aims to address the current knowledge lacuna about the CRPD, specifically in the current Irish context. Its objective is to examine the proposition that there are several 'core elements' underpinning it that – by providing for funding and resources, graded disability payments - have the potential to enable PWDs to lead an independent life and participate in key areas of social life. The specific objective of the study is to therefore bring meaning to Article 19 (living independently and being included in the community) as well as examine the relevance of Article 12 (equal recognition before the law) and the rights of persons with a disability to exercise legal capacity on an equal basis with other persons, Article 5 (equality and non-discrimination) and Article 9 on reasonable accommodation and accessibility. In this way, the study aims to contribute to current legal scholarship and case-study literature on the relevance of the CRPD to the Irish context.

#### **1.4 Research Question and Avenues of Enquiry**

Building on this, the central research question guiding the study asks:

*Independent Living for People with Disability and High Dependency Needs: Why we need a P.A. Act and what it might look like in the Irish Context.*

Following that, the following objectives were designed and aimed to be answered in the thesis:

##### **Objective 1: Legal measures**

- a. To discuss what legal measures and actions are required for Ireland to adhere to the core principles underpinning the CRPD ensuring people with disability's dignity, individual autonomy including the freedom to make one's own choices, and effective participation and inclusion in society.
- b. To explore how these legal measures might provide for the diverse needs of people with disability and high dependency needs?
- c. To explore what type of framework is needed for people with high dependency needs to practice independent living in their community?

## **Objective 2: Supports and Services**

- a. To explore what sorts of services and supports are required for Ireland to adhere to the core principles underpinning the CRPD?
- b. To explore how a person-centred home and community-based care model might ensure people with disabilities and high dependency needs have dignity, individual autonomy including the freedom to make one's own choices, and effective participation and inclusion in society.
- c. To discuss what a self-directed system of Personal Assistance Service (PAS) for independent living would look like?
- d. To explore what type of system is needed for people with high dependency needs to make independent choices and direct the types of Personal Assistance services they require?

## **1.5 Structure of the Study**

The study is divided into seven chapters. This first chapter introduced the study by describing my own experiences of independent living with high dependency needs. It then situated the study in its theoretical and empirical context. It highlighted the relevance and rationale of the thesis and then explained the research question and what research methods were used to undertake the study. Chapter two then elaborates on the conceptual foundations underlying the methodology guiding the examination of international human rights law and how its provisions might influence disability law and policy in Ireland. Chapter three focuses on Independent Living. After expanding on its key components underlying the concept, it traces the evolution and development of the independent living movement in response to the institutionalisation of disability and the way people with disabilities have been made to fit into society. It is also important to consider the evolution in thinking and emphasis at multiple levels and within key systems of governance where legal instruments are designed and promulgated promoting the rights of PWDs. This is the focus of chapters four and five which describe UN and European human rights frameworks respectively, relating to independent living, the main yardsticks being the UN Convention on the Rights of Persons with Disabilities 2006 (CRPD) and the European Convention on Human Rights (ECHR). Although the focus of the study is largely on Article 19 of the CRPD (living independently and being included in the community), through chapter four, it specifically examines the relevance of Article 12 (equal recognition before the law) and the rights of persons with a disability to exercise legal capacity on an equal basis with other persons. Article 5 (equality and non-discrimination and reasonable accommodation) and Article 9 (accessibility) are also considered. Chapter six provides relevant information about the Irish State, the empirical context under study, where evolution in thinking on the nature of disability and the rights of people with disabilities to participate in all aspects of social life - based on people's own choice - is currently not reflected in legislation, policy and services such as the shift from institutional care settings to independent or community-based living. The main concern of the thesis, the chapter calls attention to the persisting lack of legal, policy and institutional developments hampering Ireland's capacity to ensure PWDs a life free from poverty and

disadvantage and a standard of living that is commensurate with the general population. Chapter seven, the final chapter, discusses the insights and findings gleaned from the study and puts forward legal and policy recommendations for immediate action by the Irish State.

## **1.6 Limitations**

There are number of topics which are not covered in my thesis.

They include independent living provisions for people with low to medium dependency needs and people with intellectual disabilities. This was done because they are major topics in their own right and should be explored in separate theses. In addition, I wanted my research to focus on persons with high dependency needs due to the methodology used in the thesis.

Also, I made a conscious decision not to explore ‘resource allocation’ mechanisms (i.e. how it is decided and by whom and how much a direct payment or a personal budget should be) because I believe that it should be done by the government through its policies, as it is the role of the Government to allocate and distribute resources as they see fit.

And finally, specific issues concerning brokerage and supported decision making for people with high dependency needs were also not addresses in the thesis, because I believe it should always remain a personal choice of an individual.

## **Chapter Two**

### **Theoretical Perspectives and Methodology**

#### **2.1 Introduction**

The focus of this short chapter is research design and methodology. It explains how the study was conducted to address its central concern, namely how key aspects of the Irish disability legal and policy context, in which every day independent life is being practiced by people with disabilities such as myself, relate to relevant principles of the CRPD. The chapter is divided into four sections. The first is concerned with the theoretical perspectives on generating knowledge and understanding the socio-legal disability context for independent living in Ireland. It elucidates what and why the particular research paradigm and approaches to data collection and analysis were chosen. It thus clarifies the philosophical foundations of the study including its basic assumptions about claim-making and the concept of disability. Guided by the social constructivist paradigm, the methodology combines elements found within two epistemological approaches, auto-ethnography and standpoint, the theoretical perspectives of which are also critically reviewed in section one. Then in the next section, the functionality of the methodology is discussed in light of how the socio-legal and comparative legal approaches were used to address the research question.

#### **2.2 Constructivist Approaches to Disability**

The term disability is an ideological term. Furthermore, how disability is conceptualised is an ideological act<sup>1</sup> that has fundamental implications for making claims about the concept and context of disability, for the eligibility for public programmes and the scope of disability legislation.<sup>2</sup> For example, where disability is understood not as individual impairment but as

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<sup>1</sup> David Pfeiffer, "The Philosophical Foundations of Disability Studies" (2002) 22(2) *Disability Studies Quarterly* 3-23.

<sup>2</sup> Sophie Mitra, "The Capability Approach and Disability" (2006) 16(4) *Journal of Disability Policy Studies* 236-247.



discrimination and value judgements about functioning, normality and health – equal participation and due process are considered the means for countering this discrimination.<sup>3</sup> Whilst none can totally explain the concept, a number of paradigms or theoretical models have been used to define disability, each bringing a useful perspective in a given context.<sup>4</sup> This study draws on the bio-psycho-social model and its underlying constructionist conceptualizations of disability. As a conceptual framework, social constructionism underscores the cultural and historical aspects of the phenomenon, providing an important counterpoint to medicine’s largely diagnostic and deterministic approaches to illness and disability. It thus helps to broaden legal and policy deliberations and decisions.<sup>5</sup>

Borrowing a number of ideas and concepts from sociology, the study’s constructivist stance is derived from a social relations ontology that views disability as an element of human diversity, an aspect of “being”.<sup>6</sup> It constitutes experiential dimensions based on how individuals come to understand and experience their disability, forge their identity, and live with and in spite of their disability. From my view point, disability is largely but not exclusively a social construct. Furthermore, and drawing on this ‘structuralized’ thinking, the study understands disability as an existence concurrent to other states of being such as race, class, gender, age, religion, sexuality and so on. Shaped by cultural and social systems it is therefore not separate from the world but rather part of a larger system or web of subordination produced by the intersection of oppressions subsumed under multiple social structures.<sup>7</sup> Driven by this constructionist ontology, the social model is concerned with the contingency and interplay between the effects of

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<sup>3</sup> David Pfeiffer, “The Conceptualization of Disability” in Sharon N. Barnartt, Barbara M. Altman (eds), *Exploring Theories and Expanding Methodologies: Where We are and Where We Need to Go* (Emerald Group Publishing Limited 2001) 29 – 52.

<sup>4</sup> Sophie Mitra, “The Capability Approach and Disability” (2006) 16 (4) *Journal of Disability Policy Studies* 236-247.

<sup>5</sup> Peter Conrad and Kristin K. Barker, “The Social Construction of Illness: Key Insights and Policy Implications” (2010) 51(S) *Journal of Health and Social Behavior* S67–S79.

<sup>6</sup> Elizabeth DePoy and Stephen Gilson, *Branding and Designing Disability* (London: Routledge, 2014);

<sup>7</sup> Conrad and Barker, *op. cit.*, S71.

impairment and the phenomenon of disability.<sup>8</sup> ‘It recognises that disability is a contingent phenomenon imposed on the individual by social hindrances and restrictions *on top of* the social effects impairment may bring about for the individual.’<sup>9</sup> The contention that disability is an inter-related social construct has influenced the development of different versions of the social model of disability as, within constructionist conceptualizations of disability, there are many different emphases, each of which has been posited as a model of disability in and of itself.<sup>10</sup> Beyond the scope of the chapter to critically discuss each, these variations include: (a) the social model of the United Kingdom, (b) the oppressed minority model, (c) the social constructionist version of the United States, (d) the impairment version, (e) the independent living version, (f) the postmodern version, (g) the continuum version, (h) the human variation version, and (i) the discrimination version which brings together the other versions.<sup>11</sup>

To sum up, this study is aligned with the following core ideas underlying the disability paradigm: “(1) carrying out social roles and tasks produces discrimination; (2) the organization of society also produces discrimination; (3) an impairment in no way signifies tragedy and a low quality of life and to assume so is discriminatory; (4) people with disabilities are an oppressed minority; (5) all people need various services in order to live independently; (6) all people have agendas most of which result in discrimination, but especially discrimination based on disability; (7) everyone will eventually become disabled; (8) there is no "normal" human behaviour which can be the basis of social policy; and (9) discrimination against persons with disabilities is found everywhere at all times.”<sup>12</sup>

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<sup>8</sup> Solveig M. Reindal, "A Social Relational Model of Disability: a Theoretical Framework for Special Needs Education?" (2008) 23(2) *European Journal of Special Needs Education* 135-146.

<sup>9</sup> *Ibid.*, p.144.

<sup>10</sup> Elizabeth DePoy and Stephen Gilson, *Branding and Designing Disability* (Routledge 2014).

<sup>11</sup> David Pfeiffer, “The Philosophical Foundations of Disability Studies” (2002) 22(2) *Disability Studies Quarterly* 3-23.

<sup>12</sup> Pfeiffer, *op.cit.*, p.5.

### 2.3 Taking a Constructivist Autoethnographical Standpoint

Following Pfeiffer and in keeping with a social relations ontology and constructivist conceptualizations of disability, to bring meaning to the legal and policy context under investigation, the methodology for the present study is guided by an experientially based epistemology, combining autoethnography and standpoint, two social science research approaches that attempt to subvert dominant Western knowledge structures.<sup>13</sup> Turning first to autoethnography, this approach blends elements of autobiography and ethnography. An autobiography is a subjective, retroactive study of past experiences. Ethnography meanwhile is a study of a culture's relational practices, beliefs and common values in order to help both stakeholders and outsiders better understand the topic at hand.<sup>14</sup> Autoethnographers acknowledge the diverse number of ways personal experience influences researchers and how they work. They partially dispense with placing an overdue amount of importance on clinical precision and accuracy, instead focusing on producing balanced, accessible, analytically deep pieces of work.<sup>15</sup> Autoethnography acknowledges that research cannot be done from a purely neutral, objective standpoint and that assuming that it can be so done is a fallacy. Instead, the approach embraces the fact that subjectivity, emotionality and life experience play an important role in research outcomes. It examines and considers how the researcher's own self influences interpretations of what we study, how we approach said study and the conclusions drawn thereby. The approach has been likened to directing research through varying types of lenses, first through an ethnographic wide-angle lens which has its focus directed outwards and then one looking inward, allowing oneself to resist broader cultural interpretations more so creating one's own narrative.<sup>16</sup> As Custer puts it: "[a]uto-ethnography is a qualitative,

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<sup>13</sup> Pfeiffer, *op.cit.*, p.13.

<sup>14</sup>Carolyn Ellis, Tony E. Adams and Arthur P. Bochner, "Auto Ethnography: An Overview" (2011) 12 (1) Forum: Qualitative Social Research Art. 10  
<<http://nbn-resolving.de/urn:nbn:de:0114-fqs1101108>> accessed 10 August 2016.

<sup>15</sup>*Ibid.*

<sup>16</sup> Mary Deck, *et al.* "Serving Students with Disabilities: Perspectives of Three School Counselors" (1999) 34 (3) *Intervention in School and Clinic* 150-155; Deborah Reed-

transformative research method because it changes over time, requires vulnerability, fosters empathy, embodies creativity and innovation, eliminates boundaries, honors subjectivity, and provides therapeutic benefits.”<sup>17</sup> It allows the writer to be conscious of both their own circumstance and the wider societal environment, facilitating a blend of the two with the aim of balancing objectivity with subjectivity in their research.

Richards<sup>18</sup> contends that this research approach is particularly suited to writing about disability given the structure of its narrative mode of inquiry.<sup>19</sup> Creating resistance to any notion of authorial omniscience and objectivity autoethnography enables the replacement of the voice of the distant expert that is heard most often in medical narratives with the voices of those who live the reality and experience of disability.<sup>20</sup> Marks sees autoethnography as developing “an awareness of the social, economic, and cultural processes that make up our lives”.<sup>21</sup> Furthermore, and of particular relevance to this study’s conceptualisation of disability is its capacity to question the binary split between self and society and between subjective and objective.<sup>22</sup> By providing equal weight to the “auto” and the “ethnography” parts of the term, this research approach challenges the idea of an objective, coherent identity. Additionally, the other binary split autoethnography questions are that of

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Danahay, “Introduction” in Deborah Reed-Danahay (ed.), *Auto/Ethnography: Rewriting the Self and the Social* (Berg 1997).

<sup>17</sup>Dwayne Custer, “Autoethnography as a Transformative Research Method” (2014) 19(37) *The Qualitative Report* 1.  
<<https://nsuworks.nova.edu/cgi/viewcontent.cgi?article=1011&context=tqr>> accessed 10 June 2016.

<sup>18</sup> Rose Richards, “Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing About Illness and Disability” (2008) 18(12) *Qualitative Health Research* 1717–28.

<sup>19</sup> See also Laurel Richardson and Elizabeth Adams St. Pierre, “Writing: A Method of Inquiry” in Norman K. Denzin and Yvonna Sessions Lincoln (eds), *The Sage Handbook of Qualitative Research* (3rd ed., Sage 2005) 959-978.

<sup>20</sup> Richards, *op.cit.*, 1723.

<sup>21</sup> Deborah Marks, *Disability: Controversial Debates and Psychosocial Perspectives* (Routledge 1999).

<sup>22</sup> Deborah Reed-Danahay “Introduction” in Deborah Reed-Danahay (ed.), *Auto Ethnography: Rewriting the Self and the Social* (Berg 1997) 1-17.

disease as the medical understanding of the condition and illness as the embodied experience.<sup>23</sup>

Meanwhile, to facilitate an autoethnographical methodology, a similarly situated theoretical framework must be adopted. Standpoint epistemology (or way of knowing), the second approach guiding this study, aims at examining inter-subjective discourses concerned with the ways that authority is based on individuals' perspectives and the influence these have on research. This approach to knowledge creation emphasizes the socio-political context within which knowledge claims are made and thus asks the important question of 'Who knows?' or 'How do we come to know what we know'.<sup>24</sup> Standpoint theory has been traditionally (but not exclusively) associated with the feminist movement and its academic infrastructure, with scholars such as Dorothy Smith, Nancy Hartsock, Sandra Harding, Patricia Hill Collins, Alison Jaggar and Donna Haraway advocating using women's lived experiences as the basis of scientific enquiry. Clough for example summarised feminist standpoint as "the development of a feminist or women's standpoint epistemology [and a] criticism of both the methods of science and the epistemology which grounds them. A feminist or women's standpoint epistemology proposes to make women's experiences instead of men's experiences the point of departure."<sup>25</sup>

Standpoint is an approach that views knowledge as produced in specific social and historical contexts and thus not objective, value-free or universal. A person's perspectives are carved out by their social and political experiences. These combine to create a standpoint—a point of view—through which that individual interprets the world around them. Standpoint theory exposes how academic and scientific methods are built to reinforce the power structures of dominant social groups, creating accepted and distorted social norms and

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<sup>23</sup> Mark Sullivan, "In What Sense is Contemporary Medicine Dualistic?" (1986) *Culture, Medicine and Psychiatry* 331-350.

<sup>24</sup> Donna Haraway, *Modest\_Witness@Second\_Millennium. Femaleman\_Meets\_Oncomouse: Feminism and Technoscience* (Routledge 1997).

<sup>25</sup> Patricia T. Clough, *Feminist Thought: Desire, Power; and Academic Discourse* (Blackwell Publishers 1994).

perspectives. It also argues that knowledge creation is promoted by the acknowledgement of social and political factors, as opposed to being obstructed by their recognition. Those who advocate standpoint theory focus on a naturalistic concept of knowledge, maintaining that one's standpoint shapes which arguments, features and conclusions are intelligible, understood, salient, relevant and credible. Critical knowledge bases operate from their situatedness, creating partial perspectives on societal phenomena. Such situated knowledges produce maps of consciousness reflecting the various categories of gender, class, race, and nationality of the researcher.<sup>26</sup> They are especially relevant when produced by individuals from the historically marginalised categories of race and sex.<sup>27</sup> Situated knowledge is considered more complete by those who occupy such positions of subordination in society. As a response to scientific objectivity, it asserts knowledge to be positioned in communities rather than individuals, creating a collective subject position presenting a partial empirical view.

Standpoint theory argues for the creation of a well-placed, critical comprehension by considering both difference and similarity. According to McDowell, "we must recognize and take account of our own position, as well as that of our research participants, and write this into our research practice."<sup>28</sup> In other words, the sort of knowledge created is dependent on who its creators are. When conducting academic research, one must also be conscious of the positioning of the researcher's relative position to those they are studying, including the increased access to resources and the power inherent in their role.<sup>29</sup>

#### **2.4 The Functionality of the Disability Paradigm within the Study**

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<sup>26</sup> Donna Haraway, "A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century" in Donna Haraway, *Simians, Cyborgs and Women* (Routledge 1991) 111.

<sup>27</sup> *Ibid.*

<sup>28</sup> Linda McDowell, "Doing Gender: Feminism, Feminists and Research Methods in Human Geography" (1992) 17 *Transactions, Institute of British Geographers* 399-416, 400.

<sup>29</sup> For further reading on this see Melanie Nind, Alan Armstrong *et.al.*, "Time Banking: Towards a Co-Produced Solution for Power and Money Issues in Inclusive Research" (2016) *International Journal of Social Research Methodology* 1-14.

This section discusses how the methodology was used to bring meaning to the complexity of the practice of everyday independent living juxtaposed with persisting deficiencies underlying the Irish legal and policy landscape on the one hand and more developed legal environments and approaches to disability law, policy and services in different jurisdictions on the other.

Academic research on disability is often conducted by those with no experience of disability-based discrimination.<sup>30</sup> This type of research lacks experientially based knowledge as it occludes the expertise of people with lived experiences of disability, rendering us as ‘other’ (not like the norm).<sup>31</sup> Squeezed into a medicalised narrative, people with disabilities are often considered and represented as lacking capacity to articulate our experiences and own points of view about the context within which we live our lives. We are often the objects and not the agents of study. To subvert this traditional Western knowledge structure, Pfeiffer argues that disability studies or any research using the disability paradigm - such as the present study - has to include, as active partners, people with disabilities because they are the real knowers and decision makers. This is clearly outlined in Article 4.3 of the CRPD. It is in this vein that the study attempts to provide a counter-narrative to traditional notions of disability by representing it from the inside. As its sole investigator and using an insider first-person narrative I have included myself and my story about my own experiences of living independently with a disability and high dependency needs and have used these experiences and perspectives to help me to understand the context under investigation.

Autoethnographers use standard methodological tools and research literature to examine experience but also use their own personal experience to describe and decipher broader cultural and societal phenomena.<sup>32</sup> They supplement

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<sup>30</sup> Rose Richards, “Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing About Illness and Disability” (2008) 18(12) *Qualitative Health Research* 1717–1728.

<sup>31</sup> *Ibid.*

<sup>32</sup> Two examples of studies which have used this approach are Elaine B. Jenks, "Explaining Disability: Parents' Stories of Raising Children with Visual Impairments in a Sighted World" (2005) 34(2) *Journal of Contemporary Ethnography* 143-169 and Elizabeth Ettore, "Gender,

traditional methodologies, using personal experience and an authorial perspective, all the while acknowledging its influence on the research process. This approach is relevant and suitable to my subject matter as, being an individual living with a disability, I am inextricably linked to it and can bring my own personal experiences and unique perspectives to bear on my research. Having had a lifetime of interactions with public service shortcomings (particularly in health and education) as well as the constantly shifting and ineffective disability legislative landscape, I bring a personalized and individual insight and influence to bear on my research content and direction. I naturally remain conscious of the dynamic nature of one's life positioning as well as my own privilege relative to some of those I purport to represent through my writings.

The level of prominence the autoethnographical approach occupies depends on how much focus is given to the researcher's self-experience, relative to that of others as well as on the infrastructure of power interactions surrounding both. People's own narratives are given value within research and not disposed of because of their perceived lack of objectivity. Attention is given to how a story of experience is used, comprehended, and responded to by participants, writers, audiences, and the broader populace. These ring true on a myriad of levels within the content of my document as I chart the life experience of living with a disability relative to the power infrastructure of the State, EU and UN.

Clare Madge contends that when situating knowledge, it is hugely important to consider the various roles of the self, revealing how a researcher's positionality may influence the body of work assembled and, as a result, the information that becomes accepted as "knowledge."<sup>33</sup> By articulating one's own positionality from the beginning, one can counteract the tendency to rely on overly broad, general and universal claims. Having detailed my personal

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Older Female Bodies and Auto ethnography: Finding my Feminist Voice by Telling my Illness Story" (2005) 28(6) Women's Studies International Forum 535-546.

<sup>33</sup> Clare Madge, "Boundary Disputes: Comments on Sidaway (1992)" (1993) 25(3) Area 294-9.



situation *ab initio*, the positionality of my research perspective is clear and unambiguous. Because I have encountered disability-based discrimination throughout my life as a disabled person practicing independent living in Ireland, my angle on the disability legal context under study is thus not neutral. Gilbert contends that the relationship between the researcher and the researched should be made visible and open to debate and that because we cannot know our world outside of our ability to name it, the language we use can both obscure and expose that which we subsequently see theoretically, empirically, and politically.<sup>34</sup> Thus, I believe that the value of my research should not be compromised by the concealing of my own particular position.

Those of us (such as myself) who have occupied marginal positions in society have endured such struggle as to make our knowledge base complete in different ways to others, providing us with a standpoint and foundation for our worldviews and research perspectives. I see on a daily basis the barriers presented by society which create disability, enable marginalization and foster inequality. Using this standpoint and my own particular situated knowledge, I can honestly appraise the current societal infrastructure surrounding disability whilst acknowledging my own positionality and potential bias. I feel privileged that my particular situated knowledge scheme can assist me in providing a voice for other similarly positioned individuals within the disability community.

Autoethnography as a method, is often criticised<sup>35</sup> for not being rigorous, theoretical, and analytical enough and being over reliant on aesthetic and emotional factors. Those who pursue this approach have been criticized<sup>36</sup> for doing insufficient fieldwork and for investing excessive time in marginalized groups to the detriment of other cultural operators. It has also been claimed

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<sup>34</sup> Melissa R. Gilbert, "The Politics of Location: Doing Feminist Research at 'Home'" (1994) 46(1) *Professional Geographer* 90-96.

<sup>35</sup> Carolyn Ellis, Tony E. Adams and Arthur P. Bochner, "Autoethnography: An Overview" (2010) 12(1) *Forum: Qualitative Social Research* <<http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095>> accessed 30 August 2016.

<sup>36</sup> *Ibid.*

that by concentrating overly on lived experience, auto- ethnography suffers by not being sufficiently analytical, hypothetical and theoretical.<sup>37</sup> By its association with autobiography it could be argued to have a lower level of writing standard and a lack of literary posture. With my document being heavily focused on legalistic research and analysis, I do feel this structure could be argued to be overly social-scientific for my purpose. Also, having spent significant time dissecting legislation and legal instruments, I have not conducted interviews, something the auto- ethnographical approach would traditionally be associated with. Whilst acknowledging these criticisms, I feel they pale in contrast to its theoretical suitability, as I believe it allows me to combine both the empirical research conducted as well as personal experience into a concrete lens through which I can analyse the subject matter.

A main criticism of standpoint theory is that even though it challenges essentialism, is itself dependent upon it, as it places emphasis on the dualism of objectivity and subjectivity,<sup>38</sup> in other words retaining an objectivist conception of the subjective features of social reality. Others question the credibility of strong objectivity vs. subjectivity. It has been pointed out<sup>39</sup> that standpoint theorists assume the marginalized and subordinate are less biased or more neutral than the dominant groups. This runs the risk of allowing a negative redressing of the power balance, creating a privileged position for the underprivileged, a bias paradox, thereby manifesting in an unintentional overbalance of power and a tendency to vitriol and dogma. One must also be conscious of the potential for underestimating diversity and difference amongst marginal groups, for example amongst people with disabilities.

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<sup>37</sup>*Ibid.*

<sup>38</sup>Jiwa Fazeela, "Vamps, Heroines, Otherwise: Diasporic Women Resisting Essentialism" (2011) 26 TOPIA 127-44  
<<http://topia.journals.yorku.ca/index.php/topia/article/view/34422>> accessed 20 August 2016.

<sup>39</sup> Heidi Grasswick, "Feminist Social Epistemology", *The Stanford Encyclopedia of Philosophy* (2018 Edition), Edward N. Zalta (ed.)  
<<https://plato.stanford.edu/archives/fall2018/entries/feminist-social-epistemology/>> accessed 20 August 2016.

Despite these potential drawbacks, from the perspective of standpoint theory, disabled people are best suited to understand how ableist knowledge bases and systems of oppression are created and maintained. First-person testimony and oral history are pivotal in analysing these structures, and when used in combination with empirical research and objective analysis, I feel Standpoint theory in combination with an auto- ethnographical framework to be the theoretical infrastructure best suited to my work.

## **2.5 The socio-legal research methodology**

This study combined its experiential epistemology with the socio-legal research methodology which involves desk based theoretical examination of the different sources of international human rights law and domestic law, and disability policy in relation to the CRPD.<sup>40</sup> The study selected a socio-legal research methodology as it is an approach to the study of legal phenomena in a multi and inter-disciplinary way. Also, socio-legal research covers a vast range of different subject areas and methods that allowed me to move beyond a restrictive “black letter law” approach to my thesis topic.

## **2.6 The Challenges of Doing a Ph.D as a Candidate with High Dependency Needs**

Undertaking and completing this research has been shaped and especially constrained by several critical factors. Broadly these relate to the complex interplay between the doctoral process and the multiple effects of both my physical impairment and the phenomenon of disability.<sup>41</sup> My intention in this section is to briefly describe how the barriers I encountered affected my participation in fourth level education.

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<sup>40</sup> Traditionally socio-legal research has sought to bridge the divide between law and sociology, social policy, and economics.

<sup>41</sup> Solveig M. Reindal, "A Social Relational Model of Disability: a Theoretical Framework for Special Needs Education?" (2008) 23(2) *European Journal of Special Needs Education* 135-146.

Human support services tailored comprehensively to my needs have been crucial for me to live independently and to participate in an active and meaningful life including in fourth level education. This includes having simultaneous and consistent access to Personal Assistance and Education Support, both of which involve very different types of services that cannot be used interchangeably. The roles of a Personal Assistant (PA) and an Education Support Worker (ESW) are entirely distinct and different. Typically Personal Assistance Services (PAS) include common housework, personal service and personal care. I chose and manage my Personal Assistants in my home environment for their ability and expertise in high quality personal care which is essential for my well-being, sustained good health and for successful community living. Any level of academic support is neither in their job description or time allocation i.e. each 3-hour shift is totally accounted for in domestic duties and tending to my personal care and high dependency needs. Likewise, the ESW is employed on their academic qualifications to enable them to be in a position to support me in all areas of my doctoral work. Their role is very specific to my area of study – international human rights disability law and to tasks such getting books from library, internet research and downloading appropriate material, and accompanying me to supervision meetings and so forth. Personal Care is not part of their job description. At various times throughout my Ph.D there was a limited availability of ESWs with relevant educational background and qualifications and suitable skills and competencies to work with a Ph.D candidate with physical disabilities and high dependency needs such as myself. This affected not only my self-determination and ability to choose and influence their appointment but also constrained my ability to progress my academic activities significantly. Furthermore, there were extended periods of time when I encountered a severe lack of PAS, the consequences of which on both my health and well-being and my ability to engage in academic duties and participate in the Ph.D programme were far reaching.

In addition to limited access to comprehensive education and disability-related supports and services, many of the challenges I encountered doing my Ph.D also arose specifically as a consequence of my physical disability and

high dependency needs. Unlike candidates without disabilities, I experienced difficulties conducting research strategies including identifying and accessing academic research materials outside of the allocated ESW hours. Starting from the very basic task of setting up IT equipment through to locating, browsing and finding relevant reading to extracting chosen appropriate material has been a mammoth task and at times almost impossible. The disruptions by my physical support and basic needs to the day-to-day research process were constant, very time-consuming, and curtailed momentum. Using the bathroom, which entails hoisting etc., can take up to 30 minutes or more and feeding, hydration and repositioning because of pain at pressure points/postural problems all impeded the smooth flow of the necessary academic research, causing me huge frustration and loss of focus. Meanwhile, the process of writing my ideas once the necessary research was complete was an equally challenging task as the dictation of a particular chapter can only take place when an EWS is present to load the document, type dictation, insert specific extracts and cite it correctly.

The option to choose which University to attend was limited to the institution closest to my home and formal and informal support networks. PA support is limited to a specific number of hours based on my allocation and not my dependency needs and support is often topped up with family and friends living near me. I also encountered academic and other forms of isolation due to lack of social contact and freedom to travel. Some of the consequences of this were fewer opportunities for peer support and in-depth conversations with other academics and like-minded students. I felt this severely limited the stimulus, inspiration and encouragement derived from such encounters. A trip to college, in theory possible, necessitates me being physically up to the trip, having access at the time to a driver (it must be booked in advance), having a person capable of loading up and securing equipment and having a Personal assistant at hand to drive home when (not if) pressure pain is too severe.

My high dependency needs and range of related medical conditions necessitate frequent trips to out-patient and inpatient hospital appointments

which are not typically scheduled in consultation with myself. These include: orthopaedic, pain management, podiatry, physiotherapy (weekly), urology, dentistry and neurology. The appointments are very time-consuming and waiting times can be hours – all completely outside my control. While this is the same for all students (disabled or not) the able-bodied cohort has the ability to adapt and attend more readily. General Practitioner visits are also frequent and time-consuming because of illnesses ranging from frequent chest/other infections to severe pain from spasticity. My participation in the doctoral process has also been affected by having to constantly cope with severe physical limitations, examples of which include spasticity, prohibiting motor control i.e. finger movement, eye control which affects my ability to read and follow text. Often times I lose the thread of text resulting in disruption of thought control. Because of my inability to write myself, my sentences often are disjointed – the first part having no relevance to the second part of the sentence. Repetition can also be an issue because of the very nature of dictation and problems with eye control. This often only comes to light after completion of the topic. The constant re-editing required to give the desired flow and fluency is frustrating, time-consuming and completely exhausting. I experience body spasms especially in certain areas like back, knees, arms, hands and bowel, resulting in severe pain and constant disruptions to my everyday life activities. In periods of high spasticity, I have had voice problems resulting in loss of volume, loss of control over diction and at difficult times I would chose a simple word to avoid losing more time.

A combination of severe and chronic fatigue, a consequence of the side-effects of both my condition and my medication, has made sustained focus on academic tasks almost impossible for any lengthy period. Fatigue necessitates temporary closure of the task in hand and complete rest before revisiting later or even next day. This enforced stop / start situation calls for regrouping of the thought process often impeding sentence/paragraph construction owing to fatigue and difficulties taking appropriate notes. At times my energy is entirely depleted and it has been a real challenge for me every day just to keep going.

## 2.7 Conclusion

This chapter has delineated the methodology used to guide the design, implementation and analysis of this research project. In sum, the study is grounded in the disability paradigm that conceptualises disability not as an individual deficit but as the interaction of diverse human conditions and impairments with disabling environments in which barriers are erected and maintained, limiting full participation in all aspects of social life.<sup>42</sup> It is aligned with the contention that: “[i]ndividuals are perceived to be disabled by marginalization, oppression, and hostile environments - those characterized for example by a lack of ramps, limited attention to alternative formats for printed material, and a severe shortage of sign language interpreters, as well as any number of forms of social, political, and economic devaluation”.<sup>43</sup> In keeping with this world view the methodology used by the study blends experientially based epistemology namely auto- ethnography and standpoint with the socio-legal approach. After describing this, the chapter turned to some of the constraints on collecting and interpreting study findings that broadly related to individual and societal conditions including having a severe physical disability and high dependency needs and my limited access to adequate education and disability-related supports specific to my needs.

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<sup>42</sup> Elizabeth DePoy and Stephen Gilson, *Branding and Designing Disability* (Routledge 2014).

<sup>43</sup> *Ibid.*, p.160.

## Chapter Three

### Independent Living

#### 3.1 Introduction

The focus of this chapter is independent living. At once a radical philosophy, a social movement and a service paradigm,<sup>1</sup> independent living increasingly informs national social policy initiatives that respect the rights of and support people with disabilities.<sup>2</sup> The framework for such policies is the United Nations Convention on the Rights of Persons with Disabilities (CRPD) that draws on a human rights approach, promising equality, inclusion and social participation for people with disabilities.<sup>3</sup> Despite being a signatory to the Convention since 2007 and having ratified in 2018, Ireland falls considerably short of validating and delivering this right in practice.<sup>4</sup> In light of the philosophy underpinning key articles of the CRPD, this study is concerned with specific shortfalls in Irish public policy and legislation claiming to promote independent living and being included in the community. The purpose of the present chapter is to elaborate more specifically on the background, scope and tenets underlying independent living and the impact of this radical concept and social movement on policy development. It is divided into three sections. Building on the philosophical foundations of the disability paradigm set out in the previous chapter, the first section provides a short description of the core components and values underpinning the concept of independent living currently informing international human rights-based discourses. These emerged out of the Independent Living movement, the development of which has been in response to the dominance of the

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<sup>1</sup> Colin Barnes, *Independent Living, Politics and Implications* (The University of Leeds 2004).

<sup>2</sup> Simoni Symeonidou, "Rights of People with Intellectual Disability in Cyprus: Policies and Practices Related to Greater Social and Educational Inclusion" (2015) 12(2) *Journal of Policy and Practice in Intellectual Disabilities* 120-131.

<sup>3</sup> Convention on the Rights of Persons with Disabilities 2006.

<sup>4</sup> Review Group on Health and Social Services for People with Physical and Sensory Disabilities, *Towards an Independent Future: Report of the Review Group on Health and Social Services for People with Physical and Sensory Disabilities* (Stationery Office 1996).



medical model, the institutionalisation of disability and the manner in which people with disabilities have been made to fit into society. Referred to also as the "disability rights movement," debate remains as to whether these are two names for the same movement or two separate social movements, with independent living focusing on removal of environmental barriers and disability rights focusing on legal rights.<sup>5</sup> For purposes of this study, the two terms will be treated synonymously as the disability rights/independent living movement. The focus of the next three sections is independent living as a service paradigm. Section two describes the types of services the Independent Living movement demands when breaking from institutional provision and for this way of living to be realised. Sections three and four then turn to the socio-economic benefits and barriers to independent living. Section five concludes the chapter with a synthesis of findings.

### **3.2 Core Concepts and the development of Independent Living Model**

The idea of 'independent' living is a radical concept that has its roots in the ideological, cultural and pragmatic traditions of western society.<sup>6</sup> A clear grasp of the true meaning of the concept amongst disability advocates, researchers, law and policy-makers and service providers is paramount, if the right to this way of life is to be fully established and realised. Delineating basic assumptions and core concepts at this point of the thesis is particularly important as it provides a meaningful framework from which the study can address its central concern, which is the relationship between international and Irish disability law and policy.<sup>7</sup>

Although the UN Disability Rights Convention provided no definition of Independent Living, the core values of independent living such as personal

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<sup>5</sup> Andrew Batavia, "The New Paternalism: Portraying People with Disabilities as an Oppressed Minority" (2001) 12(2) *Journal of Disability Policy Studies* 107–113.

<sup>6</sup> Colin Barnes *Independent Living, Politics and Implications* (The University of Leeds 2004)

<sup>7</sup> Karrie Shogren and Rutherford H. Turnbull, "Core Concepts of Disability Policy, the Convention on the Rights of Persons with Disabilities, and Public Policy Research With Respect to Developmental Disabilities" (2014) 11(1) *Journal of Policy and Practice of Intellectual Disabilities* 19-26.

autonomy, freedom and equality are reflected throughout its text.<sup>8</sup> Adolf Ratzka, a disabled director of the Swedish Institute for Independent Living, captures the essence of the concept and practice by describing independent living as:

“... a philosophy and a movement of people with disabilities who work for self determination, equal opportunities and self-respect. Independent living does not mean that we want to do everything by ourselves... [it] demands the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves.”<sup>9</sup>

Drawing on feminist perspectives of personhood, dependency and other aspects of the human condition, scholars such as Quinn and Doyle delineate the right to live independently as having to do with the centrality of the right to life for all persons including people with disabilities.<sup>10</sup> They view the logic underlying the concept as foundational to identity – to a viable sense of self, being and belonging. Human personhood is to be shared and it is this sharing that allows us to see ‘ourselves’, connect with others and build bridges into the community. This is why, having the right to choose where to live and with whom is so central to living a fuller life. It provides people with disabilities

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<sup>8</sup> Camilla Harriet Parker and Luke Clements, “The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?” (2008) 13(4) *European Human Rights Law Review* 508-523.

<sup>9</sup> Adolf Ratzka, “*Independent Living in Sweden*” (2003) Independent Living Institute < <https://www.independentliving.org/docs6/ratzka200302b.html> > accessed 26 August 2016

<sup>10</sup> Gerard Quinn and Suzanne Doyle, “Getting a Life—Living Independently and being Included in the Community: A Legal Study of the Current Use and Future Potential of the EU Structural Funds to Contribute to the Achievement of Article 19 of the United Nations Convention on the Rights of Persons with Disabilities” (2012) *Report to the Office of the United Nations High Commissioner for Human Rights, Regional Office for Europe*.

with autonomy, as it affords ‘voice’ and ‘choice’ about how to live life.<sup>11</sup> It treats people as subjects capable of directing their own sense of belonging and personal destinies and places an onus on others to respect the will and preferences of people with disabilities, particularly in relation to their living arrangements. Resonating with this worldview is the general agreement amongst the international disability community and their supporters that the philosophy of ‘independent living’ is founded on the following four basic assumptions.<sup>12</sup>

1. That all human life, regardless of the nature, complexity and/or severity of impairment, is of equal worth, this assumption underlying most human rights instruments and emanating from Article 1 of the Universal Declaration of Human Rights;<sup>13</sup>
2. That anyone, whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices (as provided for by the CRPD);<sup>14</sup>
3. That people who are disabled by societal responses to any form of disability – intellectual, physical, sensory or mental health – have the right to exercise control over their lives; and
4. That people with disabilities have the right to participate fully in all areas – economic, political and cultural – of mainstream community living on a par with their non-disabled peers.

Emerging out of gradual shifts in the mind-sets of the general public towards disability and spurred by the development of the Independent Living movement, these core assumptions have resulted in most people of my generation in OECD countries enjoying some degree of ‘voice’ and ‘choice’ about how to live their lives, whether independently, with their family or in residential care. Beginning in the first half of the 20<sup>th</sup> century, a number of key developments influenced these gradual shifts in attitudes towards disability, paving the way for an appreciation of such concepts as autonomy

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<sup>11</sup> See Kittay, E. F. and E.K. Feder (eds) *The Subject of Care: Feminist Perspectives on Dependency* (Rowman & Littlefield 2003).

<sup>12</sup> Colin Barnes, *Independent Living, Politics and Implications* (The University of Leeds 2004).

<sup>13</sup> Universal Declaration of Human Rights 1948.

<sup>14</sup> Convention on the Rights of Persons with Disabilities 2006.

and equality. These related to the circumstances, actions and visibility of World War I veterans leading to a view of disabilities not as something to be feared but rather obtained in performing heroic acts in the service of one's country. There was also increased awareness of a wide range of disabilities as "many an amputee, blind or shell-shocked ex-soldier eventually found himself selling boxes of matches in the streets of the West End, campaign medal pinned to their lapels."<sup>15</sup> Shifts in attitudes were further spurred post World War II by disability advocate German born Jewish doctor Sir Ludwig Guttmann (Poppa). Known as the "Father of Sport for People with Disabilities," Guttmann promoted the use of sports therapy to enhance the quality of life for people who were injured or wounded during World War II. He organised the 1948 International Wheelchair Games (Stoke Mandville Games) to coincide with the 1948 London Olympics and twelve years later, his dream became a reality to have a worldwide sports competition for people with disabilities to be held every four years as "the equivalent of the Olympic Games."<sup>16</sup>

The international disability movement that was to emerge in the 1960s built and followed on from these key junctures, allowing for a gradual progression from disability discourse based on charity to one of rights and attainment of such. With its roots in the post war U.S civil rights movement<sup>17</sup> within which women with disabilities played a key role throughout the 60s and 70s,<sup>18</sup> the international disability movement led to much progressive legislation over the next three decades. This included the Rehabilitation Act 1974, the Individuals with Disabilities Education Act 1975, the Air Carrier Access Act 1986, the Fair Housing Amendments Act 1988, and the Americans with

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<sup>15</sup>A *Brief History of Disability in the United States and Massachusetts* (Massachusetts Office on Disability 2016)  
< <https://www.mass.gov/files/documents/2016/10/qx/a-brief-history-of-disability.pdf>>  
accessed 17 May 2016.

<sup>16</sup> Paralympics – The History of the Movement  
<<https://www.paralympic.org/the-ipc/history-of-the-movement>> accessed 2 June 2016.

<sup>17</sup>Polly Welch (ed.), *Strategies for Teaching Universal Design* (Adaptive Environments Center and MIG Communications 1995) Chapter 2.

<sup>18</sup> Abigail J. Stewart , Isis H. Settles and Nicholas J. G. Winter, "Women and the Social Movements of the 1960s: Activists, Engaged Observers, and Nonparticipants" (1998) 19(1) *Political Psychology* 63-94.

Disabilities Act 1990. Many provisions of the UK Disability Act 1994 are considered to have been influenced by the Americans with Disabilities Act 1990.<sup>19</sup> It was out of this wider context of disability rights and legislative reform that a powerful Independent Living movement emerged in both the US and the UK. Of significant influence on the emergence of the disability rights/independent living movement in the US were the efforts of Ed Roberts, a post-polio respiratory quadriplegic and one of the first disabled students admitted to Berkeley university. Roberts played a key role in the establishment of *The Berkeley Centre For Independent Living* (CIL) in 1972,<sup>20</sup> a key milestone in the history of the Independent Living movement as it led to the operation of thousands of independent living centres across the US, Europe and beyond by 2000.<sup>21</sup> In contrast to the previous fragmented system of provision of services, the Berkeley Centre For Independent Living in the US, along with its predecessor program, the Physically Disabled Students Program (PDSP), went on to take a holistic, integrated approach to providing a comprehensive array of services to disabled people in order to meet the needs of those people and allow them to achieve a level of functional independence.<sup>22</sup>

Meanwhile in the UK the Independent Living movement was born out of the experience of disabled people feeling that "... the services were paternalistic, institutional, second class, too medically orientated and out of touch with their real needs".<sup>23</sup> It was on this basis that persons with disabilities looked elsewhere for solutions to overcome their restricted predicament and living conditions. Founders of the UK independent living movement turned to the

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<sup>19</sup>David Bell, "The Disability Discrimination Act in the UK: Helping or Hindering Employment Amongst the Disabled?" (2005) University of Stirling Axel Heitmueller London Business School and IZA Bonn Discussion Paper No. 1476.

<sup>20</sup>Julia M. White, Rebecca C. Cory and Zosha Stuckey, "Using Disability Studies Theory to Change Disability Services: A Case Study in Student Activism" (2010) 23(1) *Journal of Postsecondary Education and Disability* 28-37.

<sup>21</sup>Susan O'Hara, "The Disability Rights and Independent Living Movement" <<http://www.lib.berkeley.edu/give/bene-legere/bene55/disability.html>> accessed 30 May 2016.

<sup>22</sup>Hale Zukas, *The History of the Berkeley Center for Independent Living* (1975) Report of the State of the Art Conference, Center for Independent Living, Berkeley, California <<https://www.independentliving.org/docs3/zukas.html>> accessed 24 June 2015.

<sup>23</sup>John Evans, "The Independent Living Movement in the UK" (2003) Cornell University, ILR School, GLADNET Collection <<http://digitalcommons.ilr.cornell.edu/gladnetcollect/436>> accessed 23 June 2015.

US for solutions and began researching the model as a possible roadmap to address the injustices, inequalities and institutionalisation experienced by PWDs. However, in comparison with the US, the development of CILs in the UK was less rapid or widespread owing to the different social welfare policy contexts and services as well as the demands put forward by the UK disability organisations themselves which argued for greater integration of disability services within ‘mainstream’ service provision rather than a ‘special needs’ approach. UK disability organisations furthered that, human relationships, which they viewed as key elements of people with disabilities’ participation in their communities, are best built and strengthened on the idea of interdependence rather than an ‘independent’ lifestyle that is considered both unrealistic and undesirable. As a result, many disability activists in the UK adopted terminology such as ‘integrated’ or ‘inclusive’ living rather than the original ‘independent’ living.<sup>24</sup> Other key milestones galvanising the rights-based movement and paradigm for independent living were the 1975 the United Nations (UN) Declaration on the Rights of Disabled Persons, the inaugural year of the Disabled Person that occurred in 1981 together with the UN Resolution entitled the UN Standard Rules on the Equalisation of Opportunities for People with Disabilities. Importantly this Resolution provided for the appointment of a Special Rapporteur whose role has been to monitor the implementation of the Rules. Discussed in greater detail in chapter four of the thesis, the Resolution also set out key principles that went on to be elaborated upon in the UN Convention on the Rights of People with Disabilities (CRPD), but in a more clear and precise manner and within a binding international human rights treaty.

There are now thousands of references to disability and the right to independent living in international policy documents and papers that reference independent living. For example, bolstering the worldwide call for an enforceable right to independent living for all disabled people, the UK Disability Rights Commission (DRC) argued in its 2002 policy paper that:

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<sup>24</sup> Colin Barnes and Geof Mercer, "Disability, Work, and Welfare: Challenging the Social Exclusion of Disabled People" (2005) 19(3) *Work, Employment and Society* 527-545, 530.

There should be a basic enforceable right to independent living for all disabled people. Policy objectives for social care must include guaranteed minimum outcomes, backed by a right to independence. The provision of social care must extend to beyond functional ‘life and limb’ support to include supports to enable participation in social and economic activities. Support services should be based on the principles of independent living. All organizations commissioning and providing services should be aware of the social model of disability and be fully committed to delivering services that enable choice, control, autonomy and participation.<sup>25</sup>

Meanwhile former Council of Europe Commissioner for Human Rights, Hammarberg put forward the EU position that the philosophy of the right to independent living is ‘about enabling people to live their lives to their fullest, within society’. At its core is the neutralisation of:

“[...] the devastating isolation and loss of control over one’s life, wrought on people with disabilities because of their need for support against the background of an inaccessible society. ‘Neutralising’ is understood as both removing the barriers to community access in housing and other domains and providing access to individualised disability-related supports on which enjoyment of this right depends for many individuals.”<sup>26</sup>

### **3.3 Independent Living in Practice: De-institutionalisation, Choice and Personalisation**

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<sup>25</sup> Disability Rights Commission, Policy Statement on Social Care and Independent Living (2002).

<sup>26</sup> Commissioner for Human Rights, The Right of People with Disabilities to Live Independently and be Included in the Community (Council of Europe Publishing, 2012).

The transition to independent living is a complex one in face of needs for personal and functional assistance, income support, housing and benefit restrictions all of which are shaped by factors such as class, race, age and gender.<sup>27</sup> To enable people with disabilities move from dependence, meet the obligations of citizenship and achieve their desired levels of social, economic and other forms of independence, the Independent Living movement promotes a holistic, integrated approach to providing a comprehensive array of social services to people with disabilities. Discussed in greater detail below, under the independent living paradigm, these services are tailored and nuanced according to the specific needs of individuals and also constantly respond and evolve so that they reflect needs as they change over time and context. In my case, to be able to combine autonomy in personal assistance with employment, education and training, housing and other aspects of my everyday social life, schemes need to include the crucial package of direct and tailored payments or individual budgets enabling me to cover the costs of prescriptions and purchase the comprehensive array of health services I rely on including nursing care, physiotherapy and occupational therapy.<sup>28</sup> As described by Clements, the main idea behind individual budgets is to put the person who is supported, or given services, in control of deciding what support or services they get.<sup>29</sup> Indeed this is very different to the system of flat payment, which is disbursed irrespective of the types and levels of disability offering very limited potential to recognise my specific and complex needs which are constantly changing throughout my life- course.

Over the course of the three decades following its inception, the Independent Living movement developed a peer-led independent living model of disability based on a holistic and nuanced approach, replacing integration and rehabilitation with concepts such as choice, control, autonomy and participation. Representing a paradigm shift away from guardianship and

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<sup>27</sup> Nicola Hendey and Gillian Pascal, *Disability and Transition to Adulthood: Achieving independent living* (Pavilion/Joseph Rowntree Foundation 2001); Tania Burchardt, "The Dynamics of being Disabled" (2000) 29(4) *Journal of Social Policy* 645-668.

<sup>28</sup>Hendey and Pascall, *op.cit.*, p.28.

<sup>29</sup> Luke Clements, "Individual Budgets and Irrational Exuberance" (2008) 11 *Community Care Law Reports* 413-430.



paternalistic attitudes, and a rejection of institutionalised services and control by medical professionals, independent living today embodies the philosophy that everyone including persons with the most “severe” disabilities and complex physical impairments should have the choice to live in the community. This philosophy is premised on the notion that independent living can be achieved through the provision of supports that facilitate choice and management of the personal affairs of people with disabilities, enabling people to gain employment, make decisions in relation to personal affairs, education, home and living in the community. A key aspect of this paradigm is the acknowledgement and removal of the environmental barriers – including the traditional paternalistic worker-client relationship - that thwart persons with disabilities from becoming active members of their community. Consumer control, advocacy and peer counselling are thus specified as ways of overcoming a dependency on professionals, family members, and medical personnel for decision-making.<sup>30</sup> According to the independence model then, if basic core services for independent living are met and people with disabilities are empowered to make personal decisions regarding community activity, housing, employment, and other aspects of civic life, they will naturally participate in their communities.<sup>31</sup>

Underlying this service paradigm is the social model of disability. Applauded for its ability to examine the disabling tendencies of society in order to generate inclusionary policies and practices, this tool is criticised for an over-emphasis on environmental barriers and a neglect of people’s subjective experiences of impairment.<sup>32</sup> There are claims from within and beyond the disability movement that it downgrades the significance of impairment and hence medical treatment and ignores social differences around gender,

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<sup>30</sup> Glen W. White et al., "Moving from Independence to Interdependence: A Conceptual Model for Better Understanding Community Participation of Centers for Independent Living Consumers" (2010) 20(4) *Journal of Disability Policy Studies* 233-240, 234-5.

<sup>31</sup> *Ibid.*

<sup>32</sup> Colin Barnes and Geof Mercer, "Disability, Work, and Welfare: Challenging the Social Exclusion of Disabled People" (2005) 19(3) *Work, Employment and Society* 527-545, 531.

minority ethnic group status, sexuality, social class, and age.<sup>33</sup> Such a model limits a nuanced understanding of how the types and degrees of impaired functionality and their interaction with social differences and wider environment might shape the basic needs and everyday independent living desires, preferences and practices pursued by people with disabilities. This has consequences for the design and implementation of appropriate legal measures, policies, services, funding mechanisms and resource allocation systems that are necessary to both address people with disabilities' diverse circumstances and basic needs and also strengthen people's capacity to make personal decisions and build relationships.

Humans are by definition "social" beings, and, regardless of the degree and nature of impairment, that we are interdependent is a feature of the human condition.<sup>34</sup> As argued both within and outside the disability movement, particularly in the UK, true (physical) independence will never be possible, and strictly speaking independent living is highly improbable, so the aim should be the most inclusive process possible.<sup>35</sup> Whilst the concept and model of independent living can lead to improved participation in the community for some people with disabilities, it can also leave others living an isolated "silo-type" existence as mere occupants in *the* community which is not desirable given certain needs regarding personal safety or health.<sup>36</sup> In his book *Anti-Discrimination Practice* (2006),<sup>37</sup> Neil Thompson cites Phillipson's<sup>38</sup> argument for a move from dependence to *interdependence* where he states:

"This involves developing a partnership between service providers and service users in relation to service providers and service delivery and development. Where independence

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<sup>33</sup> Nick Watson, "Well, I Know This is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identity and Disability" (2002) 17(5) *Disability & Society* 509-527; Tom Shakespeare, "The Social Model of Disability." (2006) 2 *The Disability Studies Reader* 197-204.

<sup>34</sup> Diemut Elisabeth Bubeck, *Care, Gender, and Justice* (Clarendon Press 1995).

<sup>35</sup> Colin Barnes and Geoff Mercer, "Disability: Key Concepts" (2003) Cambridge: Polity 6.

<sup>36</sup> White et al, *op. cit.*

<sup>37</sup> Neil Thompson, *Anti-Discriminatory Practice* (Palgrave Macmillan 2006).

<sup>38</sup> Chris Phillipson, *Reconstructing Old Age: New Agendas in Social Theory and Practice* (Sage Publications 1998).

is either not feasible or not desirable, the alternative should not be dependency based on the traditional paternalistic worker-client relationship but rather interdependency.”<sup>39</sup>

According to Barnes,<sup>40</sup> where a truly independent lifestyle is inconceivable, interdependent living presents as an achievable construct, a compromise between independent living and person-centred-planning. This model identifies relationships and interactions between persons with disabilities and nondisabled individuals as key to the former realising the greatest quality of life to the extent that they are able.<sup>41</sup> It suggests that if people with disabilities are to realise the right to independent living and fully participate as vital contributors to *their* community, core services must go beyond supports for personal decision making and meeting basic independence needs that are stripped of paternalistic involvement of well-meaning agencies but also build social capital capacity among people with disabilities. Rather than viewing models dichotomously, White et al argue for services that are based on a model of the continuum of independence and interdependence with both representing two ends on the continuum of independent living service paradigm.<sup>42</sup> There are numerous ways in which to enable people with disabilities to actively pursue an inter-dependent-independent lifestyle comparable to non- disabled peers.<sup>43</sup> Mansell et al analysed the move from residential to independent living as being made up of three key elements:<sup>44</sup>

- Progress towards transforming and reforming institutional care – evidence of separation of buildings and support
- Progress towards community living - evidence of providing options and support in the community

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<sup>39</sup>Neil Thompson, *Anti-Discriminatory Practice (Palgrave Macmillan 2006)* 96.

<sup>40</sup> Barnes and Mercer, *op.cit.*, 6.

<sup>41</sup> Nicola Hendey and Gillian Pascall, *Disability and Transition to Adulthood: Achieving Independent Living (Pavilion/Joseph Rowntree Foundation 2001)*.

<sup>42</sup> White et al, *op.cit.*

<sup>43</sup> Barnes and Mercer, *op.cit.*, 531.

<sup>44</sup>Jim Mansell et al, *Deinstitutionalisation and Community Living—Outcomes and Costs: Report of a European Study. Volume 2: Main Report (University of Kent 2007)*.

- Progress towards independent living – evidence of support for people to live in their own homes and have choice and control through independent and personalised budgets

At the core of the right to independent living is the philosophy of personalisation and personal freedom.<sup>45</sup> These are key demands of the independent living movement. Personalisation rejects the passive, paternalistic and medicalised provision of services *for* persons with disabilities that has typically assumed that people with disabilities are incapable of making life choices and determining what is most appropriate for them. Instead it embraces legal capacity and the full range of self-directed supports to facilitate persons with disabilities to choose, control, participate and live their lives to the fullest extent possible in *their* community.<sup>46</sup> The concept of legal capacity opens up zones of personal freedom, which through contract law facilitates un-coerced interactions. Referring to the realisation of personal freedom, Quinn notes:

“Michael Bach is entirely right to focus on issues like opening and maintaining a bank account, going to the doctor without hassle, buying and selling in the open market, renting accommodation, etc. This is how we positively express our freedom. This is how we can see legal capacity as a sword to forge our own way. And this has been largely denied to PWDs throughout the world. It follows that this is one of the primary added values of the United Nations convention – to bulldoze away barriers to the life world”.<sup>47</sup>

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<sup>45</sup> Leanne Togher et al, "An Exploration of Participant Experience of a Communication Training Program for People with Traumatic Brain Injury and Their Communication Partners" (2012) 34(18) Disability and Rehabilitation 1562-1574.

<sup>46</sup> Trevor Powell, Rachael Gilson, and Christine Collin, "TBI 13 Years on: Factors Associated with Post-Traumatic Growth" (2012) 34(17) Disability and Rehabilitation 1461-1467.

<sup>47</sup> Gerard Quinn, "Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD HPOD" (Conference at Harvard Law School 20th February 2010).

According to disability advocates and researchers, how personal assistance and other services are provided and financed has important implications for the extent to which people with disabilities are able to exercise personal freedom, legal capacity and live independently within their communities rather than in institutions.<sup>48</sup> Critical for de-institutionalisation and the move from dependency towards autonomy, employability and self-sufficiency is the role of the state and adequate and sustained investment in *user-directed/led* services and *personalised* initiatives supporting people with disabilities earn their own income, make decisions including how to spend it and build relationships. In many ‘developed’ nations, self-directed support systems - known also as ‘self-operated care schemes’ and ‘self-directed care’ - are rooted in disabled people’s struggle for justice and equality.<sup>49</sup> Whether state-run or in the voluntary sector, they include the operation of user-led networks of service providers and advocacy groups and the distribution of direct and tailored payments made in cash under a user-led system allowing people with disabilities to choose whether to devise, pay for and, therefore, control their own support systems including the employment of personal assistance according to their own requirements.<sup>50</sup> Under this personalisation service paradigm, a spectrum of self-directed support mechanisms operates through the use of individual funding options/packages representing varying levels of control and choice for individuals. The central idea behind each is to place the individual, who has been assessed as requiring ‘social care services’ and is in receipt of a certain amount of money, at the centre of the process of identifying needs and making choices over the services and supports they require.<sup>51</sup> Unlike the dominant model that places emphasis on restrictions and audits how the allocated money be spent, mechanisms promoting self-directed supports allow for funds to be held by the person or the family, are

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<sup>48</sup> Andrew Batavia and Gerben DeJong, “Disability, Chronic Illness and Risk Selection” (2001) 82 (4) Archives of Physical Medicine and Rehabilitation 546-552.

<sup>49</sup> Simon Prideaux et al, "Disabled People and Self-Directed Support Schemes: Reconceptualising Work and Welfare in the 21st Century" (2009) 24(5) Disability & Society 557-569, 558.

<sup>50</sup> Barnes and Mercer, *op. cit.*, 2.

<sup>51</sup> Prideaux et al, *op. cit.*, 559.

portable between service providers and can typically be used to buy support from services providers or in an open market.<sup>52</sup>

The right to user-directed personal assistance services remains a corner-stone of the independent living model as without it, disabled people who need help with everyday life activities, risk segregation and institutionalisation.<sup>53</sup> The model of choice of many working-age people with disabilities in the US and in EU member states, the independent living paradigm views the person receiving services and payments as an autonomous self-directed user, who assesses their own personal assistance and needs, determines how and by whom these needs are to be met, monitors the quality of services and assumes overall responsibility for the recruitment, training, supervision and if necessary firing of their personal assistant(s).<sup>54</sup> The employment of personal assistance under these new models of service delivery is therefore a key issue for personalisation, autonomy, self-sufficiency and other aspects of independent living.<sup>55</sup> This makes it a fundamental issue of social policy in that it is *the* essential long-term care need. A further key component of the personalisation-independent living service paradigm is that of *graded* or tailored direct payments that are underpinned by the idea that service packages need to reflect and respond to the needs of individuals practicing independent living. Contrasting with the dominant system of flat payment, this system is based on a continuous assessment of needs as they increase, decrease and constantly change according to the person's individual, immediate and wider social context and circumstances. It thus acknowledges the multiple 'bio-psycho-social factors' hindering people with disabilities to live independently and participate as equals in mainstream society and employment. Higher living costs, complex and varied personal and health

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<sup>52</sup> Sheila Riddell, Teresa Tinklin and Alastair Wilson, *Disabled Students in Higher Education: Perspectives on Widening Access and Changing Policy* (Routledge 2005).

<sup>53</sup> Mike Oliver, "The Individual and Social Models of Disability" (Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospitals, 23rd July 1990).

<sup>54</sup> Batavia and DeJong, *op.cit.*, 21-24.

<sup>55</sup> Nicola Hendey and Gillian Pascall. *Disability and Transition to Adulthood: Achieving Independent Living* (Pavilion/Joseph Rowntree Foundation 2001) 23; Jenny Morris, "Feminism and Disability" (1993) 43(1) *Feminist Review* 57-70.

needs and greater vulnerability to low pay and unemployment are some of the very real barriers demanding tailored income support if disabled people are to achieve their desired levels of social, economic and other forms of independence and meet their obligations of citizenship.<sup>56</sup>

There is increased policy interest and recognition of self-directed support models or 'cash for care' services and these are considered a positive way forward across much of the post-industrial world.<sup>57</sup> Briefly, to level the playing field for people persons with disabilities, jurisdictions have either chosen the legislative anti-discriminatory approach and/or use redistributive measures. In British Columbia, two individualised funding options are in circulation, namely the Direct Funding or Host Agency Funding. Under the former, cash payments are made directly to an individual or an agent for the purchase of supports and services whilst the latter allocates funding to a support agency that administers individualised funds and works with the individual and family to arrange and manage the supports required. Similar direct payment and individual funding options are available in the UK where 'choice' is a central guiding principle in the reform of the old social care system and the design of disability support systems. For example, representing whole system change, not change at the margins, people can choose between a direct payments scheme or the support provider managed 'individual budgets' designed for individuals who do not want to take on the responsibility of a direct payment. Under the direct payments initiative, the Independent Living Fund and/or local authorities responsible for community care services make cash payments to persons for the purchase of supports and services. These payments are not means tested and are not taken into account when assessing an individual's income or when an assessment of their social security benefits is made.<sup>58</sup> Meanwhile access which is assessed by the local

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<sup>56</sup> Hendey and Pascall, *op. cit.*, 35.

<sup>57</sup> Adolf Ratzka, "Independent Living for People with Disabilities: From Patient to Citizen and Customer" (2007)

<<https://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?referer=https://scholar.google.com/&httpsredir=1&article=1426&context=gladnetcollect>> accessed 25 May 2016.

<sup>58</sup> Simon Prideaux et al, "Disabled People and Self-Directed Support Schemes: Reconceptualising Work and Welfare in the 21st Century" (2009) 24(5) *Disability & Society* 557-569, 560.

council is based on an eligibility framework of needs required for independent living with eligibility graded into the following four bands: critical, substantial, moderate and low.<sup>59</sup> According to the Department of Health, age, gender, ethnic group, religion, impairments “or similar difficulties, personal relationships, location, living and caring arrangements, and similar factors ... may need to be taken into account.”<sup>60</sup> However these factors are not directly referred to in the framework.<sup>61</sup> To compensate for higher costs of living, the UK also distributes benefit entitlements through the disability living allowance (DLA). Norway provides a basic social safety net and welfare services to implement employment and disability policy, whilst in Sweden, under the direct payment model, support for personal assistance is provided in a variety of ways from self-management and private agencies to cooperatives and the municipality.<sup>62</sup> However, notwithstanding their philosophical underpinnings of ‘independence’ autonomy, and self-sufficiency, and being akin to running a small business, state-funded, user-directed support systems described above tend to be wedded to policy discourses of welfare dependency and are rarely financed through government departments associated with work, pensions and/or enterprise.<sup>63</sup>

To conclude, under the independent living service paradigm, individuals in need of services receive a personal budget that they can spend on tailored supports and services to meet their expressed needs. Typically needs are assessed by health and social care professionals in consultation with the service user. The *graded* personal budget is based on this assessment. The idea is that money follows the person’s needs to empower individuals to have increased personal responsibility, independence, capability and resilience through the choice and control of services, independently from how the provision of personal budget iss. From being a passive receiver of care, recipients become an active participant in the process of deciding about their

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<sup>59</sup> *Ibid.*, 560.

<sup>60</sup> *Ibid.*, 560.

<sup>61</sup> *Ibid.*, 560.

<sup>62</sup> Carmel Laragy and Goetz Ottmann, "Towards a Framework for Implementing Individual Funding Based on an Australian Case Study" (2011) 8(1) *Journal of Policy and Practice in Intellectual Disabilities* 18-27.

<sup>63</sup> Prideaux et al, *op. cit.*, 557-9.



care needs: as a purchaser, consumer and an employer. The intention is to offer PWDs more chances for self-determination and to give them sufficient independence so that they can play their roles as equal citizens.

### **3.4 The Benefits of Independent Living**

Batavia associates the increased demand for user-directed personal services under the independent living model in the US and the UK with the ethical imperative of autonomy and the political-economic imperative of cost containment.<sup>64</sup> For example, in the US, the strong trend in law and bioethics supporting individuals' desire for autonomy and control over their own lives is accompanied by federal and state government efforts to seek cost effective approaches to meet the long-term care needs of a growing disabled population. One's home is a 'materialisation of identity',<sup>65</sup> and not only serves as a source of pride and individual personification but also acts as a locus of control, of relaxation, of safety, security and privacy. Other benefits of independent living for people with disabilities relate to their engagement with their community and its informational sphere, the life skills people with disabilities generate and their interpersonal relationships with non-disabled peers. Improvements in health, satisfaction, participation in society, motivation and self-esteem are more closely linked to independent living and have traditionally been limited by the lack of choice and control and the presence of dependency and disempowerment associated with institutionalisation.<sup>66</sup> A high standard of personal assistance and other forms of user-led service provision for people with disabilities is central to the realisation of the right to living independently in their own homes and to people's attainment of a sufficient level of integration into the wider community, thereby making the disabled community feel a greater sense of

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<sup>64</sup> Andrew I. Batavia, "A Right to Personal Assistance Services: Most Integrated Setting Appropriate Requirements and the Independent Living Model of Long-Term Care" (2001) 27 *American Journal of Law & Medicine* 17-43, 22.

<sup>65</sup> Iris M. Young, "Taking the Basic Structure Seriously" (2006) 4(1) *Perspectives on Politics* 91-97;

<sup>66</sup> Andrew I. Batavia, "A Right to Personal Assistance Services: Most Integrated Setting Appropriate Requirements and the Independent Living Model of Long-Term Care" (2001) 27 *American Journal of Law & Medicine* 17-43, 22.

inclusion as opposed to institutional isolation. Notwithstanding the evidence showing that implementing the right to independent living in a user-directed way improves outcomes, including individual satisfaction and quality of care and has a positive effect on the health and functional capacity of people with disabilities,<sup>67</sup> critics contend that the *user-directed* sub-model compromises the quality of personal services, complicates service-use for vulnerable individuals and creates increased applications and demands on the state for disability benefits. Whilst some of these criticisms also apply to the informal and medical models, others are directly related in that expanded access to the IL model provided by a personal assistance programme is only relevant to those who are willing and able to manage complex service user-provider relationships.<sup>68</sup> There are also inevitable drawbacks such as cost but the right must come first in this instance. To choose how you are living and with whom you live, is of paramount importance to self-realisation and the fulfilment of one's aspirations. People who live independently are more likely to know what they need to further themselves and, as a community, will share knowledge. The 2012 case of *Stanev v Bulgaria*,<sup>69</sup> in the ECHR made clear the link between the denial of legal capacity and institutionalisation in life. Developing a greater understanding of the benefits of, and availability of community living options will undoubtedly have a knock-on effect on individuals' understanding of and insistence upon their own legal capacity.

Even where people with disabilities can technically choose between institutional care and independent living there are obstructions to the choice and there is evidence to show that people with disabilities attempting to live independently encounter a multitude of barriers. Not least is the perceived prohibitive level of expense required to support independent living in the "current economic climate". Sue Marsh summed it up very well in a 2012 Guardian article regarding the Worcester Council's plans to re-institutionalise some of its disabled citizens when she said -

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<sup>67</sup> *Ibid.*, 22.

<sup>68</sup> *Ibid.*, 24.

<sup>69</sup> Application No. 36760/06, 17 January 2012.

"In a society so desensitised by cuts, we might look at this proposal through financial eyes. We might judge on a balance sheet that we can no longer afford this "luxury". We might be fooled into believing that the dignity of "the most vulnerable" is expendable. We might decide that when times get tough, we will turn our backs on progress and decency and look only at cost. Most of all, we would be forgetting that the value of a human life is not to be found on a balance sheet. The Worcester case sets a dangerous precedent. If it goes ahead, councils up and down the country might choose not where the best place for disabled residents to live is, but where the cheapest place is." <sup>70</sup>

There is a growing body of research comparing the cost of independent living with residential care directly. According to Zarb,<sup>71</sup> independent living is actually the most cost effective means of providing proper support to disabled people "because assistance is precisely matched to individual needs and, over time, is also likely to help reduce the overall level of demand on both social care and other public services" as well as reducing dependency on informal care and charity. Zarb advocates for a focus more on the benefits and outcomes of independent living than placing all attention on the costs which should be viewed as a social investment, decisions on the allocation of which must be guided by human rights and social justice criteria. A study conducted by Hurstfield et al. identified the key elements influencing the cost of independent living to be "types of settings, types of care, types of impairment and extent of severity."<sup>72</sup> The study found that "the delivery of Independent Living support to disabled people is more cost effective, or at least no more expensive, than traditional care provision".<sup>73</sup> For example, providing

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<sup>70</sup> Sue Marsh, "Disabled People Have a Right to Live Independently, Worcester Council" *The Guardian* (London, 13 July 2013).

<sup>71</sup> Gerry Zarb, "*The Economics of Independent Living*" (Independent Living Institute 2003) <[www.independentliving.org/docs6/zarb2003.html](http://www.independentliving.org/docs6/zarb2003.html)> accessed 20 February 2017.

<sup>72</sup> Hurstfield et al, *The Costs and Benefits of Independent Living* (Office for Disability 2007) <<http://www.odi.gov.uk/research/knowledge/independent-living.php>>accessed 10 May 2017.

<sup>73</sup> *Ibid.*

supports for people with disabilities to remain in employment is estimated to be lower in cost than the benefit payments and lost taxation involved in their inability to engage in employment.<sup>74</sup> The research furthered that “investment in long-term sustainable projects, rather than small pilots is more likely to realise the potential benefits and economies of scale.”<sup>75</sup> Meanwhile a study conducted by Mansell et al found that: “community-based models of care are not inherently more costly than institutions, once a comparison is made on the basis of comparable needs of residents and comparable quality of care. Community-based systems of independent and supported living, when properly set up and managed, should deliver better outcomes than institutions.”<sup>76</sup> In the U.S, research in the late 1990s found the average yearly cost of an individual in State care was \$104,000 with that of someone living independently in the community with supports being \$30,000. Jolly feels and I tend to agree that there always exists a risk that “the worst institutions will reduce their running costs to unacceptable levels.”<sup>77</sup>

In England, the average cost of institutional/residential care of €31,200 per person per year is found to be dependent on the required support and staff and overhead costs which it covers.<sup>78</sup> The amount of funding for personal assistance depends on the needs of the individual, which are assessed by the local authorities. Personal assistance funded by the local authority is paid either directly to the individual, family member or through a provider. Most personal assistants are paid between 7.50 GBP and 11 GBP per hour (app. 10 – 14 EUR per hour). Personal assistance budget and housing support budget come from a different source and the local authority administers both and oversees the spending. It is difficult to draw any accurate conclusions from

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<sup>74</sup>Hurstfield et al, *The Costs and Benefits of Independent Living* (Office for Disability 2007) <<http://www.odi.gov.uk/research/knowledge/independent-living.php>> accessed 27 January 2015.

<sup>75</sup> *Ibid.*

<sup>76</sup>Jim Mansell et al, *Deinstitutionalisation and Community Living – Outcomes and Costs: Report of a European Study. Volume 2: Main Report* (Canterbury: Tizard Centre, University of Kent 2007).

<sup>77</sup>European Network of Independent Living, Debbie Jolly, *Research Paper on Community Living and the Support of Independent Living: Costs and Benefits* (2009).

<sup>78</sup> European Network on Independent Living, *Comparing the Cost of Independent Living and Residential Care. A Survey by the European Network on Independent Living* (December 2014).

these figures, given the wide diversity of needs and expenditure by different individuals. More often than not though, the funding is tied to a building or an organisation, meaning that were they to leave that building or service provider they may not be entitled to the same amount used to provide for their needs as was used beforehand. Generally, further assessment is prescribed in these circumstances to estimate their budget, and it is normally lower than before.

Studies costing independent living suggest that levels of efficiency and cost effectiveness rely on how independent living schemes are managed and structured. In the Netherlands, savings of 25% were identified by Gadsby who also cautions that “there is no evaluation to examine whether budget holders are getting a comparable level of care from the reduced levels of funding; or indeed whether some of the costs are being displaced to elsewhere in the system.”<sup>79</sup> She also noted that in the Netherlands and Belgium the introduction of personal budgets resulted in increased costs, as the demand was much higher than expected, resulting in restrictions having to be placed on what budgets could cover. The same review of evidence that individual budgets in England are more cost-effective in achieving overall social care outcomes is disputed by those who cast doubt upon such a positive view of the system.<sup>80</sup> Gadsby concludes that allowing individuals to decide their personal budgets gives “more choice, control and flexibility to the budget holder” helping them “identify and potentially source the most appropriate services, and to varying degrees, manage the budget and be accountable for how it is spent.”<sup>81</sup>

Under the traditional care provision system, a myriad of inefficiencies exist, such as inflexible contracts, inaccurate assessment systems resulting in individuals receiving in excess of their overall care requirements and agency charges that tie considerable resources into institutional care which if freed

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<sup>79</sup> Policy Research Unit in Commissioning and the Healthcare System, Erica W. Gadsby, *Personal Budgets and Health: a Review of the Evidence* (University of Kent 2013).

<sup>80</sup> Luke Clements, "Individual Budgets and Irrational Exuberance" (2008) 11 *Community Care Law Reports* 413-430.

<sup>81</sup> Gadsby, *op. cit.*, 5.

up and integrated into a new independent living infrastructure, would reduce the overall cost in real terms. This type of approach requires both once-off short-term investments, as well as long-term adequate emotional and practical support, if people with disabilities are to be properly equipped to manage their own care. Independent living support mechanisms when designed and implemented correctly can result in reduced costs, adding weight to the argument that one may need to invest in the short term to save in the long term. Gadsby notes the lack of cost-effectiveness analyses of Independent Living supports (such as personal budgets) in the short-term and their complete absence over the long-term “in all countries”.<sup>82</sup> On this point, Hurstfield adds that “whilst many studies have been able to capture some of the immediate benefits of independent living options for individuals, very few have managed to deploy robust methods to value benefits quantitatively”, as the “relative recency of the Independent Living agenda both in terms of research and implementation” makes long term analysis difficult.<sup>83</sup> Another difficulty must be that of quantifying the emotional and other psychological benefits to those now out of institutional care, which certainly impacts greatly on any quality of life judgement.

Much of the focus of analysis of independent living continues to be on economic savings from ‘cash for care’ type schemes and on the experience and impact of direct payments on the personal well-being and self-esteem of people with disabilities, the barriers and facilitators to take-up, the challenges to direct payments in ‘integrated’ social support and the implications of direct payment type schemes on specific user groups within the disabled community. In the UK, in terms of users, the main beneficiaries tend to be the working age population particularly younger disabled persons with user-directed support systems acknowledged in the literature as having a positive effect on their lives.<sup>84</sup> Rarely going beyond economic comparisons between the costs of traditional services with direct payment schemes, there

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<sup>82</sup>*Ibid.* 5.

<sup>83</sup> Hurstfield et al, *The Costs and Benefits of Independent Living* (Office for Disability Issues 2007).

<sup>84</sup>Prideaux et al, *op. cit.*, 559.

remains a distinct lack of holistic analysis of the less acknowledged socio-economic costs and benefits of self-directed support systems for service users, their families, personal assistants and local/national economies.<sup>85</sup> Such systems provide important social and economic advantages for all concerned across the post-industrial world.<sup>86</sup> Transforming the social relations of support, they afford people with disabilities with increased power and control over their support needs - an integral aspect of independent living. This service paradigm has also benefited the economy as direct payment users employ others for their 'care'. The employment of personal assistants in turn has the additional benefit of providing a number of disabled people with the opportunity to participate in the labour force should they choose to do so. Again, economic benefits accrue. Additionally, PA users as independent consumers contribute to the economy in many different ways. Evidence suggests that self-managed programmes have the potential to produce cost efficiencies since individuals requiring support are generally better qualified to identify their own needs and to find ways of meeting them within available resources.<sup>87</sup> In turn, as independent consumers, service users can help influence providers to be more responsive and to achieve innovations in support delivery.<sup>88</sup>

Enabling free choice in terms of personal assistance and use of social support funding, these new models of state-funded, user-directed service delivery are now recognised as being part of a broader move away from dependency, welfare and congregated services towards de-institutionalisation, independent living and human rights.<sup>89</sup> Often akin to running a small business they therefore challenge the binary distinction between work and welfare as

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<sup>85</sup> *Ibid.*, 559.

<sup>86</sup> *Ibid.*, 557.

<sup>87</sup> Prince, Jane M. Prince, Scott Manley, and Gale G. Whiteneck, "Self-Managed versus Agency-Provided Personal Assistance Care for Individuals with High Level Tetraplegia" (1995) 76(10) Archives of Physical Medicine and Rehabilitation 919-923, 919.

<sup>88</sup> James R. Spalding and Joel Hay, "Cost Effectiveness of Tumour Necrosis Factor- $\alpha$  Inhibitors as First-Line Agents in Rheumatoid Arthritis" (2006) 24(12) Pharmacoeconomics 1221-1232.

<sup>89</sup> Leanne Togher et al, "An Exploration of Participant Experience of a Communication Training Program for People with Traumatic Brain Injury and Their Communication Partners" (2012) 34(18) Disability and Rehabilitation 1562-1574.

they question the meaning of work and assumptions surrounding disabled users use of self-directed support schemes as welfare dependents.<sup>90</sup> However what has been neglected by official attempts to capture the costs and benefits of individual user-led services is an analysis of what the move away from dependency on the welfare system actually means particularly in terms of understanding of disability users as independent consumers, workers, employers and business managers. For users to run direct payment type schemes they must develop a particular skill set in order to recruit, manage and supervise personal assistants. Highly varied and transferable, these include recruitment, interviewing, management, accounting, supervisory and interpersonal skills, that in any other environment, would be classified as work.<sup>91</sup>

### **3.5 The Barriers to Independent Living**

The realisation of independent living is of crucial importance to the overall success of the CRPD as a blueprint for real and lasting change and also serves as a reference guide for its overall effectiveness. As the body monitoring Treaty implementation, the UN Committee on the Rights of Persons with Disabilities has expressed concern about the lack of resources and services in a number of state parties to guarantee the right to live independently and to be included in the community, placing the onus on the state to increase the Personal Assistant resources available to PWDs.<sup>92</sup> For example, in its Concluding Observations on the report submitted by Spain:

39.‘The Committee is concerned at the lack of resources and services to guarantee the right to live independently and to be included in the

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<sup>90</sup> Prideaux et al, *op. cit.*, 559.

<sup>91</sup> *Ibid.*, 562.

<sup>92</sup>European Coalition for Community Living, *Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities* (Focus Report of the European Coalition for Community Living 2009) 27.



community, in particular in rural areas. It is further concerned that the choice of residence of persons with disabilities is limited by the availability of the necessary services, and that those living in residential institutions are reported to have no alternative to institutionalization. Finally, the Committee is concerned about linking eligibility of social services to a specific grade of disability.

40. The Committee encourages the State party to ensure that an adequate level of funding is made available to effectively enable persons with disabilities: to enjoy the freedom to choose their residence on an equal basis with others; to access a full range of in-home, residential and other community services for daily life, including personal assistance; and to so enjoy reasonable accommodation so as to better integrate into their communities.

41. The Committee is concerned that the law for the promotion of autonomy limits the resources to hire personal assistants only to those persons who have level 3 disabilities and only for education and work.

42. The Committee encourages the State party to expand resources for personal assistants to all persons with disabilities in accordance with their requirements'.<sup>93</sup>

Across the EU, personal assistance is not offered by all local authorities or is in the experimental stages and in many places, it lacks a legal basis. Where independent living services are available, many people with disabilities are

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<sup>93</sup> *Ibid.*, 27.

not made aware of their existing experimental state and even if they are, budgetary restraints mean local authorities are restricted in their outlay of personal assistance schemes. There also exists a common perception that residential care should nearly always be the option of ‘first choice’ particularly in relation to those with higher dependency. This perception finds comfort in an environment characterised by lack of recognition and support for independent living as a human right, that views the concept of independent living as a service selection rather than a life choice and that fosters resistance amongst individuals with a vested interest in maintaining the status quo and the domination of residential institutions, who are to a degree reliant on the passive acceptance of this by the Disability community.<sup>94</sup> There is also a low level of involvement of individuals with disabilities in the development of policy and outcome measures.<sup>95</sup> A 2009 report found evidence of this, documenting levels of participation across EU member states ranging from low to medium down to none whatsoever. In Spain and Sweden, some level of involvement was observed, but this was more so implied than abundantly clear from each country. Bulgaria showed some clear evidence on the matter given that research carried out by a Centre for independent living, Sofia, included a Disability Rights Monitor project and an Annual Disability Rights Report. In Germany, the federated “German Disability Council” is consulted heavily in “official disability politics”. The report also found that in 14 countries there was no evidence of the role of disabled people in research, policy formation or planning. These countries include the Netherlands, Norway, Sweden, Denmark, Romania, Ireland, Poland, France, Latvia, Portugal, Lithuania, Italy, Belgium and United Kingdom.<sup>96</sup>

In France and Portugal there is recognition for the links between increasing accessibility to the built environment and the facilitation of independent living and the resultant effect on the quality of life of people with disabilities.

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<sup>94</sup>Jennifer Hurstfield, Urvashi Parashar, and Kerry Schofield, *The Costs and Benefits of Independent Living* (Office for Disability Issues 2007).

<sup>95</sup> Centre for Disability Studies, Ruth Townsley, Linda Ward, David Abbott and Val Williams Norah Fry, *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report* (University of Leeds 2010).

<sup>96</sup>*Ibid.*, 45.

However, the Czech Republic, Greece, Malta, Austria, Bulgaria and Latvia have no specific support for the concept of independent living whilst in countries such as Romania, legislation dealing with independent living fails to provide adequate support infrastructure and funding for service users to truly live independently. Laws in Lithuania such as the ‘Law on Equal Treatment’ (2008), ‘Law on social integration of the disabled’ (2004) and ‘Law on Social Services’ (2006) that purport to deal with issues like choice, equality and the right to live independently are said to be incompatible with one another, thereby having a negative impact on equality, disability and incapacity.<sup>97</sup> Many EU member states (Estonia, Netherlands, Slovakia, Ireland, UK and Spain for example) have central policy containing statements of support for independent living. Countries such as Finland, Sweden, Denmark, Poland, Italy, Spain have gone one step further and brought into being specific legislative instruments supporting aspects of independent living whilst Germany, Netherlands and the UK recognise personal budgets at a legislative level. Despite these legislative and policy developments, a 2015 ECCL report<sup>98</sup> identified several areas, which were still lacking across member states regarding the move from institutional care to community living. For example, the report highlights the lack of adequate policies for the removal and replacement of long-stay residential institutions with an independent living infrastructure incorporating housing, education, employment, health care, transport etc. It detects a lack of clear strategies to ensure this transition is both workable and in the end successful. The ENIL-ECCL also queried whether the EU has the ability to examine and keep abreast of member states’ implementation of their obligations in this area on a policy level. More involvement in this assessment process of PWD organisations and their affiliates were deemed essential. The report also highlighted a lack of coordination between the European Social Fund (ESF) and the European Regional Development Fund (ERDF) regarding the move

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<sup>97</sup> Centre for Disability Studies, Ruth Townsley, Linda Ward, David Abbott and Val Williams Norah Fry, *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report* (University of Leeds 2010) 13.

<sup>98</sup> European Coalition for Community Living, *Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities* (Focus Report of the European Coalition for Community Living 2009).

toward deinstitutionalisation. Particular concern was expressed that ERDF funding is geared more toward special services for PWDs like family type homes and protected housing rather than accessibility in mainstream infrastructure.

The Draft guidance for EC desk officers on the transition from institutional to community-based care provides that investments cannot be made if “the persons concerned, given the seriousness of their condition, require constant medical supervision”<sup>99</sup>. This clearly flies in the face of Article 19 of the CRPD, which provides for the right to live independently and to be included in the community for ALL people with disabilities.

In the UK, “Improving the Life Chances of Disabled People”<sup>100</sup> provided a 20-year plan for inclusion, with the “Independent Living Strategy” being the next major report following that in 2008.<sup>101</sup> The stated aims of these included “ensuring that all disabled people who need support in daily life achieve greater choice and control over how support is provided”. The strategy emphasised the values of autonomy, choice, freedom, dignity and control. Meanwhile another report, “Putting People First” encouraged moves towards the ‘personalisation’ of support - including the making of commitments towards greater individual choice and control.<sup>102</sup> This report emphasised areas of focus such as self-assessment of need, direct payments and personal budgets as well as a more upfront and documented system of allocating funding. However, like other reports many of its recommendations were sidelined by the “economic downturn” with cutbacks leading to the closure in 2015 of the Independent Living Fund, a scheme supporting persons with

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<sup>99</sup>European Commission, *Thematic Guidance Fiche for Desk Officers, Transition from Institutional to Community-Based Care (January 2014)* <[http://ec.europa.eu/regional\\_policy/sources/docgener/informat/2014/guidance\\_deinstitutionalisation.pdf](http://ec.europa.eu/regional_policy/sources/docgener/informat/2014/guidance_deinstitutionalisation.pdf)> accessed 8 November 2015.

<sup>100</sup> Prime Minister’s Strategy Unit, *Improving the Life Chances of Disabled People* (Final Report 2005) <<https://core.ac.uk/download/pdf/4156824.pdf>> accessed 10 June 2015.

<sup>101</sup> Office for Disability Issues, *Independent Living: A Cross-Government Strategy about Independent Living for Disabled People* (February 2008).

<sup>102</sup>Department of Health, *Putting People First* (2008) <<http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>> accessed 11 November 2015.

high dependency to apply for direct payments and personal assistance and train and employ their own staff since 1988. The ILF was overseen by 120 staff and 90 assessors overseeing payments to 19,000 persons. It boasted 97% user outcome satisfaction, 99.5% award accuracy and an administration overhead of 2% expenditure (in 2013-14).<sup>103</sup> The ILF closed to new applications in 2010 and will cease to exist from 30 June 2015.<sup>104</sup> The area will now be administered by local authorities in England and by the devolved regional governments in Scotland, Wales and Northern Ireland. The decision-making process was challenged in the Court of Appeal, which referred in its judgement to the CRPD saying ‘independent living might well be put seriously in peril for a large number of people’, as well as underlining the fact that public sector equality duties had not been discharged.<sup>105</sup>

### 3.6 Conclusion

There has been much evolution in thinking with regards to disability and the right to independent living both nationally and internationally. The idea of ‘independent’ living is a radical concept as it poses a direct challenge to conventional thinking on disability, combining both ideological and practical means to address the everyday impairment, environmental and social problems encountered by people with disabilities.<sup>106</sup> To provide substance to these claims this chapter examined the concept of independent living and its impact on policy development and support for the right to personal assistance and a user-led system allowing people with disabilities to devise, pay for and, therefore, control their own support systems including, but not only, the employment of personal assistance according to their own requirements. There is increased policy interest across Europe and North America in the

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<sup>103</sup>Brent Pension Fund, *Annual Report and Accounts 2013-14* (2008)

<[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/321510/ilf-ara-2013-14.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/321510/ilf-ara-2013-14.pdf)> accessed 12 November 2015.

<sup>104</sup> Department for Work and Pensions, *Closure of Independent Living Fund (ILF) and Integration into Mainstream Care and Support System* (December 2012).

<[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/184151/closure-of-independent-living-fund-eia.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/184151/closure-of-independent-living-fund-eia.pdf)> accessed 12 November 2015.

<sup>105</sup>*Bracking & Ors, R (on the application of) v Secretary of State for Work and Pensions* [2013] EWHC 897.

<sup>106</sup> Colin Barnes and Geoffrey Mercer, *Disability* (Polity 2003).

mechanism of self-directed supports through the use of individual funding. Under the sub-model of independent living people with disabilities receive a certain amount of money every month to purchase PA and other services to meet their needs. In contrast to the medical and the informal support models where others typically control the timing and manner in which services are provided, this approach to implementing the right to independent living offers people with disabilities greater control over their PA services upon which they depend.<sup>107</sup> Although personal budget delivery models vary considerably in the levels of choice and control assigned to people with disabilities, professionals, service providers and public authorities, there are some common characteristics, all based on the idea of individualised support. Services determined by the person are provided on a one-to-one basis, are flexible, reflexive and responsive to the person's changing needs and preferences. Crucially they allow a high degree of specificity based on the types and degrees of impaired functionality and their interaction with social differences and wider environment. Evaluations by both state<sup>108</sup> and independent third parties<sup>109</sup> indicate that self-directed support can enhance choice, control and flexibility, when compared with conventional service provision. The direct payment model is found to be cheaper and affords higher quality support than the residential homes provided by local authorities. Additionally, Direct Payments challenge the 'culture of welfare' across social service departments. They therefore not only represent a pragmatic and cost-effective shift in the funding and management of support but also a key goal of the independent living movement and a 'potentially revolutionary' redistribution of power.<sup>110</sup> Despite the evidence illustrating the economic and

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<sup>107</sup> Andrew I. Batavia, "A Right to Personal Assistance Services: Most Integrated Setting Appropriate Requirements and the Independent Living Model of Long-Term Care" (2001) 27 *American Journal of Law & Medicine* 17-43, 19.

<sup>108</sup> Individual Budgets Evaluation Network, *Evaluation of the Individual Budgets Pilot Programme: Final Report* (2008)  
<<https://www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf>> accessed 12 November 2015.

<sup>109</sup> Gerry Zarb and Pamela Nadash, "Cashing in on Independence: Comparing the Costs and Benefits of Cash and Services" (1994)  
<[https://www.researchgate.net/profile/Pamela\\_Nadash/publication/265280359\\_Cashing\\_in\\_on\\_Independence\\_Comparing\\_the\\_costs\\_and\\_benefits\\_of\\_cash\\_services/links/57460d9a08ae9f741b43133a.pdf](https://www.researchgate.net/profile/Pamela_Nadash/publication/265280359_Cashing_in_on_Independence_Comparing_the_costs_and_benefits_of_cash_services/links/57460d9a08ae9f741b43133a.pdf)> accessed 10 October 2015.

<sup>110</sup> Allison Cohen Hall et al, "Employment Funding for Intellectual/Developmental Disability Systems" (2011) 34(1) *Journal of Vocational Rehabilitation* 1-15.

social benefits of the independent living service paradigm, challenges and barriers to take-up remain. Whilst the disability legislation and social movements are helpful and the concept of independent living is increasingly mentioned as offering great potential for people with disabilities to live an independent life, the lack of cast-iron-rights cannot be overstated whilst historical studies in the field of disability law, such as those undertaken by Degener and Quinn<sup>111</sup> make it clear that not all Acts that affect disability and related advocacy and activist movements have failed, rather that they have achieved relatively little.

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<sup>111</sup>Gerard Quinn, Theresia Degener and Anna Bruce, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (United Nations Publications 2002).

## **Chapter Four**

### **The Right to Independent Living Under The United Nations Convention on the Rights of People with Disabilities**

#### **4.1 Introduction**

This chapter establishes the international legal and policy context of the study, focusing on the United Nations Convention on the Rights of People with Disabilities (CRPD), the international human rights treaty providing the normative framework and legal tools to promote and protect the rights of people with disabilities, including the right to live independently in the community. It is divided into four sections. Following this introduction, the first section traces the rationale and emergence of the CRPD and how article 19, the main provision designed to operationalise the right to independent living, became one of the overarching principles of the Treaty. It concludes with a brief overview of the various mechanisms under the CRPD that operationalise the Treaty. Sections two, three and four describe how article 19 operates and taps into its potential. After locating the right to independent living within the wider normative framework of international human rights, section two delineates the normative content, including the concepts, provisions and core elements of article 19. Section three turns to States parties' obligations to ensure every individual's right to live independently and be included in the community. Given its distinct role as one of the widest ranging and most intersectional articles of the Treaty, how article 19 relates to other provisions in the CRPD, is the focus of section four. Section five, is concerned with implementation at the national level. The last and final section of the chapter provides a synthesis of the findings.

#### **4.2 The Rationale and Emergence of the CRPD and Article 19**

Adopted by the United Nations (UN) General Assembly in December 2006, the UN Convention on the Rights of People with Disabilities (CRPD) is the



first human rights instrument providing clarity about people with disabilities' right to be treated as full and equal human beings and to live independently in their community. It comprises 50 articles and its Optional protocol comprises 18 articles.<sup>1</sup> Article 19 of the Convention provides that:

“States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”<sup>2</sup>

The CRPD was created in response to a specific need for a legally binding human rights instrument with clear and broad inputs. Its rationale was not to create new rights in respect of people with disabilities but rather to clarify their human rights as the existing human rights treaties as well as the non-binding nature of policy guidelines provided by such instruments, as the UN Standard Rules on the Equalisation of Opportunities for Persons with

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<sup>1</sup> Bronagh Byrne et al, "UNCRPD: Shortfalls in Public Policy and Programme Delivery in Northern Ireland Relative to the Articles of the UNCRPD" (Final Report 2014).

<sup>2</sup> United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol 2006, Article 19.

Disabilities (1993) were insufficient to counter national laws excluding people with disabilities and their particular needs.<sup>3</sup> Although people with disabilities should have been considered under the pre-existing conventions, as a group they were not specifically mentioned (except in the Convention on the Rights of the Child<sup>4</sup>). There was nothing wrong in theory with not expressly referring to persons with disabilities in international human rights law. However, we were largely invisible as a cohort and the human rights violations were so entrenched that a Convention dealing specifically with the issue is necessary.

When the Universal Declaration of Human Rights (UDHR) came into being in 1948 it set out the universality of human rights, demanding that everyone be respected as rights holders in terms of freedom and equality. In 1966 and based on the need for two separate human rights treaties, the UN further established the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). Both came into force in 1976.<sup>5</sup> The ICESCR commits its parties to work toward the granting of economic, social, and cultural rights to individuals, including labour rights and the right to health, education, and to an adequate standard of living. In 2016 it had 114 State parties.<sup>6</sup> Almost two decades following their inception, the UN Committee on Economic, Social and Cultural rights (CESCR) - the body tasked with interpreting and commenting upon how the ICCPR and the ICESCR promote and protect the rights of persons with disabilities - highlighted that the potential offered by such human rights conventions is not being tapped. Tallying with the then Secretary-General's conclusion that most Governments lacked decisive concerted measures that would effectively improve the situation of people with disabilities, the CESCR found that States Parties to these treaties were

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<sup>3</sup>Gerard Quinn and Theresia Degener, *Human Rights and Disability: The Current Use of the Potential of United Nations Human Rights Instruments in the Context of Disability* (Office of the United Nations High Commissioner for Human Rights, 2002).

<sup>4</sup> Convention on the Rights of the Child 1989, Article 23.

<sup>5</sup> Asbjørn Eide, "Economic, Social and Cultural Rights as Human Rights" in Asbjørn Eide, Catarina Krause and Allan Rosas (eds), *Economic, Social, and Cultural Rights: a Textbook* (Martinus Nijhoff Publishers 1995).

<sup>6</sup> International Covenant on Economic, Social and Cultural Rights 1966.

devoting very little attention to this issue in their reports, concluding that: ‘Even in countries which have a relatively high standard of living, persons with disabilities are very often denied the opportunity to enjoy the full range of economic, social and cultural rights recognised in the Covenant’<sup>7</sup> It was in this international legal and policy context that Mexico submitted a preliminary proposal in 2001 to the UN General Assembly, calling for a ‘comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities’ (GA Resolution 56/168, 19 December 2001, A/56/583/Add.2.). Beginning with the establishment of the Ad Hoc Committee (AHC) - called upon by General Assembly Resolution 56/168 of December 2001 - a six-year drafting process ensued. The Ad Hoc Committee (AHC) met twice a year and this along with the eight further sessions laid the basis for discussion and foundation of the disability rights Convention. The work of the AHC drew specifically on the contributions made by key stakeholders promoting the social model of disability and whose participation was also secured by the UN Resolution 56/168<sup>8</sup>. They included the UN Special Rapporteur on Disability, relevant human rights treaty bodies and international, regional and national intergovernmental and non-governmental organisations (NGOs) advocating the rights and interests of people with disabilities.<sup>9</sup> Following adoption in 2006 and after receiving a sufficient number of ratifications the Treaty came into force in May 2008. It was ratified by the European Union (EU) in 2010 thereby securing bilateral ratification in EU States the vast majority of whom have individually ratified its provisions.<sup>10</sup> The EU’s ratification of the CRPD means that institutions of the EU and member states are under an obligation to implement the CRPD

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<sup>7</sup> UN Committee on Economic, Social and Cultural Rights, *General Comment No. 5; Persons with Disabilities*, 9 December 1994, E/1995/22  
<<http://www.refworld.org/docid/4538838f0.html>> accessed 30 March 2016.

<sup>8</sup> Grainne de Burca, “The European Union in the Negotiation of the UN Disability Convention” (2010) 35(2) *European Law Review* 174-196, 183.

<sup>9</sup> Sabrina Ferraina, "Analysis of the Legal Meaning of Article 27 of the UN CRPD: Key Challenges for Adapted Work Settings" (Cornel University ILR School 2012) 9  
<<https://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?referer=https://scholar.google.com/&httpsredir=1&article=1559&context=gladnetcollect>> accessed 10 January 2016.

<sup>10</sup> Center for Society Orientation, *Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in the Republic of Serbia* (2015)  
< <http://www.disabilitymonitor-see.org/> > accessed 20 January 2016.

insofar as the provisions are within the scope of EU competence.<sup>11</sup> In 2012, a vote in the US Senate rejected the UN Treaty on disability rights – it fell five votes short of the two-thirds majority required for ratification.<sup>12</sup> As of June 2018, the Convention has 161 signatories and 177 parties, with Ireland, after waiting for almost a decade, representing the most recent and the last of the 27 EU member states to ratify the Treaty in March 2018.

The negotiation of the CRPD in little more than 2 years was considered an exceptional achievement in UN history, given the sensitivity and complexity of some of the issues, with the UN Secretary General noting that the Treaty has ‘become a landmark several times over’.<sup>13</sup> Furthermore, the fact that the treaty received more signatures than any other human rights treaty immediately after entering into force illustrates State Parties’ clear commitment to acknowledging the importance of promoting disability rights and including the right to independent living. The Treaty also represents a key milestone for disability advocacy and legislation, giving the UN and the EU enhanced procedural strength and standing, particularly in regard to rights. Marking a significant advance in the disability rights movement, it demonstrates the strength and value of advocacy, whereby subtle and deliberate changes, not least in disability terminology, had to be relentlessly advocated for.<sup>14</sup>

Decades prior to the adoption of the Treaty, the disability rights movement argued that independent living was “not a privilege conferred on us by a generous society, but that it is the right of all individuals, regardless of ability to live in the community.”<sup>15</sup> The inclusion of the right to independent living

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<sup>11</sup> Luke Clements, *Carers and their Rights: The Law Relating to Carers* (Cargo Publishing 2012).

<sup>12</sup> ‘Ratification’ is a concrete action taken by a State that means it undertakes the legal rights and obligations contained in the Convention.

<sup>13</sup> Kofi Annan, Transcript of Press Conference (United Nations Headquarters 29 March 2005) <<https://www.un.org/press/en/2005/sgsm9788.doc.htm>> accessed 12 January 2015.

<sup>14</sup> Clark, Laurence and Stephen Marsh, "Patriarchy in the UK: The Language of Disability" (Unpublished) <<http://www.leeds.ac.uk/disability-studies/archiveuk> (2002)> accessed 15 March 2016.

<sup>15</sup> Simon Brisenden, “Independent Living and the Medical Model of Disability” (1986) 1(2) *Disability, Handicap and Society* 173-178, 174.

under Article 19 of the CRPD is particularly significant in that it enshrines in international human rights law for the first time that living in the community is not by discretion and that the state has positive obligations in the area. How this norm came to be one of the overarching principles of the CRPD has its roots in the disability rights movement and key milestones, namely the United Nations (UN) Declaration on the Rights of Disabled Persons (1975) and the international Year of Disabled Persons (YDP) that occurred in 1981 together with the formation of the Disabled Peoples' International (DPI). Critical at this time, was the focus the UN directed towards the foundation of the rights-based approach we have today, as well as non-binding standards specifically pertaining to disability. This attention resulted in adoption of the Declaration on the Rights of Mentally Retarded Persons, followed by the 1985 Declaration on the Rights of Disabled Persons.<sup>16</sup> These all helped push forward the rights agenda leading to the promulgation in 1994 of the UN Resolution entitled the UN Standard Rules on the Equalisation of Opportunities for People with Disabilities. Importantly the resolution provided for the appointment of a Special Rapporteur whose role has been to monitor the implementation of the Rules. The main achievement of the UN Decade of Disabled Persons (1983-1992) is reflected in many of the principles that went on to feature in the CRPD; the Standard Rules contain the claim that “[p]ersons with disabilities are members of society and have the right to remain within their local communities“. Furthermore and critical for the realisation of the right to independent living, naming people with disabilities as the key stakeholders in how services are provided to them was included strongly in these rules (Rule 14(2)) and then repeated with clarity in the CRPD. While not legally binding, the Standard Rules were important developments that raised awareness about the human rights of PWDs. They also represented a strong moral and political commitment of Governments to take action to attain equalisation of opportunities for PWDs, thus serving as an instrument for policy-making and as a basis for technical and economic cooperation. Important as the Standard Rules were however, they “reflected

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<sup>16</sup> United Nations, *Declaration on the Rights of Disabled Persons* (Official Records of the General Assembly, Thirtieth Session s34 1975).

medical and charity models of disability and were heavy-laden with paternalism.”<sup>17</sup>

Many of the principles covered by the Standard Rules, the ICCPR and the ICESCR are now elaborated upon and solidified by the CRPD, but in a more clear and precise manner and within a binding international human rights treaty. As previously mentioned, rather than creating any new law, one of the main aims of the Treaty is to clarify, tailor and apply existing international human rights theory and law and human rights principles, such as dignity, autonomy, and equality of opportunity to the disability context. The CRPD thus represents a paradigm shift as within its text, persons with disabilities are not viewed as “objects” of charity, medical treatment and social protection but rather 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. The Convention gives universal recognition to the dignity of persons with disabilities. It brings about the acceptance of diversity as an integral part of human rights, the concept of interdependence and most importantly, it emphasises the autonomy and capability of each individual.”<sup>18</sup> According to Quinn this paradigm shift is CRPD’s greatest achievement and what makes the Treaty revolutionary.<sup>19</sup> It affords the Treaty potential to transform discriminatory disability norms and attitudes towards persons with disabilities where they would be no longer viewed as objects of care or charity but as rights holders on an equal basis with others.

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<sup>17</sup>Michael A. Stein and Janet E. Lord, “Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities” in Oddný Mjöll Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities European and Scandinavian Perspectives* (Brill Online Books and Journals 2009).

<sup>18</sup>Amita Dhanda, “Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future” (2006) 34 (2) *Syracuse Journal of International Law and Commerce* 429-462.

<sup>19</sup> Gerard Quinn, ‘Resisting ‘The Temptation of Elegance’: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?’ in Oddný Mjöll Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities European and Scandinavian Perspectives* (Brill Online Books and Journals 2009).

There are several mechanisms under the CRPD that operationalise the Treaty and have resulted in the transformation of disability norms and attitudes and the rich jurisprudence in disability. Set out under Article 35 of the Treaty are accountability mechanisms requiring each State Party to submit a report (the State Party Report) every four years detailing progress made towards the realisation of obligations under the CRPD.<sup>20</sup> Critically, this report is also supplemented with shadow reports from civil society organisations. State Party and shadow reports are reviewed by the UN Committee on the Rights of Persons with Disabilities (the UN Committee), an independent body of experts on disability who then releases its Concluding Observations, where it expresses its concerns where the CRPD has not been fully implemented, highlights the state's improvements, and provides recommendations to ensure the principles underlying the Treaty are enshrined within the state. The State party is then expected to supply a written response and also a progress report within four years or at the request of the UN Committee.<sup>21</sup> As an international human rights treaty, the CRPD also has a normative context as it sets international standards that seek to eliminate discrimination against people with disabilities with the UN Committee providing authoritative guidance on how to implement these standards.<sup>22</sup> This enables the Treaty to play a transformative role in the domestic jurisprudence on disability equality whereby the standards developed at the international level can influence and empower civil society and grass roots organisations, courts, policy-makers and legislators in creating and implementing a domestic response to disability equality. The process by which international standards become part of domestic legislation varies widely from one state to the next. Some states, such as Hungary, Slovenia and Spain provide that the human rights conventions have direct legal effect domestically and are applicable in the courts therein. Other countries, such as the U.K and Australia view the international and domestic legal systems as completely separate and distinct. In these countries, legislation must be adopted to incorporate such

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<sup>20</sup> Bronagh Byrne et al, "UNCRPD: Shortfalls in Public Policy and Programme Delivery in Northern Ireland Relative to the Articles of the UNCRPD" (Final Report 2014).

<sup>21</sup> *Ibid.*

<sup>22</sup> *Ibid.*

instruments into the domestic legal framework. Critically, ratification also requires State Parties to establish state oversight mechanisms by resourcing a framework, including Disabled Person's Organisations (DPOs) and other independent groups, to promote, protect and monitor implementation of the Convention by submitting independent alternative reports to the Committee.

As a normative framework, the CRPD gathers the formal commitment of States to recognise the principles of human rights law whilst also serving as a traditional tool for lawyers in enforcing Treaty provisions, promoting the rights of the groups protected under the Convention. Notwithstanding this and the important space it creates for accountability, ratification and commitment towards implementing Treaty provisions however do not result in automatic change. The CRPD, 'like any other UN treaty, is a visionary law designed to transform society into a more just society and these visions cannot be achieved overnight'.<sup>23</sup> Neither can they be realised without strategies of persuasion nor socialisation at domestic level,<sup>24</sup> as international law cannot guarantee that new values, ideas and principles enshrined in the Treaty will be internalised and operationalised by state parties.<sup>25</sup> Critical for the transformation of discriminatory disability norms and attitudes and the generation of jurisprudence, ensuring disability rights are such concepts and principles as progressive realisation, reasonable accommodation and the indivisibility of rights. Underpinning the CRPD, these are discussed in some more detail in the next section, the focus of which is the legal framework for the right to independent living.

### **4.3 The Normative Content of Article 19**

In its draft General Comment No.5 (2017) on article 19, living independently and being including in the community, the UN Committee on the Rights of Persons with Disabilities stresses that at 'the foundation of this right is the

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<sup>23</sup> Gerard Quinn and Theresia Degener, *Human Rights and Disability: The Current Use of the Potential of United Nations Human Rights Instruments in the Context of Disability* (Office of the United Nations High Commissioner for Human Rights 2002).

<sup>24</sup> Quinn, *op. cit.*, 256.

<sup>25</sup> *Ibid.*, 216.



core human rights principle that all human beings are born equal in dignity and rights and all life is of equal worth'.<sup>26</sup> Article 19 is firmly rooted within the normative framework of international human rights, including the Universal Declaration of Human Rights (UDHR), which emphasises in article 29 (1) the interdependence of an individual's personal development and the social aspect of being a part of the community. Furthermore, article 19 has its roots in civil and political as well as economic, social and cultural rights: the right to liberty of movement and freedom to choose one's residence (art 12. ICCPR) and the right to an adequate standard of living (art.11 ICESCR) are indispensable conditions for human dignity and the free development of a person (Human Rights Committee, General Comment No. 27, Art. 12 (Freedom of Movement)). Like the UDHR, the ICCPR and the ICESCR, the Convention on the Elimination of Discrimination against Women (CEDAW) too forms the basis of the right to live independently and be included in the community. CEDAW emphasises equality of women and men including in legal matters relating to legal capacity (art. 15 (2)), the movement of persons and the freedom to choose their residence (art. 15 (4)).<sup>27</sup>

Article 19 of the CRPD is based on the human rights model of disability rather than the medical care or charity models. It represents a direct response to persons with disabilities' experiences of abandonment, forced dependency, institutionalisation and isolation. It is an answer to human rights violations against persons with disabilities and recognises the equal right of all persons with disabilities to live independently and be included in the community and with choices equal to others regardless of their level of intellectual capacity, self-functioning or support requirement. Before discussing the provisions and core elements of article 19, this section briefly revisits the definitions of independent living, community living and personal assistance as they are the key fundamental concepts underlying this right. Together they encapsulate

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<sup>26</sup> United Nations, Committee on the Rights of Persons with Disabilities, "Draft General Comment on the Right of Persons with Disabilities to Live Independently and be Included in the Community (Article 19)" (2014) <<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticle19.aspx>> accessed 23 March 2016.

<sup>27</sup> *Ibid.*

the individual and social dimensions necessary for interdependency, a critical element of the human condition and long term and daily well-being. The concept of independent living implies an individual dimension as it involves place of residence, lifestyle and the living arrangements of a person. According to this concept individuals with disabilities are enabled to exercise control over their lives and make all decisions that concern their lives. Forming the basis of who we are, these include place of residence, daily routine and personal relationships to clothing, nutrition, health care, religious, cultural and sexual and reproductive rights. It is the freedom to choose and control personal lifestyle and daily activities, as enshrined in article 3 (a) of the Treaty. The concept of independent living therefore constitutes a core part of an individual's autonomy and freedom.<sup>28</sup>

The second concept, the right to be included in the community refers to a social dimension including social interactions with others in the community. It concerns the principle of full and effective participation in the society as enshrined in article 3 (c) of the Convention. It means having access to all services offered to the general public and to specialised services offered to persons with disabilities, to enable them to be fully included and participate in social life.<sup>29</sup> These services include housing, personal care, transportation, shopping and so forth. As the right to be included in the community is about social interaction and communicative relations, it also means having access to political and cultural life from elections and public meetings of local governments to recreation events. Independent living and being included in the community counteract institutionalisation, which refers not to life settings or arrangements but rather the rigidity, isolation and loss of choice and control as a result of the imposition of a certain setting or arrangement. Meanwhile personal assistance, the third concept, is the essential tool for living independently and being included in the community. It refers to person-directed/user-led human support to persons with disability who are to control and allocate funding so as to purchase any assistance required based on a

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<sup>28</sup> *Ibid.*, 4.

<sup>29</sup> *Ibid.*

continuous needs assessment and a person/user's life circumstances. Personal assistance is led by the individual with the disability who either contracts the service from a variety of providers or acts as an employer. Under this model, as the individual has the option of custom-designing their service thus deciding by whom, how, when, where and in what way the service is delivered, they can freely choose their preferred degree of personal control over service delivery according to their requirements, capabilities and life circumstances.<sup>30</sup>

The main provisions covered by article 19 include the notion of non-discrimination, choice and decisions, personalisation and accessibility and adaptability of community facilities, goods and services which together reaffirm the equal right of persons with disabilities to live independently and in the community, regardless of the level of intellectual capacity, self-functioning or support requirements. According to article 19 (a), legal capacity and equal recognition before the law are preconditions for the realisation of the right to independent and community living. In other words, exercising choice and being able to make decisions about all aspects of one's public and private life, from living arrangements, choosing one's residence, where, how and with whom to live, to a way of life and lifestyle, are central to the idea of the right to independent and community living, regardless of disability and self-functioning. Meanwhile under article 19 (b), individualised support services are considered a right rather than a charity, affording people with disabilities the right to choose services that are based on their individual requirements and preferences and that facilitate independent living and full and effective inclusion and participation in the community. Therefore, any form of institutionalised support is not covered by article 19 (b). Extending beyond the home to the spheres of employment, education or political and cultural participation, individualised services include personal assistants, personal readers or sign language interpreters, guide dogs, social work services and technical aids. Finally, article 19 (c) is concerned with the right to equal community services and facilities, specifically equality of access for

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<sup>30</sup> *Ibid.*, 5.

all persons in the community to non-disability goods and services. For housing and facilities such as public libraries, hospitals, schools and public transport to be accessible to people with disabilities and allow for inclusion and participation, they must be affordable, acceptable and responsive to the requirements of persons with disabilities and thus based on reliable analysis of data disaggregated by gender, sex, age, ethnic background, social condition, refugee, asylum-seeking and migrant situation.<sup>31</sup>

#### **4.4 States Parties' Obligations Under Article 19 Relating to the Right to Independent Living**

To ensure the realisation of a minimum essential standard of the right to independent living and being included in the community, State parties have an obligation to respect, protect and fulfil the right of all persons with disabilities to independent living and being included in the community. In this regard States parties must ensure that the following core elements of article 19 are respected particularly in times of financial austerity. If persons with disabilities are deprived of these, it counts as a failure of States parties to fulfil their obligations:

- 'To have legal capacity to decide where and with whom and how to live is a right for all persons with disabilities, irrespective of impairment;
- The right to choose where to live requires a realistic option of accessible housing to choose from;
- The right to live independently does not entail dependence on informal support from family and friends;
- To have access to basic personalised and human rights-based disability specific services;
- To have access to basic mainstream community-based services and support on an equal basis with others; and

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<sup>31</sup> *Ibid.*, 8.

- The possibility of living independently must not be negatively affected by measures taken to respond to economic constraints'.<sup>32</sup>

To fulfil these duties, State parties are obliged to respect the hybrid legal character of the norm whereby the right to choose one's residence and where, how and with whom to live (art. 19 (a)), is a civil right, the right to access individualised assessed disability support services (art. 19 (b)) is a social right and the right to avail of community services and facilities (art. 19 (c)) is a social and cultural right.<sup>33</sup> As social and cultural rights are subject to systematic and progressive realisation, States parties must take steps to the maximum of their available resources (art.2 91) ICESCR). Progressive realisation imposes an immediate obligation on States parties to enter strategic planning in close consultation and partnership with disabled people, in addition to a range of other individuals and organisations such as family members, service providers, schools and employers. As a first step, the UN believes States should make a commitment to realising the right of all disabled people to live in the community.<sup>34</sup> While accepting that it takes time to achieve economic, social and cultural rights, the Convention requires States to act with a view 'to achieving progressively the full realisation of these rights'. Article 4(2) of the CRPD adopts the concept of progressive realisation of economic social and cultural rights, stating that:

“With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.”

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<sup>32</sup> *Ibid.*, 10.

<sup>33</sup> *Ibid.*, 10.

<sup>34</sup> United Nations, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities, Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol* (United Nations 2007).

It is important to note that this does not mean that State Parties to the CRPD are not required to take any measures in respect of its obligations under Article 19. While the full realisation of the relevant rights may be achieved progressively, steps towards that goal must be taken within a reasonably short time after the Covenant's entry into force for the States concerned. Such steps should be deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognised in the Covenant. The methodology, which should be used in order to satisfy the obligation to take steps, is stated in article 2(1) to be "all appropriate means, including particularly the adoption of legislative measures". The Committee recognises that in many instances legislation is highly desirable and, in some cases, may even be indispensable. For example, it may be difficult to combat discrimination effectively in the absence of a sound legislative foundation for the necessary measures. In fields such as health, the protection of children and mothers, and education, as well as in respect of the matters dealt with in articles 6 to 9, legislation may also be an indispensable element for many purposes.

It is likely that the Committee on the Rights of Persons with Disabilities will adopt the approach (outlined above) taken by the Committee on the International Covenant on Economic, Social, and Cultural Rights (ICESCR). Parker and Clements make the point that Article 4(2) of the CRPD on progressive realisation is expressly "without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law", meaning that rights are to be expressed without discrimination.<sup>35</sup> An important point to make is that the right to independent living set out in Article 19 goes beyond economic social and cultural rights, as there are also civil and political dimensions to it such as the right to liberty. Parker and Clements argue that this is only relevant to persons "who are placed in institutions due to the lack of alternative community based services but also where local funding arrangements for community support

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<sup>35</sup>Camilla Parker and Luke Clements, "The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?" (2008) 4 European Human Rights Law Review 508-514.

services (or special education needs) impair or entirely negate a disabled person's right to liberty of movement."<sup>36</sup> The issue of liberty of movement might also be an issue where funding limitations do not facilitate movement of a person requiring services. Often family members step in to areas at times where the state fails to continue providing adequate services and enough support to facilitate independent living. Indeed, the arguments made above by Parker and Clements can be taken further than merely the right to liberty, to other civil and political rights. For example, disabled persons' experiences of cruel, inhuman or degrading treatment or punishment in institutional settings could be argued as requiring immediate action under Article 19 CRPD.

The fact that the progressive realisation of the right to independent and community living requires structural changes holds particular relevance for de-institutionalisation, a precondition and fundamental element of independent living and being included in the community. Progressive realisation imposes a duty on States parties to implement structural reforms that must extend beyond the closure of institutional settings to include individualised support services and the allocation of adequate resources.<sup>37</sup> Structural reforms therefore, involve the implementation of programmes and entitlements that cover disability-related costs and result in the availability of accessible and affordable housing and disability support services to individuals. They also must ensure that access to such services is based on personal requirements and preferences. Informed by an open concept of disability complaint with article 1 of the CRPD, this requires a human rights-based and cross-government approach to change at all levels and sectors of government. One way in which States parties are to provide support for people with disabilities to live independently is through cash transfers such as disability allowances that recognise disability-related expenses and address

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<sup>36</sup> *Ibid.*, 514.

<sup>37</sup> United Nations, Committee on the Rights of Persons with Disabilities, "Draft General Comment on the Right of Persons with Disabilities to Live Independently and be Included in the Community (Article 19)" (2014) <<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticle19.aspx>> accessed 23 March 2016.

material hardships and poverty experienced by people with disabilities. States parties must ensure that any conditionality and distribution regime governing such supports be based on a human rights model of disability. States parties must also ensure personalisation of support. This means tailoring personal budgets to individuals' specific needs and circumstances so that they have access and control over community support services irrespective of their age, sex, ethnic background, language, social condition, migrant, asylum-seeking or refugee status and whether they live in rural or urban areas.<sup>38</sup>

#### **4.5 The Interrelatedness of Article 19 with other Specific Articles of the CRPD**

There is a vast array of general principles underpinning the Convention that exist in conjunction with other rights. Together these represent an interconnecting web that when put in place, provides the necessary framework for achieving independent living thereby reducing people's reliance on institutional care.

At the foundation of the equal right of all persons with disabilities to live independently and be included in the community, are the general principles set out in Article 3 of the Convention. These include: respect for the individual's inherent dignity, autonomy and independence (art.3 (a)) and the full and effective participation and inclusion in society (art. 3 (c)). The other principles of the Convention specified as essential to understanding and applying the right to independent living include: non-discrimination (art.3 (b)), respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (art 3.(d)), equality of opportunity (art.3 (e)), accessibility (art 3.(f)), equality between men and women (art 3. (g)), and respect for the evolving capacities of children with disabilities (art 3. (h)). Equality of opportunity, accessibility and respect for the evolving capacities of children with disabilities and respect for the right of such children to preserve their identities, is an important issue that requires State Parties to

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<sup>38</sup> *Ibid.*



look beyond the medical approach to seeing persons with disabilities as rights and stakeholders. This principle in conjunction with Article 24 helps facilitate the transition to independent living and participating in the community.

Key to the realisation of the right to independent living is Article 5 of the Convention which addresses equality and non-discrimination. It requires States Parties to recognise that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law. In addition, Article 5(1) requires State Parties to “prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.” Beyond imposing an obligation on State Parties not to discriminate on the basis of disability, it also imposes a positive obligation to prohibit all such discriminatory actions within the State. Specifically, Article 5(3) of the CRPD imposes a positive obligation to take all appropriate steps to ensure that reasonable accommodation is provided. The reasonable accommodation duty recognises that in order to achieve substantive equality for disabled persons, it may be necessary to treat people with disabilities differently. For example, in a work environment this may consist of making adjustments to policies or practices, physical features or by providing auxiliary aids such as specialised equipment. The requirement of equality and non-discrimination and the provision of reasonable accommodation in Article 5 empowers PWDs to remove barriers to living independently in the community and facilitates the exercise of their will and preferences in respect of how they live their lives.

The CRPD sets out that the failure to provide “reasonable accommodation” is a form of disability-based discrimination. The term “reasonable accommodation” is defined in Article 2 as the “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”. The duty to provide reasonable accommodation applies to a wide range of institutions and individuals within

the social sphere including the State itself, employers, educational and healthcare institutions, providers of goods and services and many more. These actors are under an obligation (although open to interpretation due to the inclusion of “disproportionate or undue burden” in its definition (Article 2)), to modify any policies, practices or structures that hinder participation of those with disabilities. Appropriate accommodations must be tailored to the individual involved and the situation that needs to be rectified.<sup>39</sup> The negative duty not to discriminate – which includes the positive duty to provide reasonable accommodation – falls on the State. Cutting across all aspects of rights of persons with disabilities, the concept of reasonable accommodation thus requires specific needs of a person with disabilities to be taken into account when providing appropriate modification and adjustments for independent living and being included in the community. In the workplace, depending on the needs of the employee, reasonable accommodation might require an alternative work-schedule, adaptations to physical space, or the use of interpreters. In the case of education such as my own, reasonable accommodation might require the provision of alternative ways of assessment, additional teaching assistance, or assistive technology, depending on the needs of the particular student.

To enable persons with disabilities to live independently and participate fully in all aspects of life, the CRPD under article 9 sets out an obligation on States parties to:

‘[t]ake appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environments, to transportation, to information and communication, including information and communication technologies and systems, and to their facilities and services open or provided to the public, both in urban and in rural areas’ (art. 9).

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<sup>39</sup> Lisa Waddington, “When It Is Reasonable for Europeans to be Confused: Understanding When a Disability Accommodation Is Reasonable from a Comparative Perspective” (2007) 29 *Comparative Labour Law & Policy Journal* 317- 325.

Any goods, products, and services that are provided to the public must be accessible to all in a way that ensures equal access by persons with disabilities. Access must respect people’s dignity, regardless of the type of impairment and whether the goods, products, or services are owned and/or provided by a public authority or a private enterprise. Article 4(1) (e), the CRPD also sets out an obligation on the State to:

“take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise. Thus, the State must ensure that reasonable accommodation is being provided, for example, by a private transport company, a provider of public health services, or even an individual personal assistant. The central authorities have a duty under international law to ensure that even services run by local or municipal governments do not discriminate, because the State has a duty in Article 4(1) (d) “to ensure that public authorities and institutions act in conformity with the [CRPD]”.

Furthermore, discussing the relationship between reasonable accommodation and accessibility under the CRPD, General Comment No.2 on Article 9 (Accessibility) emphasises that:

‘[a]ccessibility is a precondition for persons with disabilities to live independently and participate fully and equally in society. Without access to the physical environment, to transportation, to information and communication, including information and communication technologies and systems, and to other facilities and services open or provided to the public, persons with disabilities would not have equal opportunities for participation in their respective societies’ (UN General Comment No.2 on Article 9 (Accessibility)).

What constitutes reasonable accommodation is often difficult to quantify for those bound to provide it. However, it is vital that the responsibility is insisted upon in order to solidify its position as a justified expectation. Jolls, in *Anti-Discrimination and Accommodation*, noted that “the relationship between anti-discrimination and reasonable accommodation has doctrinal as well as normative and analytic dimension.”<sup>40</sup> It embodies an instructional as well as an aspirational and examinational spirit. The CRPD frames the concept of reasonable accommodation in a similar manner, as, in Article 12, it focuses on the capacity of those with disabilities as distinct to a presumption of lack of capacity. It explains how the adjustment in work environments should happen but includes the terms “disproportionate or undue burden” unfortunately leaving such modifications open to subjective interpretation. This is as distinct from the definition provided in the EU Framework Employment Directive Article 5 (November 2000):<sup>41</sup>

“In order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided. This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned.”

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<sup>40</sup> Christine Jolls, "Antidiscrimination and Accommodation" (2001) 115(2) Harvard Law Review 642-699.

<sup>41</sup> Paul Skidmore, "European Development. EC Framework Directive on Equal Treatment in Employment: Towards a Comprehensive Community Anti Discrimination Policy?" (2001) 30(1) Industrial Law Journal 126-132.

Lawson suggests that “the CRPD will reinforce awareness of the importance of the notion of reasonable accommodation and its centrality to disability equality.”<sup>42</sup> She makes the point that the CRPD, unlike the European legal instruments, clearly states that reasonable accommodation is an “essential element” of the non-discrimination principle as it relates to persons with disabilities. The Framework Directive’s use of the term “disproportionate burden” leaves a path open for self-justified evasion of responsibility and unfortunately the CRPD follows this language despite its more assured stance overall.

The failure to provide reasonable accommodation is now a specific ground upon which to found a claim for disability discrimination under the CRPD in the European Courts or International Court of Justice. The following are cases of the Committee relating to reasonable accommodation. In the case of *H.M. v Sweden*, a petitioner whose physical disability causes her to be housebound, filed a complaint with the UN Committee on the Rights of Persons with Disabilities (the UN Committee).<sup>43</sup> She claimed she was discriminated against by the decisions of the State party for failing to take into account her rights to equal opportunity for rehabilitation and improved health as the Local Housing Committee had rejected her request for building permission on the grounds that it went against the regulations of the city’s development plan. The UN Committee found that this refusal was inappropriate and amounted to discrimination because Sweden had failed to make reasonable accommodations such that the person with disabilities could enjoy their rights. It held that the petitioner’s rights under articles 5(1), 5(3), 19(b), and 25 of the CRPD and the State Party’s obligations under article 26 of the Convention, along with articles 3 (b), (d), (e), and 4 (1) of the Convention had been violated. The Committee found that the State Party failed to apply the principle of proportionality in weighing the interests of the petitioner against the gender interest. Additionally, the Committee held that the State’s actions

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<sup>42</sup> Anna Lawson, “The UN Convention on the Rights of Persons with Disabilities and European Disability Law: A Catalyst for Cohesion?” in Oddný Mjöll Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities European and Scandinavian Perspectives* (Brill Online Books and Journals 2009).

<sup>43</sup> CRPD/C/7/D/3/2011.

were discriminatory as defined under article 2, paragraph 3, of the Convention. The State's decisions resulted in a discriminatory effect that adversely affected the petitioner's access to the health care and rehabilitation required for her specific health condition.

In the case of *F v Austria*,<sup>44</sup> on the subject matter of accessibility to live information in public transport on an equal basis with others, a petitioner who is blind filed a complaint with the UN Committee that the State's failure to install a digital audio system to the extended rail network violates the two-senses principle of accessibility, according to which all information, including guidance aids, must be provided by a minimum of two senses out of three (hearing, sight and touch) to enable visually impaired and hearing impaired people to access all important information without assistance. The petitioner argued that the lack of an audio system prevents him from assessing the information that is only visually available. He considers this communication barrier as amounting to discrimination, as it deprives him to the use of transportation services on an equal basis with others, in breach of articles 5 and 9 of the Convention. The refusal by Austria, a State party to the CRPD, to remove those barriers constitutes a breach of articles 19 and 20, as the lack of an audio system on tram line 3 prevents him from living an independent life and violates his right to personal mobility. The Committee found violation of articles 5 and 9 but not 19 or 20 (UN Committee 2015 Communication No.21/2014).

Article 8 on awareness raising is included in the Convention as an attempt to address the fundamental roots of discrimination experienced by PWDs and was to be achieved through nurturing respect for their rights and dignity. Providing details of what constitutes effective human rights protection for disabled people, the CRPD is an excellent support to educating both non-disabled and disabled people in our rights and equality. On this, Article 8(1) of the CRPD is significant in requiring States Parties to undertake "immediate, effective and appropriate measures to raise awareness

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<sup>44</sup> CRPD/C/14/D/21/2014.

throughout society, including at the family level, regarding PWDs, and to foster respect for the rights and dignity of persons with disabilities”. Article 8(1)(b) extends this with a requirement to combat stereotypes, prejudices and harmful practices relating to PWDs in all areas of life. In addition, there is a requirement in Article 8(2) to “promote awareness of the capabilities and contributions of persons with disabilities”. Like all UN human rights instruments, the CRPD is not just a legal tool. It also sets an international cross-cultural minimum standard for the treatment of disabled people by which states, governments, public bodies and all human beings should abide. The difference between moral and legal rights/code should be noted, and how something which is legal, may not be necessarily moral and vice versa.

Article 12 on legal capacity is at the core of the Convention as equal recognition as a person before the law is central to the enjoyment of all the other rights enshrined within. Beyond this, Article 12 also places an obligation on States Parties to provide a range of supports to assist persons with disabilities to exercise their legal capacity and make decisions. It deals with the capacity to both hold rights and exercise those rights. The recognition of legal capacity for people with disabilities on an equal basis in Article 12 of the CRPD is a significant step forward and should permeate all aspects of society with particular impact in the realms of legal and healthcare practice. Quinn states that legal capacity makes personal choice and freedom possible.<sup>45</sup> Choice is often undervalued in terms of its meaning and significance; one may have an opinion but may not have a choice and vice versa. It is also often associated with age and other demographics, one of these being disability. People with disabilities have often had their freedom of choice limited by extraneous factors, some environmental, some familial. To facilitate real choice, one must appreciate what choices are important, for which groups of people and in what areas of their lives. The CRPD expresses the real meaning of choice through open ended legislative guidelines rather

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<sup>45</sup> Gerard Quinn, “Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD” (HPOD Conference, Harvard Law School, 20 February 2010).

than static and prohibitive language which traditionally led to more exclusion than inclusion.

Article 12's provisions on capacity reflect a shift in emphasis from a restrictive to an enabling perspective, and an emphasis on capacity as opposed to a lack of capacity. The international trend is to reduce substituted decision-making where possible and focus on strengthening peoples' capabilities with support. Bach has referred to facilitated or "co decision making."<sup>46</sup> Within the CRPD there is a carefully considered definition of capacity. Those that are defined as not having full capacity have a right to have their capacity supported, whether by means of an advocate or otherwise. Regarding primary care, without the appreciation of independent living, health care professionals often come into people's home for example, with a purely medical view, and therein bring with them conflicting assumptions, particularly in regard to legal capacity.

An indication of the difficulty that participants in the treaty deliberations had in reaching consensus is illustrated by the inability to agree on the definition of the term "legal capacity." Some delegations recommended translating this term into native languages and interpreting it accordingly. According to the comments of delegates from the corresponding states in the Sixth Session, in Arabic, Chinese and Russian, the term legal capacity refers to the "legal capacity for rights" rather than the legal capacity to act<sup>47</sup>. A background conference document prepared by the Office of the United Nations High Commissioner for Human Rights on legal capacity made the distinction as follows:

"Unlike the capacity to be a person before the law – which belongs to all human beings since the moment of birth and

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<sup>46</sup> Michael Bach, "Service Broker/Independent Planning Support Role" (First International Conference on Self-Determination & Individualized Funding, Seattle, Washington 2000).

<sup>47</sup> Clarence Sundram, "A Discussion of Legal Capacity in the Draft Convention on Disability" (National Disability Authority, 15 June 2006) <<http://www.mdri.org/mdri-web-2007/pdf/A%20discussion%20of%20Capacity.pdf>> accessed 10 February 2016.



is lost only with death – the actual exercise of the capacity to act is subject to the possession of such additional requirements as the minimum age and the capacity to understand the meaning of one’s actions and their consequences. It is therefore acquired at the achievement of major age and may also require additional requirements, which vary according to the act performed (matrimonial capacity, capacity to own and administer property, contractual capacity, capacity to bring claims before courts, capacity for tortious liability, etc.). Moreover, the capacity to act – which is presumed in adult persons – can be limited or restricted when individuals become unable to protect their own interests. In these cases, the person remains the holder of substantive rights (e.g. the right to property or the right to inherit), but cannot exercise them (e.g. sell his/her property or accept an inheritance) without the assistance of a third-party appointed in accordance with the procedural safeguards established by law”<sup>48</sup>

The Convention provides for a paradigm shift on the previous negative approach which viewed people as lacking in the ability to make decisions to a situation where the capabilities of persons are strengthened. A core focus of Article 12 is on the “will and preferences” of the person requiring a move away from the paternalism associated with the “best interests” approach. The main approaches in the field of legal capacity are known as the status approach, the outcome approach and the functional approach to legal capacity. The status approach operates by considering that a person lacks legal capacity on the basis that they have an intellectual disability or are old (for example). In Ireland being considered disabled is enough to take a person’s

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<sup>48</sup> Office of the United Nations High Commissioner for Human Rights, “Background Conference Document Prepared by the Office of the United Nations High Commissioner for Human Rights” (2006)  
<<http://www.un.org/esa/socdev/enable/rights/documents/ahc6ohchrlegalcap.doc>>  
accessed 11 January 2016.

legal capacity and provide for the provision of substituted decision-making by a third party by way of the antiquated Ward of Courts System.

Under the status approach a person either has full legal capacity or they lack capacity entirely. The second approach is described as the outcome approach. The outcome approach operates in a way to deprive a person of capacity when they make what is considered to be a foolish or unwise decision or a series of foolish or unwise decisions. This approach to capacity is now out-dated, as there is recognition that “we all have the right to make our own mistakes” and that it is unjust to set the decision-making bar higher for persons with disabilities. The functional approach to legal capacity is a more modern approach and reflects the evolution in thinking in relation to PWDs. At its core it looks at legal capacity in an issue specific way. For example, a person might not be able to make decisions about selling their home but might be considered to have capacity to make decisions about care. When a person with disabilities enters a hospital there is often a one dimensional view of that person defined by their disability, and negative assumptions regarding their capacity. This is an example of the damaging impact of the status approach to capacity which is no longer acceptable in light of Article 12. My question and my concern is whether the presumption of capacity as provided for by the CRPD will permeate the ongoing development of primary care centres, in which all parties, such as occupational therapists, physiotherapists, psychiatrists, personal assistants and social workers work together with the interests of the client and respect for their capacity as their priority. I am confident it will, particularly if due attention is paid to the Committee on the rights of Persons with disabilities and its General comment no1 on Article 12. Here it affirmed that all persons with disabilities have full legal capacity and that the rights to equal recognition before the law implies that legal capacity is a universal attribute inherent in all persons by virtue of their humanity and must be upheld for persons with disabilities on an equal basis with others.<sup>49</sup>

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<sup>49</sup> Convention on the Rights of Persons with Disabilities 2014, Article 12.

Article 12(3) outlines the adoption of supported decision making (assisting the person to make a decision personally) in contrast to substituted-decision making (someone else making a decision for the person).<sup>50</sup> Supported decision-making models should be designed in a manner such that will allow the individual to exercise his/her legal capacity independently without transferring autonomy and control over decision making to a third party. Supported decision-making models require legal reform at the domestic level, as well as being sufficiently resourced and customised to meet an individual's particular needs. In British Columbia for example, there are formal representation agreements (as enshrined in law<sup>51</sup>) which clearly express the wishes of the person.

Where a person's capacity may be limited, 'Assisted-Decision-Making' involving the advocate can be employed involving an informed third party acting on behalf of the client. This would normally be an advocate who may be better equipped to tease out what the client wants, or what is right for them, rather than a medical professional, as the advocate will have spent more time with, and have a vested interest in that person. They will have an informed professional opinion on what the client's choice would be and will have consulted with the client on a face to face level beforehand enabling the optimum degree of capacity on the client's part.

Protections against abuse are necessary in any supported decision-making framework used to implement the provisions of Article 12. As provided for in Article 12(4), these safeguards should include an obligation to assist the person with a disability to make decisions, and not substitute their own will and preferences. The type of support provided should be proportionate to the person's needs, individualised, and free from undue influence from third parties (or an unprofessional advocate) as well as being the subject of consistent review and appraisal.

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<sup>50</sup> *Ibid.*

<sup>51</sup> Representation Agreement Act 1996.

Under a guardianship system, a person who is thought to lack capacity to make their own decisions is placed under the control of another in terms of autonomy through the provision of “substitute decision-making”. Individuals placed under plenary (full) guardianship may not be permitted to make any decisions of a legal nature, for example entering into employment, getting married or opening a bank account. This would appear to be completely contrary to the intention of Article 12 and Article 19 also. International developments are addressing law reform to minimise or eliminate this level of substituted decision making. It could certainly be argued that in general, substituted decision making, where not completely warranted, is in violation of the principle of Article 3, which assures the ‘freedom to make one’s own choices, and independence of persons.’

Regarding the equality issue, if one is of equal standing, one should be able to live life on an equal basis with others, whatever the disability is. The CRPD rightfully emphasises the need for change in focus with regard to disability from a charity to rights based approach. The idea that community living is the new and appropriate target is welcomed but no one wants further lip service. This needs to be a working reality. If governments have reservations about the Convention, it becomes diluted; if one country does not ratify the Convention the document loses credibility. There must be public pressure applied to achieve full ratification (including the Optional Protocol) worldwide using both traditional activist and advocacy mechanisms as well as social media focussed pressure such as the project recently launched by the International Disability Alliance called #CRPDNow.

The CRPD is not differentiating in importance between the indivisible, interrelated and interconnected characteristics of human rights. As Article 1 puts forward - “The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”. In order to achieve this process, the centrality of Articles 12 is undeniable.

The fulfilment of the right to live in the community is interlinked with the aspirations of other rights detailed in the Convention. For instance, under Article 16 of the Convention PWDs have the right to be free from exploitation, violence and abuse. Article 16(1) requires that State Parties to the Convention “shall take all appropriate legislative, administrative, social, educational and other measures to protect PWDs, both within and outside the home, from all forms of exploitation, violence and abuse.” Article 16(2) also places an obligation on State Parties to engage in a range of positive measures to prevent exploitation, violence and abuse and the provision of education on avoiding, recognising and reporting such conduct. Article 16(3) provides that State Parties are required to “... ensure that all facilities and programs designed to serve persons with disabilities are effectively monitored by independent authorities.” Similarly, Article 16(5) places a positive obligation on States Parties to provide “effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.” Importantly, when there is exploitation and abuse Article 16(4) requires the State Party to ensure that the person recovers and is reintegrated. However, the State Party’s role is limited to a requirement to ensure that recovery and reintegration shall take place in an environment that promotes the health, welfare, self-respect, dignity and autonomy of the person and takes into account factors such as gender and age specific needs. I consider Article 16 a key component in realising the right to independent living as it clearly places positive obligations on the State to ensure that persons with disabilities are not exploited and abused. There is a danger, however, that the state could argue that Article 16 places an obligation on them to curb independent living were the state to consider that exploitation, violence and abuse to be more likely to occur in the community than in an institution. However, this argument is clearly hollow in light of the appalling legacy of exploitation and abuse of persons with disabilities while in institutional settings that took place in Aras Attracta home in Co. Mayo, the Holy Family Special School and Woodlands Centre at Renmore in Galway City and at the Kilcoran Centre for Young Adults with Disabilities in Clarinbridge, Co. Galway. Respect for inherent

dignity, individual autonomy (including the freedom to make one's own choices), and effective participation and inclusion in society does not equate with restricting the will and preference to live independently. The state might also argue that its positive obligations under Article 16(3) to ensure independent investigations of services provided to persons with disabilities can in certain circumstances justify the retention of specialised housing. This argument flies against the general principles of the Convention, in particular that of equality and non-discrimination and cannot be used as a justification to negate the State's responsibility to uphold Article 19. The principles of equality and non-discrimination mean that Article 16 cannot be used to infringe on decision-making capacity and privacy rights.

Other provisions in the Convention that are also very relevant in the shift toward the full recognition of capacity and independent living include: Article 9 (accessibility), Article 21 (freedom of expression and opinion, and access to information), Article 25 (Health), Article 26 (habilitation and rehabilitation), and Article 27 (work and employment). The right to habilitation and rehabilitation and the right to work on an equal basis with others are not attainable to their full extent if PWDs are not supported to live in the community as per Article 19 and resources are not made available to do so. Furthermore, for Article 19 to be fully and effectively implemented several key actors must be included in the process. As independent living and community are inextricably linked in the facilitation of full participation by people with disabilities in society, this process must include people with disabilities and their representative organisations as well as governments, service providers as well as local communities and individuals.

Article 24 requires States Parties to recognise the right of PWDs to education and ensure that the education system is inclusive at all levels and provides lifelong learning. The right to this level of inclusion means that children with disabilities will have the opportunity to acquire the life skills necessary to live independently.

#### **4.6 Implementation at National Level: De-institutionalisation, Person-to-Person-Centred-Planning and Community-Based Services**

Article 19 makes it clear that isolation, segregation and separation in institutions are a violation of international human rights law. Despite this proclamation, States across the world persist in using institutions as the primary service provision model for those with disabilities. This was a key finding in the report “De-institutionalisation and community living: outcomes and costs” discussed earlier in chapter three. To continue to use institutions in this manner and not afford persons with disabilities equal opportunity to live in the community is a violation of Article 19. As discussed in the previous section, States Parties to the CRPD are now required to move away from the institutional model of service provision and report on how they are doing this. Some have submitted their initial reports to the UN Committee on the Rights of Persons with Disabilities which has furnished them with its response and comments. For example, in its Concluding Observations to Germany, the Committee raised the problem of persisting high levels of institutionalisation and the lack of alternative living arrangements or appropriate infrastructure, which present additional financial barriers for persons with disabilities. It expressed further concern that, currently, access to benefits and support services in Germany impedes the right to live in the community with an adequate standard of living, owing to the means-testing of those benefits, which do not cover disability-related expenses. The UN Committee made recommendations for Germany to take all the immediate necessary legislative, administrative and judicial measures that would: (A) amend legislation to prohibit involuntary placement and promote alternative measure that are in keeping with articles 14, 19 and 22 of the Convention; (B) allocate sufficient financial resources to facilitate de-institutionalisation and promote independent living, including increased financial resources to provide community-based outpatient services providing the required support to persons with intellectual or psychosocial disabilities based on the free and informed consent of the individual concerned throughout the country; (C) increase access to programmes and benefits to support living in the

community and ensure they cover disability-related costs.<sup>52</sup> Meanwhile in relation to the EU, the Committee recommends that it develops an approach to guide and foster deinstitutionalisation and strengthen and monitor the use of the European Structural and Investment Funds, so they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions. Furthermore, the Committee recommends that the EU suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.<sup>53</sup> In its Concluding Observations and Recommendations to Mexico, the Committee expressed concern at the lack of State strategy for the inclusion of persons with disabilities in society and their ability to live independently. It is further concerned with the absence of a specific and effective strategy for the deinstitutionalisation of persons with disabilities. To address this, the Committee recommends that Mexico adopt legislative, financial and other measures to ensure that persons with disabilities may live autonomously in the community. These measures should include personal assistance services, be culturally appropriate, enable beneficiaries to choose their lifestyle and place of residence and express their preferences and needs, and contain a gender and age perspective.<sup>54</sup>

Aids can occasionally be used to define the nature of a service. This is as distinct from person-centred planning which puts forward a different vision of service provision. At present there are varying definitions of what a service is, leaving the room for interpretation too wide, where services can be understood as a right and thus carry more weight, or as a service that typically can be withdrawn or altered by the State more readily than if it were an established right inherent in the service user. The CRPD stipulates that

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<sup>52</sup>United Nations, Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Germany” (2015)  
<<https://documentsddsny.un.org/doc/UNDOC/GEN/G15/096/31/PDF/G1509631.pdf?OpenElement>> accessed 10 October 2015.

<sup>53</sup> *Ibid.*

<sup>54</sup> United Nations, Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Mexico” (2014)  
<[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fMEX%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fMEX%2fCO%2f1&Lang=en)> accessed 3 March 2016.



persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support independent living and inclusion in the community. Meanwhile community services and facilities for the general population are to be available on an equal basis to persons with disabilities and are responsive to their needs. In terms of rights, I believe that the more people with disabilities have been integrated into and are visible in society the better the standard and availability of a reliable service has been. Knowledge and awareness about the availability of services is helping promote the assertiveness of PWDS in terms of their right to these services and the quality thereof. As PAs and SNAs become more established and visible, general expectations ought to rise in tandem. More disabilities are being diagnosed such as Autism and Aspergers Syndrome and the area as a whole is becoming a greater part of culture and society. The CRPD requires State Parties to respect difference as part of humanity and that requires tailoring services to personal needs.

As a social model, Independent Living is not always viewed as an essential service by the public. From the perspective of those that are receiving it, such as myself, it is interpreted as such. Article 19 represents the first legal reference to Independent Living as a right. If people with disabilities are understood to be autonomous beings, like their “able-bodied” counterparts, they should naturally get to choose what happens to them without any confusion about who makes the choices. Article 3(a) of the Convention is key to realising the right to independent living in this regard, as it requires State Parties to have “respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons”. The demographics show that the number of people in an elderly age group is increasing in proportion to the total population<sup>55</sup> which further illustrates the need to improve services going forward. Indeed, there is consideration at the

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<sup>55</sup> United Nations, *Profiles of Ageing 2017*  
<<https://population.un.org/ProfilesOfAgeing2017/index.html>> accessed 8 February 2018.

moment of the formulation of a Convention on the Rights of Older Persons.

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The shift away from the medical model reflects the movement from institutional care to person-centred-planning, the shift from a focus on impairment to a focus on the broader societal factors and environment surrounding the condition. The holistic or social element is crucial. Person-centred-planning in any service provision has to be welcomed. Article 19 shifts the obligation onto the state to ensure that communities adapt to include people with disabilities instead of making the person conform to the community and its set parameters environmentally, socially and economically. It takes the philosophy of the independent living movement and enshrines it in international human rights law. Critically the CRPD includes an *obligation* to “closely consult with and actively involve PWDs, including children with disabilities, through their representative organisations in the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities” (Article 4(3)). The participation requirement is also reflected in the provision on inclusive development, which refers to the partnership with civil society, particularly PWDs and their representative organisations (Article 32 (1)). Dr Jane Pillinger considers that improved coordination and integration of services is vital if they are to become more community based and organised within a social model of disability.<sup>57</sup> She identifies the range of statutory and non-statutory service providers that could deliver services as well as forming the main questions in this area, that is, who the service is being provided for, provided by and the level of interaction between the two parties. Thus participation, consultation and involvement must play a role in the transition

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<sup>56</sup> Bill Mitchell, “Towards a Convention on the Rights of Older Persons” (ADA Australia National Conference, Gold Coast, Australia, 23-24 March 2017) <<https://social.un.org/ageingworkinggroup/documents/eighth/TowardsConvention.pdf>> accessed 17 February 2016.

<sup>57</sup> National Disability Authority, Jane Pillinger, “Towards Best Practice in Provision of Health Services for People with Disabilities in Ireland” (2002) <<http://nda.ie/Publications/Health/Health-Publications/Provision-of-Health-Services.html>> accessed 12 January 2013.

from institutional to community-based services. It is vital that, upon the winding up of an institution, it be replaced with an adequate system that will offer the kind of supports and opportunities that are needed.

Reforms within society to implement the provisions of Article 19 must be user-led, with the key stakeholders being closely consulted with and actively participating in the design, delivery and evaluation of new and improved services. Maintaining a system of special institutions, for example special kindergartens, schools and sheltered workshops cannot lead to the effective participation and inclusion of PWDs in the community. Services that are available to the community in general should be adapted and reformed in order to be available and accessible to those with disabilities. Article 19 details important life factors such as choice of living arrangements, location, an equal playing field and inclusiveness, all of which are positive assertions previously unmentioned in international documents. The rights-based perspective does not interpret people as “problems” or see them in terms of “deficits” but relies chiefly upon the presumption that all persons are equal, and they should be entitled to live in the community on an equal basis with others. It is premised on equality and lack of hierarchy of age, gender, disability, social profile, health etc. With recent ratification of the CRPD, Ireland can now expect to see radical change including an end to the link between charity and disability.

#### **4.7 Synthesis of Findings**

This chapter examined the United Nations Convention on the Rights of People with Disabilities (CRPD), the international human rights treaty created to legally clarify existing rights and provide the normative framework and legal tools in respect of people with disabilities and high dependency needs. The chapter interpreted the underlying concepts and key provisions of Article 19 as it is the Treaty’s main provision designed to operationalise people with disabilities’ right to independent living in the community with choices on an equal basis with others. Given its distinct role as one of the widest ranging and most intersectional articles of the Treaty, the chapter

further identified how Article 19 relates to other provisions in the CRPD. Finally and importantly for Ireland, the study's empirical case study and CRPD's most recent signatory, the findings identified what States Party's obligations are to ensure implementation at the national level promotes and protects every individual's right to live independently and be included in the community.

## Chapter Five

### Independent Living and Europe

#### 5.1 Introduction

Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) provides the most developed articulation of the right to live in the community of any international human rights instrument to date. However, the right to live in the community with choices on an equal basis with others has evolved from an array of international legal norms and political commitments emanating from the UN, Council of Europe and European Union, and is based on empirical research conducted in several jurisdictions. This chapter sets out and discusses some of the developments in international law, paying attention to the interrelationship between the work of international bodies and Article 19 of the CRPD. The chapter is divided into four sections after this introduction. The first covers the Council of Europe's treaties, institutions and actions in the field of disability, paying attention to the European Convention on Human Rights (ECHR), the European Social Charter specific policy initiatives including disability strategies and action plans. It also discusses relevant decisions of the European Court on Human Rights (ECtHR) related to the rights of people with disabilities. The second section provides an overview of the European Union (EU) disability law and policy focusing on the EU Charter of Fundamental Rights, the EU's Disability Strategy and European Structural and Investment Funds. It also pays attention to the role of the Court of Justice in endorsing the rights of EU citizens with disabilities. Next, since the CRPD is the first human rights treaty that the EU has concluded, the chapter provides a critical assessment of the interaction between the Convention and EU legislation, as well as the actual implementation of the CRPD at the EU level. It focuses on the significant changes within European disability law and policy resulting from the adoption of the CRPD, paying some attention to its implementation in the EU and selected States. The fourth and final section concludes with a synthesis of chapter findings.

## 5.2 The Council of Europe

The right to live independently and to be included in the community with choices on an equal basis with others stems from some of the most fundamental human rights standards, both within the United Nations and European systems and institutions. Notable is the role of the Council of Europe, (CoE) which has been important in establishing a range of civil, political, social and economic rights in the European region. The Council of Europe (CoE) is an international intergovernmental organisation that aims to achieve a greater unity between its members for the purpose of preserving peace and safeguarding human rights, fundamental freedoms and equality among citizens. It currently has 47 member states, 28 of which are members of the European Union (EU). Whilst the CoE is distinct and totally independent from the EU, the two entities collaborate in certain domains. Founded in 1949, the CoE has been important in promoting a range of civil, political, social and economic rights across the European region. It is committed to safeguarding the rights of people with disabilities since its inception including the right to independent living for people with disabilities which is one of its stated aims. The work of the CoE is underpinned by an anti-discriminatory and human rights framework and is guided by legal treaties, instruments, standards and policies which support the equal treatment and human rights of people with disabilities.<sup>1</sup> The CoE cannot make binding laws but does have the mandate and power to monitor states' progress and enforce select international agreements reached by European states on topics relating to human rights, parliamentary democracy and rule of law. It does this through its main organs and independent expert monitoring bodies. Its two statutory bodies are the Committee of Ministers and the Parliamentary Assembly (PACE) and its three institutions include the Commissioner for Human Rights, the European Court of Human Rights and the Congress of Local and Regional Authorities. These are based on CoE treaties and conventions of which there were 220 in 2016.

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<sup>1</sup> Council of Europe, *Disability Action Plan 2006-2015*, 9.

### 5.2.1 Legal Treaties and Conventions Promoting Independent Living

All legal standards of the CoE apply equally to all persons, including all persons with disabilities. The most significant CoE treaties for disability rights and independent living are the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) and the Revised European Social Charter. Discussed in greater detail in the chapter, ECHR provides the foundations for the CoE work to protect and promote human rights for all, including the rights of people with disabilities. The European Court of Human Rights (ECtHR), another key CoE instrument, has enshrined these rights in its case law and plays an important role by prompting States to undertake legislative changes to safeguard human rights of persons with disabilities.<sup>2</sup> Meanwhile the European Social charter contains specific rights for persons with disabilities, in particular Article 15 (right of persons with disabilities to independence, social integration and participation in the life of the community) and Article E (providing that the rights of the Charter shall be secured without discrimination on any ground). Other important CoE instruments impacting on disability are the Convention on the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Biomedicine and Human Rights (1997) and the Convention on the Prevention of Torture and Inhuman and Degrading Treatment (1987). This Convention has been important in the context of people with intellectual disabilities and mental illness and has visited Ireland on a number of occasions highlighting possible human rights violations.<sup>3</sup> Finally there are a number of legally binding standards especially relevant to the rights of persons with disabilities which include: the CoE Convention on Preventing and Combating Violence Against Women and Domestic Violence (Istanbul Convention); on the Protection of

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<sup>2</sup> Council of Europe, *Human Rights - a Reality for All. Council of Europe Strategy on the Rights of Persons with Disabilities 2017-2023* (2017) 8.

<sup>3</sup> Council of Europe, *Report to the Government of Ireland on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment* (2014).

Children against Sexual Exploitation and Sexual Abuse (Lanzarote Convention); and on the Action against Trafficking in Human Rights.<sup>4</sup>

### **The European Convention on Human Rights**

To safeguard the rights of people with disabilities, the CoE draws on the principles set out in the European Convention for the Protection of Human Rights and Fundamental Freedoms. Better known as the European Convention on Human Rights (ECHR), this Treaty is designed to protect human rights, democracy and the rule of law. The European Court of Human Rights (ECtHR) oversees its implementation in the CoE's member states, all of which have signed up to the Treaty. As with several other international human rights law instruments, the ECHR does not specifically refer to disability rights. However recent case law and several of the Treaty's provisions elaborated further below are relevant to establishing the right to independent living.<sup>5</sup>

The ECHR was signed by 12 CoE member states in 1950 and entered into force in 1953. It was the first instrument to give effect and binding force to certain rights stated in the Universal Declaration of Human Rights. It was also the first treaty to establish a supranational organ – the European Court of Human Rights - to ensure that the States Parties fulfill their undertakings. In order to join the CoE, a State must first sign and ratify the European Convention on Human Rights, thus confirming its commitments, to the aims of the Organisation, namely the achievement of greater unity between its members based on human rights and fundamental freedoms, peace and respect for democracy and the Rule of Law. Once states had accepted that a supranational court could challenge decisions taken by their own courts, human rights *de facto* gained precedence over national legislation and practice. Thus, the ECHR was also a milestone in the development of international law. Today, any individual, group of individuals, company or

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<sup>4</sup> Council of Europe (2017) *op. cit.*, 8.

<sup>5</sup> Council of Europe, Commissioner for Human Rights, *The Right of People with Disabilities to Live Independently and be Included in the Community* (Council of Europe Publishing 2012) 3.



non-governmental organisation can apply to the Strasbourg Court, provided that they have exhausted all domestic remedies.

There are a number of provisions in the ECHR relevant to the establishment of the right to living independently and in the community. Article 8, safeguarding the right to respect for private and family life, home and correspondence, most directly invokes rights that are infringed when a person is isolated or segregated from the community. Cases brought by people with disabilities alleging that the State has failed to guarantee access to the physical environment have been unsuccessful to date. In other cases, such as *Botta v Italy* the Court has clarified that the concept of private life embraces a person's 'physical and psychological integrity' as well as the 'development, without outside interference, of the personality of each individual in his relations with other human beings.'<sup>6</sup> In a number of cases people with disabilities have argued that their rights stipulated in Article 8 have been violated by a State's failure to provide laws and policies to enable them to take decisions on an equal basis with others.

In *Stanev v Bulgaria*,<sup>7</sup> the ECtHR found violation of Article 5 of the ECHR which sets out the parameters of the right to liberty in relation to someone living in a social care institution.<sup>8</sup> The applicant, Rusi Stanev, had been institutionalised for nine years. The distance and isolation from the community he experienced, the institution's regimented daily schedule, the rules on leave of absence, the lack of choice on everyday matters, and the lack of opportunity to develop meaningful relationships, as well as the fact that Mr Stanev had been deprived of legal capacity, were all factors that led the Court to find a violation of the right to liberty within the meaning of Article 5 of the ECHR.

## **The European Social Charter**

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<sup>6</sup> Application No. 21439/93 (1998) 26 EHRR 241.

<sup>7</sup> Application No.36760/06, judgement 17 January 2012.

<sup>8</sup> *Ibid.*

The CoE's endeavour to promote the rights and full participation of people with disabilities in all aspects of social life is also based on the principles embodied in the revised European Social Charter (ESC), namely the right of persons with disabilities to independence, social integration and participation in the life of the community.<sup>9</sup> The European Social Charter (ESC) is the counterpart in the field of economic and social rights, of the CoE's much better known ECHR. Originally the only machinery that the Charter provided for seeking to ensure that its parties complied with their obligations was a system of reporting, obliging state parties to report every two years on their implementation of the Charter. Such reports are first examined by the European Committee on Social Rights (ECSR), a 13-member body of independent experts in international social questions (formerly known as the Committee of Independent Experts (CIE)). Thereafter, reports and the ECSR's views on them are considered by the Governmental Committee (a body of national senior civil servants) and the Committee of Ministers. The latter may make recommendations to State Parties that are not fully complying with the Charter.

In the early 1990s the CoE embarked on a process of revitalising the Charter. In 1995 as part of this process (which also included overhauling the reporting system and drawing up the Revised Charter), the Council adopted a Protocol to the Charter. It provides an additional compliance mechanism in the form of a system of collective complaints. This Protocol came into force in July 1998. The first complaint under the new system was made in October 1998, and by September 2014, a further 110 complaints had been made.

The 1961 European Charter<sup>10</sup>, was very much centred on the medical model of disability<sup>11</sup>. The updated European Social Charter<sup>12</sup> (Article 15) reflected the prevailing international shift, particularly emanating from the U.S, toward the social model and rights based approach, emphasising the wish to ensure

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<sup>9</sup> Council of Europe, *Disability Action Plan 2006-2015* (2015).

<sup>10</sup> Council of Europe, *European Social Charter* (Turin, 18.X.1961).

<sup>11</sup> Gerard Quinn, "The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability" (2009) 15(1) *Texas Journal on Civil Liberties & Civil Rights* 33-52.

<sup>12</sup> Council of Europe, *European Social Charter (Revised)* 1996.

the rights of those with disabilities to “independence, social integration and participation in the life of the community.”<sup>13</sup>

In its Conclusions the European Committee on Social Rights (ECSR) asked in 2008<sup>14</sup>: ‘What steps, if any, have been made or are planned to move away from a medical definition of disability toward a more social definition such as that endorsed by the WHO in its International Classification of Functioning (ICF: 2001)’. This shows how the prevalent trend toward a social, rather than a medical definition of disability is now becoming the standard at European level. The Revised Charter, in Article E, contains a provision explicitly prohibiting discrimination, stating that:

‘The enjoyment of the rights set forth in this Charter shall be secured without discrimination on any ground such as race, colour, sex, language, religion political or other opinion, national extraction or social origin, health, association with a national minority, birth or other status.’

Highly relevant to establishing the right to living independently and in the community, Article 15 in the Revised Charter now reads:

“right of persons with disabilities to independence, social integration and participation in the life of the community. With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community, the Parties undertake, in particular:

to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever

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<sup>13</sup> *Ibid*, Art. 15.

<sup>14</sup> Council of Europe, *European Social Charter. European Committee of Social Rights Conclusions* (2008).

possible or, where this is not possible, through specialised bodies, public or private;

to promote their access to employment through all measures tending to encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialised placement and support services;

to promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.”<sup>15</sup>

The implication of these revisions are threefold, obliging States to assess barriers and identify necessary support measures, provide technical aids and appropriate housing support arrangements and provide other types of support services such as personal assistance and auxiliary aids.<sup>16</sup> The European Committee on Social Rights (ECSR) advises that to implement the European Social Charter effectively, States must adopt laws and policies including comprehensive non-discrimination legislation covering ‘both the public and private sphere in fields such as housing, transport, telecommunications and culture and leisure activities and effective remedies for those who have been unlawfully treated.’<sup>17</sup> Additionally ‘a coherent policy on disabilities’ needs to be adopted, accompanied by ‘measures to achieve the goals of social

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<sup>15</sup> European Social Charter (Revised)1996, Article 15(3).

<sup>16</sup> Council of Europe, *European Social Charter: European Committee of Social Rights Conclusions* (2008).

<sup>17</sup> *Ibid.*

integration and full participation of persons with disabilities'. These measures need to be codified and their implementation coordinated.<sup>18</sup>

'The Committee recalls that the legal situation of persons with disabilities calls for comprehensive anti-discrimination legislation, in particular in the field of education and training, providing for effective remedies'. Article 15(3) is a completely new insertion into the Charter, the Committee stating how it "describes the positive action to be implemented in order to achieve the goals of social integration and participation of disabled persons."

The Committee has declared that such measures must not be pursued in isolation and should be programmed to complement each other on a clear legislative basis. A key reference was also made to the importance of people with disabilities being involved in the process, in that they should be consulted in the design and ongoing review of the process and that an appropriate forum should exist to enable this to happen.

The Charter requires equal access to ordinary and specialised education and that all required measures are taken to ensure access to mainstream schools whenever it is a proper orientation for the child. In *Autism Europe v France*<sup>19</sup>, the complainant claimed that France had made very little movement toward implementing statutory instruments dealing with the provision of education to people with disabilities. The State's own figures showed that, in 2009/2010 only 11,500 Autistic children were integrated into ordinary schools. Access to both full and part-time education would only be provided to 30 % of autistic children, of this 87 % in elementary school, 11% in secondary school and 1.2 % in high school. Shockingly, 90 % of young people with autism were not offered any form of education beyond the age of 16. The State claimed it was

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<sup>18</sup> Council of Europe, *European Social Charter. European Committee of Social Rights Conclusions* (2008), 15.

<sup>19</sup> European Committee on Social Rights, *International Association Autism Europe v France*, Complaint No. 13/2002.

making progress toward addressing the issue, but the Committee ruled France to be in violation of rights granted by the Charter, namely the right of persons with disabilities to education, the right of children and young persons to education, and the right of all persons to non-discrimination. Allowances could be granted for the difficulty and expense involved in setting up such an infrastructure, however such modifications must be made within a “reasonable time, with measurable progress and to an extent consistent with the maximum available resources.”

The Committee deemed France to be in violation of Article 15(1) of the Charter, deeming that measures should be taken to provide access to education for Autistic children in priority in mainstream schools and to professional training of autistic youths. Despite the ruling, Autism-Europe has claimed that improvements were negligible despite the adoption of a “new direction” by the State.<sup>20</sup> This lack of actual practical implementation has been a feature of many Committee decisions. This case was of great significance however, in that it was the first collective complaint made to vindicate the rights of persons with disabilities in Europe.

Meanwhile in *MDAC v Bulgaria*,<sup>21</sup> the ECSR found Bulgaria to be guilty of government-sanctioned segregation and discrimination against children with intellectual disabilities, having failed to implement and/or monitor legislation which aimed to protect the up to 3,000 children with intellectual disabilities living in so-called ‘homes for mentally disabled children’ across the country. The Committee found that mainstream schools were off limits for such children, that teacher training was completely inadequate in order to prepare teachers for the task of educating such children, and that as a result, only 6.2% of them received an education, in contrast to 94% of Bulgarian children without disabilities.

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<sup>20</sup> *Ibid.*

<sup>21</sup> Complaint No. 41/2007.

### **5.2.2 CoE Statutory Bodies and Institutions Promoting Independent Living**

Tying in with its three-fold focus of social cohesion, equality among citizens and respect for human rights, the CoE's duty to ensure the integration of people with disabilities in society is operationalised through two statutory bodies - the Committee of Ministers and the Parliamentary Assembly (PACE) and three institutions - the Commissioner for Human Rights, the European Court of Human Rights and the Congress of Local and Regional Authorities. The Committee of Ministers comprises the foreign ministers of each member state and is the Council's decision-making body. As the executive body of the Organisation it approves its budget and programme of activities. The Parliamentary Assembly (PACE) is composed of national parliaments of each member state and provides a forum for debate and plays an important role in examining current issues. In its resolution on 'Access to rights for people with disabilities and their full and active participation in society' it notes that the ECHR protects everyone, including people with disabilities. It furthers that Article 15 (the right of persons with disabilities to independence, social integration and participation in the life of the community) of the European Social Charter 1961, (revised in 1996) "explicitly guarantees to persons with disabilities the effective exercise of the right to independence, social integration and participation in the life of the community."<sup>22</sup> In 2008 the Parliamentary Assembly stated that:

'The practice of placing children and adults with disabilities into institutions undermines their inclusion as they are kept segregated from the rest of society and suffer serious damage to their healthy development and obstruction of the exercise of other rights. De-institutionalisation is a prerequisite to enabling people with disabilities to become as independent as possible and take their place as full citizens with the opportunity to access education and

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<sup>22</sup> Resolution 1642 (2009) 2.

employment, and a whole range of other services.’<sup>23</sup>

## **The European Court of Human Rights (ECtHR)**

The European Court of Human Rights (ECtHR) forms part of the CoE’s core legal institutions. It is its permanent judicial body, guaranteeing for all Europeans the rights safeguarded by the ECHR. The ECtHR is mandated to enforce the Convention to which all member states of the Council are party. The ECtHR has no specific reference to disability. This is not to say that it does not have relevance in this field. It is primarily concerned with protecting individuals from unwarranted interference and has been particularly influential in reform of mental health legislation. This is certainly the case in Ireland with the reform of the Mental Health Act 2001.

Recent case law shows there is an inherent implication in Article 14 (non-discrimination) of the ECHR that disability is a ground for a finding of such discrimination. In *Glor v Switzerland*<sup>24</sup> the ECtHR so applied Article 14. A Swiss diabetic who had been turned down for military service because of his illness was required to pay a military exemption tax. Those suffering from a major disability are exempt from paying the tax but the claimant's disability was not considered severe enough to take him out of the tax. The ECtHR held that there had been a contravention of Article 14 of the Convention which deals with discrimination and the Court also identified the circumstances as being in contravention of Article 8, the right to private and family life. The Court provided that the list of grounds in Article 14 is not limited to the sex, race, colour and such as listed, but includes "or other status" and thus by implication includes a prohibition of discrimination based on disability. The Court also provided that the fact that different treatment in the exercise of a Convention right is needed for a legitimate aim is an insufficient ground for

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<sup>23</sup> Council of Europe, Parliamentary Assembly, “Access to Rights for People with Disabilities and Their Full and Active Participation in Society” (2009)  
< <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=17697&lang=en>>  
accessed 30 May 2016.

<sup>24</sup> Application No. 13444/04, 10 April 2009,



such treatment. There must also be reasonable proportionality between the means used and the aim intended. States are deemed to have a certain “margin of appreciation”, that is a certain amount of discretion when engaging with potentially discriminatory measures. The scope of this margin varies depending on the individual context and it will be considered whether the objective could have been attained using other means.

In *Pretty v United Kingdom*, the ECtHR has cited human dignity and human freedom as “the very essence of the Convention.”<sup>25</sup> the Court has also said the Convention “must be understood and interpreted as a whole.”<sup>26</sup> In the UK case of *Price v United Kingdom*, with regard to the ECHR, Baroness Hale of Richmond observed that:

“human dignity is all the more important for people whose freedom of action and choice is curtailed, whether by law or by circumstances such as disability...in reality the niceties and technicalities with which we have to be involved in the courts should be less important than the core values that underpin the whole convention.”<sup>27</sup>

The protection of private life under Article 8 of the Convention was raised in the case of *Botta v Italy* which concerned access to a public beach for a person with disability.<sup>28</sup> In *Price v United Kingdom* the treatment of a disabled woman in prison was held to be degrading under Article 3 of the ECHR.<sup>29</sup> Article 14 provides for protection from discrimination relating to ECHR rights and although it is not a standalone provision, it has been used to expose indirect discrimination affecting a particular group in accessing education for children.<sup>30</sup>

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25 Application No. 2346/02, 29 April 2002, para. 65.

26 *Ibid.*, para.43.

27 Luke Clements and David Ruebain, *Disabled Children and the Law* (Jessica Kingsley Publishers, 2006) 26-27.

28 26 EHRR 241.

29 34 EHRR 1285.

30 43 EHRR 41.

In *Kiyutin v Russia* (2011) the ECtHR held that refusing the claimant's application for a residence permit on account of his HIV-positive status was discrimination in contravention of Article 14. The Court was of the opinion that HIV/AIDS was capable of being treated as a 'disability' in the context of discrimination, thereby enabling persons with the condition to rely both upon the Convention as well as the CRPD in future discrimination actions. Another case, *Kiss v Hungary*, further illuminated the position in relation to Article 14. The ECtHR here overturned a provision denying voting rights to persons with a mental disability (in this case an individual with manic depression) who were under partial guardianship. The Court agreed there was a breach of Article 3 of Protocol 1 to the ECHR, which provides for free elections and includes the right to vote. It also provided that where a restriction on fundamental rights is applied to a sector of society which has been the victim of discrimination in the past, then the State's margin of appreciation is much narrower than in other circumstances. The Court also noted that this was evident in other international legal instruments such as the CRPD.

'Discrimination' for the purposes of Article 14 of the ECHR has also been held to include indirect discrimination. *D.H. and Others* (also known as the *Ostrava case*) involved a challenge by eighteen Romani children concerning their placement in a 'special school'. According to s31(1) of the Schools Act 1984 and Article 2(4) of Decree no.127/199431 such schools are designed to facilitate the education of children with 'mental deficiencies'. The applicants claimed successfully the legislation to be racially discriminatory as the children were being treated differently simply because of their ethnicity. Research was presented supporting their case showing that only 1.8% of non-Romani children had been placed in a special school whilst 50.3% of all Romani children in the town were so placed. This was despite the fact that Romani children only made up 5% of the town's overall school population. The ECtHR confirmed that the prejudicial effects of a general policy or measure which, although drafted in a neutral manner, have a disproportionate effect on one ethnic group, can be in violation of Article 14, irrespective of the stated intent of the policy or measure. The view adopted in *DH* is widely

accepted and the formula had been adopted in other ECtHR cases since, such as *Opuz v Turkey*<sup>31</sup> and *AM (Somalia) v Entry Clearance Officer*.<sup>32</sup>

While not relating to disability, *Thlimmenos v Greece*<sup>33</sup> was also a landmark case with widespread implications in the area of discrimination with the ECtHR holding here that Article 14 "is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different". The complainant in this case was a Jehovah's Witness who had refused to wear a military uniform, making him guilty of a felony and as a result being refused employment. He argued successfully that a distinction should be made between offences committed solely because of a religious belief and other offences. This is the first case that recognises indirect discrimination.

In *Price v UK*<sup>34</sup>, there was held to be degrading treatment under Article 3 where there was serious lack of provision in a police cell and prison for a disabled person. The complainant (who is quadriplegic), claimed her treatment within prison and the failure of the authorities to provide appropriate adjustments to facilitate her were a violation of Article 3 of the Convention (freedom from degrading treatment). The Judge noted that not only did the treatment amount to such degrading treatment, it also amounted to discrimination. Even though there was no finding of a violation on grounds of discrimination, the Court's finding is significant in that it follows the jurisprudence in *Thlimmenos* that a failure to "treat differently persons whose situations are significantly different" gives rise to a breach of Article 14.

In *Burnip v Birmingham City Council*<sup>35</sup> housing benefit rules in the U.K were found to be in breach of Article 14. The rules did not contain an allowance providing for the possibility that an extra room may be needed for a carer.

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<sup>31</sup> Application No. 33401/02, 9 June 2009.

<sup>32</sup> [2009] EWCA Civ 634.

<sup>33</sup> Application No. 34369/97, 6 April 2000.

<sup>34</sup> Application No. [33394/96](#), 10 July 2001.

<sup>35</sup> [2012] EWCA Civ 629.

The Court agreed that the rules, without adequate justification, neglected to reflect the varying needs of people with disabilities.

### **Congress of Local and Regional Authorities and the Commissioner for Human Rights**

The other key institutions operationalising the CoE's body of work are the Congress of Local and Regional Authorities and the Commissioner for Human Rights. The former brings together elected officials and is responsible for strengthening local and regional democracy in its member states. Meanwhile the Commissioner for Human Rights is an independent institution within the CoE and is mandated to address and bring attention to human rights violations and promote awareness of and respect for human rights in member states. The work of the Commissioner focuses on people who find themselves in positions of vulnerability including adults and children with disabilities.<sup>36</sup> Raising concerns about the situation of people with disabilities in institutions, Commissioner Hammarberg, stated in 2010 that:

‘In Europe today, thousands of people with disabilities are still kept in large, segregated and often remote institutions. In a number of cases they live in substandard conditions, suffering abject neglect and severe human rights abuses. In too many cases, premature deaths are not investigated or even reported. Caged beds and other restraints are still used in a number of Council of Europe member states to keep persons with disabilities “under control.” Too little has been done to prevent this and other kinds of abuse and inadequate care in institutions, hidden from public scrutiny. There is an atmosphere of impunity surrounding these violations.’<sup>37</sup>

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<sup>36</sup> Council of Europe, Commissioner for Human Rights, *The Right of People with Disabilities to Live Independently and be Included in the Community* (Council of Europe Publishing 2012) 3.

<sup>37</sup> *Ibid.*

The 2008 issue paper on human rights and disability calls for the development of inclusive community-based services.<sup>38</sup> The Commissioner has consistently called for de-institutionalisation across European states and made a number of statements relevant to establishing the right of adults and children with disabilities to independent living. He highlighted the need for states to provide services to parents to enable them to keep their children with disabilities at home, thus avoiding institutionalisation.<sup>39</sup> Commissioner Hammarberg has publicised the situation of people with intellectual disabilities being housed in social care institutions,<sup>40</sup> and the practice of depriving people with disabilities of their legal capacity, stripping them of many rights including the right to decide where to live.<sup>41</sup> People with disabilities face particular difficulties in accessing the right to housing, Commissioner Hammarberg has noted.<sup>42</sup> States must “ensure access to transport, housing, cultural and leisure activities,” as well as home adaptations and home help. Commissioner Hammarberg warns that “any measure that leads to the discontinuation of a person’s rehabilitation or poses a risk to his or her health or capacity is not permitted”.<sup>43</sup> The need for regular and independent monitoring of existing institutions is another point which has been made by Commissioner Hammarberg,<sup>44</sup> as well as by other bodies.

### **5.2.3 The CoE’s Partial Agreement, Disability Strategy and Action Plan**

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<sup>38</sup> Thomas Hammarberg, “Human Rights and Disability: Equal Rights for All” (2008) 2.

<sup>39</sup> Thomas Hammarberg, “Society Has an Obligation to Support Abandoned Children and Offer Them a Positive Home Environment - Also When Budget Resources are Limited”, Viewpoint, 28 December 2009.

<sup>40</sup> Thomas Hammarberg, “A Neglected Human Rights Crisis: Persons with Intellectual Disabilities are Still Stigmatised and Excluded”, Viewpoint, 14 September 2009.

<sup>41</sup> Thomas Hammarberg, “Who Gets to Decide: Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities” (Issue Paper 2012) 2.

<sup>42</sup> Thomas Hammarberg, “Recommendation of the Commissioner for Human Rights on the Implementation of the Right to Housing”, Viewpoint, 30 June 2009, 5.

<sup>43</sup> *Ibid.*, para. 4.3.1.

<sup>44</sup> Thomas Hammarberg, “Inhuman Treatment of Persons with Disabilities in Institutions”, Human Rights Comment, 21 October 2010.

Several other legal standards or instruments support the CoE's endeavour to enhance equal opportunities, improve the quality of life and independence of people with disabilities and guarantee their freedom of choice, full citizenship and active participation in the life of the community. The focus of this section, they include the CoE's Disability Strategy 2017–2023, the Disability Action Plan 2006-2015 and the Partial Agreement in the Social and Public Health Field.<sup>45</sup>

### **The Partial Agreement in the Social and Public Health Field**

Turning first to Partial Agreement,<sup>46</sup> within the CoE this refers to a majority activity of European cooperation that is organised by the CoE but does not include all of its member states. The CoE's Partial Agreement in the Social and Public Health Field was established in 1959. Its main driving bodies are the Committee on the Rehabilitation and Integration of People with disabilities (Partial Agreement) (CD-P-RR) and the Public Health Committee (Partial Agreement) (CD-P-SP). In 2003, the CoE launched the Malaga initiative designed to extend the Agreement to all member states and transform the multidisciplinary Partial Agreement Committee CD-P-RR into a fully-fledged CoE Steering Committee, directly responsible to the Committee of Ministers. The gradual accession to the Agreement began in 2004 and then included the following 18 states: Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, Ireland, Italy, Luxembourg, the Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland and the United Kingdom. Cooperation between the state members of the Partial Agreement in the Social and Public Health Field has been supported by the CD-P-RR's ad hoc committees of experts that pool knowledge, establish social benchmarks and produce reports and analyses on a range of disability issues including the right to independent living and discrimination based on disability. Whilst noting some progress in the area of equal opportunities and

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<sup>45</sup> See in general, Council of Europe, Rights of Persons with Disabilities (2018) < <https://www.coe.int/en/web/disability/home> > accessed 2 March 2018.

<sup>46</sup> Council of Europe, Partial Agreement in the Social and Public Health Field (1959) < <https://www.coe.int/en/web/disability/partial-agreement> > accessed 10 December 2017.

disability rights, the work of these groups calls attention to direct and indirect discrimination encountered by people with disabilities, either intermittently and spontaneously or in a more regular, almost systematic fashion. Certain fundamental rights mentioned in two CoE treaties, the ECHR and the Revised European Social Charter remain inaccessible to many people, not least the right to respect for private and family life, to training, to employment and to decent housing, and protection from poverty and social exclusion. In order to set a new course, the CoE in its report on Legislation The Agreement's CD-P-RR's ad hoc committees have also made a series of Recommendations to governments. The Recommendation of the Committee of Ministers on a coherent policy for PWDs adopted in 1992 invites states to 'guarantee the right of people with disabilities to an independent life and full integration into society', and also to 'recognise society's duty to make this possible'. Furthermore, people with disabilities should 'have as much mobility as possible' and 'play a full role in society and take part in economic, social, leisure, recreational and cultural activities'. Supplemented by a regular report on national legislation that documents progress and gaps in national policies on disability, this Recommendation has given rise to many legislative amendments in member states. It was followed by the 1993 European Year of People with Disabilities promoting renewed reflection in order to ensure that people with disabilities were not overlooked in the new European social space.

Another significant output from the work of the Partial Agreement in the Social and Public Health Field is the Recommendation on A Charter on the Vocational Assessment of People with Disabilities (1995).<sup>47</sup> It prioritises abilities rather than disability, arguing for 'the greatest possible measure of social and economic participation as well as independence'. It bases its advocacy for the right of everyone to active participation in their evaluation process on the International Classification of Impairments, Disabilities and Handicaps (ICIDH) published by the World Health Organisation (WHO). The Recommendation on the adaptation of health care services to the demand for

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<sup>47</sup> *Ibid.*

health care and health care services of people in marginal situations (2001) includes people with disabilities. It advocates the development of integrated and coherent social and health policies and measures to reducing inequalities in health. Meanwhile the CoE Recommendation on a Coherent Policy for Persons with Disabilities (2001) aims to implement the principle of equal opportunities and non-discrimination principles found in the UN Standard Rules regarding prevention of, active participation in community life and independence. This includes a number of aims such as involvement in the planning and implementation of rehabilitation and integration processes, full citizenship and access to all institutions and services in the community, independence and self-determination and particular attention to the situation faced by women and older people with disabilities. In 2003 the Committee of Ministers adopted Recommendation 19 on improving access to social rights. Other recent Recommendations made by the CoE Committee of Ministers to member states include: Recommendation CM/Rec(2010)2 on deinstitutionalisation and community living of children with disabilities; Recommendation CM/Rec(2009)8 on achieving full participation through Universal Design; Recommendation CM/Rec(2009)6 on ageing and disability in the 21<sup>st</sup> century: frameworks to enable greater quality of life in an inclusive society.

### **The Council of Europe Disability Strategies and Action plans**

#### *The CoE's Action Plan 2006-2015*

The CoE's endeavour to safeguard the rights of people with disabilities by including disability and independent living as a core focus of its work is further supported by its Disability Action Plan 2006-2015<sup>48</sup>, and Disability Strategy 2017-2023.<sup>49</sup> Parker and Clements highlight independent living as a key feature of the 2006-2015 action plan whereby people with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social

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<sup>48</sup> Council of Europe, *Disability Action Plan 2006-2015. Recommendation Record* (2006) 5.

<sup>49</sup> Council of Europe, *Council of Europe Disability Strategy 2017-2023* (2017).



inclusion are first and foremost created by living in the community.<sup>50</sup> Broadly speaking the CoE's Disability Action Plan (DAP) for the period 2006-2015 translated the aims of the CoE into a cohesive European policy framework on disability.<sup>51</sup> It sought to provide national policy makers with a roadmap and practical tool for the design and implementation of plans, programmes and strategies. The DAP was grounded in and governed by the following fundamental principles: non-discrimination, equality of opportunities, full participation in society, respect for difference and acceptance of disability as part of human diversity, dignity and individual autonomy, equality between women and men, and participation in decision-making.<sup>52</sup> Its key objective was to ensure that equality of opportunity was mainstreamed throughout all policy areas for people with disabilities in all aspects of their lives for the period 2006-2015. It sought to achieve this through its design which was comprehensive yet flexible and adaptable enough to meet country-specific conditions and its specific action lines including enhancing community living. Representing its core, the DAP comprised fifteen actions or steps to be taken at national level by member state governments as well as six cross-cutting aspects to be integrated across each action line to address specific barriers encountered by vulnerable groups of people with disabilities. Some of the actions recommended by the DAP to be taken by member states to enhance community living included promoting schemes allowing disabled people to employ personal assistants of their choice and providing people with disabilities with tailored support provision to reduce any risk of social exclusion.<sup>53</sup> The DAP explains that this action line:

‘focuses on enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where they live. This requires strategic policies which support the move from institutional care to community-based

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<sup>50</sup> Camilla Parker and Luke Clements, "The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?" (2008) 4 *European Human Rights Law Review* 508-514.

<sup>51</sup> Council of Europe, *Disability Action Plan, 2006-2015. Recommendation Record* (2006) 5.

<sup>52</sup> Council of Europe, *Disability Action Plan, 2006-2015. Recommendation Record* (2006) 5, 11.

<sup>53</sup> *Ibid.*, 22.

settings, ranging from independent living arrangements to sheltered, supportive living in small-scale settings. It also implies a coordinated approach in the provision of user-driven, community-based services and person-centred support structures'.<sup>54</sup>

'Enhancing community living (No.8) requires strategic policies which support the move from institutional care to community-based settings, ranging from independent living arrangements to sheltered, supportive living in small-scale settings. It also implies a coordinated approach in the provision of user-driven, community-based services and person-centred support structures'.<sup>55</sup>

Furthermore:

'Disabled people living in the community have different needs that require different levels of care, assistance and support. Transparent eligibility criteria and individual assessment procedures which take into account disabled persons' own choice, autonomy and welfare, will promote equitable access to service'.<sup>56</sup>

Meanwhile aspects cross-cutting all of the DAP's action lines refer specifically to women and girls with disabilities, children and young people with disabilities and people with disabilities from minorities and migrant communities.<sup>57</sup> The DAP also identified people with severe and complex disabilities as one of the more vulnerable groups of people with disabilities and thus in need of a high level of support as their quality of life is very much dependent on the availability of appropriate quality services and specific, often intensive support. It emphasised the need for planning and co-ordination

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<sup>54</sup> *Ibid.*, 5.

<sup>55</sup> *Ibid.*, 6.

<sup>56</sup> *Ibid.*, 21.

<sup>57</sup> *Ibid.*, 6.

across relevant authorities, government agencies and service providers to adequately address the specific problems encountered by this group of people.<sup>58</sup>

### *The CoE Disability Strategy 2017-2023*

The other CoE instrument promoting disability rights is the 2017-2023 Disability Strategy (the Strategy). Entitled *Human Rights: A Reality for All* it was adopted in 2016. It does not prioritise or include a focus on independent living.<sup>59</sup> The overall goal of the Strategy is to achieve equality, dignity and equal opportunities for people with disabilities.<sup>60</sup> Independence and freedom of choice as well as the full and effective participation in all areas of life and society, including living in the community are considered key requirements towards achieving these goals. The Strategy comprises five priority areas and cross-cutting themes. Priority areas include: equality and non-discrimination, awareness raising, accessibility, equal recognition before the law, and freedom from exploitation, violence and abuse. These are anchored in the CoE's standards promoting and safeguarding human rights such as ECHR. Each priority area is also connected to corresponding Articles of the CRPD aiming at its implementation in practice. The Strategy thus places strong emphasis on the implementation of existing human rights standards.<sup>61</sup> Meanwhile the Strategy cross-cutting themes include: participation, co-operation and co-ordination, universal design and reasonable accommodation, gender equality perspective, multiple discrimination and education and training. These are to be considered and integrated fully in all the CoE work and in all its activities supporting member States to improve the lives of people with disabilities, including legislation, policies and activities.

Similar to the CoE's Action Plan 2006-2015, the Strategy on the Rights of Persons with Disabilities 2017-2023 is intended to guide member States and

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<sup>58</sup> *Ibid.*, 7.

<sup>59</sup> Council of Europe, *Council of Europe Disability Strategy 2017-2023* (2017).

<sup>60</sup> Council of Europe, *Human Rights: A Reality for All* (2017) 10.

<sup>61</sup> *Ibid.*, 11.

other stakeholders on policies, activities and measures to ensure implementation of priorities at national and local levels.<sup>62</sup> As a policy instrument and framework, the Strategy is flexible enough to be adapted at national level and take into account specific developments, legislation and policies. It is driven at national and local levels by the governments of member States in close cooperation with persons with disabilities, represented by their organisations. Other relevant stakeholders include National Human Rights Institutions, Equality Bodies, Ombudsman Institutions, service providers and civil society.<sup>63</sup> A number of potential barriers to implementation have been identified at the national level including insufficient financial and human resources which are expected to arise as a result of lack of political commitment. At international and regional levels, implementation is supported by both CoE partnerships, namely with the UN and the EU and by the Strategy's transversal nature encouraging all CoE decision-making, standard setting, advisory and monitoring bodies to actively contribute to the achievement of its goals and strategic objectives. The CoE enables this by fostering internal co-operation and synergies among its monitoring mechanisms, partial agreements and key entities, not least the European Court of Human Rights, the Office of the Commissioner for Human Rights and the Committee of Ministers.<sup>64</sup> The Ad Hoc Committee of Experts on the Rights of Persons with Disabilities is also mandated to support implementation of the Strategy by liaising with relevant intergovernmental bodies and providing expertise and a forum for exchange of best practices and issues of concern.

According to ENIL the absence of independent living as one of the Strategy's priority areas is a major oversight.<sup>65</sup> Whilst linked to other priority areas – equality and non-discrimination, awareness raising, accessibility, equal recognition before the law and freedom from exploitation, violence and abuse

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<sup>62</sup> *Ibid.*, 7.

<sup>63</sup> *Ibid.*, 6.

<sup>64</sup> *Ibid.*, 31.

<sup>65</sup> European Network on Independent Living, *Response of ENIL on Draft Council of Europe Disability Strategy 2017 – 2023* (2016) < <http://enil.eu/resources/reports/> > accessed 2 March 2016.

– independent living also requires specific and targeted actions. These are necessary to facilitate the closure of long-stay residential institutions in the CoE Member States and the development of community-based services, such as personal assistance, to support the right to independent living. To support the CoE reach the overall goal of the Strategy, ENIL sought to have independent living included as a priority area. It also recommended that seven key actions be set out for the CoE bodies, Member States and other relevant actors.<sup>66</sup> The first of these is to encourage the development and implementation of comprehensive deinstitutionalisation strategies in the CoE Member States and the closure of long-stay residential institutions for disabled people. CoE bodies, member States and other relevant actors should also seek to promote a moratorium on the building of new long-stay residential institutions and ensure that funding by the CoE Development Bank (CEB) is not used for the building or renovation of long-stay residential institutions for disabled people; instead these funds should be used to support the development of community-based services for disabled people.<sup>67</sup>

Other key activities to ensure independent living include the promotion of personal assistance and peer support, as key tools to ensure that disabled people are able to live independently in the community.<sup>68</sup> ENIL further recommends the Strategy include the collection of disaggregated data on the number and characteristics of disabled people in residential institutions in Europe and report on progress in the transition from institutional care to alternatives in the community in the CoE Member States. Additional actions include the promotion of good practices in supporting disabled people to live independently in the community, raising awareness among the CoE bodies, partners and in the Member States about the right of disabled people to live independently in the community and the monitoring of access of disabled people to independent living in the Member States through the work of the CoE monitoring mechanisms.<sup>69</sup> In addition ENIL also called for a stronger

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<sup>66</sup> *Ibid.*

<sup>67</sup> *Ibid.*

<sup>68</sup> *Ibid.*

<sup>69</sup> *Ibid.*

focus on the involvement of disabled people throughout the strategy and for the inclusion of definitions of the key terms, such as independent living, institution, deinstitutionalisation, community-based services, in order to ensure that they are understood correctly by the CoE bodies, Member States and other organisations and institutions targeted by the strategy.

### 5.3 The European Union

Whilst in the first few decades following its inception the European Union (EU) did very little in terms of specific action in the area of disability, EU disability law and policy has played a significant role endorsing the rights of EU citizens with disabilities, including the right to independent living. It was the EU's Council of Ministers that took the first tentative steps in July 1986 when it issued the Recommendation and Guidelines on the employment of people with disabilities in the Community. Another such recommendation, this time on the integration of children with disabilities into mainstream education was adopted by Council in 1989<sup>70</sup>. The European Commission Green Paper of 1993 on social policy stated that "social segregation, even with adequate income maintenance and special provision, is contrary to human dignity and corrosive of social solidarity and community morale."<sup>71</sup> This was the first step towards the realisation that disability provisions needed to be adapted on a European level to suit the individual, specific needs of those with disabilities, first acknowledging difference before attempting to cater on a macro level. In 1996, the European Commission further elaborated on this with its document entitled "Equality of Opportunities for People with Disabilities - A New Community Disability Strategy."<sup>72</sup> In this document, the

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<sup>70</sup> This resolution was adopted at a meeting of Education Ministers on 31 May 1990. The resolution commits the member states of the Council to "intensify, where necessary, their efforts to integrate or encourage the integration of pupils and students with disabilities, in all appropriate cases, into the ordinary education system within the framework of their respective educational policies and taking due account of their respective education system.

<sup>71</sup> Bob Hepple, "Green Paper: European Social Policy Options for the Union" (1994) 23(2) *Industrial Law Journal* 180-183.

<sup>72</sup> Commission of the European Communities, *Communication of the Commission on Equality of Opportunities for People with Disabilities* (1996) <<http://aei.pitt.edu/3953/1/3953.pdf>> accessed 10 June 2016.

Commission acknowledged that a number of obstacles to the integration of people with disabilities into society, alongside inherent failings, existed. In education, many children with disabilities are excluded from mainstream schools and confined to institutions which give them no opportunity for normal social interaction. In the field of employment, a great number of people with disabilities within the working age are excluded from the labour market; they are also two to three times more likely to be unemployed and to be so for longer periods than the rest of the working population; The Commission also noted that as regards housing, suitably adapted or adaptable accommodation is in short supply and prohibitively expensive. The document also identified that responsibility for eliminating exclusion and discrimination based on disability lay primarily with the Member States.

Whilst little progress on disability rights was made by the adoption of the Treaty of Maastricht in 1992, there was agreement to revisit disability issues at an intergovernmental conference at a later date. From this came the Treaty of Amsterdam in 1997 which added Article 13 to the Treaty on European Union and reinforced the principle of non-discrimination. This was the first reference to disability as being a ground for such non-discrimination and the first time people with disabilities were specifically mentioned in an EU treaty. Whilst something of a false dawn due to its non-binding nature, it did lead to a more forceful instrument in the form of the Framework Employment Directive, which dealt with discrimination in the area of employment, self-employment, and 'occupation' and which covered discrimination on grounds of religion or belief, disability, age and sexual orientation both directly and indirectly. It also included a requirement to make reasonable accommodation available for people with disabilities, and as a Directive was absorbed into national legislation (Employment Equality Act 2004 in an Irish context). Article 5 of the Directive provided that employers are required to take appropriate measures to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer.

The year 2000 (EU Summit in Nice) marked the beginning of the emphasis on the social model of disability currently seen in European policy statements and anti-discrimination and social exclusion measures and the EU Charter of Fundamental Rights. In the area of anti-discrimination, the EU now benefits from an advanced legal and policy framework promoting equality and non-discrimination.<sup>73</sup> The Lisbon Treaty includes non-discrimination as a cross-cutting principle, serving to guide the EU in defining and implementing its policies and activities. As previously mentioned, Article 13 of the Treaty on European Union too explicitly refers to disability discrimination. Whilst limited to employment opportunities and non-discrimination in access to employment and training, it has led to the introduction of a new generation of directives focused on anti-discrimination. Issues concerning health and social care, for reasons of subsidiarity, meanwhile remain the responsibility of the member states. Since 2001, disability also features as an important theme related to EU initiatives and measures to combat social exclusion including support to national policies, actions and programmes. The Community Action Programme to Combat Discrimination (2001-2006) aimed to support member states in developing legislation and policies for combating discrimination by strengthening the capacity to address or prevent discrimination through exchanges of information and good practice, and through awareness raising in the field of social inclusion through innovatory approaches. The Programme intended to complement the national actions plans by developing a better understanding of mainstreaming the combating of exclusion in member States and Community policies and measures and the development of priority actions chosen by Member States in accordance with their particular situation. Anti-discrimination measures were further developed under the Social Policy Agenda and through the inclusion of provisions for the respect for fundamental social rights ‘as key components of an equitable society and respect of human dignity.’<sup>74</sup>

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<sup>73</sup> European Union Agency for Fundamental Rights, *Fundamental Rights Report 2016* (2016) 59.

<sup>74</sup> *Ibid.*, 22.



Other milestones for disability rights and the right to independent living in Europe were the European Year of People with Disabilities (EYPD) and the Malaga Political Declaration both occurring in 2003. In 2001 Council Decision 2001/903/EC designated 2003 to be the European Year of People with Disabilities, the main purpose for which was stated as being to drive forward the political agenda for full integration of people with disabilities as set out in 2001 in the Commission document "Towards a barrier-free Europe for people with disabilities". The main objectives of the EYPD were to raise awareness of the rights of people with disabilities, to protect against discrimination, to encourage reflection on and discussion of the measures needed to promote equal opportunities for people with disabilities in Europe and encourage awareness of the right of children and young people with disabilities to equality in education. Meanwhile the Malaga Political Declaration of 2003<sup>75</sup> identified one of its main objectives as being "to improve the quality of life of people with disabilities and their families, putting emphasis on their integration and full participation in society, since a participative and accessible society is of benefit to the whole population."<sup>76</sup>

### **EU Charter of Fundamental Rights**

More recent developments on enhancing the right of people with disabilities to live independently and in the community include relevant provisions within the Charter of Fundamental Rights of the European Union<sup>77</sup> and the EU's accession to the CRPD, bringing the UN treaty directly into EU law<sup>78</sup>, and obliging it to combat discrimination within its competencies.<sup>79</sup> Since 2009, the Charter of Fundamental Rights provides the EU with its own legally binding bill of rights. It recognises the importance of the integration of persons with disabilities (Article 26) and the prohibition of discrimination and

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<sup>75</sup> "Improving the Quality of Life of People with Disabilities: Enhancing a Coherent Policy for and through Full Participation", Second European Conference of Ministers responsible for Integration Policies for People with Disabilities (Malaga, Spain, 7-8 May 2003).

<sup>76</sup> *Ibid.*

<sup>77</sup> Articles 21 & 26

<sup>78</sup> Council of the European Union, *Council Decision of 26 November 2009 Concerning the Conclusion, by the European Community, of the United Nations Convention on the Rights Of Persons with Disabilities* (Official Journal of the European Union 2009) 35.

<sup>79</sup> Treaty on the Functioning of the European Union 2007, Article 10.

the rights of people with disabilities “to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community” (Article 21).<sup>80</sup> Though its potential is not yet fully implemented, the Charter complements national human rights and the European Convention on Human Rights (ECHR). Unlike national human rights and the obligations under the ECHR which are binding on EU Member States in whatever they do, the Charter is binding on States only when they are acting within the scope of EU law. The implementation of the Charter relies on national actors including judicial authorities, legal practitioners, law enforcement authorities and policymakers.<sup>81</sup> Many Constitutional court decisions combine references to the Charter with international human rights law and EU law, confirming that national constitutional law and the ECHR together play a prominent role in cases referring to the Charter.<sup>82</sup> However, in 2016 no more than half of the Member States had policy documents referring to the Charter. These are typically limited in scope and intensity. Further, no EU Member State had dedicated a national policy specifically to proactively promote the Charter and protect its fundamental rights and freedoms.<sup>83</sup> Meanwhile the Charter is more commonly used in targeted policies that seek to promote populations protected by a specific article in the Charter. In Bulgaria policies refer to the integration of persons with disabilities (Article 26).

Another key institution for ensuring access to justice and endorsing the rights of EU citizens with disabilities is the Court of Justice of the European Union (CJEU), also known as the European Court of Justice (ECJ).<sup>84</sup> Established in 1952 it is the highest court in the EU system. Its role is to interpret EU law to ensure it is applied in the same way in all Member States and to settle disputes between national governments and EU institutions. The ECJ can also be used

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<sup>80</sup> Charter of Fundamental Rights of the European Union 2000.

<sup>81</sup> European Union Agency for Fundamental Rights, *Fundamental Rights Report 2016* (2016) 39.

<sup>82</sup> *Ibid.*, 42.

<sup>83</sup> *Ibid.*, 51.

<sup>84</sup> See in general, European Union, Court of Justice of the European Union (CJEU) <[https://europa.eu/european-union/about-eu/institutions-bodies/court-justice\\_en](https://europa.eu/european-union/about-eu/institutions-bodies/court-justice_en)> accessed 20 May 2017.

by individuals, companies and organisations to take action against an EU institution for infringing on human rights. Whereas the Council of Europe's ECtHR rules on the ECHR, the ECJ rules on EU law that is guided by the EU Treaties and its Charter of Fundamental Rights. Nevertheless the EU and Council of Europe systems are intertwined as many of the general principles of EU law draw on ECHR provisions that also form the basis for the EU's Charter of Fundamental Rights as the EU is legally bound to join up to the ECHR Council of Europe as a new member. Since first legislating against discrimination on grounds of disability in 2000,<sup>85</sup> ECJ case law on the notion of disability has gained some momentum.<sup>86</sup> Since the case on distinguishing disability from long-term illness in 2006,<sup>87</sup> the Court has handed down as many as six rulings on the definition of the term disability in EU discrimination law, culminating with the *Kaltoft* ruling of December 2014,<sup>88</sup> which indicated that dismissal on the grounds of extreme obesity might constitute disability discrimination within this framework.

Another important decision for the rights of employees with disabilities taken by the ECJ in 2013, relates to its judgment on disability discrimination in joined cases *Ring and Skouboe Werge*.<sup>89</sup> This ruling is significant as it represents the first decision on the definition under the Framework Directive on Employment 2000/78 since the EU ratified the CRPD in 2010. The Court moved away from the restrictive definition previously adopted and instead interpreted the Framework Directive in light of Article 1 CRPD, which 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.' The Court stated that a reduction in working hours may

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<sup>85</sup> Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.

<sup>86</sup> Dagmar Schiek, "Intersectionality and the Notion of Disability in EU Discrimination Law" (2016) 53(1) Common Market Law Review 35-63.

<sup>87</sup> Case C-13/05, *Sonia Chacón Navas v Eurest Colectividades SA*, EU:C:2006:456.

<sup>88</sup> Case C-354/13, *Fag og Arbejde (FOA), acting on behalf of Karsten Kaltoft v Kommunernes Landsforening (KL)*, EU:C:2014:2463.

<sup>89</sup>Cases C-335/11 and C-337/11.

constitute a reasonable accommodation as defined in the Employment Directive and in the CRPD. The employer is required to take appropriate measures to enable a person with a disability to have access to, participate in, or advance in employment. These measures can entail organisational measures, such as reduction of working hours. Moreover, employers with the possibility to seek public assistance (such as funding of a part of the employee's salary), must grant the employee with a disability reasonable accommodation. This judgment is also very important because it does not allow an employer to dismiss an employee who was unable to work for a long period of time due to his or her disability without looking into the possibility of providing reasonable accommodation for that employee and re-integrating the person in the workplace.

Whilst responsibility and competency for developing community-based services safeguarding the rights of people with disabilities to independent living lies with EU member states, EU law and policy has a role to play to ensure that goods and services for people with disabilities are provided in a non-discriminatory way, even though the only binding non-discrimination directive so far is limited to employment and occupation.<sup>90</sup> At policy level, the EU's "European Disability Strategy 2010-2020" focuses on the elimination of barriers. Entitled 'A Renewed Commitment to a Barrier-Free Europe' it identifies areas where EU-level action can complement initiatives by member states.<sup>91</sup> The Strategy places emphasis on how to use standardisation, public procurement or state aid rules to make all goods and services accessible to people with disabilities while fostering an EU market for assistive devices. It also provides that EU programmes and funds in policy areas relevant to people with disabilities are used to promote sound working conditions for professional and informal care providers and that the development of personal-assistance schemes be made a priority. The strategy document also encouraged more cooperation between Member States (through the High Level Group on Disability) and civil society with the aim

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<sup>90</sup> Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.

<sup>91</sup> European Commission, *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe* (2010).

of providing a forum for the exchange of data and policy coordination, in particular on the portability of rights, such as the right to personal assistance.

Other EU initiatives have also paved the way such as the European Commission Action Plan which is designed to shape how disability policies are designed and implemented by the European institutions. This is supported by various funding mechanisms to Member States, including the European Structural and Investment Funds (ESIF) which represent the ‘main source of investment at EU level to help Member States to restore and increase growth and ensure a job rich recovery while ensuring sustainable development.’<sup>92</sup> The regulation governing the disbursement of structural funds for 2014-2020 includes a number of ex-ante conditionalities to be fulfilled before funds may be allocated; several of these refer to the CRPD.<sup>93</sup> The Lithuanian Action plan to increase social inclusion 2014-2020, which includes measures to increase the availability of social housing and in-house support services for people with intellectual and psychosocial disabilities, is partly funded by the ESIF, for example.<sup>94</sup> Broadly, whilst funding needs to be provided without discrimination,<sup>95</sup> there is concern about how it is used to bolster institutions, rather than develop community-based supports,<sup>96</sup> and about the wide differences in the understanding of the right and numerous problems in its implementation.<sup>97</sup>

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<sup>92</sup> European Commission, *European Social Fund 2014-2020 Report* (2014).

<sup>93</sup> European Union Agency for Fundamental Rights, *Fundamental Rights: Challenges and Achievements in 2014 – Annual Report* (2015).

<sup>94</sup> Lithuania, Ministry of Social Security and Labour (*LR Socialinės Apsaugos ir Darbo Ministerija*), “Gyvenimo Kokybės Gerinimui, Socialinės Sanglaudos Stiprinimui bei Lygių Galimybių Užtikrinimui Numatyti Konkretūs Veiksmai”, Press release, 31 October 2013.

<sup>95</sup> Article 16 of the General Regulation on the Structural Funds provides that steps need to be taken to prevent any discrimination on the basis of disability and to ensure accessibility in the implementation of the funds, Council Regulation No. 1083/2006, 25.

<sup>96</sup> European Commission, *Second Disability High Level Group Report On Implementation of the UN Convention on the Rights of Persons with Disabilities* (2009) 218; European Commission, *Report of the ad hoc Expert Group on the Transition from Institutional to Community-Based Care* (2009); Parker, Camilla Parker, "Wasted Time, Wasted Money, Wasted Lives...a Wasted Opportunity?" (2010) 15(4) *Tizard Learning Disability Review* 4-14.

<sup>97</sup> Ruth Townsley and Lisa Ward, *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report* (Centre for Disability Studies, University of Leeds 2010); European Foundation Centre (2010) *Study on Challenges and Good Practices in the Implementation of the UN Convention on the Rights of Persons With Disabilities: Final Report* (European Commission 2010).

#### 5.4 Europe and the UN Convention on the Rights of People with Disabilities (CRPD)

The rights of people with disabilities to live independently and in the community relies significantly on the interaction between the EU and the Council of Europe (CoE) with the UN Convention on the Rights of People with Disabilities (CRPD). The CoE has taken comprehensive guidance from the CPRD in its adoption of human rights instruments<sup>98</sup>. Its statutory bodies, institutions and its programme of work set out in its Disability Action Plan 2006-2015,<sup>99</sup> and its 2017-2023 Disability Strategy ‘Human Rights – A reality for all’ are firmly anchored in the CRPD. The Treaty is also commonly referenced throughout CoE policy statements that place strong emphasis on the implementation of existing human rights standards and provisions in the Treaty. For example, in 2012 the Commissioner brought out an Issue Paper on The Right of People with Disabilities to Live Independently and be Included in the Community.<sup>100</sup> Drawing on CRPD Article 19, it provides a detailed analysis of the right to community living and also includes ‘a sample of indicators and guidance questions to help assess whether a country is transitioning from violation to implementation of the right to live in the community.

The CRPD is the first international human rights treaty that the EU has concluded, and its ratification represents the first time all EU citizens can benefit from the protection of a UN human rights treaty as Europeans. That the CRPD must be read into Recital 4 of the Council Directive by the EU organs, including the ECJ, implies it is part of the EU framework of rights. The EU’s ratification of the CRPD also marks a major political shift towards

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<sup>98</sup> Michael A. Stein and Janet E. Lord, "Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities" (2009)

<[http://web.msu.ac.zw/elearning/material/13172103542-20-09\\_stein\\_lord\\_future\\_prospects\\_for\\_un\\_on\\_disability\\_rights.pdf](http://web.msu.ac.zw/elearning/material/13172103542-20-09_stein_lord_future_prospects_for_un_on_disability_rights.pdf)> accessed 20 May 2016.

<sup>99</sup> Council of Europe, *Disability Action Plan 2006-2015* (2015) 9.

<sup>100</sup> Commissioner for Human Rights, "Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities" (2012)  
<<https://rm.coe.int/16806da5c0>> accessed 28 May 2016.

the enforcement of human rights obligations. This locates disability at the top of the European human rights agenda. Furthermore, as of 2018, all 28 EU Member States have ratified the Convention, agreeing with its principles, with 22 also ratifying the Optional Protocol.<sup>101</sup> This is important as the Convention does have the potential to influence domestic law and shape policy in these states through its status as part of European Union law.

Party to the CRPD since 2010 under Article 44, the EU interacts with the Convention by implementing its principles through EU legislation and the Charter of Fundamental Rights, EU actions, strategies and plans, the developing body of decisions by the ECJ and Europe's monitoring framework operating at both EU level and across Member States. For instance, the EU Agency for Fundamental Rights (FRA) has provided assistance and expertise to EU institutions and Member States where they implement EU law and policy concerning independent living, political participation, legal capacity, involuntary placement and treatments, non-discrimination and violence against children with disabilities.

### ***European Union Action on Article 9***

In Council Decision 2010/48/EC on the CRPD, the European Community declared its competence to address accessibility in the fields of goods, services, personal mobility (e.g. transport), and information and communication technologies. Council Directive 2001/85/EC<sup>102</sup> aims to guarantee the safety of passengers, putting in place special provisions for vehicles used for the carriage of passengers comprising more than eight seats as well as tackling the needs of persons with reduced mobility,<sup>103</sup> Regulation

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<sup>101</sup> European Union Agency for Fundamental Rights, *Has your Country Accepted the CRPD?* <<http://fra.europa.eu/en/theme/people-disabilities/ratified-crpd>> accessed 10 November 2018.

<sup>102</sup> Council Directive (EC) 2001/85 relating to special provisions for vehicles used for the carriage of passengers comprising more than eight seats in addition to the driver's seat, and amending Directives 1970/156/EEC and 1997/27/EC [2002] OJ L43/1.

<sup>103</sup> It should be noted that the definition of 'persons with reduced mobility', included in the

1107/2006,<sup>104</sup> is an instrument designed to protect the rights of disabled persons, and persons with reduced mobility, when travelling by air. Its provisions run closely in line with Article 9 of the CRPD, for example, the standard that PWDs may not be denied boarding or booking and that staff should receive disability-awareness and disability rights training. Article 9 deals with accessibility, to “enable persons with disabilities to live independently and participate fully in all aspects of life” .

### ***European Union and Article 27 CRPD***

The 1997 Amsterdam Treaty<sup>105</sup> endowed the European Community with the authority to fight discrimination on the ground of disability. The Employment Equality Directive’s (2000)<sup>106</sup> aim was to prohibit and combat discrimination on the grounds of disability as well as religion or belief, age or sexual orientation as regards employment, occupation and vocational training. Article 2 defined discrimination as any “less favourable” treatment of a person due to, inter alia, his/her disability and includes both direct and indirect discrimination, and harassment. However, it should be noted that it does not provide a clear definition of disability that may undermine its provisions.

Discrimination by association' can be illegal in the workplace under European law. In *Coleman v Attridge*,<sup>107</sup> a mother made a claim of workplace discrimination because of her child's disability. She provided various examples of this, including being refused working hours flexibility available to other worker-parents as well as being the victim of abusive comments

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Directive 2001/85/EC, is broad and includes all people who have difficulty when using public transport, such as disabled people (including people with sensory and intellectual impairments, and wheelchair users); people with limb impairments; people of small stature; people with heavy luggage; elderly people; pregnant women; people with shopping trolleys; and people with children (including children seated in pushchairs).

<sup>104</sup> Regulation (EC) No 1107/2006 of the Parliament and of the Council of 5 July 2006 concerning the rights of disabled persons and persons with reduced mobility when travelling by air OJ L 204 of 26.7.2006.

<sup>105</sup> Treaty of Amsterdam 1997, Article 5.

<sup>106</sup> Council Directive (EC) 2000/78, establishing a general framework for Equal Treatment in Employment and Occupation (2000).

<sup>107</sup> [2007] IRLR 88 (Opinion of 31 January 2008).



because of her request of accommodations to facilitate the correct care of her child. The case was referred to the ECJ to examine specifically if the Framework Employment Directive included discrimination against a person other than the disabled person. The Court held the prohibition of direct discrimination does not solely apply to individuals with a disability, but that it can also include less favourable treatment of an employee based on the disability of his/her dependent child. The Court also outlined its belief that the directive's purpose is to combat all forms of discrimination on grounds of disability.

In the case of *Chacon Navas v EurestColectividades*,<sup>108</sup> the claimant, an employee of a catering company, lost her job while absent from work because of illness, having been declared unfit for work by the public health service. The employer failed to give any reason for the dismissal and accepted its illegality, offering compensation as a form of redress. The claimant was of the view that the dismissal was itself void under Spanish law and demanded to be reinstated. She argued that she was subjected to unequal treatment and discrimination because of her absence through sickness. The Court adopted the view that the Directive refers to disability and not to sickness, and the fact that this was deliberately delineated shows that a distinct difference was intended to exist between the two issues. The Court also stated that the grounds for discrimination outlined in the Directive are exhaustive.

The ruling in the joined cases of *Ring and Skouboe Werge*<sup>109</sup> was the first decision on the definition of disability under the Framework Directive on Employment 2000/78 in the period since 2010, when the EU fully adopted the CRPD. The Court moved away from the narrow definition it opted for in the *Chacón Nava* case but rather opted to interpret the Framework Directive in the context of Article 1 CRPD. In these cases, two women were dismissed from employment, having returned from periods of sickness, the employers claiming they could no longer effectively carry out full time employment due

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<sup>108</sup> SA (2006) C-13/05.

<sup>109</sup> Cases C-335/11 and C-337/11, CJEU (Second Chamber), 11 April 2013.

to illness and that the dismissals were legal under Danish law. The claimants argued that they fell within the definition of “disabled persons” as outlined by the Employment Equality Directive and that the employers should have made reasonable accommodations for both employees under the Danish Anti-Discrimination Law which states in paragraph 2a that: “Employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to enable a person with a disability to undergo training. This does not however apply if such measures would impose a disproportionate burden on the employer. This burden shall not be regarded as disproportionate if it is sufficiently remedied by public measures.” The Court refused to completely abandon its ruling in *ChacónNavas*, instead pointing out that the ruling was made prior to the entering into force of the CRPD, stating that “the primacy of international agreements concluded by the European Union over instruments of secondary law means that those instruments must as far as possible be interpreted in a manner that is consistent with those agreements.” The Court interpreted the definition of ‘disability’ in the Framework Directive as following that (broad and socially defined view) outlined in Article 1 of the CRPD. The Court also held that the reasonable accommodation demanded was within the limits of the Framework Directive whilst at the same time recognising that it was an issue for the Court in the individual member state to determine whether such accommodation undertaken would create a disproportionate burden for the employers involved. This ruling indicated clearly the supremacy of the CRPD over EU secondary law.

The Framework Directive required employers to provide reasonable accommodations for those with disabilities (Article 5) and required Member States to ensure that employers take measures to enable PWDs to have access to participate in and advance in employment. Unlike the CRPD, this instrument did not unambiguously state that failure to provide these accommodations directly constituted discrimination – see below:

### ***EU and Article 19 CRPD***

‘Th[e] transition from residential care to community living [...] is now a clear legal obligation undertaken by the Member States and by the European Union under Article 19 of the UN Convention on the Rights of Persons with Disabilities.’<sup>110</sup>

Eight years following the EU’s acceptance of the CRPD, 28 EU Member States had ratified the Treaty thus formalising their commitment to fulfilling the right to live independently and be included in the community.<sup>111</sup> As both the EU and its Member States are separate contracting parties, and each has responsibilities in the fields covered by the CRPD, the Convention is a ‘mixed’ agreement in the context of the EU. EU law obliges Member States to implement the convention to the extent that its provisions fall within the EU’s competence. When the EU accepted the CRPD, it identified independent living and social inclusion as an area of EU competence. Just prior to EU ratification, the European Commission’s office for Employment, Social Affairs and Equal Opportunities published a report reviewing European policy and making recommendations to the EC on how best to move, as the CRPD envisages, from institutionalised care to community based living arrangements.<sup>112</sup> Major problems with institutionalisation were cited to be: (1) depersonalised treatments and interactions; (2) rigidity of routine (3) block treatment; and (4) social distance and exclusion. The report highlighted that inflexible legislative and administrative rules in some EU countries were making it difficult to provide services to persons with disabilities outside of large institutions, and persons with disabilities, as a result, have no option but to rely on institutional care arrangements as opposed to independent living within the community, as per Article 19.

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<sup>110</sup> Office of the High Commissioner for Human Rights Regional Office for Europe, “Getting a Life – Living Independently and Being Included in the Community” (2012) 8.

<sup>111</sup> European Union Agency for Fundamental Rights, “From Institutions to Community Living: Key Findings and FRA Opinions” (2017) 9  
<<http://fra.europa.eu/en/publication/2018/institutions-community-living-key-findings-and-fraopinions>> accessed 4 November 2017.

<sup>112</sup> European Commission, “Employment, Social Affairs and Equal Opportunities, ad hoc Expert Group on the Transition from Institutional to Community Based Care” (2009)  
<<http://ec.europa.eu/social/BlobServlet?docId=4017&langId=en>> accessed 5 June 2017.

Drawing on Article 19 CRPD setting out the core elements of the right to independent living, the report provided further evidence of how funding was being channeled to institutions in a way that does not allow for any choice in one's living arrangements. In Ireland for example there are 72 residential institutions<sup>113</sup> for persons with with intellectual disabilities that cost the State €500 million per year to operate,<sup>114</sup> whilst some 4,000 persons with disabilities live in institutions predominantly operated by voluntary organisations / religious groups. Meanwhile according to a recent European Coalition for Community Living report on Slovenia:

“If a disabled person lives in a long stay residential institution, living expenses are covered by the State, with funds given directly to the institution. Disabled people who choose to live alone or by themselves lose this financial support. This means that disabled people who want to live independently need to have a source of income or be financially supported by their families.”<sup>115</sup>

A study of EU Member States and Turkey entitled “De-institutionalisation and Community Living: Outcomes and Costs (DELOC)” also highlighted the relevance of the CRPD and its focus on changing societal approaches from institutionalised care to community based supports and independent living.<sup>116</sup> It estimated that 1.2 million children and adults with disabilities live in long-stay residential institutions.<sup>117</sup> It stressed the importance of Member States to

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<sup>113</sup> The European Commission defined a residential institution as an establishment in which more than 30 people lives, of whom at least 80% are mentally or physically disabled. See Jim Mansell, Martin Knapp, Julie Beadle-Brown and Jamie Beecham, *Deinstitutionalisation and Community Living – Outcomes and Costs: Report of a European Study. Volume 1: Executive Summary* (Canterbury: Tizard Centre, University of Kent, 2007), p.19.

<sup>114</sup> Carl O'Brien, “Institutions for Disabled Should be Closed Down” *Irish Times* (Dublin, 12 July 2010).

<sup>115</sup> European Coalition for Community Living, *Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities: Focus Report* (2009) <<http://community-living.info/wp-content/uploads/2014/02/ECCL-Focus-Report-2009finalWEB.pdf>> accessed 23 May 2016.

<sup>116</sup> European Commission, “Employment, Social Affairs and Equal Opportunities, ad hoc Expert Group on the Transition from Institutional to Community Based Care” (2009) 20 <<http://ec.europa.eu/social/BlobServlet?docId=4017&langId=en>> accessed 5 June 2017.

<sup>117</sup> Jim Mansell et al, *Deinstitutionalisation and Community Living—Outcomes and Costs: Report of a European Study. Volume 2: Main Report* (University of Kent 2007)

involve those most affected in the decision-making, the importance of utilising structural funds to stimulate the growth of community based care and the vital role increased coordination between government departments and agencies involved in the transition process could play. Council Regulation (EC) No 1083/2006<sup>118</sup> sets forth general provisions for the European Regional Development Fund, the European Social Fund and the Cohesion Fund. There is a requirement in the Regulation that all appropriate measures should be taken to prevent any discrimination on the basis of disability in the context of the funds implementation. This is in line with provisions contained in the CPRD. Article 16 of the Regulation provides that accessibility for PWDs should be “one of the criteria to be observed in defining operations co-financed by the Funds and to be taken into account during the various stages of implementation.”

A three-part report carried out by FRA in 2017 concerning different aspects of deinstitutionalisation and independent living for persons with disabilities concludes that the CRPD plays a significant role spurring legal and policy changes in the EU and its Member States, thus strengthening the structures and consolidating obligations States Parties have committed to fulfil. It cites monitoring frameworks established under Article 33(2) of the Treaty as essential, both in highlighting the gap between the standard and the right to independent living in practice and in identifying challenges and progress made towards implementing reforms at European and national levels, such as those stemming from recent reviews conducted by the CRPD Committee.<sup>119</sup> Examples of new or amended legislation to promote choice of living arrangements, personalised support, and access to community services and facilities open to the general population are now found in most EU Member

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[http://eprints.lse.ac.uk/3460/1/Deinstitutionalisation\\_and\\_community\\_living\\_%E2%80%99\\_outcome\\_and\\_costs\\_vol\\_2\(lsero\).pdf](http://eprints.lse.ac.uk/3460/1/Deinstitutionalisation_and_community_living_%E2%80%99_outcome_and_costs_vol_2(lsero).pdf) accessed 23 February 2016.

<sup>118</sup>Council Regulation (EC) No. 1083/2006 of 11 July 2006 laying down general provisions on The European Regional Development Fund, the European Social Fund and the Cohesion Fund and repealing Regulation (EC) No. 1260/1999.

<sup>119</sup> European Union Agency for Fundamental Rights, “Fundamental Rights Report 2017 – FRA Opinions” (2017) 21  
<http://fra.europa.eu/en/publication/2017/fundamental-rights-report-2017-fra-opinions>  
accessed 2 May 2016.

States.<sup>120</sup> Bulgaria and Latvia have introduced a statutory right to personal assistance whilst Belgium has reformed the funding system such that in addition to the basic budget provided to all persons with disabilities and support needs, a second, larger, personalised budget is now available as either cash or voucher for particular services. In the UK, the Human Rights Act<sup>121</sup> has particular relevance in that people with disabilities can now legitimately litigate against the withdrawal or restriction of medical services and the abuse and degrading treatment of disabled people in institutional care.<sup>122</sup> Meanwhile in Italy, following the adoption of the 2013 National Action plan (NAP) on Disability, the Ministry of Labour and Social Policies has been financing innovative projects in more than 170 local authorities. These seek to establish a national intervention model on independent living consistent with the CRPD, based on the full involvement of people with disabilities and experimentation of new solutions such as social co-housing for persons with intellectual disability. More recently a law promulgated in 2016 on support measures for persons with disabilities includes a dedicated annual fund to foster deinstitutionalisation and the development of community-based services.

In 2015 the EU's progress in implementing the CRPD underwent its first periodic review by the CRPD Committee. In its General Comment on Article 19, the Committee noted 'a gap between the goals and spirit of article 19 and the scope of its implementation'.<sup>123</sup> It found that despite wide-ranging legal and policy reforms across the EU, some initiatives at EU and Member State level do not fully incorporate the human rights-based approach to disability required by the CRPD.<sup>124</sup> Its assessment of Member States' efforts to fulfil

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<sup>120</sup> European Union Agency for Fundamental Rights, "From Institutions to Community Living: Key Findings and FRA Opinions" (2017) 9  
<<http://fra.europa.eu/en/publication/2018/institutions-community-living-key-findings-and-fra-opinions>> accessed 10 November 2018.

<sup>121</sup> Human Rights Act 1998, Chapter 42.

<sup>122</sup> Disability Rights Commission, Rowena Daw, "The Impact of the Human Rights Act on Disabled People" (2002).

<sup>123</sup> Office of the High Commissioner for Human Rights Regional Office for Europe, "Getting a Life – Living Independently and Being Included in the Community" (2012) 15.

<sup>124</sup> European Union Agency for Fundamental Rights, "From Institutions to Community Living: Key Findings and FRA Opinions" (2017) 21  
<<http://fra.europa.eu/en/publication/2018/institutions-community-living-key-findings-and>

the obligations of Article 19 identifies six major challenges most of which relate to deinstitutionalisation. These include high levels of institutionalisation and, in some Member States, a trend towards re-institutionalisation. The continued high number of large-scale institutions in operation is resulting in persistent ostracism and exclusion, and on occasion, almost inhumane living conditions.<sup>125</sup> Some deinstitutionalisation initiatives have been put on hold or abandoned completely on account of financial constraints brought about by the global financial crisis. In some cases specialised institutions have been replaced by inappropriate alternatives, which fail to respect the right to live independently in the community and waste both time and resources, even though it has been shown that independent and community-living initiatives, such as co-housing or autonomous small groups, produce excellent results in practice.<sup>126</sup> Owing to a shortage of alternative, community-based living arrangements, persons with disabilities lack choice of residence. There is insufficient availability of personal assistance services and a greater financial investment in institutional services than community-based services. Benefits continue to be means tested, impeding the right to living in the community with an adequate standard of living. Overall, whilst most EU Member States have adopted strategies that cover deinstitutionalisation, some lack adequate funding, clear timeframes and benchmarks, and involvement of disabled persons' organisations required to make them effective.<sup>127</sup> Only a minority have made commitments to not building new institutions or to stopping new admissions into existing institutions. How EU Member States organise deinstitutionalisation varies greatly across the region, with responsibility for community-based services lying with national authorities in some Member States, regional authorities in others, and a mixture of regional and national authorities in a final group. Few Member States have deinstitutionalisation

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fra-opinions> accessed 10 November 2018.

<sup>125</sup> Council of Europe, *Abridged Evaluation Report* (2015) 42  
< <https://rm.coe.int/168069962d>> accessed 2 March 2017.

<sup>126</sup> *Ibid.*

<sup>127</sup> European Union Agency for Fundamental Rights, "From Institutions to Community Living: Key Findings and FRA Opinions" (2017) 7  
<<http://fra.europa.eu/en/publication/2018/institutions-community-living-key-findings-and-fra-opinions>> accessed 10 November 2018.

strategies or have set up modes of cooperation between national, regional and local authorities as well as the different sectors involved in the process. Unsurprisingly, a major challenge to implementing meaningful and sustainable deinstitutionalisation within Member States is coordinating the different levels and sectors of government involved. This resonates with a 2015 evaluation of the CoE's Disability Action supporting Member States in implementing the right to independent living. It revealed insufficient levels of commitment to and mainstreaming of community living and independent living resulting in inappropriate and poor quality short and long-term alternatives to institutional care, slow progress of the deinstitutionalisation process and inadequate person-centred attention to the needs of people with disabilities. Frameworks and services providing opportunities for equal private life, including sexual life are severely lacking.<sup>128</sup>

## **5.5 Conclusion**

The right to live in the community with choices on an equal basis with others has evolved from an array of international legal norms and political commitments. Focusing on the Council of Europe and European Union, this chapter explored the European legal and policy commitments to disability rights, critically examining their potential contribution to enhance the right to independent living and to be included in the community. The purpose was to provide key knowledge which can be applied by Ireland, the empirical context under study in terms of its legislative and policy reforms currently under way to enable independent living to become a reality for all persons with disabilities. The chapter's findings drew out guidance contained in standards in the Council of Europe, specifically the European Convention on Human Rights (ECHR) and the European Social Charter and discussed relevant decisions of the European Court on Human Rights (ECtHR) related to the rights of people with disabilities. The chapter also presented key guidance from European Union (EU) disability law and policy. It focused on

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<sup>128</sup> Council of Europe, *Abridged Evaluation Report* (2015) 40  
< <https://rm.coe.int/168069962d>> accessed 2 March 2017.



the EU Charter of Fundamental Rights, the EU's Disability Strategy and European Structural and Investment Funds and identified how the role of the Court of Justice endorses the rights of EU citizens with disabilities. Finally, since the CRPD is the first human rights treaty that the EU has concluded, the chapter critically assessed the interaction between the Convention and EU legislation, as well as the actual implementation of the CRPD at the EU level. It identified the significant changes within European disability law and policy resulting from the adoption of the CRPD, paying some attention to its implementation in the EU and selected States.

## Chapter 6

### Choice, Support and Access to Personalised Support Services for People with High Dependency Needs in Ireland

#### 6.1 Introduction

The central line of inquiry in this study is the legal, policy and social service reforms required in Ireland for people with high dependency needs to live independently and with dignity in the community on an equal basis with others. To this end, the present chapter aims to understand how Ireland is responding to the principles underpinning the CRPD<sup>1</sup> by implementing international human rights law and policy that promote a more person-driven approach in meeting their needs and enabling choice and control over one's own services and way of life. Signed by Ireland in 2007 and ratified in 2018, the CRPD is the first human rights treaty to expressly articulate a right for people with disabilities to live independently and be included in the community. This right is set out in Article 19 of the Convention, providing a positive philosophy and global standard for independent living and living in the community (community living). Article 19 breaks down the right into three distinct interrelated elements namely choice, support and availability of community services and facilities. As a State Party to the Treaty, Ireland is now required to guarantee persons with disabilities and high dependency needs the right to 'have access to a range of in-home, residential and other community supports services, including personal assistance to support living and inclusion in the community.'<sup>2</sup> A P.A. Act would guarantee people with disabilities and high dependency needs this right.

Over the past three decades, there has been increased policy interest in self-directed home and community-based supports and services, including Personal Assistance, for independent living, which aimed at the reduction,

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<sup>1</sup> Convention on the Rights of Persons with Disabilities 2006.

<sup>2</sup> *Ibid.*, Article 19.

internationally and in Ireland, in the number of people with a disability living in institutional settings. The result has been a move away from traditional service-centred models supporting institutionalised ways of life, towards more flexible and individualised alternatives to service provision.<sup>3</sup> It is in this context of the shift to community living, that the concept of personalisation and relevance of individualised supports and services such as Personal Assistance becomes particularly germane. Another key driver of relocating disability supports to social and community settings has been the shift in emphasis within disability policy globally towards independent living where it now features as the optimum situation for people with disabilities.<sup>4</sup> The National Disability Authority (NDA), the independent statutory body providing advice to the Government on disability policy and practice, promotes an understanding of independent living as people with disabilities ‘having choice and control over the support they need to go about their daily lives and any practical assistance being based on their own choices and aspirations.’<sup>5</sup> Echoing the CRPD, this definition is underpinned by the idea that independent living is community-based, whether in a group home, other forms of supported accommodation, living with friends or living alone. Underpinned by the principles of inclusion, participation, and equality, it is well acknowledged that approaches and community-based services supporting independent living enhance the quality of life of people with disabilities<sup>6</sup> and also accrue exchequer savings and benefits to the state.<sup>7</sup> Such developments are also shaping disability policies, reforms and measures such as person-centred planning, individualisation and direct payments.<sup>8</sup>

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<sup>3</sup> National Disability Authority, *Annual Report 2011* (2011).

<sup>4</sup> *Ibid.*

<sup>5</sup> National Disability Authority, “A Review of Literature on Natural Community Supports – A Contemporary Developments in Disability Services Paper” (2011) <http://nda.ie/nda-files/A-Review-of-Literature-on-Natural-CommunitySupports1.pdf> accessed 5 February 2016.

<sup>6</sup> Rachel Forrester-Jones et al, "The Social Networks of People with Intellectual Disability Living in the Community 12 Years after Resettlement from Long-Stay Hospitals" (2006) 19(4) *Journal of Applied Research in Intellectual Disabilities* 285-295.

<sup>7</sup> Raymond A. Lemay, "Deinstitutionalization of People with Developmental Disabilities: A Review of the Literature" (2009) 28(1) *Canadian Journal of Community Mental Health* 181-194.

<sup>8</sup> National Disability Authority, *Annual Report 2011* (2011).

Examining where the Irish State, the empirical context under study, is situated on the spectrum of this reform agenda is the core focus of the current chapter. It provides relevant information about Ireland, where evolution in thinking on the nature of disability and the rights of people with disabilities to participate in all aspects of social life is currently not reflected in legislation, policy and services such as the shift from institutional care settings to independent or community-based living. The chapter thus examines the status quo, clarifying what legal measures and supports and services are in place and in need of reform to enable people with high dependency to make their own choices and live independently in their communities with dignity.

The chapter is divided into six sections. After briefly setting out the cultural and political context of Irish disability law and policy reform, section one traces the evolution and recent developments intended to promote disability rights and independent living in Ireland. Section two then provides a short profile of people with disabilities and high dependency needs. In section three current disability law, policy and strategies are summarised and key themes within them amplified with references to specific supports for people with high dependency needs to live independently. Next, section four reviews the current situation on the ground including the configuration of funding and the range and types of community led services - such as Personal Assistance and direct payments- available to support community participation and independent living. Section five critically reviews current legal and policy commitments and mechanisms intended to support people with high dependency needs to control their own services and direct their own lives. It highlights key areas of concern and debate in relation to the types of issues that need to be considered by policy makers in designing measures to promote independent living. The last section concludes with a synthesis of chapter findings.

## 6.2 An Overview of Developments in Irish Law, Policies and Services for People with Disabilities

Over the past three decades, the disability sector in Ireland has been undergoing significant reform in terms of its underlying concepts, policy and models of service delivery.<sup>9</sup> This process is deeply influenced by Ireland's distinct cultural and political context and policy and practices from the past. Historically Ireland shared the tendencies prevalent in other countries towards 'paternalism, medicalisation and segregation'. It also had specific local characteristics, including significant reliance on religious organisations to provide disability services and a very high degree of institutionalisation.<sup>10</sup> The scale and reliance upon institutions in Ireland throughout its history has been staggering. This was very pronounced when it came to persons with intellectual disabilities as well as those who were civilly committed to mental institutions. An intrinsic factor in this history was the enduring legacy of the Poor Laws of the nineteenth century.<sup>11</sup> "The concept of the deserving and undeserving poor was central to welfare provision throughout this period. Generally associated with middle-class values and perceptions, and often assumed to be an English importation to Ireland, the concept nevertheless became deeply rooted in Irish popular culture. The respectable poor, those who had fallen on hard times through no fault of their own, such as the elderly and disabled, were regarded as deserving of sympathy and relief...".<sup>12</sup> A second key theme is the considerable imprint of the Protestant and Roman Catholic Churches on the history and evolution of social services for and the formulation of attitudes toward people with disabilities in Ireland. Both churches and the religious bodies associated with them, such as the Society of St Vincent de Paul, undertook significant roles in the development and management of disability support provision. There was nothing inherently wrong with this. However, it perpetuated social assumptions about those with

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<sup>9</sup>Andrew Power, Janet Lord and Allison DeFranco. *Active Citizenship and Disability: Implementing the Personalisation of Support* (Cambridge University Press 2013).

<sup>10</sup>Power et al, *op. cit.*, 343-344.

<sup>11</sup>Virginia Crossman, *The Poor Law in Ireland 1838 – 1848* (Economic and Social History Society of Ireland 2006).

<sup>12</sup>*Ibid.*

disabilities being deserving of pity and care as distinct from ordinary citizenship. Rivalry between both churches became apparent as the religious orders competed to provide denominationally separate services. This history marks Ireland as relatively unique in terms of the way in which its support infrastructure and unique mixed model of welfare provision developed.

In the 1960s, the medicalised model dominating the provision of disability services in Ireland became increasingly 'specialised', with professionals recommending the necessary services to address the health care needs of people with disabilities.<sup>13</sup> Meanwhile the rate of institutionalisation peaked in the mid-1980s, and since then, Ireland has been grappling with developing the provision of less congregated support in the community. After the 1980s and influenced by global trends and what was emerging in other jurisdictions, significant changes began to take place in the Irish disability sector. This included a marked shift away from segregationist and institutionalised services towards supporting people with disabilities to live their lives independently in the community. Key to that development was a shift from a medical model of disability which emphasised care, to a more social understanding which emphasised independent living.<sup>14</sup> This understanding holds that the main barriers to full citizenship faced by people with disabilities are imposed by the economy, culture and society in which they live.<sup>15</sup> Triggered by the UN standards on equality underlying international human rights frameworks, disability came to the forefront of the Irish political/policy agenda in the mid-1990s with a flurry of legislation in the area of disability being enacted throughout this decade.<sup>16</sup> The UN standards on equality were in effect the springboard for Ireland to take actions to improve the lives of people with disabilities.<sup>17</sup> Legislative reform for this period was further

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<sup>13</sup>Brad McDaniels and Allison Fleming, "Sexuality Education and Intellectual Disability: Time to Address the Challenge" (2016) 34(2) *Sexuality and Disability* 215-225, 225.

<sup>14</sup>James W. Conroy, Charles S. Ferris and Ron Irvine, "Microenterprise Options for People with Intellectual and Developmental Disabilities: An Outcome Evaluation" (2010) 7(4) *Journal of Policy and Practice in Intellectual Disabilities* 269 - 277.

<sup>15</sup> National Disability Authority, *Annual Report 2011* (2011).

<sup>16</sup> *Ibid.*

<sup>17</sup> Iain M. Carey, et al, "Health Characteristics and Consultation Patterns of People with Intellectual Disability: a Cross-Sectional Database Study in English General Practice" (2016) *British Journal of General Practice*

<<https://bjgp.org/content/bjgp/early/2016/02/23/bjgp16X684301.full.pdf>>

spurred by the establishment of supporting institutions, namely the Commission on the Status of People with Disabilities in 1993, generally viewed as a significant landmark. The shift in Irish disability policy also came about as a result of demands made by people with disabilities themselves, who were arguing for improved policies and services to facilitate independent living.

In its report, *A Strategy for Equality*, the Commission on the Status of People with Disabilities argued for a rights-based approach to disability<sup>18</sup> and made a number of recommendations based on three guiding principles – equity, maximising participation, and enabling independence and choice.<sup>19</sup> These echoed the demand for greater inclusion in all aspects of Irish society by people with disabilities and also the emergence of a call for a rights based approach to disability.<sup>20</sup> In brief, the Commission recommended a redesign and restructuring of all the disability services and a change in legislation, which would be pivotal in ensuring the provision of mainstream services. It also identified avenues through which people with disabilities could be incorporated in services by loosening restrictions that hindered their participation in mainstream society.<sup>21</sup> Thus, began the move within the Irish disability sector towards an individualised and person centred model, drawing on a more holistic view of what is required to live a fulfilled and healthy life, including personal and social care needs.<sup>22</sup> The driving forces behind this change were family and advocacy-led organisations many of which went on to form voluntary and semi-autonomous non-governmental organisations (NGOs). Funded largely by the government, they became the main provider of vocational training, sheltered work and other activities for people with disabilities. Some include Inclusion Ireland, the national organisation advocating for the rights of people with intellectual disabilities, the Irish

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accessed 30 November 2016.

<sup>18</sup> Clodagh Nolan et al, "Higher Education Students Registered with Disability Services and Practice. Educators: Issues and Concerns for Professional Placements" (2015) 19(5) *International Journal of Inclusive Education* 487-502.

<sup>19</sup> National Disability Authority, *Annual Report 2011* (2011).

<sup>20</sup> Department of Health Promotion, Maureen D'Eath et al, *The Experience of People with Disabilities in Accessing Health Services in Ireland: Do inequalities exist? Report to the National Disability Authority* (2005).

<sup>21</sup> Conroy, *op. cit.*, 270.

<sup>22</sup> Fleming, *op. cit.*, 250.

Wheelchair Association (IWA), the Centre for Independent Living (CIL) and the Disability Federation Ireland (DFI). With a focus on ‘choice’, ‘rights’, ‘empowerment’ and ‘independence’, these organisations, to this day continue to deliver services across the country.<sup>23</sup> For example, in its Strategic Plan (2013-2015), the Centre for Independent Living (CIL) stipulates that state and communities should ensure people with disabilities access to the same range of choice options as to everyone else.<sup>24</sup> Its vision is to promote direct payments as a mechanism for choice facilitation, which the CIL views as the most crucial aspect of independent living.

By the end of the 1990’s disability policy and legislative reforms had gathered significant pace in Ireland. Notable around this time was the enactment of equality legislation, namely the Employment Equality Act 1998 and the Equal Status Act 2000, and the establishment of supporting institutions such as the National Disability Authority (NDA). The purpose of the NDA was to provide independent policy advice to government and public bodies, promote relevant research and advise on standards and guidelines in services to people with disabilities.<sup>25</sup> This was followed in the early 2000s by bodies empowered to coordinate the development of disability policy and to perform information and advocacy roles. In 2004-5 an explicit National Disability Strategy (NDS) and related legislation was enacted to encourage government departments to meet their obligations across a broad spectrum of policy areas which impact on the support needs of people with physical, sensory and intellectual disabilities.<sup>26</sup> Then in 2008, Ireland became one of the first signatories of the CRPD, which it ratified over a decade later on March 8<sup>th</sup>,

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<sup>23</sup> *Ibid.*

<sup>24</sup> Iain M. Carey, et al, "Health Characteristics and Consultation Patterns of People with Intellectual Disability: a Cross-Sectional Database Study in English General Practice" (2016) British Journal of General Practice  
< <https://bjgp.org/content/bjgp/early/2016/02/23/bjgp16X684301.full.pdf>> accessed 30 November 2016.

<sup>25</sup> Clodagh Nolan et al, "Higher Education Students Registered with Disability Services and Practice Educators: Issues and Concerns for Professional Placements" (2015) 19(5) International Journal of Inclusive Education 487-502.

<sup>26</sup> Ireland Inclusion, "Intellectual Disability: Causes and Prevention—Your Questions Answered" (2013) 1  
<<https://www.inclusionireland.ie/sites/default/files/attach/basicpage/512/causesandpreventionbooklet.df>> accessed 22 May 2017.



2018.<sup>27</sup> Despite these developments however, many challenges remain to promoting disability rights and achieving full community living in Ireland and there is an on-going search for more effective policies and practices to support people with disabilities to live independent lives.

### 6.3 Disability in Ireland

Estimates of the prevalence of disability can vary widely depending upon the definitions used. The ‘biopsychosocial model’, whereby disability is understood as emerging from an intersection between the individual and the physical and social environment (NESC, 2009), is the model of disability advocated by the World Health Organisation (WHO).<sup>28</sup> This model also underlies the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) which in turn provides the framework for Ireland’s National Disability Survey (NDS), which followed up a large sample of those identified in the Census of Population 2006 as having a disability. The most recent data on the prevalence of disability in Ireland is from *Profile 9: Health, Disability and Carers* from the 2016 Census of Population by the Central Statistics Office (CSO Ireland).<sup>29</sup> This and other official surveys draw on the following definition of disability:

A person with one or more of the following long-lasting conditions or difficulties:

Blindness or severe vision impairment

Deafness or a severe hearing impairment

An intellectual disability

Difficulty with learning, remembering or concentrating

A difficulty with basic physical activities

Difficulty with pain, breathing or other chronic illnesses

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<sup>27</sup> John Cullinan and Seán Lyons, *The Economics of Disability* (Manchester University Press 2015) 4.

<sup>28</sup> *Ibid.*, 4.

<sup>29</sup> *Ibid.*, 6.

Psychological or emotional condition  
Difficulty in dressing, bathing or getting around home  
Difficulty in working or attending school/college  
Difficulty in participating in other activities  
Difficulty in going outside the home alone<sup>30</sup>

Disability was self-reported in the 2011 Census which answered questions related to whether an individual had one of the above long-standing conditions and whether they had difficulties undertaking any of four specified activities.<sup>31</sup> According to the profile, there were 595,335 persons, accounting for 13.0% of the population, who had a disability. In April 2016, this had risen to 643,131, accounting for 13.5% of the population.<sup>32</sup> Meanwhile the two main sources of data on the living arrangements of people with disabilities are the National Intellectual Disability Database (NIDD), which relates to people with an intellectual disability and the National Physical and Sensory Disability Database (NPSDD), which relates to people with a physical or sensory disability.<sup>33</sup> These are maintained by the Health Research Board and also estimate the number of people receiving or on a waiting list for specialist disability services. In 2008 this was approximately 53,000 of which 26,000 were on the NIDD, and 27,000 on the NPSDD.<sup>34</sup> As of December 2009, the number of people with a physical disability registered on the NPSDD had risen to 29,948 people. 26,169 were aged less than 66, of which 85.6% lived with family members, 9.6% lived alone and just 2.9% were in residential services.<sup>35</sup> The scale of difference between the numbers produced by the National Disability Survey 2006 and the disability databases suggests that most people with a disability, and particularly those with physical or sensory disabilities, are supported through mainstream rather than specialist disability

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<sup>30</sup> Central Statistics Office, *Census of Population*, Profile 9 Health, Disability and Carers (2011).

<sup>31</sup> Central Statistics Office, *Census of Population* (2012).

<sup>32</sup> Central Statistics Office, *Census of Population* (2016).

<sup>33</sup> The coverage of the National Physical and Sensory Disability Database (NPSDD) is acknowledged as incomplete owing to the voluntary nature of participation and uneven progress in achieving target coverage for several groups and areas. See National Disability Authority, *Advice Paper* (2010) 10.

<sup>34</sup> National Disability Authority, *Advice Paper* (2010) 10.

<sup>35</sup> *Ibid.*

services.<sup>36</sup> This highlights the importance of maintaining and strengthening the capacity of mainstream services to support people with disabilities to live at home in independence.<sup>37</sup>

In Ireland people with disability experience high levels of poverty and deprivation.<sup>38</sup> A 2009 survey of living conditions found that people with a disability experienced deprivation levels of 42%, which was the highest level compared with unemployed people, students or older people (Survey on Income and Living Conditions (SILC)).<sup>39</sup> This is attributed to austerity measures and high levels of unemployment amongst people with disabilities.<sup>40</sup> In relation to unemployment, in 2008, an OECD study comparing disability policies in Ireland and three other European countries emphasised the need to improve the rate of employment for disabled people in Ireland, which had been falling despite the country's strong rate of economic growth at that time.<sup>41</sup> Still in 2012, only 20% of people with disabilities were at work compared with 50% of the general population.<sup>42</sup> Ireland's low rate of employment amongst people with disabilities was seen to contribute to their low incomes and high rates of income poverty (earning less than 60% of median equivalised income), as compared to those in other developed countries.<sup>43</sup> Exclusion from the labour force and the labour market leaves people with disabilities highly reliant on welfare payments as their only source of income. However passive income support alone is not sufficient if poverty and social exclusion are to be adequately addressed.<sup>44</sup>

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<sup>36</sup> *Ibid.*

<sup>37</sup> *Ibid.*

<sup>38</sup> Ireland Inclusion, "Intellectual Disability: Causes and Prevention—Your Questions Answered" (2013) 1  
<<https://www.inclusionireland.ie/sites/default/files/attach/basicpage/512/causesandpreventionbooklet.df>> accessed 22 May 2017.

<sup>39</sup> Central Statistics Office, *Census of Population* (2012).

<sup>40</sup> Ireland Inclusion, *op.cit.*, 8.

<sup>41</sup> Cullinan et al, *op. cit.*, 6.

<sup>42</sup> Central Statistics Office, *Census of Population*, Profile 8: Our Bill of Health –Health, Disability and Carers in Ireland (2012).

<sup>43</sup> Cullinan et al, *op. cit.*, 6.

<sup>44</sup> Government of Ireland, *National Action Plan for Social Inclusion: 2007–2016* (2007) 42.

The high levels of poverty experienced by people with disabilities are also attributed to austerity.<sup>45</sup> Austerity in Ireland resulted in harsh cuts to respite services, non-replacement of front-line staff providing disability services, cuts to home-help and personal assistant hours, restriction on funding for school leavers, withdrawal of payments to people with intellectual disabilities working in sheltered work and attending rehabilitative training, and the erosion of community based supports and programmes. These cuts have undermined confidence in the Programme for Government's commitment to ensure that 'every person with a disability would be supported to enable them as far as possible to lead full and independent lives to participate in work and in society and to maximise their potential'.<sup>46</sup> Disability rights advocates have become increasingly concerned that these types of policy decisions and actions and the failure to date to fully implement the legislation impact severely on the lives of people with disabilities. This is incongruous with the government's stated commitments to address poverty and protect the human rights of people with disabilities. The failure of the Irish state to address the disproportionately higher levels of unemployment and unacceptable levels of poverty and deprivation amongst people with disabilities also runs contrary to the principles and standards of international human rights treaties.<sup>47</sup> For example, the CRPD places an obligation on the government to recognise the right of people with disabilities to work on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted, in a labour market and a work environment that is open, inclusive and accessible to persons with disability (Art 27, CRPD). Cuts to essential payments, services and supports also run contrary to the right to an adequate standard of living and social protection as stipulated in Article 28 of the CRPD.<sup>48</sup>

#### **6.4 An Overview of Current National Disability Law & Policy for Independent Living**

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<sup>45</sup> Ireland Inclusion, "Intellectual Disability: Causes and Prevention—Your Questions Answered" (2013) 1.

<sup>46</sup> *Ibid.*, 6.

<sup>47</sup> *Ibid.*, 8.

<sup>48</sup> *Ibid.*, 8.

In recent years many developments have taken place in the Irish disability sector in terms of policy, legislation and service provision with Cullinan *et al.* describing the trend as leaning towards “a rights-based approach with enhanced support for independent living and a greater emphasis on personal assistance.”<sup>49</sup> Today disability is increasingly being considered in the Irish policy context to be a socioeconomic phenomenon whereby people with disabilities are prevented from participating fully in society due to the presence of various barriers in many domains relating to societal attitudes, public and private infrastructure and institutions.<sup>50</sup> This understanding emphasises the need for services to be offered in multiple ways, including on a common basis for those with and without disabilities, known as ‘mainstreaming’, on a ‘life course’ basis, whereby supports are flexible enough to cater for the changing profile of individuals’ needs and preferences over the life course; and for supports to be provided on a bespoke basis in accordance with the specific needs and available resources and for disabled people to be involved in decisions about the supports they receive.<sup>51</sup> Discussed in greater detail in the next section of the chapter, Ireland has started to move towards a more personalised model of service delivery. This has benefited from key policies and legislative acts that promote the rights and choice agenda for people with disabilities and high dependency needs, so critical for their independent living opportunities.<sup>52</sup> The two key policy documents are the National Disability Strategy 2004 and the National Disability Strategy 2017-2021. Both provide comprehensive frameworks committing the State to removing everyday barriers in life and empowering people with a disability to enjoy their rights, including the right to independent living, as full and equal citizens.<sup>53</sup>

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<sup>49</sup> Cullinan *et al.*, *op. cit.*, 117; National Disability Authority, *Advice Paper* (2012).

<sup>50</sup> Cullinan *et al.*, *op. cit.*, 1.

<sup>51</sup> *Ibid.*, 1.

<sup>52</sup> Iain M. Carey, *et al.*, "Health Characteristics and Consultation Patterns of People with Intellectual Disability: a Cross-Sectional Database Study in English General Practice" (2016) *British Journal of General Practice*  
<<https://bjgp.org/content/bjgp/early/2016/02/23/bjgp16X684301.full.pdf>> accessed 30 November 2016.

<sup>53</sup> Inclusion Ireland, *op. cit.*, 9.

Announced by the government in 2004, Ireland's first National Disability Strategy (NDS) built on the existing equality framework of the Employment Equality Act, 1998; the Equal Status Act, 2000; the Equality Act, 2004; and the progress that had been made in mainstreaming services for people with disabilities.<sup>54</sup> Its main focus has been the empowerment, participation and the integration of people with disabilities into mainstream society.<sup>55</sup> The Strategy contained three key pieces of legislation and a multi-annual investment programme for disability supports services for the period 2006-2007.<sup>56</sup> Its legislative components included the Disability Act 2005, the Citizens Information Act 2007 and the Education for Persons with Special Educational Needs Act 2004.<sup>57</sup>

A major watershed in Irish social policy, the Disability Act 2005 recognises for the first time the place of persons with disabilities in Irish society and the State's responsibilities to ensure persons with disabilities participate on an equal basis to other citizens.<sup>58</sup> Underlying the Act are the Equality Acts 2000-2008, namely the Employment Equality Acts 1998 and 2004 and the Equal Status Acts 2000-2008. The Disability Act 2005 views 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' (Disability Act 2005). It sets out the legal requirements of public bodies and provides for an independent assessment of individual needs and a related service statement. It also makes provision for independent redress and enforcement for people with disabilities.<sup>59</sup>

The Citizens Information Act 2007, another key legislative component underlying National Disability Strategy 2004 also promotes the choice and independent living agenda by providing for the establishment of a statutory

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<sup>54</sup> *Ibid.*

<sup>55</sup> Cullinan, *op. cit.*, 114.

<sup>56</sup> National Disability Authority, *Advice Paper* (2011).

<sup>57</sup> Inclusion Ireland, *op. cit.*, 9.

<sup>58</sup> National Disability Authority, *Advice Paper* (2011).

<sup>59</sup> *Ibid.*, 10.

Personal Advocacy Service (PAS) to people with disabilities and the general population.<sup>60</sup> Known as the Citizens Information Board (CIB), the mandate of the PAS is to ‘support the provision of, or to provide directly, advocacy services to individuals, in particular those with a disability, that would assist them in identifying and understanding their needs and options and in securing their entitlements to social services.’<sup>61</sup> Based on international best practice, there are other Irish policy documents significant for people with disabilities and high dependency needs particularly in the context of independent living. The 2000 Department of Social Welfare Report “Supporting Voluntary Activity” introduced service agreements and a higher degree of formal monitoring between the state and service providers. The National Health Strategy (2001) set out ‘people-centred services’ as a core principle.<sup>62</sup>

One of the most significant policy documents relating to the choice and independent living agenda is *Time to Move on from Congregated Setting: a strategy for Community Inclusion*.<sup>63</sup> The strategy highlights the need for people with disabilities who live in congregated settings to move into community living, the vision being that people would: “be able to exercise meaningful choice, equal to that of other citizens, when choosing where and with whom they will live”.<sup>64</sup> Commitments to independent living for people with disabilities and high dependency needs are further evident in the *Government for National Recovery*.<sup>65</sup> In this policy document the Government announced its intention to promote ‘choice and voice for service users’ and proposed moving a proportion of public spending from a direct

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<sup>60</sup> National Disability Authority, Janet Carter Anand et al, “The Transition to Personal Budgets for People with Disabilities: A Review of Practice in Specified Jurisdictions” (2012)

< [http://nda.ie/ndasitefiles/Personal\\_Budgets\\_State\\_of\\_Evidence.pdf](http://nda.ie/ndasitefiles/Personal_Budgets_State_of_Evidence.pdf)> accessed 17 February 2016.

<sup>61</sup> Citizens Information Act 2007, Section 4(b).

<sup>62</sup> Government of Ireland, “Quality and Fairness: A Health System for You” (2001)11 < [https://health.gov.ie/wp-content/uploads/2014/06/q\\_and\\_f\\_progress.pdf](https://health.gov.ie/wp-content/uploads/2014/06/q_and_f_progress.pdf)> accessed 5 May 2017.

<sup>63</sup> Health Service Executive, *Time to Move on from Congregated Setting: a Strategy for Community Inclusion*(2011). <<https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/>> accessed 14 May 2017.

<sup>64</sup> *Ibid.*

<sup>65</sup> Government of Ireland, *The National Recovery Plan 2011-2014* (Stationery Office 2010).

service model to one based on personal budgets with the intention of increasing the level of choice, control and flexibility people with disabilities have over the services and supports they need. Rather than providing fixed budgets to traditional public service providers of social care services, the Government was proposing to place some of these resources in the hands of citizens, to enable them to acquire services better suited to their individual needs.<sup>66</sup> “*New Directions: Review of HSE Day Services and Implementation Plan 2012- 2016*” also signals that a more serious intent and new policy direction was in place with a much more person-centered focus.

The *2008-2011 Value for Money and Policy Review Initiative* and *Towards 2016* both emphasise the tenets of independent living namely inclusion in the mainstream community, independence, choice and participation.<sup>67</sup> *Towards 2016* is a ten-year framework agreement drawn up under the social partnership process. It states: ‘parties to this agreement share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and as part of their local community’.<sup>68</sup> Critically the goal articulated in this document is that persons with disability would have support to enable them to lead full and independent lives, to participate in work and in society, and to maximise their potential. Meanwhile the Department of Health’s interim report (2012) on the policy implications of the ongoing ‘Review of the Efficiency and Effectiveness of Disability Services in Ireland’ is another important document with Keogh and Quinn noting that the disability sector has advanced since its publication.<sup>69</sup> It is currently being used as the benchmark for achieving disability sector improvements and is one of the few reports acknowledging

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<sup>66</sup> National Disability Authority, Janet Carter Anand et al, “The Transition to Personal Budgets for People with Disabilities: A Review of Practice in Specified Jurisdictions” (2012)  
< [http://nda.ie/ndasitefiles/Personal\\_Budgets\\_State\\_of\\_Evidence.pdf](http://nda.ie/ndasitefiles/Personal_Budgets_State_of_Evidence.pdf)> accessed 17 February 2016.

<sup>67</sup> National Disability Authority, *Advice Paper* (2010).

<sup>68</sup> *Ibid.*, 4.

<sup>69</sup> Independent Living, Sinead Keogh and Gerard Quinn, *Independent Living: An Evaluation of the Aiseanna Tacaiochta Model of Direct Payments. Report* (2018)  
< [https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent\\_Living\\_An\\_Evaluation-of-the-A%CC%81iseanna-Tacai%CC%81ochta-model-of-Direct-Payments.pdf](https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent_Living_An_Evaluation-of-the-A%CC%81iseanna-Tacai%CC%81ochta-model-of-Direct-Payments.pdf)> accessed 10 November 2018.



failings in terms of what was promised and what has been implemented in terms of costs, adherence to the desires and self-determination of people with disabilities.

Citing new policy goals including the goal of self-determination of people with disabilities, a central theme in the *Value for Money* report is the personalised approach which underlies its key policy proposals including the provision of personal ‘supports’, rather than ‘services’ comprising a range of assistance and interventions required to enable the individual to live a fully included life in the community.<sup>70</sup> Of particular relevance to this thesis, it examined the need for a direct payments scheme to be available to people with disabilities, enabling total control over personal assistance and service needs. The *Expert Reference Group on Disability* which completed the Policy Review of Disability Services (2011) understands personal budget schemes as: ‘assistance provided by others, whether in the form of personal care, communication or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment, and so on’.<sup>71</sup> Based on this understanding, it proposed restructuring disability services through personalised supports, in other words, ‘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 centered on group-based delivery towards a model of person-centered and individually chosen supports’ (p. xvii). It recommended that: ‘the necessary actions be taken to put in place a system of individualised funding for people with disabilities. This system should include a range of options for the administration of individualised funding and should consider the required processes for individualised resource allocation’.<sup>72</sup> This means using person-centred plans and personal budgets to bring Ireland in line with the global changes within the disability sector.<sup>73</sup>

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<sup>70</sup> *Ibid.*

<sup>71</sup> National Disability Authority, *Annual Report 2012* (2012) 12.

< <http://nda.ie/nda-files/Annual-Report-2012.pdf> > accessed 10 November 2017.

<sup>72</sup> *Ibid.*, 150.

<sup>73</sup> Brad McDaniels and Allison Fleming, "Sexuality Education and Intellectual Disability: Time to Address the Challenge" (2016) 34(2) *Sexuality and Disability* 215-225, 225; Padraic Fleming, Sinead McGilloway and Sarah Barry, "The Successes and Challenges

More recently the Minister of State for Disability, Finian McGrath T.D has reaffirmed the Irish government's aim to empower people with disabilities to live independent lives by providing adequate and appropriate services and supports for people to access services with greater independence and tailor the support required to meet their needs and plan their lives.<sup>74</sup> Its current commitment towards achieving this aim is the establishment of the Task Force on Personalised Budgets (2016). It is mandated to make recommendations on a personalised budgets model intended to enhance people with disabilities' choice and control in accessing health-funded personal social service.<sup>75</sup> Personal Budgets and individualised funding are prioritised in the Health Service Executive's (HSE) annual National Service Plan (NSP) with the 2016 NSP stating that one of its goals for 2016 is to "support the phased transition to person-centred models of services and support".<sup>76</sup> Meanwhile the 2017 NSP lists the support of the Taskforce on Personalised Budgets as one of its priorities.<sup>77</sup> To sum up this section, the main thrust of Irish disability policy over the last 20 years has been towards support for independent living, expansion of provision of personal assistance, and providing new residential care places within the mainstream community.<sup>78</sup> This next section of the chapter clarifies the status quo in terms of the configuration, funding and model for Personal Assistance services currently in place in Ireland that aim to empower people with disabilities and high dependency needs to live independently with dignity.

## **6.5 The Configuration and Funding of the System and Supports for Independent Living in Ireland**

Whilst Ireland does not yet have an independent living strategy, disability service provision over the years has achieved some progress in supporting

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of Implementing Individualised Funding and Supports for Disabled People: an Irish Perspective" (2016) 31(10) Disability & Society 1369-1384; Keogh and Quinn, *op. cit.*

<sup>74</sup> Keogh and Quinn, *op. cit.*, 5.

<sup>75</sup> *Ibid.*

<sup>76</sup> Keogh and Quinn, *op. cit.*, 12.

<sup>77</sup> *Ibid.*

<sup>78</sup> National Disability Authority, *Advice Paper* (2010) 15.

people with disabilities and high dependency needs to live independently.<sup>79</sup> Since the mid-1990s, the funding for disability services has expanded. Residential places, service staffing and support hours under the 2005-2009 Multi-Annual Investment Programme increased significantly with the number of personal assistant and home support hours increasing from 2.5m hours in 2006 to 3.2 million in 2009.<sup>80</sup> A key value driving the relative progress and changes in Irish disability service provision has been a more person-centered approach, incorporating an appreciation of the person as a unique individual, and that all planning be designed to support each individual to lead their life as and how they wish.<sup>81</sup> This evolution is closely associated with the emergence of the Independent Living movement in the 1990s, notably the establishment of the first Centre for Independent Living (CIL) in Dublin in 1992, the second in Galway two years later and since then over 27 centres across the country. Central to the Irish Independent Living movement have been the principles of choice and control over the way care is delivered including the idea of personal assistants working under the direction of persons with disabilities.<sup>82</sup> This trend in Ireland is in keeping with the global shift from a welfare system which treated people with disabilities as dependents and passive recipients of state 'care', towards an acknowledgement of the need for an alternative approach that would enable people to direct their own services, supports and everyday lives.

In Ireland, disability policy remains highly centralised, with the Department of Health and Children maintaining responsibility for setting policy, strategies and plans guiding community and hospital-based services. It also maintains overall control of health and personal social service provision through the Health Service Executive (HSE). Under its direction, the HSE manages the health care system including the delivery of specialist disability services and personal care packages aimed at meeting the essential care and social needs of people with disabilities. These are delivered through its funded service

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<sup>79</sup> *Ibid.*, 10.

<sup>80</sup> *Ibid.*, 15.

<sup>81</sup> *Ibid.*

<sup>82</sup> Keogh and Quinn, *op. cit.*, 14.

providers across nine different Community Healthcare organisations (CHOs) throughout the country.<sup>83</sup> The budget and the type and volume of health and personal social service are set out in the HSE's annual National Service Plan (NSP) which in 2017 was to provide 2,357 adults with physical and/or sensory disabilities 1.4 million Personal Assistance service hours. These are typically distributed across the nine CHOs.<sup>84</sup> All individuals referred to the HSE as needing a care package to cover essential and social needs are assigned a case manager and also entitled to a needs assessment. As the HSE holds budgetary responsibility for disability services, all benefit claims are assessed at a national level.<sup>85</sup> Meanwhile a standardised needs assessment tool for disability services does not yet exist and service provision tends to be organised by type of impairment rather than assessed needs.<sup>86</sup> The HSE has identified the selection and implementation of a needs assessment tool as a priority action in its 2017 NSP. This would be used not just for initial assessments but also on an on-going basis to review and address the changing care needs of each individual.<sup>87</sup>

Personal assistance programmes are one of several supports available in Ireland for independent living. Others include home help, grants to cover housing adaptation and mobility aids, social housing as well as supports to carers which include financial support such as the Carers Allowance and Carers Benefit.<sup>88</sup> The current funding model for Personal Assistance and other services for independent living does not include individualised funding mechanisms. Instead it comprises elements of formal contracting based on service agreements,<sup>89</sup> whereby most funding is directed to service providers rather than linked to supported individuals. Whilst the HSE is a significant provider of such services, the voluntary sector provides about 90% of specialist intellectual disability services and about 60% of specialist physical

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<sup>83</sup> *Ibid.*, 12.

<sup>84</sup> *Ibid.*, 12.

<sup>85</sup> National Disability Authority, *Annual Report 2012* (2012).

<sup>86</sup> National Disability Authority, *Advice Paper* (2010) 17.

<sup>87</sup> Keogh and Quinn, *op. cit.*, 12.

<sup>88</sup> National Disability Authority, *Annual Report 2011* (2011) 18.

<sup>89</sup> John Cullinan and Seán Lyons, *The Economics of Disability* (Manchester University Press 2015) 5.

and sensory disability services. Funded by the HSE under Section 39 of the Health Act 2004, locally-based voluntary and non-statutory organisations play a key role in the delivery of personal care packages aimed at meeting the essential and social needs of people with disabilities.<sup>90</sup>

All funding agreements between the HSE and what are now known as Section 39 agencies, are regulated by complying with a Governance Framework, whilst the specific requirements in relation to the standards of care and level of service provided by Section 39 organisations are set out in Service Level Agreements (SLAs). Mostly originating as support groups for people with a particular condition or difficulty, Section 39 service providers are now viewed as a considerable locus of expertise.<sup>91</sup> Drawing less on the medical model, they have developed innovative ways of providing a range of community services and supports to people with disabilities,<sup>92</sup> with the Assisted Living Service representing the largest service delivered.<sup>93</sup> Some of the traditional service providers include the Irish Wheelchair Association (IWA), Cheshire, Rehab, Bluebird Care and Enable Ireland. In 2016 80% of all the Personal Assistance hours was provided by one section 39 agency whilst a number of other organisations also receive grants to provide Personal Assistance under service level agreements.<sup>94</sup> Whilst rates vary from organisation to organisation, typically they receive €23 per standard hour of personal assistance. Currently in Ireland, the concept of a personal budget - typically characterised by an amount of funding allocated on the basis of a resource allocation system (RAS) - remains absent from disability law and policy. Thus, a national strategy and framework in the area of Direct Payments for independent living does not exist.

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<sup>90</sup> Keogh and Quinn, *op. cit.*, 13.

<sup>91</sup> Chris McInerney and Cian Finn, "Caring at What Cost? Rebuilding and Refinancing the Community and Voluntary Sector" (Department of Politics and Public Administration, University of Limerick 2015)  
<[https://www.ul.ie/ppa/content/files/Funding\\_Community\\_voluntary\\_sector\\_organisations\\_to\\_deliver\\_services.pdf](https://www.ul.ie/ppa/content/files/Funding_Community_voluntary_sector_organisations_to_deliver_services.pdf)> accessed 10 May 2017.

<sup>92</sup> National Disability Authority, *Advice Paper* (2010).

<sup>93</sup> Keogh and Quinn, *op. cit.*, 13.

<sup>94</sup> *Ibid.*

However, a direct payment system of individualised funding – whereby a cash payment is made directly to an eligible person to enable them to purchase their care and support needs – recently became an option for people with disabilities through *Áiseanna Tacaíochta* (ÁT), a peer-led network established in 2010 in response to the inadequacies of traditional models of service provision. Supporting both self-directed and family-led service provision, ÁT acts as an intermediary on the basis of Service Level Agreements between the HSE and its 30 or so members. Members are known as Leaders who wish to manage their own lives, have control over their budgets and direct influence over their services including their care package and the recruitment and hiring of Personal Assistants, such that it is they who decide when and how to use this service.<sup>95</sup>

Echoing the international literature, analyses by Fleming<sup>96</sup> and Keogh and Quinn<sup>97</sup> of how individualised funding initiatives can work in Ireland, found high levels of satisfaction amongst users as a result of greater flexibility, choice, independence, continuity of support and person-centered care packages. Those in receipt of direct funding described themselves as more successful, confident, adaptive, skilled, empowered, independent and in control and with a greater sense of purpose.<sup>98</sup> Critically, people felt they were able to exercise control and thus influence their personal assistance and achieve greater levels of social integration, personal life goals and economic independence and participation. However, it must be emphasised that the system of direct payments is not suited to all people with disabilities and high dependency needs and if people are adequately assessed it can be decided which method of budget/service is suitable. If a person with a disability is cognitively capable of managing a budget and/or if they have a family member acting on their behalf, then direct payment should apply. However, people with more severe cognitive and complex needs may not be able to take

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<sup>95</sup> Keogh and Quinn, *op. cit.*, 15 and 30.

<sup>96</sup> Padraic Fleming, Sinead McGilloway and Sarah Barry, "The Successes and Challenges of Implementing Individualised Funding and Supports for Disabled People: an Irish Perspective" (2016) 31(10) *Disability & Society* 1369-1384.

<sup>97</sup> Keogh and Quinn, *op. cit.*, 5.

<sup>98</sup> *Ibid.*

advantage of the direct payment model and rely on agency support. According to Beadle-Brown this has been the experience in many local authorities across the UK.<sup>99</sup> Meanwhile the advantage of self-directed support is that the person can buy support services i.e. Personal Assistance hours, either directly or indirectly, from existing services or can enable new supports to be developed. Where a person has self-directed payments, they are in a much stronger position to direct their own support as they see fit. As Beadle-Brown asserts: "unlike direct payments, it enables people to choose from a wider range of options on how to spend and control their payments or budgets. They can receive them directly, to organise their own support; they can have them paid to a third party or to an agent, to provide services; they can have the payments made to a trust, which can then support the person to decide the type of support they prefer; they can have them paid to an organisation providing residential care, as an individual support fund; or they can allow their care manager to remain in control of some or all of their money and arrange services for them".<sup>100</sup>

## **6.6 Key Issues in Irish Disability Law, Policy and Supports for People with High Dependency Needs to Live Independently**

The Irish government has been slow to develop a modernised, person-centred approach in the disability arena, despite having commissioned and published a plethora of reports on the topic in recent times. Reviewed in earlier sections of this chapter, several reports emerged in the 1990s that pointed towards a shift in policy even though this turned out not be as significant as had been hoped. The 1996 Strategy for Equality, from the Commission on the Status of People with Disabilities proposed legislative change and recommended a redesigning of all disability services to enable provision 'in the mainstream'. In the same year, the Department of Health published "Towards an Independent Future: Report of the Review Group on Health and Social Services for People with Physical and Sensory Disabilities". This was widely

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<sup>99</sup> Julie Beadle-Brown, "Person-Centred Approaches and Quality of Life" (2006) 11(3) Tizard Learning Disability Review 4-12.

<sup>100</sup> *Ibid.*

criticised as it identified an average need of 10 hours of service per person per week, and that this level of service could only respond to the essential personal care needs without accounting for the quality of life requirements.

Meanwhile, the ‘legislative centerpiece’ of the National Disability Strategy, the Disability Act 2005 has been criticised on a number of grounds, namely for not being robust enough in protecting and promoting the rights of people with disabilities and failing to implement its key provisions.<sup>101</sup> De Wispelaere and Walsh argue that key aspects of the Act have a limited rights-based grounding and there are no agreed foundational benchmarks that specify what rights must be protected, or at what level.<sup>102</sup> Notable also is the absence of a substantive role for the legal system in providing remedies where any of the provisions are not carried out.<sup>103</sup> These are some of the concerns of people with disabilities and their representative organisations and were also shared by the Irish Human Rights Commission and the UN Committee on Economic, Social and Cultural Rights (Shadow Report to the Third Period Report of Ireland under the International Covenant on Civil and Political Rights, FLAC, ICCL, IPRT, 2008)). As well as falling short of the comprehensive rights-based legislation that had been campaigned for, rights provided for by the Act have not been realised such as the right to an Assessment of Need for health and education and an entitlement to services occasioned by people’s disability, despite being a key provision of the Act.<sup>104</sup> Critically the Disability Act 2005 lacks a provision for the monitoring or review of standards relating to how the statutory assessment of need should be undertaken. There is no systematic national monitoring of compliance with the standards developed by the Health Information and Quality Authority (HIQUA).<sup>105</sup> Lack of implementation has resulted in both a two-tier assessment of need system

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<sup>101</sup> Ireland Inclusion, "Intellectual Disability: Causes and Prevention—Your Questions Answered" (2013) 1  
<<https://www.inclusionireland.ie/sites/default/files/attach/basicpage/512/causesandpreventionbooklet.df>> accessed 22 May 2017.

<sup>102</sup> Jurgen De Wispelaere and Judy Walsh, "Disability Rights in Ireland: Chronicle of a Missed Opportunity" (2007) 22(4) Irish Political Studies 517-543.

<sup>103</sup> *Ibid.*

<sup>104</sup> Ireland Inclusion, *op. cit.*, 10.

<sup>105</sup> *Ibid.*



discriminating against those who do not qualify on age grounds and a lack of consistency in how assessments are carried out. This has left people without support and assistance in making applications and appeals in respect of the assessment of need under the Disability Act.<sup>106</sup>

There are also concerns about the consequences for independent living of the Government's failure to fully implement the Citizens Information Act 2007 particularly the section providing for the establishment of a Personal Advocacy Service (PAS). NAS advocates have not been afforded the statutory powers envisaged by the Personal Advocates in the Citizens Information Act, and there is no statutory duty on public bodies or disability service providers to co-operate with NAS advocates.<sup>107</sup> Overall NAS has encountered resistance, lack of co-operation and exclusion from public bodies including the HSE, Legal Aid Board and the Courts Service.<sup>108</sup> This has led to the absence of a broad spectrum of advice and supports limiting people with disabilities' rights and ability to make choices, direct influence over the design and delivery of the services and supports they need to live independently to take control over their lives. The CRPD places an obligation on the government to protect and promote these rights. In addition to a commitment to introduce the Personal Advocacy Service, the implementation plan for the National Disability Strategy should include an explicit commitment to the provision of broader advocacy provision and a process to engage with key stakeholders to explore how such provision might be resourced.<sup>109</sup>

Ireland's emphasis on human rights in social care provision indicates a progressive approach to developing policies for people with disabilities.<sup>110</sup> However, these policies are generic in nature. Notable is the absence of provisions specifically for people who experience severe physical disabilities

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<sup>106</sup> *Ibid.*

<sup>107</sup> Inclusion Ireland, *op. cit.*, 10; National Disability Authority, *Annual Report 2012* (2012) 16.

<sup>108</sup> Inclusion Ireland, *op. cit.*, 11.

<sup>109</sup> *Ibid.*

<sup>110</sup> Inclusion Ireland, *Annual Report 2011* (2011); Inclusion Ireland, *Annual Report 2012* (2012).

and have high dependency needs. Carey points out that it is not clear from the literature whether the need for a strategy specifically for people with severe physical disabilities has been advocated for.<sup>111</sup> Furthermore, the right to or legislation regarding Personal Assistance (PA) currently does not exist in Ireland and there is also no national resource allocation system in place to provide for a system of direct payments that would enable persons with a disability to purchase their own PA services.<sup>112</sup>

The availability of supports for independent living, including Personal Assistant (PA), home support and home help is acknowledged as key to enabling people with higher levels of dependency to live in community setting.<sup>113</sup> The European Commission has described many of the disability services and the institutions that organise, fund and deliver them in Ireland as falling a long way short of satisfying the aims and objectives of Article 19 set out in the CRPD.<sup>114</sup> Whilst resource limitations caused by Ireland's deteriorating fiscal position, culminating in the 2010-EU-IMF Economic Adjustment Programme partly accounts for this, there were nevertheless substantial increases in the public resources allocated to disability services prior to this.<sup>115</sup> Between 2005 and 2009, HSE expenditure on disability services rose by more than a third before falling by approximately 5% in the two years prior to 2011.<sup>116</sup> Some of the rise relates to increased pay rates as well as increased numbers of staff, which fell again by 5% up to 2011.<sup>117</sup> Generally speaking, there are concerns with regards to the number of agencies providing disability services, the likelihood of inadequacies in the system, the potential for inequalities in resource allocation and service provision as well as the level of administrative costs, management structures, advertising and infrastructure.<sup>118</sup> More specifically, according to a study conducted by

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<sup>111</sup> Carey et al, *op. cit.*, 115.

<sup>112</sup> *Ibid.*, 119.

<sup>113</sup> Kevin M. Scott et al, "Mental-Physical Co-Morbidity and its Relationship with Disability: Results from the World Mental Health Surveys" (2009) 39(1) *Psychological Medicine* 33-43, 37.

<sup>114</sup> Cullinan et al, *op. cit.*, 14.

<sup>115</sup> *Ibid.*, 2.

<sup>116</sup> Department of Health, *Annual Report 2012* (2012).

<sup>117</sup> *Ibid.*

<sup>118</sup> Keogh and Quinn, *op. cit.*, 10.

Browne on the accommodation needs of people with disabilities,<sup>119</sup> whilst there are some comprehensive support packages for independent living in place, supports for independent living are under-resourced and there is uncertainty about entitlements and options arising from different models of delivery of supports for independent living around the country.<sup>120</sup>

The under-resourcing of supports for independent living is highlighted by the Citizens Advice Board (CAB) and Disability Federation Ireland (DFI), who add that there is a lack of clarity about entitlements and options arising from different models of delivery in different parts of the state.<sup>121</sup> In its 2009 report on Ireland, the Centre for Disability Law and Policy for the Academic Network of European Disability Experts (ANED) highlighted specific inadequacies in the implementation of policies intended to support independent living for people with disabilities.<sup>122</sup> The report noted the barriers encountered by people who want to live in their own homes but cannot afford to buy a property. ANED too described personal assistance and home help services as underfunded, subject to waiting lists, and unevenly provided across the country and states that ‘this underfunding and uneven access may indicate that Ireland is falling short of the standards required by Article 19(b) of the UN Convention of the Rights of Persons with Disabilities’.<sup>123</sup> Furthermore, formal mechanisms for measuring the quality of community-based assistance and services, or their impact on the quality of life, currently do not exist.<sup>124</sup> There are also concerns regarding the appropriateness of traditional model of service provision, particularly the relatively standard nature of packages of services provided to specific groups on the basis of type of disability rather than need, the limited extent to which these are bespoke or flexible enough to be tailored to the needs of the

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<sup>119</sup> A Citizens Information Board/ Disability Federation of Ireland, Michael Browne, “Executive Summary: The Right Living Space Housing and Accommodation. Needs of People with Disabilities” (2007) <<https://www.disability-federation.ie/download/legacy/Summary%20Report.pdf>> accessed 10 April 2016.

<sup>120</sup> *Ibid.*, 6.

<sup>121</sup> *Ibid.*

<sup>122</sup> National Disability Authority, *Annual Report 2011* (2011).

<sup>123</sup> *Ibid.*

<sup>124</sup> *Ibid.*

individual, or the extent to which service users can actually exercise control over the package of services they receive.<sup>125</sup>

In response to policy recommendations made by the ‘Value for Money and Policy Review of Disability Services in Ireland’<sup>126</sup> for the provision of ‘supports’, Irish-based NGO *Genio* provided innovation funding for service providers to pilot individualised funding initiatives in four locations throughout Ireland. The idea was to use person-centred plans, individualised supports and personal budgets to bring Ireland in line with the global changes within the disability sector.<sup>127</sup> Initiatives included the Direct Payment model, a Direct Payment using a Broker model, the Independent Support Broker model and the Self-Management model. The individualised funding initiatives were reported to have had many positive impacts on the lives of individuals with disability in terms of increased control and choice over what they do with their lives and how they are supported. However, there were a number of challenging aspects of implementation for all four initiatives, not least access to funding as there was no national resource allocation system in place. As each individual case was different, the process of getting funds released from the block grants of service providers or directly from the HSE proved to be overly complex and time-consuming with two initiatives never succeeding in getting funds reconfigured by the HSE so that they could be used to provide the actual individual budgets for the duration of the pilot. Without a national resource allocation system, the route to accessing individualised funding was unclear with many people with disabilities being unaware that the pilot option existed. Furthermore, there was no application process or apparent eligibility criteria for people to follow. This lack of transparency gave rise to inequalities in the system.<sup>128</sup> Meanwhile without the

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<sup>125</sup> Keogh and Quinn, *op. cit.*, 12.

<sup>126</sup> Department of Health, *Value for Money and Policy Review of Disability Services in Ireland: Final Report* (2012)

[https://health.gov.ie/wpcontent/uploads/2014/03/VFM\\_Disability\\_Services\\_Programme\\_2\\_012.pdf](https://health.gov.ie/wpcontent/uploads/2014/03/VFM_Disability_Services_Programme_2_012.pdf) accessed 10 May 2016.

<sup>127</sup> Padraic Fleming, Sinead McGilloway and Sarah Barry, "The Successes and Challenges of Implementing Individualised Funding and Supports for Disabled People: an Irish Perspective" (2016) 31(10) *Disability & Society* 1369-1384.

<sup>128</sup> *Ibid.*

appropriate support mechanisms in place, there was the potential for individuals to become overwhelmed with their new life circumstances.<sup>129</sup>

It is important to point out however that there are some section 39 organisations, particularly those providing supports and services to people with physical disabilities, that aim to protect and promote choice, control and independence and operate an individualised client-focused model of service, delivering personalised rather than standardised packages of care and supports. These agencies provide examples of good practice which can be used to inform decision-making in the wider disability sector.<sup>130</sup>

## **6.7 Synthesis of Findings**

Overall there is a dearth of disability studies relating to the Irish context. In particular, the evidence base for independent living identified by the search strategy for this chapter is lacking. Furthermore, the quantity, quality and type of studies the chapter drew on to understand and critique the provision of Personal Assistance supports, assessment of need and access to advocacy from the perspective of high dependency is limited. Therefore, the conclusions that can be drawn from the evidence are tentative. Bearing this in mind, the present chapter has highlighted the persisting lack of legal, policy and institutional developments hampering Ireland's capacity to protect and enhance people with high dependency needs to live independently and free from poverty and disadvantage and ensure them a standard of living commensurate with the general population.

Ireland is on the cusp of reforming how disability services for independent living are designed, managed and funded. Set out in national policy frameworks discussed in this chapter, the move in Ireland towards a new model of disability service provision is gathering momentum. The Task Force on Personalised Budgets set up in 2016 by the Government has recently announced its recommendations on a personalised budgets model intended to

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<sup>129</sup> *Ibid.*

<sup>130</sup> Keogh and Quinn, *op. cit.*, 12.

give people with disabilities more control in accessing health-funded personal social service.<sup>131</sup> Historically, most disability services were standardised and often provided in segregated group settings. Today the aim of disability policy is to ‘mainstream’ services where possible, delivering supports that enable people with disabilities to live and work in the community, as do those without impairments. In its ‘Value for Money and Policy Review of Disability Services in Ireland’, the Department of Health acknowledges that, while there has been some movement towards a more person-centered approach, ‘the pace of change has been slow and uneven’.<sup>132</sup> Amongst others, Browne emphasises that community care should be underpinned by clear legislative entitlement and dedicated funding provided to ensure that this legislation entitlement is delivered.<sup>133</sup> This would require the State to provide the services to *all* those who need them on the grounds of dependency or social circumstances. Some areas of legislation have not yet been made commensurate with the CRPD, most notably Personal Assistance and there is a notable absence of provisions specifically for people who experience severe physical disabilities and have high dependency needs. Findings from this chapter would indicate that Ireland has made some commitments to the advancement of personalised service provision to enable persons with disabilities to pursue an independent life. However, many disability services and the institutions that organise, fund and deliver them in Ireland fall a long way short of satisfying such objectives as those set out in international and national disability law promoting independent living.<sup>134</sup>

The implementation of person-centered approaches based on assessment of need and access to advocacy ensuring individualised funding and user control

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<sup>131</sup> *Ibid.*, 5.

<sup>132</sup> Department of Health, *Value for Money and Policy Review of Disability Services in Ireland: Final Report* (2012)  
<[https://health.gov.ie/wpcontent/uploads/2014/03/VFM\\_Disability\\_Services\\_Programme\\_2012.pdf](https://health.gov.ie/wpcontent/uploads/2014/03/VFM_Disability_Services_Programme_2012.pdf)> accessed 10 May 2016.

<sup>133</sup> A Citizens Information Board/ Disability Federation of Ireland, Michael Browne, “Executive Summary: The Right Living Space Housing and Accommodation. Needs of People with Disabilities” (2007)  
<<https://www.disability-federation.ie/download/legacy/Summary%20Report.pdf>> accessed 10 April 2016.

<sup>134</sup> John Cullinan and Seán Lyons, *The Economics of Disability* (Manchester University Press 2015) 1.

over such supports as Personal Assistance has not become a reality, except for the limited numbers using the Direct Payments model facilitated by ÁT.<sup>135</sup> Another key finding therefore is that the policy aspiration of providing personalised packages of community care supports based on a case management approach is far from being put into practice on the ground. There is a lack of implementation of the legislation underpinning the National Disability Strategy, namely the Disability Act 2005, which proclaimed the right of people with a disability to an assessment of need. However, while individual need assessment for children under 5 years has commenced, similar provision for adults has been deferred indefinitely making an informed link between on-going needs and resources difficult.<sup>136</sup> Complicating matters has been the absence of an implementation framework linked to the development of a comprehensive information system on the needs of people with high dependency. For packages of supports to be any way personalised and designed to ensure people with high dependency the right to independent living, they must be grounded in needs-based support plans. The systematic adoption of a person-centered planning approach to identifying and meeting the on-going needs of people with high dependency is thus essential. Ultimately what this requires is a reform of the policy and legislative framework comprehensive enough to ensure people with high dependency needs greater choice and control over their funding and use of Personal Assistance services.

Currently the Disability Act 2005 is not delivering on The Assessment of Need and delays in carrying out these assessments are very significant. Part 2 of the Disability Act 2005 established a system for the assessment of individual health service needs and, where appropriate, education needs for persons with disabilities over age 18 years.

Part 2 provides a statutory entitlement as follows:

- “an independent assessment of health and education needs

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<sup>135</sup> Keogh and Quinn, *op. cit.*, 5.

<sup>136</sup> Cullinan, *op. cit.*, 117.

- a statement of the services (Service Statement) which it is proposed to provide
- pursue a complaint through an independent redress mechanism if there is a failure to provide these entitlements.”<sup>137</sup>

The Disability Act 2005 provides that an assessment must be commenced within three months of an application being received and completed within a further three months from date of commencement. If not completed within that time, the reasons why must be set out, as must a time frame for completion. This failure to deliver on the Assessment of Need is widely recognised by the disabled community and representative bodies. Inclusion Ireland has said “As well as falling short of the comprehensive rights-based legislation that had been campaigned for, rights provided for by the Act have not been realised such as the right to an Assessment of Need for health and education and an entitlement to services occasioned by people’s disability, despite being a key provision of the Act.”<sup>138</sup> In addition, there is no provision for the monitoring or review of standards relating to how the statutory assessment of need should be undertaken. Where there is no monitoring it is inevitable that people will fall through the cracks in the system.

This results in a lack or total absence of coordinated services such that: ‘everyone is fighting their own little patch to look for additional money or to use up money that has to be spent. Why does a person with a disability need so many people involved in his/her life? At policy level, it is really wrong that our government works in such an adhoc way from department to department’.<sup>139</sup> In addition the wholly inadequate access to information exacerbates the powerlessness and inability to access the critical point of Assessment of Need and subsequent services to the extent that “sometimes

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<sup>137</sup> Department of Justice, Equality and Law Reform, Guide to the Disability Act 2005 (2005)

<<http://www.justice.ie/en/JELR/DisabilityAct05Guide.pdf/Files/DisabilityAct05Guide.pdf>> accessed 2 May 2017.

<sup>138</sup> Inclusion Ireland, *Annual Report 2013* (2013) 10.

<sup>139</sup> National Disability Authority, John A. Weafer, *Independent and Community Living: Focus Group Consultation Report* (2010) Section 5.2.



people are unaware of activities, possibly due to information being presented in ways that are not accessible to some people with disabilities.<sup>140</sup>

Ireland is at a critical juncture in the development of disability services, given its long-overdue and recent ratification of the CRPD and that legislative and policy reform in its infancy and only at the stage of being explored. That such frameworks and enabling measures for independent living are in place in other jurisdiction deems it appropriate that the ongoing formulation of Irish disability law and policy be informed by international best practice and supporting research. This could be the focus of further research, bringing together and critically reviewing available evidence on the role and potential of individualised supports including Personal Assistance based on assessment of need and access to advocacy intended to enhance the autonomy and independence of people with high dependency needs.

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<sup>140</sup> *Ibid.*, Section 7.6

## Chapter Seven

### Discussion, Conclusion and Recommendations

#### 7.1 Introduction & Contribution to Knowledge

##### *Introduction*

In this thesis I have focused the study on examining the legislative context for independent living for people with high dependency needs. The CRPD provides the key platform for this as it has the key role in articulating the vision of disabled people and laying out the guiding principles for nations to reform their independent living provisions. It is also the first international human rights treaty that the EU has concluded. Ireland ratified the CRPD in March 2018 in its own right as a state – the EU recognised and ratified the CRPD principles in December 2010 and Ireland, as a member, would have been included to the extent of the EU competence. Ireland's ratification gives protection of a UN human rights treaty to all its citizens. Unfortunately, Ireland failed to ratify the Optional Protocol (OP), which leaves people with high dependency needs, like myself, unable to use it. Ratifying is a great achievement, but action is necessary at national legislative level. It also sets out shortcomings of the OP, which leaves people with disabilities and high dependency needs in Ireland unable to use this significant tool to assert their rights unlike many other European states<sup>1</sup>. As a result, the failure to ratify the OP means there is no way to enforce the CRPD tenets for people with disabilities and high dependency needs. I acknowledge that I, as a person with a disability and high dependency needs myself, occupy a marginal position in society and endure struggles on a daily basis to cope with the barriers presented by society.

My personal experiences, seen through a concrete lens and rooted in auto-ethnographic approach, allows me to portray inside information that cannot

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<sup>1</sup> Shivaun Quinlivan, "The United Nations Convention on the Rights of Persons with Disabilities: An Introduction" (2012) 13(1) ERA Forum 71-85, 83.

be found elsewhere. In chapters 1 and 2, I candidly share aspects of my experiences throughout my life and the challenges I face from early childhood to the present day. The playing field, as it stands, counteracts my determined efforts to cope with and overcome the shots and just when I feel I am making headway, I am kicked back a few hundred meters. For instance, as recently as last week I was left in bed, facing the wall, without any means of communication, medication or sustenance for over 8 hours due to a blip in the support services. The overwhelming hardships and difficulties for a student with a disability and high dependency needs endeavoring to undertake and complete a PhD thesis, or any third level course are monumental. These challenges are outlined in detail in Chapter 2, section 2.6. Article 4 of the CRPD, analysed in Chapter 4, section 4.4, makes particular reference to the economic, social and cultural rights of a person with a disability, and outlines how the State must provide for them within the framework of international cooperation. Furthermore, the financial difficulties faced by a person with a disability and high dependency needs are subject to circumstances outside their control depending on where they live. The disability allowance is currently the same for all people with disabilities regardless of the severity of their disability and high dependency needs. A disabled person with low dependency needs may be capable of taking public transport without assistance, enabling them to attend college, go shopping, etc. At the high end of the spectrum, a disabled person with high dependency needs requires support both physically and financially to enable getting out of bed, getting dressed and personal care. Added to that they must have their own adapted transport or use a special disabled bus or taxi to get anywhere because public transport is largely inaccessible.

In addition, I outline the relevance of graded or tailored payments versus the current system of flat payments that is currently in use. In particular, in Chapter 3, section 3.3, I outline the importance of user-directed personal assistance services to ensure that persons with disabilities and high dependency needs are facilitated and supported to live independently and given equal opportunities with regard to participating in mainstream society

and employment. In summary, the thesis discusses these themes and builds upon the following central aim guiding the study:

**Independent Living for People with Disabilities and High Dependency Needs:**

**Why we need a PA Act and what might it look like in the Irish Context.**

Following that, the subsequent objectives are designed and aimed to be answered in the study:

**Objective 1: Legal Measures**

- a. To discuss what legal measures and actions are required for Ireland to adhere to the core principles underpinning the CRPD ensuring people with disability's dignity, individual autonomy, the freedom to make one's own choices, and effective participation and inclusion in society.
- b. To explore how these legal measures, provide for the diverse needs of people with disabilities and high dependency needs.
- c. To explore what type of framework is needed for people with high dependency needs to experience and practice independent living in their community.

**Objective 2: Supports and Services**

- a. To explore what services and supports are required for Ireland to adhere to the core principles underpinning the CRPD (Chapter 6).
- b. To explore how a person-centered home and community-based care model would ensure people with disabilities and high dependency needs dignity, individual autonomy, the freedom to make one's own choices, and effective participation and inclusion in society.
- c. To discuss what a self-directed system of Personal Assistance Service (PAS) for independent living would look like

- d. To explore what type of system is needed for people with high dependency needs to make independent choices and direct the types of Personal Assistance Services they require.

To address the aims and objectives, during the research in the presented thesis, I looked at the following three disability areas:

- 1. Legal Measures** - to assert a right to independent living following the CRPD, endeavoring to go a step further by taking the principles of the Convention and make them legally binding in our country in the form of a P.A. Act. Currently, independent living in Ireland is in its early stages. Although supports have moved towards a more personalised model of service e.g. direct payments, only few persons with disabilities and high dependency needs are receiving it. Nevertheless, a direct payment system of individual funding introduced in Ireland has proved very satisfactory by those eligible. Users of this system reported positively due to greater flexibility, choice and independence. Thus, I argue in Chapter 6 that supports and services modelled to each individual with disability and high dependency needs should be available.
- 2. Funding Mechanisms and Resources** – the current Disability Act 2005 in Ireland lacks clarity. Throughout the thesis I discuss how funding is provided; who provides funding; which department is responsible for funding; and how to gain access to funding (Chapter 6).
- 3. Graded Disability Payments** – I argue that at present the flat payment does not cater for the person with high dependency needs. Support needs are complex, and the spectrum is wide and payments should mirror this.

Drawing from Chapters 1 – 6, I discuss how each of the research objectives of the study are addressed and conclude with recommendations for the practice, policy and future research in this chapter. In order to address Objective 1, I focused on Article 4.3 (Chapter 2) and Article 19 (Chapters 3 and 4) of the CRPD and the impact of ratification of the CRPD on the lives

of people with disabilities and high dependency needs and identified gaps in service provision caused by structural inequalities. Following that, to address Objective 2, I argue how these articles of the CRPD cannot be fulfilled in practice in social and legal services in Ireland due to the structural inequalities and how these inequalities impact on my life experiences as a person with a disability and high dependency needs (See chapters 2, 4 and 6). Finally, following the analysis and discussion of the thesis and its objectives, I articulate specific recommendations for future research, policy and practice and the conclusion of the thesis.

### *Contribution to Knowledge*

There are number of key theorists in my area of the research such as Luke Clements, Camila Parker, Gerard Quinn and Adolph Ratzska. They discuss some of the issues raised in my PhD such as Independent Living and Irish policy on independent Living. However, my thesis is original in a way that it provides an integrated and comprehensive analysis of the myriad aspects of independent living such as independent living provisions in Irish context for people with disability and high dependency needs. Aspects, that are often not considered in the literature in combination.

## **7.2 Objective 1: Legal Measures**

The following part of the chapter discusses Objective 1 with reference to Article 19 and Article 4.3 in detail.

### **What legal measures and actions are required for Ireland to adhere to the core principles underpinning the CRPD?**

Much evidence suggests that the Irish government has been slow to develop a modernised, person-centred right-based approach in the disability arena, despite having commissioned and published a plethora of reports on the topic in recent times. Reviewed in Chapter 6, several reports emerged that pointed towards a shift in policy even though this proved not to be as significant as

had been hoped. For instance, the 1996 Strategy for Equality, from the Commission on the Status of People with Disabilities<sup>2</sup> proposed legislative change and recommended a redesigning of all disability services to enable provision in ‘mainstream’. In the same year, the Department of Health published<sup>3</sup> a widely criticised report that identified an average need of 10 hours of service per person per week. This level of service could respond to essential personal care needs only, but quality of life requirements were not accounted for. As I discuss in Chapter 6, many people suffered more acutely because of the recession but, in particular, people with disabilities and high dependency needs. Harsh cuts were imposed on all the minimal services that were in place at that time. Moreover, these cuts have remained. Austerity cuts on disability services in Ireland mirror that experienced in the U.K. Sue Marsh, a disability campaigner and author of the *Diary of a Benefit Scrounger Blog* as well as a regular *Guardian* columnist has articulated the profound effects these cuts have had: "In a society so de-sensitized by cuts, we might look at this proposal through financial eyes. We might judge on a balance sheet that we can no longer afford this "luxury". We might be fooled into believing that the dignity of "the most vulnerable" is expendable. We might decide that when times get tough, we will turn our backs on progress and decency and look only at cost."<sup>4</sup> Marsh’s quote enlightens us to the fact that the value of human life cannot be found on the balance sheet and that cutbacks or recessions cannot deny people with disabilities the right to dignified standards of living.

A rights-based legislative principle is imperative to transform the way in which service providers support people with disabilities. Partnerships of trust and empathy must exist between service providers and people with disabilities (service users) at local community levels and communication lines must be open between the respective parties. A rights-based approach, I argue,

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<sup>2</sup> Department of Equality and Law Reform, *A Strategy for Equality: Report of the Commission on the Status of People with Disabilities* (1996).

<sup>3</sup> Inclusion Ireland, *Towards an Independent Future: Report of the Review Group on Health and Social Services for People with Physical and Sensory Disabilities* (1996).

<sup>4</sup> Sue Marsh, “Disabled People Have a Right to Live Independently, Worcester Council” *The Guardian* (London, 13 July 2012).

is the only way forward to enable the voices of ‘distant experts’ (e.g. social care professionals) to be replaced by people living the reality and experience of disability. In particular, as I discuss in Chapter 2 in detail, the voice of experience allows people with high dependency needs to express the challenges of daily realities rather than opinions on how the life of these people should be according to the distant voices of medical and other experts<sup>5</sup>.

My understanding of independent living has been focused on the areas of choice, control and funding together with the necessary resources to underpin independent living on a rights-based system. In particular, as I discuss in chapter 2 (section 2.4), chapter 3 (section 3.3) and chapter 4, Article 4.3 of the CRPD acknowledges the need to be listened to and the right to active participation and expression: “... in the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, including children with disabilities, through their representative organizations”<sup>6</sup>. If the rights-based approach would be implemented within the legal framework, the change in payment model would provide more choice and options in active participation for people with high dependency needs. Thus, I argue that Ireland needs to move forward from the infancy stage of exploration of disability service reform, put in place frameworks and enabling measures for independent living for its people with disabilities and high dependency needs as other countries have. The legal requirements of the public bodies to provide a service statement for each person are pointless unless people with disabilities are aware of the process and necessary steps of how to access information and locate the relevant person or place where information can be provided.

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<sup>5</sup> Rose Richards, “Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing About Illness and Disability” (2008) 18(12) *Qualitative Health Research* 1717–1728.

<sup>6</sup> United Nations Convention on the Rights of People with Disabilities 2006, Article 4.3.



The steps in this process ought to be clear, transparent and accessible. In my personal experience, it is common for the ‘experts’ to overshadow the voice of the service user and blankly assume that they are more experienced and knowledgeable in every facet of disability instead of listening intently and patiently to the testimony of the person who is best suited to discern and identify their needs. This is summarised in the principle “Nothing about Us Without Us”<sup>7</sup> that emphasises that the people with disabilities must be valued as integral and essential contributors to every sector, industry and community<sup>8</sup>. Thus, this slogan is underpinned with CRPD Article 4.3 as it argues for the principle of active participation of people with disabilities in all parts of their life in the society. As a result, I recommend the future approach to people with disabilities will be reflected upon and improved towards a more person-centred focus.

### **How might the legal measures provide for the diverse needs of people with disabilities and high dependency needs?**

Article 19 of the CRPD states that: “Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.”<sup>9</sup> The kernel of the concept and practice of the right to independent living guaranteed by CRPD has been articulated by the famous disabled activist Adolf Ratzka, director of the Swedish Institute for Independent Living: “[...] a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect would be facilitated. Independent living does not mean that we want to do everything by ourselves... [it] demands the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school,

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<sup>7</sup> Eli A. Wolff and Mary Hums, ““Nothing About Us Without Us” Mantra for a Movement” Huffpost (2017)  
<[https://www.huffingtonpost.com/entry/nothing-about-us-without-us-mantra-for-a-movement\\_us\\_59aea450e4b0c50640cd61cf](https://www.huffingtonpost.com/entry/nothing-about-us-without-us-mantra-for-a-movement_us_59aea450e4b0c50640cd61cf)> accessed 20 November 2017.

<sup>8</sup> Ibid.

<sup>9</sup> United Nations Convention on the Rights of People with Disabilities 2006.

use the same bus as our neighbours, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves”.<sup>10</sup> In other words, Ratzka argues on what I describe and discuss as my own experience with school systems in Chapter 1, with going through the dark days in Chapter 2 and what I call the poverty of discrimination in Chapter 3. For instance, I discuss the examples of my struggles for autonomy while being educated in the traditional system that didn’t take my individuality and personal needs into account. In my everyday life, although I need assistance with almost everything, I want freedom to choose. I argue that independent living should not be taken in its literal sense as ‘living alone’ but living with support in the community – hence, ‘community living’ is my preferred term. Thus, in terms of ‘community living’ – commonly referred to as ‘independent living’, I want to make my own decisions and control how and with whom I live as specified in Article 19 of CRPD.

Following the CRPD, the European Network of Independent Living (ENIL), set out with the expressed aim to “support the CoE reach the overall goal of the CRPD Strategy, sought to have independent living included as a priority area”<sup>11</sup>. In particular, ENIL recommends seven key actions to encourage the development and implementation of Independent Living and the closure of residential institutions for people with disabilities. I discuss these seven key actions in detail in Chapter 5. The first key action is to close long-term residential institutions and redirect funding instead, to promote and develop community-based services for people with disabilities. As a person with a disability and high dependency needs, the promotion of independent living is paramount to my life. People with disabilities and high dependency needs require tailor-made packages to support independent/community living within local communities. In other words: “Other key actions to ensure

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<sup>10</sup> Adolf Ratzka, “What is Independent Living: A Personal Definition” (Independent Living Institute 2003)

< <https://www.independentliving.org/def.html> > accessed 18 November 2018.

<sup>11</sup>European Network on Independent Living, “ENIL’s Contribution to the Consultation on the Draft Council of Europe Disability Strategy 2017 – 2023” (2016)

<[http://enil.eu/wp-content/uploads/2016/05/ENILSubmissionCoE\\_230516.pdf](http://enil.eu/wp-content/uploads/2016/05/ENILSubmissionCoE_230516.pdf)> accessed 15 November 2018.

independent living include the promotion of personal assistance and peer support, as key tools to ensure that disabled people are able to live independently in the community”.<sup>12</sup> I argue that a key tool to ensure the positive outcomes of independent living is access to personal assistance and personalised budget funding in keeping with Article 19 of CRPD. For myself, it would allow me the freedom to make choices according to my needs and desires.

In addition, ENIL recommend supporting and monitoring disabled people to live in the community. They “called for a stronger focus on the involvement of disabled people throughout the strategy and for the inclusion of definitions of the key terms, such as independent living, institution, deinstitutionalisation, community-based services, in order to ensure that they are understood correctly by the CoE bodies, Member States and other organisations and institutions targeted by the strategy<sup>13</sup>.” In other words, one’s place on the spectrum of life should match the level of supports specific to the needs of the person with a disability and high dependency needs. For instance, the isolation and hardships I encountered as a person with disability and high dependency needs over the last 15 years of having varying degrees of services, depending on funding, were extremely difficult. This situation is continuing to the present day. As a result, I struggle to cope with independent living/community living and, at times, feel overwhelmed and ready to give up. These barriers must be eliminated to enable facilitation to everyone in spite of their challenges to participate fully and inclusively in their community and in any field of their choosing, be it education, work, health etc. In addition, this type of ad hoc existence needs be eradicated sooner rather than later. Lack of funding, which, in turn, leads to lack of support is a huge barrier in the area of disability services. As a result, I and many others constantly face the reality of missing out on opportunities that could/would enhance my life. For instance, the number of times I have had to miss

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<sup>12</sup> Ibid.

<sup>13</sup> Ibid.

conferences, talks etc. because of lack of personal assistance support is enormous.

**How is Ireland, a state party to the Treaty, responding to philosophy and global standards for independent living and the interrelated elements of choice, support and availability stated in Article 19 of the CRPD?**

In many ways supported living in local communities with adequate supports – otherwise known as independent living – is the core concept of my thesis. I analyse the daily struggles of people with disabilities and high dependency needs living with inadequately funded services. In particular, I analyse the current literature and policy papers as well as using my own experience with autoethnographic approach to analysis in the thesis. As a result, I identify how this can exclude and prevent them from having the same choice, freedom and management as members of the local and national communities. In particular, I discuss the issue as follows: In Chapter 1, I outline, from my personal experiences, the pitfalls and shortcomings of the current funding system that people with disabilities and high dependency needs, like myself, have had to survive on in Ireland. My experiences of living with very diverse and high dependency needs in my own home and ‘constantly watching the clock’ to ascertain how much I can get done before I will inevitably be left alone, most likely in bed, has had catastrophic effects on my well-being both mentally, physically and socially. Extensive lack of support, choice and freedom to make decisions, have frustrated me, knowing what I could have had in my everyday life. On the other hand many people with disabilities and high dependency needs would not have endured the hardships and struggles I endured to realise independent living. Instead, they may have succumbed to returning to the security of the family home or settled for sheltered supported living, such as group homes. This is particularly pertinent to young people with disabilities who move from rural areas to towns and cities to pursue third level education and employment. Family/parental support is not available to them because of distance and without proper support and services this can be a mountain too steep to climb.

In Chapter 3, I highlight the background, scope and tenets supporting independent living and its influence on society. I discuss how people with disabilities ought to be included in their communities. In particular, based on the international legal and policy context of the thesis focussing on the CRPD, I outline and argue how Ireland could move from an oppressive institutional landscape, to more progressive inclusive and dignified social services for people with disabilities in the future. To coincide with the tenets of the CRPD I discuss in Chapter 4, I argue that Ireland needs to reform its legal policy and social service provision to a more rights-based approach.

In Chapter 5 I discuss the international perspectives and theories including policies on disabilities and how these might be implemented in the Irish legal framework. In particular, I argue that the new policy goals include the goal of self-determination of people with disabilities following the personalised approach<sup>14</sup> which underlies key policy proposals. These proposals include the provision of personal ‘supports’, rather than ‘services’ comprising of a range of assistance and interventions. The aim of these is to enable the individual to live a fully included life in the community<sup>15</sup>.

Following that, I conclude several recommendations for the practice of Irish law and social services for people with disabilities and high dependency needs. I particularly examine the need for a direct payments scheme to be available to people with disabilities, enabling total control over personal assistance and service needs. In my case a ‘Flat disability payment’ did not assist me in the transition from post-primary education to third level education and does not support me as I strive for independent living which leaves me in the position of having to rely on family support as well as disability benefit. As a result, I argue that the severity of the disability and

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<sup>14</sup> Independent Living, Sinead Keogh and Gerard Quinn, *Independent Living: An Evaluation of the Aiseanna Tacaiochta Model of Direct Payments*. Report (2018) < [http://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/IndependentLiving\\_An\\_Evaluation-of-the-A%CC81iseanna-Tacai%CC%81ochta-model-ofDirect-Payments.pdf](http://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/IndependentLiving_An_Evaluation-of-the-A%CC81iseanna-Tacai%CC%81ochta-model-ofDirect-Payments.pdf)> accessed 10 November 2018.

<sup>15</sup> National Disability Authority, *Annual Report 2012* (2012) 12.

dependency has to be taken into account and addressed accordingly. Individual needs ought to be supported and people with disabilities empowered to make the choices and decisions that are taken for granted by their non-disabled peers.

### **7.3 Objective 2: Discussion and Recommendations on Supports and Services for People with Disabilities**

As a person with a disability and high dependency needs, I have used an autoethnographical approach along with Standpoint theory to illuminate my own personal experiences to highlight the life difficulties and struggles experienced on a daily basis. Thus, the study is informed by my insights into the relationship between disability, support required by people with high dependency needs, and the realities of trying to achieve active participation in the community. Through my personal experiences of support required by people with high dependency needs, and the realities of trying to achieve active participation in the community, I have developed a profound appreciation of the nexus that currently exists between disability and poverty. For instance, I discuss the difficulties of trying to survive on the current social welfare payment. These difficulties can only be eradicated with the provision of adequate funding and support. The following section discusses Objective 2 and its sub-questions; and recommends solutions for policy and practice based on the analysis as well as on my experience. Finally, recommendations for the future research and conclusions of the thesis are also set out.

#### **Supports and services required for Ireland to adhere to the core principles underpinning the CRPD?**

To discuss Objective 2, I address and give recommendations for personalised supports and services in terms of financial management and independent living. These are divided into the following sections:

- **Assessment of needs**
- **Graded payments**

- **Personalised budgets**
- **Supported Community/Independent Living with adequate Personal Assistance provision**
- **Supported access to Higher Education with adequate/tailor-made Personal Assistance provision**
- **Support in the Workplace/Employment with adequate Personal Assistance provision**

Recommendations for practice, policy and research are concluded after each discussed section.

#### ❖ **Assessment of Needs**

The current ‘assessment of needs’ services for people with disabilities and high dependency needs in both health and education fields, falls short in many areas such as personal assistance services, independent living and support to work in the community. I argue, that the current principle of ‘assessment of needs’ under the Disability Act 2005 in Ireland discussed in Chapter 6 should be the first step to follow towards providing adequate support for a person with a disability. The assessment is particularly vital for a person with high dependency needs given the complex and variable nature of the supports necessary. At the moment, the person with high dependency needs may receive different payments for different services but may not receive the services according to their needs and requirements. For example, a person with a disability with high dependency needs may receive adequate personal assistance support but may not have access to the full range of electronic assistive technology to enable them to work independently. Thus, a full and comprehensive ‘assessment of need’ should be carried out for the person with a disability in the presence of the aforementioned person together with appropriate experts where all the services would be combined and targeted to the person’s needs.

In other words, a centralised direct payment in one lump-sum with the control allocated to the person themselves would be better targeted to their needs according to their own choice, with the added benefit of empowering the recipient. As articulated by Neil Thompson - “This involves developing a

partnership between service providers and service users in relation to service providers and service delivery and development. Where independence is either not feasible or not desirable, the alternative should not be dependency based on the traditional paternalistic worker-client relationship but rather interdependency.”<sup>16</sup> In other words, individual budgets can give greater autonomy to the person with a disability and high dependency needs to choose the services best suited to their needs, some of which are very complex and imperative to the health and well-being of the individual as well as supporting them to reach their full potential. As a result, the following services vary depending on the nature of the disability and, if applicable, should be documented on the Assessment of Needs Service Statement:

- Personal assistance services
- Physiotherapy
- Occupational therapy
- Speech therapy
- Psychology
- Dietitian (if appropriate)
- Other services as requested by the service-user during the assessment

#### **Recommendations – Assessment of Needs:**

- **Accurate and flexible service statements arising from ‘Assessment of Needs’ of a person with disability to include:**
  - **A care and support plan for the person with a disability**
  - **A guarantee that support plan/needs will be funded**
  - **A time-frame when support plan will be become effective**
  - **A time-frame if some or all of support plan not be granted will become effective**
  - **A written explanation why some or all of support plan is refused or delayed**

#### **❖ Graded Payments**

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<sup>16</sup> Neil Thomson, *Anti-Discriminatory Practice* (Palgrave Macmillan 2006) 96.



As I argue in Chapter 3, income support should meet the direct and indirect expenditure needs of the person with a disability and high dependency needs. Income support should allow for the costs incurred because of disability. For instance, as I identify in previous chapters, the tax-funded Swedish National Social Security Fund (Försäkringskassan) pays monthly amounts to eligible individuals regardless of their circumstances. This is exactly what I recommend in this thesis under the aims and objectives for our Irish social system and Irish people with disabilities following the rights-based approach underpinned by the CRPD. In addition, payments in Ireland should constitute a legal entitlement independent of the state's financial situation. The flat Disability Living Allowance payable to all people with a disability needs to be reviewed and graded according to the severity of the disability and high dependency needs. This should be reviewed periodically to ensure any changes in individual specific needs are addressed. However, if the nature of the disability is 'permanent' and unlikely to fluctuate, a review should only be carried out every 5 years<sup>17</sup>. The extra dimensions and exceptional costs incurred by a person with a disability and, in particular, with high dependency needs, often unseen by others, must be reflected in payments.

#### **Recommendations – Graded Payments:**

- **A new grading system to be introduced for every person with a disability based on an Assessment of Needs Service Statement**
- **Social Welfare Disability weekly payment be revised and implemented as per revised Assessment of Needs Service Statement**
- **Current flat payment should be replaced by a graded payment taking into account the severity and restrictive nature of the disability that impedes the disabled person in carrying out day-to-day activities as per the Assessment of Needs Service Statement**

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<sup>17</sup>Adolf Ratzka, "Independent Living for People with Disabilities of All Ages" (11th Research Conference, Iceland, May 2011).

- **Recommendations to be implemented by Irish State starting with Assessment of Needs Service Statements for each person with a disability with immediate effect**

#### ❖ **Personalised Budgets**

I highlight the shortfalls in the Irish public policy and legislation with regard to the facilitation of independent living for people with disabilities and high dependency needs. Following that, I argue that people with disabilities and high dependency needs, like myself, would benefit greatly from a policy and system of direct payments, where wages are paid directly by the service users if they so choose, giving them more control as well as responsibility, autonomy and tailored supports where necessary. In particular, I argue, in chapter 3, the importance of individual budgets for people with disabilities and high dependency needs to access the quality of life that can only be attainable by tailored funding and support. For instance, Luke Clements, Professor of Law and Social Justice at Leeds University, provides a visualisation of how individual budgets could work in practice: “Individuals who are eligible for these funds will then have a single transparent sum allocated to them in their name and held on their behalf, rather like a bank account. They can choose to take this money out either in the form of a direct payment in cash, as provision of services, or as a mixture of both cash and services, up to the value of their total budget. This will offer the individual much more flexibility to choose services which are more tailored to their specific needs<sup>18</sup>.”

Following that, I argue in Chapter 5 the role of the ECtHR on the issue of personalised budgets. In particular, the ECtHR is mandated to enforce the Convention to which all member states of the Council are party. The ECtHR has no specific reference to disability; however, it includes more recent developments on enhancing people with disabilities’ right to live

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<sup>18</sup> Luke Clements, John Bangs and Emily Holzhausen, “Individual Budgets and Carers: Updated Briefing Paper” (Choice Forum 2009)  
< <https://www.choiceforum.org/docs/ibac.pdf> > accessed 20 November 2018.

independently and in the community. In particular, the ECtHR has cited human dignity and human freedom as “the very essence of the Convention”.<sup>19</sup> As a result, the CoE recommended new policy goals which included the goal of self-determination of people with disabilities - the personalised approach,<sup>20</sup> which underlies its key policy proposals. These proposals include the provision of personal ‘supports’, rather than ‘services’ consisting of a range of assistance and interventions. The aim of these is to enable the individual to live a fully included life in the community.<sup>21</sup>

Of particular relevance to this thesis, CoE examines the need for a direct payments scheme to be available to people with disabilities, enabling total control over personal assistance and service needs.<sup>22</sup> Thus, this brings the issue of personalised budgets, discussed in Chapter 3, to consideration relevant on the structural level. Tailor-made individual budgets are not to be compared or misinterpreted with graded payments/flat weekly disability allowances as discussed in the previous recommendation. Individual budgets encompass different criteria of needs centred on the person with a disability. Adolf Ratzka, himself a service user, advocated that personal assistance users can choose from different service providers or, if they prefer, recruit, train and direct their own staff. In this way, they are able to custom-design and optimise services gaining more control over their everyday life. Typical for these solutions is that the user decides who is to work for him or her, with which tasks, where and when.<sup>23</sup>

### **Recommendations – Personalised Budgets:**

- **Tailor-made financial packages must be provided to people with disabilities and high dependency needs which supports their needs according to their Assessment of Needs Service Statement**

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<sup>19</sup> Application no. 133444/04.

<sup>20</sup> Keogh and Quinn, *op. cit.*

<sup>21</sup> National Disability Authority, *op. cit.*

<sup>22</sup> *Ibid.*

<sup>23</sup> Adolf Ratzka, “Independent Living in Sweden” (Independent Living Institute 2003) <<https://www.independentliving.org/docs6/ratzka200302b.html>> accessed 10 May 2016.

- **Service Users should have the choice of which service provider to use or have the flexibility to recruit, and train their own staff to suit their individual needs and circumstances**

**Additional Recommendations:**

- **The Mobility Allowance Scheme which was closed to new applicants in 2013 should be paid to all people with disabilities and high dependency needs over the age of 16 until the proposed replacement Transport Support Scheme is introduced into Irish legislation and becomes effective. At present monthly payments are only made payable to people with disabilities who were in in the scheme before 2013**
- **The Motorised Transport Grant, another casualty of the recession and abolished in 2013, has also not been replaced. It consisted of a grant to assist people with a disability and high dependency needs in purchasing or adapting a vehicle and was payable once every three years in the sum of €5,020. The proposed alternative ‘Transport Support Scheme’, which is alledgedly at ‘an advanced stage’, should be progressed by the Minister for Health. I propose that this ‘transport funding’ be expediated and legislated for with immediate effect.**
- **The current housing adaption grants for people with disabilities does not meet high dependency needs and grants should mirror the severity of the disability and should cover the total cost of the approved works.**

**❖ Support in Community/Independent Living**

As I continually argue, there are thousands of international policy references to the right to independent living of people with disabilities and high dependency needs. Article 19 of the CRPD argues that independent living must facilitate people with disabilities and high dependency needs with freedom of choice to live where they desire and be encompassed by a

comprehensive range of supports.<sup>24</sup> This is also highlighted in the UK Disability Rights Commission (DRC) as reviewed in Chapter 3 in section 3.2. It argues that social care provided should extend beyond the basic human functioning and include participation in social and economic activities in the community. According to these (ibid), supports and funding must be assembled and flexible to meet the changing needs that are inevitable for people with disabilities.<sup>25</sup> Following that, I continue to emphasise how the various facets of living with high dependency needs require more than minimum standards. For me, article 19 of the CRPD<sup>26</sup> is a refreshing development unlike any other legal document, which recognises the person behind the disability and their need to lead a fulfilled existence. As I discuss in detail in Chapters 1 and 6, living in the community is fraught with difficulties in the Irish context. Every facet of my life is touched with high dependency needs and so requires all aspects of the support package to meet my needs. A direct tailored support package would enable me to deal adequately with the array of extra costs incurred because of high dependency needs which leads me to propose the following key recommendations to be implemented to praxis of Irish law and services.

#### **Recommendations - Community/Independent Living:**

- **Supports and Funds must be available to people with disabilities and High Dependency Needs to allow them to live in their local community with dignity, support and security**
- **Provide comprehensive frameworks to facilitate independent living and remove barriers to empower people with disabilities to live in their communities as equal citizens (National Disability Strategy 2004 and the National Disability Strategy 2017-2021 – both provide comprehensive frameworks committing the State to removing everyday barriers)**

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<sup>24</sup> United Nations Convention on the Rights of Persons with Disabilities 2006.

<sup>25</sup> Disability Rights Commission, Policy Statement on Social Care and Independent Living (August 2002).

<sup>26</sup> United Nation Convention on the Rights of Person with Disabilities 2006, Article 19.

### ❖ Support for students up to PHD level

Reports show that over 9,000 students with disabilities attend third level education in Ireland<sup>27</sup> which is somewhat encouraging. Nevertheless, although access had improved, disabled school leavers should be entitled to have the same expectations of college life as their abled bodied counterparts, gaining qualifications and should also have aspirations to a career in the working world. The academic environment is difficult to navigate for anyone and, in the current climate, almost impossible for people with disabilities and especially students with high dependency needs. Though supports and access for students with disabilities have improved in some respects since I started in 2002, there is a long way to go before it gets to an acceptable level for students with high dependency needs. For instance, when I started in NUI Galway I was barely able to get to the lecture hall and, in most instances, I had to ‘park’ myself on the platform beside the lecturer. For example, I was unable to attend tutorials that commenced from 8pm to 10pm due to the fact that my Academic Personal Assistant finished work at 6pm. This meant that I had to miss these valuable tutorials on many occasions or request a one-to-one tutorial during the day which seldom happened because of limited availability. In addition, I missed out on the valuable discussion and social interaction with other students. Normal socialising with fellow student outside of college hours, an essential part of student life, was not possible for me. Limited disability access to the library at that time, meant long time-consuming journies each time via a roundabout route in all weathers, again with a curfew of 6 p.m.

Exposure to the multiple layers of legal entitlements that a person with a disability is supposed to have in terms of reasonable accommodation mentioned in many Acts in Irish law inspired me to ask questions. The Employment Equality Act and the Equal Status Act recognise disability as grounds for discrimination. In my experience of third level education (NUI

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<sup>27</sup> Association for Higher Education Access & Disability, Christine Hynes, “Number of Students with Disabilities Studying in Higher Education in Ireland 2016/17” (AHEAD Educational Press 2018).

– Galway), though reasonable accommodation was provided, I feel it was given on an ad hoc basis. However, there were occasions when my supervisor intervened and advocated on my behalf resulting in a positive outcome. In the future, I would hope that legal measures would be established to put disabled students on par with their abled-bodied counterparts and afford them similar choice as per the ethos of the CRPD. Again I would like to reiterate here that the full range of facilities and services needed by students with disabilities and high dependency needs should be available as a right and not depend on favours or need for advocacy. Academic research on disability is often conducted by those with no experience of disability-based discrimination.<sup>28</sup> This type of research lacks experientially based knowledge as it occludes the expertise of people with lived experiences of disability, rendering us as ‘other’ (not like the norm).

#### **Recommendations – Educational Support:**

- **Access to all areas of educational establishments planned as suitable for people with disability and especially high dependency needs**
- **Availability of an Educational Support Worker (ESW) with relevant educational background and qualifications together with suitable skills and competencies (ESW would be assigned to the student for assistance with educational work only)**  
**Personal Assistant for personal care must be a separate entity**
- **Flexible and accordingly funded working hours for the Educational Support Worker to accommodate needs of the person with disabilities**
- **Supports provided for any Special Needs that the Person with a Disability requires including socialising with student peers**
- **Availability of relevant IT equipment assistance**

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<sup>28</sup>Economic and Social Research Institute & Irish Human Rights and Equality Commission, Joanne Banks, Raffaele Grotti, Éamonn Fahey and Dorothy Watson, “Disability and Discrimination in Ireland: Evidence from the QNHS Equality Modules 2004, 2010, 2014” (Research Series 2018)  
<<https://www.ihrec.ie/app/uploads/2018/09/Disability-and-Discrimination.pdf>> accessed 21 November 2018.

- **Allowance for disruptions during the academic lectures due to ill-health, toileting, physical discomforts etc. by ensuring disability officer meets regularly with disabled students to monitor progress and ascertain how best to facilitate them**
- **Extra time and resources allocated to the student with high dependency needs regarding completing assignments, thesis or conducting research which is often a strongly challenging task for students with disabilities by ensuring that disability officer meets regularly with them to ensure that they are not unduly pressured by meeting deadlines and accommodate accordingly**

### ❖ **Support in Employment**

Equally challenging, and often out of reach of people with disabilities and high dependency needs is finding and maintaining a place in the workplace that is both sustainable and manageable through having the necessary support services. The average working week of 39 hours may not be possible for all persons with high dependency needs because of the nature of the disability. More flexible options, in terms of shorter working days or job-sharing situations would be more feasible and manageable. A Wage Subsidy Scheme (WSS) offers support for employers who employ certain people with disabilities – “Workplace Support for Employers” is provided by the Department of Social Affairs and Protection (DEASP) to encourage the employment of people with disabilities. The flexible nature of the working hours (21 hours up to 39 hours) is encouraging for, not only the employers but also the employees with high dependency needs.<sup>29</sup> The disability allowances are means-tested, and any earnings will affect this allowance unless a person with a disability wishes to do rehabilitative work which allows a person to earn up to €120 per week. In addition, people on PRSI-based payments may work a maximum of 20 hours a week, subject to approval of the Department of Social and Family Affairs, while keeping their

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<sup>29</sup> Department of Employment Affairs and Social Protection, *Wage Subsidy Scheme Guidelines 2018* (2018)

<<http://www.welfare.ie/en/downloads/WSS-GUIDELINES-2018.pdf>> accessed 21 November 2018.



social welfare payment. For people on PRSI benefits, such transitional arrangements last for a maximum of one year.

As a result, the biggest drawback of active employment for a person with a disability and high dependency needs is the loss of the disability allowance package. This loss may include the loss of the array of services and benefits attached to receiving the disability allowance such as medical card and household benefits package. Thus, I argue that the loss of benefits attached to the disability allowance disempowers the person with disability and high dependency needs in active participation in paid employment. For instance, the loss of benefits like the medical card is monumental to the people with disabilities. The medical card recipient is entitled to a series of protection and supports like bespoke aids and appliances, environmental controls, assistive technology etc. which could not be afforded on a basic salary. As a result, it may be difficult to leave the safety of an arrangement where you can retain your welfare payments as well as associated benefits such as medical card, mobility allowance, free electricity and other household benefits and take up a job. It is particularly difficult for people whose earning power may be low because of their level of education or their disability.<sup>30</sup>

In conclusion, I propose the following points to be implemented in order to improve quality of life of the person with disability and high dependency needs while they are employed and thus integrated effectively into the community according to article 19 of CRPD.

#### **Recommendations – Support in Employment:**

- **Disability Allowance must not be affected when a person with disabilities takes up employment because the disability remains and the associated costs are an extra burden on the person**
- **Access to working establishments made barrier-free for disabilities**

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<sup>30</sup> National Disability Authority, “Disability and Work: The Picture we Learn from Official Statistics” (Disability Research Series 2016)  
<<http://nda.ie/nda-files/Disability-and-Work-The-picture-we-learn-from-official-statistics.pdf>> accessed 21 November 2018.

- **Flexible working hours<sup>31</sup>**
- **Funding made available for Work Support Assistant with relevant educational background, qualifications and suitable skills and competencies to work with a person with disability in a particular field and adequately funded to reflect support position**

### **Summary of Discussion and Recommendations:**

Following an outline of the original aims and objectives, this discussion chapter has synthesised and discussed the key arguments of the thesis. Objective one was discussed with relevance to the Article 19 and the Article 4.3 of the CRPD. Following that, objective two was discussed in several key points crucial for implementation in praxis of Irish law and services for people with disabilities and high dependency needs. In conclusion, the following key points summarise the discussion chapter and its recommendations for praxis, law and theory on people with disabilities and high dependency need and their rights:

- **Provision of comprehensive assessment of needs statements for each person with a disability**
- **Provision of relevant supports and funding to enable people with disability and high dependency needs to live in their local community with protection, dignity and security**
- **Provision of a framework of consumer-controlled services and funds - from which PWDs such as myself could get as many personal assistance hours as we require**

**This can only be achieved in the Irish Context by the introduction and implementation of a new and comprehensive Personal Assistance Act (P.A. Act)**

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<sup>31</sup> Employee Assistance and Counselling Service (EACS), previously known as Employee Assistance Programme (EAP).

Diverse and varied services are necessary for enhancing the quality of life for people with disabilities depending on their needs, and are imperative to their day-to-day lives which can include some or all of the following:

- **Disability Payments** - graded to suit severity of disability and Individual/Personalised budgets are social welfare services crucial for support of autonomy and empowerment of PWDs
- **Direct Payment Scheme** - crucial for support of empowerment and autonomy of people with disabilities
- **Physiotherapy** - availability on a regular basis to avoid crisis and acute conditions – regular maintenance will enhance the life of the person with a disability and alleviate unnecessary suffering
- **Occupational therapy** - essential for daily needs and maintenance of equipment used by the person with a disability. The ever-changing developments in the ‘aids and appliances’ technological advances must be conveyed to enhanced the lives of users
- **Speech therapy** - to avoid frustration and allow the person with a speech disability reach their full potential
- **Psychological therapy** - fundamental to the well-being of many people with disabilities who struggle to cope with the nuances of their disability
- **Dietician** - many people with disabilities have dietary requirements that affect their daily lives and access to dietician would enhance their quality of life and avoid possible serious medical conditions
- **Other Services** - specified in Assessment of Needs Service Statement as deemed appropriate and adequate
- **Mobility** - The proposed ‘Transport Support Scheme’ to be re-established with immediate effect as a matter of urgency because it is an unnecessary environmental impediment in the midst of difficulties experienced by people with disabilities in getting out, getting to medical appointments, getting to college, getting to work etc. The difficulties are not to be compounded by futile red tape
- **Student Support** - with suitable Access to places and provision of

ESW support are crucial in supporting education of PWDs

- **Community living and working support** - crucial for active integration into the community and sense of belonging to the community that enhances the well-being and quality of life of PWDs

**These recommendations should be implemented by the Irish State with immediate effect starting with Assessment of Need Service Statements for each person with a disability incorporating a new grading system as soon as is reasonably possible.**

#### **7.4 Conclusion of Thesis**

In this chapter, I discuss the key findings addressed in each previous chapter of the thesis and summarise the key findings to articulate particular substantial recommendations for both policy and praxis. I argue that people with disabilities and high dependency needs are better suited and equipped to understand the depth of oppression that exists in their world and first-person testimony is pivotal to analyse these structures, highlight pitfalls or shortfalls and propose progressive recommendations and solutions. As its sole investigator and using an insider first-person narrative, I have included myself and my story about my own experiences of living independently with a disability and high dependency needs and have used these experiences and perspectives to help me to understand the context under investigation. Using an autoethnography approach as a person with disability and high dependency needs, I describe my life experience with its difficulties and barriers encountered from my birth to the present day of trying to complete PhD studies. Drawing on these experiences has helped to embed my voice in the thesis. I argue that the use of an autoethnography approach which blends elements of autobiography and ethnography brings life to the study. This, I argue, enriches the legal policy review of the thesis and adds to current debates in the field of disability, law and policy<sup>32</sup>.

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<sup>32</sup> In particular, throughout the thesis I have highlighted my personal difficulties without reservation throughout Chapter 1, challenges of doing a PhD. as a candidate with high dependency needs in Chapter 2, Section 2.6 and in this final concluding Chapter in the introduction, 7.2.1, 7.2.3, 7.3 and in the conclusion.

In particular, as a researcher and research participant of autoethnography study, I chart the life experiences of living with a disability relative to the power infrastructure of the State, EU and UN. Having had a lifetime of interactions with public service shortcomings (particularly in health and education) as well as the constantly shifting and ineffective disability legislative landscape, I bring a personalised and individual insight and influence to bear on my research content and direction. I naturally remain conscious of the dynamic nature of one's life positioning as well as my own privilege relative to some of those I purport to represent through my writings. People with disabilities and high dependency needs have a right to the same standard of living as their able-bodied counterparts. 'Human Rights – A reality for all'<sup>33</sup> is firmly anchored in the CRPD. There are, however, shortfalls despite all the initiatives and recommendations on a human rights-based approach to disability, as I discuss in Chapter 5.

“In 2015 the EU's progress in implementing the CRPD underwent its first periodic review by the CRPD Committee. In its General Comment on Article 19, the Committee noted ‘a gap between the goals and spirit of Article 19 and the scope of its implementation. “In other words, despite wide-ranging legal and policy reforms across the EU, some initiatives at EU and Member State level do not fully incorporate the human rights-based approach to disability required by the CRPD<sup>34</sup>. ” As a result, despite the CRPD ratification, Ireland has introduced little or no change on contemporary disability funding policies. The many pitfalls and shortcomings experienced in my life in Ireland are paramount to elude people with disabilities living their lives based on human rights.

Despite all the odds I *have* reached this point – the final paragraph of the final chapter of my thesis. It has been a journey of highs and some very extreme lows. My experience has helped me greatly in analysing the short-comings of

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<sup>33</sup> European Network on Independent Living, “ENIL's Contribution to the Consultation on the Draft Council of Europe Disability Strategy 2017 – 2023” (2016) <[http://enil.eu/wp-content/uploads/2016/05/ENILSubmissionCoE\\_230516.pdf](http://enil.eu/wp-content/uploads/2016/05/ENILSubmissionCoE_230516.pdf)> accessed 15 November 2018.

<sup>34</sup> *Ibid.*

our existing provision in all areas and in all situations in Ireland and to formulate conclusions and recommendations for much improved policy and practice to enhance the lives of people with disabilities and high dependency needs. We need to look forward and continue our active participation, criticism and advocacy for independence that make our world an inclusive, secure and supported community environment where our struggles will not be so profound.

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