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Recessionary Tales: An Investigation into how Intellectually Disabled Young People, and Their Families, Experienced the Economic Downturn.

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Ph.D. 2018
Declaration

I, the Candidate, certify that this thesis is all my own work and that I have not obtained a degree in this University or elsewhere on the basis of any of this work.

Signature: _______________________

Susan Flynn
Date: 26th May 2018
Recessionary Tales: An Investigation into
how Intellectually Disabled Young People,
and Their Families, Experienced
the Economic Downturn.

A thesis presented in fulfilment of the requirements for the
degree of
Doctor of Philosophy
in Political Science and Sociology
National University of Ireland, Galway.

Submitted by: Susan Flynn
Supervised by: Professor Caroline McGregor

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National University of Ireland, Galway
May 2018
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Please note that pseudonyms are used within this thesis to protect the identity of participants, members of the public, and organisations relevant to this study.
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Abstract

This study presents an original contribution to knowledge through investigating the impact and lived experience of economic recession for intellectually disabled young people and their families in Ireland, who use services from the disability sector. This is important because in 2008, Ireland was hit with the greatest period of economic recession since the great depression of the 1930s. As the longevity of the recession played out, research evidences that the nation’s children may have been hardest hit, rendered significantly poorer, and within this, disabled children and their families were a particularly vulnerable socio-economic group, at significantly enhanced risk of poverty. Yet, in the context of a relative wealth of statistical data on the equality impacts of recession, little attention within research has been given to the lived reality, voices and experiences of disabled young people and their families in recessionary Ireland (Flynn, 2011; Flynn, 2017b). In this way, this study interjects into a comprehensively investigated sphere, albeit maintaining exceptionality, by way of focusing on voices and lived experiences.

This study used the purest or most classic application of the Biographical Narrative Interpretative Method (BNIM) from initial interviewing through to completion of the ten stage data analysis process. BNIM draws on the assumption that individuals construct meaning in their lives through narrative. Rather than impose categories for exploration, this method allows themes to be engendered by way of participant’s preference. Self-biographising narrative accounts were elicited through BNIM from a sample of 4 intellectually disabled young people (one constituting a pilot study), 4 of their parent/guardians, and 4 disability social work staff members. Congruent with the conventions of BNIM, a smaller sample of 3 cases were chosen for in-depth analysis. The remaining 8 were analysed through a Framework Method that offered a contextual framework of themes and subthemes. In terms of theoretical and epistemological concerns, the study takes up an Affirmative Non-Tragedy Model that situates itself overall within the broad field of Critical Disability Studies.

Among study findings, evidence is presented that lived reality for intellectually disabled young people and their families of the impact of recession is a complex and individualistic amalgam of cultural, material and psycho-social factors. These factors, rather than simply co-existing within a static matrix; incited, aggravated and alleviated one another. This interactive process was complex and temporal, but to an extent was predictable. The combined existential experience (or lived reality) of these factors was subjectively felt to be misunderstood by those in positions of power, leading families to seek comfort in the expertise of one another. Findings were numerous, for instance, insufficient cohesion of view points between families, and those perceived to be in power, may be alleviated by better data and a partnership approach that is meaningfully perceptible on the ground level. Furthermore, austerity appeared in reality to galvanise some
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backward regression in disability service delivery towards more outdated and inappropriate models. Overall, it is hoped that findings from this study can be put to practical usage for disabled young people, their families, and their allies, through both the increment of academic knowledge, and their application as a technology of advocacy. Furthermore, recommendations made by this study outline the specific contribution to knowledge and future practice made by this study, for instance, related to the development of the existing partnership approach to practice, or the generation of more qualitative data.
1. Introduction

1.1 Background

Ireland has been subject to massive macro-economic turbulence (Allen, 2009; OECD, 2009; 2013). In just a few years, the fiscal opulence dubbed the ‘Celtic Tiger’ gave way to staggering and unprecedented economic and social decline (Allen, 2009; Flynn 2017b). Here one of the highest levels of Gross Domestic Profit (GDP) and employment growth (related to the working age Irish and non-national cohort), capsized into one of the highest cases of unemployment, emigration and debt (Barry & Conroy, 2012, p.1; Flynn 2017b; Whelen & Maitre, 2012). In its rags to riches story, Ireland had donned its glad rags by way of overspending and borrowing, and even vulgar extravagance that was the engine and product of a speculative boom. Within this, the Celtic Tiger’s lifespan from cub (early 1990s) to eventual mauling (2008) was characterised by exceptional economic growth and prosperity, partly an artefact of foreign investment lured through provocative policy development (Flynn, 2017b; Paus 2012). Yet, dubious lending practices, an over-inflated housing bubble, and rising debt were indicative of an impending crash, and in the end, Ireland got its comeuppance in the form of protracted economic recession (Allen, 2009; Drudy & Collins, 2011; Featherstone, 2011; Flynn, 2017b; O’Flynn, Monaghan, & Power 2014; McWilliams, 2012). The year 2008 brought with it the deepest period of economic recession since almost a century before (Barry & Conroy, 2012; Flynn 2017b). In a bitter harvest Ireland had reaped what it had sown. Yet, in many ways, this was the cultivation of financial elites, rather than those resigned to the opposing marginality of society (Allen, 2009).

Now the poster child for austerity in the E.U. (Flynn, 2017b; O’Flynn, Monaghan, & Power, 2014), Ireland was cracking under crippling debt. Draconian policy conditions were imposed through the implementation of austerity measures as a governmental reactive strategy (Carney, Dundon & Ni Leime, 2012; Flynn 2017b; NYCI, 2013). The unfolding longevity of the recession brought with it palpable fear for the welfare of the indigenous and marginalised. In this context it was “widely accepted that the economic crisis poses a serious challenge to the protection of fundamental rights” (European Union Agency for Fundamental Rights, 2010, p.3).

Notwithstanding the case of recession, poverty itself has been a central concern for social scientists (Moran, 2015). In the Irish context, economic inequality certainly could be conceded to be the most pressing or defining social problem of our time (Moran, 2015). Consider within this, that child poverty is the most dangerous kind of poverty. It is inter-generational and longstanding, and contaminates broader society. So often its legacy is adult poverty (Nolan, 2000). Children who do not get a proper start at life may not attain proper education or achieve developmental milestones; therefore they lose the basic foundation
1. Introduction

necessary to function well as members of society, for the rest of their lives (Nolan, 2000).

In this context, Ireland had now experienced the worst impact of recession of almost all EU countries (Barry & Conroy, 2012; Whelen & Maitre, 2012). Irish children were hit hard (Flynn 2017b; UNICEF 2013a) and within this, rendered vividly poorer (Conroy, 2013; End Child Poverty Coalition, 2011; Flynn 2017b; Holland 2012; UNICEF, 2013a). In the context of skyrocketing post-recession unemployment rates, it had been already established that parental unemployment was the single biggest factor in Irish child poverty (Combat Poverty Agency, 2004). It then came as no surprise that Irish children and young people identified in large scale governmental research that economic recession was their number one concern (Conroy, 2013).

I had worked with intellectually disabled children during this time, and in this way had been privy to the impact of recessionary cutbacks on them at a grassroots level. I was interested in making visible these effects through research. Following a masters degree research investigation, the present study was conceived as a means to investigate the impact and experience of the Irish recession on a specific subset of children and young people well evidenced to be at a heightened risk of poverty (Emerson et al., 2010). Here I was navigating unchartered waters, so to speak, with no research in Ireland at the time, or to date, having comprehensively examined the socio-economic situation of disabled children and their families (Cullinan & Roddy, 2015).

For the purpose of consistency in recruitment processes, children who took part were deemed to need to have an intellectual disability. This was partly because this is the most common form of disability, alongside those disabilities classified as ‘remembering and concentrating’ in nature, and is in most cases accompanied by another form of disability (Watson & Nolan, 2011, xi). The research, however sought not to isolate these disabled young people’s socio-economic experience, from that of their immediate family, as for the most part, this is the context within which poverty recycles and expends itself (Caples & Sweeney, 2011; Chadwick et al., 2013; Kelly, Craig & Kelly, 2008). Overall I wanted to address the gap in knowledge presenting around the socio-economic experience of a subset of the population already well established to be at considerable risk of poverty (Emerson et al., 2010). This would be done with a focus on the unknown impact and experience of economic recession that would by general estimation, only elevate that risk (Conroy, 2013). Ultimately, it was my contention, that the phenomena of economic recession, as a catalyst of massive social change in Ireland, cannot be ignored by social science as an opportunity for research investigation.

1.2 Research aims and objectives

The study is refined by way of a central research question:
1. Introduction

How have intellectually disabled young people, and their families, who avail of services from the disability sector, experienced the economic downturn?

Within this the objective of the study is:

To give voice to the experiences that intellectually disabled young people and their families have of the recession with specific reference to the impact on their lives, in a manner which informs policy and practice.

Within this, research aims refine the task of responding. They are:

- To investigate how both intellectually disabled young people and their families have experienced the economic downturn.
- To explore the impact of the recession on the lives of intellectually disabled young people.
- To critically inform practice and policy development for intellectually disabled young people with a view to informing a partnership approach to service provision.

1.3 Theoretical framework

The theoretical framework for this study combines an Affirmative Non-Tragedy Model that I then locate within the broader field and paradigm of Critical Disability Studies (CDS). The Non-Tragedy approach is developed by French and Swain (2000; 2008); with its application in the Irish context as an operational lens for working with disabled children progressed by Flynn and McGregor (2017). A defining feature of the model is affirming the positive aspects of disabled lifestyles (French & Swain, 2008; Swain & French, 2000). In doing so it is compatible with the overarching CDS paradigm which contests disableism and biological conceptions of disability better associated with the traditional medical model of disability (Flynn & McGregor, 2017; Goodley, 2001). CDS occupies a trans-disciplinary space, lying where disability studies intersect with other agendas such as queer, class, postcolonial and feminist transformative theories (Flynn, 2014a, p.29; Goodley & Runswick-cole, 2010; Goodley, 2011). Overall, the emphasis of the study is phenomenological, whilst the orientation is toward social justice. This theoretical framework will be discussed in greater depth within the literature review chapter to follow.

1.4 Research design and methods

In selecting a research method one needs to be clear about what they are trying to achieve. I was interested in not just the impact, but the experience of recession. Furthermore I learned to recognise that methodologically speaking, impact and experience are very different things. In a phenomenological sense, I was interested in lived experience as a product of how the social phenomenon of
economic recession, had revealed itself to the structures of participant’s consciousness. Yet, in looking at this engineering of experience, epistemologically, I wished to retain connection with the societal influences, and not deny their culpability by an undue focus on individual agency or subjectivity. The Biographical Narrative Interpretative Method (BNIM) as the study’s core elected method allowed me to strike this balance between individual subjective and societal realms. This was critical in order to honour the insights of the disability rights movement and defining social model, and in particular, socio-political activism as their under-labourer, through recognising that disability is a product of society and not solely due to impairment (Oliver, Sapey & Thomas, 2012).

General statistical indicators of the impact of recession were already available from the comprehensively investigated sphere of quantitative data in the Irish context. The state-of-the-art or original contribution of this study is located within its elucidation of the implications of these indicators in terms of lived experience, on a population subset that had not been well researched, socio-economically speaking. BNIM offered a means to examine the lived experience of large scale social change, through the retrospective study of that process, and was well rehearsed in this way through existing projects (such as Chamberlayne, Rustin & Wengraf, 2002).

Finally, BNIM was particularly equipped for working with intellectually disabled children as it is often applied with sensitive populations and subject matter. For instance, its particular conventions allow participants to take an open consideration of the topic and generate themes for themselves and in this way it may address power imbalances particularly well (Wengraf, 2001). It also allowed me to explore the impact and experience of ‘recession’, without ever using the word, or needing young participants to know its meaning. Furthermore, poverty was evidently key to both the impact and experience of recession. Yet, despite the clear wider acknowledgment that poverty is a pressing issue for the social sciences, and perhaps even the greatest threat to humanity overall, our capacity to address the issue is time and time again undermined by the deep complexity that characterises it (UNICEF, 2013a). BNIM is a sophisticated method in terms of in-depth analysis which would seem aligned to this complexity. Framework Analysis was then implemented in the case of those interviews not selected for the purest application of BNIM. This usefully generated themes around the impact, as opposed to the experience of recession, as another core component of the study’s aims. Overall, the study’s methodology in terms of both Framework Analysis and BNIM will be discussed in more detail in the methodology chapter to follow.
1. Introduction

1.5 Terminology

This thesis uses the term ‘disabled’; for example ‘disabled children’, ‘intellectually disabled young people’. Therefore in its disability etiquette, it exercises a decision not to use ‘person first terminology’. The latter, as evident in the title, places the person before the disability. Recognizing the individual as just that, full of the unique inherent capacities, complexities and even oddities that we all possess as social beings; disability being only one ingredient of this exclusive positioning (Flynn, 2014, p.8; Flynn & McGregor, 2017, p.261). Yet, this has been contested by disabled people who consider their disability as indivisible from their identity (Ruch & Lymbery, 2008). In this way, person first terminology has been understood to draw attention away from disability as a form of social oppression (Kelly, 2007).

The alternative term 'disabled people' is more indicative of disability as a social creation rather than an individual condition (Flynn & McGregor 2017; Kelly, 2007; Oliver, Sapey & Thomas, 2012; Skalecka, 2014). This is aligned to the study’s Affirmative Non-Tragedy Approach that retains many underpinning aspects of the social model. Overall, whilst the points that support person first terminology are critical points, the term ‘intellectually disabled’ is the one that shall be adopted herein for the purposes of this research to convey my contention that disability is largely a social construction, and to ensure that the language used, is theoretically consistent with the study overall (Flynn, 2014; Flynn & McGregor, 2017).

1.6 Dissertation outline

This dissertation is comprised of nine chapters of which this has been the first. A synopsis of each chapter is as follows:

1. **Introduction chapter.** This encompasses the background to the study, research question, aims and objectives, theoretical framework, research design and methods, terminology and dissertation outline as presently presented.

2. **Context chapter.** This chapter demarcates the relevant policy, law, socio-demographics, political and socio-historic context for the research at hand.

3. **Literature review chapter.** This chapter combines synthesis and summary of the study’s relevant literature through a critical review of it. Within this, it is possible to identify a number of themes that indicate enhanced socio-economic risk for intellectually disabled young people and their families, under conditions of complexity that make it difficult to discern and amend. Theory is also discussed in depth with a view to locating this study’s particular approach.

4. **Methodology.** This chapter considers methods used and their sustaining philosophies. The mechanics of recruitment, sampling, data collection and analysis, alongside ethical observances, are discussed.

5. **Findings chapter: The framework method.** This chapter presents the thematic findings of the application of a framework method with a sample of eight participants.
6. **Findings Chapter: BNIM cases.** This chapter presents the three individual BNIM case accounts developed through the purest application of BNIM analytic conventions.

7. **Cross Case Theorisation.** This chapter represents step 10 in the BNIM comprehensive analytic approach. It displays the cross case theorisation that generates insights from a combined examination of the three BNIM cases.

8. **Discussion Chapter.** Here the combined findings of the study’s methods overall are discussed in terms of implications for the study’s original objectives and aims.

9. **Conclusion.** Finally I consider here the study as a whole in terms of the increment of academic knowledge as well as its implications, limitations and recommendations for future research and policy endeavours.
2. Context

2.1 Introduction

There is an important, remote and necessarily complex relationship between historical, political, legal and policy considerations, and the present circumstances of intellectually disabled children and their families in Ireland. This chapter sets out the former context. In doing so it takes account of the established divide between the lived reality of Irish intellectually disabled young people and their families, and defining Irish policy aspirations (Browne & Millar, 2013). As disability services in Ireland have traditionally not been a priority for the State, and rather have been run by voluntary organisations, a complex and critical historical context has developed. This context is also central to the literature that follows.

2.2 Introduction to austerity measures

Disproportionately worse effects of governmental austerity on vulnerable social groups are alleged (Maher & O’Brien, 2014). Disable Inequality in 2016 published an easy-read fact sheet that set out extensive examples of cutbacks affecting disabled people, and within this, intellectually disabled young people and their families in the post recession period 2008-2016 in Ireland (Browne, 2016). Approximately 40 examples of significant losses are provided in simple succession. This has been integrated here with a comparable factsheet from the Irish Nurses and Midwives Association (2015) looking specifically at Irish intellectual disability services in Ireland. Some examples drawn out of the extensive lists include:

- Respite Care Grant cut by 19% (over 300 euro) in 2013, not restored until Budget 2016.
- Capping of the number of Special Needs Assistants in 2011. This then had to be reneged on incrementally to permit an extra 493 posts in 2013-2014, 169 in 2014-2015, and 666 in 2015 to meet demand.
- The overall budget for disability services has been reduced by €159.4 million or 9.4% since 2008.
- Funding for access programme to Universities for disabled students cut by 20% in 2012.
- Over 1000 disabled children and adults in 2014 were waiting for Occupational Therapy and Speech and Language Therapy services. At the time of reporting, waitlists continue to grow.
- Home Help provision decreased by 21% (2.5 million hours) since 2007.

Such examples are indicative of the extensive Irish austerity measures that interface with an existing risk profile as will be detailed in the section to come.
2.3 Developing a pen portrait of intellectually disabled children and young people in Ireland

It is necessary to draw a pen portrait of intellectually disabled young people and their families, socio-demographically speaking. In doing so, the present section will draw upon statistical information in particular. A conclusion will ultimately be reached that such statistical data remains invariably limited in its insight into the lived reality of austerity for intellectually disabled children and young people. In this sense, this section will reflect the conclusions of Flynn (2017b) in the presentation of similar data—that statistical data can offer a valuable skeletal framework to broadly understand the impact of recession for intellectually disabled children and young people, and their families, categorically and through generalisation. Nonetheless, the lived reality of the recession as demonstrated through the voices and experiences of those most affected must properly complement this framework (Flynn, 2015). Yet, baseline data that displays the lived experience through listening to disabled children and young in Ireland has been at a considerable deficit within an overall abundance of statistical data (Flynn, 2011; Flynn, 2015).

With this in mind, intellectually disabled children and young people in Ireland are a marginalized population with a high dependency on social support infrastructures (Browne & Miller, 2013; Caples & Sweeney, 2011; Nicholl & Begley, 2012). Disability prevalence itself rises with age. For instance, in 2011 in the Irish context, 3.5 per cent of children were estimated to have a disability as compared with between one-in-five and one-in-six in cases across the life course (Watson & Nolan, 2011). Later Irish figures (NIDD) reflect this, with 6.16 per 1,000 population estimated to have an intellectually disability in 2016 in the context of an overall increase in the lifespan of Irish intellectually disabled people. A higher prevalence of intellectual disability among boys (4.4%) than among girls (2.6%) ordinarily occurs within this (Watson & Nolan, 2011, xi). In addition, the two most common forms of disability identified among children, in the 2011 study, were categories referred to as ‘intellectual and learning disability’, and also ‘remembering and concentrating disability’ (Watson & Nolan, 2011, xi). Overall, in the Irish context children and young people make up a significantly elevated proportion of the country’s population by European standards (Social Inclusion, 2007). This is evidenced by Eurostat demographic figures (2018) that show that live birth rates for Ireland in 2016 were at 1.8 births per woman, with only Sweden (slightly over 1.8) and France (slightly over 1.9) scoring higher out of European Union countries.

In the above sense, Flynn (2017b, p. 679) demarcates how the characteristics of intellectually disabled children and young people in Ireland as a group, are to an extent statistically monitored. The Health Research Board (HRB) is the foremost funding source for health research in Ireland (Health Research Board, 2010). Its database’s most recently published figures (Doyle, Hourigan & Fanagan, 2017; Kelly, 2015) ascertain that within the Republic of Ireland there are 10,160 intellectually disabled children. Including this figure, overall there were 28,275 adults and children registered on the National Intellectual Disability Database (NIDD) at the end of December 2016, an increase of 8% from the same period in 2014 (Doyle, Hourigan & Fanagan, 2016, p.9; Kelly, 2015). Moderate (40.5%), followed by mild (32.0%) and then severe (13.9%) were the most common medicalised categorisations of intellectual disability (Doyle, Hourigan & Fanagan,
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2016, p. 10). Overall, male gender outweighed female at 58.2% to 41.8%, whilst on a gradient Sligo has the highest prevalence of intellectual disability and Leitrim constituted the lowest (Doyle, Hourigan & Fanagan, 2016, p. 9; Kelly, 2015, 16).

Nevertheless, Flynn (2017b) concedes that whilst useful, the data is limited as follows. First, registration on the NIDD is voluntary. Therefore at best it can only offer an indication of the needs of this group rather than an absolute depiction. In this way, children aged between zero and five years old are reportedly vulnerable to underrepresentation in the data, on the grounds of the lack of a complete diagnosis. It is also surmised that those with a mild intellectual disability are also under-represented due to non-usage of specialist services (Flynn, 2017b; Kelly, Craig, & Kelly 2008; Kelly, Kelly, & O’Donoghue, 2012).

With this in mind, the aspiration to honour the study’s elected Affirmative Non Tragedy Model, and declare the reading of this literature through a non-tragedy lens (Flynn & McGregor, 2017), ultimately must be balanced with a fair portrayal of the distinct disadvantages that disabled children and young people face. These disadvantages are also important to delineate here in terms of progressing an accurate overview of socio-demographic positioning in this section, and are not intended upon strengthening associations between disability, pity, tragedy and loss. Furthermore, it is important to consider social problems concurrent to our consideration of poverty and economic recession, as for intellectually disabled children and young people, often these are considered to be separate considerations rather than variables that aggravate and incite one another (Emerson et al., 2010).

With this in mind, we have heard how these children are for the most part, a population on the margins of society, with an elevated dependency on social support infrastructures (Browne & Miller, 2013; Caples & Sweeney, 2011; Nicholl & Begley, 2012). The majority of this cohort in Ireland also live at home with one or both parents. Consequentially they experience social disadvantage in the context of their families (Caples & Sweeney, 2011; Chadwick et al., 2013; Kelly, Craig & Kelly, 2008). As it stands, environmental adversity is significantly pronounced for disabled children, for instance, household poverty, living in poorer neighbourhoods and being subject to bullying (Emerson, 2012). Albeit secondary in effect, being poorer contributes to poor parental wellbeing, and therefore poorer parenting of the disabled child (Emerson, 2004). Poverty is also tied to poorer health and wellbeing in intellectually disabled children (Emerson 2004) whilst economic recession has been linked to increased child maltreatment by parents (Brooks-Gunn, Schneider & Waldfogel, 2013). Disabled children overall are significantly more likely to endure conditions that “impede development, educational attainment and adjustment, and increase the risk of poor health, additional impairment, and social exclusion” (Emerson et al., 2010, p. 224).

A literature review by Flynn and McGregor (2017) outlines the many adversities these children face in the Irish context, as detailed further within the following. Such adversity is aggravated by the fact that demand exceeds supply for vital services such as respite (Caples & Sweeney, 2011). Situated at the raw end of many social harms (Flynn & McGregor, 2017; Marchant & Jones, 2000 cited in Kelly et al., 2012), intellectually disabled children and young people experience an increased susceptibility to poverty (Emerson, 2004), neglect and abuse, (Ziviani et al. 2013; Northway et al., 2013; Kelly et al., 2012) substance misuse problems,
(To et al., 2014) negative involvement with the criminal justice system (van Vugt et al., 2011) and over-representation in looked after populations, in child protection and public care systems (Braddock et al., 2001; Flynn & McGregor, 2017; Kelly et al., 2012, p.21; Lightfoot, Hill & LaLiberte, 2011; Read & Harrison, 2002; Stalker & McArthur, 2012; Trout et al., 2009). This acute social vulnerability was further amplified by these children's constrained ability to make their voices heard at a macroeconomic or political level and indeed the historical absence of the same (Flynn, 2011). Later in the literature review, correlations and direct causations, between the above named social problems and the circumstance of poverty itself, will be explored in greater depth.

With this in mind, Watson and Nolan (2011) developed the post recession social portrait of disabled people in Ireland. This helps to progress the socio-demographic picture of intellectually disabled children and young people that this section is focused upon building. Therein Watson and Nolan (2011) demonstrate that intellectual and learning disabilities are the most common forms of disability for children and that overall disability in Ireland is tied to poverty and social exclusion. To better understand how the latter circumstance came to be, Flynn (2017b, p. 679) suggests that one might consult NIDD pre-recession and post-recession data as follows.

The economic recession commenced in 2008 in Ireland (Barry & Conroy, 2012). Flynn (2017b, p. 679) concedes that if we compare NIDD data from 2007 (Kelly, Kelly, & Craig, 2008, p.58) with those from 2011 (Kelly 2012b, p. 49), some decreases in service provision are evident for intellectually disabled children and young people aged under 18 years; for instance, less home help support service going from six to two children in receipt of home help support. Nevertheless, an increase in children availing of the early intervention team (434 in 2007, compared with 496 in 2011) and in special pre-school for intellectual disability (348 in 2007, compared with 384 in 2011) is at first glance not so disconcerting (Flynn, 2017b, p. 679).

Yet, in Flynn’s (2017b, p.679) further analysis, we are asked to consider that the 2011 data-set in fact pertains to a larger group of intellectually disabled children (9918 as opposed to the 8886 in 2007). What’s more, even in the fortuitous ‘Celtic Tiger’ Ireland of 2007 waiting lists for fundamental services, such as early intervention and residential care, were inadequately high for intellectually disabled children and young people (Conroy, 2012; Gartland, 2007; Kelly, Kelly, & Craig, 2008). Therefore it is perhaps palpable that economic recession has halted the development of basic services. In fact, Flynn (2017b, p.679) notes, that even in Ireland’s ‘Celtic Tiger’ years, substantial waiting lists for vital services such as respite care were increasing, with 1954 waiting for respite in 2006 (Gartland, 2007). If one compares this with NIDD data it would appear post recession in 2011 that the unpardonable respite situation for intellectually disabled children and adults had not by any real measure improved (4242 individuals in 2006 receiving respite out of 25,613 compared with 4963 out of 27,000 in 2011) (Flynn, 2017b, p.679; Kelly, 2011, p.38; Kelly, Kelly, & Craig, 2008, p.15).

In drawing to a close, this section overall has looked to build a socio-demographic picture of intellectually disabled children and young people, drawing partially upon such statistics therein. Yet, as stated at the outset, statistical comparisons
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such as these are invariably limited. The location, efficiency, relevance, duration and quality of the service experienced, or the emotional impact of such variables as high staff turnover are considerations often omitted (Flynn, 2017b). The meaning behind statistics is further likely to be dissimilar in the individual lives of each young person. Statistics therefore usefully contribute to an understanding of the impact of the recession but not the lived experience according to Flynn (2017b, p. 679).

2.4 Insult and injury: an introductory history of intellectual disability in Ireland

Consider in this section an overview of the history of intellectual disability in Ireland, with the express intention of a balanced portrayal of a seemingly troubled past. Yet, in the reading of the literature it remains important that this troubled nature does not overwhelm clear elements of brilliance and prestige in disability culture and disabled identities today, in line with the operation of a Non Tragedy Lens (French & Swain, 2008).

With this in mind, insult and injury have epitomized the history of intellectual disability in Ireland (Flynn, 2014, p.31). Intellectually disabled children and adults have endured a long and chequered history of oppression and abuse (Browne & Millar, 2013; Flynn, 2014a, p.11; Ife, 2012; Robinson, 2013; Skalecka, 2014; Yuen, Cohen & Tower, 2013). With one of the highest rates of institutionalization in the world in the 1950s, particularly pronounced for the intellectually disabled population, life was often something which transpired 'behind closed doors' (Flynn, 2014, p. 31; Power, Lord & DeFranco, 2013; Redmond & Jennings, 2005). Overall, there are few critical accounts of how Irish services for intellectually disabled young people have developed (Sweeney, 2010).

The McCoy Report (2007) was specifically conducive to exposing shrouded institutional life for Irish intellectually disabled children and adults. It is particularly known for exposing a catalogue of abuses that occurred within one of the largest providers in the country, the Brothers of Charity Services Galway (Flynn, 2014a, p. 12). The number of historical accounts of Catholic religious orders such as this, and the shape and nature of the intellectual disability services they provided in Ireland are modest (Sweeney, 2010). This acquires further significance given that historically within Ireland the church, religious organizations and family members constituted the main providers of care (Skalecka, 2014, p.1). In fact, research on the Irish history of institutional care for intellectually disabled children and adults on the whole is considered to be under-researched, complex and troubling (Kelly, 2010, p.1).

The 2009 publication of the Ryan Report (Department of Health and Children, 2009) was a decisive occurrence in the substantiation of child abuse which occurred in Irish reformatory and industrial schools. It demarcated seventy one industrial schools and ten reformatories in Ireland during the latter half of the 19th century with the majority of reformatories closed due to a lack of children to occupy them (Powell et al., 2013).
Redmond and Jennings (2005) provide a historical account of services for intellectually disabled children and adults in Ireland. Their analysis begins at the latter half of 18th century Ireland. At this time intellectually disabled adults, and even children, were chiefly cared for in a workhouse or district lunatic asylum system. Specialist services for the intellectually disabled, discounting Stewart's Hospital (1869), did not materialize until the early 20th century. At this time almost all such services were based in large residential institutions (Flynn, 2014a, p. 12). Contextually, divergence was evident at the time between medical and religious discourses around intellectual disability, then known as mental handicap. Medical approaches were increasingly focused upon curing disability using scientific evidence, whilst religious discourses followed a charitable approach to disability (Sweeney & Mitchell, 2009, p.276).

Finally, a move toward smaller community settings was made, with large Institutions closing after the 1970s and 1980s (Redmond & Jennings, 2005; Flynn, 2014a, p. 12) in line with overall social service development in Ireland (Skehill, 1999; Whyte, 1980). Indeed today best practice still reflects a move from congregated settings toward dispersed community based housing combined with supported living through individualized supports for intellectually disabled children and young people (HSE, 2011): given that such a move progresses social inclusion for them (McConkey & Collins, 2010). In Ireland, as a reflection of Article 41 and 42 of the Irish Constitution, the family is afforded a position of privilege and protection (since developed through referendum and explicit statement of children’s rights through incorporation of Article 42a) (Shannon, 2016). The natural family home in Ireland is considered the best place for any child, and for Irish intellectually disabled children, notwithstanding the enhanced vulnerability therein as compared to non-disabled counterparts, this is fortunately where they predominantly reside today (Kelly, Craig & Kelly, 2008; Chadwick et al., 2013; Caples & Sweeney, 2011).

On a socio-political level, Skalecka (2014, p.1) notes how within Ireland at the latter half of the 20th century, societal attitudes were evolving due to Ireland joining the United Nations in 1955 and the European Union in 1973. Consequently Irish policy and service provision became more cognizant of human rights. Within this, the advocacy aphorism, 'Nothing About Us Without Us' embodied a move toward inclusion and consultation with intellectually disabled people (Flynn, 2014a; Shakespeare, 2014; Skalecka, 2014, p.1; UN Enable, 2004).

Nevertheless Skalecka reflects on how the inception of recession and concurrent demise of the Celtic tiger brought with it some regression in progress for Irish disabled people. She aptly remarks that somehow; 'the motto Nothing about Us without Us seems to have lost its importance in the bigger picture of trying to make savings in public spending in order to save the Irish economy' (Skalecka, 2014, p. 1).

It is important to remain cognizant however, given the implicit challenge in the motto, ‘Nothing About Us Without Us’, that the voices of intellectually disabled young people have not always been explicit or consulted within literature and historical accounts of the history of intellectual disability. Given this, a progression toward a more inclusive history of intellectual disability is required (Atkinson & Walmsley, 2010). The incorporation of material from Irish life stories authored by
intellectually disabled people themselves has been a starting point for the study at hand (Roberts & Hamilton, 2010).

2.5 The nature of the service infrastructure in Ireland at the time of the recession

Having considered a brief history of intellectual disability in Ireland, it is useful to narrow focus towards service provision both historically, and its nature at the time of the inception of recession. Historically, it has been religious philanthropic and non-profit organizations within Irish civil society that have provided services to intellectually disabled children and adults. The Irish state has been comparatively hesitant on an international scale to interfere in this realm (Flynn 2015; Power, 2009; Power & Kenny, 2010; Quinn & Redmond, 2003). Today however the state constitutes the principal source of funding to disability services. It does so from afar, allowing the voluntary sector to spearhead sector development (Flynn, 2014a, p.14; Flynn, 2015; Quinn & Redmond, 2003). Ireland is comparatively unique in this sense, given that the state has an abnormally long history of depending upon, ‘local, relatively autonomous, voluntary organisations within a relatively decentralised monitoring framework’ in the provision of support services (Power & Kenny, 2010, p.422).

Power (2009) outlines the nature and form of services for disabled people at the time of economic recession. He concedes that the most comprehensive data source on volunteerism in Ireland was the Directory of Services by Inclusion Ireland (NAMHI, 2003). The directory established that there were 237 centers providing support to intellectually disabled children and adults in Ireland (Flynn, 2014a, p.14). Within children’s services listed are principal providers KARE, The Muiriosa Foundation, St. John of Gods services, St. Micheals House, Ability West, HSE, Western Care Association, Central Remedial Clinic, Cheeverstown House, COPE Foundation, St. Hilda's Services and Brothers of Charity (BOC) services.

Intervention in civil society disability sector services has been amplifying since the immediate impact of recession, embodied by the State's health and social care watchdog, HIQA (The Health Information and Quality Authority). HIQA’s mandate extends, through statutory responsibility, to the inspection of services for intellectually disabled children and young people. It does so against pre-determined standards (HIQA, 2012; HIQA, 2013; Flynn, 2014a, p.14).

Other major changes have been underway. The Progressing Disability Services for Children and Young People initiative recognized disparities in service provision and sought to change the way all services were offered with a view to making them more equitable and consistent for all. This was a comprehensive reform of service provision through the establishment of new multidisciplinary Children’s Disability Network Teams (National Reference Group on Multidisciplinary Disability Services for children aged 5-18 years, 2009). In this context, families today access many services from within a community team approach; For instance, those teams colloquially referred to by their acronyms; the SAT (School Aged Team); EIT (Early Intervention Team), CAMHS (Child and Adolescent Mental Health Service) and YAMHS (Mental health services for mid teens through to early adulthood).
At the time of economic recession however, disparity in the nature and multitude of services was geographically evident. Funding acquisition was a key determinant of the spatial properties of service provision (Power, 2009). At this time (2009) there were 32 Local Health Offices and 134 Health and Social Care Networks within the HSE (National Reference Group on Multidisciplinary Disability Services for children aged 5-18 years, 2009). Outside the HSE large state funded organizations like The Muiriosa Foundation or Brothers of Charity Services were significant service providers in a locational sense. They supported intellectually disabled children (and adults) and their families through particular programs and multidisciplinary professional support (such as from Speech and Language Therapists) that could be offered to service users in the locality. In order to receive a service one had to be accepted under threshold criteria (Department of Health, 2012).

Individualised funding (a progressive concept that requires funding to be in the direct control of service users rather than service providers) was not a reality in Ireland (Power, Lorde & Defranco, 2013). Therefore largely autonomous organizations determined from within them what services they would offer to particular service users. They did so by attaching a package of funding to the service user from their core funding derived from the state body, the HSE, under the auspices of service level agreements (Department of Health, 2012). In this context Government cuts to services had a complex effect, whilst the “dialectic of state-voluntary sector interdependence in social welfare” was subject to much debate (Power, 2009, p.231). Brendan Broderick, CEO of the Muiriosa Foundation published a statement in 2013 that acknowledged that cut backs lead to ‘families having to live in an emergency zone because service providers can’t respond to new crises’ (Broderick, 2013, p.2). Many families may also require a number of services that work in combination, such as clinical support, teamed potentially with respite or residential services. If one service is not provided it may undermine the efficiency of other services provided.

Overall, the Greater Dublin Area demonstrated strong patterns of provision as did a number of the larger Irish cities and towns (Power, 2009). Whilst the 2011 HSE report, ‘Time to Move on From Congregated Settings ’ surmised that approximately 4,000 intellectually disabled children and adults still abide in institutional settings. It concedes that within such recessionary times, a significant challenge is posed to housing authorities in supporting these citizens to vacate housing in community settings (Flynn, 2014a, p.15; 2017b). Such a move is deemed progressive in light of a growing body of literature which demarcates that disabled children and adults experience greater social exclusion in congregated or institutional residential settings (Emerson et al., 2005; McConkey et al., 2007). Within this, the move from congregated settings amounts to the practical expression of Wolfensberger’s seminal Normalization Theory within Ireland (Doody, 2012). Children, who cannot remain at home full-time, may have their home placements supported by respite care in Ireland. Nevertheless, research by Caples & Sweeney (2011) highlighted huge intra-country variations in the availability and provision of respite, which overall, is a specific high demand service. It would appear that such inequity accompanies remnants of “paternalism, overprotection, medicalisation, and segregation” as features of overall service development in Ireland (Power, Lorde & DeFranco, 2013, p.36).
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2.6 Human rights law and intellectually disabled children in Ireland

Pursuant to establishing context for this study, we have thus far considered socio-demographic statistics; a brief history of intellectual disability and an overview of the present service infrastructure. The following sections will build upon this by reflecting a shift in focus towards the legal and policy context. Within this, human rights will be considered, as it stands, to act as a natural reference point for concerns about the effects of austerity (Siaz, 2009).

There are many implications of human rights law for intellectually disabled children, young people, and their families in recessionary Ireland. In 2012, a briefing report was published by Holland (p. 2) which interrogated the human rights implications of the Irish recession. It surmised that Ireland will be, ‘traversing stormy seas for quite some time’. Troublingly Holland alleges that the National Recovery Plan 2011-2014 (NRP) prioritised drastic cuts in social expenditure over tax reforms, leaving Irish disabled children and adults largely in need of advocacy (Government of Ireland, 2011). Here a rights-based approach has particular applicability to intellectually disabled children and young people in Ireland according to Browne and Millar (2013, p.18).

The approach is a rapidly evolving, comparatively new concept which has acquired an additional concern with the duties and obligations of governments over its counterpart, the needs-based approach (Degener, 2016; Skalecha, 2014). It is important as one of the most visible consequences of the prevailing economic crisis has been the socio-economic decline of vulnerable populations, such as intellectually disabled children (Flynn, 2017b; Strier, 2013). Furthermore, such a decline has compromised some of the most overtly recognisable human rights principles, such as equality, participation and inclusion (Arnardottir & Quinn, 2009; Ignacio, 2009).

The UN Convention on the Rights of People with Disabilities (UNCRPD) is the first convention to be legally binding and disability specific (Blanck & Flynn, 2016; Flynn, 2016; Hamilton, 2012; Harbur, 2012; Quinn, Degener & Bruce, 2002). In this way it offers a practical expression of the notion that all human rights are indivisible and interdependent (Arnardóttir & Quinn, 2009; Parkes, 2013). It structuralizes the arena of government funding and disability in Ireland (Flynn, 2014a, p.20). In addition it communicates the inherent challenge to researchers who work with disabled children and adults to establish ways to include them in the progression of research which pertains to them (Tierney, 2009). Finally and providentially, it contains provisions explicitly related to children, including those that are intellectually disabled, supplementary to the universality principle of human rights (Degener, 2016; Kilkeley, 2008; 2013; United Nations, 2006).

Article 4 of the Convention places an obligation on the State to act to the maximum of its available resources. Alternatively, Article 33 provides for oversight of national monitoring and implementation, shining the proverbial spotlight on Government funding decisions. Prior to adoption of the UNCRPD in 2006, none of the eight core Conventions of the United Nations, excluding the UN Convention on the Rights of the Child (UNCRC), referred explicitly to disability (Hamilton, 2012).
Despite Ireland being one of the first signatories however, Ireland has been longed poised to ratify the UNCRPD without doing so (Doyle & Flynn, 2013; Flynn, 2011; Power, Lord & DeFranco, 2013). It wasn’t until 2018 that steps were taken to finally ratify the Convention. The architecture of domestic law has only just aligned itself with the Convention, replacing antiquated capacity legislation with the new Assisted Decision Making Capacity Act (2015) (Flynn, 2011; Flynn, 2014a, p.1; Power, Lord & DeFranco, 2013). This arises from the somewhat dichotomous system of law within Ireland which fashions international and domestic law into two independent axes. Such is prescribed for under Article 29.6 of the Irish Constitution (Bunreacht na hÉireann, 1937; Doyle & Flynn, 2013; Forde & Leonard, 2013; Flynn, 2014a, p.1; Moriarty & Massa, 2012).

This dualist prerogative in Irish law may be better explained using the case of Kavanagh vs the Governor of Mountjoy Prison (2002) 3 IR 123. Here the Supreme Court found in para. 43 that the Oireachtas has the exclusive domestic law making competency in Ireland. Paradoxically however it is the Government who has the exclusive function of entering into international agreements. Thus for international agreements to take effect within Ireland they must be enacted by the Oireachtas (Flynn, 2014a, p.1; 2014b).

The publication of the new Assisted Decision-Making (Capacity) Bill on July 17th 2013, and then following this, the Act in 2015, was allegedly the last significant hurdle for Government in ratifying the UNCRPD (Flynn, 2011). Given that the Irish Government has alleged that the remaining obstacle to its ratification has been Ireland’s archaic Wards of Court system which, Doyle and Flynn (2013, p.1) observe shall, ‘upon a finding of incapacity, remove all decision-making rights (legal capacity) from an individual’. By 2016 promises were still unfulfilled as Government approved the Disability (Miscellaneous Provisions) Bill. It did so as another speculative last straw in enabling ratification by Ireland of the UNCRPD that to date, is only now being ratified. This is not, however, reducible to a straight forward thrust towards ratification. Measures such as the Criminal Law (Sexual Offences) Act 2017, which repeal its 1993 counterpart that makes it an offence to have sexual intercourse with a mentally impaired person, are part of the amendment of domestic law architecture that seeks to enhance Irish state compliance with international obligations. For many disabled people and their allies, hasty ratification should be matched with the achievement of the best possible domestic legislative framework, even if it means the exhaustion of further time.

Dichotomy, as a feature of the Irish dualist State, also presents itself in the case of human rights for intellectually disabled young people in Ireland. Here both children's rights and disability rights concerns are to the fore. Children's rights principally have expression within international human rights treaties which governments accede to through ratification and domestic law (Howie, 2010; Kennan et al., 2011). Arguably most applicable to children's rights is the international human rights treaty, the 1989 UN Convention on the Rights of the Child (UNCRC) (Kennan et al., 2011; United Nations, 1990).

It explicitly refers to disabled children under Article 2 and 23 (Browne & Millar, 2013; Flynn, 2011; Lansdowne, 2009; United Nations, 1990). Concurrently all
children's rights referred to therein have applicability to disabled children. Nevertheless a precise reference to disabled children is symptomatic of an appreciation that these children are particularly vulnerable and marginalized (Lansdowne, 2009; Browne & Millar, 2013). Within the Convention's preamble is also the assertion that the child has membership of the 'human family' and thus confers a personhood on the child which recognizes them as more than merely an incomplete adult (Howie, 2010, p.757).

UNICEF (2007) have examined the influence of the Convention on the Rights of the Child (UNCRC), the Convention on the Rights of Persons with Disabilities (UNCRPD) and the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, on disabled children on an international scale (Browne & Millar, 2013; Lansdowne, 2009). They provide ten specific directions for the implementation, on a national level, of the rights of children as they stand within the UNCRPD. One direction in particular pertains to resources. It calls for concerted efforts which ensure that essential resources are allocated to and for disabled children and their families (Brown & Millar, 2013, p. 44).

The UNCRC associated Committee on the Rights of the Child has further observed that disabled children are somewhat susceptible to a double discrimination, both in their capacity as children in the first instance and secondly as humans with a disability (United Nations, 2002). This is a particular impediment to the successful implementation of Article 12 of the Convention which pertains to the opinion of the child and the right to express it (Parkes, 2013; United Nations, 2002). Comparatively within the Irish domestic policy context, the publication of the Ryan Report in 2009 represented a decisive occurrence in the recognition of the human rights of both children and intellectually disabled children subjected to abuse within Irish Reformatory and Industrial Schools. Therein was also recognition of the marginalized status of children's voices in Ireland (Powell et al., 2013).

Nevertheless, beyond domestic policy and indeed peripheral to the exacting Convention on the Rights of People with Disabilities and the UN Convention on the Rights of the Child, are important instruments, conventions, charters and papers which have incrementally advanced the intercontinental field of human rights (Flynn, 2011; Power, Lord & DeFranco, 2013). The 1971 Declaration of the Rights of Mentally Retarded Persons has been flagged by Rimmerman (2012) as the first UN document to address the rights of people with a disability.

Prior to this, Universal Declaration of Human Rights 1948 was another progression albeit not disability specific (Browne & Millar, 2013; Power, Lord & DeFranco, 2013). It provides a well regarded itemization of human rights which aimed to constitute a standard to aspire to for all people (Forde & Leonard, 2013). Building on this was the successive European Convention on Human Rights (ECHR) (Convention for the Protection of Human Rights and Fundamental Freedoms) (Browne & Millar, 2013; Council of Europe, 1950). Whilst complementary to the aforesaid convention is the European Convention on the Exercise of Children's Rights 1996 (Council of Europe, 1996). This is particularly constructive in advocating for the principle of hearing the voices of children (Parkes, 2013).
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The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1993) as espoused by the UN General Assembly in 1993 is pertinent also. It has been elemental to the expansion and advancement of disability law (Flynn, 2011; UNICEF, 2007). Beyond this, Browne & Millar (2013) underscore the UN General Assembly Document: ‘A World Fit for Children’ (United Nations, 2002) as consequential for disabled children in Ireland. It demarcates the rights of disabled children, paying particular heed to the right to freedom from discrimination and the entitlement to access services.

Children’s rights in the broader sense have been addressed within the Geneva Declaration of the Rights of the Child of 1924, the Declaration of the Rights of the Child adopted by the UN General Assembly in 1959, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights (Browne & Millar, 2013, p.22; Flynn, 2011). It is the weight assigned to the rights of children, as rights requiring particular care, which Browne and Millar (2013, p.22) consider imperative within the aforesaid. Alternatively of particular consequence to the economic context is the Council of Europe treaty, the European Social Charter (Council of Europe, 1996). It certifies basic economic rights applicable to all humans such as the right to protection from poverty (Browne & Millar, 2013; Council of Europe, 2007, p. 579).

Arising from the prior mentioned measures is also a constellation of children's rights which may be itemized through broad categories. The UNCRC contains numerous elemental rights which pertain to safety and protection, for instance, such as the right to live, survive and develop (Article 6) and the right to protection from violence (Article 19). Some rights have particular applicability for hearing the voices of children. The right to expression (Article 13) and to respect for the views of the child (Article 12) are exemplary of such (United Nations, 1990).

A bone of contention nevertheless, and important point of interest for disability rights in the Republic of Ireland has been raised by De Wispelaere (2013). They highlight that any efforts towards compelling government action through litigation have been broadly unsuccessful. Claims for myriad disability services have been undermined by the lack of a substantive equality guarantee paired with a conservative Supreme Court position on socio-economic rights (Flynn, 2017b, p. 694; Keller & Sweet, 2008; Walsh, 2006 cited in De Wispelaere et al., 2013, p.125; Whyte, 2002).

Considering this, Kilkenny (2002 cited in Browne & Millar, 2013, p. 41) recognizes four shortcomings of the UNCRC as it could apply to the case of intellectually disabled children and young people in times of Irish austerity:

1. Article 23 (1) fails to guarantee the right of disabled children to enjoy a full and decent life through conditions which ensure their dignity, promote self-reliance and facilitate their active participation in the wider community. As such the State has no obligation to act upon achieving this end.

2. The reference to “subject to available resources” undermines the right of disabled children to special care under Article 23 (2) (Kilkelly, 2002, p.120, cited in Browne & Millar, 2013, p. 41).
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3. The stipulation within Article 23(3) that assistance to disabled children should be granted free of charge in any instance possible whilst considering the financial resources of the parents or other persons caring for the child, undermines the basic right to assistance (Kilkelly, 2002).

4. There is no comprehensible needs based entitlement to access to the aforesaid services within Article 23 (2).
   (Kilkelly, 2002 cited in Browne & Millar, 2013, p.41.)

Neverthelesson the whole, the recognition of the rights of intellectually disabled children and young people has incrementally advanced over time (Browne & Millar, 2013; Flynn, 2011; Lansdowne, 2009; Parkes, 2013; Power, Lord & DeFranco, 2013; De Wispelaere et al., 2013). Partially through rights based approach commonly recognized as the preeminent practice within disability movements (Skalecka, 2014) and partially through the honorable persistence of disability self advocates and advocates alike.

2.7 Disability law and policy in Ireland

In the following section, domestic law and policy is considered. As is the case in Ireland, the law and policy infrastructure presents a sometimes useful but necessarily partial means of redress for intellectually disabled children, young people and their families (De Wispelaere et al., 2013; Hamilton, 2012). Within this, it is perhaps important to approach the law for intellectually disabled children holistically rather than exclusively entertaining a sequestered focus on disability specific provisions. Of course general children’s law has applicability to intellectually disabled children; but moreover, some generic provisions could be argued to be more relevant to this population subset. Disabled children are well evidenced to be at a risk of neglect and abuse that is vividly higher, as best evidenced in the large scale study by Sullivan and Knutson study, 2000, (DCYA, 2011) and furthermore, are over-represented in state care (Flynn & McGregor, 2017; Kelly, Dowling & Winter, 2012; Stalker & McArthur, 2012). Therefore Irish generic child protection law characterised by cornerstone legislation the Child care Act 1991, as well as peripheral measures such as the Child Care (Placement of Children in Foster Care) Regulations 1995, are arguably of heightened importance for disabled children.

Bearing these considerations in mind, in 2004 the Irish Government executed sweeping reform of disability legislation (Flynn, 2014c, p.2; Power, Lorde & DeFranco, 2013). Central to the Irish legal framework surrounding disability is the National Disability Strategy (NDS) (2004). The strategy itself was ultimately orchestrated to promote the equal participation of disabled people, the Disability Act 2005 being its cornerstone (Flynn, 2014c, p.2; OECD, 2008; Power, 2012; Power, Lorde & DeFranco, 2013).

At first blush De Wispelaere et al. (2013) remark, the strategy situated Ireland as a frontrunner in the implementation of the UNCRPD. This government strategy amalgamates law and policy in the furtherance of social inclusion for disabled people in Ireland, including intellectually disabled children and young people, and incorporates a multi-annual investment program. Core legislative ingredients are the Education of Persons with Special Educational Needs Act (EPSEN) 2004, the

The Disability Act 2005 as the strategy’s legislative centerpiece (Hamilton, 2012) placed the establishment of a centre for universal design and a statutory entitlement to an assessment of health and educational needs within its myriad progressive measures. Yet Flynn (2011) concedes the human rights foundation of the Act is undermined by stern restrictions on resources that limit enforceability (Hamilton, 2012). The HSE employee or ‘Liaison Officer’ as referred to under the Act, is charged with preparing the assessment report, and should not take account of cost or availability within this. However, the subsequent ‘service statement’, outlining services that are to be provided, is obliged to account for available resources. Section 11 of the Act requires the assessor to take account, \textit{inter alia}, the ‘practicability’ of providing services to the applicant and ensure service provision does not exceed expenditure in excess of the amount allocated to the approved service plan for the HSE for the relevant financial year. Finally, Section 5 (5) of the Act prescribes additional limitations on resources by requiring the Minister of Health to not allocate additional resources even if the cost of provision under the Act cannot be met out of resources allocated for the year (Hamilton, 2012, p.222).

Nonetheless, within the legislative and policy matrix advocacy can become the methodology through which intellectually disabled people contest funding decisions, or lack thereof (De Wispelaere et al., 2013; Flynn, 2014a). The relevance of the Citizens Information Act 2007 can be seen in light of this. It provides for the establishment of a National Advocacy Service (NAS) to enable marginalized disabled people to access an independent advocate (Flynn, 2014a, p. 19). NAS regional advocates are sanctioned to act toward the empowerment of disabled people in the pursuit of access to justice, services and supports (Power, Lord & DeFranco, 2013). Regrettably in practice this service is unattainable for children and young people due to their tender age, leaving them at a distinct disadvantage in the context of recessionary cutbacks (Hamilton, 2012).

Beyond this, one of the most progressive and critical ingredients of the NDS are the sectoral plans. These were delivered for six government departments and delineated a pathway for the delivery of services to disabled children and adults (OECD, 2008; De Wispelaere et al., 2013). In terms of intellectually disabled children and young people for instance, the Education of Persons with Special Educational Needs Act 2004 affords a right to an education appropriate to their needs and preferably, where favorable, in an inclusive manner (Ward, 2010).

Such measures have been more than a promise, yet less than a reality. Indeed the government’s commitment to the NDS has been a contentious issue since the advent of the downturn. Disability advocates have vigorously campaigned for this commitment to persevere in the face of economic austerity (National Federation of Voluntary Bodies, 2011; Power, Lord & DeFranco, 2013).

Subsequently and resultantly the National Disability Strategy Implementation Group furnished the government with a National Disability Strategy Implementation Plan in July 2013. Such a plan embodies a renewed commitment to the promises enshrined within the 2004 Strategy (Flynn, 2014a, p. 19; Power,
2. Context

Lord & DeFranco, 2013; National Disability Strategy Implementation Group, 2013). Concurrently the implementation of the strategy has been supervised by the Senior Officials Group on Disability which provides reports to the Cabinet Committee on Social Inclusion and the National Disability Stakeholder Group (Flynn, 2014; Power, Lord & DeFranco, 2013, p.382).

Needless to say, the most prominent threat to the promises of the 2004 strategy and justifiability relating to services per se, has remained the economic recession. Relevant here is the World Report on Disability (WHO and World Bank, 2011) which collates information for the support of the global implementation of the UNCRPD. It offers nine key recommendations. One of which is the prerequisite for adequate funding in order to actually implement domestic measures arising from the UNCRPD (Officer & Shakespeare, 2013).

Indeed whether the promises exchanged for this implementation plan shall be fully realized has yet to be seen. As Professor McCallum remarks in the foreword to Flynn’s (2011, p.xviii) critique of the 2004 strategy, one must bear in mind; ‘no matter how well-intentioned policy makers may be, without adequate funding such programs remain aspirational’ (Flynn, 2014a, p. 20). It would be remiss to omit here the shortage of resources highlighted within the Report of the National Reference Group on multidisciplinary disability services for children aged 5 to 18 years. It advises the HSE for the purpose of informing the Cross Sectoral Team for the implementation of the Disability and EPSEN Acts and concedes that children are both subjected to long waiting lists and a concerning absence of interdisciplinary services for children with mild intellectual disability (National Reference Group, 2009).

One can see the importance, given this ineptness of provision, of Ireland's equality framework. Here broadly speaking, the Disability Act 2005 extends from Irish legislation such as Employment Equality Act 1998, the Equal Status Act 2000 and the Equality Act 2004. The Employment Equality Act 1998 is responsible for a government policy watchdog; The Equality Authority (Power, Lord & DeFranco, 2013) which was restructured under the Irish Human Rights and Equality Commission Act (2014) to the Irish Human Rights and Equality Commission.

Alternatively the Equal Status Acts 2000-2004 pertain to the prohibition of discrimination on the grounds of disability, in the provision of services and entertainment (Curry, 2003; Flynn, 2011; Hamilton, 2012; Ward, 2010). A condemnation exists therein whereby a service fails to do all that is reasonably practicable to accommodate a disabled person through special treatment or facilities (Hamilton, 2012, p.221; Quinn & Redmond, 2003). Again however, the practicality, accessibility, and even possibility of utilising these measures as an intellectually disabled child or young person appear modest. Furthermore under Equal Status Acts, service providers are not obliged to provide special facilities or treatment when the cost involved is greater than a nominal cost. Parents and guardians may bring discrimination issues to the Equality Tribunal under legislation on behalf of their disabled child or young person (Hamilton, 2012, p.220).

Given this, the Value for Money Report is also crucial to a choate perspective on the policy context of the great recession and childhood intellectual disability. It is
a review document of the Department of Health on the Value for Money and Policy Review of Disability Services Program. The program scrutinized both HSE Disability Services and disability services that had service level agreements with the HSE. Its intention was to quantify the efficiency with which funding was allocated. Numerous recommendations were made, espousing a person-centered ethos; all of which were unaccompanied by funding (Department of Health, 2012; Flynn, 2014a, p. 19).

In terms of constitutional law, Howie (2010) examines legislation for children with special educational needs in the Republic of Ireland. She considers an important talking point to be the contrast between the use of the term 'people' and 'citizens' in the Irish Constitution as all those deemed equal before the law (Bunreacht na hÉireann, 1937) and the explicit reference to disabled people in the Disability Act 2005 and the Education Act 1998. Whilst there is no specific reference to disability in the Constitution of Ireland, the need to satisfactorily resource services for disabled people is sustained from the pledge contained in Article 45.4.1. as follows, ‘the State pledges itself to safeguard with especial care the economic interests of the weaker sections of the community, and, where necessary, to contribute to the support of the infirm, the widow, the orphan, and the aged.’ (Government of Ireland, 1937; Hamilton, 2012).

Finally in terms of housing, as mentioned already, a departure from the residential circumstance of disabled people living in congregated settings, has been broadly governed by the HSE Report, 'Time to Move on from Congregated Settings: a Strategy for Community Inclusion', published in June 2011. This report has galvanized a rapid process of downsizing the institutional populace of disabled people in the Republic of Ireland (Health Service Executive, 2011; Rimmerman, 2012; Soldatic, Morgan & Roulstone, 2014). The National Housing Strategy for People with a Disability 2011-2016 (Dept. of the Environment, Community & Local Government, 2012) is important also given that it aims to promote equality of access to appropriate housing for disabled citizens.

Where a disabled child is residing within a residential home provided by the State, the monitoring of standards regarding the same falls within the remit of the Health Information and Quality Authority (HIQA). The progressive National Standards for Residential Services for Children and Adults with Disabilities (HIQA, 2013) aspire to safe, effective and person-centred services. Concurrently the response to disabled children living in the community and in contact with TUSLA child protective services is subject to the National Standards for the Protection and Welfare of Children (2012) and peripheral legal framework typified by the Child Care Act 1991 (Hamilton 2012; Nester, 2003; Nester, 2011; Shannon, 2010a; Shannon, 2010b; Ward, 2010). Yet, within this, families may also find themselves caught in the convergent space between TUSLA and disability services, as services vie for accountability with respect to the provision of funding. Overall, disconnect between the wider operation of services (as an under labourer to the aspirations of Irish policy discourse) and the reality for intellectually disabled children and adults is regrettably evident (Browne & Millar, 2013, p.3; Flynn, 2015, p.31).
2.8 Disability and the economic policy landscape

Whilst progressive change in children’s rights has been realised in the Irish context (Hamilton, 2012; Kilkelly, 2008) in-egalitarian austerity policies may undermine this (Lynch, Cantellon & Crean, 2017). In this final section economic policy concerns will be contextualised.

Through austerity and arduous recovery (Flynn, 2015), Tusla, the Child and Family Agency is the dedicated State agency for improving outcomes for children in Ireland (McGregor, 2014). In 2013, Tusla published a guide for parents of children and teenagers in Ireland trying to cope with the aftermath of economic recession. It responded to findings of a major Irish study conducted in 2012 by the Department of Children and Youth Affairs (DCYA) which included intellectually and learning disabled children and young people who attended mainstream schools. The guide reported that, for children and teenagers, the worst thing about living in Ireland is the recession and current financial situation.

It was recognised that parents often pass the stress of financial worries onto their children as acknowledged in UNICEF’s international work (2013). Tusla was also concerned with the children’s self-reported distress around the ‘doom and gloom’ perpetuated by Irish media coverage of the recession which Kiernan Allen (2009) alludes to in his account. The guide conceded that; “It is striking that primary school aged children were concerned about the recession and the financial problems which faced their parents, struggling to pay bills and parents’ employment situation” (Conroy, 2013, p.7).

Yet, as Flynn (2017a) discusses, there are a number of competing perspectives on economic recession. For some, it would appear that the recession was a social artefact (Gamble, 2009). Something not about economic determinism, but rather in Polanyi’s (1944) terms, concerned with how capitalist crisis coexists with social crisis: compromising social bonds under the free forces of the market (Dodd, 2016). Here Polanyi’s work focuses upon the early globalisation of capitalism. Yet, commonalities between classic and contemporary articulations of economic recession are evident according to Flynn (2017a). In this way Keirnan Allen’s (2009, 2012) work, and complementarities such as Gamble (2009), are also of the contention that recession is principally related to social suffering- suffering socially constructed through inequality within society. Such conceptualisations of economic recession run counter to austerely economic and essentialist perspectives that maintain focus upon finance, material and monetary deprivation alone. Rather, Flynn (2017a) contends, social constructionist and social justice positions better align themselves, albeit in some cases unintentionally, with a ‘materialist’ social model of disability.

This ‘materialist’ social model refers to ‘materialism’ in the classic Marxist sense. In this way it is related to the Marxist Theory of Capitalism, and the analysis of economic redistribution in the economic structures within society, for instance, the division of labour or property ownership (Flynn, 2017a) or the generosity of social protection that tempers the effects of recession (Visser, Gestuizen & Scheepers, 2014). This point feeds back to the topic of the study at hand, as childhood intellectual disability and economic policy in Ireland are fundamentally grounded in the distribution of capital in society. Discretion should be exercised...
however, so as not to conflate ‘materialism’ -as something related to the critique of the allocation of wealth and economic structures in a given society-with ‘materialism’ where ‘material’ is referencing physical actuality.

The latter reference, Flynn (2017a) argues further, is one perhaps best understood as an antithesis to non-material concerns, such as culture, language and discourses. Here a disparity is evident between the traditional foci of Critical Disability Studies (CDS) pertaining to culture, language and discourses; and the foci of the classic social model, as concerned with political activism grounded in the ‘material’ domain – for instance, the practical and material deprivation that Irish intellectually disabled children and young people must endure within the adverse effects of austerity. Here CDS, through its affair with the ethereal must strive for insights that retain practical application for disabled people, and within this, intellectually disabled young people (Flynn, 2017a). Overall, these differing positions are relevant to the present concern with economic policy, as Marxist materialism, and the juxtaposition of material reality to cultural, lingual and discursive matters, all represent cornerstones within the constellation of focal points, from which economic policy has had its appraisal. Indeed, the DCYA’s research consultation in 2011, where 66,705 children and young people in Ireland took part, reflected a multifaceted experience of austerity for the young participants. A culture of stagnation, for instance, where young people reported ‘knowing they couldn’t get a job when they finished school’, ran concurrent to their exposure to the language of despondency recycled in the media; and was again additional to everyday material concerns around, for instance, the cost of food and clothing (Conroy, 2013; DCYA, 2012a).

Bearing this in mind, the harmful effects of culture and discourses for intellectually disabled young people, and their families, in terms of economic policy may be covertly embedded, a circumstance that CDS is well placed to address. Flynn (2017b) identifies how, in post-socialist welfare states, particular challenges are posed for disabled people by free market economics and the neo-liberalist project. Austerity measures within disability policy that foster dependency on the open market (Harris, Owen, & Gould, 2011) or reduction in public expenditure on social services (Grover & Soldatic, 2013) are some of those most explicit. Others take a more clandestine guise, as identified by Mladenov (2015). Upon his inspection of neo-liberalism, post-socialism and disability, Mladenov claims surprise at uncovering the neo-liberal and neo-conservative underpinnings of the discourse that surrounds concerns for a ‘dependency culture’ that is nurtured by social welfare payments (Flynn, 2017b).

Progressing this further, by way of CDS insights, the notion of a ‘dependency culture’ appears potentially reinforced by an able bodied: disabled binary that assigns disabled people to a category less advantageous. Such an ‘othering’ of disabled people, and within this, intellectually disabled children and young people, may make the distribution of wealth divert from their prerogatives. Yet, there is an irony in the antagonism towards welfare provision, when one considers the fragility of the human condition, and the instability of categories such as disabled and able-bodied, where perhaps disability might best be considered as a position that we are all liable to associate with (Davis, 2002). In this line of thought, and as Strier (2013) restates, the original intent of the welfare state was to afford a measure of insurance (for all human bodies) against the cyclical nature of capitalism (Flynn, 2017a, p. 154).
It would appear, however, that neo-liberal economics in Ireland have been particularly threatening for intellectually disabled young people, and their families. As Judith Butler (2015) concedes, we are in a time of neo-liberal economics in which economic self-sufficiency is presented as a moral imperative. Under circumstances where such economic self-sufficiency is unattainable, it leaves some communities grappling with a devastating contradiction. Mladenov (2015) builds upon this, contending that contemporary disability policy, such as that being discussed at present, should not be examined without critical engagement with the doctrine of neo-liberalism. Flynn (2017b) raises concerns however, that within such an engagement, there are trappings which one may be challenged to evade. Firstly, Ganev (2005, p. 345) points to an ‘anti-neoliberal orthodoxy’ in modern academia. Such orthodoxy may well convert into a gullible acceptance of the anti-neo-liberalist stance that lacks critical engagement with the doctrine in question. Neoliberalism then risks becoming a complex phenomenon largely left unproblematised; whilst it may be true that with every dark cloud comes a silver lining (Flynn, 2017b, p. 2). Progressing this further, Flynn (2017b, p.679) then points to Sheldon (2009) who claims that economic meltdown brought with it a new synergy for anti-capitalism, helping to divert attention towards the social divisions at the heart of economic inequality.

Yet further pitfalls are raised by Flynn (2017b) in the engagement with neo-liberalism and disability; In particular, Mladenov’s guidance towards the avoidance of a one-size-fits-all approach to neo-liberalism that neglects local specificities (2015). In this way, it is clear that the practical application of Medicalisation, expert-focused models of disability, and developments such as Wolfensberger’s (1972; 1991) Normalisation and Social Role Valorisation, have greatly manipulated the present form of service provision for intellectually disabled children and young people. However, just as is the case with marketisation and neo-liberalisation, these driving forces have distinct consequences in differing localities (Flynn, 2017b; Grover & Soldatic, 2013).

With this in mind, Flynn (2017b, p. 679) describes Conneely and Garrett’s (2015) work on social justice and the post-recession period of intensive neo-liberalism specifically within the Republic of Ireland. Here the recent government response to economic crisis is considered particularly destructive, occurring in the context of the acquisition of resources by the very wealthy through pathways such as the reclamation of gains from public services. Further to this, Conneely and Garrett (2015) present research evidencing the manner through which Irish newspapers principally have supported the programme of austerity whilst neglecting to engage with the assortment of alternative options. Conneely and Garrett contend that re-igniting attempts to accomplish social justice is critical in times of intensive neo-liberalisation, ultimately conceding that the current Irish context remains one of ‘precarious hegemonic neo-liberalism’ (Flynn, 2017, p.679). In this economic climate, it would appear that intellectually disabled children and young people, their families, and their allies, may be at a significant disadvantage.

2.9 Overall conclusion

This chapter offered context for the study. Following a socio-demographic pen picture, an introductory history of intellectual disability in Ireland introduced key areas, cognisant of the omission of disabled voices in available accounts, and therefore avoidant of universalistic judgements that might colonise
unrepresented voices (Atkinson & Walmsley, 2010; Marks, 1999). It examined segregation through institutionalisation; religious Catholic Orders; divergence between medical and religious discourses; and progression towards a more inclusive social model (Redmond & Jennings, 2005). The nature of the present day service infrastructure followed. Here increased state interference in historically autonomous providers (Power & Kenny, 2010); lethargic and as of yet incomplete deinstitutionalisation (HSE, 2011); and inequitable intra-county variation in service provision (Caples & Sweeney, 2011) were noted. Next, human rights law was considered as a natural reference point for concerns about the effects of austerity. And following this, domestic law and policy were over-viewed paying heed to De Wispelaere’s (2013) assertion, that any efforts towards compelling government action through litigation, had thus far been broadly unsuccessful. Finally, the economic policy context was discussed as it pertains to intellectually disabled children and young people, their families, and their allies, in Ireland. While allowing this context to intellectually ferment, we progress now to critical literature review as follows.
3. Literature Review

3.1a Introduction

Having just established some context to the topic at hand, the present chapter will offer a critical review of the study’s relevant literature. That is, the study concerned with the core research question: How have intellectually disabled young people, and their families, who avail of services from the disability sector, experienced the economic downturn? Within this, research aims refine the task of responding. They are;

- To investigate how both intellectually disabled young people and their families have experienced the economic downturn.
- To explore the impact of the recession on the lives of intellectually disabled young people.
- To critically inform practice and policy development for intellectually disabled young people with a view to informing a partnership approach to service provision.

The chapter progresses as follows. First, the conventions of the particular literature review strategy are clarified. Next, by way of a narrowing focalisation towards the particular instance of intellectually disabled young people in Ireland, it is possible to identify a number of emergent themes, arranged into sections as follows. First, the theoretical framework of the study is set out in the context of discussion of relevant theory. Then, the contested nature of the impact of recession on intellectually disabled young people, and their families, is established (Flynn, 2017b; McGinnity et al., 2014) by reviewing the existing marginal material towards the positive implications of economic recession, and building upon discussion in the former context chapter. Next, the review considers the technicalities of making calculations around the impact of economic recession on intellectually disabled young people and their families. Here, it would appear that the task at hand is inherently complex, by way of such abstract and ethereal considerations as opportunity costs and emotional suffering (Cullinan, 2015; Emerson et al., 2004; UNICEF, 2013b). The review then examines established cutbacks and losses to the service infrastructure for intellectually disabled children and young people, and their families (DFI, 2010; Disable Inequality, 2016). Finally, taking a broader societal perspective, the notion of the disproportionate disadvantage of intellectually disabled young people, and their families, is tentatively addressed.

3.1.b Epistemic defence:
Why particular themes are shown and others not; And why some literature is featured and discussed more than other literature.

Before proceeding, some further clarification is required with regard to the structure of the literature review. In the methodology chapter that follows, in-depth discussion of perceived dichotomy between quantitative and qualitative poles of research is presented (Becker, Bryman & Ferguson, 2012; Silverman, 2017; Silverman, 2015). Adjunct to this is an exploration of sustaining philosophies
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and peripheral concerns such as ‘social constructionism’; ‘rigour’; and ‘validity’ (Bryman, 2015). In addition to this, the present chapter will soon outlay precise methodological search strategies for the review of literature at hand. First and foremost, however, the present section must speak to the question of why certain themes and material feature in the literature review, and others do not.

Scepticism towards seemingly subjective research processes arises from naturalised epistemology that promotes research activity exclusively under a rubric of objectivity and systematisation (Bryman, 2015; Silverman, 2017). The transcendence of ‘truth’ over subjective opinion is an assumption that is held in the practices of quantitative science that adopts this stance (Carey, 1998 cited in Outhwaite & Turner, 2007). The themes featured in this study’s literature review are featured, or accordingly named, because the researcher simply considered them to most accurately summarize the overall body of literature reviewed; having comprehensively considered, critically reflected upon, and critically discussed the material (Bryman, 2015). In this way it is a classic or narrative literature review (Bryman, 2015; Silverman, 2017). Within this, the researcher sought to disregard any assumptions, hopes or biases, and best represent the patterns in the material as objectively as possible. This differs from methods of literature review, such as systematic review, where numerical calculations dictate the patterns of reduction and presentation of material (Bryman, 2015).

By way of further defence, Micheal Foucault’s work, namely, Archaeology of Knowledge (Foucault, 2012) and his critical insight into the interrelationship of power and knowledge (Foucault, 1980) delegitimizes claims of a particular and proper hierarchy of knowledge that is progressive and linear. Descartes’ (Descrates & Moriarty, 2008) work, as an under-labourer of ontology and episteme, undermined confidence in predictable and measurable causality between the structures of our consciousness and ‘external’ phenomena. Further and notable extensions of phenomenological debates around episteme are developed by key thinkers as Heidegger, Husserl, Satre and Derrida. Suffice to say, the philosophical field of epistemology (concerned with knowledge, and what it is to know) is extensively developed with regard to validity and nature of paradigmatic epistemological ‘facts’ and knowledge claims (Jarvie & Zamora-Bonilla, 2011).

It is well beyond the scope of this thesis to map this. Some synthesis, albeit an over-simplification of complex debates, can however identify broad areas in the social sciences around which scholarship on formal knowledge has developed. For instance;

- Historical analyses of shifts from Modernity to Post-Modernity (and to a lesser extent, towards High-Modernity) concerning the dawn of scientific reasoning (Garrett, 2013; Grey & Webb, 2012; Payne, 2014)
- Oppositional dichotomy between Social Constructionism and Essentialism (Burr, 2003). (In disability theory this has been predominantly expressed in Social Model vs. Medical Model/biological essentialism as an oppositional dyad (Goodley, 2004; Oliver, 2013; Oliver & Barnes, 2012; Oliver, Sapey & Thomas, 2012).
- Cultural imperialism of knowledge: How identity politics has disenfranchised minority communities’ theories and ways of knowing; and prioritised white western patriarchal systems of thought (Grey & Webb,
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2012; Payne, 2014); CDS develops this argument in disability theory around the divide between Global North and Global South (Erevelles, 2011; Goodley, 2013).

In the context of these areas, the influence of Poststructuralism and Postmodernism have deconstructed and de-authorised existing frameworks, leaving perhaps a sense of having little to cling onto (Garrett, 2013; Shildrick, 2012). Nonetheless, as John Francis Lyotard’s (1984) classic ‘incredulity towards metanarratives’ usefully instilled, new confidence was found in small and localised knowledge claims.

Overall, the central point being made is simple: there is perhaps no best way to conduct a literature review, because there is no universally agreed best way to know something. Nonetheless, there are practices generally accepted to be appropriate and responsible. Being comprehensive in the literature review search; being theoretically and philosophically consistent throughout a research study (inclusive of the grounds for literature review strategy); and fairly presenting material (Bryman, 2015; Silverman, 2017). Further, the present review may be judged on its merit in terms of its aspired outcomes, as listed below and derived from Bryman (2015, p. 95):

- To afford the researcher an in-depth knowledge of the research topic so as not to replicate existing studies.
- So that readers of this thesis can understand the topic and background.
- To afford the researcher an opportunity to learn from others mistakes.
- To identify unconsidered variables, research questions, and to inform methodology and theory.
- To inform interpretation of findings.
- To establish the significance of this study in the context of wider research. (Bryman, 2015, p.95)

With these outcomes in mind, the following section will offer transparency around the mechanics of conducting the review.

3.2 Methodological observations

The literature review was carried out as follows. A computer based search was undertaken. A literature search aid formed the basis of the same, which, for instance, listed search terms of synonyms arising from components of the central research question. The main search engine was the James Hardiman Library database, whilst within this, an expert University based subject librarian was liaised with in respect of search strategies. Truncation and wild card operators were also employed therein. Specific search criteria were pre-standardised. In this way, an example of one such exclusion criterion was literature older than 1980, where such literature is not already classed as seminal work. Both peer-reviewed and non-peer reviewed material was included to support the incorporation of ‘grey literature’ (Bryman, 2015). In addition, the initial search was confined to English language only and extended beyond an abstracts only search.

Twenty-one databases were searched, sometimes under the refinement category of ‘Arts, Social Sciences & Celtic Studies’ databases. Databases were as follows: 1. Arts and Humanities Citation Index, 2. Applied Social Sciences Indexes and
3. Literature Review


Search terms used in varying combinations were: “disability/disabled, recession, children, child, economic, funding cuts, childhood, vulnerable, learning disability, downturn, financial crisis, finance, impact, effect, autistic, autism, collapse, civil society, education, policy, Ireland, Irish, poverty, voluntary, sector, cuts, cutbacks, financial collapse, cost, special needs, intellectual disability, learning difficulty, Downs Syndrome.”

An excel spreadsheet recorded the exact combination of search terms and databases used alongside the date of the search and citations retrieved. The replication of results, and incrementally increasing difficulty experienced in sourcing new material, was perceived to be a welcome indication that the search strategy was working. Studies and literature located and accepted for inclusion were inputted in a document, which characterised them using a legend in terms of their significance or form (i.e., quantitative). This document served only as a focusing aid for the compilation of the narrative literature review. Papers or material were initially selected for screening where they adhered to one, or a number of the following:

1. Pertained to intellectual disability.
2. Pertained to children/young people or their families.
3. Pertained to Great Britain or Ireland.

Furthermore, generic Google and Google Scholar searches were undertaken, again using replicable and recorded search terms and pathways. A search based upon more specialised or specific search terms was also later conducted geared at generating specific data, i.e; ‘medical model’ or ‘affirmative non-tragedy’ during the process of constructing the narrative review. Finally, field trips were undertaken to St. Micheal’s House, the Muirioisa Foundation and HSE libraries for hand searching of books within disability service provider’s archives, whilst material was also manually obtained from the James Hardiman library and through conferences, seminars and other fora.

At this juncture, a presenting limitation of this literature search methodology was also circumspectly considered. This limitation has been coined the ‘file drawer problem’ or issue of publication bias (Bryman, 2015). Bryman (2015, p. 106) succinctly sets out this phenomenon as the instance of a researcher finding that an independent variable does not achieve the intended effect. He/she therefore experiences difficulty in getting the work published leaving the file to be demoted to a drawer somewhere. In reparation for the above, this study also commenced an active search for unpublished material by liaising with relevant academics. This generated some, but comparatively little further material. Nonetheless, it formed
only part of an overall literature search strategy that incorporated comprehensive record keeping within its modus operandi. It would appear that such a premeditated systematic approach, whilst not systematic reviewing per se, contributed to the author’s confidence and efficiency within the task at hand.

Bearing these procedural matters in mind, this chapter will now progress the insights of the prior introduction and context chapters, through drawing out key themes from the body of core literature and research material. It does so in order to investigate the impact of the economic recession upon intellectually disabled children and young people, and their families, within the Irish context.

3.3. Theory informing the specific approach to disability

To begin, it is useful to consider the theoretical context of the study. From the early 1980s a paradigmatic shift from biological reductionism to social constructionism began to be perceptible (Oliver, 2013). The latter encompassed social approaches such as the Nordic Relational Model, Social Constructionist and the North American Minority Group Approach (Shakespeare, 2014). In the Irish and British context it was the seminal Materialist Social Model (and its varied reiterations) that brought with it new vitality for socio-political activism (Goodley, 2013). It performed, notwithstanding material gains for disabled people and their allies, a discursive exorcism of the traditional causal link between impairment and disability (Oliver & Barnes, 2012). Influenced by Marxist sociologies of the 1970s and radical structuralism (Goodley, 2016), the social model offered some release from the stranglehold of the medical model’s essentialist and modernist conceptions of the body and mind (Flynn, 2017a; Shakespeare, 2014). Concurrently, there was much to gain from outstanding empirical research contributions from the medical model and medical sociologies (Shakespeare, 2014).

Yet, the economic determinism and dictatorial Marxism allied to the social model (Flynn, 2017a; Meekosha & Shuttleworth, 2009) seemed increasingly ill-equipped for the nuanced cultural, lingual, relational and discursive ‘realities’ of disablement (Goodley, 2013). As other abstract responses to social location emerged, such as Butlerian Performativity, new possibilities came with Critical Disability Studies (CDS) and its post-conventional, post-structural, and post-modernist ingredients (Flynn, 2017a; Goodley, 2013; Shildrick, 2012). Nonetheless, with such developments came the threat of over-abstraction, driving theoretical responses to ‘dis/ability’ beyond the realm of practical application or potency for disabled people constrained by the corporeality of impairment, and the impasse of their material worlds. As Flynn (2017a) concedes, the capitalistic crisis of economic recession would at first blush seem to be a problem of material deprivation; aligned to the maldistribution of capital in a given society- a traditional agitation of historical materialism and classic Marxism (Bukharin, 2011). Recession brought with it new reformulations of disability, and raised the question of the usefulness of existing theorisation (Goodley, 2013). Yet, comparatively little theoretical engagement with macroeconomic phenomena such as recession had arisen from the scholarship of disability studies thus far (Dodd, 2016).
Whilst capitalist structural subordination and governementality (Berlant, 2007, p.754) may have shone in the spotlight of economic recession; it’s off stage persona followed in the form of neo-liberal abelist capitalism (Goodley, 2014). Here, the present nature of disablement fell within a historical epoch of neoliberal-abelism (Goodley, 2014). In Goodley, Lawthom and Runswick-Cole (2014, p.981) this term is further refined: “Neoliberalism provides an eco-system for the nourishment of ableism.” Yet in light of the particularity of neoliberalist doctrine to differing geo-political locations (Mladenov, 2015) abelist ‘precarious hegemonic neoliberalism’ (Conneely & Garrett, 2015), albeit complex phraseology, is perhaps the bespoke alternative for the present post recession Irish context. Pedants aside, local specifities and global capitalistic phenomena are owed balanced consideration in theorisation. Berlant’s ‘slow death’ or mass labour induced physical attenuation (Goodley,Lawthom & Runswick-Cole, 2014); and neo-liberalist ‘precarity’ (developed by such key thinkers as Judith Butler, Lauren Berlant, and Isabell Lorey) (Puar, 2012) are some intercontinental phenomena (albeit of scattershot global significance) relevant to the Irish case at hand.

At the same time, Irish local specificities and theories of political economy must take account of historic church-state relations. In this way, Esping-Anderson (1990) nominates the Irish welfare regime in the liberal category of his seminal typology of welfare capitalism. Yet, Irish social policy analysis has begged to differ. Here Ireland is ‘Catholic corporatist’ (Cochrane & Clarke, 1993) in line with its comparatively hesitant state interference in Catholic welfare provision. Either way (and putting wider and developed debates around deregulated capitalism, communism and socialism aside), classic disability theory generally shares with Keynesian economics a support of state intervention into free market economics. In this way, Keynesian economics offered an addendum to classical economic theory (Keynes, 2017) unwilling to suffer the naivety of the claim that the free market economy could always be self regulating.

Re-shifting focus back to disability theory, but not necessarily to disability: Abelism as the latter component of ‘neoliberal-abelism’ is largely mapped out in Kumari-Campbell’s (2008; 2009) work. Concerned less with the corporeality of impairment, abelism sought not just to problematise but to refuse the notion of able(ness) (Campbell, 2008). This marked a shift in perspective from its disability orientated counterpart, disableism. It further followed the positioning of disability in CDS as a place from which to consider the nature of all human bodies (Flynn, 2017a; Goodley, Hughes & Davis, 2012; Shildrick, 2012) A perspective operating outwards from the notion of ‘self and other’ (Flynn, 2017a; Goodley, 2013).

Overall, the epistemologies and ontologies of abelism (Campbell, 2008), and questions about how the corporeal ideal is sustained in ideological reiterations of the perfect body and mind, are important in the context of identity politics. Yet, post-colonialism and CDS’ critical consciousness of the gulf between Global North and the Global South (Erevelles, 2011) raises uncomfortable questions about the centrality of social location: Lest we not forget the incitement of disability and poverty at staggering rates, by way of mass militarised violence, lack of healthcare or abject poverty (Erevelles, 2011; 2014) that are standard features of many foreign geographies. In the Irish context, as recession provoked harsh material realities, peers in Marxist and materialist social camps continued to be suspicious of the capacity of CDS to respond (Flynn, 2017a). Yet, agendas with ostensibly
more theoretical grit in terms of post recession practical application, such as the Human Rights Model (Degener, 2017) or social model approaches underpinned by neo-Marxist and Gramscian analyses (Goodley, 2013) might seem crude or archaic. Sophisticated approaches could attune to the contemporary state of disablement incorporating the psychologisation of disability (Goodley, 2016); material exclusion as a potential product of discursive or cultural problems; and intersectional aspects of discrimination en route to poverty, such as queer corporealities (Sherry, 2004). In this way, post-conventional analytics (Shildrick’s work (2012)) and engagements with postmodernity (i.e. Judith Butler) were more nuanced and adjusted.

Beyond the socio-spatial, the temporal realm of disablement has been of theoretical importance. Priestley (2003) has progressed the life course perspective on disability, helping to address what is perhaps theoretical amnesia in terms of disabled childhoods. Davis’ dismodernism reacts to conditions of postmodernity within which disability is misconceptualised. Furthermore, dismodernism, CDS and other agendas recognise disability as different to other identity positions, e.g. race or gender. Disability is a position that we are all liable to associate with, a continuum of disablement, or pervasive feature of all human life. Bearing economic recession in mind, as we have attuned to the cyclical nature of capitalism (Strier, 2013) and instability of conditions such as ‘disability’, the “precarious nature of the corporeal ideal comes into focus, uncomfortably raising questions about what it is to be able-bodied (Marks, 1999) in a time of economic austerity.” (Flynn, 2017a, p.154). As Flynn (2017a) further suggests framing disability as an anomalous or deviant feature of society supports the misdistribution of wealth away from the priorities of disabled communities.

Beyond this, Intersectionality (as a facet of CDS) offers another theoretical appendage to the discussion at hand. It progresses a unitary perspective on disability studies towards allegiances with other theoretical agendas such as critical race theory, feminism, post-colonialism, queer theory and class constituencies (Flynn, 2017a; Goodley, 2013; Goodley & Runswick-Cole, 2010). It also recognises that sites of signification such as gender and disability are not divorced, and contends that the identity of individual people may occupy the convergent space between multiple and interrelated sites of oppression, e.g. disablement and race (Goodley, 2016). With intersectionality came innovation: Running full speed on the euphemism threadmill (a repetitive cycle of stigma assigned to terms for disabled people e.g. idiots, morans, handicap, retarded etc.) McRuer’s crip theory, queer crips, activists and artists turned to word reclamation and embraced ‘crip’ identities. Other useful collations had been forming; For instance, Garland Thompson’s work (2002; 2005) in feminist disability studies or Campbell (2008) on critical race theory (Flynn, 2017a).

Finally, cross fertilisation of classic theorists and contemporary concerns of disablement also continued to be fruitful. Michel Foucault’s (2012) biopower, as an example, might illuminate how post recession, stringent restrictions to welfare payments forced parents to narrate their children’s disablement and identity, in a language acceptable to welfare professionals. Beyond this, the poststructuralist project had increasingly concerned itself with normalcy in the lingual domain, recognising the ablebodied: disabled binary to be increasingly problematic (Flynn, 2017a). Other departures from arborescent theory were evident. DeleuzoGuattarian CDS, whilst still embryonic (Goodley, 2007), had been in
expansion. Roets and Bradiotti (2012) consider nomadology and subjectivity in the DeleuzoGuattarian context. Therein they called for a shift in disability discourse from the politics of mourning and melancholia, a shift perhaps best embodied in the present study through the application of the Affirmative Non-Tragedy lens (Swain & French, 2000). Seminal Canadian theorist Wolf Wolfensberger responsible for developments of normalisation and then social role valorisation (1995), along with colleague Thomas (1983), encapsulated this melancholia of disability conceptualisation in their typology of disability identities (e.g object of pity, eternal child). Here the pervasive tragedy view of disablement was evident. This perhaps leads us naturally into discussion of the position of the present study in the context of these theoretical developments. In sum, the theoretical framework for this study places an Affirmative Non-Tragedy Model within the broader field and paradigm of CDS. The emphasis of the study is phenomenological, whilst the orientation is toward social justice.

The Affirmative Non-Tragedy Model was developed by French and Swain (2000). Flynn and McGregor (2017) have progressed its potential and practical application in the Irish context, as an operational lens for working with disabled children. The social model is a significant model in the Irish and British context and therefore can provide a useful illustrative comparison to the Non-Tragedy Model. The social model locates the problems of disability in society rather than with the impaired individual (Llewellyn, Agu & Mercer, 2008). The Non-Tragedy Model builds upon the social model rather than opposing or contradicting its conventions. It acquires its individuality, however, through fortifying the implicit resistance in the social model against conceptualisations of disability associated with tragedy, pity and loss. Therefore its central character becomes about affirming the positive aspects of disabled lifestyles (French & Swain, 2008; Swain & French, 2000). An illustrative implication of this, in the study at hand, was that any assumption that disabled young people might wish not to be so, was at the outset discarded. The model reinforced the need to listen to disabled children’s voices (Flynn & McGregor, 2017; French & Swain, 2008) in line with the research aims. Further, it usefully addressed the concern that the study’s findings might contribute to charity and tragedy discourses which disabled people and their allies had already deemed unhelpful (Goodley, 2011). With this in mind, it would be remiss to omit the models criticisms: Namely and primarily that its focus on the positive implications of disability may neglect the lived reality of impairment such as chronic pain (Feely, 2016a; Flynn & McGregor, 2017). Comparatively, as demarcated in Flynn (2017b), the astringent reality of austerity, and the social-economic disadvantage that made it permissible for disabled children and adults, (DFI, 2010) could not be diluted by an undue focus of affirmative aspects of disability.

Overarching the Non-Tragedy Model in this study is the paradigm of CDS, as previously demarcated. Flynn (2017a) establishes the potential of CDS as an appropriate means to understand the impact and experience of economic recession for disabled children and adults. As implied, CDS contests disableism and biological conceptions of disability better associated with the traditional medical model of disability (Flynn & McGregor, 2017; Goodley, 2001). Furthermore, it is essentially concerned with the social inclusion and empowerment of disabled children (Flynn & McGregor, 2017). As noted, it occupies a trans-disciplinary space, lying where disability studies intersect with
other agendas such as queer, class, postcolonial and feminist transformative theories (Flynn, 2014a, p.29; Goodley, 2011; Goodley & Runswick-cole, 2010).

In terms of potential criticisms of CDS, Flynn (2017a) establishes how its post-structuralist and post-modernist ingredients have been criticised for failing to engage with the material world within which disabled people encounter barriers (Feely 2016; Flynn 2017a; Shakespeare, 2014). This occurs through a prioritised focus upon cultural, lingual and discursive matters. Flynn (2017a) takes up Barad’s work in drawing to a close on the matter:

“As Barad (2003, 801) concludes, ‘Language matters. Discourse matters. Culture matters. There is an important sense that the only thing that does not seem to matter anymore is matter. (Puns intended’). In this article, I have posed the question of how we might come to understand this circumstance, in the wake of a momentous economic recession, in which what matters appears to be exactly that – matter, or more precisely the lack thereof.”

Nevertheless, bearing this challenge in mind, Flynn (2017a) ultimately concludes that CDS can generate insights into economic recession that can have practical application for disabled children. In this way it is deemed a useful and appropriate paradigm to come to bear on the present research.

3.4. Playing the Devil’s advocate: Could the recession be a good thing?

Theory aside, there are a number of points to cover with regard to the overall reading of the literature, as it relates to the impact of the recession in Ireland on intellectually disabled young people and their families. The recession itself, as a transformational period, offers an opportunity to progress the limited knowledge base on the socio-economic experience of intellectually disabled children, young people, and their families in Ireland. To date, this is a critical area for attention, with respect to the well established links between intellectual disability and poverty (Emerson et al., 2010), and yet remains broadly neglected (Flynn, 2017b). Major changes have been brought about through austerity, contributing new meaning to the term disability, and raising the question of how useful current theories of disability are (Goodley, 2013). Yet, the present discussion must interject into the persistent debate around what social groups constitute those most vulnerable in times of socio-economic threat (Flynn, 2016; Streir, 2013). Within this, a limited proportion of the literature is contrary to the case sustained in this chapter overall. With a view to achieving some balance in the literature, this section will engage with this minority material in discussing the possibility that economic recession has not impacted intellectually disabled young people and their families significantly, nor to a greater extent than others.

Hogarth et al. (2009) contend that there is no substantial evidence, to support the contention that disabled people have been disproportionately impacted by the negative effects of recession. Flynn (2017b, p290) aligns this to the ostensibly inclusive discourse referred to by Allen (2009) as being emergent in post-recession Ireland. As Allen explains, this was a discourse seemingly embodied in the common message of post-Celtic Tiger Ireland. The message was that ‘we are all in this together’ (Allen, 2009, p. 150). Of course, the fact is, that we are not (Flynn, 2014). Flynn (2017b) points to Power, Lord, and DeFranco’s (2013)
contention that Ireland has in fact maintained its commitment to pursue the reform of disability services since the inception of recession. Within this, they contend that the positive reconfiguration of expenditure may even have been achieved through recession, leading to an increased cost-efficiency in the administration of services. Yet, Flynn (2017b) makes the case that whilst the administration of services may indeed have improved; this doesn’t seem to substantially detract from the overall decimation of services with specific respect to intellectually disabled children and young people in Ireland. For instance, sources such as McGinnity et al. (2014), assert that the onset of economic recession has strictly curtailed the resources available to execute progressive measures. This follows evidence that previous recessions disproportionately negatively impacted disadvantaged social groups (Gore & Parckar, 2009).

Overall a significant absence of material is palpable, in terms of validating the opinion that the recession was positive. Jackson (2011) for instance finds that a flagging of the quality of services for intellectually disabled children and young people invariably arises from economic recession, as is the resulting and momentous damage to their general quality of life. This may be considered in the context of Emerson and Hatton’s (2009) assertions that the lower socio-economic, and poverty status, that intellectually disabled children and young people in particular experience, may be a substantial basis for their increased vulnerability with respect to health care problems. Therefore, in considering both perspectives, Flynn (2017, p691) concedes that in times of recession, intellectually disabled children and young people might be considered to be in particular need of quality health care services at a time when Jackson suggests such services are compromised for them. Whilst Jackson’s work pertains to the U.K. context, Flynn (2017b) points to Eilionoir Flynn’s work (2011) establishing a similar deterioration of services in the Republic of Ireland, and shedding light on prolific system failings as a result of economic recession. These are just some examples of the majority material that suggests that the recession has been negative for intellectually disabled young people and their families.

3.5 Complexity in the relationship between childhood intellectual disability and financial status

Flynn (2017b) examines the impact of the Irish economic recession on intellectually disabled children and their families, establishing a high risk of poverty in times of economic austerity. The relationship between poverty and intellectual disability is comprehensively established through decades of research evidence (Emerson & Parish, 2010). Therein, intellectually disabled children and young people are significantly more likely to be poor (Emerson, 2004; Flynn, 2017b); to form part of income-poor families; and to encounter material hardship, than their non-disabled peers (Emerson et al., 2010; Flynn 2017b, 682).

Heightened unemployment produced by Irish economic recession (Allen, 2009) is relevant to families of intellectually disabled children and young people, as they are more inclined toward income poverty and material hardship, and this is most attributable to changes in employment wage status (Emerson et al., 2010; Flynn, 2017b). Furthermore, where the Irish economic recession resulted in a high rate of jobless households, this was most so in the case of those homes containing children (NESC, 2013).
Parents of intellectually disabled children are more susceptible to experiencing poverty than parents of non-disabled peers (Parish, Roderick, & Swaine, 2010). Women were most vulnerable to unemployment due to caring for intellectually disabled children and young people (Emerson et al., 2010), whilst men have incurred most job losses in the Irish recession (McGinnity et al., 2014) with unemployment of parents in the Irish recession overall linked to parent’s decreased psychological well-being (Breslin & Breslin, 2013). Finally, “a socially and statistically significant proportion of the increased risk of poorer well-being among mothers” of intellectually disabled children may be a result of their “increased risk of socio-economic disadvantage” (Emerson et al., 2006).

Emerson and Parish (2010) assert that, the question of whether “researchers concerned with understanding the life experiences of people with intellectual disabilities” should consider the relationship between intellectual disability and poverty, is by their estimation, a rhetorical question. They reference here a broader awareness spanning centuries that being poor is associated with greater health problems and poorer life opportunity (Davey Smith, Dorling, & Shaw, 2001). Yet, the intellectual disability research community has predominantly disregarded the implication of poverty in the understanding of intellectually disabled people life’s experiences (Emerson, Graham, & Hatton, 2006).

Challenges to understanding the impact of austerity on disabled children, however, are immediately apparent; with Cullinan and Roddy (2015), in Flynn (2017b), noting a particular limitation. In 2015 no prior Irish research had specifically examined their socio-economic position. The profile of intellectually disabled children and young people, is to an even lesser extent, understood. This is concerning as childhood poverty increases risk of emotional and behavioural difficulties, and in intellectually disabled children and young people is linked to poorer mental health (Emerson, 2004; Flynn, 2017b). In this way, a UNICEF study (2013, p.41) concluded that “comprehensive assessments should be undertaken of the recession’s impact on children” because “one certainty is that economic indicators alone do not reveal the complexity of social reality”.

Further difficulties present in calculating the poverty effects of childhood intellectual disability. Consider the concept of ‘conversion handicap’ (Cullinan & Lyons, 2015). Therein, households must translate more of the overall household income into disability-related costs due to the intellectually disabled child/ren, potentially increasing poverty and deprivation. Such complexity masks the effect of austerity (Flynn, 2015), making it difficult to notice, measure and evidence (Flynn, 2017b, p.684).

Poverty itself is not a stable condition (Emerson, 2007). Nor is intellectual disability a label that one either possesses, or does not. In U.K. research (Emerson, 2007), the 20% most socio-economically disadvantaged families were four-fold at risk of intellectual disability than those in the 20% least disadvantaged (Emerson & Hatton, 2007). This raises the issue of ‘reverse causality’ as highlighted by Cullinan, Lyons and Nolan (2015) who refer to the Irish context. Intellectual disability status impacts upon socio-economic outcomes, whilst in turn, socio-economic status may in some cases produce or exacerbate intellectual disability, complicating the matter of causality as something that works both ways, so to speak. In this way poverty can cause intellectual disability whilst intellectual disability may generate poverty.
Progressions, Flynn (2017b) asserts, in understanding the cost of disability through modelling frameworks based on the standard cost of living approach, are spearheaded in the Irish context by such authors as Sean Lyons, Brian Nolan, and John Cullinan (Cullinan, Gannon, & Lyons, 2011). Watson and Nolan (2011) consider Cullinan’s work on an approximation of the long-run cost of disability, estimated to be between 30% and 33% of the average weekly income – the same, broadly accurate for intellectually disabled young people (Cullinan, 2015). The extra cost of having a disability, is often not included in the calculation of consistent or at-risk of poverty rates. In light of this, disability-adjusted poverty, inequality estimates and equivalent scales are called for (Flynn, 2017, p. 684; Watson & Nolan, 2011).

Also insightful are findings of the Growing up in Ireland Longitudinal Study (DCYA, 2012b). It evidenced that the kind of families that Irish intellectually disabled children are more susceptible to be a part of, such as single parent families, or parentally unemployed families (Emerson & Hatton, 2007), were often those most financially devastated. A staggering 61% of families said they had significantly been affected by the recession. Of particular concern was that 31% of these families reported that they could not afford, or had to cut back on basics.

The manner in which poverty may sustain itself for intellectually disabled young people and their families, through deteriorating familial functioning, is however complex. Flynn (2017b) suggests that deprivation indicators provide a non-monitory methodology for measuring poverty (Whelan & Maitre, 2010). Consider that in 2010 post-recession data found that 20.9% of schoolchildren in Ireland had reported going to bed or school feeling hungry because there was not enough food to eat in their household (Callaghan, 2012; Flynn, 2017b). Yet, deprivation indicators are necessarily limited. Here the requirement for in-depth qualitative research to fulfil a broader exploratory role, and address the information deficit around this complexity, is evident. Particularly as “socio-economic gradients in the prevalence of child disability have been repeatedly documented, less is known about the causal processes that underlie these gradients.” (Emerson et al., 2010, p. 225).

With such causal processes in mind, Flynn (2017b) points to Emerson’s work (Nevin, 2003) around potential deficits within research into intellectual disability that traditionally often did not appropriately account for poverty. In the enhanced incidence of emotional and behavioural difficulties exhibited by intellectually disabled children and young people, poverty issues such as going to school hungry were often not considered as potential contributing factors. Rather, the behaviour is automatically equated to intellectual disability.

Yet, poverty can cause intellectually disability as a result of increased exposure to environmental and psychosocial hazards (Emerson, 2007). Within the recent Irish recession childhood poverty increased considerably, with the most vulnerable children and young people such as those labelled as having an intellectual disability, suffering disproportionately more (UNICEF, 2013). Within this, Irish children largely experience poverty in the context of their families (Social Inclusion, 2007); whilst, in particular, families with intellectually disabled children are more likely to experience poverty, fall into poverty and to be unable to escape from its effects (Emerson et al., 2010; Flynn, 2017b).
Einfeild et al. (2010) demonstrate that increased emotional and behavioural disturbance in intellectually disabled children was associated with increased cost of care, as behavioural problems are a principal factor in indirect costs associated with intellectual disability. Here a cross comparison might be made with data from the Growing Up In Ireland longitudinal study (Department of Children and Youth Affairs, 2012b). The latter found an increase in behavioural problems in Irish children as a result of the impact of the recession. Therefore, a double negative may be incurred by some Irish families with an intellectually disabled young person: Increased challenging behaviour caused by economic recession and parental financial strain, might then in turn increase costs, re-contributing to parent’s experience of economic strain in a cyclical process of entrapment.

Finally, the heterogeneity of intellectually disabled young people must be considered. Indicators of the impact of macroeconomic change might feature across a number of axes such as income poverty, subjective economic stress and material deprivation (Whelan & Maitre, 2014). Intellectually disabled young people may have unique transportation needs or may require assistive technology or specialised medical treatments (Flynn, 2017b; Turner, 2003). Revill et al. (2013) further find that families may experience subjective and practical financial strain in meeting these children’s exceptional needs. In the case of more severe intellectual and physiological disabilities, long term hospital inpatient care or homecare service provision may be required. Furthermore, Irish cost comparisons between both forms of care evidence that financial considerations are not the only ones to the fore for families (Revill et al., 2013). Surplus expenses serve only to achieve an ordinary standard of living in some facets of the child’s life (Turner, 2003). At the same time, the multi-dimensional risk profile, (Whelan & Maitre, 2014) based upon needs and costs, does not always easily translate into quantitative indicators of poverty, again pointing to an invariable complexity with the potential to cloak the effects of austerity according to Flynn (2017b).

As such, the familial repercussions of childhood intellectual disability are multifaceted (Moysen & Roeyers, 2011). Conroy investigates the equality impacts of the recession in Ireland, progressing the knowledge base on quality of life for parent carers of intellectually disabled children in Ireland (Conroy, 2011; Barry & Conroy, 2012; Flynn, 2017b). Therein is reported that carers in Ireland have felt overwhelmed by their caring duties, surmising that service provision had been obscured by a smokescreen or scarcity of advertisement for available services (Flynn, 2017b). Parent carers claim financial hardship as a result of their caring responsibilities, and dissatisfaction at the need for funding from services to improve their family’s quality of life (Flynn, 2017b). This relates to the costs of intellectual disability as delineated in Doran (2012): These are notably wide ranging; not just on an individual, but familial and societal level encompassing actual expenditures, opportunity costs, associated morbidity and pre-mortality losses alongside losses to role performance and social participation.

In drawing this section to a close, literature review by Flynn (2017b) outlines repercussions of macroeconomic turbulence as complex and individualistic for intellectually disabled children and young people. Flynn (2015) points to senses of stagnation or hopelessness, or the loss of possibilities for advancement attributable to recession (focussing upon intellectually disabled adults in the Republic of Ireland). As we have heard, authors like Fujiura and Yamaki (2000) establish that intellectually disabled children and young people experience
poverty within the familial context. At the same time they are more susceptible to poverty than adults given that they more frequently are confined to poorer households (Emerson et al., 2010).

Flynn (2017b) concludes that raising intellectually disabled children within a financial crisis makes for a costly proposition, because their exceptional health care needs can elevate their parents’ expenses (Parish 2013), increasing financial vulnerability for families (Ghosh & Parish, 2013). More frequently omitted are those more implicit financial stressors that families with intellectually disabled children may specifically experience, such as higher divorce rates (Emerson, 2004; Flynn, 2017b). Relevant here is the contagious nature of parent’s subjectively experienced economic strain and financially induced stress for their children, from losses such as a pay cut (Flynn, 2017b). Research by UNICEF (2013b) is insightful in this regard. It confirms the potential for children to inherit the emotional impact of their parent’s financial trauma: Rather than being insensitive to the same as so often can be the assumption (Flynn, 2017b).

3.6 Cutbacks and funding losses to the support service infrastructure

Erosion of the support service infrastructure is also evident. Flynn (2017b) establishes that the voluntary and community sector offers a significant service infrastructure for intellectually disabled children and young people in Ireland by international comparison. In this way, the Irish government has been comparatively hesitant to interfere in intellectually disability services traditionally offered by philanthropic and non-profit religious organisations (Power, 2009). Further, the service infrastructure is also notably critical if we consider that approximately 96% of intellectually disabled children and young people were receiving a service pre recession in 2006 (Barron & Kelly, 2006). Therefore, in terms of the sub-set of the population labelled as being ‘intellectually disabled’, the sector’s recessionary funding losses and service cutbacks become particularly damaging on a broader scale. This is because it is clear from sources such as the National Economic and Social Council (2013) and the Disability Federation of Ireland (DFI, 2010) that the community and voluntary sector has been badly affected by the recessionary economic climate. This is directly a result of stringent and cumulative cutbacks and funding losses (Department of Health, 2012; DFI, 2010; Flynn, 2017b).

The losses to services have sometimes occurred in convoluted ways. Such an example is outlined by Flynn (2017b) in the case of residential circumstances. Here a substantial body of literature establishes that intellectually disabled children and young people experience enhanced social exclusion in congregated or institutional residential settings (McConkey & Collins, 2010; McConkey et al., 2007). Yet, the important Irish policy document and HSE (2011) report entitled ‘Time to Move on From Congregated Settings’ finds that the practical application of aspirations for social inclusion are far from realised. It is reported therein, that approximately 4000 intellectually disabled people still abided in institutional settings at the time. Within a climate of financial crisis, a significant challenge was reportedly posed to housing authorities in supporting people to vacate housing in community settings (Flynn, 2017b).

With this in mind, Flynn (2017b) further develops her analysis of the case of residential circumstances, finding that some funding losses from the progression
of de-institutionalisation, have not been so definitively problematic. Institutionalisation itself is costly. As a result, in times of economic affluence it becomes a more committable sin. Residential care for intellectually disabled children and young people, as is the case with any child, should be considered a last resort. This is because intellectually disabled children and young people are ordinarily considered to be best placed with their families (Flynn, 2017b; Moysen & Roeyers, 2011).

In progressing her case, Flynn (2017b) takes up Kelly’s work (Kelly, 2000; Kelly, Dowling & Winter, 2012) which has contributed to the academic field of knowledge regarding disabled children’s circumstances in the Northern Irish context. A literature review by Kelly, Dowling, and Winter (2012) examining the case of disabled children in care populations demonstrated that disabled children are disproportionately more likely to be in state care. The review established how disabled children are less likely to return home, often experience a longer duration in care, and are older upon returning home (Flynn & McGregor, 2017).

Therefore it is perhaps fortunate, Flynn (2017b) asserts, that with post-recession cutbacks less intellectually disabled children and young people were consigned to living within community home placements; placements recognised in themselves to be quasi-institutional. In this sense, figures support a decrease in admission to residential care over the recessionary period. Barron and Kelly (2006), for instance, outline that 3.6% of all intellectually disabled children and young people were in residential care in 2006. In 2010 that figure appeared to drop to 2% resident within community group homes or residential centres (Kelly & Kelly, 2011). Of course, (Flynn, 2017b) establishes that there is a compelling and opposing argument. One might concede that intellectually disabled children and young people who desperately required residential care may have been unable to attain it as a result of funding cutbacks. In addition, anti-institutionalisation and anti-residential care discourses might have clouded the water covering funding cutbacks, and justified efforts to keep intellectually disabled children at home where this was in some instances not in their best interests (Flynn, 2017b).

Nonetheless, the experience of care provision within the Irish family unit has likely declined, or been inconsistently altered, in many instances by recession. The impact of newfound parental unemployment, for instance, may lead to better care provision within the family unit, or vice versa in the case of increased reliance on the support service infrastructure. Nolan and Maitre (2017) examine how children of the Celtic Tiger era faired within subsequent economic crisis in Ireland. Within this, they establish that, in understanding children’s experience of the Irish recession, one must be cognisant of their experience of the Celtic Tiger economy that came before, and the stark transition between the two.

Nolan and Maitre (2017) offer detailed figures and calculations in terms of the economic estimations of the impact on children, pre- and post-Irish recession. Changes to the family unit around employment were significant, and where one or both parents had employment and then lost a job in the recession, children experienced particular losses. This supported the overall case that, those on social welfare payments alone incurred less financial decline, over the recessionary period. Combining Nolan and Maitre’s (2017) findings with the assertions of the European Foundation Centre, that between 2008 and 2012, the number of Irish disabled people, who were at risk of poverty rose by 26.16% in Ireland, it is clear
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that the support service infrastructure must respond to a combination of changes to the family unit, in the context of increasing poverty and marginalisation of social groups such as children and those who are disabled (European Foundation Centre, 2012).

Shifting focus more broadly towards cutbacks to all services, including those that are not publically funded, Flynn (2017b) finds that ground-level service provision appears to have been significantly compromised by cutbacks. Within this, the DFI provides a good reference point to ascertain the impact of tightening purse strings with regard to service provision. As an umbrella organisation it represents 132 Irish disability sector services in Ireland. In this capacity it achieves critical insight into the effects of austerity on intellectually disabled children and young people (Harvey, 2008). Staff travel restrictions, for instance, and support from temporary agency staff within Irish disability services are cited as limiting the scope of supportive work. Furthermore, a freeze on the development of support services and the absorption of emergency placement places ordinarily retained for vulnerable children and young people have been noted (DFI, 2010; Flynn, 2017b).

Post recession, Flynn (2017b) further contends, a number of disability sector organisations had predicted that cutbacks to personal assistant hours would lead to reduced social activities, and consequently social exclusion, for intellectually disabled children and young people (Centre for Independent Living, 2011; DFI, 2010). Whilst within this, it can be acknowledged that to an extent there may be increased efficiency in application and administration of services, the lived experience of these cuts remains in forms such as increased social isolation and a loss of independence according to the DFI (2010).

With this in mind, Nolan and Maitre (2017) conclude that in the case of economic recession for Irish children, the centrality of the tax-transfer system is evident as a means of protection; and whilst this section considers losses to the support service infrastructure more specifically, the two are by no means divorced. Nolan and Maitre (2017) concede that public expenditure regarding the availability and quality of public services is a critical aspect of the economic recession for Irish children. Further, conventional indicators of poverty and social inclusion, they ascertain, do not readily capture what they refer to as ‘fiscal correction’ of the welfare system for children. They conclude that, “the impact of the crisis on the relatively small numbers of children who are in specific circumstances that leave them highly vulnerable and reliant on, for example, effective intervention from social services, is also difficult to measure and assess” (Nolan & Maitre, 2017, p. 168). This difficulty is one interfacing with a support service infrastructure eroded by stringent and cumulative losses.

According to Flynn (2017b), cutbacks to services affect not only the child but the entire family system around them. This circumstance is linked back to poor governmental strategy, a case particularly illustrated in the instance of respite care. Here the gradual withdrawal and reduction of respite supports is evident; supports which afford intellectually disabled children and young people a measure of autonomy. Flynn (2017) draws supporting evidence from several studies. Research by Caples and Sweeney (2011) for instance, confirms that respite, as a specific high demand service within Ireland, is subject to very limited availability. McConkey, Kelly, and Craig (2011) further report on research conducted within the Republic of Ireland demonstrating clear intra-country
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variations in the provision of respite breaks to families with an intellectually disabled relative (Flynn, 2017b).

Consider then that another impact of the economic recession on intellectually disabled young people, and their families, is emigration. According to Mosca and Barrett (2016) the Irish Longitudinal Study of Ageing conducted by Trinity College showed negative mental health implications, such as feelings of depression, for Irish mothers whose children emigrated following the recession. Therefore, in the context of a dearth of respite, families might also experience a reduction to their social support infrastructure in the instance where adult children emigrate, alongside resulting feelings of despondency. Furthermore, respite care is also relevant to young siblings residing within the home. Moysen and Royers (2012) examined the views of siblings of intellectually disabled children with regard to their quality of life. Findings demonstrate in this instance, a significant disparity between the definition of quality of life of siblings, and that of parents. Overall, it would appear in the context of the circularity of effect within the family unit as illustrated so far in the cases of respite and residential care cutbacks, that it is necessary to recognise individual social reality as somewhat embedded in interdependent systems (Bronfenbrenner, 1979) and wider oppressive structures that can sustain them (Fergusan & Lavallette, 2007; Mullally, 2007). In this way the approach required must marry individual personal level, familial level, and broad societal level phenomena in the context of social multi-dimensionality.

In purely economic terms, Flynn (2017b) finds that respite may be critical for mothers of intellectually disabled children specifically, because maternal unemployment is a contributing factor to poverty in such families, as demonstrated in Emerson et al. (2010). In this sense, it is mothers who appear to primarily take on the role of care giver for their disabled children and young people; a circumstance exacerbated further by the lack of respite. With this in mind, Flynn (2017b) finds that the overall regression in services such as respite can be at least partly attributed to poor Irish financial recovery policies, which represent an inappropriate governmental reactive strategy against the recession (Skalecka, 2014). Holland (2012) concedes that the strikingly retrogressive character of such policies would appear to endanger the reforms and advances achieved over previous years (Flynn, 2017b, p. 688).

Such retrogressive practices appear, according to Flynn (2017b) to have occurred in the context of a hardening of attitudes towards intellectually disabled children brought about by the overall financial hardship societally, and post recession. Here educational cutbacks are offered as an illustrative example of the detrimental effect of cutbacks. In this instance, a move towards participation and inclusion of children with learning impairments in mainstream schools appears to have moulded the altering Irish disability sector service infrastructure (Browne & Millar, 2013; Children and Youth Programme, 2012). Such a move is derived partially from international human rights instruments and more specifically from provisions under domestic law (Flynn, 2017 p. 688).

Flynn (2017b) looks to human rights legislation for further illustration within this. Article 24 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD), for instance, is an example offered in Browne and Miller (2013, p.25) (United Nations, 2006). It is considered of particular relevance to children and young people as a result of its lucid commitment to the principle of
inclusive education. Nonetheless stringent cutbacks to education services are demonstrated to have occurred in the context of economic recession. This is compounded by the assertions of intellectual disability services indicating that an increasing number of parents cannot secure a place for their child within their local mainstream school (Mc Keogh, 2012).

Escalating this concern, Flynn (2017b) further asserts, is the findings of a national survey of public attitudes to disability in Ireland. The study was conducted by the National Disability Authority and conveys a hardening of attitudes across all forms of disability. However a particular loss of affirmative attitudes towards intellectually disabled children, and children with mental health difficulties in mainstream education is evident (NDA, 2011). 50% of respondents in 2011, for instance, believed that disabled people did not achieve equal educational opportunities, a figure which had lowered from 52% pre recession in 2006. In addition to this, the 2006 study evidenced that 61% of respondents felt it was society that in fact disables people (NDA, 2007); in 2011, post recession, this figure had dropped to 57% (NDA, 2011). Perhaps most troublingly, in 2011 only a minority (38%) of participants believed intellectually disabled children should be included in mainstream schools. This is troubling if one considers that improvements in attitudes should really be expected in the context of continued efforts by disability organisations and advocates alike, towards promoting awareness, and combating the harmful effects of ableism.

This hardening of attitudes comes in the context of an overall case of economic decline for Irish intellectually disabled children and young people. In 2012, Watson, Maitre and Whelan published key findings towards understanding childhood material deprivation in Ireland, with findings inclusive of the case of intellectually disabled children and young people. Analysis drew themes and trends from the 2009 SILC questionnaire which contains a special module on child-specific deprivation. Poverty was considered particularly detrimental for children due to its long-term effects on life chances and outcomes. What was noted as particularly striking however in the findings was the importance of mother’s employment in protecting children. This is troubling if one draws parallels to Emerson’s work (et al., 2010) where women were deemed most vulnerable to unemployment during the recession due to caring responsibilities for intellectually disabled children and young people.

Particularly bearing in mind this financial hardship as a contextual factor, discourses may offer some insight into the cause of attitudinal decline over the course of the recession, according to Flynn (2017b). In this way, the literature implies that economic recession has perhaps reinvigorated old hostilities towards those groups in the marginality of society (Gaughan & Garrett, 2012). Such discourses may be fuelled by the distress of families as they themselves struggle to cope in a time of financial crisis. The Growing Up in Ireland Study (DCYA, 2012b), according to Flynn (2017b) offers a candid snapshot of this struggle. The study was comprehensive and tracked almost 20,000 children before and after the recession in Ireland. Figures demonstrate that only 7% of families experienced ‘some’ or ‘great difficulty’ initially, whilst this figure had multiplied threefold post recession. It clearly demonstrated that the recession had significantly affected Irish children overall, with 61% of families reporting difficulty ‘making ends meet’. The argument made here is that this forms a basis for hardened attitudes towards intellectually disabled children. Furthermore, in the realm of educational
attainment, this becomes an additional disadvantage on top of damaging cutbacks.

With this in mind, perspectives such as intersectionality (Goodley, 2013) are necessary to progress statistics and social indicators towards a more considered and cohesive understanding of the erosion of the service infrastructure. O’Connor and Staunton (2015), representing TASC, reflect this contention, in their analysis of economic equality in modern Ireland. Upfront they offer some interesting facts, for instance, drawing upon Eurostat 2013 figures, 17.7% of households within working-age Irish population were unemployed. Furthermore, inequality itself is illustrated through the instance of the top 10% of the Irish population holding an estimated 42% to 58% of Ireland’s wealth, whilst the bottom 50% retains only 12%. However in presenting facts they state their intention, as is the case with the present analysis, that one must go beyond the presentation of bare statistics as already achieved elsewhere, and progress to some synthesis or analysis of the same. This study would further add that the voices of those behind the statistical indicators should be heard in such an analysis. O’Connor and Staunton (2015), in their final holistic assessment of economic inequality in Ireland, incorporate the analysis of seven distinct factors. They identify these as; 1. Income 2. Wealth 3. Public Services 4. Taxation 5. Family Composition 6. Capacities 7. Cost of Goods and Services.

With the above in mind, and drawing this section to a close, Flynn (2017b) concedes that health care service provision is a key area impacted by recessionary cutbacks. Within this, Skalecka (2014, p.88) looks at diminishing public expenditure on social welfare and service provision, and the reduction in HSE expenditure on such areas as primary care, clinical spending or medical care schemes. It appears therein that intellectually disabled people have been adversely affected. The Department of Health (2012) report ‘Value for Money and Policy Review of Disability Services in Ireland’ is illustrative in this regard (Flynn, 2017b). It represents a key articulation of the efficiency discourse aimed at improving attainments from a scarcity of resources. It also delineates the projected direction of the governance, funding and focus of the Disability Services Programme. In doing so, its recommendations occur in the light of the financial crisis and the National Recovery Plan. Yet whilst an increased efficiency in service provision may arise from cutbacks, Flynn (2017b, p 689) is still of the contention that this cannot be conclusively assumed to have, by any manner or means, alleviated the harmful effects for intellectually disabled children and their families.

It is not just public expenditure cutbacks that require our consideration. In the context of increasing demand for services, owing to the social and personal repercussions of Ireland’s macroeconomic turbulence, general losses to funding have also been incurred. Yet, non-profit organisations mandated to the support of intellectually disabled people and their families, require external funding to survive (DFI, 2010; Flynn, 2017b; Power, 2009). Flynn (2017b) highlights that in 2012, the DFI were highlighting that a ‘danger point’ was in sight if services continue to experience such cutbacks (Costello & Cox, 2013). Prior to this assertion, in 2010, a report published by the DFI had examined the impact of the economic recession upon disability sector organisations, including those for intellectually disabled children and young people. Significant funding losses were among the findings with respect to the majority of member organisations; notably
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A direct consequence of the prevailing financial crisis (Flynn, 2017b). Such losses were attributable in part to a reduced statutory funding, for instance, funding from local authorities or HSE National Lottery Grants. Further accountability lay within a reduction in non-statutory funding. Overall, 77% of organisations alluded to a decrease in earned income, whilst 85% incurred a decline in philanthropy income, and 86% of organisations reported a decrease in fundraising income. Corporate sponsorship had also declined for 95% (DFI, 2010).

Finally, Flynn (2017b) draws upon Power (2010) and Skalecka’s work (2014) in delineating the compromised post-recession service infrastructure. Here, Skalecka (2014) points to the necessary adaption of working practices and prioritisation of delivery of basic services and supports that has become a reality (Department of Health, 2012; Skalecka, 2014). Power (2010) has further examined the manner in which economic recession has impacted upon charitable giving patterns pertaining to the mid-west region of Ireland. Therein is asserted that, historically, an approximate drop of 0.7% in donations has been evident in times of economic recession. Such examples would appear to be locatable within a constellation of losses overall, to intellectually disabled children, young people, and their families. It is those losses to the service and support infrastructure that has been of particular concern in this section.

3.7 Intersectionality: Vulnerability within the vulnerable.

Having considered the nature of the post-recession service infrastructure, this final section will consider the impact of recession with respect to identity. The term ‘vulnerable’ does not rest easy with this study’s Affirmative Non-Tragedy perspective that from the outset, has not assumed that intellectually disabled young people wish not to be so (French & Swain, 2000; 2008). Nonetheless, to date strong concerns are noted for intellectually disabled children and young people in the economic climate of austerity (Flynn, 2017b). This final section will consider these concerns with respect to ‘childhood’ and ‘disability’ as interrelated sites of oppression and signification.

Disability advocates and allies must vie for just wealth distribution against other social groups. Whelan and Maitre (2012) evidence a discourse; focused upon a pressing desire to defend the vulnerable within a time of financial crisis, yet within this maintaining little consensus around what social groups actually constitute its focal point (Flynnb, 2017, p. 691). The disquieting and volatile focus moves unsystematically between such social groups as the so-labelled ‘sick’, ‘elderly’ and ‘disabled’. Flynn (2017, p691) concedes that such social partitioning, lacks intersectionality, and in turn neglects the interrelated character of poverty for intellectually disabled children and young people, whose disability may be directly arising from parental poverty. A practical example of this is the correlation between child poverty and low birth weight, and the significantly advanced risk of intellectual disability associated with a low birth rate, as established by Emerson (2004).

For intellectually disabled children and young people, the ‘disability’ label equates to particular equality concerns post recession. The DFI (2016) assert that the Irish recession was harsh for disabled people who often were already surviving on disposable incomes below the poverty line, only then to observe vital services
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being cutback. They concede that, “the recession pushed people with disabilities further out onto the margins of Irish society” (p. 5).

Organisations for intellectually disabled children and young people allege that they have not been prioritised. Regarding government budget 2014, for example, they deploy such evidence as 763 children who have had to wait six months or more for an assessment of need, and a 15% reduction in resource teaching hours since 2011 (Inclusion Ireland, Irish Autism Action, and Down Syndrome Ireland, 2014). Correlations between economic recession and plunging quality of life for disabled people have largely been evidenced through research (DFI, 2010; Flynn, 2015; Nolan, 2014). Holland (2012) for instance, asserts that disabled children and young people, and within this, those who are intellectually disabled, have been disproportionately disadvantaged by the recession within Ireland in such ways as social exclusion and education cutbacks. Further, the effects of poverty for these children and young people are abundant as compared to peers’ not experiencing poverty. Greater exposure to environmental hazards and impeded functioning in cognitive and linguistic spheres are some examples (Emerson, 2004).

International literature is broadly consistent with this. In Europe children and adults with learning difficulties have been considerably disadvantaged by the recession, according to sources such as UNICEF (2013) and Nolan, (2014) and in addition, farther afield in Australia (Bittman & Bradbury, 2012) and the USA (Oberg, 2011) (Flynn, 2017b). Yet, Emerson (2012) demonstrates that large population based studies, many of which have been conducted internationally focusing on disabled children, cannot address lived experience, and therefore this is an area that remains lacking.

In drawing to a close, and thinking intersectionally, it would appear however, that it is the label of ‘child/young person’ that may be most potent in terms of economic disadvantage in the context of Irish recession. The impact of recession is not just about financial loss but has psycho-social implications. Whilst pre-recession, families with intellectually disabled children and young people were generally already psycho-socially and socio-economically disadvantaged (Shatahmasebi et al., 2011). The Families Special Interest Research Group of the IASSID, for instance, published a paper (2013) on the current overall state of scientific knowledge on families supporting an intellectually disabled child. Mothers of intellectually disabled children reported increased demands in parenting, by comparison to parents of non-disabled children, alongside higher levels of stress and poorer physical and psychological health condition. Slightly higher incidence of parental separation and divorce is also suggested by some studies. Further, Susan Parish’s work in the U.S. context has spanned over a decade within which she has examined the pronounced financial hardship in parents who raise co-resident intellectually disabled children, such as having less savings, reduced asset accumulation or less belongings, drastically altered life trajectories (Parish et al., 2004), as well as increased child and household food insecurity (Rajan et al., 2016).

Within the domestic context, international findings are mirrored. What is however most palpable in the Irish case, is the significant evidence that children may be the social group most deprived by Irish economic recession (with substantial media coverage of the same; see Gleeson, 2014; McNamee, 2014; O’Regan, 2014). It is
particularly important to recognise this economic risk imposed by childhood, as a concurrent identity and social position to intellectual disability, for the young participants of this study. It seems that children have been principally impacted, as evidenced in such statistics as one in five of all Irish children (a staggering total of 185,000) in 2010 deemed to be at risk of poverty under EU-SILC standards (Holland, 2012). Particularly stark, A UNICEF (2013a) report published in 2014 evidenced a confounding child poverty rate increase of over 10%. This invariably translates into 130,000 more poor children in Ireland as a result of the economic recession. In addition, the End Child Poverty Coalition (2011) reports that increasingly more children and families are experiencing hardship making ends meet as a result of the wider economic crisis. It references staggering figures such as 96,000 more children living inconsistent poverty in Ireland in 2009 than 2008 – that’s 28,000 more than in the year before. In 2008, there were 205,000 children at risk of poverty. In the years that would follow, these figures, they assert, are likely to be even higher. They concede that, “the longer a child is poor, the greater the deprivation he or she is likely to experience in later life. Poor children become poor adults and the cycle continues, influencing the life chances of the next generation and the one after that” (p.3). Consider then, that within this, intellectually disabled children and young people are more likely to be poor than their non-disabled counterparts (Emerson, 2004). In order to develop a picture of the lived experience of this disproportionate disadvantage, direct data from children and young people would usefully complement generalisations already made about them.

3.8 Conclusion

Before considering the study’s methodology, at this juncture it is helpful to present some summary of literature and themes covered so far in the introduction, context, and the current literature review chapter.

To begin, the introduction chapter sought to establish the research problem. Ireland’s short lived fiscal opulence, or ‘Celtic Tiger’ economy, was supplanted by staggering and unprecedented economic and social decline (Allen, 2009; Flynn 2017b). Within this, there is a gap in the knowledge base presenting around the socio-economic experience of a subset of the population, intellectually disabled young people, already well established to be at considerable risk of poverty.

Moving forward with a socio-demographic pen portrait, the proceeding chapter aimed to provide some context to the research problem. Here it was clear that disability services in Ireland have not traditionally been a priority for State intervention, and rather have been run by voluntary and religious organisations, leading to a complex and critical historical context. The nature of the present day service infrastructure was considered, as was human rights law as a natural reference point for concerns about the effects of austerity. Following this, domestic law and policy were over-viewed paying heed to De Wispelaere’s (2013) assertion, that any efforts towards compelling government action through litigation, had thus far been broadly unsuccessful. Finally, the economic policy context was examined with reference to the capitalistic economic conditions of intensive neo-liberalisation.

This led us into the present chapter, or the substantive product of literature review. First, a discussion of relevant theory framed an exploration of this study’s
particular theoretical framework. Here it was noted that the study would apply and locate an Affirmative Non-Tragedy Model, within the broader field and paradigm of CDS. The emphasis of the study is phenomenological, whilst the orientation is toward social justice. Following this, existing marginal material towards the positive implications of economic recession was considered. Next, the technicalities of making calculations around the impact of economic recession on intellectually disabled young people and their families were demarcated. The review examined established cutbacks and losses to the service infrastructure for intellectually disabled children and young people, and their families (DFI, 2010; Disable Inequality, 2016). Finally, taking a broader societal perspective, the notion of the disproportionate disadvantage of intellectually disabled young people, and their families, was tentatively addressed.

Having grasped the context and literature relevant to the research problem, the following chapter now marks a shift in focus, towards the study’s methodology.
4. Methodology

4.1 Introduction

We have just considered the literature around the impact of the economic recession on intellectually disabled young people and their families, as presented thematically. This chapter now forms a shift in focus warranted at this juncture. In doing so, it will provide justifications for the qualitative methodology of the study. That is, the study which has concerned itself with how the current economic recession has both impacted upon, and been experienced by intellectually disabled young people, and their families. The research is highly aligned with an inductivist qualitative approach (Flynn, 2014a). This is because of its concern with perspectives. Finally, embracing the innovatory, this study’s sustaining philosophy might be communicated through the contention that one;

"must revisit the idea that science is a methodology and not an ontology"

-Deepak Chopra

4.2. Research question, aims and objective

This research study will contextualize the experiences that intellectually disabled young people, and their families, have of the current economic downturn. It intends on illuminating these experiences in the form that they are narrated.

A reminder of the core research question is as follows;

How have intellectually disabled young people, and their families, who avail of services from the disability sector, experienced the current economic downturn?

Further to this, the research objective is:

To give voice to the experiences that intellectually disabled young people, and their families have of the recession with specific reference to the impact on their lives, in a manner which informs policy and practice.

Finally, the research aims to:

1. Investigate how both intellectually disabled young people, and their families have experienced the current economic downturn.
2. Explore the impact of the recession on the lives of intellectually disabled young people.
3. Critically inform practice and policy development for intellectually disabled young people, with a view to informing a partnership approach to service provision.
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4.3 The research approach

Bearing these questions in mind, it is helpful to critically consider the research approach. Binary division commonly forms between qualitative research and quantitative research (Becker, Bryman & Ferguson, 2012; Silverman, 2015; 2017). Consequently these are considered to be differing research strategies (Bryman, 2004; 2015; Flynn, 2014a, p.39).

This research study adopts a qualitative approach, which is an interpretative and naturalistic mode of enquiry (Denzin & Lincoln, 2003; 2011; Outwaite & Turner, 2007; Silverman, 2017). Epistemologically, its interpretative and material practices are often translated into narrative descriptive accounts of events or experiences (Alasuutari, Bickman & Brannen, 2008). Such dense narrations will allow this research to take an open consideration of the topic. It will afford a flexibility which resonates well with both serendipity, and the anticipation, that where participants choose from multiple pathways their chosen narration, they can then provide a more congruent account of their perspective (Flynn, 2014a, p. 39).

Furthermore, a qualitative approach prescribes that phenomena can be understood through the meanings people bring and assign to them (Merriam, 2009; Richie & Lewis, 2003). The phenomenon to which this study pertains is the recession. Whilst the elucidation of meaning pertains to that which disabled children, their families, and staff have ascribed to the recession and the experiences it has bestowed upon them (Flynn, 2014a, p. 39).

These particular qualities of a qualitative approach are often not present in a quantitative research strategy. Disparity between qualitative and quantitative strategies has often translated into dogmatic and polarized stances in favor of either (Corbin & Strauss, 2015). Such politics of partiality is a key feature of the field of discourse surrounding quantitative and qualitative strategies (Outhwaite & Turner, 2007).

Proponents of the quantitative persuasion can demote qualitative research to fiction. In this way, qualitative research may be deemed unscientific, un-theoretic or bias laden (Bryman, 2015; Outhwaite & Turner, 2007; Silverman, 2011). Such oppositions may partially arise from the obligation of qualitative tradition to critique positivist and post-positivist orientations. Orientations associated largely with a quantitative strategy, yet not synonymous with the same (Bryman, 2015; Outhwaite & Turner, 2007).

The notion of an objective world is also key to the debate between the two families of research (Becker, Bryman & Ferguson, 2012; Bryman, 2015). The ontological position of objectivism essentially concludes that social phenomena and their meanings exist autonomously of social actors. Objectivism is a classic way of understanding which is associated with a quantitative research strategy (Alston & Bowles, 2013; Bryman, 2015; Becker, Bryman & Ferguson, 2012; Silverman, 2015).

Objectivism favors the existence of an objective reality. In this way it differs from Constructionism, the ontological position which concludes that social phenomena and their meanings are being continuously accomplished by social actors (Bryman,
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This position is associated with a qualitative research strategy (Becker, Bryman & Ferguson, 2012; Bryman, 2015). Silverman (2017) advises a dose of caution when considering this subjective/objective polarity. Qualitative research can offer a continuum of methodological options many of which are also concerned with some sense of objective reality.

The methodological application of each research family is often used to differentiate them in debate (Becker, Bryman & Ferguson, 2012; Bryman, 2015; Tashakkori & Teddie, 2010). The transcendence of 'truth' over opinion and personal subjectivity is an assumption that is held in the practices of quantitative science (Carey, 1998 cited in Outhwaite & Turner, 2007). Adjunct to this assumption is the often cited but unjustifiable reduction that qualitative research is about words whilst quantitative research is about facts (Tashakkori & Teddie, 2010).

The province of qualitative research expands beyond words however to a holistic approach to the research of phenomena, in some senses less constrained and structured than its quantitative counterpart (Corbin & Strauss, 2015). Qualitative inquiry emphasises the socially constructed nature of reality as a product of the social actors which inhabit it (Blaikie, 2009; Bryman, 2015; Outhwaite & Turner, 2007; Silverman, 2017). This is divergent from the concept of rigor central to the quantitative pole. Given that qualitative research takes a flexible and open consideration of phenomena (Corbin & Strauss, 2015).

Of course methodological variations in the application of either family of research does not prevent their coexistence within the same research study (Becker, Bryman & Ferguson, 2012; Bryman, 2015; Silverman, 2017; Tashakkori & Teddie, 2010). Indeed the inception of growing body of literature in the 1980s set out that qualitative and quantitative strategies were not mutually exclusive (Tashakkori & Teddie, 2010, p.220).

Mixed method research often assigns the qualitative ingredient into a preparatory role pertaining to its quantitative counterpart. Inferences consequent of the qualitative phase are investigated further through quantitative inquiry (Bryman, 2015). A recognition that it is possible to achieve a seamless integration of both poles of inquiry, may arise from some research being neither classifiable as quantitative, qualitative or mixed method (Silverman, 2010). Implicit in the existence of this fusion is a substantiation of the fact that qualitative and quantitative poles are unworthy of any purely oppositional relationship status.

More specifically, a major agenda of this research project is to hear the voices of intellectually disabled young people. A dichotomy of quantitative and qualitative strategies within the mixed method field has also been attributed to a reduced likelihood that previously silenced voices will be heard (Howe, 2004 cited in Outhwaite & Turner, 2007, p. 582). Howe concedes that the dichotomous allocation of qualitative work to exploration, and quantitative to confirmation functions is harmful. This is due to its propensity to weaken the democratic and dialogical possibilities of the research. As such, critical reflection on the application of a qualitative strategy within this research is imperative. It is obliged by the status of intellectually disabled young people as a population who has historically been subjugated and silenced (DCYA, 2011; Gordon et al., 2010; Gray & Winter, 2011; Kelly, 2005).
Finally, researchers may be socialized into a qualitative or quantitative paradigm within specific disciplines and paths of academic qualification (Tashakkori & Teddie, 2010). Ultimately a persuasion toward either paradigm should be based upon an aspiration to achieve the best route for generating valuable theory. Hence when theorizing neither paradigm should take overall primacy, rather the best paradigm to address the task at hand should be adopted (Corbin & Strauss, 2015). As such, a cognizance was taken of the value of this study in its procurement of knowledge through sound findings, and its potential hitherto as a base for further investigative ventures. From this starting point a suitable research strategy was then devised based on the research question, objective and aims.

Some critics of mixed method research nevertheless conclude that quantitative and qualitative approaches can genuinely not be combined. This is because a preference toward either is indicative of more than just the election of a particular data collection tool. A commitment to a particular epistemological stance is implied therein (Becker, Bryman & Ferguson, 2012; Bryman, 2015; Tashakkori & Teddie, 2010).

Moreover an epistemological stance deemed compatible with a qualitative approach will at the same time be deemed adversative or antithetical to a quantitative one (Becker, Bryman & Ferguson, 2012). This tendency to bind quantitative and qualitative families with corresponding and opposing epistemologies or world views, has nevertheless been thoroughly criticized in methodological literature. Consequently a body of work has been developed which offers a practical continuum on which research can be situated in proximity to a qualitative or quantitative pole (Tashakkori & Teddie, 2010).

Nonetheless, ultimately, both qualitative and quantitative research is underpinned philosophically. As such is the case, the sustaining philosophies of each family of research may provide valuable insight into their nature (Bryman, 2015) and therefore will be critiqued in more detail within the following section.

4.4. Qualitative research method discussion
- philosophical ingredients of the study

Myriad philosophies and interpretative projects fall under the umbrella of qualitative research (Denzin & Lincoln, 2011). As a result there is a continuum of options, deductive to inductive in character, which affords the qualitative researcher greater diversity than their quantitative counterpart (Bryman, 2015; Flynn, 2014a, p. 40).

This qualitative research study inquires through an interpretivist epistemology. This means it understands social reality to be a ‘product of its inhabitants’ (Blaikie, 2009, p.99). Such a position aligns itself well with the research question and aims. This is because the study looks to illuminate and give expression to the impact of the recession. Including therein the lived experience of the research subjects as expressed through their voices (Flynn, 2014a, p. 40).

Given this, Interpretivism as a philosophy can also be said to hold an anti-positivist stance (Bryman, 2015). That is, where positivism is a philosophical position of science which contends that an objective reality exists: A reality from which we can derive truth through empirical evidence (Alston& Bowles, 2013; Silverman,
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2017). As an adjunct to this position, our study could also be said to take a social justice orientation, common to a traditional critical social science approach. As prior mentioned, historically this kind of qualitative approach has been vulnerable to de-legitimisation by the alternative paradigm of positivism; a paradigm associated with quantitative research (Flynn, 2014a, p. 40; Shaw et al., 2010; Silverman, 2017).

Positivism is an epistemological position which alleges that science can be conducted free of bias and thus objectively (Alasuutari, Bickman & Brannen, 2008; Bryman, 2015). Bryman (2012, p.28) advises that positivism advocates the application of methodologies associated with the natural sciences, to the study of social reality. The positivist position is in turn partly sustained by the principle of phenomenalism (Bryman, 2015). This principle maintains that only phenomena and resultant knowledge which is confirmed by the senses can actually be warranted as knowledge (Bryman, 2012, p.28).

Not to be confused with phenomenalism, another important philosophical paradigm is phenomenology (Rubin & Babbie, 2011; Schutz, 1967). It underpins this inquiry. Phenomenology focuses on experiential essence and how phenomena reveal themselves to the structures of consciousness (Flynn 2014a; Rosenberger, 2013; Schutz, 1967).

The relevance of this cannot be understated considering that the study aims to uncover how intellectually disabled young people and their families have experienced the recession, as a necessary ingredient of its impact upon them. Again however, this approach is intrinsically subjective and susceptible to assault on its validity from objective positivist orientations. The subjectivity of the approach lends itself exceptionally well to the complexity and fluidity of social phenomena and social worlds, for which this study has concerned itself (Flynn, 2014a, p.41; Gilgun & Abrams, 2002).

Finally, this study aims to critically inform practice and policy development for intellectually disabled young people, with a view to informing a partnership approach to service provision. Given the concern for achieving a balance of power implicit within the aspiration toward a partnership approach, an appraisal of the expression of power within the study would not be remiss. Critical inquiry, as a philosophy concerning power relations, is fitting for such a critique. It is a methodological philosophy upon which social research can rely (Gray, 2009).

Critical inquiry can be applied to the void, which situates itself between the researcher’s perspective and interpretation of how the participants have been impacted by the recession, and then how the participants themselves perceive that they have. As Flynn (2014) states, data passing through this void is filtered, like the making of a cup of coffee, through the normative lens of the researcher. Therefore it is not the finished beverage alone we must concern ourselves with, but also the reclaim and interrogation of the discarded sediment (p.41).

Such an endeavor ensures we meet our research aim and consider the impact upon the lives of the research subjects, in a sincere rather than paternalistic fashion, which is steeped in the norms and values of the researcher. The prudence of this is somewhat incontestable. Given that a paternalistic ascription of professional and societal values on disabled people, has historically contributed to their disempowerment (Flynn, 2014a, p.42; Keith & Keith, 2013).
Towards the beginning of this PhD research project, much time was devoted to investigating and considering potential research methodologies, including attention to the possibility for creating a bespoke method of analysis. It was ultimately determined that the most appropriate means for in-depth analysis in line with this study’s particular research question was to conduct qualitative unstructured interviews and analysis in line with a Biographical Narrative Interpretive Model (BNIM) approach. This is a phenomenologically orientated qualitative approach.

As Wengraf (2001; 2015a; 2015b; 2015c) explains, BNIM draws on the assumption that individuals construct meaning in their lives through narrative. Rather than impose categories for exploration this method allows the participants to identify themes for themselves (Becker, Bryman & Ferguson, 2012; Hesketh, 2014; Wengraf, 2001; 2015a; 2015b; 2015c). The research thus concedes that a BNIM approach is the best way to address power imbalances between interviewer and the research participants. Similarly, and as was concluded in Hesketh’s 2014 PhD research, the BNIM provides a strong methodology for rapport building and empathetic bonding with marginalized young people. Finally, BNIM approach may be used for a retrospective study of a particular event, in this instance, the recession and its impact on well-being (Flick, 2007; Flynn, 2014a, p.42).

Considering the aforementioned, BNIM is fittingly equipped to address the research aims. This is because the research aspires to explore how the changing macro-level economic variables occasioned by the recession have impacted on intellectually disabled young people, and their families. However it is those who are affected, and the lived reality of these macroeconomic variables that research must give expression to, rather than the wider economic context itself. In this manner the research shall engage with, and interject within, a comprehensively investigated sphere; preserving however it’s inimitability through focusing on the voices of those most affected.

BNIM can access not only articulable and explicit knowledge but tacit and subconscious understanding and thus is a powerful instrument for understanding phenomena (Wengraf, 2001; 2015a; 2015b; 2015c). The BNIM provides a means to expose dormant or latent levels of meaning which a person has drawn from experiences (Goodwin, 2012; Wengraf, 2015b). This is fitting given that intellectually disabled young people are a population whose voices have been subjugated and marginalized (DCYA, 2011; Gray & Winter, 2011; Gordon et al, 2010; Kelly, 2005). The researcher then connects the personal meanings back to the lived life. In this way BNIM anchors the personal meaning to some sense of objective reality: Preserving a real concern with the event of economic recession in this case (Goodwin, 2012).

Finally, the BNIM method can be situated within a number of qualitative, biographical, and phenomenological methodologies. It takes a smaller number of cases however, and applies to them a deeper scrutiny than many of its counterparts as illustrated in fig 4.1. below (adapted from Wengraf, 2001);
4. Methodology

Fig. 4.1; Trade off between number of cases (N) and intensity of interviewing method (Wengraf, 2001, p.148).

4.5.1. The research process

BNIM is both a psychosocial and socio-biographic method (Becker, Bryman & Ferguson, 2012; Hesketh, 2014; Hollway & Jefferson, 2012; Wengraf, 2001; 2015a; 2015b). Data analysis within the research also takes a life course dimension as the BNIM can suitably elucidate past and present narratives (Wengraf, 2006; 2015a; 2015b). As Corbally and O'Neill (2014, p.35) advise, the BNIM seeks to analyse three interconnected aspects of humanity: the individual’s whole life history or life story (biography), the manner in which he or she tells it (narrative) and the social interpretation (interpretive). As a research methodology, BNIM employs a data elicitation technique of unstructured interviewing entitled, ‘Single Question Aimed at Introducing Narrative’ (SQUIN). This question was carefully considered as BNIM is a sensitive tool (Hesketh, 2014; Wengraf, 2001; 2006; 2015a; 2015b; 2015c).

The purpose of the SQUIN is ultimately the provocation of narrative from the interviewee (Hesketh, 2014; Wengraf 2001; 2015a; 2015c). A SQUIN may be full or partial. A full entirely ‘open’ or ‘whole life story’ version might look something like:

‘I want you to tell me your life story, all the events and experiences which were important for you, up to now. Start wherever you like’

(Wengraf, 2001, p.121)

The SQUIN for this study was partial and conceptually focused. This essentially denotes that it looked to evoke narratives which consider the impact of the recession as a specific phenomenon through a plurality of life experiences liable to feature in the narrative account (Wengraf, 2001). The SQUIN for this study for
young person participants was adapted from Wengraf (2006, p.60) and was as follows:

“As you know I am interested in how your life has been since the recession happened . . . please tell me the story of how your life has changed in the last 10 years or so. All the experiences and the events which were important for you, personally. Start whenever you like. Please take all the time you need. We’ve got about an hour. I’ll listen first, I won’t interrupt. I’ll just take some notes in case I have any further questions for after you’ve finished telling me all about it.”

Somewhat similar to the above, the SQUIN as it stood for parents/guardians was as follows;

“As you know I am interested in how both your life, and your child’s life, has been since the recession happened . . . please tell me the story of how your life has changed in the last 10 years or so. All the experiences and the events which were important for you, personally. Start whenever you like. Please take all the time you need. We’ve got about an hour. I’ll listen first, I won’t interrupt. I’ll just take some notes in case I have any further questions for after you’ve finished telling me all about it.”

and finally for service provider staff participants;

“As you know I am interested in what effect the recession has had on children with an intellectual disability, and their families . . . please tell me the story of your employment with (insert organization name) . All the experiences and the events which were important for you, personally. Start whenever you like. Please take all the time you need. We’ve got about an hour. I’ll listen first, I won’t interrupt. I’ll just take some notes in case I have any further questions for after you’ve finished telling me all about it.”

Prior to data collection a safety protocol was produced by the researcher as per NUI Galway Research Ethics Committee Guidance (2013). Therein precautionary measures were outlined, such as the researcher conducting interviews without money or valuables on her person.

Subsequently the BNIM was executed through three sub-sessions. At the onset of sub-session one, variable length biographic narratives were elicited from the interviewees through use of the SQUIN (Hesketh, 2014; Wengraf, 2001; 2006; 2015a; 2015c; 2016c). These narratives, within the free-associative SQUIN interview, were then captured by two dictaphones. Dictaphones featured audible and visual signals for their recording status and were accompanied by surplus batteries (Chamberlayne, Rustin & Wengraf, 2002; Wengraf, 2001). The researcher had emergency service contact details to hand whilst a third party (a parent) remained in the room during child interviews (Kelly, 2013b) for child protection purposes as per the study’s protocol on the management of child protection concerns.

The interviewer did not console, advise, interpret or interject. In this way, the interviewer made virtually no interjections into the stream of narrative beyond
the SQUIN to ensure data was not a co-production between interviewer and interviewee. This minimalist interjection was limited to only 'facilitative noises and non verbal support'. Such non-intrusive active listening partly constituted the approach taken, of non-directional facilitative support (Hesketh, 2014; Wengraf, 2001, p.113; Wengraf, 2015a; 2015b; 2015c). Such was in accordance with the Gestalt principle, which obliges the spontaneous narrations of the interviewee to be permitted to arrive at their natural conclusion (Tashakkori & Teddlie, 2010; Wengraf, 2001; 2015b).

A short interlude was then commenced upon the natural cessation of the narrative and sub-session one. Informal talk with the interviewee was avoided therein considering its capacity to de-potentiate the second sub-session (Flynn, 2014a, p. 46; Wengraf, 2001; 2006; 2015a; 2015b). The interviewer provided no personal information to the interviewee. The rationale for such was the elimination of the interviewee's ability to deduce the interviewer's preferences - given that this might accordingly result in bias within the interviewees proceeding narration (Bryman, 2015; Wengraf, 2001; 2015a; 2015b). Cognizance of the susceptibility of interviewees, to framing their forthcoming interview and narrative in light of their subconscious construal of information which pertains to the interviewer, resulted in a careful and distanced interaction between interviewer and research subjects right from the inception of the study itself (Wengraf, 2001; 2015a).

During sub-session one, BNIM prescribes that the interviewer compile a number of narrative provoking cue words called SHEIOT notes on a SHEIOT notepad. The abbreviation refers to 'Situation, Happening, Event, Incident, Occasion /Occurrence, Time' (Hesketh, 2014; Wengraf, 2001, p.123; 2015a; 2015b; 2015c). A tension between active and supportive listening, and note taking, obliged some exertion from the interviewer's perspective. Once completed these notes combined with topics which surfaced explicitly during sub-session one, were used by the interviewer in the second sub-session, in the order in which they had been narrated. The rationale for this was not to disturb the Gestalt sequencing (Flynn, 2014a, p. 46; Miller & Day, 2012; Wengraf, 2001; 2006; 2015a; 2015b; 2015c). The discernment between a silence in the narrative, and the narratives actual end, was a decisive endeavor overall. In this way the interviewer remained careful about interjecting into silences and pauses (Wengraf, 2001; 2015a).

This practice of note taking amounted to the formulation of a number of questions during the interlude, which were specifically wedded to the salient topics within the sub-session one narration. As aforesaid the questions simulate the sequence in which the topics had been formerly narrated (Hesketh, 2014; Wengraf, 2001; 2015a; 2015b; 2015c). These narrative eliciting questions called TQUINS (Topic-Questions Seeking Narratives) were then asked during sub session two of interview one (Wengraf, 2001, p.135; 2015a; 2015c). They amounted to provocation of more in-depth storytelling around the topics of the sub session one narrative only. SHEIOT notes were also compiled by the interviewer as sub-session two progressed (Flynn, 2014a, p. 46; Hesketh, 2014; Miller & Day, 2012; Wengraf, 2001; 2006; 2015a; 2015c). Intersession breaks or interludes lasted an average of 20 minutes.

At the heart of sub-session two was the practice of 'pushing' for Particular Incident Narratives (PIN). A PIN is defined as, "An account of a particular
experience that the person has lived through - The best PINS are narrations in which the person appears to be re-living the experience that they are talking about" (Wengraf, 2010, p.547 cited in Wengraf, 2015b). These 'experiencing PIN’s' are referred to as ‘in-pins’ and it was the assignment of the interviewer to orientate questioning towards evoking ‘in-PINs' from more surface level 'about-PINs'. Another tricky discernment here was often made between PINs and the less concrete General Incident Narratives (GINs) and Typical Incident Narratives (TINs) (Wengraf, 2015a; 2015b).

In addition, the interviewer was mechanical in the dissemination of questions, based on the agenda contrived from the topics. In this sense the interviewer made no attempt to interpret the meaning of the narrative as it was unfolding, leaving this for the next research phase. Experiential de-briefing notes were made instantly by the interviewer upon the interview’s termination (Flynn, 2014a, p.47). This immediacy of experiential de-briefing allowed for the vital critique of the impact of the interview process on the interviewer to inform later data analysis. It also facilitated non-linguistic data recording of occurrences not captured via audio recording (Wengraf, 2001; 2015a; 2015c; 2015b). An approximation of an hour was allowed for their compilation during which provisions were made to ensure no interruption occurred. The notes reflected a free associative flow of writing without any effort to amend, order or censor its content (Wengraf, 2001, p. 143). One hour of experiential debriefing notes were also undertaken after the first listening of the tape, and again after first transcription in ‘gold star’ cases.

Narratives recorded by Dictaphone were fully transcribed verbatim following the cessation of sub-session two, interview one (Flynn, 2014a, p. 47; Wengraf, 2001; 2006). Throughout the interviewer strictly abided by the courtesies of please and thank you (Flynn, 2014a, p. 47; Wilkinson, 2000).

Sub-session three, interview two, was commenced following a usual lapse of a month to facilitate data analysis in the interim (Wengraf, 2001; 2006). Wengraf (2006) advises that the purpose of sub-sessions' three is to evoke reflection on the meaning of the experiences within the narrations. It is non-obligatory and frequently executed at the discretion of the researcher. Whilst sub-session one was unstructured, sub-session three was structured through ordered questioning (Hesketh, 2014; Wengraf, 2001, p.151; 2015a; 2015c).

Sub-session 3 narrative-eliciting questions were broadly conducted by the conventions of BNIM sub-session 2 with respect to ordering topics, interjection and active listening. Narrative evoking questions were followed by non-narrative ones which sought to elicit specific or pragmatic pieces of data to clarify or address contradictions in earlier narrations (Hesketh, 2014; Wengraf, 2001; 2006; 2015a; 2015c). As Wengraf (2006, p.18) advises, humility and tact was required here to ensure that the interviewer did not shift to a mode of, ‘aggressive demolition’ interviewing' by attacking interviewee’s for internal contradictions in their stories-due principally to the inclination of the same toward generating resentment in research participants who have been generous and gracious in sharing their life stories.

Sub-session 3 was interviewer directed. This obliged a re-orientation toward the interviewer’s preference in topics and questions. Sub-session 3 also lasted longer than previous sessions ordinarily. The protracted duration ensured an unhurried ambience conducive to achieving the necessary depth to data generated
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(Wengraf, 2015a; 2015c). This was punctually followed by one to two hours of experiential de-briefing. This experiential debriefing task was performed again for each interview after listening to the tape for the first time, and after transcription.

4.5.2 BNIM and data analysis

The full BNIM interpretation and data analysis procedure was applied in its purest form to three of the twelve participant's cases for this study. As per Wengraf's (2015b) advice, this study selected these three 'gold star' cases, given that they were determined to be the best cases for in-depth analysis with respect to the study's research question. The researcher individually selected the cases and then critically discussed the selection decisions with the research supervisor in formal supervision.

Data analysis for the BNIM followed nine steps which were applied to each 'gold star' case. A tenth step then made a comparison across all cases (Corbally & O'Neill, 2014; Wengraf, 2015a; 2015b; 2015c). Within each step a multitude of interrelated subtasks were completed. Adapted from Corbally and O'Neill (2014, p. 37) the following pictorial depiction spells out the order in which each step occurred;

Fig. 4.2; Ten step BNIM data analysis strategy. Adapted from Corbally & O'Neill (2014, p.37)
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The lived life . . .

Step 1: Create a Biographical Data Chronology (BDC).

Step 2: Create hypotheses with the help of a lived life interpretive panel.

Step 3: Create a Biographical Data Analysis (BDA).

The told story . . .

Step 4: Carry out Text Structure Sequentialisation (TSS).

Step 5: Told Story Interpretative Panel Analysis

Step 6: Carry out microanalyses and present to interpretive panel.

Step 7: Create Thematic Field Analysis

Step 8: Now compare the lived life and the told story

Step 9: Create a case history account

Other cases analysed using the same 9 step BNIM analysis

Step 10: Cross case theorisation
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Subsequent to data elicitation and by the conventions of BNIM, data analysis followed a twin track interpretation procedure (Wengraf, 2001; 2015a; 2015b; 2015c). The first step of data analysis obliged that a chronology of objective life events was constructed. Next the subjective components were stripped from these biographical data occurrences (Corbally & O'Neill, 2014; Miller & Day, 2012; Wengraf, 2001; 2015b; 2015c). For instance, where one had asserted, 'I loved my wedding day', there would be a segregation of the objective life event, 'wedding', from the subjective experience, 'I loved' (Flynn, 2014a, p. 47; Wengraf, 2006). The result of this first step was the creation of a Biographical Data Chronology (BDC) (Corbally & O'Neill, 2015; Wengraf, 2001; 2006; 2015a; 2015b; 2015c). From early analysis, and concurrent to the researcher’s overall PhD journal notes, a reflective diary was also kept with specific regard to BNIM analytic processes where trends, thematic observations and thoughts were recorded.

For the second step, the leftover naked Biographical Data Chronology was then analyzed with the assistance and consultation of a Lived Life Interpretive Panel (also referred to as a 'kick start' panel or Biographical Data Analysis (BDA) panel). Therein panel members were incrementally exposed to data chunks pertaining to the participant's life or narrative story. This culminated in the formulation of a series of Experiential Hypotheses (EH), Counter Hypotheses (CH) and Tangential Hypotheses (TH). These hypotheses were born from an interrogation of how each life event might have been experienced at the time it occurred for that person (Corbally & O'Neill, 2014; Wengraf, 2001; 2006; 2015b; 2015c). Efforts also pertained to constructing life events which might plausibly transpire next, or 'Following Hypothesizes' (FH) (Corbally & O'Neill, 2014; Wengraf, 2001; 2006; 2015b; 2015c). Finally, Structural Hypothesizes (SH) materialized through this process which pertained to the overall life story as it was unfolding before panelists. Overall it was the intention of this interpretation process to understand the “experiencing, interpreting, acting, subjectivity of the biographical agent in their historically evolving situation” (Wengraf, 2015c p. 30; Flynn, 2014a, p.47). Upon completion of the panel, each panellist, and later the researcher, demarcated their own synthetic understanding of the case or life story account(s) which was presented in written reports. Keywords and images were also sought and recorded. The researcher, in most cases, checked back with panellists after a number of weeks to ascertain if they had any grievances following the panel (they did not), or further thoughts/reflections (in some cases).

With all information sources thus far to hand, the researcher next undertook specific analysis of the turning points and phases in the lived life. The products of this task were compiled into a written document for each case. After this, detailed research was undertaken into the socio-political and historical context for each particular case which again, was compiled into written documents.

For the third step, the BDC, socio-political-historical research, transcripts, notes, turning points and phases document, and both the panel and the researchers analysis of the lived events of the interviewees life story, all combined for the creation of a Biographical Data Analysis (BDA) for each participants case. This was the product of the interpretation and analysis of the events which happened in
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the participant’s life story (Corbally & O’Neill, 2014; Wengraf, 2001; 2015b; 2015c). This was written up in a document for each case.

Before proceeding to the second track (told story) of the twin track interpretation method; an analytic task was undertaken referred to as ‘imagining’ whereby the researcher imagined how the told story might come to be, based on the BDA now available. This analysis was then written up in a report for each case.

Step four to step seven were concerned with how and why the narratives have been told as they were. Step four concerned itself with the textual formation of the narratives. A Text Structure Sequentialisation (TSS) was created by assessing the text for alterations in speaker, topic and tone (Corbally & O’Neill, 2014, p.37 Wengraf, 2001; 2015b; 2015c). A ‘TextSort’ was performed therein which required an evaluation of the text to look for distinct changes or categories in its structure which are summarised in the acronym DRAPES (Description-Report-Argumentation-Particular Incident Narrative-Evaluation-Condensed Situation).

Finally a form of thematic analysis was undertaken to draw topics and sub-topic summaries or ‘Gists’ from the unaltered or raw verbatim transcripts (Wengraf, 2015b, p.205; 2015c). In addition to these tasks, analysis of subject positions and topics was thematically undertaken for each case. At this point, images were created as visual representations of the essence of cases emerging from analysis thus far, and documents called ‘selected reorganised quotations’ were constructed as reference aids.

Overall step five was underpinned by an interpretive panel analysis (Teller Flow Analysis or TFA) for the told story which usefully generated numerous hypotheses (Structural, Experiencing, Counter, Tangential and Following) about the narrations (Corbally & O’Neill, 2014; Wengraf, 2015b; 2015c). This ‘Lived Life’ Interpretive Panel (LLIP) was focused on interpreting how and why the interviewee told their story in the manner that they did (Corbally & O’Neill, 2014, p.38; Wengraf, 2015b; 2015c). The research panel reviewed the case, acting like a ‘sounding board’ for the researchers’ ideas and reflecting upon the researchers interpretations thereof. In turn this ensured the researchers own reflexivity (Becker, Bryman & Ferguson, 2012; Wengraf, 2001; 2015a; 2015b; 2015c).

The panel, future-blind as was the focal protagonist of the narrative, considered how they might have experienced events sequentially that occurred within that narrative. This resulted in a number of hypotheses (Wengraf, 2001; 2006; 2015c). Constructively, the biographic narrative interpretative panel analysis as a process also formed a means for members of the panel to reflexively scrutinize each other’s points of view (Becker, Bryman & Ferguson, 2012).

Within step 5 the researcher also analysed for themes in the flow of narrative, and contextual and environmental influences (Corbally & O’Neill, 2014, p. 38). Here an action of the BNIM was the segregation of two flows of decision making inherent in the narratives. One flow of decisions pertained to those made within the actual series of objective lived events explicated. The second flow existed within the narratives, for instance the decision of what to say or what image of oneself to portray to the interviewer. Teller Flow Analysis was undertaken and a document was written up around this for each case (Flynn, 2014a, p.47; Wengraf, 2015a; 2015b; 2015c).
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Indeed whilst executing the BNIM, the interviewer was also required to conduct a number of Micro-analyses of oddities or intriguing potentialities for learning which occurred within the transcripts of narratives. These 'Microanalyses' were presented to an optional microanalysis panel for each case which constituted step six of the data analysis process (Corbally & O’Neill, 2014; Wengraf, 2001; 2006; 2015b; 2015c). Later step seven then amounted to the amalgamation of the earlier structural analysis of the text with the thematic analysis of the data which produced one last interpretative analysis of the participant’s story which was referred to as a ‘Thematic Field Analysis’ (TFA) (Corbally & O’Neill, 2014 p.38; Wengraf 2001; 2015b; 2015c).

Following this, step eight boiled down to a comparison between the chronological lived life on one hand, and the told story on the other. Within this, the researcher commenced and completed construction of the BNIM 4 column chart for each case. Once completed, the researcher then undertook a review task by going back over all of the materials and re-reading and correcting for any error or misinterpretation.

The ninth step then involved constructing a History-of-the-Case-Evolution for each case. It collated the various interpretative outputs in one description of the historical evolution of the case (Miller & Day, 2012; Wengraf, 2001; 2006; 2015b; 2015c).

To wrap up, step ten then drew an overall comparison across all 3 gold star cases. This cross case comparison is detailed in discussion Chapter 7.

In total, nine panels were held. As established previously, each case had a Lived Life Panel, a Told Story Panel, and a Microanalysis Panel. According to Corbally (2014) 3 is the maximum number of panels that can be held for a case, and within this, the microanalysis panel is optional. Corbally (2014) further advises that panels should have between 3 and 8 members which this study adhered to.

In an effort to be inclusive, most panels incorporated at least one panelist that was a mother of a child with a learning difficulty (6 out of 9), and at least one experienced frontline staff member from an Irish Intellectual Disability organization, who works with intellectually disabled children (9 out of 9). This was deemed essential in order to add the necessary disability awareness to the panel process to address the potential for harmful processes such as Ableism (Campbell, 2008; NDA, 2009). This was also particularly important, as there were no intellectually disabled young people or adults on any panels as ethical approval would have been required for this. No panel had less than 3 panelists and all panels were mixed gender and mixed ethnicity. All panels lasted at least 3 hours. A pool of 10 people was drawn from to populate the 9 panels, and where possible different groups did the Lived Life, and Told Story Panel for each case.

All panelists were chosen strategically due to having a qualification relevant to the research (such as a related professional role, related academic background, or for instance, being a stay at home mother and/or mother with a learning disabled child). Panelists were recruited in three ways. An email advertisement was circulated to relevant researchers, academics and lecturers in the University (for instance, those with a political science or sociological background). Further, as the researcher is also an experienced practitioner from the field, relevant professional associates and colleagues who work with young people with learning difficulties
and their families were recruited (similar to Bolton’s (2008) PhD Thesis using BNIM with mental health service users). Finally, given that Wengraf (2001) advises that panels should have someone like the research participant on them, and should also be heterogeneous, it was deemed important to represent the stay-at-home mother role; and family carer role; two acquaintances with the relevant experience kindly agreed to do so. The research wrote to the developer of the method, Tom Wengraf, prior to recruiting in the latter way to gain confirmation that it was OK, methodologically and ethically speaking.

All panelists signed a confidentiality agreement. All panelists were spoken to sometime after the panels to ensure they had no grievances or further reflections, and were updated on the research progress. All panels generated structural hypotheses and all individual panel members provided a written synopsis of their own synthetic understanding of the case once the panel was completed (Wengraf, 2001). The researcher also completed a similar written synopsis immediately after each panel. Keywords and images were recorded from each panel (Bradley, 2014). Upon the commencement of most panels, panelists stated their professional background, but then were encouraged to add something surprising about themselves in light of their profession and/or some information about them personally, and were asked to bring that role into the panel with them also. This strategy was adapted from Jones (2003).

<table>
<thead>
<tr>
<th>Panelist.</th>
<th>Qualification as Panelist.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MALE 1.</strong></td>
<td>Presently works as Residential Social Care Practitioner with intellectually disabled children and adults (borderline to profound). Extensive experience in this role, and in day services, key working and behavior support, respite, independent living services, youth justice work with intellectual disability, and child care practice with special needs children. Honors Degree in Social Care Practice and college certificate in Community Development and Social Studies. Experienced volunteer also in intellectual disability buddy program. White Irish.</td>
</tr>
<tr>
<td><strong>FEMALE 1.</strong></td>
<td>Presently employed and extensively experienced as a Social Care Practitioner and Program Facilitator in intellectual disability services with children and adults (particularly day services). Also experienced Share-A-Break respite carer (taking intellectually disabled children to stay in her home for breaks). Honors degree in Social Care Practice. White Irish.</td>
</tr>
<tr>
<td><strong>FEMALE 2.</strong></td>
<td>Mother of a young person with a learning difficulty. Presently employed in Social Care managerial role. Extensive experience working with intellectually disabled young people and young people with learning difficulties in residential care. Managed a Neurobehavioral Rehabilitation Unit for young people for several years. Also director of a company that provides afterschool support to children. Degree in Social Care Practice and College Certificate in Child Care. South African.</td>
</tr>
<tr>
<td><strong>FEMALE 4.</strong></td>
<td>Contributing many years experience as a stay-at-home mother (only recently employed). Also chosen for experience as a sibling to a person with intellectual disability. Chinese and White British.</td>
</tr>
</tbody>
</table>
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| **FEMALE 5.** | Doctoral researcher and occasional lecturer examining case of mothers in prison. Academic interest and familiarity with theoretical perspectives on motherhood. White British. |
| **MALE 2.**  | Extensive experience as a school principal in Kenya and school teacher in Ireland, having worked with children with learning difficulties throughout. White Irish. |
| **FEMALE 6.** | Several years as one of the head members of MS Ireland (disability service). Extensively experienced school teacher and chaplain having worked with children with and without learning difficulties in a school with an autism unit. White Irish. |
| **FEMALE 7.** | Mother of a child with has had speech impairment and required Speech and Language Therapy (similar to BNIM young person case). Lecturer and recent doctoral graduate in Sociology. |
| **FEMALE 8.** | Studied Child Care and Social Care Practice at third level and experienced working with disabled children in child care settings. White Irish. |
| **MALE 3.**  | Family member of a young person on the autistic spectrum. White Irish. |
4. Methodology

Fig 4.3 Photographs taken during panels.
4. Methodology
4. Methodology

Fig 4.4 below, adapted from Wengraf (2006, p.46) provides a diagrammatical illustration of the BNIM process;

4.6 Framework analysis

The remaining eight non-gold star cases, not subjected to the BNIM twin track interpretation procedure, were analyzed by the conventions of a Framework Analysis approach. This obliged a number of distinct phases of analysis aimed at drawing or eliciting themes from the data. For the purpose of this study, a theme amounted to a combination of codes, which provide the researcher with a theoretical understanding of the data relevant to the research question (Alasuutair, Bickman & Brannen, 2008; Becker, Bryman & Ferguson, 2012; Bryman, 2015).

Step one obliged the construction of verbatim transcripts. For step two, the researcher read and re-read transcripts to incrementally refine her understanding of the data and its implicit patterns and repetitions. This second step is commonly referred to as ‘familiarization’, and was succeeded by the third step which required the production of initial codes. Open coding was undertaken which saw codes produced which pertained to an array of concepts and/or perspectives (Gale et al., 2013). This iterative process of coding was followed which elicited
patterns from the verbatim transcripts with large margins for analytical note recording purposes (Alasuutair, Bickman & Brannen, 2008; Bryman, 2015; Gale et al., 2013).

Step four obliged the construction of a working Analytical Framework. At this juncture a number of cases had been coded. The labels generated from the same were critically analyzed in order to produce a set of codes by which the remaining cases would be critiqued. This reflected also a movement away from looking at codes, towards a categorical level of analysis (Alasuutair, Bickman & Brannen, 2008). Codes were analyzed and organized into prospective clearly defined categories with the assistance of a tree diagram (Gale et al., 2013). Such formed the body of the Analytic Framework. As foreseen by Gale et al. (2013, p.4) several iterations of the Analytic Framework were required before no new codes emerged through the process. The Framework itself was not deemed complete until the last transcript was coded.

Step five called for the practical application of the Analytic Framework. In this sense, transcripts were indexed using the aforementioned codes, which were replaced with abbreviations for convenience.

Step six commenced now that the nature and location of patterns were recorded and data was condensed into codes. A coding matrix was established through use of an excel spreadsheet which inputted summarized or condensed data in the form of categories. As anticipated by Gale et al. (2013, p5) the researcher experienced difficulty balancing competing requirements. On one hand there was the prerequisite for data reduction, whilst on the other, the need to preserve the original aesthetic and message of the transcript. References were also recorded for illustrative or exemplary quotations at this juncture (Gale et al., 2013; Smith & Firth, 2011).

The final step seven was based upon an analytical reflexivity journal which contained reflective note taking compiled by the researcher throughout the Framework Analysis process thus far. Notes therein pertained to oddities, vivid verbatim quotations or intriguing potentialities for learning, pertaining to theoretical concepts, patterns, themes, perspectives ect. Consultation with fellow researchers on the content of the journal also occurred. The journal itself was used to nourish the overall interpretation process (Gale et al., 2013; Smith & Firth, 2011).
4.7 Ethical observances

In total, this study had to obtain three ethical approvals from three separate Research Ethics Committees, located in various organizations. The social research study, such as this, should agitate for high ethical standards, pervasive within all its component parts (Miller et al., 2012; Shaw et al., 2009). Resultantly, ethical observances have been adhered to within this study to the highest standard practicable taking account of particular dimensions raised by disability (Good, 2005). A starting point in this regard was the studies’ application to the NUI Galway Research Ethics Committee in 2015 as per NUI Galway policy requirements. Approval from the same was granted on the 24th June 2015. Therein a number of formal risk assessments were conducted preceding data collection and recorded and stored on a risk assessment form. This was signed off by the relevant NUI Galway official.

As aforesaid, the sample was confined to young people availing of some degree of service from a disability services sector organization alongside their parent(s)/guardian(s) and service provider staff. Here a second ethical approval was required in accordance with disability sector organizations’ internal policy and own Research Ethics Committee. Approval for this was granted in mid 2016 after reformulations and resubmissions. Finally, a third ethical approval was required to permit the forming of the study’s Advisory Committees which was granted from its respective organization in January 2016. The approval was most readily granted in this instance, as the Advisory Committees were deemed to reflect a
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good example of the Public-Patient (service user) involvement in research as a key research priority in the HSE, who funded the organization.

On a more specific level, confidentiality is a core consideration within social research (Babbie, 2012; Bryman, 2015). This research was conducted in strict accordance with Data Protection Acts of 1988 and 2003 and guidance from the Office of the Data Protection Commissioner. Records were maintained in a manner fitting with confidentiality.

Verbal and written assurance of confidentiality was furnished to participants prior to the research commencing (Flynn, 2014a, p.49). This was inclusive of an easy read option with pictorial illustrations for child participants. Prior to this, a small pilot study was undertaken with one intellectually disabled young person that included the testing of the efficiency and acceptability of the easy to read materials provided to participants. In line with data protection legislation parental permission was sought by service providers before any release of records or disclosure of information occurred pertaining to potential participants (DCYA, 2012b).

Only the minimal quantity of data required was collected and retained. Data was put to no other use than that which was required for the purposes of this study as agreed with participants prior to data collection. Consent was sought from participants to enable access to data by a research party other than the researcher. Direct identifiers were removed and pseudonyms applied to transcripts to achieve anonymity. Security safeguards ensured physically and electronically stored data could not and cannot be accessed by parties other than the Principal Investigator (DCYA, 2012b). Data will be registered under the Data Protection Act if and where required (NDA, 2006). Permission to disseminate findings via direct quotations was specifically sought, and findings verified for accuracy with participants before dissemination (NDA, 2006). In this way, parents were met with to review transcripts and check the researcher’s interpretation for congruency with their intentions. Intellectually disabled young people were also met with, and the researcher took a more child friendly explanatory approach in this instance to going through transcripts.

A central research record tracked the location of all data records and provided a protocol for data storage and retention as per Epigeum recommendations (2012). Electronic material was password protected. All confidential information enjoyed secured storage. Child participant’s disability status enjoys more thorough standards of protection as it is deemed to be sensitive information under the aforementioned Data Protection Acts (NDA, 2009). Participants were additionally afforded anonymity in data presentation. Paper data records were shredded immediately upon becoming redundant as an excess record.

As per NUI Galway’s Data Protection Policy and Draft Policy on Data Retention, audio tapes were retained no longer than necessary. As the NUI Galway Draft Policy on data retention advises, it is international best practice to store other data for several years subsequent to any publication of research. In compliance with the recommendation of the draft policy, other records for this study will be retained for five years subsequent to the studies completion. Regrettably as the studies audio tapes could not be reasonably anonymised they were retained no longer than needed for cross reference purposes for the study. As soon as they
became redundant they were destroyed whilst a second party witnessed and signed off on the same.

Participants and their guardians were explicitly informed verbally and in writing that a guarantee of confidentiality would likely be breached in the event of a child protection concern arising (NDA, 2009). In this sense the research was conducted in strict adherence to the Children First: National Guidance for the Protection and Welfare of Children (2011) (DCYA, 2011 cited in DCYA, 2012a).

The researcher acquired a Garda vetting prior to commencing the research. A child protection risk assessment was conducted preceding data collection and recorded and stored on a risk assessment form which was signed off by the NUI Galway Head of Department. A protocol for the management of child protection concerns was further compiled.

Beyond this, the researcher had accrued practice experience in the capacity of a professionally qualified and registered Child Protection Social Worker. Accordingly no further training was required in order to meet the child protection competency level recommended by the Department of Children and Youth Affairs (2012). Finally an adult third party provided a level of surveillance during the interviews and was not required to attain disability awareness training (DCYA, 2012a, p. 12) as they were a familial support person identified by the young person. In this way the third party also fulfilled an emotional support role during the interview process. Research was conducted in accordance with NUI Galway’s in-house policies and procedures. UNESCO Child and Family Research Centre NUIG, Child Protection Policy and therein the Protocol for Interviewing Children were both strictly adhered to.

This study also rigorously drew upon Whyte's (2005) Research Checklist entitled, 'Research with Children with Disabilities: A Review of Practical and Ethical Concerns and Guidelines and Checklist for Good Practice’. The document is available through the National Disability Authority. Furthermore Lewis’ work led (2001; 2002; 2004; Lewis & Portor, 2004) literature informing the research strategy with intellectually disabled children in the present study.

Consequentially from the inception of this study the researcher has sought to involve intellectually disabled young people, and their families as per Whyte's (2005) recommendation. In the planning phase a steering and advisory committee was established populated by intellectually disabled people, and parents of intellectually disabled children and adults. On-going consultation with the same occurred intermittently over the duration of the study from research design to dissemination phases with three formal meetings occurring (NDA, 2002a; Whyte, 2005). The committee was arranged through a different disability sector organisation than that subject to the research, to promote standards of objectivity. Peer review of the research proposal and protocol was also achieved from peers within academia and colleagues in the field (Whyte, 2005). Finally, panels also included individuals who met the sample population inclusion criteria.

Another core ethical consideration was the potentiality for a power imbalance between interviewer and interviewee. Tangible efforts were made to redistribute power back to the interviewee through their active participation in the research process from planning to dissemination (NDA, 2009; 2007; DCYA, 2012b). Important here was the discernment between procedural ethics, such as this
application, and ethics in practice (NDA, 2009). The researcher approached ethics in practice partly through the application of critical reflection and reflexivity throughout the research process primarily in the form of a reflective journal. Core considerations were the promotion of the well-being of participants through respecting their dignity, autonomy, equality and diversity (NDA, 2009).

Finally, an ethical concern presented itself with regard to the use of research panels in this study. As prior mentioned, by the conventions of a BNIM approach, this study utilised a number of interpretative panels. A Biographical Data Chronology was analyzed with the assistance and consultation of a Lived Life Interpretive Panel (also known as a 'kick start' panel or Biographical Data Analysis Panel). Therein panel members were incrementally exposed to data chunks pertaining to participant's life story such as for instance, "I was fired from my position in the factory". Panel members developed Experiential Hypotheses (EH) by hypothesizing and counter hypothesizing around how that life occurrence was actually experienced for the story's focal protagonist. Following Hypotheses (FH) were also generated by questioning, "what might have happened next in this person's life story?" Finally, Structural Hypotheses (SH) were fabricated which pertained to the overall life story as it is unfolding before panel members (Wengraf, 2001; 2015b; 2015c).

A similar 'kick start' panel, entitled the Teller Flow Analysis (TFA) panel was convened within the study's data analysis phase which took panel members through a comparable journey, within which they were incrementally exposed to the subjectivity of the story's focal protagonist as he/she experienced each unfolding life occurrence (Wengraf, 2001; 2015b; 2015c). At the end of both panels, each panellist demarcates their own overall understanding of the case or life story account in a written report (Wengraf, 2001; 2015b; 2015c).

Within both panels the researcher also pushed for precision and depth of hypothesizing from panel members. A consequent risk and ethical consideration then surrounded the potential emotional impact on panel members, of reflecting on and psychologically projecting themselves into, possibly upsetting life occurrences. Whilst it would appear from past applications of the methodology, that this potential for emotional distress was minimal, some doctoral research concerning emotive topics had warned considerably against the same (Wengraf, 2015b).

Cognizance of a similar risk applied to the study's use of a Microanalysis Panel. Here panel members assisted the researcher to analyze and hypothesize around intriguing potentialities for learning or oddities which occurred within the verbatim transcripts (Wengraf, 2001; 2015b; 2015c). Thankfully feedback and debriefing with panel members around their emotional journey within, and following the panel process, confirmed no adverse experiences.

4.8 Sampling

The sample population comprised of 4 intellectually disabled young people (including one pilot study), 4 parents/guardians of intellectually disabled young people, and 4 service provider staff members. All young people were in receipt of some form of service from a disability sector organization. All children, staff and parents/guardians were given a minimum of a week to decide whether or not to
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participate in the study. The research also aspired to capture the diversity of children, within the sampling frame, in respect of categories other than disability such as social class, gender, and ethnicity (NDA, 2009). This aspiration was achieved with respect to all categories except ethnicity (all children were white Irish). The sample size was kept minimal due to the intensity of the BNIM analysis processes as is customary (Corbally & O’Neill, 2014; Wengraf, 2001; 2015a; 2015b; 2015c).

Overall for the study both purposive and convenience sampling strategies were adopted. Purposive sampling is a non-probability form of sampling, by which participants are chosen strategically based on the purpose of the research. Conversely a convenience sample is chosen simply by virtue of its accessibility (Alasuutari, Bickman & Brannen, 2008; Bryman, 2015; Flynn, 2014a, p.49; Krysik & Finn, 2013; Lewis-Beck, Bryman & Liao, 2004; Whitaker, 2012). Both strategies are acceptable within qualitative research (Carey, 2017).

Staff, parents/guardians and intellectually disabled young people, were recruited via the service provider. In line with data protection legislation parental permission was sought by service providers before any release of records or disclosure of contact information occurred in respect of potential participant young people or indeed parent(s)/guardian(s) themselves (DCYA, 2012b).

Finally, the study’s young person sample population was in adherence with the following inclusion criteria:

1. Fully informed written consent from the intellectually disabled young people, and their parent/legal guardian(s).
2. Appropriate level of verbal articulacy.
3. Young people with a mild or moderate level of ID.
4. Young people above the age of 16 years old.
5. Young people who avail of a service from a disability sector organization.
6. Young people whose participation in the study is ascertained to be unlikely to result in any harm coming to themselves or others as estimated through risk assessment.
7. Young people who are not subjected to pressure to participate or subjected to foreseeable burden through participation.

Alternatively staff members were chosen based on their adherence to the following:

1. Employed by a disability services sector organization through which they are privy to insight into the effects of the recession on intellectually disabled young people, and their families.
2. Fully informed written consent
3. Not subject to any pressure to participate.

Lastly, parents/guardians were chosen by virtue of fulfilling a parent/guardian role in respect of a participant child. Similar to the afore-mentioned, they must provide fully informed consent and be subject to no pressure to participate.
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4.9 Recruitment strategy

Recruitment was a challenging phase for this study. Given the time foreseeable in gratifying numerous Ethics Committee processes, it was deemed essential from the outset, that accurate in-depth research informed a thoughtful recruitment strategy to mitigate against timely mistakes. Research by Lennox et al. (2005) speculated a low compliance rate from organisations. Therein researchers approached 180 (90%) organisations, whilst 111 (62%) agreed to participate, dwindling to 77 participant organisations once all structural and internal bureaucratic impediments had been imposed (Lennox et al., 2005). Whilst research findings like the prior mentioned informed the macro and minutiae of the recruitment strategy, comprehensive field investigation was also requisite. In the end the largest service provider for intellectually disabled young people was engaged with. Yet, after months of planning and approval seeking, the research almost couldn’t continue due to the dearth of available young people who met inclusion criteria: Young people who were deemed ‘intellectually disabled’ and therefore in receipt of associated services, but yet had the necessary level of verbal articulacy, and fell within the narrow age margin required for the study.

As a result of the many such variables, risks and possibilities presenting with respect to recruitment, a substantial length of time was afforded to desk and field research on the same. Relationships were developed with a number of head officials in prospect organisations. Site and organisation archive/library visits were obliged as organisations didn’t publically publish up to date data with respect to the number of service users and their actual geographical dispersion within each age category. I also needed to consider their research policies, procedures and ethics processes; again not always publically obtainable. Overall recruitment planning was recorded in report form, whilst in the end, the strategy employed proved successful. Nevertheless, recruitment was not without its grievances. One private sector prospect organisation initially indicated their full willingness to proceed with the research, and then, several weeks later, withdrew. In this instance an unexpected increase in service demands were cited as evaporating staff resources initially available for the research.

Overall the process of recruitment of intellectually disabled participants for research, has been deemed both taxing and contentious in the available literature (Nicholsen, Coyler & Cooper, 2013). This is not generally the reflection of a lack of desire to participate from those with intellectual disability, but rather of paternalistic gate keeping practices (Brown & Millar, 2013; Feely, 2015; Kelly, 2007; Lennox et al., 2005; Nicholsen, Colyer & Cooper, 2013). This process becomes more difficult when it is intellectually disabled children and young people that the research seeks; a process which at the very least requires some knotty negotiation with adult gate keepers (Kelly, 2007).

As per its Research Ethics Committee and Graduate Research Committee agreements, this study sought out participants for its Pilot Study, Advisory Committees, and indeed the main study, simultaneously through Irish disability sector organisations. This decision was informed by a cognisance of the lengthy processes that some organisation’s internal ethics committee’s oblige, which could see six months elapsing before a verdict is arrived at (Morgan, 2007).
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The first in the chain of command of consent is the most senior member of each organisation, who must be contacted first (Lennox et al., 2005). In this sense, potential children or their parent/guardians cannot normally be contacted directly (Feely, 2015). A gate-keeper was identified who conducted the actual face to face recruitment, referred to by the organisation as the ‘internal sponsor.’ His allocation by a Research Officer occurred after formal ethical approval was granted. The organisation kindly made available facilities and amenities for the research including interview rooms, beverages, and a security guard on site for after-hours interviews.

The recruitment strategy had sought to primarily advance upon non-governmental organisations given that research concedes that they offer a better compliance rate, but in the end went for the larger providers (Tisdall, 2012). At the same time, the research steered away from the more traditional route for the identification of learning-disabled children, namely, through the mainstream school system (Morrison, MacMillan & Kavale, 1985). This was due, in part, to the difficulty associated with ascertaining which students also received supports from a disability sector organisation. In the instance that the recruitment strategy failed, and too few participants were secured, a number of contingency strategies were at hand:

1. Go through self-advocacy groups (Feely, 2015). Whilst children themselves run such groups, it would be necessary in light of consent limitations, to contact self-advocate parent/guardians first.
2. Go through disability specific sporting groups.
3. Approach peer-support groups.
4. Go through regional and national advocacy organisations, such as the burgeoning National Advocacy Platform.

Thankfully the initial strategy proved successful. From the first contact, officials were made aware that three tiers of participation would be recruited for; the Pilot Study, Steering and Advisory Committee and indeed the main study. The researcher tried to convey to prospective organisations, her professional status as a Social Worker with experience working with disabled children and drew upon personal and professional affiliations from the same. The researcher also sought to informally greet in person senior staff in prospective organisations prior to the formal written expression of interest (Nicholsen, Colyer & Cooper, 2013). Of course as prior mentioned, in line with data protection legislation parental permission was sought by service providers before any release of records or disclosure of contact information occurred in respect of potential participant children or indeed parent(s)/guardian(s) themselves (DCYA, 2012b). Once organizations agreed to participate, the following consent and permission processes were worked through.

4.10 Consents and permissions

This research adhered to a form of consent called process consent with respect to its young person participants. The application of which occurred in an earlier study with people with learning difficulties conducted by Tuffrey-Wijne et al. (2008). Process consent essentially involves on-going attention to the status of whether or not the participant appears happy to engage with the researcher
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(NDA, 2009). Participant young people were explicitly informed of their right to withdraw from the research at any time and to revoke their consent. Any observed unhappiness to engage would oblige the immediate conclusion of data collection. Consent was also formally recorded incrementally at key junctures. In this way consent was specifically obtained at the studies inception and again prior and specific to interview audio recording.

This research was in compliance with the legal requirement to provide a thoroughly supported process before surmising that a child lacks capacity to consent (NDA, 2009). Parent(s) and/or guardian(s) as a starting point provided permission for their children to be invited to participate in the study. Consent/assent was then obtained from the young people themselves to participate. Following this, consent was achieved from the young people’s parent(s) and/or guardian(s) for both their child's participation and their own. All consent was witnessed and recorded (Whyte, 2006, p.19). Coloured cards were made obtainable as a communication tool for intellectually disabled young people in line with NDA (2009) recommendation. Whereby if a young person presented a red card, the interviewer did not proceed with the question at hand: Whilst a green card was deemed indicative of a desire to proceed with questioning. In practice, the young people had good verbal articulacy and therefore coloured cards were never used.

Prior to the researcher meeting with the young people, the young person’s parent/guardian or a support worker demarcated the purpose and nature of the study and ensured that they comprehended the same. An easy to read information leaflet was made available for this purpose. Subsequently the researcher went through an additional and similar easy to read information leaflet and ensured the young person was fully informed before written consent was obtained. Parent(s)/guardian(s) co-signed this consent form. Young people were made explicitly aware of their right to withdraw from the study at any time without incurring a penalty or reprimand as were parent(s)/guardian(s) and staff participants. The latter group was inducted to the study through a comprehensive information sheet. All participants also signed a release form pertaining to the publication and usage of their statements.

The methodology of consent adhered to in this study is not without its limitations. The NDA (2007; 2009) advises a dose of caution when using carer or support staff to solicit the consent and contribution of disabled participants. They advise that as a likely consequence, participants may be left feeling that there would be negative repercussions for their quality of care if they have declined their participation. In the same sense they advise that caution should be exercised when interviewing in care settings. This study has considered and complied with the same.

Concurrently, information sheets and consent forms were made available in easy read formats with picture imagery to support text. Intellectually disabled people themselves were involved both via a pilot study and an advisory panel in the construction and design of informed consent materials. These materials were produced in large print to cater for individuals with visual impairments whilst visuals and signage provided facilitation of participants with a hearing impairment (NDA, 2009). Access to a range of linguistic interpreters via a linguistics solutions
company left the study open to the participation of children who speak a language other than English.

The interviewer was also cognisant and sensitive at all times to the possibility that in-depth interviewing may evoke traumatic memories (Alderson & Goodey, 1996; NDA, 2009). As a result of the same, a protocol was devised to attend to instances whereby a participant experienced upset generated by traumatic memories surfacing within the research process. It lists key signs of distress and provides details of relevant counselling and support services to refer the participant to, for follow up (NDA, 2009).

Inclusivity as a study aspiration also extended to ensuring accessibility. This aspiration was realized in accordance with the National Disability Authority 'Code of Practice on Accessibility of Public Services and Information Provided by Public Bodies' and the Disability Act 2005. The physical orientation of the interview venue was wheelchair accessible with easy read signage. The venue reflected a cognizance by the researcher of participants who may have impaired mobility. As aforementioned, letters, information sheets, and consent forms were made available in easy read formats with picture imagery to support text. Intellectually disabled people themselves were involved both via a pilot study and an advisory panel in the construction and design of informed consent materials.

Finally, I had experience employing pictorial tools for the purpose of communication with intellectually disabled young people. I had also acquired training in areas such as the use of LAMH, sign language and Picture Exchange Communication Systems, having accrued many years experience using the same during my time employed in the field. Picture communication tools were present in the venue and displayed on the walls however in the end were not required. Tact and sensitivity was required throughout the research process. This is frequently addressed through disability awareness training (NDA, 2002a; Whyte, 2006). I drew upon my extensive experience and skill base within the disability sector to ensure the research was conducted in such a manner. Below is a table of additional materials developed to support the research that is not included in appendices:

Table 4.1. Additional documentation for study

<table>
<thead>
<tr>
<th>Document developed</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Protocol for signs of distress in</td>
<td>Identifies behaviors of concern, response actions for interviewer and</td>
</tr>
<tr>
<td>interview participants.</td>
<td>information on support agencies such as counseling and psychology.</td>
</tr>
<tr>
<td>b) Complaint and research misconduct</td>
<td>Details responses in line with NUI Galway policies and procedures.</td>
</tr>
<tr>
<td>c) Protocol for management of child protection concerns.</td>
<td>Protocol developed in line with Children First Guidelines.</td>
</tr>
<tr>
<td>d) Research safety protocol.</td>
<td>Sets out protective measures for researcher.</td>
</tr>
<tr>
<td>e) Release form.</td>
<td>To permit publication of participant statements.</td>
</tr>
<tr>
<td>f) Advisory Committee recruitment</td>
<td>To aid Advisory Committee</td>
</tr>
</tbody>
</table>
4. Methodology

| poster, recruitment pamphlet, agendas and minutes. | functioning. |

4.11 Limitations of the study

All research has its limitations. Thus one can concede how a discussion becomes imperative, in exposing how the research is bound by and located within its specific milieu (Flynn, 2014a, p. 52; Becker, Bryman & Ferguson, 2012; Bryman, 2015; Marshall & Rosman, 2010; Shaw et al., 2010).

Recent Irish doctoral research conducted through NUI Galway performed interviews with intellectually disabled young people. It applied an age restriction to its sample population of children aged 16 years and over only. It did so through deliberation on the vulnerability of the group (Browne & Millar, 2013). Upon some perusal of ethical guidance and allied literature, a conclusion was reached that this study would follow the precedent set by the aforementioned. As such the sample of young people for phase two of this study was confined to those aged 16 years old and over.

It would be remiss to omit the controversies of this conclusion. Atkinson (2007) concedes that a cognizance of the vulnerability of a population preceding data collection can ultimately achieve their omission from the same. Such an omission denies the opportunity for them to have their voices heard. Consequently research which does not empower such individuals to participate will otherwise further stigmatize and marginalize them (Atkinson, 2007, p.134).

Inclusiveness was nonetheless aspired to in considering the sample population. In this way the sample was comprised by young people with varying degrees of disability from mild to moderate levels. An ethical limitation which cannot be evaded is the research’s resultant failure to give credence to any full measure of participatory or inclusive research through sampling bias (Bryman, 2015; Flynn, 2014a).

This is because young people at a highly profound level of disability were not included in the final sample, as the method required a good level of verbal articulacy from participants. It is also arguably these young people who are most vulnerable and least likely to have their views, needs and wishes heard (Vorhaus, 2005). Nevertheless, the NDA (2009) advises that participatory approaches should never be taken at the expense of reliability or validity. Additionally they concede that it is unethical to place excessively burdensome demands on disabled participants. Such concerns still stand even where the method is adapted in length and intensity to meet participant needs. Overall, this is a somewhat contentious and hypocritical issue, given that the methodology herein commits to giving expression to the commonly submerged voices and experiences of disabled people.

Incidentally the NDA (2009) underscore research conducted by Tuffrey-Wijne et al. (2008) with people on a spectrum of intellectual disability. Therein they conceded that it was unethical to omit people with more severe learning difficulties from research which could grant valuable insight into their experiences. Browne and Millar (2013, p. 126) further touch on the matter, demarcating the work of McVilly and Dalton (2006, p.187). The latter questions
the validity of depending on surrogates to gratify what they regard as the progressively more stringent requirements of Research Ethics Committees. They contend that a dependency on surrogate consent is ultimately at odds with "one of the major aims of contemporary social policy, namely that opportunities for disabled people to exercise choice and self determination should be maximised" (McVilly & Dalton, 2006, P.187).

Any research strategy nevertheless comes with inherent limitations (Becker, Bryman & Ferguson, 2012; Bryman, 2015; Silverman, 2015). It would be remiss of this research to attest to any sentiment of generalisability or conclusiveness, given the limits of its sample size. Its insubstantiality would simply compromise the accuracy of generalisations made (Blaikie, 2009; Bryman, 2015; Moule & Hek, 2011). Whilst a dearth of generalisability is not a limitation per se, cognizance should be taken of the value of the study in its procurement of knowledge through sound findings, and its potential as a basis for further investigative ventures (Flynn, 2014a, p.52).

The application of the BNIM herein deserves attention in this regard. As aforesaid, in its purest form the BNIM as applied in this study can suitably illuminate the complexities and intricacies of participant’s lived social reality. It cannot at the same time achieve the generalisability viable in a quantitative inquiry comprising of a larger sample population. The BNIM’s application within this study was also dependent upon self report data from research participants, subject to the limitations of their subjectivity and selective memory (Bryman & Burgess, 1994; Wengraf, 2001). Whilst the latter constitute common research limitations, by the conventions of BNIM they are suitably addressed. This happens through methodological ingredients such as the compilation of a chronology of objective lived events, but more ultimately through a real and decisive concern with actually capturing the participant’s subjectivity itself.

Whilst this study was devoid of willful bias and thus aspired to full transparency in its practices, (Bryman, 2015) bias as a research phenomenon could not be eradicated. This bias potentially and primarily presented as follows:

- The sample of young people were subject to restrictions pertaining to their age and degree of disability hence not an entirely representative sample.
- This study applied exacting measures to ensure that the narrative accounts did not amount to a biased co-production between interviewee and interviewer. Nevertheless Silverman (2015) concedes that any interview process, no matter how constrained or restricted, becomes an unavoidable collaboration. Therein interviewee and interviewer are bound into interaction amounting to a constant interpretative practice. A step taken to address this limitation was consultation with participants and feedback subsequent to data collection around the study’s findings and the validity of interpretations made therein (NDA, 2009).
- In light of this, the social position of interviewer becomes a potential source of bias (NDA, 2002; Silverman, 2015; Whyte, 2006). Feminist research critique recognizes that this position may attribute the interviewer power over the interviewee (Becker, Bryman & Ferguson, 2012; Bryman & Burgess, 1994; Buchanen & Bryman, 2009). As with Browne and Millar’s study (2013, p.127) tangible efforts were made to
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redistribute power back to the interviewee, in particular the young person interviewee, through their active participation in the research process from planning to dissemination.

- Similar also to Browne and Millar (2013, p.127), a key study limitation herein was the potential bias towards protecting the name or reputation of a service provider affiliated with or in support of a participant. A limitation which this study concurs would need to be addressed in future research of this nature.

- Wengraf (2001) recognises that the interviewee may be prejudicial, in the process of biographical narration, due to perceiving themselves to be at risk. In this sense, they may convey a self preserving or unduly positive self representation in order to protect themselves from acquiring a negative identity.

4.12 Advisory Committees

An Advisory Committee of intellectually disabled service users and parents/guardians of children and adults with intellectual disability was established to make recommendations with regard to the research. The Committee was subject to on-going consultation (NDA, 2002b; Whyte, 2005) and advised on the development of research materials such as brochures and information sheets. The Committee also engaged in general discussion around the topic and focus of the research. Ethical approval was obtained for the Committee through the disability sector organisation which also provided facilities and amenities, and assisted with recruitment and transportation.

The Committee met on three occasions, namely:

1. Immediately prior to the inception of the pilot study data collection phase (six members in attendance)
2. Immediately prior to the data analysis phase (seven members in attendance)
3. Immediately prior to the dissemination phase with a view to informing the dissemination strategy (nine members in attendance).

4.13 Pilot study

4.13.1. Planning phase

Five aims informed the pilot study, as follows:

1. To test the efficiency of this study’s elected data collection tools and procedures with specific respect to achieving the study’s aim, objectives and over-arching research question.
2. To test the efficiency of this study’s existing risk assessment, protocol and procedure documents.
3. To ascertain if unidentified risks or deficiencies exist which compromise safety and welfare of participants or relevant others and to inform strategies for addressing the same.
4. To test the skill level of the interviewer with regard to the study’s unique modus operandi.
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5. To test the validity and reliability of results generated.

Naturally, the pilot study provided a yardstick by which the research’s original research question, aim, objectives and hypothesis could be measured and amended.

4.13.2 Data collection phase

The data collection phase of the pilot study was implemented in February 2016. It consisted of one BNIM interview conducted with an intellectually disabled young person. The pilot study demonstrated its value immediately. The young person who took part, despite reporting their enjoyment of the process, could not cope with the unstructured method, due to not having the expressive language skills as a result of their impairment. This insight was put to immediate effect as a means to inform study design. The internal sponsor was liaised with, and an agreement made around the new benchmark for verbal articulacy deemed necessary for the recruitment of remaining candidates. This worked well, and all further young people participants, who were labeled with a mild to moderate intellectual disability, were fully able to partake in the method without adaptation.

4.13.3 Data analysis phase

As previously discussed, the BNIM data analysis process is both complicated and sophisticated. In light of the above, the pilot study also included work to test the suitability of these data analysis tools to the raw data generated—where that data came from an interview with a young person labeled as having ‘intellectually disability’.

4.14 Adverse events

On a pragmatic level, preparatory work to mediate against and prepare for the occurrence of adverse events took a number of directions in this study. Upon perusal of the NUI Galway Professional Indemnity Policy and liaison with NUI Galway’s Internal Auditor with regard to the University’s Indemnity and Public Liability Policies, it was determined that NUI Galway’s legal liability was covered with respect to both negligent and non-negligent harm incurred as a result of the study.

As aforesaid a Protocol for the Management of Child Protection Concerns (2015) was developed following formal risk assessment on the same (see appendix 2). A Protocol for the Management of Signs of Distress in Interview Subjects (2015) (see appendix 6) was also developed again subsequent to risk assessment. Medical emergency and fire safety considerations for interviewing were addressed via risk assessment and perusal of the service providers own internal policies alongside the professional support of service providers own Occupational First Aiders and Designated Fire Officers.

A Complaint and Adverse Events Procedure (2015) was developed for this study (see appendix 7). Therein the modus operandi is demarcated by which misconduct by the researcher or research team, and indeed complaints arising from or alleging the same can be fittingly and expeditiously handled. Parent(s)/guardian(s) and participants were made aware of the existence of this procedure via information sheets during their induction to the study and informed
of their right to access the same. Parent(s)/guardian(s) and participants were furnished with a contact sheet (see appendix 8). It explicitly states both independent and non-independent individuals who are contactable in the event of a person wishing to make a formal complaint.

Should allegations of research misconduct arise they will be addressed in line with the pathways of the 'National University of Ireland, Galway Code of Policy and Procedures for Investigating and Resolving Allegations of Misconduct in Research.'

4.15 Conclusion

In conclusion, this chapter outlined the study’s methodological toolkit for establishing how the economic recession has impacted upon, and been experienced by intellectually disabled young people and their families. Within this, lay the rationale for the research strategies used, alongside a discussion around the sustaining philosophies of qualitative and quantitative design (Flynn, 2014a, p. 53).

The studies limitations, ethical dimensions, research and sampling processes were also addressed in this chapter. It was contended that at the heart of the study's choice of the BNIM, lay a desire for an open consideration of the topic, liberated from imposed categories and aspiring to greater balance of power (Flynn, 2014a, p. 53).
5. Findings Chapter 1: Framework Analysis

5.1 Introduction

We have just considered the methodological underpinnings of this study, and as it were, the scene is finally set for consideration of study findings. This chapter begins with the presentation of findings of Framework Analysis. This is the first of the two methods applied in this study. Within the following, verbatim quotations illustrate themes. Ultimately, findings speak to the central research question;

How have intellectually disabled young people, and their families, who avail of services from the disability sector, experienced the economic downturn?

5.2 The framework

The results of framework analysis are represented by emergent themes and subthemes. These are outlined as follows:

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#### THEME 3: Services and payments: Expenditure cutbacks, funding losses and shortages of services, multidisciplinary supports and social transfers

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#### THEME 4: Employment losses: Parental job loss or recruitment embargo within staff team leading to higher caseloads

| Subtheme 4.1: Parental job loss |
| Subtheme 4.2: Recruitment embargo affected services and families |

#### THEME 5: Emotional and lived experience of economic recession for intellectually disabled children and their families

| Subtheme 5.1: Sense of fear, persistent fear, anxiety, worry and devastation |
| Subtheme 5.2: Social worker upset and distressed because can’t get a needed service for family |
| Subtheme 5.3: Left not knowing until the last minute if a needed service will be granted |
| Subtheme 5.4: Sense of feeling lucky to have gotten basic service or |

Middle
5. Findings Chapter 1: Framework Analysis

**Subtheme 5.5:** Parents having to ‘fight’ or ‘battle’ to get service for child

**Subtheme 5.6:** Families who can’t fight ‘falling through the cracks’

**THEME 6: Familial crisis, breakdown and demoralisation arising from economic recession**

**Subtheme 6.1:** Parents having to do demoralising and unacceptable things to get child needed service - e.g. Beg

**Subtheme 6.2:** Families have to reach significant crisis point to get service or indeed reach crisis because of not getting a service

We will now look at each theme, and its subthemes in more detail. This will involve viewing quotations taken directly from research participants that are illustrative. Please note that terms like ‘disability organization 1’ will be used as pseudonyms to protect the identity of organizations referred to in quotations.

**5.3: THEME 1: Characteristics, needs and aspirations of intellectually disabled young person**

**5.3.1. Subtheme 1.1: Behaviours that challenge and/or complex needs**

The first subtheme in this section relates to the behaviours and needs of intellectually disabled young people as a matter frequently raised:

“He pushed me against the door and this was the result” (shows bruise) . . . “I said it to him (young person’s father) . . .what are you going to do when he starts getting mad and he pushes you over and you’re an old man and your on the floor with a broken hip in your eighties.”

(Sarah, mother)

Intellectually disabled young people could have serious medical needs accruing financial cost for parents, and in the following instance, preventing the parent from being able to work:

“there are appointments, not as many as there used to be in the week but eh, and then she used to be sick an awful lot, she got pneumonia and I don’t know if you ever heard of, she got septic arthritis and her hand she nearly lost her hand, ear infections as I say . . . And she was sick a lot . . . She always had pneumonia constantly and she was in and out of temple street (Hospital).”
“She cried maybe for two days constantly and so I brought her in so they opened her and clean out and flush out because it was eating away at the bone – you know- you know what it is septic arthritis?” Interviewer: “yeah…” “She was there for thirteen weeks on antibiotics in Temple Street and that was a horrible experience and he did say she was very lucky she didn’t lose her hand because people have lost limbs through this.”

(Cathleen, mother)

Young people’s needs affected the capacity of others to provide care and support to them:

“We have children who have complex medical needs, wheelchair user, peg fed, epilepsy, significant medical problems” . . .”We can’t really expect extended family members to take on that responsibility"

(Helen, social worker)

Disabled lifestyles, for young people, obliged many appointments, services and activities to attend which naturally incurred costs;

“My mam drives a lot, a long week, along a lot of roads, yeah my mum does a lot of driving”

(Brigid, young person)

“I never stop from Monday to Friday”

(Cathleen, mother)

Whilst social workers identified that the young people’s needs had a significant bearing on service provision;

“The children who have higher needs, and they need a new service then that is where the delays were unfortunately. The people with higher needs even though they should be getting the service much earlier because they are much more complex and the families are more burned out.”

(Maire, social worker)

5.3.2. Subtheme 1.2: Disabled children costing more

A number of participants appeared to believe that disabled children cost more than their non-disabled counterparts. One mother saw social welfare payments as saving the Government a lot of money;

“An allowance that your looking after your special needs kid at home instead of him being out there in a facility where he would cost more like say the likes of here they employ Doctors, Nurses, O.T., Physiotherapy, you know all of that costs
money and I don’t know if you remember the big problem was that protest that was there in front of the Dail two years ago.”

(Sarah, mother)

Parents also could find the appointments and activities for their young people costly;

"Very expensive-very expensive . . . before I was funding all of this . . . but now I have actually lost this four hundred and fifty Euros (cut from disability related social welfare payment)"

(Cathleen, mother)

“I go to do drama and do yoga with disability organisation 1 and on Thursday I have disability organisation 2 and then on Friday I have Bowling club . . . and on Wednesdays I do hip hop and Saturday I do disability organisation 1 . . . disability organisation1 and I went to a Panto on Sunday and also sports club”

(Brigid, young person)

5.3.3.Subtheme 1.3: Young person conscious of community resources: Enjoys doing community activities, engaging with services and/or shows career aspirations

It also appeared that the possibility that young people, either by virtue of their intellectual disability or their age, were oblivious to the pressures of finances and work was not accurate. Overall, two of the three young people who took part in the study voluntarily and spontaneously identified that they must establish a career and possibly engage with further education;

"well I’ve to graduate- graduating – with the hats” . . . ”so I can go to college . . . and I’m going to do some work in organisation1 to sort out my career.”

(Ted, young person)

5.3.4.Subtheme 1.4: Strong social focus in young person’s narrative

Rather than a materialist inclination, another emergent theme within the young person’s interviews was a strong social focus on friends, family and professionals as compared to adult interviewees:

“I won’t just starting talking about Casey, I’ll talk about Melinda, Kate and Maggie and Lola”

(Ted, young person)
“My friends . . . and my best friend is in fourth year and my best friends name is Kelly Walsh and she is crazy -but she is warm and she is lovely and she’s kind.”

(Brigid, young person)

5.4: THEME 2: Residential circumstances: Homelessness and shortage of respite and residential care

5.4.1. Subtheme 2.1: Not enough respite care

A perceived lack of respite care due to economic recession was a strongly emergent theme. Participant social workers were clear that respite services were significantly cut as a result of recession:

“Respite services they have been reduced significantly . . . we only have one residential respite house for children which is six beds for the entire north and north east region . . . at least four of our residential respite houses have been closed.”

(Colleen, social worker)

“It’s when you can’t access the respite because the money just isn’t there.”

(Helen, social worker)

Social workers also made clear that the lack of funding for respite as a result of the recession had an impact on families, who at times were:

“Really very angry about the respite service that it wasn’t provided at all . . . frustration from people about the lack of respite and people were really going years without getting anything and they would say they couldn’t cope.”

(Helen, social worker)

“I work in the respite bookings with the Manager we do the bookings every month . . . there were so many burned out families and families in crisis to be honest the adults do better . . . I haven’t got respite and they think we are forgetting about them.”

“I have had to cancel agreed respite with people who may have made plans, when an emergency happens . . . that’s very hard”

(Maire, social worker)

Respite was also a concern for participant parents:
"They are after cutting all the bed arrangements so that sizes, like there used to be six of them able to go and now there is only 3 . . . It is only once in six months now we get respite."

"I got a letter stating there’s no more respite being offered. Well it has been a long time since Brigid has had respite."

(Cathleen, mother)

Young people who took part in the study raised the issue of respite also:

“I went to Location1 and I had ice-cream and I went to the cinema and had dinner and learned about how to relax . . . emm long ago I went there . . . now we got a letter. No more respite . . ."

Interviewer:
“. . . And you said you got a letter, no more respite and do you remember how your feelings changed?”

“I was sad- my other friends get to go to respite today- they get to go.”

(Brigid, Young Person)

Shortly after recession hit, one mother remembered attending a meeting with other parents who were distressed about the lack of respite;

“I remember being awful upset . . . I saw elderly parents here and people were very angry and upset . . . Because respite was virtually gone.”

(Aideen, mother)

Regrettably, the lack of funding for respite led to young people having to be mixed together that weren’t suited:

Interviewer:
“You said that when the recession hit there was less funds and children might be mixed together in respite that wouldn’t have been mixed together if ideal funding was available, do you remember any example particularly strongly? . . ."

“Yeah definitely now safety is paramount so there is nobody being mixed with and put in unsafe situations so that’s not happening here even though the recession, but the one thing that is happening the group mixes with children are not as good, they are not as good, because of the recession, because we are under so much strain, because we are only managing to get one group of kids in a month now.”

(Maire, social worker)

One mother explained her son’s experience:
“He’s apprehensive usually going but when he gets there he loves it – as long as it isn’t too mixed with Disability Organisation1 . . . I suppose with the downturn they were mixing a lot of quite profound kids and you know it’s very daunting to go in and find somebody who got, you know rocking or banging their heads, making noises . . . you go into somewhere and there is somebody acting a bit strangely its very- and it can be terrible so that would put them off.”

(Aideen, mother)

Her son separately raised the matter in his interview spontaneously and unprompted. It appeared that part of his difficulty with respite was hearing the sounds made by other unfamiliar service user(s) during the night when it was dark leading to him being frightened;

“I’m not going to respite . . . I did -I did like it and me and my friends Aedan, Cian and Saoirse went one Christmas -Liam and me, Liam and me went to respite –just went three times to respite already but now I don’t want to go back to the Disability Organisation 1 respite . . Yeah yes I put my suitcase, in respite, on the floor out in the grass, so I would sneak home – because I didn’t want to go . . . with the other people there was awkward.”

(Ted, young person)

Later, he was asked about it again;

Interviewer:
“You said you didn’t like respite and wanted to leave, do you remember any moment in particular?”

“. . . emm I just don’t like it because I don’t know any of them and I’d hear . . . . I had to sleep on my own – and I cant – I cant do it at all and I’m not going to Location1 I mean to Location1 - I mean to Location2 anymore so now I won’t go back anymore – tell Niamh- tell Disability Organisation1 I’m not going- it was the worst . . .”

(Ted, young person)

Interviewer:
“. . . You said you didn’t like it and do you remember anything In particular? . . .”

“. . . because I can’t spend any of my life there anymore – yeah . . .(long pause) yeah, afraid . . .”

(Ted, young person)

Interviewer:
“. . .And you said afraid and that you could hear do you remember how that all happened? . . .”
“...Yes. Yes (long pause) . .”
(Ted, young person)

Interviewer:
“...You said you were afraid do you remember anything in particular? . .”
“...Afraid about the dark – and the lights off . . yes. And its – its just- (long pause)”
(Ted, young person)

Interviewer:
“...And you said you could hear and- (young person interrupts) . . .”
“...Yes. That’s what it was all about –the people”
(Ted, young person)

Interviewer:
“...And you said it was all about the people –do you remember anything in particular? . . ”
“...Don’t know its just its -their weird- Niamh won’t want to take me to respite its just because I told her I’ll just I’ll leave ...so.”
(Ted, young person)

5.4.2. Subtheme 2.2: Not enough residential care

As one might expect, lack of residential care as a result of the recession was also thematic:

"There were people literally who had nowhere, they had nowhere to leave their adult children and could not die in peace."
(Aideen, mother)

“We only have two children’s residential houses emm and there hasn’t been any scope I don’t think for more to be opened emm and that has resulted in a lot of crisis situations for children."

“In terms of the impact that the recession has had one of the big things for me from a social workers point of view has been the lack of support services being available so in terms of our residential respite services they have been reduced significantly.”

“Don’t have residential . . .over a year 24 months that person has been availing of emergency support.”
(Colleen, social worker)
“Asking for residential care for children which we wouldn’t have really experienced a massive amount of that before but I think it has just been the accumulation of stress for all different levels and families can’t cope and things escalate.”

“They won’t consider residential until they have absolutely reached breaking point.”

(Helen, social worker)

“We need residential really badly . . . when the HSE weren’t funding them residential and there was delays in funding.”

(Families you know we are not just getting money for residential houses so they are really worried about the future.”

(Maire, social worker)

One social worker recalls an instance where she could not obtain funding for families:

“It was just an awful awful situation, really really worrying huge safety issues and really 8 letters later the HSE, after a year of this, they eventually approved a residential placement.”

(Maire, social worker)

5.4.3.Subtheme 2.3: Respite care for child’s benefit not just parent’s

Young people and parents expressed that respite benefited their children once the conditions were right:

“She wants to go, she does seem to enjoy it.”

(Cathleen, mother)

“. . .Learn skills, and I like to go”

(Brigid, young person)

5.4.4.Subtheme 2.4: Shocked/upset by cutback to respite care grant

Following the recession in 2012, the Irish Government revealed plans to cut Respite Care Grant for families by more than 300 euro, and subsequently did so:
“One of the first things that was cut was the respite care grant . . . that was cut- in one sweep- to fourteen hundred- from seventeen to fourteen hundred . . . here is the bitterness coming out.”

(Aideen, mother)

“They dropped the Respite Care Grant . . . big protests outside the Dáil and I used to watch this on the news . . . I used to do day trips with Darragh try to get him to come up to Belfast with me (using payment).”

(Sarah, mother)

5.4.5 Subtheme 2.5: Homelessness

The issue of families with disabled children becoming homeless as a result of the recession was also raised frequently in interviews:

“There is my school leaver (disabled social work service user) at the moment who is likely to become homeless . . . this is a trend . . . and this will be impacting children now . . . turned 18 just homeless situations . . . increase in repossessions.”

“The banks are doing more repossessions.”

(Maire, social worker)

5.5 Theme 3: Services and payments: Expenditure cutbacks, funding losses and shortages of services, multidisciplinary supports and social transfers

5.5.1 Subtheme 3.1: Cutbacks/losses to education and support services such as Speech and Language Therapy and Occupational Therapy

Lack of funding for special education supports for schools was raised:

“There was still always the question of, well, we will have to see if we can get funding and that would have been around 2009, whatever, but we, I begged the headmistress at the time.”

“The problem was going up into secondary school and again the same getting started again all over and we were worried we would not get him locally and they were worried, would they have the resources because the recession was hitting bad at that stage and there is always that worry.”
“I have two good friends who on transition from secondary to whatever and from primary to secondary they didn’t know where they were going until nearly September and the worry of that and the anger, and you don’t mean to be angry about these things but I have got to the stage where I think I am not going to worry because at the last minute they will pull it off somehow they will find money somewhere.”

“Resource hours that’s the other thing resource hours very very short, very short I think it was three and a half hours in a week yeah . . . we were allowed . . . that was all down to funding.”

(Aideen, mother)

“Schools – em several hundred (cutback) and once a month like eem like that’s dreadful and they spend a week taking in everybody and I mean Seamus only gets I mean, maybe, I mean, I think he only gets 20 minutes with (support service) I think that’s it, I mean twenty minutes a month that’s dreadful.”

(Sarah, mother)

Lack of support services such as Speech and Language Therapy was a strongly emergent theme:

“Waitlists are much longer and everything has to be a referral and writing and that can be really upsetting for families.”

(Aideen, mother)

“Because of the recession and because of the budgetary restraints . . . support services groups and Link . . . would have been more readily available . . . isn’t available any longer . . . the clinical team are having to deal with crisis . . . as opposed to getting in earlier.”

“I suppose the recession has had a knock on effect on for community based supports we can’t access them either anymore.”

“But the likes of OT and SLT in particular . . . the waiting lists are really long and I am seeing families that are like in real despair . . very hard.”

(Colleen, social worker)

Cutbacks to transportation to services was another issue raised:

“Really unfair and upsetting yeah that’s tough.”

(Colleen, social worker)

“A huge issue the lack of transport which is directly caused by cutbacks to resources . . . lack of funding.”
“It (recession) had a massive impact on families and children and as a social worker the biggest impact that families would have reported to me was the lack of practical supports . . . children that were considered a very high priority . . . couldn’t get access . . . frustrated . . . at the lengths of time on waiting list . . . we didn’t have clinical people to meet the demands so people really went through a horrific time . . . it’s not being able to get what they need . . . practical supports . . . clinical supports . . . challenges at home . . . they would be hitting their parents, hitting their siblings so you would have a lot of depression and lack of coping . . . regularly have families saying they can’t cope . . . they just weren’t getting any of the help they need.”

(Helen, social worker)

“Young people . . . just turning 18 and coming out of school is the lack of day service placements.”
“Managers have no money.”
“(clubs) just once monthly because of the cuts.”

(Maire, social worker)

5.5.2. Subtheme 3.2: Change in social work/client relationship: More strain; families more hostile to; or social worker providing more emotional support

In the relational sense, cutbacks to services and lack of funding arising from the economic recession appeared to affect the relationship between social workers and families:

“Social workers and Psychologists are kinda always on the other end of a phone and providing support and emotional support . . . getting really upset parents coming in and distressed you know just that the delay or the wait.”

(Collen, social worker)

“Not enough action and sometimes emotional support can be frustrating when it is all that can be offered . . . they (families) react very badly . . . shouted at aggressively . . . show up at reception . . . frustrated with you personally . . . very angry families . . . (social workers) at the receiving end . . . of frustration and the anger of families.”

(Helen, social worker)

“The mum was very annoyed that we couldn’t do anything.”

“What someone is really desperate . . . like that mum was so annoyed with us and you feel really bad after it and that mum was really annoyed after.”

(Maire, social worker)
5.5.3. Subtheme 3.3: Cutbacks to support services described as worst impact/biggest issue of recession or described as or demonstrated to be dreadful or severely damaging

The intangible aspects of cutbacks to support services were considered damaging:

“The most appalling thing about the recession and again it wasn’t for the money bit it was the whole principle of it. . .one of the first things cut was the Respite Care Grant”

(Aideen, mother)

“It all comes back to the cutbacks and the impact that all of that stress has had on them (families).”

(Helen, social worker)

Yet, lack of practical supports also had tangible effects:

“Like the main piece is really the support services and the staff and that has been the main impact of the recession . . .on services for families with children with intellectual disabilities.”

“There is very limited resources available for families so in terms of support and for me that is the biggest issue.”

(Colleen, social worker)

5.5.4. Subtheme 3.4: Service lacking: Being offered inappropriate service instead of needed one; waiting lists causing stress for families or receiving vital service very late, relying on friends instead or parent run organisations

One social worker describes the impact for a family of waiting for a service:

“(Young person) probably going to be abandoned and then the HSE will have to do something about it pay a private provider 2 hundred thousand and somewhere down the country away from their family in a residential house and not with us.”

(Maire, social worker)

As outlined earlier, lack of funding also led to poor mixing of children in respite:

“Was not really a good mix for them.”

(Maire, social worker)

And long waiting lists, staffing issues and delays:

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“Waiting lists . . . (families) on that list for years . . . huge problem with getting staff . . . they (staff) are not qualified . . . young person delayed service from September . . until November.”

(Maire, social worker)

Lack of services led families to have to inappropriately rely on informal care of friends or family in some instances:

“Sister passed away and she was 43 she will be thirteen years dead when Brigid was born, we knew she had cancer, my sister, but in order for me to go back to work after I had Brigid, my sister minded her for as long up until (her death).”

“No support, no, I didn’t, just what I got from friends.”

(Cathleen, mother)

And for young people it was clear that voluntary services provided by organisations created by parents in the locality were the only services that were significant other than school:

“Emm yes, we did a Hollywood theme on our night- that was with Parent Led Organisation1” Interviewer: "And you said you did a Hollywood Theme with Parent Led Organisation1 and then you did a movie night with Parent Led Organisation1 and do you remember anything more in particular?” Brigid, young person: "Yeah and all the help we get from Parent Led Organisation1, they really help us, and they have a lot of things for us to do, and themed things, and nice things” Interviewer: "And you said Parent Led Organisation1 do a lot of things for you, do you remember anything like that in particular from Official Government Services Organisation*?” Brigid, young person: "em No."

5.5.5.Subtheme 3.5: Cutbacks to entitlements/allowances

Cutbacks to social welfare entitlements featured in the interviewee’s responses:

“She said (a researcher) by the time they are diagnosed with whatever their condition is, I think her child had cerebral palsy up until they die and they do go into adulthood they have mentally challenged people, and they live to be old men and old women and she said 5billion . . so instead they give us this pippy amount and so we will stay at home with them.”

(Sarah, mother)

“Now I have actually lost this four hundred and fifty euro a month . . . I was cut because of the disability and the carers allowance . . . after getting cut in my money, so they say it all adds up.”
Subtheme 3.6: Services coping strategies for cutbacks

On an institutional level, services changed and adapted following economic recession. Health Information and Quality Authority (HIQA) input was sometimes perceived bitterly:

“You have some children with things like Angel Syndrome, who are chair bound and profoundly intellectually disabled and they were no longer getting the respite because HIQA claimed that the rooms had to be single rooms but to cut respite without saying here is some money lets sub divide rooms . . . very upsetting for a lot of people.”

(Aideen, mother)

One school couldn’t cope with existing resources and kept placing telephone calls to the young person’s mother:

“I thought to myself it’s not my problem he’s with you and your supposed to look after him.”

(Sarah, mother)

Services attempted to be more cost effective:

“I suppose the Value For Money Policy document is looking at what is cost effective but also what is individualised . . . I see the positive side of that”

(Maire, social worker)

Services may have become more crisis orientated:
“Dealing with crisis . . . as opposed to getting in earlier.”

(Maire, social worker)

More responsibility may have been put back on families:
“I don’t think parents were empowered enough or given enough responsibility.”
“Have had to encourage parents to tap into natural resources.”

(Maire, social worker)

Service users may have been given more independence as a consequence of there being no service available in the context of:

“Historically a balance between protection and a right to self determination.”

(Maire, social worker)

And subsequent to recession but perhaps not as a consequence of it:
“An awful lot of paperwork . . . become less flexible around things . . .”

(Maire, social worker)

5.6: THEME 4: Employment losses: Parental job loss or recruitment embargo within staff team leading to higher caseloads

5.6.1. Subtheme 4.1: Parental job loss

It emerged that three of the four mothers who took part in the study overall reported that they were not able to work due to their young person’s disability. It further emerged that two of these mothers also had husbands who lost their jobs as a direct result of the recession:

“My husband . . . he’s 40 years, 40 odd years working, he was let go there in 08-08 yeah recession just hit then -Yeah he hasn’t been working since 09 . . . I was worried I wasn’t going to be able to pay the bills and at one point we did go behind I think it was the ESB and we owed them hundreds.”

(Sarah, mother)

“I actually gave up work . . . I went back to work for a year and two months and I just felt I couldn’t cope with it.”

(Cathleen, mother)

5.6.2. Subtheme 4.2: Recruitment embargo affected services and families

The recruitment embargo in Government funded disability services was also identified as being detrimental for families following the recession:

“The impact of the embargo and recruitment and not having the funding . . . is having a big impact and negative impact on families.”

“There is not enough of us to provide the level of support that is required.”

“The fact that people aren’t being replaced and we are being expected to cover a lot more.”

“Guilt of taking a career break because I knew . . . my colleagues . . . to cover my workload as well as their own.”

“When I started here there would have been . . . maybe seven social workers . . . now there is four of us full-time.”

(Colleen, social worker)

“(Families) not being able to access the help they need . . . so emm that was largely to do with posts not filled.”
“Have a waitlist system . . . Because there wasn’t enough of us to cover”
(Helen, social worker)

“There is less flexibility . . . it is just that they are overworked.”
(Maire, social worker)

5.7: THEME 5: Emotional and lived experience of economic recession for intellectually disabled children and their families

5.7.1. Subtheme 5.1: Sense of fear, persistent fear, anxiety, worry and devastation

Fear and worry was related to whether a vital service would be provided, denied or retracted:
“There is always kind of the fear . . . Always the fear hanging over us . . . but anyway there was always the fear . . recession was hitting bad at that stage and there was always the worry . . are we going to be shown the door?”
“And the worry of that and the anger, and you don’t mean to be angry.”
“There was always the fear.”
“There is always the few months you are worrying and waiting and wondering.”
(Aideen, mother)

“You are really annoying and really upsetting people who really need a break”
(Maire, social worker)

Due to seeing a family who couldn’t get funding for vital support:
“a neighbour was so distressed by what she saw that she wrote a letter to the HSE”

“People tell you that they are suicidal. . . but in a moment of madness sometimes people do things very impulsive . . . we are all really worried about things like that happening here.”
“So there is certainly huge fear and worry and worry for parents and they were always worried about it but now since the recession there is nothing there.”
(Maire, social worker)

5.7.2. Subtheme 5.2: Social worker upset and distressed because can’t get a needed service for family
The relationship between social workers and service users was at times strained by the lack of resources, lack of services and funding cutbacks due to economic recession:

“It quite upsetting and distressing at times when I can’t coordinate that for a family... that’s quite difficult because you are trying your best to support them.”

(Colleen, social worker)

“Everyone is in bad form... bad form, at times too, because you are just, there is just so much that is so difficult that people are so burned out that they are less flexible and I suppose that I can get a bit cross myself when things aren’t... are getting, burned out because you are just so sick of all of these blocks the real it’s a real impact of the cuts.”

(Helen, social worker)

“Social workers too they would regularly listen to that emmm just the frustration of not being able to access the help that they needed for children... When people aren’t getting the support that they need the level of stress really increases and we had to deal with so many more crisis situations then because things were really escalating for so many families.”

(Maire, social worker)

5.7.3. Subtheme 5.3: Left not knowing until the last minute if a needed service will be granted

Another strongly emergent theme was that of delays in providing a service, and families left not knowing if or when a needed service would be provided:

“And we were never, never sure until the last moment.”

“From secondary to whatever and from primary to secondary they didn’t know where they were going until nearly September and the worry of that and the anger.”

(Aideen, mother)

“So respite has been cancelled and for – for the on-going future so we don’t know how long it will go on for so you know so like one of the parents up here was saying it could be a year – or it could be – we don’t know.”

(Cathleen, mother)

One social worker talked about a family holiday that required a disabled service user to avail of respite:
“booked and paid for it and everything . .booked their holiday almost a year in advance . .I couldn’t give that family a guarantee until literally three days before very stressful.”

(Colleen, social worker)

In addition, families might be told they were getting a respite break, and then this would have to be subsequently cancelled to accommodate emergencies as they arise in other families:

“You would say to the staff no put them ahead put them ahead of that mother’s son because they just need it.”

(Maire, social worker)

5.7.4.Subtheme 5.4: Sense of feeling lucky to have gotten basic service or entitlement

With specific respect to the basic services that participant parents had received, such as their young person being able to attend school, they perceived themselves as having been privileged:

“We were lucky we went right through that senior cycle emm in national school . . . And then luckily for us there was a child older that Chris . .led the way.”
“We are lucky you know we just kinda we are there snuck in behind because you know catchments comes into the fray.”
“Within the catchments area that was our saving grace that was our pure saving grace.”

(Aideen, mother)

Another mother was grateful for advice about her son’s disability allowance:

“you know after all he is entitled to it he’ll not to get it under 16 and like that it was actually the lady in the I mean I was in the post office said it to me she was like oh (changes her voice to mimic) “He’s entitled to disability” she said make sure you apply for that.”

(Sarah, mother)

5.7.5.Subtheme 5.5: Parents having to ‘fight’ or ‘battle’ to get service for child

A particularly emergent sub-theme was parents and social workers perception of the need to “battle” for services and entitlements:
“We are starting our battle for next year we are already looking at School1.”
“I’ll fight for it you know.”

(Aideen, mother)

“I suppose I should have spoke up I should have had my say and let them know how I felt but of course I just took a back seat and said nothing.”

(Sarah, mother)

“You can’t have it in Government Funded Disability Sector Organisation and you can’t get it in the community so that can be a real battle.”

(Colleen, social worker)

5.7.6. Subtheme 5.6: Families who can’t fight ‘falling through the cracks’

Building upon the last sub-theme, was the notion that if families don’t fight then they “fall through the cracks”.

One mother said in relation to the post recession cutbacks to services and supports:

“Just made me feel that when times are good well, here is the bitterness coming out now, they are like awwh god bless them and we will give them money but the first time there is a turn, you know, that they would be forgotten, if things get bad we will take the cheapest option, lump them all together, or whatever you know, and you would wonder if it got so bad would it have gone back to the institutions stage.”

(Aideen, mother)

“Really high priority people who get the opportunity to avail of it unfortunately others fall through the cracks.”

(Colleen, social worker)

“They were non national they don’t know their rights I rang I checked it up and it turned out they had got way less.”

(Maire, social worker)

5.8: THEME 6: Familial crisis, breakdown and demoralisation arising from economic recession
The final theme is that related to familial crisis and demoralisation. This was by far the most strongly emergent theme.

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Regrettably, but perhaps realistically, parents showed an expectation of having to battle for needed services or they wouldn’t receive them:

“*Because we are not banging down the door.*”

(Aideen, mother)

Having to justify receiving entitlements:

“*Try to justify.*”

(Aideen, mother)

Feeling that they had to make their own child seem more disabled to get services:

“*Nearly making them out to be worse.*”

(Aideen, mother)

Begging;

“*Please give him a chance.*”

“I begged the headmistress at the time to give us a chance.”

(Aideen, mother)

“I just think that families need more breaks or not the guilt or not have to ask or plead for do you know I just find that this is really difficult, but I feel I have been so negative but . . .”

(Colleen, social worker)

Having to depend on friends or family for young person’s care:

“*Didn’t depend on any one when Brigid was in respite.*”

(Cathleen, mother)

Having to make difficult decisions:

(Mother) “*Would have to take him home without a homecare package unless she left him months in the hospital.*”

(Maire, social worker)
Some parents took it upon themselves to undertake extreme measures to support their child:

“I was with other families with autistic children and they say what are you going all the way to Boston for? And I said if I have to go to New Zealand I will go to the end of the earth to study about autism.”

(Sarah, mother)

An emergent sub-theme was related to parents threatening to take their own life or murder their children as a direct result of not being able to get a vital support service:

“I had a situation that was a real crisis, the mam was threatening to commit suicide, the daughter, she also threatened to kill her daughter who had special needs . . . as we had no residential and respite and its horrendous and that’s how serious the situation had escalated.”

(Colleen, social worker)

In another case:

“I remember being so worried about her because that’s the level of stress . . .that she was going end her own life she was feeling and the lack of, she perceived the lack of practical support.”

“And families will say anything they have to I’m going to harm my child or im going to harm myself if you do not do something.”

(Helen, social worker)

“You know, they are only going to . . . they seem to be only funding the life and death, and clients and emmm just when I worked . . .parents so stressed that the entire time they talked about trying to kill themselves and kill their child and they emmm they got residential in my case which was another one where suicide was threatened there was huge safety concerns that got funded so really it’s the only the HSE are only funding those ones where there is life or death issues.”

(Maire, social worker)

5.8.2.Subtheme 6.2: Families have to reach significant crisis point to get service or indeed reach crisis because of not getting a service

One social worker comments:

“Unfortunately it is only those situations and families that are in quite significant crisis that are in a position to access support and again because of the recession.”
“Lack of support over the extended period of time people’s resilience is going to dwindle.”
“Clinical team are dealing with crisis... as opposed to getting in earlier.”
“Our priority...where children are at death and dying.”
“Having to stay at home with families that can’t care for them.”

(Colleen, social worker)

Another social worker explains that for one mother who has not got the services she needed due to lack of funding:
“It had led to a complete breakdown.”

(Helen, social worker)

Cases made to the HSE for funding were reportedly:

“Rarely successful...Families left holding situations that you just couldn’t imagine being in yourself.”
“Won’t consider residential until family have absolutely reached breaking point.”

(Helen, social worker)

Another social worker recalls family breakdown that occurred where a vitally needed service wasn’t funded:

“It just sort of fell apart...out of desperation...because his mum was so desperate...huge safety issues at home and in the day service.”

And on a separate issue;

“We have one child in absolute crisis who should have been in residential long ago.”

(Maire, social worker)

Finally, it was highlighted that by giving a service to one family who was falling apart, it then meant that other another family did not get that service perhaps leading to them “falling apart”. A social worker recalls one case where funds were finally provided:

“I think because they were threatening suicide and they felt like killing him the HSE finally” (provided funding).

(Maire, social worker)
6. Conclusion

This chapter formed a consideration of framework analysis findings, and as it stands, the subjective lived experience of recession appears to have been, albeit in varying degrees, predominantly negative (as in DCYA, 2012; DFI, 2010; Flynn, 2017b). Before proceeding to impending BNIM findings, perhaps a moment of reflection could be seized, pursuant to the question of veracity (or conformity to fact) (Silverman, 2017). The present study, methodologically speaking, formed neither a pure economic nor cost-benefit analysis; therefore it is not appropriate nor particularly helpful to make generalisations about whether disability services required better funding, or whether intellectually disabled young people and their families have been disproportionately impacted by austerity. Whatever the case may be, the unique and particular qualitative findings here do provide certain validations. Disability services, whether with funding that was affluent, absent or mismanaged (Department of Health, 2012; Quinn, 2014), were subjectively and grossly interpreted as failing this study’s participants in the aftermath of recession. This could be applied also to the wider government response (Allen, 2009; Skalecha, 2014) which was necessarily limited (Department of Health, 2012). Lived experiences of austerity seemed to be about much more than simply lack. As temporal, social, symbolic and cultural concerns converged within narrative (Reissman, 2008), the fear of losing; the worry of the unknown; and anguish of waiting, were such ethereal and emotive variables identified as meaningful by this study’s participants: Variables perhaps not readily nor confidently quantifiable, but nonetheless of great importance to participants’ lives.
6. Findings Chapter 2: BNIM Cases

6.1. Introduction

The framework analysis findings just considered have perhaps imbued a sense of the lived reality of recession and the complexity it espouses. Building on these Framework Analysis findings already viewed, this chapter will present the three cases that are the outcome of the purest application of the Biographical Narrative Interpretative Method (BNIM) across nine stages. Breandan’s case is presented first, then his mother Aoife’s case, and finally the case of Siobhan, a Principal Social Worker in the organisation that is publicly funded to support Breandan. In Breandan’s case, the researcher also interpreted Lamm signs that Breandan used as a signing system to augment his speech. Ultimately, Breandan had a good level of verbal articulacy and therefore this wasn’t necessarily required, however it did help with robustness of interpretation.

The three cases can be considered with respect to the studies central research question;

How have intellectually disabled young people, and their families, who avail of services from the disability sector, experienced the economic downturn?

6.2.1. Breandan

“I love talking to people”

Breandan is a young person of 17 years of age and an accomplished athlete. On our first meeting, Breandan was slightly disarming in his self-assuredness and pleasant manner that although quite understated, seemed to instantaneously command my attention. Within this, he portrayed a positive outlook, “I love my friends. . .I love going- I see my friends with respite. . . . On my road I have a lot of my friends . . .” . . .and . . . “I really like when it is raining, I love when it’s raining because dad teaches me to play the Xbox, I love it because we stay in to play the Xbox .”

Breandan is diagnosed with Down Syndrome, and labelled as having a mild/moderate intellectual disability. Breandan’s told story conveys elements of both resilience and aspiration. It is also a story centred upon a struggle to speak.

Breandan was born just before Christmas. He had an older brother and sister, both under 7 years old. His parents were married and owned a home in Ireland’s capital city. Notwithstanding subsequent adversity and strain on their relationship, Breandan’s parents are implied to be a great support; “My dad and mum are married 34 years and yeah, they are happy.” “Before mam worked at a pizza place but long ago, and then mam met my dad and they got married but my dad was shy and my mam was shy.”

Breandan’s mother already had a diagnosis of Depression at the time of his birth, when almost straight away, something appeared to be wrong. Hospital staff advised Breandan’s parents that their son had Down Syndrome. It followed that
Breandan did not speak until he was nine years old in the context of on-going struggles for Breandan and his mother to get adequate Speech and Language Therapy (SLT) provision. As Breandan evaluated, “it wasn’t fair, I needed it.”

In the Republic of Ireland, the state paid the voluntary disability sector to provide disability services at their own discretion, rather than giving the budget directly to service users so that they may purchase the services that they believed that they required (Power, Lord & DeFranco, 2013). Breandan’s publically funded disability services provider is referred to here as CAS.

CAS offered Breandan Physiotherapy to start with, despite the fact that he learned to walk by 18 months. Breandan’s mother asked repeatedly for SLT to no avail, and expressed her desire to give the allocated Physiotherapy to a neighbour whose child was also a service user, and seemed to desperately need it. Then in 2003, Breandan’s little sister was born. The family now had 4 children under the age of 9.

Breandan’s mother began to pay for private SLT which was costly at about €60 or €70 a session, excluding mileage. This created significant financial and time stress over the many years that followed. Moving forward, Breandan began to attend any services offered to help with speech.

At 5 years old, Breandan started mainstream primary school. As the SLT provision was poor, Breandan’s mother later made the decision to move him to another school, a Catholic special school where he could access more SLT. Following his move of school, and the subsequent macro-scale impact of economic recession, CAS reported that they were going to cut the limited provision of SLT that they were giving him. At this time, Breandan still wasn’t speaking despite appearing cognitively able and bright.

Breandan remained in this school: “Im there yeah a long time, to get educated, since I was 8” and therein avails of limited SLT, “I like seeing Paula. She was teaching me the Lamh signs and mam, yeah, she seen the Lamh signs, and, 500 Lamh signs, I can do it, and Paula taught me a lot of Lamh signs and this has helped a lot . . . and I show the teachers what I am doing . . . yeah . . . I help the teachers with the Lamh signs.” Breandan comments, “I see her in the next room and she has a small room and I can hardly fit in.”

Economic recession hit in Ireland in 2008. Almost straight away, Breandan’s father and sole breadwinner of the family became aware that his employer had been hit hard, and may have to start letting people go. Breandan’s mother was unable to work as direct consequence of Breandan’s care support needs. She has been unable to work since he was born. In this context, SLT became even more of a scarce commodity as the Therapists started emigrating, and a public sector embargo on recruitment left sick leave and maternity leave uncovered.

Having advocated and campaigned for families struggling without SLT in the economic recession, Breandan and his mother decided to go on national television to tell the story of their struggle for speech therapy, “I love talking to people, I went on the television, I went on TV3, we went on to highlight lack of speech and language . . . It wasn’t fair I needed it.”
Breandan father was let go from his job as a result of the recession; “dad who had a job used to work and lost his job, sad. He lost . . . he lost his job . . . and then the same week as nanny died . . . same week as his mammy died, . . . he lost his job on the 13th and then nanny died on the 17th.” This was framed by Breandan as a particularly dark time, especially seeing his father so broken and vulnerable, “yeah my dad lost his job, it was sad, and yes my daddy sang a song and cried, he sang a song and cried – both, and we then cried together, he was singing a song and crying.” Breandan became worried about his father and the family’s financial struggles, and potentially began to focus upon how he could earn a living and build a career as a result, “I was worried, yes, worried.”

Yet, Breandan’s speech difficulties continued to impose boundaries upon him. He identified a number of potential employers such as Harvey Norman, but ultimately, “I want to be a DJ all my life . . . I’m going to college to be a DJ, yeah, I like working, yeah, and working on the decks, yeah, and working with my uncle James abroad. . . . I love college, going to college, and then to work, I can do it . . . after college . . . I’m gona be working in a bar.” However, Breandan’s effort to undertake paid work as a DJ with his uncles assistance were undermined because, as he advises, he couldn’t talk properly to notify that he was putting the next song on, as is the customary practice,

‘and he said he would give me a job as a DJ, and when I am here I’m not playing. I wished I could have played but I couldn’t talk well to show the next song was coming on.’

Breandan was eager in his desire to earn a living and eagerly recounted instances where he had. At his granddad’s funeral, “I helped and the undertaker gave me 20 euro” and through DJing, “James gave me to DJ a 50 euro note in Portugal.”

Breandan’s father remained largely unemployed for three years despite efforts to get a job and further training. Breandan’s father briefly gets work but it is unsuitable, and he became unemployed again; “he couldn’t get to see us, he was working late and sleeping during the day, and working nights, and he couldn’t.”

Breandan’s difficulty gaining speech was also problematic in psychological ways, leading to an effect on his behaviour at times. In addition to Breandan’s paternal grandmother passing away, both of his grandfathers die over a few short years, “alot of people died.” Breandan was very close to his maternal grandfather and supported him throughout his illness until his eventual passing, “it is stuck in my head the memory of me seeing my granddad die and lying on the bed.” Without speech Breandan struggled to cope with his feelings, “cus when my granddad died and was buried I needed to talk about it.”

Today Breandan sees things as having transitioned into a better way of life, “it is more a good life, more good things.” Breandan’s father has a career now, “daddy works as a Taxi and an odd time he is late and he goes out early in the morning . . . and he is much happier now.” This affords Breandan more quality time with his father, “we go to play pool and I like when my dad goes, but now he can, he used to be busy.”
6. Findings Chapter 2: BNIM Cases

Breandan’s speech took much longer to acquire due to the cutbacks to SLT. Breandan now presents as very verbally articulate and celebrates his ability to speak, “I like talking to people, talking every day, saying hey, hello say out saying my words out give my news.” This underpins what presents as a vibrant social and recreational life, “I love my friends” “I love school and even homework”. Breandan is an accomplished athlete with Special Olympics, having recently travelled to Los Angeles where he won a silver medal in the floor event, gold on the pommel horse, silver on the rings, silver on the high bar, gold on the vault and bronze in the all-round section;

“we took part a lot and in events, and I love events, and had some great wins yeah, and we travelled over and back on the plane with team Ireland, and I went out with my own, and yeah, and yeah well not my parents didn’t go until after, and we did very well and our team was happy.”

Breandan appears to be an exceptional young man as he has undertaken substantial fundraising and advocacy work for disabled people in need of services such as SLT and general disability services that were cutback. Breandan has raised thousands of euro for these causes.

6.2.2 Particularities of Breandan’s case

Subject to his mothers agenda to protect him. Breandan’s mother admits that she tried to hide the family’s financial hardships from him. This interfaces with two social categorisations interrelated within Breandan’s identity; being intellectually disabled; and being adolescent. Intellectual disability is often subject to paternalistic efforts to protect, as the disabled subject is construed to be vulnerable and helpless (French & Swain 2000; 2008; Shakespeare, 2014). Furthermore, as an adolescent, Breandan still was subject to the protective efforts of his parents. Nevertheless, despite these factors, Breandan shows a strong cognisance of the need to gain paid work and become independent, perhaps reflecting the precarious hegemonic neoliberalism of the country’s wider economic context (Conneely & Garrett, 2015). Overall, Breandan’s mother’s efforts to cloak him from their financial woes seem to have been only partially successful.

Strong social focus. As is often established to be the case in qualitative research with young people (Parkinson et al., 2015), a strong social focus on friends and social events characterised Breandan’s case. A sociological Life Course Perspective locates individual development in cultural and historical contexts consistent with the BNIM approach, rather than seeing developmental stages as rigid, inevitable and universal. Life Course Perspective also emerged partly as a reaction to the strong impact of the economic conditions of the Great Depression on individual life pathways (Hutchinson, 2005) and therefore is a fitting lens for the present case.

Breandan seemed to place intense value on social interactions and friendships. This seemed to fit well with the contemporary social construction of ‘adolescent’. Economically inexpensive encounters, for instance a positive interaction with an admired peer, seemed to represent significant gain for him, taking the form of social capital. This relates to the impact of economic recession as Breandan’s case
demonstrates the importance of one’s stage in the life course in terms of how they are impacted by, and experience economic recession.

**Strong identification with father’s role as ‘breadwinner’, and gender expectations around paid work.** The invisibility of Breandan’s mother in his biographical account is vivid. Despite her enduring presence on a practical level, as his primary caregiver, she seems to take on a position as somewhat of a silent ‘rock’ in the family. Breandan’s narrative shows strong association between his father’s identity and the role of paid work. Breandan seems to admire and aspire towards his father more so than his mother, and there is a sense that this is tied to gender role performativity (Butler, 2011). This raises the importance of gender roles in considering the impact and experience of economic recession.

6.3.1 Breandan’s mother, Aoife

“Breandan was born- when we were told he was Downs – and one of the first questions I asked is will he be able to talk? That was the one thing he couldn’t do and that was hard, that was really really hard.”

Aoife adopted a narrative strategy of emphasising the key struggles that she had been through first and foremost as the priority to convey, but when satisfied that her hardship was recognised, she would counterbalance the negativity with her recognition that things are better now; “everything is going well at the moment”. The first time I spoke to Aoife was over the phone in order to schedule our first interview. I said that we would explore how the recession may, or may not have affected her family. She used an assertive tone to reflect her defensive disposition, stating that no such exploration was required, as the recession had certainly been detrimental for her family offering her husband’s job loss as one such example.

As she tells it, Aoife first got married and then bought a home in the same city that she and her husband had been raised in, and had two children. Following this, Aoife’s mother passed away and Aoife developed depression. Deciding to have more children, Aoife began going through foreign adoption, but then she discovered that she was pregnant with Breandan.

In terms of the later economic recession, for Aoife this was represented foremost as a struggle to get Speech and Language Therapy (SLT) for her son who couldn’t speak, “main thing -speech and language; with recession is the talking,” . . . “we worked really hard on it over the years.”

Aoife’s life changed when her son was born. This marked the beginning of a long struggle to “fight” for services; “everything is a battle”, “going to be another battle, everything seems to be, you have to fight for everything.” Aoife also found that she was unable to work due to her son’s disability care needs, “like I’d love to go out to work, I would go out to work for a rest.” For Aoife this reflected more than just loss of earnings; “even it is not necessary for the money it’s for your health.”

When the economic recession hit, and her husband lost his job, the financial stress added to her struggles; “Rick lost his job in the same week that his mother
6. Findings Chapter 2: BNIM Cases

died . . . turned out he was out of work for three years and emmm he did some college courses . . . I found it really really difficult to have him home during the day . . . that was the toughest years.” As Aoife notes, “we had an idea that he was going to lose his job and in actual fact the worry beforehand built up to the whole lot so the day he lost his job was the 13th May 2011 on a Monday.”

The job loss was experienced sorely on more than one level; “it was very very tough, we found it very tough for Rick to be at home it was very tough for both of us. Then it took probably a good year, maybe year and a half to get up and running again and emmm its tough financially but I think it more the emotional and more so on men than on women and so he felt he should have been working you know he didn’t deserve to lose his job, he was never out of work emmmm he found it tough then because he hadn’t eh he hadn’t got his leaving certificate and he hadn’t been to college that was just you know just making it more tough to try and get a job but emm thankfully then, he was three years out of work, but then thankfully things got up and running then.”

Financial worries lead to marital difficulties, “rowed more often in those years when he was out of work than we ever did, I hated him being here.” The children were protected as much as possible from the reality of the struggles, “you do protect the kids, and you protect them from the financial end of things, they were used to getting things that they asked for and wanted . . . there was a lot of worries”. In some ways for Aoife the worry was reportedly worse than the material reality of the recession; “it was huge worries – yeah with money”. Consideration for the children’s welfare compounded matters, “it was a big worry, it was a worrying time you know but you can’t let the kids know.” In this way, Aoife portrays a protective and maternal role that she perceives as mandatory; “you can’t let kids know you’re worried about food on the table.”

For Aoife, the loss of three parents concurrent with the economic downturn, between herself and her husband, was extremely difficult. “The death of three parents . . . Rick’s father in 2008, his mother in 2011 and then my father in 2014”. When Aoife’s father died, she also struggled with supporting Breandan in his grief, “My father took really sick and he developed kidney disease and was a dialysis patient which in turn lead to him in turn developing dementia . . . Difficult with a child with a disability trying to explain all of those changes.” This led to behavioural problems for Breandan who seemed to struggle to cope without speech, “I did a course for . . . behavioural needs in adolescents – As even normally adolescents might become fixed on things-but he (Breandan) reverts back to that all the time, back to dad dying all the time.” Bereavement issues combined with her husband’s job loss and resulting fear over finances became overwhelming, this led to Aoife seeking out professional help, “I went to counselling, counselling for two years” commencing in 2014.

Aoife struggled with Breandan’s behavioural difficulties which often appeared interlinked with speech. This had implications socially such as difficulty for Aoife in taking Breandan places; “its behaviour . . . it was very hard to work it out then, but at least he can talk now mostly” and even meeting his medical needs, “he got into trouble a couple of times. . . he got sick and it turned out he was covered in a rash.”
Aoife puts forward a global assessment that she was ill-equipped to deal with a disabled child overall as she had not got the information and support that she needed from publically funded disability services, “CAS don’t make things easy for anybody they are not good at supplying information.” “We would have liked is more help from emm the state or CAS or whoever is supposed to take some sort of responsibility, we would like to have emmm say more kinda of support from the likes of, our service would be CAS, and we had to pay privately for speech and language for a very long time, emmm he had to change school because, and go to a special school, where really he should have been able to go to school in our local area but we couldn’t get the support we needed.” Yet, only when Aoife changed Breandan’s school, he was then denied his original provision of SLT by CAS as a consequence.

A sense of being left in the dark was also significant for Aoife, “you could do with more advice, advice and guidance . . . you are left to your own devices . . . they don’t provide you with information, they don’t they don’t provide you with anything.” Aoife believes that lack of information and early support and service intervention contributed to her son experiencing and perpetrating sexual abuse; “regarding development and sexual development and there were huge holes, huge gaps, and we fell into a big downfall.” “If they (CAS) had of been able to make clear the emm the changes in these kids lives at that age at a young age and be aware of why and what might happen -things happened here with kids on the road and interference happened to him and then he copy cated onto somebody else around – huge- you know with my neighbours and you know huge thing if there had of been steps taken place say from the age of ten, eleven or twelve rather than waiting for it to happen and the trying to correct it – it was huge.”

Aoife identified other parents as her real source of support: “We learn a lot from other parents, that’s the biggest, we have a great group of friends.” With the lack of disability services, and service cutbacks detailed, Aoife’s narrative conveys a thematic sense of worry, “we are kinda worried and nervous and afraid of the future and all the parents, all of our friends, we all say the same thing we are all concerned . . . we are constantly fundraising, constantly.” Aoife concedes that, for her, worry encompasses not just the near, but distant future, “it is a huge worry you know what happens in the years you know where we are not there.”

In particular, the struggle to get SLT for her son was centred upon economic recession, “all the Speech and Language Therapists were emigrating off to Australia and America emmm they were trying to get staff in and it just wasn’t happening and the Speech and Language Therapists were going on maternity leave, they weren’t being replaced there was huge gaps in the service . . . I go on this programme on television to highlight the lack of Speech and Language Therapists in Ireland at the time and how we were paying €60 - €70 or pounds for half an hour and then we were given pages and pages of work to do and so we were driving around looking for Speech and Language Therapists, and you would go maybe on Saturday or whatever day we would have to go, and then you would go home and do the work ourselves. . . . speech and language, we were crying for it and yet we couldn’t get it.”

Aoife conveys cognisance of the economic decline of disability services. SLT wasn’t the only service she reported as cutback with the recession which she perceived
the need to fight for, “the same with respite you know trying to get a night, he hadn’t gotten respite since 2009 . . . you know so everything is a battle, “as ultimately “you get no respite with CAS”. As Aoife describes she was “dying” for a break due to being “worn thin” with the demands of her life, and supporting her son with his disability: “We spread ourselves so thin.” Based upon such explanations, Aoife didn’t seem unreasonable in her desires, rather just to “go away for maybe a weekend and not have to look and worry about who is going to mind him.”

Aoife highlights that she received no respite provision until she eventually felt she had to shout and beg, “they are telling you on the phone they haven’t got it, it’s not available, and so then you end up fighting with them.” “CAS do nothing, absolutely nothing, I could sit and talk about it forever all the negatives . . . the whole bottom line comes down to money, every aspect.” Aoife wanted to make clear in saying this, that she felt there was some really good people working in CAS, doing their best, but there simply wasn’t the funds allocated properly.

Aoife and her husband arranged a meeting with a head official of CAS and asked for the specific funding that was provided to the organisation for her son to be given directly to them so they could pay for SLT, but they were refused. Within this, it appeared that Aoife’s desire for services was largely motivated by her son’s needs and not her own. Considering respite care, for instance, “to be fair to the children it’s good for them to mix with their own kind” . . . “I think for the kids to move on and progress and for their own independence, he likes going away”. Aoife’s devotion to her son’s needs is further evident in her hectic schedule of supporting his attendance at services, “your driving here, and driving there.”

Breandan was approved at 16 for disability allowance but no plan for any services or supports was in place for him upon his transition to adulthood, “I definitely won’t sit back and take it and I will hand them back their 188 euros . . . I will camp outside Leinster House.” Aoife took part in protests, and expressed her belief that her son should have the opportunity to pursue a meaningful adult life, with a career, job, and/or education, rather than being confined at home with a meagre payment, “people don’t want payments they want a job.” At times she resented having to do so much as a disability advocate, when parents are “going to protests and stuff and you know there should be more paid advocates.”

Even when it came to making adaptations to her home, in order to accommodate Breandan’s needs, or when entitlements were applied for, a struggle was evidently imposed by bureaucratic processes; “trying to get an allowance, it’s hard enough trying to pay for everything, but emm if there is an allowance there, they don’t give it to you, and they don’t make it easy, so they say that you might be entitled to an allowance but we need a letter from an OT but we are waiting a year to get that letter, and Breandan has no physical needs you know, he is not entitled to it, and I asked is it emm do they have to be in a wheelchair? and he said no, and it’s not to do with intellectual disabilities but somebody has to come out and assess Breandan and the house and whatever so at the end of it you would nearly say would ya bother? Would you bother? It’s exhausting and we probably at the end of it won’t bother trying to get it you know.”
Over the recessionary years, Aoife and Breandan involved themselves in fundraising and voluntary work in the disability community, “myself and Breandan went to Kerry on Valentine’s Day and we raised 10,000 for speech and language and we never saw one red cent.” Further fund raising with Paddy Power raised considerable money, “Paddy Power was so impressed with Breandan they gave him a thousand Euros to do as we pleased with it, a thousand Euros paid for the speech and language for so many classes.” Aoife also helped to found organisations run by parents built upon principles parents espoused, “there is going to be a film about it on TV programme 1.” Overall this reflected a thematic disconnect between services and parents in Aoife’s account, ‘so we are constantly looking and chasing and seeing what is appropriate and for our kids CAS do nothing, absolutely nothing.”

Overall Aoife remained largely dissatisfied with CAS due to a sense of being unsupported, “I could sit and talk about it forever all the negatives, all the negatives that’s all I don’t think there is one positive thing I could say about CAS . . . it’s not down to the people who are working in it, it’s just there are no provisions there is absolutely none.”

Similar to Breandan, Aoife showed a marked desire to leave the past in the past “things are better now”, and move on from the dark times of the recession which she associates with worry and loss, and instead be happy now in embracing a better today.

6.3.2. Particularities of Aoife’s case

The need to counterbalance negativity. Narrative is a function of self and identity (Bamberg, 2011). Within this, narratives can be constructed with a view to protecting one’s identity from the negative inferences of their audience (Wengraf, 2001). In this way, narrative accounts are not considered objective or divorced from their audiences (Reissman, 2008) but rather as Mark Freeman (2006; 2011) deduces, narrative is an unstable and self-fashioned function of its context. Whilst it is acknowledged that there are many and varied interpretations of the meaning of ‘narrative’ (Connelly & Clandarin, 1990; Clandinin & Connelly, 1994; Flynn, forthcoming) as a reflection of the broad field encapsulating it (Flynn, forthcoming; Squire, Andrews & Tamboukou, 2013); narrative could be thought of as “verbal technique for recapitulating experience” (Labov & Waletsky, 1967, p.16) that may aim to convey a particular message to its audience (Reissman, 2008). For Aoife, she seemed to feel bad when she criticised disability services, or complained about her negative experiences throughout the recession. Despite a catalogue of losses over the recessionary time, and clear challenges and hardships, Aoife seemed to restrain her negativity so as not to appear consumed or characterised by it, reverting back to things that she was thankful for, and acknowledging the positives and constraints of disability services.

Highly proactive. Aoife took a very proactive approach to the impact of the recession on herself and her intellectually disabled son. She engaged in socio-political activism through attending protests, and going on national television. She undertook extensive fundraising, and extensive voluntary work for parent-led disability services. She paid privately for services that her son should have obtained publically and travelled country-wide to get him what he needed. She
also moved his school in an effort to get him help. Overall, this proactive approach would have been demanding of her time and resources. In this context, Shakespeare (2014) identifies a long overdue acknowledgement of the impact of disability on families, given that disability studies and disability activists have long focused on the oppression and exclusion of disabled people. Goodley (2013) further acknowledges this, referring to the notion of the ‘disabled family’ in terms of material, cultural and personal challenges faced by disabled children and their families.

**Particular resilience in the face of adversity.** The Risk and Resilience Framework is a component of the professional social work knowledge base (Gitterman, 2014). Whilst often applied to the case of youth, it overall acknowledges that ordinarily, neither risk nor resilience in individual lives are easily attributable to one or two sources. Rather they are a complex interaction of factors (Gitterman, 2014; Jenson & Fraser, 2015). Dr. Ungar’s work (2005; 2010) on the International Resilience Project extends this definition of resilience to incorporate its nature as a social construction rather than an inherent quality of one’s personhood alone.

With these definitions in mind, Aoife experienced three significant bereavements over the course of the direct impact of the recession. Multiple experiences of loss aggravated each other. Bereavements would have undermined her ability to cope with her husband’s job loss, or to advocate in the face of recessionary service cutbacks. Yet, in spite of her personal difficulties, emotional and practical, Aoife’s case perhaps showed particular resilience in continuing to maintain a positive outlook and be proactive in addressing the family’s situation.

**6.4.1. Siobhan**

“The bit that really makes me unbelievably angry is that marriages and mental health and all the relationships have to go down the swanny before something actually happens and I just think that’s really shocking, really really shocking.”

“It is absolutely despairing when you see need there and you only have one answer sorry there is no money we can’t do anything about it.”

When I first spoke to Siobhan, she told me that she feared she could lose her job for telling me, and others, the truth as she had seen it. Nonetheless, she said it was now more important to her to expose the truth of what families had gone through, “I just say to people, be it the HSE, or families, or internally in CAS, the only thing that you can do is to absolutely represent the truth.” To the families Siobhan works with, “I tell them I will absolutely tell the truth about their story.”

Siobhan works for CAS as a Principal Social Worker. Siobhan had practiced initially as a Social Worker in child protective services in the city; “served my time on the front line” and then moved into disability services where she started to work in a special school as a Social Worker in 2003. Then economic recession hit in 2008, “I had a career break between em 2007 and 2010 and when I came back . . . the HSE Disability Manager has no money, no funding.” Her return was a turning point that marked a new life phase encapsulating perceived decline, bureaucratisation,
and proceduralism that were contextual to a new powerlessness for Siobhan in her changed professional role.

Siobhan structures her account around the basic argument that the economic recession has had a detrimental impact on CAS services that have been “catastrophically cut”, deploying many specific examples as evidence through her biographical accounts;

“Six respite houses on the north side of City, Ok at one time eh . . .four adult houses and two children’s houses and one here on the south side, . . .and in the past year. . . that was reduced to one adult house and one children’s house for a population of sixteen hundred service users so. . . you put that together you have got a massive ehh reduction in the amount of respite nights.”

“Those (social groups) have just been em catastrophically affected, a number of those children would have very little other social outlet.”

“In the late summer of every year for the last three years CAS has been unable to pay some staff salaries and the HSE has had to come in and bail us out on the QT.” “We are constantly on the verge of bankruptcy”.

In keeping with a rigorous confinement within the professional and educated role of Principal Social Worker, that she seldom breaks, Siobhan ties her arguments and examples to wider social, political and cultural changes around the recession. In doing so she wittingly or unwittingly makes the case that the impact of the recession is complex for intellectually disabled children and their families;

“In a very general sense the funding that an organisation like CAS receives for services we provide to children, its centralised funding for children, so it’s not individualised, so the expectation is that we would provide a service to children from within that core funding regardless of the number of children that would be coming into our service OK, so emmm . . . we have a service level agreement with the HSE which in its simplest form says no matter what happens . . .with regard to funding . . . you will continue to accept new referrals from children and from that young population when they come in, be it forty a year, or four hundred a year, and you will do as you have to with your core funding and our core funding has been cut by something like 12 million in the last five years . . .so that would be our first difficulty.”

Siobhan marks out a range of factors that “have been very difficult to predict” that made cutbacks worse such as “the whole homeless situation” which “has had a phenomenal impact.” She explains that,” where the banks have taken back the houses”, there are “a number of children with significant difficulties living in hotels in town, children with peg feeds and the whole nine yards in one room, shocking absolutely shocking.” As an on-looker she contends that, “the level of distress for those children is phenomenal but they don’t get any special compensation they just have to get into the queue with everybody else.”

Furthermore, Siobhan points to immigration in the Celtic Tigers years immediately prior to the recession, “and also within that, massive population growth area we have a very significant population of families that have come to Ireland in the last
ten years . . . it wasn’t possible for people to predict what the level of disability was within those populations and it’s been quite significant.”

The establishment of the Health Information and Quality Authority (HIQA) who now inspect disability services is put forward as another aggravating factor; “our core funding being cut- some of the external pressures on the organisation . . .the most obvious one around HIQA . . . I think in the first year of HIQA inspections, the cost to the organisation, had to be entirely funded by the organisation there was no way for us to go back to the HSE and say oh well you know we need more so the cost of the first year of HIQA to the organisation was 1 million euro.”

Separate to a seemingly careful mobilisation of evidence and argument around aggravating factors to the negative impact of recession; Siobhan gives examples of negative effects on the quality of services that she explains are hard to quantify;

“clinical reasoning around pairing people and all the rest of it.”
“Literally the amount of respite available to children has been catastrophically cut . . . emm . . . so really only children that are in families that are risk of breakdown would be receiving ehh respite so we know that there are a category that are not at risk of breakdown that you could absolutely see that they would be in two to three years . . . and that is the group which is most likely to have been, you know to have needed it but to have lost out on it.”

Siobhan’s life story account, however, is also about personal loss. In particular, the loss of power in her role following economic recession, and changes to the way she and her colleagues work that is conveyed as “despairing”. The “role of social work within CAS has so fundamentally changed because I suppose traditionally we were a well resourced organisation . . . we were progressive forward thinking.” This phase of her life is also characterised by multiple changes in working environment;

“In years gone by I don’t remember social workers all over the organisation crying, and now I see that.” “I’m starting to hear people in their forties thinking I’m not going to be able to go to retirement age in this job and we have lost people through mental health.”

As a Social Worker, Siobhan says that families became quite abusive at times towards social work as they needed help in recessionary times and couldn’t get it, “their style of advocating for that was to be incredibly aggressive and menacing.” “Extremely difficult to take it all on personal abuse from people because that’s where they feel they are at.” “You have very abusive people who literally tear strips off staff and say oh you, Ill finish your career.”

Siobhan’s account overall transitions from reports and evaluations that explain the structural impact on the organisation and managerial considerations, towards the lived reality for service users and various individual cases;

“the mum had kind of said to me a couple of times when she was driving the car that it would have been so easy to just swerve across the road and just end it, and that would have been you know a reasonable thing to do.” She was struggling with “a very autistic young man in his early twenties at home with a single parent
mother, a tall strong powerful young man with very challenging behaviour, very significant epilepsy eh her being a single carer alone he had a seizure in the bathroom fell down blocked the door she couldn’t push open the door because of his size to give him emergency medication emm the risk of death for him in seizure is very high . . .he did assault her, luckily for her in a public park and it took four men to bring the assault to an end and until I wrote to the HSE somebody is going to die in that house, somebody is going to die in that house, and this is my seventh letter to you in six months on this topic.”

Siobhan made the case that colleagues, and not just families were struggling with such risk where staffing was cut. In one case there was a “catalogue of near misses and one very serious assault on a staff member that has finished that person’s working life.” Yet, despairingly Siobhan remarks: “If the funding was flexible and responsive you could head off all of these terrible crisis . . . that’s really shocking, really really shocking.” Siobhan alludes to the nature of the funding process as problematic; “split second decisions” made “at the last minute” about whether a desperately needed service such as residential care would be provided. Within this, Siobhan felt that if social work assessment was better depended upon by the organisation rather than increased cost down the line could be avoided:“We know that there are a category that are not at risk of breakdown that you could absolutely see that they would be in two to three years.”

Siobhan as an employee of CAS advised that she found herself wrapped up in practices she wanted no part of, “absolutely shocking to be a party to that”. She observed a manager, for instance, who wouldn’t give funding for a family who then suggested at a meeting to the family that they should abandon, or threaten to abuse their child so that the child would be taken by Tusla Child Protective Services, “I was just disgusted because it was a way of menacing that family.” Siobhan conveyed that she felt powerless against dangerous rhetoric in her organisation, “the peddling of the idea that if someone got sufficient home support that they would in fact be able to cope.”“Pretending that the policy is the most important thing is, it’s a complete falsehood because when you keep knocking at the door eventually, eventually, you realise it is actually just the funding so it’s actually you know a funding issue.”

Siobhan’s worry was not just encouraged by what she observed happening, but also what was suspected to be going on behind closed doors. She notes that without residential care or respite care that was cut back; “families who were in desperate need started to fling open the door and say that, yes, we will take the homecare package, started to discover that eh the care agencies themselves, often that were not regulated, and that didn’t have particularly well trained staff, became also kind of a witness emm to what was really going on in those houses and they would come back and they would have to go to Tusla (child protective services) and say well I saw this or I saw that . . . at the moment we are being told that there is no homecare package funding . . . that’s the official line.”

Siobhan’s narratives reflect juxtaposition. On one hand, is new heartless corporate managerialism, brought about by recession, where it is an asset to be able to retain limited resources by saying no to families in need; “you have a staggered process of holding it all down.” “I believe there is a toughening of that
position.” “There seems to be a culture of fear.” “Holding the door closed that's
the most valuable characteristic now – how much can you hold the door closed?” Disability Managers are remarked to be “on the verge of complete collapse
themselves.” “I kind of wonder about what it does for people’s health to be
constantly holding the door closed – because it is absolutely despairing when you
see need there and you only have one answer sorry there is no money we can’t do
anything.”

This is then juxtaposed against families in need during the recession who couldn’t
get help: “For families it is absolutely soul destroying . . . absolutely soul
destroying. A family threatened to smother the child and after a long period of the
HSE deciding how serious that was or that wasn’t.”

This juxtaposition was well illustrated by Siobhan through examples, for instance
where parents had brought their child to a management meeting: “Rocked and
shouted for most of it really loud and the professionals have tried to conduct the
meeting in that setting because the parents wanted the HSE to see what their child
was like.”

Overall, Siobhan’s narrative accounts convey a thematic sense of powerlessness
and devaluation of her role: “We spend a lot of our time in this department
advocating with the HSE . . . we write very strong letters, we request case
conferences, it goes to the disability manager, after a long period it goes above
the disability manager, it gets stuck there for a long period, eemm sometimes an
external private agency is asked to do a costing and that will then stall it for
another 6-12 months and ultimately it ends up on the Director of Social Care’s . . .
desk where it seems to sit indefinitely, and that is a pattern.”

In the meantime Siobhan says she must bear witness to families doing what they
have to do to survive whilst caring for a family member that they can’t cope with,
and left without the service they need: “We would know it isn’t a job that one
person can do so we know that we would suspect that there is lots of restrain and
door locking and things that are necessary that would never be tolerated in
another setting like a residential setting.” “It forces people into a terrible corner.”

“A number of children with significant difficulties living in hotels in town, children
with peg feeds and the whole nine yards in one room shocking absolutely
shocking, the level of distress for those children is phenomenal.” Within this, she
more specifically details cases; “at the moment we have three families with
children who have had their eviction notices and expect to be out of their homes in
this catchment in the next month with nowhere to go and no accommodation em
and it’s most likely that those three are going to end up in hotels.”

Siobhan felt that after the recession hit priorities changed, and it was only where
immediate death was a risk that she could get funding for families. At this time
the media in Ireland had provided widespread coverage of the story of a mother
who was also a doctor, who was struggling to care for her profoundly disabled
daughter. The mother administered a lethal overdose of chloral hydrate to her
daughter and then made two unsuccessful attempts to kill herself (Irish Times,
2016).
“I spend a lot of my time writing very strong letters to the HSE saying em I know that you are aware of the seriousness of this situation”, yet, “unless really now I’m writing a letter that says that somebody will die because they didn’t get adequate attention or that somebody may kill somebody else in a property I actually get very little response from them.” “That’s the light bulb moment when you realise how far the bar has dropped, its not about clinical assessment, or need, or best practice, or gold standard, it is about is somebody gonna die?”

Siobhan determines that this left families forced into situations where they had to abandon their disabled children:

“If a family says to me would it be awful if I left them in (Hospital) . . . because I can’t take it anymore I would be saying to them no it wouldn’t be awful, it wouldn’t be awful, and we would all understand.”

“Just barely holding it and the HSE said no you are not getting the funding and in the past three months three of those children have been abandoned in (hospital).”

Within this, Siobhan advised that families were getting services too late for them to be effective; “for an awful lot of families it is going to come too late and their needs are too high and too complex” with much of this down to, “unprecedented delays.”

Perhaps most pervasive in her biographical accounts however was her role as powerless witness. “People say they can’t, I really can’t cope, in my experience have never met a parent that has said that casually or hysterically or dramatically.” Within this, Siobhan’s story was saturated with emotion for families “in despair” who she conveyed a sense of admiration for ““I have nearly wept with relief when someone has gotten a placement”.

Siobhan remarks;“hard working genuine people who would have done absolutely everything who would spend 90 minutes feeding a child on a cutegenic diet every three hours to see if it would do anything as part of trial to reduce that child’s seizures and to do that for three years to be told that it has had no impact to have parents that would take every second night downstairs, people that would sleep for twenty minutes on a loop and then go back in and check what is happening with their child to be told no by the disability manager – plus you know manage their two little other ones emm you know shocking, absolutely shocking, you know what I mean absolutely shocking.” In this context Siobhan recognised that sometimes some children simply have needs that are “not compatible with family life.”

Siobhan’s intense focus on the families, left little of herself to talk about, and this perhaps reflected her commitment to the role of Social Worker in her narrative where the families she worked with were her priority. This was a positive departure from the wider disconnect between families and service provision that she alluded to, for instance where services are “trying to impose a solution of a problem that they (families) didn’t believe was the problem”. In this context there is notably “an incredible arrogance that comes out of social policy”.

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6.4.3. Particularities of Siobhan’s case

Tension between her role as an advocate, and as an agent of the oppressing state. The Care vs. Control (Kearney & Skehill, 2005) debate in social work in Ireland is about how social workers employed by the State can work anti-oppressively with their clients, advocating for and empowering them: Yet still being agents of the State they are mandated to, and acting on behalf of an oppressing organisation. Negotiating others perceptions of her culpability as a Social Worker in the state funded organisation that wasn’t doing enough to help her clients, was a central difficulty for her; as was fulfilling her general social justice mandate as a Social Worker in the context of austerity (Goldberg, 2012). Clients may not have understood the constraints of her role in terms of helping them, leading to frustration for her when she saw need and was not able to meet that need due to a lack of resources.

Location within hierarchal formal systems of power. Michel Foucault’s work (1982) is notable on power and emphasises its omnipresent nature; diffused, non-linear, changing and embodied in various forms. Whilst this complex definition of power is supported (Cleg & Haugaard, 2009) it would appear that a traditional hierarchal conception of power was particularly espoused in Siobhan’s narrative account.

The organisation that employs Siobhan has hierarchal systems within which employees are located; for instance CEO role is superior to a frontline practitioner role. Access to resources and power to make change is intimately tied to one’s location on this ladder. Siobhan had a relatively senior role and was empowered by this, but was constrained in what she could do to help by those who held resources at a higher level than her.

Entanglement between her professional life and her clients lives. Social Workers help families and individuals in need, and therefore it is not the Social Workers own plight that is the focus but that of their clients (Christie, Featherstone & Quinn, 2015; Gray, Midgley & Webb, 2012; Payne, 2014; Thompson, 2015). Burn-out as a feature of contemporary social work partly reflects the entanglement of worker and client lives (Trevithick, 2011); and what Koprowska (2010) refers to as emotional labour related to the social work role.

In Siobhan’s narrative, the nature of the work is more like a vocation than a job, and therefore her life story is partially constructed from her focus on the lives of her clients, with little sense of her own needs put forward. She makes it clear nonetheless, from a work perspective that she is personally impacted by her client’s struggles, for instance, her frustration due to lack of resources, or constraints from within the organisation.

Useful perspective on the impact of the recession due to career break timing. Siobhan’s case is particularly useful as she worked in the service, then left to go on career break immediately before recession hit, and then returned shortly after the economic recession had taken hold. This afforded her the ability to see in stark terms, how the recession had impacted the service, having seen the services immediately before, and immediately after the economic decline had taken hold.

Reissman (2000; 2008) is an authority on narrative research who has considered ‘situated truths’ and how the situated perspective of the researcher, epistemologically, should be declared because ultimately perspective relates to
the trustworthiness of research work. Other sources support the contention that the validity of claims are tied to the epistemological and observational perspective from which such claims are engineered (Becker, Bryman & Ferguson, 2012; Bryman, 2015; Silverman, 2015). Siobhan’s vantage point on the disability services and the recession better qualifies her assertions, and within this, it is notable that her job satisfaction was significantly negatively affected after recession took hold due to depletion of resources.

6.5. Summary of Cases

This chapter presented the three BNIM cases of this study; Breandan, Aoife and Siobhan. Cross case theorisation in the following chapter will engage with the generalisable nature of the cases when aggregated analytically. This chapter more modestly sought to present cases as standalone entities, emphasising the particularities of each case. The cases represent the knitting together of the analytical ingredients of the nine stage BNIM processes that constructed them, such as interpretative panel analysis, and facts compiled from research into the socio-political context of each case.

Overall, the three cases represent three people with interconnected lives, but situated in very different roles and/or stages in the life course. Their cases demonstrate how the impact of economic recession expressed itself in very particular and complex ways, differentiated in different lives. What appears evident in the cases is a layered process of cloaking the recessionary impact that is multifaceted, not just confined to financial repercussions, but social, emotional and relational ones. Just as Siobhan could not tell her clients about her frustrations that her own management would not allocate her resources, so too did Aoife hide from her son the true strain of her husband’s job loss. This dilution of the impact is one of a number of such considerations subject to greater exposition in the following chapter.
7. Discussion Part 1: Cross Case Comparison

7.1a Introduction

Having just considered the auto-biographical accounts of Breandan, Aoife and Siobhan, the present chapter builds upon this, and presents the findings of cross case comparison - the final stage of the BNIM 10 stage intensive analytic process (Corbally & O’Neill, 2014; Wengraf, 2001).

This study applied two distinct methods which were Framework Analysis, and the BNIM, situating them within the parent conceptual lens of the Affirmative Non-Tragedy Model (French & Swain 2000; 2008). To this end, an informed response was sought to the overall research question:

How have intellectually disabled young people, and their families, who avail of services from the disability sector, experienced the economic downturn?

Taking a narrowing focalization towards the minutiae of that response, Framework Analysis findings were presented in Chapter 5, moving to BNIM autobiographical case accounts in Chapter 6. The intention, however, has never been to alienate these from one another. Rather, cross case comparison will weave together these otherwise divergent threads, making a hopeful move from methodological patchwork quilt towards analytic tapestry. Retaining the euphemisms a moment longer, within this, cross case comparison acts as the allegorical spinning wheel, or modus operandi for interlinking these otherwise estranged methods. In this way the present chapter will discuss only the findings of the three BNIM cases, but under the frame of themes generated from Framework Analysis. The following chapter will then consider both Framework Analysis findings and BNIM findings together.

Wengraf (2001; 2015a) who is primarily associated with the development of BNIM, confirms the flexibility of BNIM with regard to utilising one’s own method of cross case comparison. Considering the aspiration of any study such as this, namely, the procurement of sound findings, towards the increment of academic knowledge, this framework has been populated with;

1. Existing and authoritative literature and research primarily taken from the literature review chapter.
2. Literature that specifically informs biographical narrative methods of analysis.
3. Insights generated from the nine stages of BNIM intensive analysis.
4. The voices and subjectivity of BNIM auto-biographers Aoife, Siobhan and Breandan, as well as the many panellists involved in analysis. Within this, a decision has been made to intersperse verbatim quotations taken from Aoife, Breandan and Siobhan, with the other material presented here. This is in an effort to retain accuracy in the representation of material. In doing so, no
new material is presented only reiterations of data presented previously.

Furthermore, it is acknowledged that this chapter is presented through the primary voice of the researcher, however, it is hoped that retaining quotations from Aiofe, Breandan and Siobhan will help prevent any perversion of their intent.

Finally, ‘key points’ that arose from the comparison of literature to the particular BNIM findings of this study are highlighted in bold text to improve the readability of otherwise dense content. These ‘key points’ might not be thought of as findings per se, but rather substantiated inferences, validated by the application of existing authoritative literature to the particular data (verbatim quotations) taken from BNIM case accounts.

In presenting cross case comparison, a number of tensions must be negotiated. Firstly, a defining anxiety of the socio-biographical study, is to retain links between the socio (society or sociologically defined contexts) and the biographical (individual) (Chamberlayne, Rustin & Wengraf, 2002). Secondly, over abstraction and generalisation of case data risks reducing the particularities and coherence of individual lives to mere aggregates and averages (Chamberlayne, Rustin & Wengraf, 2002, p.3; Wengraf, 2015b). Third and finally, it is important to recognise the individual agency of participants as social actors who exercised discretion in the construction of their life trajectory. Yet, at the same time, it must not be forgotten that in the context of the economy, participants may also have felt like they had little choice in the decisions that they made. In this way, as macroeconomic change pauperised individual lives, aspirations inevitably collided with hurtful external realities (Chamberlayne & Rustin, 2002). Here the element of choice largely absents itself. Modern capitalist societies and the contemporary influence of globalisation, accustom people to more nomadic lifestyles, imbued with qualities of precarity and change (Butler, 2015). Yet, this political economy may bring with it possibility as well as hurt. In this way, contrary to neoliberal orthodoxy, Bauman’s (2000) liquid modernity suggests there is liberation as well harm to come from this. It is this multi-dimensionality in line with the “individual historical, psycho-social and biographical dynamic of people’s lives” that research so often fails to capture (Corbally & O’Neill, 2014, p.35); qualities better aligned to the BNIM as applied here.

Leaving pragmatics to the side, through the chameleon quality of empathy one can assign a certain paramountcy to lived experience. In the order of such a belief, evidence and acumen is not quite enough: Rather, it is of importance in this chapter to also retain connection with the essence of the lived experience as articulated through the original self-biographising narratives. This balance is also tenuously pursued within the following chapter.

We will now look at the various themes and subthemes from framework analysis, presented in chapter 5. These will look like headings and will be numbered (7.2; 7.2.1. etc.). Under each of these subthemes there will then be some discussion about how that particular subtheme was relevant to BNIM cases when the cases were compared against one another.
7. Discussion Part 1: Cross Case Comparison

7.2 Cross case comparison of Aoife, Breandan and Siobhan’s accounts

7.2.1: THEME 1: Characteristics, needs and aspirations of intellectually disabled young person

7.2.1.1. Behaviours that challenge and/or complex needs

Behaviours that challenge and complex needs underpin the first subtheme applied to the case findings. In making this application, and insomuch as can be learned from doing so, a number of key points were emergent and perceptible from participants’ extempore autobiographical accounts. Rather than hypothetico-deductive in nature, inductive inference, in line with the conventions of BNIM, is the basis of such insights (Chamberlayne & Rustin, 2002; Wengraf, 2001).

As a first key point, it appeared that material poverty was subjectively interpreted by BNIM autobiographers to be connected to social problems in their lived experience (like social isolation). In turn, social problems were related to the behaviour of intellectually disabled young people. Yet, within this, the presence of impairment could often be conceptualised best as a scapegoat or complicating factor, rather than causal factor. The particular findings of Aoife and Breandan BNIM accounts illustrate this, as follows.

First, material poverty had the capacity to cause behavioural problems. As a direct consequence of recessionary cutbacks to Speech and Language Therapy (SLT), and lack of means to fund private therapy, Breandan exhibited challenging behaviour. This in turn led to a degree of social isolation for him. As Aoife advises, there was times when Breandan’s behaviour deteriorated and it turned out he was sick or in pain due to an ailment that he couldn’t properly communicate, “he got into trouble a couple of times. . . he got sick and it turned out he was covered in a rash.” Behavioural problems lead to social isolation as Aoife conceded, she couldn’t take him into the community; “its behaviour . . . it was very hard to work it out then, but at least he can talk now mostly.”

As behavioural problems translated into social problems, intellectual disability appeared to present in itself, a complicating factor. Referring to the literature momentarily, it is established that interventions such as SLT are effective as a means to treat behavioural problems in intellectually disabled people (including self-injurious behaviour) due to the relationship between communication impairment and challenging behaviour (Bott, Farmer & Rhode, 1997; Sturmey & Didden, 2014). In fact, existing research accounts for a high degree of correlation between impoverishment, environmental deprivation, and particularly as Aoife explained in Breandan’s case, social isolation and behavioural problems in intellectual disability (Emerson et al., 2010; Sturmey & Didden, 2014).

Developing this further, Siobhan, Aoife and Breandan’s cases, when combined, usefully illustrate the manner in which poverty and environmental deprivation (recessionary cutbacks, reduced family income) then led directly to decreased SLT (as articulated by Aoife; “all the SLT’s were emigrating”). This led to communication difficulties for Breandan, as he succinctly puts it, “I needed to talk,” which in turn, directly caused challenging behaviour and resulting increased
social isolation for Breandan. Furthermore, this chain reaction effect appeared to be, at least in part, corroborated by existing studies (i.e., DCYA, 2012b). The particular contribution of this study’s unique findings is around the conclusion that the lived reality of austerity may be somewhat masked or misrepresented by the presence of impairment.

With this in mind, a further key point is perceptible from the BNIM’s particular findings under this subtheme. Namely, the concept of cumulative harm appeared also to be of significant importance in understanding the lived reality and impact of recession. In this way, through circularity of effect, for instance, the outcome of services denied can then reinforce original need. Furthermore, over time, reinforcing circles of need can lead to cumulative harm. Siobhan explicitly referred to this circularity of effect: “We know that there are a category that are not at risk of breakdown that you could absolutely see that they would be in two to three years.” Siobhan remarks that these clientele can then deteriorate as a result of services denied, in the end amounting to crisis, challenging behaviour, and much greater support service requirement. Such is the grounds for the preventative nature of many support services that were cut back by austerity (Department of Health, 2012; DFI, 2010). The unique contribution of the present study findings is that cumulative harm was not just an effect of services denied but an important aspect of the lived reality (in this way present lived experience of post-recession suffering, was substantially a product of the cumulative effects of suffering).

### 7.2.1.2 Disabled children costing more

Moving to the next subtheme, the first key point perceptible is as follows. Prompted by their narrative omission from the extempore auto-biographies, it appeared that siblings of intellectually disabled young people may be vulnerable to material, social and emotional deprivation in the recession as a result of the distribution of household and parental resources towards disability related needs.

This study’s particular findings illustrate this as follows. Disabled children cost more (Cullinan & Roddy, 2015; Emerson et al., 2010). For Aoife, Siobhan and Breandan through narrative rendering, the financial and associated psychological costs of disability were conceptualised as a wider familial issue rather than something suffered by the young person alone (Caples & Sweeney, 2011; Chadwick et al., 2013; Kelly, Craig & Kelly, 2008). The silence of Breandan’s little sister in the autobiographical accounts, for instance, seemed to convey something about the forgotten siblings of intellectually disabled children. This may be considered with particular regard to such variables as poverty or the proven higher levels of general life dissatisfaction that such siblings encounter (Tomeny et al., 2017). Her untold story raised the question of what she had to go without, in order for her brother to have costly speech therapy, when overall the family was struggling to “put food on the table” as articulated by Aoife.

This leads into a second key point under this subtheme: The lived experience of the recession for intellectually disabled young people encapsulated deprivation of basic capacities that aren’t ordinarily applicable to people without
7. Discussion Part 1: Cross Case Comparison

impairment. In earlier literature review, Allen (2009, p.150) stated that one of the key messages set out in post Celtic Tiger Ireland to dampen concerns for austerity measures, was the notion that ‘we are all in this together.’ In Aoife’s particular case, she explained that for her and Breandan, despite serious unemployment concerns, and the absence of a range of services that were cut back such as respite, the most significant thing “about the recession was the talking.” This was linked to extensive cutbacks to SLT caused by austerity (Browne, 2016; DFI, 2010). Denial of basic services in this case, is perhaps illustrative of the illegitimacy of the claim that we are ‘all in this together’ (Flynn, 2017b), because for most of us, losing the ability to talk or walk will not be a consequence of austerity.

7.2.1.3 Young person conscious of community resources: Enjoys doing community activities, engaging with services and/or shows career aspirations

This next theme concerns itself with youth civic engagement and cognisance of community resources. The first key point in this subtheme is outward looking: Namely, social exclusion and regression in independence and civic engagement, appeared to be a feature of the subjective lived experience of economic recession. In this way, paradoxically, cuts to social inclusion programs and transportation aids for intellectually disabled young people could affect their social integration in the context of recessionary poverty that already enhances social exclusion (Emerson et al., 2010). The particularity of Breandan’s case illustrates this as follows.

Breandan’s appreciation of disabled lifestyles, such as specialised social activities was notable. This fit coherently with the Affirmative Non-Tragedy Model (French & Swain 2000; 2008). Yet, Siobhan’s account demonstrates that post-recession for CAS, these were some of the first services to be cut; “those (social groups) have just been em catastrophically affected, a number of those children would have very little other social outlet.”

For Breandan, career barriers were also imposed by speech impairment in the absence of therapy. Such intellectual disability costs correspond to loss of role performance and social participation (Doran, 2012). Breandan’s narrative was imbued with a sense of urgency to gain employment as a corollary to witnessing his parent’s anxieties around his father’s job loss. As Breandan reflected, “Yeah my dad lost his job, it was sad, and yes my daddy sang a song and cried.”

Accordingly, a second key point might then be that: The lived experience of recession appeared capable of provoking psychological anxiety in intellectually disabled young people around the need to earn money to survive. The particularity of Breandan’s extemporaneous narrative illustrated this. Breandan had surveyed employment opportunities, for instance, at a funeral, “I helped and the undertaker gave me 20 euro” and DJing where he was given a “50 Euro note in Portugal.” Chamberlayne (2004, p.341) identifies the term biographical ‘chasm’ as representational of the lowest point in one’s told story, or autobiography. The death of Breandan’s grandfather, the inability to communicate, “I needed to talk about it”, and the family’s financial struggles seemed to accompany Breandan into biographical chasm. A legacy of this might be Breandan’s hyperawareness of the need to gain employment and develop Curriculum Vitae. Research by Frasquilho
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et al. (2016) on youth with parental unemployment in the economic recession demonstrates such psychologically negative effects upon them.

This leads into the third and final key point under this subtheme: **Intellectually disabled young people and their families may have a constrained capacity to understand and communicate the negative impact of recession upon them, and therefore enjoy less safety in this context.** The particular findings of this study illustrate this in a number of ways. A thematic sense of constraint arose across cases, in terms of addressing austerity-produced impediments to accessing community resources. Breandan was fully aware that SLT could not be obtained due to the economic recession (Browne, 2016; DFI, 2010): A contention he voiced on national television, “*it wasn’t fair I needed it*”. This reflects the research findings (DFI, 2016, p.5) that Irish cutbacks forced disabled people into the marginality of society; pushing them outside “the circle of opportunity”. Breandan was able to raise publicity around issues through socio-political activism, advocacy, awareness- and fund-raising, but only with sizeable effort. This reflects the constrained capacity of Irish disabled children to make their struggles heard at a macro-political level, and indeed the historical absence of the same (Flynn, 2011; Flynn, 2017b).

7.2.1.4 Strong social focus in young person's narrative

A focus on social processes underpinned the next subtheme, as applied to findings. This was refined to one key point only: **Namely, that one's life course position was an important constituent of the lived experience of austerity for them.** Cross case comparison findings illustrate this as follows.

A strong social focus formed a narrative thread (Reimann & Schutze, 1991; 2005) in Breandan’s autobiography. This is potentially linked not just to his disposition, but his stage in the life course (Preistley, 2003a; 2003b) as discussed in the earlier chapter with regard to the particularities of his case. Watson and Nolan (2011) build a post recession portrait of the socio-demographic position of intellectually disabled children and adults, and establish that intellectual disability is tied to social exclusion. For Breandan it would appear that speech was a mechanism to make social connections, as he advises “*I like talking to people talking every day . . . saying my words out, giving my news . . . “*

Limited social capacity, however, equates to limited labour market participation. Breandan’s case particularly raises the need to contextualise social isolation in terms of a life course perspective and life course theory (Priestley, 2003a). This is because access to the labour market is directly related to one’s stage in the life course, whilst also directly correlated to one’s life satisfaction and quality of life (Priestley, 2000; 2001; 2003a). As Priestley identifies, disabled people are often resigned to a life-stage similar to childhood or older age as they face barriers to the labour market (2001;2003a). This is troubling in the context of cutbacks to support services through austerity that were partly designed to increase disabled young people’s capacity to gain employment in future.
7.2.2: THEME 2: Residential circumstances: Homelessness and shortage of respite and residential care

7.2.2.1 Not enough respite care

Albeit mediated by the biographical preconditions of each participant’s impromptu narrative (Schutze, 2008); respite care formed another important and emergent concern. A key point here was that recessionary cutbacks to respite were interpreted to increase familial crisis, breakdown and lived experience of distress. Expanding upon this, as the literature designates, austerity in Ireland brought with it unprecedented economic and social decline (Allen, 2009; Flynn, 2016). Aoife and Breandan lost their respite provision upon the impact of recession (in 2009), and then went without it for over 5 years. In the end, Aoife felt compelled to enter a verbal confrontation with CAS staff in order to get the provision that her son required. This deficiency of respite was emergent across all autobiographies; unsurprising in the context of established and significant demand (Browne, 2016; DFI, 2010). As Aoife articulated, “you get no respite from CAS”, whilst Siobhan confirmed that respite provision had been “catastrophically cut.” The lived reality, however, of respite cutbacks, appeared to be a push towards familial breakdown.

This is indicated in the study findings. Aoife’s caring responsibilities, as a labour market barrier, according to Flynn (2017b), may have enhanced her urgency for respite. Furthermore, such barriers relate to impoverishment in Ireland (SILC, 2013) and therefore to financially induced subjective stress. Aoife required a necessary break from caring responsibilities, as she needed to “go away for maybe a weekend and not have to look and worry about who is going to mind” her son.

There were clear elements of emotional strain on Aoife and Rick. Three parental deaths, poverty due to the sole breadwinner’s unemployment in the context of economic recession, and a lack of capacity for Aoife herself to acquire gainful employment were notable. Aoife’s caring responsibilities for a disabled child in this context could plausibly lead to personal or familial breakdown. Particularly as in Ireland, the recession elevated family relationship problems and stress levels (DCYA, 2012b), yet, ironically austerity imposed cut-backs to services such as respite tailored to addressing those problems (Browne, 2016). Furthermore, stressors such as those experienced by Aoife, could be linked to the over-representation of intellectually disabled children in care, and child protection systems in Ireland (Flynn & McGregor, 2017; Kelly, Dowling & Winter, 2012).

7.2.2.2 Not enough residential care

Recessionary cutbacks to residential care were a preoccupation of Siobhan’s account rather than a pervasive feature of Aoife or Breandan’s autobiographies. Siobhan’s observations, when cross referenced against existing research, appeared accurate. Her concerns included lowered staffing levels, agency and lower qualified workers, decrease of quality and availability of placements, and sheer stoppage of service provision (Browne, 2016; DFI, 2010).
This contextualizes the first key point of this subtheme: **Although intellectually disabled children and young people are best placed with their family, hopelessness and desperation can greatly undermine this in cases where residential placements are required and funding constraints disallow provision.**

This key point could be illustrated as follows. Cognitively and emotionally ordering one’s life through the medium of narrative (Reimann & Schutze, 1995; 2005), is a practice dependent upon what one can afford to narrate about. It could be a privilege to narrate one’s life in rich and diverse terms, when for those experiencing subjective desperation for a basic service or support (DFI, 2010), that desperation can become tragically enveloping.

Siobhan recognised that institutional and congregated settings are not the best residential circumstance for disabled children (HSE, 2011; Wolfensberger, 1972). Best practice and deinstitutionalisation processes in Ireland prescribe that children should remain with their families (HSE, 2011; Wolfensberger, 1972). Yet Siobhan conceded that anti-residential discourses sometimes didn’t connect with the lived reality for service users whose needs just weren’t “compatible with family life”. This supports the divide between policy aspirations and lived reality noted in Browne and Millar’s research work with respect to intellectually disabled young people in Ireland (2013).

This prompts the second key point under this subtheme: **Policy and higher management were perceived as disconnected from the sometimes harsh lived reality of coping with an intellectually disabled young person without adequate service provision.** Siobhan continually takes up a narrative strategy (Reissman, 2008) of contrasting the ivory tower of upper management, to the candid lived reality of family life. In one illustration of the oppositional binary, parents brought their disabled child to a meeting where the child, “rocked and shouted for most of it really loud and the professionals have tried to conduct the meeting in that setting because the parents wanted the HSE to see what their child was like.”

Overall, narrative tales are structured temporally (Ricoeur, 1981) and spatially (Reissman, 2000; Schutze, 2008) and allow us to construct a picture of who we are; an identity that we can communicate to ourselves and others through story (Bamberg, 2011). Siobhan’s accounts sympathised with, and claimed membership of the collective identity of disabled service users and their allies. In this capacity, with regard to residential care provision, the emotional toll of observing families “in despair” was significant. As Siobhan reports, “I have nearly wept with relief when someone has gotten a placement.”

### 7.2.2.3 Respite care for child’s benefit not just parent

This subtheme was less fertile with regard to cross case comparison insights. Notwithstanding this, a key point to consider was as follows. **The idea that respite care is for the child or young person’s benefit to promote social embeddedness, rather than for the parent, was prevalent in Aoife and Breandan’s biographical accounts. Aoife had advised “to be fair to the children it’s good for them to mix with their own kind,” and that for Breandan, “I think for the kids to move on and progress and for their own independence he likes going away.”**
7.2.2.4. A reported sense of upset caused by cutbacks to Respite Care Grant

On June 11th 2013, the Irish daily broadsheet newspaper entitled, ‘The Irish Times’ published an article with the headline; ‘Respite Care Grant Cuts Leave Carers ‘Angry and Bitterly Disappointed’.’

It is noteworthy that this theme, generated from Framework Analysis, was the only theme that did not feature in BNIM cases. It is presumed that its non-emergence reflects a lack of significance in the individual cases observed. As BNIM allows participants to generate themes for themselves and therefore is less directive (Wengraf, 2001; 2015a; 2015b), no closed questions could be targeted during the interview to mine for data with respect to the Respite Care Grant. Therefore it is unknown if any of the participants were in receipt of the payment.

7.2.2.5 Homelessness

Homelessness is the linchpin of the next subtheme to consider. The key point here is that, in terms of the lived experience, intellectually disabled young people, made homeless in the recessionary housing crisis may have their existing lived reality of distress grossly aggravated by their disability needs. This is predominantly conveyed in Siobhan’s case account. Based upon direct observations in casework, Siobhan’s autobiographical rendering of the immorality of denied needs in terms of housing, is sincere and extensive, “the whole homeless situation” and “where the banks have taken back the houses”, occurring on account of the recession housing crisis; “a number of children with significant difficulties living in hotels in town, children with peg feeds and the whole nine yards in one room, shocking, absolutely shocking.” In this context, Siobhan provides her subjective assessment of how their disabled status affords them little compensation.

7.2.3: THEME 3: Services and payments:
Expenditure cutbacks, funding losses and shortages of services, multidisciplinary supports and social transfers

7.2.3.1 Cutbacks/losses to education and support services such as Speech and Language Therapy and Occupational Therapy

As would be expected, cross case comparison between Aoife, Breandan and Siobhan’s extempore auto-biographical accounts, evidenced the unitary contention, that education and support services were badly depleted by financial crisis. This corroborates existing and extensive literature to the same effect (Browne, 2016; DFI, 2010). As Aoife had appraised, “there is huge gaps in CAS I could talk about forever.” The key point here is that in terms of lived reality, considerable subjective distress can be experienced in seeking to obtain such resources/services, in living without them, or in anticipating their potential reduction or removal.

In this way, Breandan and Aoife’s autobiographical account of moving school is illustrative. Breandan had attended a mainstream school but as he was getting
little or no SLT provision, the family made the difficult decision to transfer schools with a view to increasing provision. Yet, only when Breandan had transitioned to his new school, was his existing allowance of SLT cut. This dispiritingly impersonal, and unforeseen turn of events, frames well Aoife’s global assessment, that “the whole bottom line comes down to money every aspect.”

7.2.3.2 Change in social work/client relationship: More strain; families more hostile to; or social worker providing more emotional support

Under this section, there is only one key point to note: **Austerity lead to subjective experiences of hostility towards Social Workers in disability services that were an important aspect of their lived experience of recession**. First, the literature offers some necessary context. Flynn examined social work practice in the context of Irish economic recession (2017c). Social Workers felt that they were rendered powerless (Flynn, 2015). Positioned within a fragile, dispirited and grossly underfunded public sector (Featherstone, 2011), Social Workers bore the additional burden of being a frontline face of service cutbacks. As Siobhan explains, Social Workers were often shouted at, verbally abused or threatened, “I’ll end your career”, because they weren’t offering services that families greatly needed. Siobhan concedes that families might not understand that Social Workers themselves were constrained in materialising funds.

Aoife’s extempore auto-biographical account is further illustrative. Aoife claims that after many years without respite, she was forced into a verbal dispute with social work staff in order to realise some limited provision. Concurrently, Siobhan, as a manager outlined her observations of Social Workers all over the organisation crying under the intense conditions of austerity and resulting verbal abuse directed at them by families who were at their last tether, so to speak. The case for an increased ambience of hostility brought about by austerity (Gaughan & Garrett, 2012) is perhaps effortlessly made in the context of research studies on the recession evidencing diminished population wellbeing (DCYA, 2012b).

7.2.3.3 Cutbacks to support services described as worst impact/biggest issue of recession or described as or demonstrated to be dreadful or severely damaging

This next subtheme relates to support service cutbacks. Here, particular findings of Breandan and Aoife’s auto-biographical narrative support the key point that; cutbacks to support services can have covert, complex, potentially longstanding and severe repercussions that are an important aspect of the lived experience of austerity.

Rather than clear-cut, as sense of disarray around this was reminiscent of the notion of “cumulative mess” as derived from the work of Anselm Strauss (Corbin & Strauss, 1988; Strauss et al., 1985). Methodologically speaking, the complexity of such ‘messes’ creates the analytic tightrope walk between, in Wengraf’s words (2001), ‘generalising’ whilst still ‘particularising’ accounts. As we strive to find our foothold on this swaying tightrope, some props are helpful. Yet, it would seem that whilst necessary and constructive, caution should be exercised in reducing the impact of service cutbacks to generalised data given the potential for confounding variables, and an overall sense of having ‘missed the picture’: For
instance, the aspects of disablement that are deeply psychological, psycho-social, or relational (Goodley, 2013). To this end, Schutze (2008) advocates for approaching biographical analysis in a ‘non-naive’ way; and speaking to this study’s particular findings, autobiographical story telling provides a powerful representational mechanism (Schutze, 2008) for the lived reality of economic recession.

One such representation of the particular lived experience of cutbacks, as related to generalised data, might be as follows. For Breandan and Aoife, the lack of funding for SLT was the most demoralizing impact of recession. This is not unforeseen. Breandan’s struggle to speak would no doubt have been difficult for Aoife to watch, particularly as Breandan acted out emotionally and behaviourally. The presence of behavioural problems in intellectually disabled children can threaten the child’s safety and welfare, and is related to maternal mental health problems and maternal experiences of stress (Emerson, 2003). Social isolation related to cutbacks to SLT (DFI, 2010) would have been a further concern for Aoife. Moreover, time pressure within mother’s caring role with regard to their disabled children is also correlated to maternal mental health problems (Totsika, 2011). In this context Aoife had expressed her frustration around the extensive travel and time pressures in getting Breandan to and from SLT. Finally, the inability to speak affected Breandan in almost every aspect of his life, including his educational attainment. As Breandan comments, he was later able to use SLT tools such as LAMH signing system to communicate more effectively with teachers. However, as Law, Denis and Charlton (2017) conclude, lack of SLT can have far reaching implications for children including co-morbid social, emotional and behavioural problems, and poorer adult outcomes in literacy, mental health and employability.

7.2.3.4 Service lacking: Being offered inappropriate service instead of needed one; waiting lists causing stress for families or receiving vital service very late, relying on friends instead or parent run organisations

This next subtheme is concerned with deficit of services. Within it, a key point supported by particular study findings might be presented as follows: For some families, a subjective lived experience of being ‘left in the dark’ about available supports was central in the context of austerity. Lack of funding for advertisement of limited services was a concern, related to Aoife’s assertion that information provision by CAS was scant and inadequate. Pauline Conroy’s work (Conroy, 2011; Barry & Conroy, 2012) enquired into the circumstances of Irish family carers. Here carers reported feeling overwhelmed by their duties in the context of a scarcity of advertisement for limited support that was available post recession. As Aoife remarked, “you could do with more advice, advice and guidance . . . you are left to your own devices . . .they don’t provide you with information, they don’t they don’t provide you with anything.”

7.2.3.5 Cutbacks to entitlements/ allowances

Moving on from the notion of service deficit, and to cutbacks to entitlements, this subtheme generated further key points worthy of attention. First, the impact of
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**economic recession could encompass significant experiences of subjective economic stress.** Consider that in the context of increased costs arising from Breandan’s disability care needs, compounded by a wider climate of austerity (Browne, 2016; DFI, 2010) and parental unemployment, the social welfare system might be considered to be a protective factor. Through economic recession, social welfare payments are intended as a societal insurance policy taking account of the cyclical nature of capitalism (Flynn, 2017a). Yet, as Whelan and Maitre (2014) outline, the impact of macroeconomic turbulence must be considered not just with respect to material deprivation, but subjective economic stress. In Aoife’s case the ever looming fear of being taken off her welfare payment exacerbated existing financial stress caused by her husband’s job loss. Aoife was taken off her payment more than once wrongfully, but successfully appealed each time. Aoife had been entitled to the payment as she could not work on account of Breandan’s disability care needs.

Related also to social welfare provision was the notion of gender, and more specifically gender performativity, or the performative and socially constructed character of gender (Butler, 2015). This underpinned the second key point emergent from this subtheme: **That gender role expectations play an important part in the lived experience of economic recession.** This was specifically illustrative in the BNIM case accounts. Gender role expectations, for instance, were significant for Breandan, whereby he embraced a traditional conceptualisation of the family in which the mother is the caregiver, and the father is the breadwinner. In this context, when Rick lost his job as a reflection of the increased unemployment rates among men in the Irish recession (McGinnety et al., 2014), social welfare payments became utterly indispensable.

The invisibility of Aoife in Breandan’s autobiographical accounts was notable. The absenteeism may be a reflection of the privileged status, for Breandan, of time spent with his father. Breandan articulates that due to prior employment commitments, his father had limited availability for his family, “*he couldn’t get to see us he was working late and sleeping during the day and working nights and he couldn’t.*” As Nolan and Maitre (2017) establish, in order to understand children’s experiences of recession, including large changes to family composition, it is important to take account of their experiences of the Celtic Tiger economy that came before. In this way, Breandan may have benefited from the new found presence of his father in the family home. Certainly, it would appear that this was the case, “*we go to play pool and I like when my dad goes, but now he can, he used to be busy.*” Yet, this newfound presence led to a reconfiguration of caring roles for Aoife and an unsolicited adjustment to her routine, “*I hated having him here.*” European Foundation Centre (2012) findings conclude that reconfigurations of roles in the family unit are a feature of economic recession that the support service infrastructure must accordingly adapt to.

Nonetheless, a potential positive implication of joblessness for Breandan relates to the higher levels of marginalisation and dependency on social support infrastructures that Browne and Millar (2013) evidence Irish intellectually disabled children are at risk of. Breandan’s father through unemployment may have been able to support Aoife with her considerable caring responsibilities, spend more time with his son, and therefore improve the robustness of Breandan’s existing social support infrastructure.
7.2.3.6 Services’ coping strategies for cutbacks

This subtheme concerned service coping strategies. Here a tentative key point was as follows. **Disability service cutbacks or funding misuse, whichever the case may be, may have led not just to overt, but also purposefully concealed risk to staff and families.** Siobhan’s autobiographical account evidenced this where it included observations concerning coping strategies that disability services and families had employed, and been forced to employ, in the context of austerity. Oscillating claims of irresponsibility between Tusla and disability services left parents “forced into a terrible corner” where harming their child seemed the only option to get help. As the Disability Federation of Ireland (DFI) identified in Costello and Cox (2013), a danger point would be reached if cutbacks continued. Such danger was apparent in many of Siobhan’s autobiographical observations, for instance, an assault on a staff “that ended that person’s working life” because funding was not provided for the sufficient standard of safety through the appropriate service provision.

Flynn (2017b) concedes that the use of progressive discourses can form a smokescreen for lack of funding or willingness to fund. Both sincere and ostensible ignorance such as this, contributes to a mismatch between policy solutions and reality where families become invested in ill-fitting solutions: As Siobhan observes, “trying to impose a solution of a problem that they didn’t believe was the problem.” Overall, indications across BNIM case accounts remain indicative of a top-down rather than partnership approach to service provision as a second key point supported by this study’s data.

More troubling, a third evident key point relates to subjective lived experiences of stress for Social Workers: **Social work assessment, as an informed and evidence-based professional mechanism to identify levels of need, was perceived to have been disregarded and dismissed by upper management.** This was perceived so profusely that it was illustrated in Siobhan’s account, as a Principal Social Worker, through times when she was not even getting a response to her correspondence.

7.2.4: THEME 4: Employment losses:
**Parental job loss or recruitment embargo within staff team leading to higher caseloads.**

7.2.4.1 Parental job loss

Theme 4 concerns employment loss. The first key point identifiable here, is that **parental job loss as a result of recession posed particular risk to intellectually disabled children with regard to the imposition of a negative lived reality.** In particular, because one or both parents might already be unemployable due to caring responsibilities.

Study findings illustrate the lived reality of this. Aoife’s inability, for instance, to work as a result of caring responsibilities for Breandan was one opportunity cost incurred (Doran et al., 2012). It is of concern for Breandan that maternal
employment was found to be particularly important in protecting disabled children from socio-economic disadvantage (Emerson et al., 2010). Sequestered concern for ‘disabled people’ as one of several vulnerable groups in the recession (Whelan & Maitre, 2012), according to Flynn (2017b), neglects the interrelated nature of poverty for intellectually disabled children with parental poverty. This is demonstrated in Breandan’s case, where poverty was a knock on effect from parental unemployment in the recession. As Aoife confirmed; “you can’t let kids know your worried about food on the table.” It is this lived reality that biographical methods are aligned to. As Wengraf concedes, “the situated subjectivities of contemporary social agents” are characterised by an attempt to come to terms with changes such as regimes of neoliberal capitalism and associated crises (Wengraf, 2010, no page).

In terms of the downward trajectory into poverty, Breandan’s case was quite representative of the Irish recessionary context. Intellectually disabled children such as Breandan in the Irish recession were at the most risk of experiencing poverty in the context of their families, just as Breandan did (Social Inclusion, 2007; UNICEF, 2013b). Furthermore, young people like Breandan were most likely to fall into poverty due to changes in employment wage status as was the case with Rick’s job loss (Emerson et al., 2010). Although Breandan may not have been aware of the full extent of the poverty characterising his family, indications of financial vulnerability post recession were troubling.

The family were also representative, in a gender typical way, of the heightened unemployment rates of recessionary Ireland (Allen, 2009) particularly in homes where there are children (NESC, 2013). As an intellectually disabled young person, Breandan was most likely to encounter poverty as he did, due to parental unemployment (Emerson et al., 2010; Flynn, 2017b). It was Breandan’s father who lost his job reflecting figures for Ireland in the case of men primarily facing unemployment (McGinneety et al., 2014) contributing to the colloquial phrase ‘mancession’ (McWilliams, 2012). Furthermore, Breandan’s mother couldn’t work as his primary caregiver, again reflecting the norm in the Irish context in terms of gender roles (Emerson et al., 2010). Breandan’s family, in the context of newfound parental unemployment were yet further pushed into poverty by the extra cost attributable to his disability. This mirrors data on families that concludes that households with disabled children experience more poverty than similar households with non-disabled children (Parish, Roderick & Swaine, 2010). The cost of disability was evident where significant mileage was accrued, for instance, by Aoife and Breandan, driving to and from SLT sessions or other disability related services “your driving here, and driving there.”

Bearing this representativeness of Aoife’s and Breandan’s cases in mind, another key point is that families such as Aoife’s were already socio-economically disadvantaged entering the recession, and therefore had a lowered capacity to draw themselves out of poverty. The case accounts illustrate this in a number of ways. Even if it was as simple, for instance, as Aoife trying to take on paid work after her husband was made unemployed, with a view to acquiring some further income for the family, Aoife earlier outlined how attempts to gain some training to develop her CV were brought to an end by having to attend to Breandan’s disability care needs. In one example, she articulates how her attendance at a part-time computer course was cut short due to her requirement to engage with
behavioural supports around Breandan’s care needs. This reflected Emerson et al.’s (2010) findings that families of intellectually disabled children are not just more likely to experience poverty and fall into poverty, but also are more unable to escape from its effects. With little capacity to populate her Curriculum Vitae, Aoife would be ill-equipped to compete for scarce work opportunities in the context of skyrocketing unemployment rates and protracted economic recession (Barry & Conroy, 2012; Whelan & Maitre, 2014).

This downward trajectory leads into a third notable key point under this subtheme: In terms of lived experience, parental loss due to recession appears to aggravate negative factors attributable to disability in the family. In this way, it is not just the financial opportunity cost of Aoife being unable to work (loss of earnings) (Cullinan, 2015) but also the psycho-social loss, as Aoife articulated; “even it is not necessary for the money it’s for your health.” As already established in Aoife’s case, marital difficulties and “rowing more often” were a direct consequence of Rick’s job loss, “it was very very tough, we found it very tough for Rick to be at home it was very tough for both of us.” This would have exacerbated an already higher divorce rate established in research for families such as theirs, who have a disabled child (Emerson, 2004; Flynn, 2017b). Notable here is Flynn’s (2017b) assertion that the contagious nature of financially induced stress and parental economic strain should be considered in terms of the impact of economic recession on intellectually disabled children.

7.2.4.2 Recruitment embargo affected services and families

With regard to this particular subtheme, a key point raised in earlier sections seemed to resurface with respect to the recruitment embargo, namely: Albeit subtle and pervasive; patriarchy, gender performance and gender role expectations (Butler, 2011) appeared to be defining in the context of the lived experience and impact of economic recession for Breandan and Aoife.

Breandan ascertained, lack of SLT partly due to recruitment embargo, led directly to difficulties in him progressing his job opportunity of DJing in the UK. Here, there was a direct causal relationship between the recruitment embargo and lack of SLT, and his later non-employment. Furthermore, this connects to Breandan’s envisioned biographical trajectory in terms of who he thought he could become, and what he believed that he could achieve. In the DCYA (2012b) study, loss of future opportunity was significant for young people who reported despondency through cognisance of the bleak job market and knowing they could not get a job after school. This builds upon the manner in which narrative performs as a key function of self and identity (Bamberg, 2011). Stories construct identity in an effort to render meaningful that which is otherwise incoherent and inchoate (Bamberg, 2011; Reissman, 2000; 2008). For Breandan gender role expectations were heavily tied to the breadwinner identity of masculinity in a patriarchal society (Butler, 2011), a conceptualisation emphasised by the visibility of his father’s unemployment in his narrative account as a contrast to the invisibility of his mothers unemployment. As a young man, Breandan was aware that speech difficulties would make it difficult to realise the patriarchal ideal of masculinity, dependent on paid employment in a capitalist economy. It would seem that the recruitment embargo played a significant rather than peripheral part in this, by
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preventing Breandan from getting the SLT he required to gain speech, alongside other vital services such as respite.

7.2.5: THEME 5: Emotional and lived experience of economic recession for intellectually disabled children and their families

7.2.5.1. Sense of fear, persistent fear, anxiety, worry and devastation

Progressing now to theme 5, BNIM auto-biographical renderings of fear, worry, despair, anxiety and even devastation were evident. A key point within this was: Parental mental health, jeopardised by economic recession, formed a risk factor for intellectually disabled young people in terms of negative lived experience. It is already known that households such as Breandan’s during Irish recession are linked to poorer parental mental health. Poverty in children often results in poorer educational attainment and mental health outcomes - although the exact cause of the latter in children is as of yet unclear (DCYA, 2012b). Finally, caregiving responsibilities were a concern in the perceived absence of a ‘safety net’ provided by services (Barry & Conroy, 2012; Conroy, 2011). As Aoife remarked, “it is a huge worry you know what happens in the years you know where we are not there.” Research verifies that worsened child to parent relationships were associated with the heightened anxiety of children as well as children’s decreased happiness and poorer conduct across the Irish recession (DCYA, 2012b). As Aoife explained, she felt a duty to hide from the children the true extent of the family’s worries and financial issues. This in itself would be a pinnacle of stress for Aoife and Rick.

7.2.5.2. Social Worker upset and distressed because can’t get a needed service for family

Shifting focus now towards the lived reality for social work practitioners, a key point drawn out from Siobhan’s auto-biographical narrative might be that: Role expectations associated with the professional identity of ‘Social Worker’ that were conflictual, contributed to increased stress in the context of economic recession. This might be illustrated as follows.

Economic recession poses particular stress for Social Workers due to the social justice orientation of their work (Featherstone, 2011; Flynn, 2014; 2015) and neoliberalisation that reproduces patterns of social inequality (Featherstone, 2011; Conneely & Garrett, 2015). For Siobhan, it was clear that she felt distress and hurt by not being able to do more for the families that she worked with. This was a difficulty that she observed for her social work colleagues also. In her autobiography, there was a biographical action scheme emergent, centered upon intended patterns of action, around her expectation that she would make things better for families in the context of austerity. This appeared to be really important to her, and tied to personal, and institutional expectation patterns related to her role as a Social Worker (Schutze, 2008). Yet, within her self-biographising narrative, Siobhan was living a contradiction, employed by an organization to help families in need, but not provided with the resources to do so, by that organization. As Siobhan tells it, “I have nearly wept with relief when someone
has gotten a placement”. This sentiment is extended to the collective identity of social work in her organisation.

7.2.5.3. Left not knowing until the last minute if a needed service will be granted.

This next subtheme relates to anticipation of services. Huaben et al. (2012) convey the impact of austerity measures as multidimensional, inclusive of such other variables as elongated waiting lists and stricter criteria on admission to services. Aoife explains, “CAS don’t make things easy for anybody they are not good at supplying information”: Whilst Siobhan talks about “split second decisions” made “at the last minute” about whether a desperately needed service such as residential care would be provided. As a consequence of these shortcomings, families could not plan for later service provision or rely upon the same. This incited pressure to accrue savings to cover service deficit in future, or form contingency plans.

This provokes a particular key point as follows: Anticipation of the unavailability of a vital service can leave families caught in a lived experience of suspense. Aoife sees her family having transitioned from darker and more austere times of monetary struggle to greater financial stability with her husband’s new career as a Taxi Driver, “things are better now.” The latter improved circumstance reflects a biographically metamorphosed self, having transitioned from austerity and emerged stronger than portrayed in earlier stages (Gubrium & Holstein, 2001). Yet BNIM data also conveyed that families may be left lingering, unaware of whether a vital service will be provided, or when it will be provided for that matter. In this interim period, where families seem to linger indefinitely, a sense of biographical paralysis may be imposed (Schutze, 2008).

7.2.5.4. Parents having to ‘fight’ or ‘battle’ to get service for child

Building on previous sections, the key point under this subtheme extends the picture of the cumulative stress, or ‘mess’, of living through recession (Corbin & Strauss, 1988; Strauss et al., 1985). The point is that the negative lived experience of recession for parents such as Aoife appeared enhanced by expectations of socio-political activism. Aoife and Siobhan’s particular telling of their lived experience illustrates this as follows.

Cultural milieu and historical contexts are key to storytelling (Reissman, 2000). Aoife and Siobhan allude to the practice and expectation of parents ‘fighting’ and ‘battling’ for services and supports during economic recession. This need to ‘fight’, is exacerbated by an economic recession that imposes legitimate human rights concerns for disabled people (Browne, 2016; DFI, 2010), and yet also imposes reduction in the capacity of professional advocates, such as Social Workers, to advocate, due to circumstances such as increased caseload demands (Featherstone, 2011).

In the context of Aoife’s and Siobhan’s lives, this practice seemed to take on both a cultural and functional element to it. Aoife uses ‘we’ to identify herself as one of a collective of parents who feel the need to ‘fight’: ‘So we are constantly looking and chasing and seeing what is appropriate and for our kids CAS do nothing,
absolutely nothing.” Regrettably, experiences of worry and fear seemed to underpin and galvanise these efforts; “another battle, everything seems to be -you have to fight for everything.”

7.2.5.5. Families who can’t fight ‘falling through the cracks’

Related to the previous subtheme, the key point here is one that is implied rather than explicit. Namely, there was a subjectively perceived sense of risk for families, who do not have the capacity to self-advocate, to be defeated by the social system, by virtue of their silence.

This is illustrated by findings in many ways. Somewhat linked to the notion of fighting for services, Aoife’s autobiography often appeals to a metanarrative of disability that specifies that disabled people are disadvantaged and rendered subordinate to the more privileged able-bodied society (Goodley, 2016; Shakespeare, 2014). Subtly ordering her narrative around plot, character and setting (Reissman, 2000) and the passage of time (Ricoeur, 1981) Aoife continually positions herself in the role of advocate and aggressor where such roles are necessary due to being denied vital services. This narrative positioning is thematic, as the need for families to fight for services is acknowledged broadly across Siobhan’s and Breandan’s cases also.

Aoife’s attempts to make her home accessible through a grant entitlement system are exemplary, here her stress appeared amplified by bureaucratic and convoluted processes that make entitlements difficult to access: “would you bother? It’s exhausting and we probably at the end of it won’t bother.”

7.2.6: THEME 6: Familial crisis, breakdown and demoralisation arising from economic recession

7.2.6.1. Parents having to do demoralising and unacceptable things to get their child a needed service - e.g. Beg

The need for parents to impose upon themselves experiences of ridicule or demoralisation in an effort to get their children what they needed was to a degree, thematically emergent across Aoife’s and Siobhan’s cases. The key point here was that the stress caused in this context, may have damaging effects on wellbeing and health where conceptualised holistically.

Aoife talks about needing respite care, yet seeing her provision stopped following the recession in 2009. She explains that she eventually had to fight with staff to get some provision, “they are telling you on the phone they haven’t got it, it’s not available, and so then you end up fighting with them.” Siobhan talks about parents who are “backed into a terrible corner”, and children who are abandoned in hospitals as parents cannot get residential care and feared for their children’s lives. In instances such as these, the toll on management in saying no to families in need was also a concern for Siobhan, “I kind of wonder about what it does for people’s health to be constantly holding the door closed.”
7.2.6.2. Families have to reach significant crisis point to get service or indeed reach crisis because of not getting a service

This is the final subtheme to be applied to cross case comparison. The key point emerging from findings within this relates to risk management: It appeared that the impact of recession may have had the potential to generate increased risk of abuse of intellectually disabled young people. As noted in the literature, Breandan, as an intellectually disabled young person, is subject to acute social vulnerability and a risk of neglect and abuse that is considerably higher (Flynn & McGregor, 2017; Kelly et al., 2012; Northway et al., 2013; Ziviani et al., 2013). For Breandan, Aoife felt that a lack of information and support services provided by CAS contributed to him experiencing and perpetrating sexual abuse as outlined in her earlier BNIM case presentation; “regarding development and sexual development and there were huge holes, huge gaps, and we fell into a big downfall.” In this context, lack of information from disability services has been established to be concern post recession for parent-carers (Conroy, 2011; Conroy & Barry, 2012).

Aoife reported that CAS took due responsibility for their ineptness and offered support after the abuses occurred, when requested by her, but that this was effectively too late. This reflects findings of the DFI (2010) that the recessionary recruitment embargo led to a limitation of the scope of supportive work and serious compromise to ground level service provision. Furthermore, as Siobhan evidences in her accounts, social workers caseloads had risen, extra supports were cut (Featherstone, 2011; Flynn, 2017b), and ultimately this led to crisis driven work rather than preventative, “we are constantly on the verge of bankruptcy”. Such crisis orientation to disability service provision is a natural consequence of recessionary cutbacks that have depleted resources (Browne, 2016; Centre for Independent Living, 2011; DFI, 2010; Irish Nurses and Midwives Association, 2015). As Siobhan articulates, she experienced the shock of watching crises occur for families because clinical teams cannot get funding to do preventative work even when they see crisis ahead: “If the funding was flexible and responsive you could head off all of these terrible crisis . . .that’s really shocking, really really shocking .”

7.3 Conclusion

This discussion chapter presented the findings of cross case comparison - the final stage of the BNIM 10 stage intensive analytic process (Corbally & O’Neill, 2014; Wengraf, 2001). Cross case comparison was achieved by applying the framework (Chapter 5) developed through earlier Framework Analysis to the BNIM autobiographical accounts. The purpose of the chapter overall was to progress the study’s response to its central research question.

As already identified, disabled children have been a social group hit hard by Irish recession (Flynn, 2017b). UNICEF (2013b) conducted comprehensive research on the impact of economic recession on child well-being in ‘rich countries,’ including Ireland. A strong and multifaceted relationship between the impact of recession
and a decline in children’s well-being was established since 2008. The study further conceded that children will bear the consequences longest, in countries where the recession has hit hardest (p.2). By comparison, Ireland experienced the worst impact of recession of almost all EU countries (Barry & Conroy, 2012; Watson & Maitre, 2014). Within this, disabled children in Ireland are considerably more likely to be poor than non-disabled children (Cullinan & Roddy, 2015; Emerson, 2004; Emerson et al., 2010; Parish, Roderick, & Swaine, 2011) and are at enhanced risk of almost all social problems (Flynn & McGregor, 2017; Kelly et al., 2012; Northway et al., 2013; Ziviani et al., 2013). As the UNICEF study concluded, “the poorest and most vulnerable children have suffered disproportionately” (2013b, p.3).

The present study was not concerned, however, with children nor intellectually disabled children alone. Rather, the familial aspect of the impact and lived experience of recession fell within the focus of the central research question. This was in accordance with the already interlinked nature of the socio-economic profile of Irish disabled children (Cullinan, 2015) and that of their families (Emerson et al., 2010). This familial standpoint was also particularly important considering illustrative economic concepts such as conversion handicap (Cullinan & Lyons, 2015) that demarcate how intellectually disabled children experience poverty in the context of their families (Emerson et al., 2010) and vice versa (Cullinan & Lyons, 2015). Yet, the impact and lived experience of recession was in this study, not just about poverty and material deprivation, but also more predominantly concerned with social indicators. This conceptualization of Irish recession follows Kieran Allen’s work (2008; 2009) in terms of recognizing the phenomenon to be primarily a catalyst of social suffering.

Overall, an existing comprehensively investigated sphere of quantitative data in Ireland has usefully generated indicators of the impact of recession. As outlined in Flynn (2017b), it is in fact exploratory qualitative research such as this, on the lived experience of the recession for intellectually disabled children and their families that remained absent. Furthermore, the specific economic profile of intellectually disabled children in Ireland is grossly underdeveloped (Cullinan, 2015). Nevertheless, Flynn (2017b) concludes that existing statistical data provides a valid skeletal framework to understand the generalisable nature of the lived experience in this context. Therefore, this data was heavily integrated into the present cross case theorization chapter.

In terms of the overall findings of cross case comparison, there were many points to consider. A culture of anxiety within disability services and lack of attention to social work assessment was alluded to. The extent of the difficultly intellectually disabled young people and their families are left struggling with, in the absence of funding for such services as respite and residential care was further articulated. Finally, the longstanding, multifaceted and complex repercussions of cutbacks to Speech and Language Therapy were apparent. Of course, these are just some of the points raised herein.

Perhaps in drawing to a close, it is the pervasive, multifaceted and often covert nature of the impact and lived experience of the recession that is now most clear. As so many of the consequences of austerity are secondary in nature, the economic roots of social problems remain too often buried beneath the soil. From
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here, it appears that economic recession has had the capacity to infiltrate and undermine so many aspects of familial life.
8. Discussion Part 2: Overall Analysis

8.1. Introduction

Thus far, discussion has consolidated the framework of themes and subthemes generated through Framework Analysis with BNIM autobiographical accounts. It did this through cross case comparison. As of yet, however, recommendations arising from this study remain obscure.

This chapter offers some remedy for this through the concluding discussion of the overall PhD research project. More specifically, it settles the question of whether this PhD has achieved what it set out to do from the start. In doing so, this chapter uses the study’s original aims as a basis for discussion. Recommendations are also made for the future.

Within this, the present chapter considers both the findings of Framework Analysis and the findings of BNIM. For Study Aim 1, the major findings and resulting recommendations are based on the findings of BNIM. This is because it was the most epistemologically and methodologically appropriate research approach for the particular aim.

For Study Aim 2, its major findings and resulting recommendations are all based on the findings of Framework Analysis, and the findings of cross case comparison in Chapter 6 that applied this framework to BNIM autobiographies. Again, this was most methodologically appropriate given the particular phrasing and remit of Study Aim 2.

Finally, discussion of Aim 3 is informed by findings of the Framework Analysis and findings of the BNIM in combination.

Overall, the chapter draws in some external supporting literature; it does so to render discussion more authoritative and robust, and at times to install literature illustratively. Some new literature is incorporated here, however none of this is of the nature or form that would be better placed in the literature review chapter itself, but rather is brought to bear on the present and evolved discussion, given its particular relevance at this moment in time.

8.2 Aim 1: To investigate how both intellectually disabled young people and their families have experienced the economic downturn

The first aim of this study was to investigate how both intellectually disabled young people and their families, experienced the economic downturn. Methodologically, BNIM was the pathway toward achieving this. The BNIM as a method is orientated towards capturing lived experience whilst retaining connection with the social context, including macro-level phenomena such as recession, and peripheral cultural-historical context. Within this, it accommodates the retrospective study of macro-level events, processes or phenomena (Wengraf, 2001; 2005a; 2015b; 2015c). Therefore, on a practical level, the three BNIM autobiographical accounts of this study, and their cross case comparison,
constitute the investigation needed to achieve Aim 1 of this study which is concerned with capturing the lived experience of the recession.

The intentions of this study were twofold with respect to BNIM. Firstly, to capture the particularities of individual lived experience through BNIM, but then to further explore the connection between the lived experience and larger social and economic context (economic recession) as rehearsed in major applications of BNIM (Chamberlayne, Rustin & Wengraf, 2002). This reflects the socio-biographical nature of BNIM, as Chamberlayne, Rustin and Wengraf (2002) articulate; ‘biographical’ necessary entails individual biography whilst ‘socio’ compels connection with wider society. With specific regard to the interconnection of lived realities and macroeconomic context (the focus of study Aim 1) it is interesting to discuss the major findings of this study, as they relate back to the literature. These findings are:

a) That consensus around the perception of economic recession as a social phenomenon and a social justice matter was evident from participants of this study.

b) Intellectually disabled young people and their families were disproportionately disadvantaged during the economic recession.

c) The subjective lived experience of economic recession was predominately negative, and characterised by complexity (related to factors such as cumulative effect; and primary, secondary and tertiary effects (domino effect)).

d) A sense of a shared culture and comradely support was evident between families with an intellectually disabled young person and this encompassed the lived reality of recession.

e) Strongly emergent sense that families had, that their lived reality was not understood by disability services, policy makers and those in power.

f) There is a culture that promotes socio-political activism and advocacy within disabled communities (Shakespeare, 2014). This culture had both positive and negative implications for those communities during the recession.

(a) Consensus around the perception of economic recession as a social phenomenon and a social justice matter was evident from participants in this study. Participants defined the recession in terms of social injustice. Traditional definitions of economic recession relate to technical economic indicators (Gasski, 2012), such as quarterly declines in Gross Domestic Product, as is the case with the Oxford English Dictionary (2017) and Encyclopaedia Britannica (2017). The predominant conceptualisation of economic recession that emerged from participants in this study was different however. Rather, participant’s conceptualised recession consistent with Kieran Allen’s work (2008; 2009), whereby recession was interpreted to be a macro-economic event most characterised by the social suffering it imposes. This definition arising from participant accounts extended to include a conceptualisation of economic recession in terms of a matter of ‘social justice’ rather than of individual misfortune. ‘Social justice’, as referred to here, might be defined as ‘justice in terms of the distribution of wealth, opportunities and privileges in society’ (Oxford English Dictionary).
Participant’s definition of recession as social injustice was not unexpected. Participants conceptualisation of their lived reality seemed to reflect the popular contemporary culture of the identity politics of wealth distribution, in the context of Irish austerity (Whelan & Maitre, 2014). In this way participants lived reality in terms of austerity seemed to be thought of as a consequence of their identity position in an unjust capitalist economy (Moran, 2015); albeit told by them more implicitly and less academically. This might reflect the increased preoccupation with ‘the acquisition and maintenance of identity’ in contemporary Irish society of high-modernity (Bendle, 2002, p.1).

One could also suggest that this conceptualisation of recession, as a social justice issue (somewhat akin to classic Marxism (Marx & Engels, 2012)), is the modern cultural norm. In this way, without undue generalisation of findings, participant’s rationalisation of their lived reality as ‘social injustice’ could be thought to be a reflection of the dominant norm in terms of explanatory discourse for the recession; in this way such an explanation of the recession as social injustice could be thought of as rhetorical, predictable or even compulsory (because the present cultural context espouses this explanation). This is not to suggest that the economic recession was not about social injustice in Ireland, but rather that a balanced consideration of viewpoints should be entertained, for the purpose of discussion of findings. There were, in fact, other potential conceptualisations of the lived reality of recession available to participants. A classic individualistic justice explanation related to recourse under the law, for instance, for one’s victimhood (Bunreacht na Eireann, 2011) is an alternative to a collective rationale of social injustice. On the other hand, a purely economic definition of recession as a reflection of the unstable and cyclical nature of capitalism (Marx & Engels, 2012) could have been espoused by participants, therefore omitting blame on financial elite groups and privileged social classes. Finally, the notion that one’s assets are a reflection of free market economy that regulates wealth distribution and concentration fairly based on merit and competition, enhancing the economic progression of our society, social justice, and therefore well-being for all (Marx & Engels, 2012; Moran, 2015) was not entertained, either, by this study’s participants. Instead, findings demonstrate that participants understood their lived reality in austerity to be a reflection of their disadvantaged identity position in modern society and a lack of associated capital. This leads to the second key finding.

**(b) Intellectually disabled young people and their families were disproportionately disadvantaged during the economic recession.** It seemed that young people and their families in this study were disproportionately disadvantaged during the recession. Throughout and following recession, the economy based upon a capitalistic free market was assumed by many to be self-regulatory (Moran, 2015). Nonetheless, it did not appear to offer equality of opportunity nor equality of outcome, for intellectually disabled young people and their families in this study. This was primarily due to such factors as labour market barriers and extra disability related costs, both occurring at a familial level. As a result, government intervention at familial and individual levels, through funding for services and supports, and the social welfare system is vital. This is particularly so if one considers the barriers to labour market participation (Preistly, 2001; Shakespeare, 2014) and increased socio-economic cost (Cullinan, 2015; Cullinan & Roddy, 2015; Emerson, 2004; Emerson et al., 2010) correlated to childhood
disability; it is hard to justify these families’ general low socio-economic standing (Cullinan, 2015) under a rubric of merit and competition in the present economy. Within rationalisations of social injustice, principles of morality and fairness appeared to form important features of participant’s narrative construction of their lived reality of austerity. Within this, their disproportionate disadvantage in economic recession seemed to particularly resonate with notions of unfairness.

(c) The subjective lived experience of economic recession was predominately negative, and characterised by complexity (related to factors such as cumulative effect; and primary, secondary and tertiary effects (domino effect)). It would appear from the BNIM findings pertaining to the lived reality, that economic recession could be sociologically conceptualised similar to any societal-scale adverse event such as a natural disaster. Within this, its effect appeared to be negative and complex. This might be illustrated through commonalities between findings here and the significant scholarly field of the sociology of disaster (Quarantelli & Dynes, 1977). In this way, findings of this study, considered in the context of the literature, demonstrate that economic recession as a macro-level phenomenon was complex in its presentation within participant’s lived reality, through its expression in primary, secondary and tertiary effects. Within this, the family unit acted like a microcosm for the societal impact. In this context, the negative experiences children and families had, were not always realised by them, to be ultimately rooted in the impact of economic recession. There was, however, a sense for families of the foreboding presence of recession, as articulated by the DCYA study with the phrase “doom and gloom” (2012b).

(d) A sense of a shared culture and comradely support was evident between families with an intellectually disabled young person and this encompassed the lived reality of recession. Applying this study’s elected Affirmative Non Tragedy Lens (French & Swain, 2000; 2008) requires attunement to the positive aspects of disabled culture and identity. It was notable that between parents in this study was perceptible a shared culture that entailed elements of positive and practical support. As French and Swain (2000) note, membership of a community defined by shared identity can, per se, be a positive implication of that identity. Peer-group relations seemed to function in terms of emotional and practical support for parents; already established to be the case in the literature in terms of the benefits of facilitative social support systems for parents of disabled children (Oyebode & David, 1999). In this way, peer-group systems evidently addressed a deficit that professional systems neglected. This was so much the case that the present study showed examples of friendships and parent-peer groups formalised into official organisations. Overall this speaks to the (e) strongly emergent sense that families had, that their lived reality was not understood by disability services and policy makers, as will be addressed later through recommendations.

Finally, (f) there is a culture that promotes socio-political activism and advocacy within disabled communities (Shakespeare, 2014). This culture had both positive and negative implications for those communities during the recession. In terms of positive implications, it is clear that political activism and advocacy measures combat the negative effects of austerity, for instance, through awareness-raising and fund-raising (Oliver & Barnes, 2012; Oliver, Sapey & Thomas, 2012). Therefore these measures are vital.
Nonetheless, negative undertones to this culture were perceptible also. One undercurrent was that advocacy claims may have been somewhat delegitimized by those in power as being an obligatory or rhetorical expression of disability activism or the social work role, rather than consistently having substance in actual concerns. Ingrained, for instance, in the practices of Social Workers and parents was an expectation to behave oppositionally against identified oppressive social structures and hierarchies. For professional Social Workers, this was naturally aligned to a traditional social justice orientation (IFSW, 2014) and to a lesser extent the influence of structural and radical conceptualisations of the discipline (Ferguson & Lavellette, 2007; Mullally, 2007). Yet when Social Workers, disabled people, and allies advocated for entitlements or better services and supports, this may have been at times, taken less seriously by persons in power, as it was not considered to be unusual or unexpected.

A second troubling undercurrent was that participant parents in this study, a subset of parents already experiencing increased demands due to their children’s disability care needs (Revill et al., 2013), now believed that it was the natural order of their role to have to advocate and act in an activist capacity (an expectation that may have been produced or recycled through disability culture) contributing to feelings of guilt and stress for them when they were not engaging in activism or advocacy. In this way, some parents articulated that it would be better if there were more paid advocates and activists to do this work.

Overall, these major findings are demonstrative of the study’s accomplishment of its first aim, to investigate how both intellectually disabled young people and their families have experienced the economic downturn. As follows, some recommendations will now be discussed that extend these findings in the direction of remedial action.

**8.2.1. Study Recommendation 1:**
Individualised and person-centred approaches to service provision are most appropriate. Yet, austerity may in reality have prompted a backward regression towards the ethos of a more traditional group-based model of service provision.

This study has evidenced the complexity and non-static nature of human needs and social realities. Therefore, determinations of the socio-economic needs of intellectually disabled children and young people must account for “highly complex and flexible individual profiles” (Cullinan, Lyons & Nolan, 2014, p.3). Thankfully, the case for individualised person-centred services is well rehearsed and recommended in the Irish context, most notably in major articulations of Government disability policy (Department of Health, 2012; Expert Group on Mental Health, 2006; HSE, 2011). What the findings of this study may add to this, is evidence of considerable need for improvement in disability service provision during the recessionary period, with regard to particular areas of deficit. This is not to dismiss the positive aspects of disabled lifestyles in Ireland facilitated by existing services and supports (French & Swain, 2000; 2008) and within this, gains brought about by disabled people and their allies (DFI, 2008). Elements of excellence in the administration of disability services are also perceptible (Department of Health, 2012).
Yet, the emergent policy dialogue around personalisation of services and supports (Power, Lorde & Defranco, 2013) remains aspirational if available and constrained funding is not put to appropriate effect within organisations (Department of Health 2012; DFI, 2008; Quinn, 2014). From this study’s findings, more funding for disability services would have been required in the aftermath of recession: However, there is also a case made in existing literature and governmental policy that it is the misuse of existing funds that has been a particular problem, for instance, in terms of surplus expense on staff salaries (Department of Health 2012; Quinn, 2014). This debate is better played out elsewhere (such as Department of Health, 2012). Herein, findings more specifically point to a troubling reconfiguration of the prevailing model of service provision brought about by austerity. Such a concern was initially raised by Skalecka (2014) in research accounting for the effects of austerity on disabled adults in Ireland. In Skalecka’s research, the throwback is framed in terms of a backward regression from a social to a medical model of disability galvanised by austerity measures.

Herein, findings seemed to indicate that those resources and services that were available were offered to families in need. However, where economic recession and austerity measures particularly undermined the availability of some services such as Speech and Language Therapy, these could not be provided (DFI, 2008; 2010). Therefore, the central ordering principle of service provision became in reality, availability rather than personalisation, as austerity encouraged a backward regression from person-centred individualised service provision to a more traditional group-based model (Department of Health, 2012) that surpassed the walls of congregated settings.

**8.2.2. Study Recommendation 2:**

**Negative emotion was a central component of the lived experience of economic recession.** Within this, there was a perception that policy makers and politicians did not understand the lived reality for intellectually disabled young people and their families. Consideration should be given to addressing this.

Negative emotion was a central part of the experience of economic recession for participants. It appeared that this negative emotion for intellectually disabled service users and their families was partly amplified or aggravated by a perception of ignorance or naivety of others with regard to their lived reality. External research and literature has already captured this to a limited extent, for instance, Browne and Millar (2013) note the perceived divide between disability policy aspirations and the lived reality for intellectually disabled service users in Ireland. Such a divide indicates a requirement for policy makers, politicians and senior management to better sensitise to the lived reality for intellectually disabled young people and their families, or perhaps more accurately, better articulate the existence of that sensitivity. This is because the severity, extent and cumulative effect of self injurious behaviours; behaviours that challenge; complex medical needs; and broad disability care needs, on service users and their families, weren’t believed to be understood. This translated into powerful negative emotion where families weren’t getting appropriate support or services.
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8.2.3. Study Recommendation 3:
Place intellectually disabled children and their families at the top of government priorities.

This study further determines that intellectually disabled children and young people, and their families, should be placed at the top of Government priorities.

The requirement for this is well established by now. Stringent losses to the community and voluntary sector (NESC, 2013); to public sector services such as SLT (Inclusion Ireland, Irish Autism Action & Down Syndrome Ireland, 2014) and to social welfare payments (Disabled Inequality, 2016; Irish Nurses and Midwives Association, 2015) interfaced with an existing and sobering disposition to poverty (Cullinan & Roddy, 2015; Emerson, 2004; Emerson et al., 2010; Parish, Roderick, & Swaine, 2010) and enhanced risk of almost all social problems (Flynn & McGregor, 2017; Kelly et al., 2012; Northway et al., 2013; Ziviani et al. 2013). As intellectually disabled children experience poverty in the context of their families and are more likely to be resigned to poorer families (Cullinan, 2015; Emerson et al., 2010) the general destitution of underprivileged Irish families in Ireland’s economic meltdown had been particularly brought to bear upon them. Intellectually disabled children and young people are more inclined toward income poverty and material hardship, and this is most attributable to changes in employment wage status (Emerson et al., 2010; Flynn, 2017b). In the context of skyrocketing unemployment rates (Featherstone, 2011), the heightened rate of jobless households was most visible in those homes containing children (NESC, 2013). Within this, a compelling case to protect the poorest children such as intellectually disabled children is founded in the context of a confounding child poverty rate increase of over 130,000 more children poor in Ireland’s recession (UNICEF, 2013).

Yet, these assertions reflect only a cursory reiteration of the evidence considered so far. There is decades of research that proves intellectually disability enhances risk of poverty (Emerson, 2004). There are also multiple sources to reference with respect to children’s heightened economic disadvantage in Ireland’s recession (UNICEF, 2013; End Child Poverty Coalition, 2011; Holland, 2012). Finally, Whelan and Maitre (2014) determine that in Irish economic recession, multi-dimensionality of socio-economic disadvantage as outlined earlier, is a means to best recognize which groups are most vulnerable.

The findings of this present study make their own contribution. Indications are that the lived reality for intellectually disabled young people and their families is characterized by much complexity, within which multiple strands of socio-economic disadvantage converge upon, intensify, and construct one another: Therefore, Government should not confidently assume that future social protection measures will provide a sufficient safety net, nor that existing data is sufficient to justify such an assumption. In addition to robust social protection measures, these families must occupy, and then continue to retain a priority status for Government.

It is regrettable that existing awareness of these children’s hardship was not sufficient to better safeguard them against the impact of economic recession (Browne, 2016). This research sought to extend the field of comprehensive quantitative data discussed above, to illustrate the lived reality of indicators of the
impact of recession. It is troubling that the findings of this study indicate particular instances within which significant suffering and risk was enabled by the lack of provision of funding. The intention of the study’s methodology has never been to generalise these findings or to suggest that they predictably reflect the wider population of intellectually disabled young people and their families consigned to austerity (Wengraf, 2001; Bryman, 2015). Rather, it is hoped that empirical research findings herein can illustrate the complex ways in which the recession played out in particular lives. The study further aimed to raise awareness and deepen understandings of the lived reality of recession. In seeking to qualitatively capture the circumstances of everyday lives (Bryman, 2015) it is further clear from this research that participant families’ capacity to advocate for themselves was often undermined by already constrained resources and taxing schedules centred upon changing and complex disability care needs. In this context, the present study reiterates that intellectually disabled young people and their families need to be placed at the top of Government priorities.

8.2.4. Study Recommendation 4:
Produce better data to inform public and policy debates in relation to services and supports for intellectually disabled children and their families.

As in Skalecka (2014), Flynn (2011) and Flynn (2017b) more qualitative research such as this is required to interject into debates presently sustained by a comprehensive sphere of quantitative data around the impact of recession. John Cullinan (2015) has made some inroads with colleagues (such as Cullinan, Lyons & Nolan, 2014) to developing the socio-economic profile of disabled children in Ireland from an economic perspective, recognising that as it stands, the area is underdeveloped. Yet, given that poverty is a multidimensional social and cultural problem (UNICEF, 2016), to complement this, further qualitative research is required to elucidate the attitudes, behaviours and perceptions sustaining evidenced indicators of socio-economic disadvantage. Accurate statistics must be complemented by careful analysis (UNICEF, 2016), qualitative research findings, and suitably sophisticated research methods (Flynn, 2017b) due to the complexity of poverty and social disadvantage as phenomena.

8.3 Aim 2: To explore the impact of the recession on the lives of intellectually disabled young people

The application of Framework Analysis in this study was the basis for achieving Aim 2 as is specified above. Indicators of the impact took the form of themes and subthemes which were presented in research findings in Chapter 5. In addition, findings of cross case comparison in Chapter 6 that applied this framework to BNIM autobiographies also constitute the achievement of Aim 2.

Some of this study’s findings around the impact of recession were relatively novel, albeit suspected but not well evidenced empirically. For instance, this study evidenced that families and service users at times were in positions of real danger and suffering as a result of not being allocated funding for needed services. The potential for this, but not presence, had been highlighted by previous research in 2010 (DFI, 2010). Furthermore, evidence presented of parents having to engage in demoralising behaviours to get their children services, such as entering verbal confrontations with staff, or taking their disabled children to management meetings unannounced. Shakespeare calls for recalibration, reanalysis, and
revision of the strategies of disabled activists in the context of austerity (2014) whilst Goodley (2013; 2016) calls for better theoretical resources, as reformulations of the meaning of disability take place on the grounds of austerity. Suffice to say the present study’s findings around the impact of recession certainly point to deterioration in the quality of life of intellectually disabled children and young people, and their families, and would call into question how effective the strategies of disability activism and scholarship have been, and whether new approaches are now required. As a starting point further recommendations can be made, arising from the findings of framework analysis and BNIM cross case comparison around the impact of recession:

8.3.1. Study Recommendation 5:
Decisions regarding the allocations of funds, services and supports by disability services should be made on the basis of a sufficiently comprehensive understanding of service user’s individual circumstances.

Individually chosen and person centred services (Department of Health, 2012) are striven for in disabilities services. At a grassroots level this is realised in a number of ways, such as use of person centred plans; behaviour support plans; key working; service user consultations; and strategies that support service staff use such as promoting service user led activities. However this study showed that achieving individualised and effective services is complex when funds are required, particularly where this is at short notice. It appeared that those who have the power to make decisions about what money is spent, where and when (such as Area Managers); are often not the people who actually have direct day-to-day contact with families. This appears to make the funding allocation process more convoluted and therefore lengthier, and at times decreases the effectiveness of funding use e.g. funding an ill-fitting service or providing a service so late that the service is then more expensive as it must cater to crisis rather than getting in earlier and doing preventative work. Therefore this study’s findings support and reiterate the need for timely resource allocation based on a strong understanding of the service user and family’s present and individual circumstances.

8.3.2. Study Recommendation 6:
More meaningful regard for social work assessment should be pursued.

It appears that more meaningful regard for social work assessment is required. There may be a number of reasons that social work assessment seemed to be somewhat dismissed by upper management in this study’s findings. One explanation, for instance, is that stereotypes about the social work profession might be problematic. As with any profession, Social Workers or “street-level bureaucrats” (Bourdieu in Bourdieu et al., 2002, p. 183), are part of a profession that is socially constructed in the context of contestations about its character (Thompson, 2015; Payne, 2014). One, albeit extreme prejudice towards social work, is that social work assessment is too preferential towards clientele’s needs, to reconcile itself with the practicalities of the managerial agenda, such as having to make a constrained budget work. This might be considered to be particularly the case in radical or structural strands of social work practice (Ferguson & Lavellette, 2007; Mullally, 2007). Within this, is a sense of the social work profession as an ideological and adversarial mass to be placated, disaffected by
default, through a necessarily jaundiced view of social service provision. Put more simply; some might not take Social Workers seriously, when Social Workers ask for better standards for their clients- because they expect Social Workers to do this anyway, regardless of what client’s circumstances actually are. Of course this view is disputable and disputed.

In any case, this research study has evidenced a lack of adherence and responsiveness to social work assessment in intellectual disability services. Many instances where social work assessment indicated that a service should be provided, and then it wasn’t, real harm occurred to service users and their families as detailed in the research findings. Whilst austerity measures were a reality, making a level of social suffering unavoidable (Allen, 2009), it is the extent of distress and level of unmet need outlined in this study that is unsettling.

Social workers are well placed to inform resource allocation. Particularly as social work assessment is holistic, taking account of the structural-societal perspective within person-in-environment assessment (Gray, Migley & Webb, 2012; Payne 2014). In this study it is concerning that there was little evidence of a predictable causal relationship between allocation of resources and professional social work assessment. It is therefore recommended that more meaningful regard for social work assessment be pursued in disability services as social workers in this study demonstrated a good understanding of their client’s needs as well as how funds could be better used to meet those needs.

8.3.3. Study Recommendation 7:
The socio-economic disadvantage of disabled children should be strongly considered in the context of their immediate family, if this is where they predominantly reside. This may help to avoid the misconceptualisation of presenting social problems as emergent from the child’s impairment(s) alone, rather than arising from poverty or material deprivation as the real root cause (Emerson 2004).

Findings of the present study appeared to illustrate and confirm existing literature. This was with respect to a strong familial aspect to the socio-economic disadvantage of disabled children (Cullinan, 2015; Emerson et al., 2010). Furthermore, the potential for Emerson’s (2004) observation to be accurate- that intellectual disability may be wrongfully blamed for behavioural problems attributable to poverty issues such as hunger, was further illustrated by findings herein.

The disability self advocacy movement has been embodied in the aphorism and recurrent rally cry, 'nothing about me, without me' (Shakespeare, 2014). Furthermore, through research there is growing recognition that children can provide valid and valuable views and opinions to inform service provision and policy and contribute to a more democratic society (Aubrey & Dahl, 2006; Badham, 2004; Ireland & Holloway, 1996; Kahn, 2001; Matysiak, 2001; Preece, 2002; Turner, 2003; Watson et al., 1998). As such it has become the new orthodoxy to involve children in such matters (Badham, 2004; Boylan & Dalrymple, 2009; Turner, 2003; Ward, 1997; Watson et al., 1998). This can be
framed within an advancement of the children’s rights perspective, and within this, regard for the right to be heard and included (Kilkelly, 2002).

Paternalistic expert-led approaches to disability have been predominant in Ireland’s service history, progressively reconfiguring from medicalised individualistic conceptualizations of disability towards a social model in recent years (Skalecka, 2014). Alongside this, the emergent policy discourse around promoting person-centered approaches looks to personalize service provision with individual needs placed at the centre of assessment (Department of Health, 2012).

Yet despite clear advancement, practically and economically speaking, the socio-economic disadvantage of disabled children who live with their families is for the most part sustained and produced within that family system (Cullinan, 2015; Emerson et al., 2010). As evidenced in this study, children and young people are often oblivious to the full mechanics of their family’s financial maintenance. Furthermore they may be purposefully shielded from financial concerns by their parents who wish to spare them distress.

In light of this, the present study determines that progressive moves that place the child at the centre of planning in their lives (Department of Health, 2012; HSE, 2011), and that honor the child’s right to be heard and included (Kilkelly, 2002), should be not be allowed to sideline assessments of family circumstances in the interest of the child. Rather, family functioning should remain an important variable in the assessment of the child’s presentation as is the case in traditional social work assessment (Redmond & Jennings, 2005). This also takes account of Shakespeare’s assertion that, there is a long overdue recognition of the affect of disability on families, and not just focuses on oppression and exclusion (Shakespeare, 2014).

8.4 Aim 3: To critically inform practice and policy development for intellectually disabled young people with a view to informing a partnership approach to service provision

The final aim of this study relates to a partnership approach to service provision: More specifically, to critically inform practice and policy development with respect to the same. The point was to develop recommendations based on the study’s findings that inform a partnership approach (but not necessarily promote it). Thus far recommendations listed in this chapter have aspired to this, most notably the recommendation yet to come. Discussion of this final aim is informed by findings of the Framework Analysis and findings of the BNIM in combination.

Rather than rigidly adhering to the aim, the intent was to appraise its usefulness also in light of subsequent data collection and analysis, remaining critically reflective, without maintaining any allegiance to the aim. In this way, the purpose of research aims are to structuralize and state intent (Becker, Bryman & Ferguson, 2012; Bryman, 2015; Silverman, 2015) rather than manipulate data presentation to attain their satisfaction. Nonetheless, in retrospect, partnership seems to have held its own, as a suitable aspiration for service provision, and therefore a valuable point of discussion, in the context of findings of this study. Under the
8. Discussion Part 2: Overall Analysis

First, it should be made explicit that this study’s findings support a partnership approach to service provision as a justifiable and progressive strategy, but not as a replacement for other existing strategies disabled service users and their allies already take up. It is beyond the scope of this study to make such assertions. The value and role of an explicit rights based approach to disability (Degener, 2016) for instance, or other progressive and substantial modes of disability activism and scholarship such as the decisive social model and associated socio-political activism (Barnes, 2012; Goodley, 2004; Oliver & Barnes, 2012; Oliver 1983; 2009; 2013) are clear. Yet, as noted in Goodley (2016) and Shakespeare (2014) austerity has reformulated disability, requiring tailored and revised responses. It would seem that as the individualising nature of neoliberalism and associated precariousness gains ground (Conneelly & Garrett, 2012; Goodley, Lawthom & Runswick-Cole, 2014) approaches emphasising social solidarity, support, and mutual interdependence such as those that embrace partnership have become of increased relevance. More significantly it would seem that Irish disability policy and service administration already very much aspires and configures itself toward partnership with children and families, however the findings of this study clearly indicate that partnership as a strategy and principle is not considered to be realised on the ground level. The final recommendation captures this;

8.4.1. Study Recommendation 8:
Political entities, disability service providers and policy makers should endeavour to work in partnership with intellectually disabled young people and their families in a manner that meaningfully translates to sufficient cohesion of viewpoints

In its entirety, the final recommendation stems from particular study insights, as follows;

- Social disadvantage of intellectually disabled young people was demonstrated to be a complex and multifaceted familial issue. Partnership with children and families is required to gain sufficient information for informed assessment of circumstances and needs.
- At times families didn’t feel that their lived reality was understood in the context of austerity.
- At times families felt as though they were left in the dark in terms of information provision regarding services and supports.
- Families saw a need to behave in an oppositional manner towards disability service providers and politicians in order to get basic needs met.
- Families were having to resort to covert and/or dangerous practices, or were consigned to circumstances that they could not cope with, as a result of lack of funding allocation to required services and/or supports.
- Prioritisation of immediate need that shifts from preventative intervention to crisis driven service provision, may have incurred greater expenditure as it lead to more costly interventions and most critically, greater toll for families.
- Funding application process for services was a particular problem area, and could be drawn out and convoluted. In the interim, some families and
service users were consigned to a prolonged lived experience of considerable distress, within which exposure to substantial risk may have been an aggravating factor.

A comprehensive and meaningful operationalisation of a partnership approach to service provision and disability policy, may help to ameliorate some of the specific concerns as noted above. In the conclusion chapter to follow, some reflection on the study’s theoretical frame and the contribution it has made will shed further light on what partnership might entail.

8.5 Conclusion

The foci of this chapter were eight recommendations framed within consideration of the study’s aptitude for meeting its original aims. Perhaps a tentative intellectual ambience is most appropriate for untested phenomena, and in this regard, the lack of research on the topic at hand (Flynn, 2011; Flynn, 2017b) has encouraged broader and fewer recommendations. Nevertheless, further research of the present kind has been called for within such recommendations, whilst overall recommendations here offer a vital starting point to remedy the serious concerns and practical challenges identified by this study’s findings.

Study Recommendation 1 supported individualised and person-centred approaches to service provision that incorporate regular review. Yet, troublingly it was conceded that austerity may in reality have prompted a backward regression towards the ethos of a more traditional group-based model of service provision. In this context Study Recommendation 2 recognised that negative emotion was a critical part of the lived experience of economic recession. Within this, there was a perception that policy makers and politicians did not understand the lived reality for intellectually disabled young people and their families, and the recommendation was, that consideration ought to be given to addressing this.

Study Recommendation 3 sought to place intellectually disabled children and their families at the top of Government priorities. Correspondingly, Study Recommendation 4 sought to produce better data to inform public and policy debates in relation to services and supports for intellectually disabled children and their families. Notwithstanding existing criteria such as transparency and equity (Department of Health, 2012) Study Recommendation 5 prescribed that decisions regarding the allocations of funds, services and supports by disability services should be made on the basis of a sufficiently comprehensive understanding of service user’s circumstances. Alternatively, Recommendation 6 sought more meaningful regard for social work assessment.

In drawing to a close, the second last of the recommendations advised that socio-economic disadvantage of disabled children should be strongly considered in the context of their immediate family, if this is where they predominantly reside. The ambition was to avoid the mis-conceptualisation of presenting social problems as emergent from the child’ s impairment(s) alone, rather than arising from poverty or material deprivation as the real root cause (Emerson, 2004). Finally, Study Recommendation 8 prescribed that political entities, disability service providers and policy makers should endeavour to work in partnership with intellectually disabled young people and their families in a manner that meaningfully translates to sufficient cohesion of viewpoints.
Overall, eight recommendations are provided as a reflection of the generalisable nature of some aspects of the lived experience. The importance of such recommendations is significant; perhaps best evidenced through the severity and complexity of suffering depicted in study findings.

The final chapter of this thesis follows, and is brief. It reconsiders the central research question, in the context of what we now know. Brought to bear is the Affirmative Non Tragedy Lens -to further unravel the tangled mass of contradictions between resource constraints, service user’s needs, stakeholders, and benefactors: And to impress upon us some necessary closure for the arising lived reality that seemed at times to have been so unsympathetic.
9. Conclusion Chapter

This PhD dissertation has been concerned with responding to its central research question:

How have intellectually disabled young people, and their families, who avail of services from the disability sector, experienced the economic downturn?

It went about this through the application of two methods; primarily, the Biographical Narrative Interpretative Method (BNIM) and secondly, Framework Analysis. An Affirmative Non-Tragedy Lens was explicitly acknowledged. At the same time, the inclusion of intellectually disabled children and adults, and their families, from study design through to dissemination phases, was addressed by way of an Advisory Committee. Arising from this research was varied qualitative findings. These findings helped to inform the provision of eight recommendations.

The significant value of this study’s findings is evident in many ways. Consider that in order for a problem to be solved, it must first be understood. This is particularly the case when it is a complex problem, such as socio-economic disadvantage. Trying to solve such problems without fully understanding them first, wastes time, money and most regrettably as shown in study findings, can leave families bitter and distressed. This study uncovered the little understood patterns, processes and lived experience of socio-economic disadvantage for the most vulnerable children in economic recession. It did so in the context of the greatest period of recession in almost a century before, when it is already known that children have been worse impacted. In doing this, the study’s findings allow services and policies to better understand the disadvantage they seek to resolve, and therefore to adopt an evidenced based and informed approach in order to more effectually tackle the significant and complex problem of disadvantage for these families. This is particularly critical as study findings evidenced that existing government responses were at times insufficient and ill-fitting. At the same time, families felt their circumstances were misunderstood. Furthermore, services become ineffective if families and service users are not invested in them. Better connection to family’s lived reality needs to be felt by those who are suffering. Viewing and commissioning research such as the present study offers a starting point for concerned service providers and funders.

The value of the study findings is also evident in providing disability advocates, activists and artists with data to support and inform their work. Furthermore, they enlighten the research community and wider population by filling a significant gap in the existing knowledge base about the little known impact and experience of recession for a distinctly socio-economically vulnerable group. Finally, whilst this study was concerned with a particular phase of recession, its findings teach us about much more than that, for instance, about how poverty is experienced and sustains itself, and how childhood intellectual disability affects family life.

Ultimately, study recommendations support a partnership approach to policy development and service provision with, and for intellectually disabled young people and their families. As this thesis draws toward an end, perhaps it should be acknowledged that with this comes the potential for an element of insensitivity.
Partnership (rather than political activism or an explicit rights based approach) sifts out the grit of opposition, settling rather, for the sediment of accord: In this way, partnership implies an element of letting go, of forgiving and forgetting.

Of course, with this is raised the question of culpability, and certainly if one is to consider the negative impact and lived experience of austerity detailed herein, then there should be no pardon begged. Fiscal decline was experienced harshly; to a sizeable degree it was the illegitimate brainchild of Machiavellian bankers and profiteers. Exotic and predatory lending practices, featherweight market regulation, and obscenities of pecuniary speculation were not the preserve of this study’s participant population. Instead, Government and financial elites retain much culpability (Allen, 2008; 2009; Barry & Conroy, 2012; Marx & Engels, 2012). As deceit was the rubric of Celtic Tiger economics, from minor transactions to capitalism’s grand claim of self-regulation—at times little more was appreciable than vulgar acts of subterfuge (Allen, 2008; 2009). In this context, it is acknowledged that aesthetically, partnership may appear to afford impunity for misdemeanours that intellectually disabled young people and their families had neither part nor parcel in.

Yet, it is Shakespeare’s (2014) contention that disability studies has considerably focused upon oppression and exclusion of disabled people rather than focusing upon building partnership and alliance between disabled people, their allies, and non-disabled people. Similarly, actualising our Affirmative Non-Tragedy Lens (French & Swain, 2000; 2008) would seem to require an element of moving on from transgressions of disablement, of letting go of the wrongs, and shifting focus towards the rights.

As the longevity of recession revealed its complex character (Allen, 2009; Barry & Conroy, 2012) the individualising and free forces of the market further deconstructed social bonds (Dodd, 2016). Social solidarity seemed to diminish somewhat in the context of draconian austerity measures (Allen, 2009; NESC, 2013), and prevailing individualising forces of precarious hegemonic neo-liberalisation (Conneely & Garrett, 2015) that offered little shelter from personal and sovereign debt. Simultaneously, paternalistic welfare states in the context of the neo-liberalist project (Grover & Soldatic, 2013) still ruminated upon disabled self-advocate’s call for direct payments (Mladenov, 2015). This context is perhaps one of opposition rather than confederation, ostensibly packaged by Irish Government as a necessary ‘sharing of the pain’ that sought to legitimise stringent and avoidable austerity policies (Allen, 2009).

Yet, perhaps the ministerial adage ‘we are all in this together’ (Allen, 2009) holds potential as a rubric of another kind: A reconfiguration from blatant inaccuracy, to ideological roadmap. Within this, a partnership approach to disability services is perhaps well rehearsed in disability policy-albeit implicitly (Department of Health, 2012; HSE, 2011; NESC, 2012); and certainly to a significant extent must be realised in practice by now. In this way, working in partnership with disabled children and their families to develop and operationalize services and policy, seems almost too rudimentary to be worth proposition, or indeed reiteration, as the case may be.
Yet the particular contribution of this study is that it justifies a partnership approach ultimately because findings showed that disabled young people and their families were competent experts on their own lives: Nevertheless, during economic recession, participants in this study were troubled by a sense of being under supported, under consulted and misunderstood. Partnership was therefore not meaningfully perceptible at a grass roots level, despite the aspirations, and the rhetoric alike. In this context, it is suggested that the recommendations of the study offer a starting point to more meaningfully build partnership between intellectually disabled young people, their families, service providers and policy makers.

An affirmation of disabled lifestyles, in line with the operation of a Non-Tragedy Lens (Swain & French, 2000) is reassuring in the context of the precarious nature of neoliberalist capitalism and fragility of the corporeal ideal. Here, in the context of an overarching CDS perspective, disability teaches us how all people might best react to conditions of austerity, embracing innovation rather than melancholia as a defining feature of disability.

In this way, the particular brand of partnership sought should not be one based on compliance between the ‘able-bodied’ and ‘disabled’ (and allies), reinforcing a false and outdated dichotomy between the two that ‘others’ disabled people. Instead, incorporating CDS and ableism theory, disability becomes the site from which to problematise the nature of all human life and question able-bodiness, rather than disability, in times of austerity (Campbell, 2008; 2009; Goodley, 2013). In doing so, one can begin to disavow dependency as a feature of disability, in favour of its proper nature, as an expression of the interdependence of all human life.

Concluding this on more personal level, the completion of this PhD would not have been possible without the input and work of disabled participants, advisors and many others who assisted and supported me. As with so many tasks in the modern capitalistic world (and its globalised markets), success at all phases of this research seemed to arise from collaboration, rather than independence and autonomy. This is ironic given the value placed on the latter by our modern neoliberal economy.

Nine disability self-advocates, through this study’s final advisory committee meeting, consulted on the dissemination of this study’s findings. It was suggested that verbal reports to self-advocacy groups on study findings combined with written reporting to Government and media, would best ensure findings put change into effect. Upon concluding this thesis, it is to these plans that I now look for my next assignment.
Appendix I

Detailed overview of the particular application of BNIM for data collection and analysis in this study.

The following steps were undertaken for each of the three BNIM cases.

<table>
<thead>
<tr>
<th>Data Collection.</th>
<th>BNIM task carried out.</th>
<th>Purpose of task.</th>
<th>Actions undertaken.</th>
<th>Source of information used to complete the task:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop SQUINs.</td>
<td>Develop a SQUIN for parent participants, young person participants (taking account of intellectual disability), and staff participants.</td>
<td>Consultation with advisors and literature.</td>
<td>Assistance from Tom Wengraf. Further developed through Advisory Committee, pilot study, supervisor, and advice of other researchers.</td>
<td></td>
</tr>
<tr>
<td>Advisory Committee meeting one.</td>
<td>To achieve user participation and integrate disability awareness into data collection. To advise on SQUIN, recruitment, consent and other study materials.</td>
<td>Ethics approval and assistance of external agency. Organisation, minute taking and chairing of meeting.</td>
<td>Advise of parents/guardians of intellectually disabled young people, and intellectually disabled young people and adults.</td>
<td></td>
</tr>
<tr>
<td>Pilot study.</td>
<td>To test the SQUIN and feasibility of using BNIM with intellectually disabled young people.</td>
<td>Pilot study interview raised some concerns leading to amendment to recruitment strategy but no change to SQUIN required.</td>
<td>SQUIN.</td>
<td></td>
</tr>
<tr>
<td>BNIM interviews conducted. Lamh hand signing system utilised in</td>
<td>To record qualitative interviews.</td>
<td>In most cases a second interview was undertaken,</td>
<td>SQUIN.</td>
<td></td>
</tr>
<tr>
<td>Appendix I</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Breandan’s case.**

| Incorporating sub sessions 1, 2 and 3. |

**Experiential debriefings.**

| To allow for non-linguistic data recording. |
| One hour of debriefing notes taken immediately after interview one, again after interview two, after first listening to the tape, and also after finishing transcription. |
| Researcher’s personal experience. |

**Verbatim transcription of interviews.**

| To create a transcript for each recorded interview. |
| Type dialogue adhering to Wengraf’s guidance (e.g. methods of recording non-verbals). |
| Dictaphone recordings. |

**Track one (lived life) of twin track interpretation procedure.**

<table>
<thead>
<tr>
<th>BNIM task carried out.</th>
<th>Purpose of task.</th>
<th>Actions undertaken.</th>
<th>Source of information used to complete the task:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commence diary.</td>
<td>To record any researcher hypotheses, impressions, cross case comparisons that come to mind during analysis process.</td>
<td>On-going diary entries.</td>
<td>All materials and experiences throughout the research process.</td>
</tr>
<tr>
<td>Advisory Committee meeting two.</td>
<td>To achieve user participation and integrate disability awareness into data analysis.</td>
<td>Ethics approval and assistance of external agency. Organisation, minute taking and chairing of meeting.</td>
<td>Advice of parents/guardians of intellectually disabled young people and, intellectually disabled young people and adults.</td>
</tr>
<tr>
<td>Construct a B.D.C. for each case.</td>
<td>To establish and record the chronological order of ‘facts’</td>
<td>Researcher extracts and locates biographical</td>
<td>1. External sources such as newspapers or published</td>
</tr>
<tr>
<td>Lived Life Interpretative Panel.</td>
<td>To conduct a kick start interpretative panel that generates structural, experiencing, counter, tangential and following hypotheses.</td>
<td>Future blind chunk by chunk presentation of data to panellists. Panel conducted, hypotheses generated. Written synopses constructed of each case by researcher and panellists after panel. Key words and images also discussed and recorded.</td>
<td>1. Data chunks from verbatim transcript/ B.D.C.</td>
</tr>
</tbody>
</table>
| Analysis of phases and turning points of the lived life. | To understand the nature of the lived life as characterised by important phases and turning points. | This analysis was recorded in a written document by way of narrative summary for each case. | 1. Panel flip chart notes. 2. B.D.C. 3. Written synopses of ‘synthetic understanding’ of case completed by all panellists.
### Biographical Data Analysis (B.D.A.)

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Verbatim transcript.</td>
</tr>
<tr>
<td>2</td>
<td>B.D.C. (Biographical Data Category).</td>
</tr>
<tr>
<td>3</td>
<td>Information obtained from historical research.</td>
</tr>
<tr>
<td>4</td>
<td>Information generated from panel analysis including written synopses after panel.</td>
</tr>
<tr>
<td>5</td>
<td>Relevant notes.</td>
</tr>
</tbody>
</table>

To address a defining anxiety of the socio-biographical study: To retain links between the socio (society or sociologically defined contexts) and the biographical (individual) (Chamberlayne, Rustin & Wengraf, 2002).

At this point significant and thorough research is undertaken into political, macro-economic, cultural, social and other important contextual influences on the life over the particular time period lived. This is recorded in a document for each case called ‘broad historical-societal context research’.

The researcher then goes back and amends the B.D.C. and the original transcript after analysis of information generated from the panel.

The B.D.A. is written up in a narrative summary document for each case entitled, ‘current understanding’.
Before moving to Told Story track in the twin track interpretation procedure.

<table>
<thead>
<tr>
<th>BNIM task carried out.</th>
<th>Purpose of task.</th>
<th>Actions undertaken.</th>
<th>Source of information used to complete the task:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Creating an imagining narrative summary.</td>
<td>Researcher hypothesises and imagines the various ways that some-one who lived their life as outlined, might then tell their story.</td>
<td>This imagining and hypothesising was recorded in a narrative summary document for each case.</td>
<td>1. B.D.C.  2. B.D.A.</td>
</tr>
</tbody>
</table>

Track two (told story) of twin track interpretation procedure.

<table>
<thead>
<tr>
<th>BNIM task carried out.</th>
<th>Purpose of task.</th>
<th>Actions undertaken.</th>
<th>Source of information used to complete the task:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Text Structure Sequentialisation (T.S.S.)</td>
<td>To establish the underlying structure of the told story within the text of the transcript.</td>
<td>Structural and topic changes in the text are identified according to: 1. When the speaker changes, and when: 2. The topic changes, and when: 3. The TextSort changes. The BNIM textsort typology at the time of this research study outlined 6 types of Textsort:</td>
<td>1. Dictaphone recording.  2. Verbatim Transcript.</td>
</tr>
<tr>
<td>Told Story Interpretative Panel.</td>
<td>To open the researcher to new potentialities regarding the told story. To generate multiple hypotheses, and move the researcher</td>
<td>Future blind chunk by chunk presentation of data to panellists. Kick start interpretative panel generates, multiples, strengthens or</td>
<td>1. T.S.S.</td>
</tr>
<tr>
<td>away from the present or now perspective on the story. To address researcher bias.</td>
<td>disproves the following forms of hypotheses; structural, experiencing, counter, tangential and following. Written synopses of each case by researcher and panellists after panel. Key words and images also discussed and recorded.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wengraf (2001) identifies some key questions to pose during the panel: 1. <em>At this point, why does she/he make that point about the topic in that way, at this time? What could she/he have said but didn’t?</em> 2. <em>Why is the researcher presenting this</em></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Teller-Flow Analysis (T.F.A.f) | To uncover the diachronic process of the told story. | Researcher constructs T.F.A. through analysis of materials and also writes up a narrative summary of this in a document. | 1. All information generated during and immediately after panel.  
2. Transcript.  
3. T.S.S.  
4. Tape |
| Appendix I |
|------------|--|---|
| **Microanalysis Panel.** | To look in great depth at any intriguing potentialities for learning or oddities in the text. | Similar to previous panels, future blind chunk by chunk presentation of data to panellists. Data taken from puzzling section of text. Kick start interpretative panel generates, multiples, strengthens or disproves; structural, experiencing, counter, tangential and following hypotheses. Written synopses of each case by researcher and panellists after panel. Key words and images also discussed and recorded. |
| **Thematic Field Analysis (T.F.A.-s)** | Taken from the now perspective, thematic fields applied to data through structural analysis. | All previous analysis undertaken on this track analysed and thematic fields generated and applied. |

| 1. Transcript |
| 2. T.S.S. |
| 3. Transcript |
| 4. All information generated during and immediately after told story, and microanaly |
## Appendix I

<table>
<thead>
<tr>
<th>Process</th>
<th>Purpose</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symbolic images created for told story.</strong></td>
<td>To provide visual or pictorial illustration of essence of told story.</td>
<td>Image created by researcher: Example for Siobhan’s case:</td>
</tr>
<tr>
<td><strong>Development of BNIM 4 column summary.</strong></td>
<td>To create a thinking aid to support the researcher in later construction of BNIM case summary.</td>
<td>Input data into framework as per appendix 2.</td>
</tr>
<tr>
<td><strong>Development of a page of ‘selected and reorganised quotations.’</strong></td>
<td>To act as a thinking aid for researcher in writing up BNIM analysis.</td>
<td>Researcher takes out the key quotations and orders them chronologically on a page for each case.</td>
</tr>
</tbody>
</table>

1. Socio-historical research information.
2. Researcher’s now holistic sense of the evolution of subjectivity of the person as they moved through their lived life to achieve their now perspective.
3. B.D.A and B.D.C.
4. T.F.A.-f
5. T.F.A.-s

1. Transcript
### Constructing History of the Case-Evolution.

<table>
<thead>
<tr>
<th>BNIM task carried out.</th>
<th>Purpose of task.</th>
<th>Actions undertaken.</th>
<th>Source of information used to complete the task:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constructing a ‘History of the Case-Evolution’.</td>
<td>To marry together all previous strands of analysis, ‘particularising whilst still generalising’, and taking account of socio-historic context and historical subjectivity (combining the individual and the societal, as well as the lived life and told story).</td>
<td>History of the Case-Evolution is written up by the researcher in a narrative summary document (extra/optional). In addition to this the researcher separately wrote up the case evolution in a chapter of the thesis (chapter 6).</td>
<td>All documents and recordings.</td>
</tr>
</tbody>
</table>

### Cross Case Comparison.

<table>
<thead>
<tr>
<th>BNIM task carried out.</th>
<th>Purpose of task.</th>
<th>Actions undertaken.</th>
<th>Source of information used to complete the task:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cross case comparison</td>
<td>To create a chapter of the thesis that offers a theoretically informed answer to the research question.</td>
<td>The researcher goes back over all materials and amends any errors. The researcher compares the three BNIM accounts against one another using ‘Generalising whilst still Particularising Theory’. Wengraf advises that the product of cross</td>
<td>Case accounts.</td>
</tr>
</tbody>
</table>
## Case Comparison

Case comparison is a theoretically informed answer to the research question. Cross Case Comparison is presented in chapter 7 in terms of a language and style adapted for the reader population.

## Advisory Committee Meeting Three

<table>
<thead>
<tr>
<th>Advisory Committee Meeting Three</th>
<th>To achieve user participation and disability awareness in dissemination of findings.</th>
<th>Ethics approval and assistance of external agency. Organisation, minute taking and chairing of meeting.</th>
<th>Advise of parents/guardians of intellectually disabled young people, and intellectually disabled young people and adults.</th>
</tr>
</thead>
</table>
### Appendix II

**BNIM 4 Column: Aoife**

(societal context, BDA phases, subjectivity phases, TFA) for BNIM case summary

<table>
<thead>
<tr>
<th><strong>Objective Data</strong></th>
<th><strong>Subjective Data</strong></th>
<th><strong>Thematic Field Analysis – Structural analysis of the telling of the told story</strong></th>
</tr>
</thead>
</table>
| **Broad historical societal context** | **Biographical Data Analysis: Phases of the lived life** | **Subjective phases-mutating subjectivity at the time of experiencing (hypothesis)** | 1. Son first born, couldn’t talk  
2. Most difficult years  
3. Return of good times, re-employed  
4. Coping without services and supports  
5. Trouble with sons development  
6. Other parents and friends, the real resource  
7. Afraid about the future  
8. The most difficult years, bereavement and poverty  
9. Battling for SLT  
10. Battling for support services and entitlements  
11. Getting an extension  
12. Left in the dark, needed practical information  
13. The time CAS was there for us  
14. Realising it all comes down to money  
15. Trip to Los Angeles  
16. Trip to Lourdes  
17. Realising it all comes down to money  
18. Parent led organisation |
| Early 1990’s- Ireland poor by European standards.  
1992: Fianna Fail largest political party until 2011  
Mid 1990s- Celtic Tiger economy booms, between 2001 and 2003 working class protest against the inequality of the Celtic Tiger - resistance against bin charges –on a national scale social partnership was prevailing  
2005: Leas Cross Scandal leads to HIQA establishment.  
2007: Housing bubble bursts leading to significant debt in population.  
Phase 2: Loss: Mother’s death, depression, fertility difficulties, disability: 1998-2003  
1998: Aoife’s mother dies, depression commences 1999- Son Brendan born whilst going through adoption, diagnosis disability, 2001- Brendan starts to walk, but still not talking | Phase 1: Childhood, follows middleclass traditional pathway to marriage, home ownership and children. Then things declined when “we moved here in May 1997 and 11 months later my mother died the following April . . .half way through the foreign adoption and then we had Brendan”  
Phase 2: Grasping Brendan’s diagnosis and potential inability to speak Not talking “its nearly worse than Down Syndrome . . . that was hard that was really really hard.”  
Phase 3: Working hard at developing Brendan’s | |
phase of economic decline commences since the great depression of the 1930’s, austerity protests begin, emigration to destinations such as Australia increase, unemployment increases dramatically, stringent and cumulative cutbacks to disability services commence 2009- recruitment embargo put in place, SLT’s not being replaced when on leave. 2010- Croke Park Agreement regarding public sector working conditions/pay. 2013- HIQA standards for disability services published. 2013-Haddington Road Agreement regarding public sector working conditions/pay. 2014- Economy starts slowly recovering. 2014- CEO pay scandal. 2014- Figures estimate approximately half the SLT exist that are required countrywide. 2015 –Special Olympics world summer games held in LA.

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 4: Getting no help from services “CAS do nothing absolutely nothing I could sit here and talk about it forever all the negatives” “with respite you know trying to get a night he hadn’t gotten respite since 2009 . . .you know so everything is a battle.”</td>
<td>speech Gets private speech and language Move school to access it. Advocating, awareness raising, fundraising “we worked really hard on it over the years.”</td>
</tr>
</tbody>
</table>

**Phase 5: ‘toughest years’- loss of the three parents and the sole breadwinners job**

“The death of three parents . . . Rick’s father in 2008, his mother in 2011 and then my father in 2014” “Rick lost his job in the same week as his mother died” “turned out he was out of work for three years . . . .I found it really really difficult to have him here.” “there was alot of worries . . .how to put food on the

provide support where CAS should have
19. Not people, there’s just no provisions
20. Worried about the future and will
21. Couldn’t work due to sons disability
22. Cut off social welfare allowance
23. Couldn’t work due to sons disability
24. Fighting back-advocacy and fundraising
25. Mother died at time of foreign adoption
26. How CAS became involved
27. Challenge of getting SLT- Main thing
28. Lack of respite
29. Blossom Ireland-good work]
30. Son’s disability still preventing her from working
31. Husbands unemployment lucky had mortgage protection
32. Huge worries about money
33. Sons preoccupation with granddad passing
34. Older children’s circumstances
35. Where husband and Aoife are from
36. Couldn’t get respite
37. Sons preoccupation with granddad passing
38. Breandan not prioritised for SLT anymore
Appendix II

<table>
<thead>
<tr>
<th>Very brief summary of socio-historical context</th>
<th>Very brief summary of BDA pattern</th>
<th>Very brief summary of inferred pattern of mutating subjectivity over the lived life period</th>
<th>Very brief summary of TFA and how it related to the interview as a whole</th>
</tr>
</thead>
</table>
| Central factor has been massive economic change through economic depression, creating unemployment and emigration. Also increased state involvement in disability services. | Getting married, buying first property, having children, mother passed, infertility, son’s diagnosis Down Syndrome, son not speaking, advocating and fundraising, loss of 3 parents, husbands unemployment, then his new career. LA trip. | 6 Phases:
Phase 1: Childhood, follows middleclass traditional pathway to marriage, home ownership and children.
Phase 2: Grasping Breandan’s diagnosis and potential inability to speak.
Phase 3: Working hard at developing Breandan’s speech.
Phase 4: Getting no help from services.
Phase 5: ‘toughest years’- loss of the three parents and the sole | Main topics arising within Thematic Fields were:
1. Lack of Speech and Language Therapy and son not speaking.
2. Family passing away R.I.P.
3. CAS didn’t support us
4. Help from friends and other parents
5. Parent led local organisations
6. Husbands unemployment, her unemployment
7. Lack of support from Government, services outside CAS |
<table>
<thead>
<tr>
<th>breadwinners job.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 6:</strong></td>
</tr>
<tr>
<td>Husbands reemployment and coping with loss- wanting to move on in a positive way.</td>
</tr>
</tbody>
</table>
# Appendix III

## Excerpt from a text structure sequentialisation with thematic field analysis

### Aoife - Sequentialisation

<table>
<thead>
<tr>
<th>Page/line no</th>
<th>Line bulk</th>
<th>Text sort/speaker</th>
<th>Gist- brief indication of content</th>
</tr>
</thead>
<tbody>
<tr>
<td>2/10 - p1</td>
<td>8</td>
<td>EVAL/report</td>
<td><strong>TOPIC: 1. Lack of Speech and Language Therapy and son not speaking.</strong></td>
</tr>
<tr>
<td>10/15 - p1</td>
<td>5</td>
<td>narrative</td>
<td><strong>Thematic Field Analysis: 1. Son first born, couldn't talk.</strong></td>
</tr>
<tr>
<td>22/31 - p1</td>
<td>9</td>
<td>report/GIN</td>
<td><strong>Level 2: Not talking almost worst part of son's disability diagnosis. Level 1: &quot;nearly worse than Down syndrome&quot;</strong></td>
</tr>
<tr>
<td>32/34 - p1</td>
<td>2</td>
<td>eval</td>
<td><strong>Level 2: Reports chronologically on series of difficult life events</strong></td>
</tr>
</tbody>
</table>

### Main Topics:

1. Lack of Speech and Language Therapy and son not speaking.
2. Family passing away R.I.P.
3. CAS didn’t support us.
4. Help from friends and other parents.
5. Parent led local organisation s.
6. Husbands unemployment, her employment.

### Main Subject Position:

1. Mother left stranded
### Thematic Field 3: Return of good times, re-employed.

<table>
<thead>
<tr>
<th>Page Range</th>
<th>Argument</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>34/37</td>
<td>arg</td>
<td>Level 2: Claims that nominated years were hardest and then provides evidence Level 1: &quot;and then in those years&quot; and lists difficulties</td>
</tr>
<tr>
<td>37/45 - p1/p2</td>
<td>arg/DESC</td>
<td>Level 2: Explains about grandfather passing and not same for children Level 1: &quot;they don’t get it they don’t understand in the same way&quot;</td>
</tr>
</tbody>
</table>

### Thematic Field 4: Coping without services and supports.

<table>
<thead>
<tr>
<th>Page Range</th>
<th>Argument</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>48/59 - p2</td>
<td>arg/EVAL</td>
<td>Level 2: explains how she must give more time to disabled son Level 1: &quot;I think it is paying I think it is paying off&quot; evaluates that more help was needed from CAS</td>
</tr>
<tr>
<td>59/66 - p2</td>
<td>report</td>
<td>Level 2: Explains son had to change school because Level 1: &quot;couldn’t get the support&quot;</td>
</tr>
</tbody>
</table>

2. Bereaved daughter and wife and bearer of hard financial times.
3. Mother coming to terms with son's Down Syndrome.
4. Mother wishing to put hardship behind her.
5. Alpha mother who will fight for what her children need.

TOPIC 1: Lack of speech and language therapy and son not speaking and TOPIC 2: CAS* didn’t support us.

Mother left stranded without services, funding or supports for son.

Mother left stranded without services, funding or supports for son.
Sample of future blind hypothesising by Told Story Panel on a datum chunk for Aoife’s case.

For this panel, a total of eight datum chunks similar to below were presented to panellists, gradually building a picture of Aoife’s told story. Throughout hypothesising, a number of Structural Hypotheses (S.H.) were developed and disproven until panellists finally agreed on the following finalised S.H. for the Told Story:

“Aoife has reached a psychological maturity in understanding the impact of recession, through fitting elements of her life into a coherent pattern and drawing conclusions about her ‘self’: the process has been centred around friends and family.”
Datum chunk presented to Told Story Panel.

<table>
<thead>
<tr>
<th>Appendix IV</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emmmm but that was the toughest years.</strong></td>
</tr>
<tr>
<td><strong>E.H. 1: Experiencing bad memories from a tough past</strong></td>
</tr>
<tr>
<td>F.H.1.2. Brings out resilience in her.</td>
</tr>
<tr>
<td>F.H.1.3 She mends relationships.</td>
</tr>
<tr>
<td>F.H.1.4. Strengthens character.</td>
</tr>
<tr>
<td>F.H.1.2. Neither confirmed nor disproven by future datum.</td>
</tr>
<tr>
<td>F.H.1.3. Confirmed.</td>
</tr>
<tr>
<td>F.H.1.4. Confirmed.</td>
</tr>
<tr>
<td><strong>C.H.2: Experiences understanding</strong></td>
</tr>
<tr>
<td>F.H.2.1. Understands her past experiences better.</td>
</tr>
<tr>
<td>F.H.2.2. Understands her relationship journey.</td>
</tr>
<tr>
<td>F.H.2.3. Comes to understand the present in light of the past.</td>
</tr>
<tr>
<td>F.H.2.4. Conceptualises her family as survivors and not victims.</td>
</tr>
<tr>
<td>F.H.2.5. Comes to admire the past and admire their collective strengths.</td>
</tr>
<tr>
<td>F.H.2.2. Confirmed.</td>
</tr>
<tr>
<td>F.H.2.3 Confirmed.</td>
</tr>
<tr>
<td>F.H.2.4. Confirmed.</td>
</tr>
<tr>
<td>F.H.2.5. Confirmed.</td>
</tr>
<tr>
<td><strong>T.H.3: Experiences psychological distance from the past</strong></td>
</tr>
<tr>
<td>F.H.3.1 Moves away from having a strong focus on finances.</td>
</tr>
<tr>
<td>F.H.3.2 Now views the past like it is the past of another person.</td>
</tr>
<tr>
<td>F.H.3.1. Disproven.</td>
</tr>
<tr>
<td>F.H.3.2. Neither confirmed nor disproven by future datum.</td>
</tr>
</tbody>
</table>
Appendix V:

Sample of recruitment materials: Recruitment Poster and photograph of opened pamphlet
Appendix VI:

Example of note-taking technique during interviewing on BNIM notepad
Appendix VII:

Interlude work taken from Wengraf (2015d)

7.5. Interlude work before Subsession Two:

Can you remember...any particular YYY [magic word]? How it all happened?

7.4. Example page, see also next 2 pages for discussion

FIRST. If appropriate, verbally recognise any emotional upsetness or difficulty [and only if necessary help work it through] so as to help interviewee cope with it. [This may be their difficulty or, in some circumstances, your own]

SECOND. Pause, and then move from the “emotional recognition” to N-pointed question
You said “Do you remember anything about...” 
XX- below (any more about) 
their words that particular
have you any IMAGE-feelings thoughts about that?

Mother – hit me once when I wouldn’t go to school “She hit me this; I’ve forgotten”

Mummy was angry when she was small
2a) Didn’t like it. University was very peculiar
2a1) Married in my final year
2a2) Loss of friends is a year
2a3) Missed grandfather

I’m always feeling stupid
THOUGHT/IMAGE

I always feel good in the countryside
EXAMPLE

Grandad died before I was born
TIME

Went to university and did reasonably well
PERIOD

Father – can’t recall anything

FEELINGS THEN (only if no response FEELINGS NOW)
Appendix VIII:

consent form for young people
for the study called:
'Recessionary tales: An investigation into how intellectually disabled young people, and their families, experience the current economic downturn.'
by the researcher named Susan Flynn.

Please tick the box if you agree:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="Image" /> I have read the information sheet for the study named above on this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>date _____ I have been able to ask questions about the study if I want.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><img src="image2" alt="Image" /> I understand the information I was given. I had enough time to</td>
<td></td>
<td></td>
</tr>
<tr>
<td>decide if I wanted to take part in the study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><img src="image3" alt="Image" /> I know that I can leave the study whenever I want. I know that I</td>
<td></td>
<td></td>
</tr>
<tr>
<td>will not be in trouble for this.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><img src="image4" alt="Image" /> I agree to take part in this study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><img src="image5" alt="Image" /> I want to meet with Susan who is the researcher.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><img src="image6" alt="Image" /> I might tell the researcher that I am being hurt. I might also</td>
<td></td>
<td></td>
</tr>
<tr>
<td>say someone else is being hurt. I know that if I do this then the researcher will</td>
<td></td>
<td></td>
</tr>
<tr>
<td>have to tell someone else.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of participant or child</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>___________________________</td>
<td>______</td>
<td>___________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of parent/guardian</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>___________________________</td>
<td>______</td>
<td>___________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>___________________________</td>
<td>______</td>
<td>___________</td>
</tr>
</tbody>
</table>

1 for participant; 1 for researcher; 1 to be kept with research notes

(Please note: Actual form has font size 16- resized to fit thesis)


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