# Mums' Aspirations for their Family Member with Down syndrome in Adulthood within the Context of Knowing the Rights of Disabled People

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**Abstract:**

This research studies parents' aspirations for their family member with Down syndrome in adulthood and the actions and changes required to realize those aspirations. This study also seeks to understand parents' aspirations for independent living with choice, control and any necessary supports, in the context of parents being cognizant of articles 12 and 19 of the CRPD. The research is underpinned by the social model of disability and adopts a participatory action approach, thereby seeking to both understand parents' aspirations and build knowledge among participants to facilitate their own self-determination and empowerment. Qualitative methods, consisting of two focus groups and ten follow up individual interviews, were applied.

The findings indicate that parents in this study aspire to their family member having an ordinary life through inclusion in employment and education. Parents also aspire to friendship for their family members with peers and for many parents congregated or clustered living arrangements was a realistic way of facilitating this aspiration. For others, these arrangements were institutional and excluding but the only conceivable

alternative was family support.  Therefore, this study indicates that parents' aspirations for their family members' living arrangements tend to be within the range of what parents perceived as realistic possibilities.

In this study parents' expectations were not discernibly changed by the knowledge of the CRPD.   Parents appeared not to expect the convention would deliver adequate support that would facilitate independent living entailing choice, control and autonomy and social participation with mainstream society and disabled peers.   Some parents expressed concerns about their family member's ability to make safe choices.  However, according to the parents in this study, it is the risk from society and the lack of supported options which generate parents' primary fears about choice.  In addition, for many of the parents, economic participation, a prerequisite to independence in a capitalist society, is unresolved by the convention.  Although, parent's aspirations tended to be bound by expectations, for all of the parents, in an ideal world with a valued position in society and with any necessary support for their family member, autonomy and participation as defined by the articles 12 and 19 were wanted.  However, the possibility of intimate personal relationships was an idea too far for some.

The main recommendations are: (i) legislation to address the issue of hate crime directed at disabled people, (ii) the legal right to fully funded direct payments to cover *all* aspects of social and economic participation and the right to and full access to support in managing those payments, (iii) the cessation of unpaid employment of people labelled with an 'intellectual disability' and legislation obliging the public sector to employ this marginalized group (iv) the belief that a fair system is possible.

**Contents:**

## Abbreviations

| | |
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| ANED | Academic Network of European Disability experts |
| CDLP | Centre for Disability Law and Policy, National University of Galway |
| CRPD | United Nations Convention on the Rights of Persons with Disabilities |
| CSPD | Commission on the Status of People with Disabilities |
| CICA | Commission to Inquire into Child Abuse (Ryan Report) |
| CAG | Comptroller and Auditor General |
| DCEGA | Department of Community, Equality and Gaeltacht Affairs (2010) |
| DECLG | Department of the Environment, Community & Local Government |
| DH | Department of Health, UK |
| DOH | Department of Health, Ireland |
| DOHC | Department of Health and Children, Ireland |

DSI    Down Syndrome Ireland

DSP    Department of Social Protection

DT    Department of the Taoiseach

ERG    Expert Report Group on Disability Policy

FG1    Focus Group 1

FG2    Focus Group 2

HSE    Health Service Executive

IHRC    Irish Human Rights Commission

LRC    Law Reform Commission

NDA    National Disability Authority

NIDD    National Intellectual Disability Database

SNA    Special Needs Assistant

# Chapter 1: Introduction

This research will focus on the parental struggle to attain the rights for people with Down syndrome. This study aims to build understanding of parental aspirations for their family member with Down syndrome and the social actions required to achieve these aspirations, within the context of parents knowing the rights of disabled people.  This introductory chapter will describe the background to this study, the research questions, aims and objectives, the structure of this dissertation and the terminology employed.

## 1.1 Background

The declaration by people with Down syndrome, adopted during the 11th World Down Syndrome Congress, demonstrates how people with Down syndrome demand and aspire to the right to social participation, personal relationships, employment ,financial independence, access to education and leisure, independent living and having their voice heard (Down Syndrome International, 2012). In Ireland, the right to an independent life with choice, control, access and any necessary support does not exist (CDLP, 2009).

Historically, in Ireland, predominately, people labelled with an 'intellectual disability' have been segregated and excluded from mainstream education (McDonnell, 2003), employment (Conroy, 2003), family life and mainstream living arrangements (Conroy, 2003, CDLP, 2009). This systematic and institutional segregation began in the mid nineteenth century (McDonnell, 2003) and for those people labelled with an 'intellectual disability' or with the label of the time 'chronic and incurable classes', the dominant practice was to be sent to a workhouse or 'a low grade custodial asylum' (Finnane, 1981:71, cited in McDonnell, 2003:29). By the 1950's, disabled people were sent to special schools founded by voluntary organizations which included parents (McDonnell, 2003).

Traditionally, funding is allocated to service providers by the HSE, resulting in service providers determining how funding money is spent (ERG, 2011, DECLG, 2011). Services, residential, day or medical, for a person labelled with an 'intellectual disability' are typically provided by one organisation (ERG, 2011, DECLG, 2011). The disabled person is then dependent on service providers and denied the opportunity to make choices and have

control over their own lives (ERG, 2011).  People labelled with an 'intellectual disability' are in the main excluded from paid employment, and dependent on their families (Kelly, 2011) and congregated service provision controlled by professionals (ERG, 2011).

In 2008, Ireland signed the CRPD and committed to ratifying the treaty (Houses of the Oireachtas, 2012). The CRPD, specifically articles 12 and 19, obligates states to ensure that disabled people enjoy legal capacity, the right to choose where and with whom they live, and be included in the community with any necessary supports (United Nations, 2006). Yet, for many disabled people it remains to be seen how effective the CRPD will be in realizing disabled people's rights (Jolly, 2010). According to Russell (2002) and Oliver and Barnes (2012), rights do not guarantee emancipation as they do not change society itself. In contrast to the traditional individual medical model of disability where impairment is viewed as the root cause of disability, the social model of disability asserts that impairment does not cause disability; social and economic exclusion, discrimination and oppression cause disability (Oliver, 1990).  Therefore, for Russell (2002) and Barnes and Oliver (2012) rights do not address the

'material forces' that exclude disabled people from employment and then participation in society.

However, according to the disabled people's movement, the first step to independent living is information (Jolly, undated). Knowing that an independent life should be possible is then a prerequisite to demanding and achieving that right. Dean (2003) found that young disabled people's aspirations for independent living are limited by their knowledge of the options available. Young people depended on their parents and 'care' professionals to provide information on the options available (Dean, 2003). In addition, Dean (2003) and Irwin and Ellen (2013) found that parental aspirations are closely aligned to parents' expectations of what is possible. Therefore, this study will focus on building knowledge with parents on what should be possible and then exploring their aspirations in the context of this information.

## 1.2 The Research objectives and questions

My personal interest in this study stems from my belief, that the rights of disabled people should be realized as stipulated in the CRPD (United Nations, 2006). This study focuses on the parents of people with Down syndrome as opposed to parents with a

family member labelled with an 'intellectual disability'. My reason for narrowing my focus to this group is that my daughter has Down syndrome. I am a member of DSI Cork (DSI Cork, 2010) and I hoped this would assist me in recruiting participants (see Chapter 3). More importantly, I want my daughter to have an independent life. If my daughter achieves this despite the disabling barriers that exist, then she may find herself in mainstream society without her peers who have Down syndrome, without support and the possibility of valuable relationships. My aspirations for my daughter are therefore, inextricably linked to her peers and I believe parents have a collective role in the social change required to realize independent living.

This study aims to understand parents' aspirations for their family member with Down syndrome. By sharing knowledge and understanding on the rights (CRPD) of disabled people to have choice, control, community participation and any necessary supports, it seeks to understand if that knowledge impacts aspirations. It also aims to understand how effective parents believe these rights will be in realizing their aspirations and identify what social policies and actions are required to achieve parents' aspirations for their family member. The planned outputs of this study include a dissertation underpinned by the

social model of disability, a report for parents and an accessible report for adults with Down syndrome, to be submitted to DSI for publication, in order to share the knowledge gathered during the research.

The Research questions are:

1. What are parents' aspirations for their family member with Down syndrome in adulthood?

2. In the context of being cognizant of the rights of disabled people, specifically articles 12 and 19, do parents aspire to their family member having choice, control and an independent life with any necessary supports?

3. Do parents expect Articles 12 and 19 of the CRPD will be realized?

4. What social policies and changes, do parents believe, are required to realize their aspirations for their family member?

## 1.3 Structure of the Dissertation

This dissertation consists of seven chapters. Chapter 2, 'Our Aspirations are our Possibilities', focuses on socially created dependency and independent living set within an Irish context, the

CRPD and then research on parents aspirations.  Chapter 3, 'The

Research Approach and Process', discusses the epistemological

position of the research, the methodology employed; the

participatory action approach, and then the process of knowledge

production and the ethical issues for this study.  Chapters 4, 5

and 6 discuss the results of data generated. Chapters 4 and 5

examine parents' aspirations for their family members, the

barriers to these aspirations and the changes parents believe are

required to realize aspirations.  Chapter 4, 'An Ordinary life –

acceptance and a job' focuses specifically on inclusion in

mainstream society and meaningful employment. Chapter 5,

"Housemates" concentrates on friendship, living arrangements

and love.  Chapter 6,"The CRPD – 'It's not worth the paper it's

written on'", considers whether parents aspire to articles 12 and

19 and believe they will be delivered, and considers what policies

changes could realize independent living.  Lastly, Chapter 7,

'Conclusion', outlines the limitations of this study, gives an

overview of the knowledge produced in answering the research

questions posed and then finally proposes future research areas

and policy recommendations.

## 1.4 Terminology

Society's perception and definition of 'intellectual disability' or whatever name society chooses to apply to people perceived to be intellectually deficient or deviant, is socially constructed and changes depending on the prevailing economic circumstances and social values of the time (Manion and Bersani, 1987, Barnes and Mercer, 2005). In addition, the social model of disability is founded upon the premise that 'it is society which disables' and not impairment (UPIAS, 1976: 3). Therefore, a person cannot be disabled by their intellect. The term "people labelled with an 'intellectual disability'" is then used throughout this dissertation.

Although this dissertation had aimed to explore parents' aspirations for their family member with Down syndrome, as chapter 3 will explain, it was all mothers who agreed to participate. I have always rejected the imposition of the label 'carer'. For Morris (1997), 'Care …has come to mean not caring about someone but caring for in the sense of taking responsibility for' (Morris, 1997: 54). Relatives or friends who provide support to disabled people are viewed as 'carers' and the disabled people 'cared for' are viewed as 'dependents' (Morris, 1997: 55). For

Oliver (1990) and Barnes (1990), as will be discussed in Chapter 2, dependency is a social creation.  As chapters 4, 5 and 6 will discuss, none of the participants' aspirations included dependency.   Therefore, I wanted to reclaim the lost title of 'Mum'.


## 1.4 Conclusion

This chapter has introduced this study by outlining the context of this research; the historical and current day exclusion of people labelled with an 'intellectual disability' in Ireland.  This chapter then explained why this research area was chosen and the aims and questions research questions.  The structure of this dissertation was then outlined and the language used briefly explained.

**Chapter 2: 'Our aspirations are our possibilities'**

**2.1   Introduction**

This chapter contextualizes the study and examines the research from other relevant studies. First, the concepts of socially created dependency and independent living will be discussed and then placed within an Irish context.  Next, research on the CRPD, focusing on its potential to deliver independent living, will be discussed. Finally, research on parents' aspirations for their family member's for independent living with autonomy and support is assessed.

**2.2 From Dependency to Independent Living**

Since the emergence of the industrial revolution, disabled people have been predominately viewed as 'dependent' and a 'burden' on society (Oliver, 1990).  Their dependency and exclusion from society has been attributed to individual impairment (Oliver, 1990).   The myth of dependency has been created in the areas of support (Barnes, 1990, Oliver, 1990) and employment (Oliver, 1990).   Professional support services have created and reinforced the notion of dependency by imposing professionally prescribed services upon disabled people, which ignore disabled

people's actual needs and rights to autonomy and inclusion and serve to exert control and power over disabled people (Oliver, 1990, Barnes and Oliver, 2012). Disabled people are much more likely to be excluded from paid employment due to 'perceived inabilities' and the creation of a workplace that excludes disabled people (Oliver, 1990: 86).  In reality, many disabled can and do successfully contribute economically through paid employment, while many more disabled people have contributed through unpaid or poorly paid sheltered schemes (Oliver, 1990). Dependency is then a social creation (Barnes 1990, Oliver, 1990, Barnes and Mercer, 2003).

Since the 1970's, the disabled peoples' movement has demanded autonomy and the removal of socially constructed barriers that deny disabled people the opportunity to be included in society and fulfill their 'aspirations' (Hunt, 2001: 22).  However, mainstream society can be a lonely and isolating place for people labelled with an 'intellectual disability' (Tiplady, 2008).  Independent living is not just about residing in the local community; it also entails having the necessary support and access to live and be part of community economically and socially (Finkelstein, 1996).   It is about choosing where and how you live, where you work, who you spend your time with and having and controlling the

necessary supports to achieve these choices (Finkelstein, 1996,

Jolly, undated). To achieve independent living, disabled people

must, with the support of organizations governed and led by

disabled people, control funding and services and of equal

importance the disabling structures in wider society must be

addressed (Barnes, 2004, Jolly, undated).

Over the last twenty years, disabled people across Europe have

established Centers for Independent Living (CIL), centers

organized and controlled by disabled people themselves, to

provide services to support independent living (Evans, 2003).

According to Evans (2003), personal assistance through direct

payments is essential for independent living. Personal Assistance

includes any supports that a disabled person may require to live

independently in the community (Evans, 2003). Direct payments

involve disabled people procuring their own personal assistance

as they choose through state funding (Evans, 2004). Support in

the task of employing and managing personal assistance can be

facilitated through advocates or disabled peoples' organizations,

where needed (Evans, 2004). In Ireland, despite underfunding by

government and legislation to support direct payments, CIL's

have been developed (CDLP, 2009).   However, these centers

have been limited to people with physical and/or sensory

impairments, for the most part people with labelled with

'intellectual disabilities' have yet to be involved (CDLP, 2009).


## 2.3   Dependency in Ireland

Independent living is not a supported option for the vast majority

of adults labelled with an 'intellectual disability' in Ireland (CDLP,

2009).  While there has been some movement from residential

institutions in recent years, this change has not been to

independent living (CDLP, 2009, Kelly, 2011). Instead, remaining

in the family home or living in a congregated setting in the

community are the alternatives (Kelly, 2011). For those living in

community settings it means living in a home with people and in

places they have not chosen (ERG, 2011).   However, people

labelled with an 'intellectual disability' are increasingly more likely

to outlive their parents; therefore, as age increases so too does

the prospect of living in congregated settings (Kelly, 2011).

Similar to residential services, the majority of day services (90%)

available are in congregated settings; separate from mainstream

society (ERG, 2011).  'Community participation' typically means

outings in groups to places not usually chosen by the people involved (ERG, 2011). Persons labelled with an 'intellectual disability' are also largely excluded from paid employment, with only 5.6% of those registered with the NIDD in paid employment (Kelly, 2011). The HSE estimates that over 4000 people labelled with an 'intellectual disability' engage in work where payment is at the 'discretion' of the employer or service provider (HSE, 2012: 38-39).

The current reliance on family support and 'communal' service provision is maintained by legislation and policies which view the family as the primary source of support and place support outside the home in the control of service providers. Living at home is underpinned by the social welfare system through family carer payments (DSP, 2011). Funding for services (90%), day and residential, is paid directly by the HSE to the voluntary sector where it is then absorbed and cannot be traced to an individual (ERG, 2011). There is little evidence of 'transparency' and 'accountability' (CAG, 2005:41). Medical and social professionals dominate the assessment of needs process and as a consequence needs are based on professional services available (ERG, 2011). Legislation to enforce standards and independent inspections of residential and community based congregated

settings is still pending (CDLP, 2009). In addition, disabled

people do not have a legal right to and in the main, access to

independent advocacy (Flynn, 2012b, HSE, 2012). Furthermore,

current legalisation in Ireland does not afford people with an

'intellectual disability' the assumption of legal capacity (Flynn,

2013). Legislation also denies people labelled with an 'intellectual

disability' the same legal right to protection from abuse as their

non-disabled peers and freedom to consenting sexual

relationships outside of marriage (LRC, 2006, CDLP, 2011).

There is also evidence to indicate that in practice efforts are made

to prohibit intimate relationships between people labelled with an

'intellectual disability' (Kelly et al., 2009) Therefore, people

labelled with an 'intellectual disability' do not have the right to

choose and in the main, do not have the opportunity or the

necessary support to act upon their choices.


## 2.4 The Possibility of Rights

The CRPD and its Optional Protocol, which came into effect in

2008, aims to ensure that disabled people have the legal right to

'equality, autonomy, participation and solidarity' (Flynn, 2011: 13).

Article 19 of the CRPD states that disabled people have the right

to 'live in the community', with 'whom and where they choose' and avail of the necessary supports to live and be included in the community (United Nations, 2006: 13-14).  Article 12 of the CRPD states that disabled people have the right to enjoy legal capacity, the supports necessary to act upon that capacity should be provided and safeguards should be implemented to protect any limitations to legal capacity (United Nations, 2006:  3-4).  For Quinn (2011), Article 12 and 19 are inextricably connected; in order to build legal capacity the individual must have the opportunity and experience of living in the community with life choices and accompanying supports (Quinn, 2011).

Ireland has signed the CRPD and has committed to ratifying the convention once legislation concerning legal capacity has been brought in line with Article 12 of the CRPD (Flynn, 2012a, Houses of the Oireachtas, 2012). There is a recent shift, amongst policy makers in Ireland, towards a rhetorical acknowledgement of the need to move from services designed to manage people within groups to individual based support services (DT, 2006, HSE, 2011, HSE, 2012, DOH, 2012a, DOH, 2012b).  Nevertheless, the most recent vision for change in disability policy, is explicitly not

placed within the context of 'the whole of society', the financial resources made available by the state will limit services, and participation in society is limited by individuals 'full potential' and not the disabling structures in society (DOH, 2012b: 161-162). In addition, the voluntary sector; organizations not controlled by disabled people, is identified as a key stakeholder in the process for changing service delivery (DOH, 2012b). It is also unclear whether pending legislation, addressing legal capacity, will adhere to article 12 (Flynn, 2013). There is a danger, as Barnes (2004) and (Jolly, undated) explain, that we will end up with more of the same, that the language will change to 'independent living' but little more.

Moreover, Jolly's (2010) pilot study, with 117 participants from 31 countries including Ireland, indicates that disabled people and non-disabled people have reservations about how effective the CRPD will be as a mechanism to deliver emancipation. Many of the participants were sceptical that the political will required to realize the CRPD existed (Jolly, 2010). The CRPD's inclusion of the notion of 'reasonable accommodation' is one of the main concerns identified by disabled people (Jolly, 2010). As Jolly

(2010) argues it is the only equality legislation where rights can be denied on the basis that they are 'too troublesome' or 'too expensive' (Jolly, 2010:14). I was unable to find any further research including views of the CRPD in Ireland. However, 'Your Voice Your Choice', (NDA, 2012), a report on a recent public consultation in Ireland, does include disabled people and their families discussions on the CRPD. The report indicates that participants in the consultation echoed Jolly's (2010) findings; the political will to realize the CRPD does not exist. However, this report also states that some participants also indicated that ratification of the CRPD could 'provide a catalyst for attitudinal and institutional improvement' (NDA, 2012: 19). However, this was a public consultation rather than research and it is unclear from the report the extent of participants' actual knowledge of the CRPD or what information on the CRPD was presented at the consultation. Therefore, it is difficult to draw conclusions on parents' actual knowledge of and then attitudes towards the CRPD. This consultation and report also included parents' aspirations for their family member in adulthood; it is this topic that I will now further discuss.

**2.5 Parents' Aspirations**

Parents have been identified as a both oppressive (Morris, 1997; Barnes, 1990; Aspis, 2000 and Campbell & Oliver, 1996, cited in Murray, 2000; DOHC, 2010) and supporting (Dean, 2003; Weafer, 2010a; Weafer, 2010b; DOHC, 2010).  On the one hand, for some people labelled with an 'intellectual disability', their parents can be reluctant to support their desire to live independently, in terms of living arrangements and interpersonal relationships (Weafer, 2010a).   As one person labelled with an 'intellectual disability' explained: 'Take more risks with us and let us make mistakes…. Let us stay at home on our own. .' (Weafer, 2010a: 37).

On the other hand, some parents want to support their family members, as do their family members (Weafer, 2010a). However, as age increases, the possibility of being able to provide that support decreases and fears for the future exist (Dean, 2003, Weafer, 2010a, DOHC, 2010). As Hendey and Pascal point out (2001), policies which have increasingly relied on parents to support their disabled family member have created a barrier to independent living which is difficult to surmount.

Weafer (2010a, 2010b) and DOHC's (2010) research suggests that many parents with family members labelled with an 'intellectual disability' in Ireland are dissatisfied with existing

services, in particular the lack of choice and control and support available.  Yet, at the same time, this research (Weafer, 2010a, 2010b, DOHC, 2010) also indicates various degrees of satisfaction regarding existing services and 'independent living'. However, neither of these studies adheres to the social model of disability (Oliver, 1990) or the concept of independent living as defined by disabled people (Finkelstein, 1996, Jolly, 2010).  While Weafer's (2010a) concept of independent living includes: 'personal choice, alternatives, rights, and control… and having sufficient support and resources to ensure it happens', independent living is crucially also seen as 'living a normal life, within the constraints of a person's disability' (Weafer, 2010a: 87). Inevitably then, Weafer's (2010a) findings include the assertion that along with structural barriers independent living is limited by 'the nature of a person's disability' (p.88).   Similarly, in DOHC (2010) the 'opportunity to live a full and independent live' and social and economic participation is constrained by the clause 'to the greatest extent possible' (p.5).

Therefore, both studies are underpinned by the subjective assumptions of a medical model of disability where impairment is the root cause of disability (Oliver, 1990) or a relational model where 'people are disabled by society and by their bodies'

(Shakespeare, 2006: 56; Watson, 2010; Goodley, 2011). In either case it is impairment that can be identified as the cause of disability, thereby avoiding the need to address the underlining disabling structures that actually cause disability (Barnes, 2012).

In addition, Weafer (2010a, 2010b) and DOHC (2010) research does not provide any indication of participants' knowledge of articles 12 and 19 of the CRPD. As discussed, there is some indication that knowledge of the CRPD is not widely available and accessible to disabled people (Jolly, 2010). Therefore, their research does not specifically address whether aspirations correspond with the CRPD and did not give participants the opportunity to reflect on the rights of the CRPD and its implications on their aspirations and expectations. Since the first step to independent living is information (Jolly, undated), then knowing that an independent life is a right and should be possible is then a prerequisite to demanding and achieving that right.

Irwin and Elley (2013) found that parents' expectations and actions are intrinsically connected to 'the social and economic contexts in which they are forged' (Irwin and Elley, 2013: 127). In other words, what parents 'hoped for appeared to be strongly

grounded in what they saw as, at least potentially, realistic' (Irwin and Elley, 2013: 116). In Ireland, the context is a society where currently people labelled with an 'intellectual disability' have neither the right to choose nor in the main, the necessary support and access to independent living to make choices. Moreover, Ireland is in a chronic economic crisis with continuous cutbacks by government on welfare expenditure (Bergin, 2011). Therefore, parents' expectations may well be low and in turn their aspirations. Research which includes the possibility of independent living through a realization of the CRPD and seeks to understand aspirations within this potential context is required. At the same time, whether parents expect the rights of people labelled with an 'intellectual disability' to be actually realized, needs also to be understood. It is perhaps only then that one can begin to ask parents what social policy and actions are required to realize these rights informed aspirations.

## 2.6 Conclusion

This chapter has examined the concepts of dependency, independent living and then placed these concepts within an Irish context. It has identified the need for research on parents

aspirations for their family member labelled with an 'intellectual disability' where parents have access to knowledge of the rights of disabled people. The next chapter will detail the approach to be used in understanding parents' aspirations.

**Chapter 3: The Research Approach and Process**

**3. 1 Introduction**

This chapter will discuss the epistemological position of researcher and the choice of methodology employed. Then, the process of knowledge production will be explained and lastly, the ethical issues for this study will be discussed.

**3.2 The Approach**

Central to research and design strategy is the question of ontology and epistemology (Mason, 2002). 'Ontology says what exists and epistemology says how one knows what exists' (Pfeiffer, 2002: unpaged). There are different and opposing accounts of whether and how different social entities are related (Mason, 2002). Traditional research has positioned the researcher as expert (Oliver, 1992, Stone and Priestley 1996, Barnes, 2003). Consequently, irrespective of claimed objectivity in the positivist approach or subjectivity in the interpretative approach, research has been dominated by non-disabled people's subjective perception of disability as an individual problem and then, furthered disabled people's oppression (Hunt,

1981, Oliver, 1992, Abberley, 1992, Stone and Priestley, 1996, Barnes, 2003).

In line with the emancipatory paradigm, developed to address the oppressive nature of traditional disability research (Oliver, 1992), this research will be underpinned by the epistemology of the social model of disability thereby, focusing on the social and economic exclusion and discrimination that cause disability (Oliver, 1990, 2009; Barnes and Mercer, 2003). While the research will attempt to produce knowledge to serve empowered disabled people (Oliver, 1992, Oliver, 2009), due to limited time and resources, it would be unrealistic to think the outcome of this study could facilitate meaningful change. However, this study cannot claim to be emancipatory research since the research agenda is not, as the emancipatory paradigm demands (Oliver, 1992, Barnes, 2003), set and controlled by organizations of disabled people. However, in formulating the research objectives for this proposal, I did consult with DSI, an organization of people with Down syndrome and their families in Ireland.

This research aims to adopt a participatory action approach. Participatory research is primarily concerned with researchers and participants building understanding and knowledge together about social problems that impact participants (Reason and Rowan, 1981, Zarb, 1992, O'Brien, 2001). Participants are positioned alongside the researcher as 'co-researchers' working in partnership (Reason and Rowan, 1981, p.491) and 'co-learning' (O'Brien, 2001, unpaged). Research adopting this approach is judged on its ability to build knowledge among participants to facilitate their own self-determination and empowerment (Reason and Rowan, 1981, O'Brien, 2001). As Freire (1972) points out; empowerment cannot be granted by those in power, it must come from the oppressed themselves (Cited in Oliver, 1992). Unlike emancipatory research, the agenda is not necessarily set and controlled by participants (Zarb, 1992) and it is the researcher alone who finally collectivises and analyses the information in participatory action research, a weakness of this approach (Stone and Priestley, 1996). However, Zarb (1992) argues that participatory research can be a 'prerequisite' to achieving emancipatory research (p.128) and therefore empowered disabled families could then use this knowledge when driving future research controlled and led by disabled families.

## 3.3 Production of Knowledge

## 3.3.1 Focus Groups and Interviews

In line with the participatory action approach, a qualitative approach was adopted. In contrast to the interpretative approach's use of qualitative techniques, the participatory action approach seeks to understand rather than interpret (Reason and Rowan, 1981). Participatory action research is a 'cyclical' process (O'Brien, 2001, unpaged). Firstly, the approach facilitates participants in setting their own priorities within the scope of the research through semi-structured or unstructured interviews (Stone and Priestley, 1996). I found this approach facilitated a natural conversation and generation of dialogue and gave me the opportunity to ask additional questions to elicit more information as topics arose, rather than being restricted to a predetermined list of questions when using a structured approach (Mason, 2002).

Two focus groups (FG1, FG2) were conducted in the DSI Cork centre. The focus group's discussions lasted 1 hour and 45 minutes and two hours respectively and were audio-recorded and then transcribed. According to Morgan (1996) focus groups are

compatible with participatory research; focus groups make it possible for participants with common experiences to interact with each other, facilitating the sharing of knowledge, experiences and ideas with each other (Kitzinger, 1994,1995, Hollander, 2004) and thereby, building solutions to shared problems( Morgan, 1996).  In addition, according to Kitzinger (1995):


> group dynamics can allow for a shift from personal, self blaming psychological explanations… to the exploration of structural solutions  (p.299)


Secondly, the participatory approach provides opportunities for participants to reflect, validate and amend the information gathered (Stone and Priestley, 1996, O'Brien, 2001) Therefore, participants were provided with copies of the transcripts generated from their focus group. Participants were then invited to participate in follow up individual interviews so that they could convey any additional or changes in perspectives. In addition, I was concerned that some participants would be reluctant to share their actual thoughts and experiences within a group setting and therefore individual interviews were conducted (Hollander, 2004).

Due to time and resource limitations, I originally planned to conduct the individual interviews by telephone. However, on reflection, I thought it would be more appropriate to have participants decide the setting. In the end, one parent elected to have a face to face interview and the remainder choose telephone interviews. Again, in line with the participatory action approach, the individual interviews adopted a semi-structured approach. The individual interviews not only gave participants an opportunity to reflect and revise or expand upon their discussion in the focus groups but also gave me an opportunity to clarify and delve deeper into points raised during the focus groups.

Topic guides were used to keep the semi-structured discussions on track (Mason, 2002). For the focus groups, the topic guide (Appendix 1) included information on the CRPD, specifically articles 12 and 19, and some information on service provision models to generate discussion (Appendix 2) and was informed by the literature review and the research questions. Also, a pre-test focus group was held in March 2013 with two parents who have a family member with Down syndrome but who would not be part of the focus groups, in order to test the topic guide (Morgan, 1995).

The learning from the pre-test caused me to refine the topic guide further. While I had focused on Article 19 of the CRPD, dealing specifically with choices surrounding living arrangements and community participation, the pre-test participants' priorities also included choices and decision-making concerning interpersonal relationships and health. Therefore, this experience caused me to not only revise the topic guide, but also, the literature review and the research questions to include article 12 of the CRPD which deals with choice and decision making in all matters of life. This gave participants a greater opportunity to set their own priorities. For the follow up individual interviews, the topic guide was based on a review of the focus group transcripts.

**3.3.2 Sample**

Sampling decisions determine who is interviewed and the processes involved in selection (Punch, 2005). For qualitative research, the typical approach adopted is: ''Purposive sampling'…it means sampling in a deliberate way, with some purpose or focus in mind' (Punch, 2005: 187). For this research, the sample population is parents of people with Down syndrome. Morgan (1995) recommends segmenting focus groups based on common characteristics and shared experiences, so that people

are more likely to share their thoughts and experiences.   Adults

with Down syndrome and those approaching adulthood are

already encountering the challenges of this life-stage; their

parents may then have different lived experiences, knowledge

and possibly aspirations to parents of young children.  Therefore,

two focus groups were then conducted:

- Focus Group 1 (FG1) – parents with family members with

    Down syndrome who are between 5 and 15 years of age

- Focus Group 2 (FG2) – parents with family members with

    Down syndrome who are 16 years of age and over


Parents with children under 5 years of age were originally

excluded because I had felt parents at this stage may be focused

on immediate objectives rather than long-term aspirations.

However, one parent with a child under 5 years did volunteer to

participate and I could think of no logical reason to stick to an

arbitrary age of 5 years if the parent was willing and interested

and so that parent was included.

In late 2012, I began engaging with DSI and DSI Cork branch with

a view to obtaining their agreement and support for this project. In

February 2013, I sent DSI and DSI Cork a 2,600 word research

proposal which was thankfully approved by both. Towards the end of March 2013, with the support of DSI Cork, invitations to parents to participate in the research were sent to 300 of the approximate 360 family members of DSI Cork (Appendix 3). Nearly 150 invitations were sent by email and the remainder by post. An advertisement was also placed on the DSI Cork Facebook page (DSI Cork, 2010). From this process, six parents for FG1 and one parent for FG2 responded and were recruited, all were mothers. I then had to postpone FG2 and try to find alternative ways of recruiting parents.

So firstly, DSI Cork asked a number of active DSI Cork members directly to participate but finding a common available date among parents proved impossible. Initially I tried to avoid using my own personal contacts to recruit parents as I was conscious that parents might feel under pressure to participate. In the end though I had to ask a parent who I knew personally and thankfully she agreed to participate in FG2. For the final two participants in FG2, a snowball technique was employed (Kumar, 2011); my own Mum recruited the third parent, who in turn recruited the fourth participant. FG1 had then six participants and FG2 had four participants, all ten participants also participated in the follow up individual interviews and all were mothers (Appendix 4).

### 3.3.3 Data Analysis

The first step in analysing the data was to organize and process the data. As Mason (2002) recommends, the pre-test phase was used to begin the process of attempting to create the main themes. Then, as Mason (2002) and Kumar (2011) suggest, the transcripts of the focus groups and individual interviews were continuously reviewed in order to identify the main themes from the participants' discussions. The focus groups were transcribed professionally and I personally transcribed the ten interviews myself. Although the process was slow and time consuming, it gave me a great opportunity to truly familiarize myself and then reflect upon the data generated. The themes identified were not solely derived from the data collected. The process of identifying the themes was 'interactive' between the data collected, the research questions and the 'intellectual puzzle' (Mason, 2002: 160). Therefore, the process was both inductive and deductive.

In practice, I replicated a traditional paper base approach (Krueger, undated) on my computer using a standard word processing package. Copies of portions and lines of transcript were placed under categories and further sub-categories and then

cross referenced as required (Mason,2002), while paying close

attention to referencing the source of text. The challenge was not

really the mechanism used to organize and process the data but

how to remain true to the information shared by participants.  The

participatory approach necessitates that researchers understand

rather than interpret (Reason and Rowan, 1981).   At the same

time, as Mason (2002) points out, while some information can be

taken literally, inevitably some contextual and 'reflexive'

interpretation was required (p.78).  Due to time constraints, it was

not possible to involve participants in the data analysis process, a

weakness of this research (Priestley and Stone, 1996). However,

I have aimed to be true to participants' knowledge. The results of

the data analysis have been placed within the context of the

existing research and theoretical concepts identified during the

literature review, aiming to produce answers to the research

questions posed.


**3.4 Ethics**

This research will be guided by the *Statement of Ethical Practice*

*for the British Sociological Association* (BSA, 2002).  Ethics in

social research recognize the rights of participants as being of

primary concern (BSA, 2002). A guiding principle of social research is to ensure that participants are not harmed by the process or outcomes of research (BSA, 2002). The invitations to participants included an information sheet, detailing the research aims and process, and also a consent form so that participants' consent was fully informed (Appendix 3).  Participants were assured anonymity and confidentiality, names were changed on the transcripts and no identifying information included.  The actual focus group and interview recordings were not shared with any third party.  Importantly, participants were assured and reminded at each stage of the process that they had the right to withdraw from the process at any time. In addition, participants were provided with copies of the transcripts or recordings generated, to allow participants to validate their information.  The group and individual interviews were conducted with due consideration to ethical interviewing and I was conscious of the type of questions asked and the way they are asked (BSA, 2002).

Potential participants have been made aware that I am student-researcher and the research is an academic exercise, which does not have organizational or political support to bring about immediate political change (Walliman, 2011).

## 3.5 Conclusion

This chapter has outlined the epistemological position of researcher and the choice of methodology employed.  The process of data generation and the ethical issues for this study have also been discussed. The next three chapters will focus on the results of the data generated.

# Chapter 4:  An Ordinary Life – acceptance and a job

## 4.1 Introduction

*We would love him to be doing worthwhile things and having a proper ordinary life, I would call it and a valid role in society* (Sheila, FG2)

This chapter focuses on research question 1, by examining parents' aspirations for their family member with Down syndrome to be included and have an active role in society through acceptance by society, education and employment. This discussion also focuses on the barriers to these aspirations and then addresses research question 4, the changes parents believe are required to realize parents' aspirations.

## 4.2 Acceptance

All of the parents indicated that they wanted their family member with Down syndrome to be accepted, valued and then included by society.  Yet, many of the parents felt that attitudinal prejudices existed in society and society tended to underestimate people with Down syndrome: 'They think they are stupid' (Judy, FG1). For some parents at worst society viewed people with Down syndrome as worthless.   Sheila's son's experience in the

workplace illustrates this point: 'Conor can milk 99 cows.  Yeah

we are farmers and he milks the cows four evenings a week, it is

his duty at home and maybe two mornings' (Sheila, FG2).

However, Conor also has worked in *unpaid* 'work experience' with

a mainstream employer for the last two years and during his initial

time there were a few misunderstandings but no one among staff

or management would approach Conor. For Sheila (FG2),

mainstream society viewed her son as valueless:

> *The social role they occupy is hugely important that we all*
>
> *occupy is hugely important. We bow to the doctor or the*
>
> *whatever.  I think somebody with an intellectual disability is*
>
> *definitely at the bottom of the pile and ignored largely really*

Disabled people have been traditionally categorised and labelled

as 'abnormal', 'other' and viewed as outside the range of 'normal'

human existence (Hurst, 2000, Barnes and Mercer, 2003, Swain

et al, 2003).

Some of the parents identified the traditional institutional practices

of segregation and exclusion as the root cause of the attitudinal

prejudices experienced:

> *…perception was that a child with Down syndrome they never went to school, they were put into homes or they were put into the corner and that was it…* (Judy, FG1).

As discussed in the Introduction and Chapter 2, since the middle of the nineteenth century, people labelled with an 'intellectual disability' have been systemically segregated from mainstream society and institutionalized (McDonnell, 2003).  As Oliver (1990) and Finkelstein (1980) explain disability emerged during the industrial revolution when the mode of production became based on a paid labour wage.  Consequently enforced institutionalization became policy for those who were not perceived to be economically valuable (Oliver, 1990). By forcing separation from the mainstream environment, non-disabled people learn to view disabled people as 'other' (Barnes, 1992).  Therefore, unlike the idealist social model (Priestley, 1998), for Barnes and Oliver (2012), prejudicial attitudes and institutional discrimination are not primarily caused by cultural and social values.  Instead, it is the material forces resulting in the systematic exclusion of disabled people from mainstream life and institutional discrimination that have then justified the social construction of abnormality and devaluation of disabled people (Oliver and Barnes, 2012).

## 4.3 Inclusion through education

*the sooner we close all special schools the better and that*

*they are completely dispersed across society then people*

*will understand them far more and will grow with them*

(Sheila, FG2)

Most of the parents believed that mainstream education

potentially offered a pathway to acceptance and social inclusion.

Some parents felt that their sons and daughter had experienced

acceptance through inclusion in education:

*But I wouldn't feel say like Sheila that they are de-valued*

*because Eva has gone through mainstream school … they*

*now value her and appreciate her (Eileen, FG1).*

However, simultaneously parents also expressed their fears about

inclusion in education. Many believed that inclusion was

becoming increasingly difficult particularly in secondary schools:

'Very few are going to secondary setting [mainstream] nowadays

which means they haven't got it right really' (Treasa, Interview).

Therefore, while parents appeared to believe that inclusion in

education had the potential to increase social participation, they

also felt it was becoming increasingly difficult to send a child with

Down syndrome to mainstream school.

On the one hand, many of the parents felt that the barrier to being included in mainstream school was the current long term economic crisis in Ireland (Bergin et al., 2011) and the resulting cutbacks in resources (RTE, 2013). Many parents felt that parents were more and more being directed away from mainstream provision with school principals increasingly saying  : "'We may not be able to take this child because we won't have enough supports for them'" (Eileen, FG2).  Therefore the perceived lack of resources was a barrier to mainstream school.

On the other hand, some parents pointed out that the lack of resources was not necessarily the root cause of difficulties.  Some parents felt that teachers do not always differentiate the curriculum to include the student with Down syndrome in the mainstream classroom due to either unwillingness or lack of training and knowledge. Moreover and paradoxically, one parent felt that the actual presence of resources, an SNA in the classroom, meant that her child was excluded:

> *They [SNA's] are doing more harm  than good in some*
> *ways regarding taking over and telling the teacher "its ok I'll*
> *be doing a bit of colouring with him there and let ye get on*

*with it" you know kind of way that has been a big huge*

*problem for me, a huge problem*  (Treasa, Interview).

Therefore, parents' experiences appear to indicate that the

education system tends to view students with Down syndrome as

a burden in mainstream education.

It was initially thought that the process of special needs

statements would facilitate greater access to inclusion in

mainstream education (Whittaker, 2001). However, in reality for

many disabled children the process has facilitated and promoted

segregation (Whittaker, 2001). As Dyson and Millward (1999)

maintain: "most of what passes as inclusive education today is

simply reproducing 'special' education in mainstream settings"

(cited in French and Swain, 2004: 170).  It is argued that the goal

of education is increasingly the production of school leavers who

will contribute to the economy (Barton, 1986, Tomlinson, 1982,

Tomlinson, S. and Colquhoun, 1995, Lloyd, 2000, Norwich 2010)

and less to do with an ideology of 'education for personal growth'

(Oliver, 2000: 16).  Children who are deemed to be 'disruptive' or

have 'learning difficulties' are then considered to be a drain on

scarce resources within the mainstream classroom (Tomlinson,

1982).  Therefore the notion of disabled people as a burden on the education system and the need for exclusion through special education is promoted (Oliver, 1992, Lloyd, 2000).  Additionally, with the current crisis of capitalism and austerity disabled people are increasingly portrayed as a burden on society (Oliver and Barnes, 2012).

It is perhaps unsurprising then that the acceptance by society, which parents in this study seek for their family member, appears to be diminishing.  The recent NDA (2011) survey, *National Survey of Public Attitudes to Disability in Ireland,* found that in 2006 29% of participants were not in favour of  people labelled with an 'intellectual disability' being included in education but by 2011 that figure had risen to 40% of participants (NDA, 2011).  As inclusion becomes more difficult to attain so too does acceptance.

Finally, for all of the parents, education is not just about social inclusion; education is also importantly about a means to employment.  However, post-secondary education was identified as a problem.  Parents in this study feared that there is a lack of courses leading to meaningful qualifications and more importantly leading to employment: '…after secondary school there is the thing at the moment practically nothing arranged for afterwards…

(Treasa, Interview). Sheila's son's experience illustrates these fears manifested:

> He would have done a module in computers, he would have done lots and lots of PlayStation, and he would have done a bit of pottery, a bit of cookery, the odd project and that. He loved it … but in terms of coming out with anything worthwhile - unfortunately no
>
> (Sheila, Interview)

Therefore, while parents in this study want their family member to have an education which increases their employment prospects, some parents believe their family members are being denied that educational opportunity and increasingly seen as a burden on schools resources.


## 4.4 Employment – 'Biggest Difficulty'

> But what we really want for them is to get up every morning, go out every day, do a job and come home and just be like anybody else (Michelle, FG2).

For most of the participants, employment above all else was their main priority for their family member. While some parents were

concerned with the type of job that might be available to their son or daughter, for others the priority was, as Tiplady (2008) found, having something meaningful to do in life: 'It can be whatever, I don't mind so long as she is happy doing whatever it is and that she can be fulfilled or feel that she is being useful or kind of got a purpose' (Deirdre, Interview).

However, parents recognized the challenge for the family member to be included in the workplace: 'Biggest difficulty I foresee is maybe having meaningful work' (Valerie, Interview). As mentioned in Chapter 2, in Ireland people labelled with an 'intellectual disability' are largely excluded from paid employment with only 5.6%, of those registered with the NIDD, in employment (Kelly, 2011). For some parents, their family members were denied work opportunities because of perceived inabilities: 'It is back to that perception that an adult with Down syndrome or a child with Down syndrome is stupid' (Judy, Interview). Disabled people encounter exclusion from and marginalization in the employment market and this discrimination is more acute depending on how serious the impairment is perceived by society (Finkelstein, 1980, Oliver, 1990, Barnes, 1991).

Parents also recognized the structural barriers in the employment market:

> 'There is such competition out there in the world…
> [Employers] want people with the academia and with you
> know a lot of verbal, a lot of communication skills.  I
> suppose employers want the whole package really a lot of
> the time don't they?' (Marion, FG1).

The movement from an industrial based economy towards an information and technology based economy has meant that by the end of the twentieth century the need for semi-skilled or low skilled workers had dramatically been reduced (Tomlinson, S. and Colquhoun, 1995, Oliver, 2000).  This changing employment market means that "whereas an 'able body' has long been a prerequisite for inclusion in the work-force, now in the twenty-first century an able mind may prove more significant"(Cornes, 1991, cited in Barnes and Mercer, 2003: 49).  In addition, Eileen (FG2) also pointed out that increasingly the more 'menial' jobs are now no longer available to them as those jobs have moved to other more competitive countries.   In a global capitalist society, work is concerned with the quest and creation of profit and therefore

workers must compete for employment across the globe (Oliver and Barnes, 2012).

Most of the younger parents and one of the older parents indicated that it would be of equal importance that their son or daughter would be in *paid* employment and have some financial 'independence' (Ciara, FG1).   However, for two of the parents from the older group, being paid was desirable but not as important as having something meaningful to do. Eileen's comments typify this position: "if they had a job and they weren't paid you know having a job is a better thing than not having a job…" (Eileen, Interview).   As referred to in Chapter 2, like Sheila's son Conor, thousands of people labelled with an 'intellectual disability' work in unpaid or poorly paid sheltered schemes or 'work like' schemes in Ireland (HSE, 2012).   For Sheila, parents cannot complain or demand a wage because: "you are afraid the next step would be well actually we don't want him anymore because that has happened to other parents" (Sheila, FG2).   Therefore, it appears that while parents want their family member to have paid employment, in reality they feel forced to settle for much less.

Pauline, whose son John is in paid employment almost his entire adult life, went further by saying that she initially she would not have wanted John to be paid the minimum wage (Pauline, FG2), but later explained:

> '*I was afraid that he would get into difficulty and he wasn't able to keep up and that he would be expected to do the same work as the rest, if he was getting the same wages*' (Pauline, Interview).

Pauline had legitimate concerns. In Ireland employers are not legally required to make accommodations for employees beyond an unspecified 'nominal cost' in order to protect employers' 'constitutional property rights' (Murdoch, 2001: unpaged). However, atypically (Kelly, 2011), Pauline's son did obtain and has retained mainstream paid employment since the beginning of adulthood:

> *I would say I am one of the very lucky ones, I don't boast about it because I know that it doesn't work out for everybody else (Pauline, FG2).*

Why then was Pauline's son's employment experience so different?  For Pauline (FG2), John was given an opportunity and his personal attributes and characteristics were valued:

*… his supervisor was saying that he is as good as and*

*better than some in some ways. I mean he has people skills*

*that some of the other workers never have (Pauline,*

*Interview).*

However, in a capitalist society it is productivity and profit which typically are valued (Barnes and Oliver, 2012).

Parents proposed a number of changes to address the problems in employment.  Firstly, both of the parents with adults in the workplace identified the need for job coaches or advocates in the workplace to support their family member.  Since employers do not always have the appropriate communication skills or ability to address issues.  In the absence of such services parents are often compelled to fill that role which is both unwanted by the parent and their family member with Down syndrome (Pauline, FG2, Sheila, FG2). Secondly, parents in FG1 suggested that research be carried out to determine the work that would best suit people with Down syndrome, thereby, proving their suitability to employers.  However, as Erlanger and Roth (1985) argue focusing exclusively on the individual 'takes the job structure as given and tries to fit disabled people into it' (p.339).  Therefore, as Oliver and Barnes (2012) maintain policies concentrating on the

'supply' side of the employment market mean that the structural barriers in the workplace that cause discrimination are unaddressed (p.129).  Furthermore, while focusing on the individual, 'the idea that there is something different and "wrong" with them is reinforced and can lead to exclusion rather than inclusion' (Oliver and Barnes, 2012: 129).

However, parents also recognized the demand side of the problem, as Judy's (Interview) expectation for the future demonstrates: 'It's not that she's not working because she doesn't want to it's just because she can't because employers won't'. One of the parents suggested that 'there should be an onus on employers out there first and foremost that they would employ people with disabilities' (Treasa, Interview).   Already, under the Disability Act of 2005 public sector bodies are legally obliged to ensure that 3% of their employees are disabled people (DCEGA, 2010). However, only 5.6% of people registered with the NIDD are described as being 'open' or 'supported' supported employment (Kelly, 2011), a decrease from the figure of 7% reported in 2004 (Barron and Mulvany, 2004).  It appears then that the Disability Act of 2005 has had little effect on the employment of people labelled with an 'intellectual disability' included in the NIDD. The UK experience demonstrates that

although such polices in the public sector have resulted in some success, those labelled with an 'intellectual disability' have tended not to benefit, since they are considered to be too far from the productivity levels sought (Roulstone, et al. 2009).

## 4.5 Conclusion

This chapter has examined parents' aspirations for their family member to be accepted by and be included in mainstream society through education and employment, and have a meaningful life; ideally in paid employment. However, parents identify the current economic climate, cutbacks in education and the ever increasing competitive world as the main obstacles to achieving these goals. Some parents identified changes which focus on the individual; increases in resources for people in education and employment and research on people employment suitability. At the same time though, parents also identified the need for structural changes; actual inclusion in the mainstream classroom, a place in the workforce.

# Chapter 5 – Housemates

## 5.1 Introduction

This chapter concentrates also on research question 1: 'What are parents' aspirations for their family member in adulthood?' , question 4: 'What social policies and changes, do parents believe, are required to realize their aspirations for their family member?'. This chapter specifically addresses parents' aspirations for friendship for their family member, the type of living arrangements they aspire to and those they do not.

## 5.2 Friendship with Peers

*Loneliness is a terrible thing* (Eileen, FG2).

For nearly all of the parents, mainstream employment and mainstream education does not necessarily resolve isolation.  For parents inclusion was not just about social and economic participation in mainstream society; it was also about being included in and having access to a community of disabled peers (Tiplady, 2008; Weafer, 2010a).   Similar to Tiplady's (2008) and Weafer (2010a) findings, for nearly all of the parents in this study, friendship for their family member with similar peers was important: 'But you see most of their friends are going to be with

intellectual disabilities' (Judy, FG1). However, many of the parents highlighted the barriers to facilitating that inclusion.

Firstly, many of the organized social events were sports orientated but some people with Down syndrome 'are not very sporty so they don't have the sports and there are not many other things' (Eileen, FG2). Secondly, parents were often responsible for organizing social events and providing transport for their family member. As Weafer reported (2010a), some of the participants in this study noted that for many parents this responsibility was problematic, particularly for those living in isolated rural locations or those without transport. One of the older parents commented that she doesn't drive herself and relies on friends and neighbours. This prompted Pauline to remark: 'I was just going to say if you don't drive you are snookered altogether.' Thirdly, for those described as having more 'intensive' support needs, and in the absence of formal supports, exclusion from their disabled peers also occurred:

> *We can let them off at the door and let them go to the disco [disco organized by parents/service provider] you know and tell them to ring us and come back … But if you have a son or daughter who you have to be by their side the*

*whole time or somebody has to, it is a totally different kettle*

*of fish* (Sheila, FG1).

As CSPD (1996), Weafer (2010a) and NDA (2012) found, parents are then often left isolated, stressed and feeling "quite sad" (Eileen, Interview) and moreover, disabled people are alienated and isolated (Weafer, 2010a). Like Hendey and Pascal's (2001) study found and Evans (2004) points out, policies dependent on families to support their disabled family member create barriers to inclusion difficult to overcome.  For many of the parents some living arrangements potentially offered some resolution to isolation.  This chapter now turns to the living arrangements parents envisaged would be available and then preferable.

## 5.3 Home –security, friendship and support

All of the parents indicated that they anticipated their family member would need some level or type of daily living support in adulthood.  To begin with, similar to Dean (2003) and Weafer's (2010a) findings, some parents indicated that they would like their family member to remain in the family home, as one of the older parents noted: 'I kind of hold on to him.  He is the only one left at home and it just works out…" (Pauline, FG2).   However, nearly all of the parents indicated that remaining in home was not a

permanent answer.  Firstly, some of the older parents recognised that their family members had ambitions to move out of the family home, as Michelle's (Interview) comments illustrate: "She [her daughter] scrutinised the Argos catalogue there one day picking out all the things for her own place. So she has those ambitions". Secondly, some parents had ambitions themselves for their family member to live outside the family home.  Finally and most significantly, as Weafer (2010a) and Dean (2003) found, parents were conscious that they are inevitably aging themselves and therefore, remaining at home was not sustainable long term.

Parents then looked to what they perceived to be the next available options, clustered housing, group homes and for some mainstream accommodation with sibling support. All of the older participants and some of the younger participants indicated that clustered housing would be their preferred option outside the familial home and an 'ideal situation' (Pauline, FG2).  Clustered housing was described as a number of individual homes, each with single occupancy or with a very small number of peers sharing, provided by a service or housing provider, situated closely together in the community with any necessary day to day support from the service provider.   In each of the focus groups, one participant shared reports of positive experiences of clustered

housing.  Therefore, importantly, clustered housing appeared as a potential option because it was seen to exist, albeit on a limited scale at present. Secondly, like other proponents of clustered housing (Segal, 1990, Cox & Pearson, 1995), some parents perceived clustered housing to be more economically viable than dispersed or mainstream housing, due to economies of scale in support. Therefore, clustered housing appeared to be a tangible and viable possibility.

Group homes in the community were then seen by many as the next available and preferable option, particularly for those less 'able':

> *If the set up can be made that they have their own kind of little separated apartment* [clustered] *it is much better but there are some of them that wouldn't be able for that* (Eileen, FG2).

Group homes were perceived by many parents to offer more secure and greater support for those deemed less 'able' again due to the perceived economies of scale in supporting people in groups.  Moreover, a few parents indicated that those with the most 'intense' support needs would need traditional residential

institutional accommodation.  Yet, nearly all anticipated that their *own* family member would be 'able' for clustered housing.

These congregated setting were not only seen as possible and economically feasible but were also considered to have certain advantages.  Firstly these congregated settings were seen to allow access to friendship:

> *But as you go on you realize … that your son or daughter has huge needs and they are about being included some of that you can do but they're also about having friendships and mixing with their peers and while it's wonderful to go towards independent living and living on your own and all that, it is, it can be lonely too* (Sheila, Interview).

Secondly, for some parents these settings offered security: 'I think I would prefer to have Sharon in that kind of situation [clustered setting] rather than be up we'll say in North Main Street [inner city location] in an apartment on her own'.

However, a few of the younger parents were reluctant to see their family member in any of the perceived available future options outside of the family home; residential institutions, group homes,

or clustered housing.   Similar to some of the parents in Weafer's (2010a) research, these parents felt that group homes might be mini-institutions, denying choice (Jolly, 2009) but in addition, questioned if congregated settings, including clustered housing, promoted exclusion and segregation : " …are we putting them all into a little Down syndrome people in one corner or estate, instead of integrating them?"(Treasa, FG1).

However, the only perceived long term possible alternative for these parents was then support from siblings:

> *I don't want my children to be in that position, my other children but yet I would hope that …[they would be] there for their sister when I am not able anymore*  (Judy, Interview).

While Treasa (FG1, Interview) felt that it was the duty of families to support family members where possible. But most of the parents felt that it would be unfair to expect siblings to take on the role of support 'But I would just hate them to have to stop their lives for her' (Valerie, FG1) or unrealistic:

> *I mean all John's siblings are away you see so it is just you know they are in different parts of the country, .. they all have jobs and they all have commitments in different places and family* (Pauline, FG2).

However, as Your Voice Your Choice' public consultation found that many families, in the absence of adequate support from the state, are compelled to provide any necessary support and act as advocates (2012: 20).

One of the parents also indicated that it may not suit their family member with Down syndrome to be supported by their siblings, as Michelle explained:

> *Oh well I'd say Tanya wouldn't live in X [sibling's rural location] if you gave her Ireland free. I'd say she'd want to be in her own [urban] environment near home* (Michelle, Interview)

In this study, then the tangible options for living arrangement were either congregated settings in the community or living in the community with support by family members and as Dean (2003) and Irwin and Elley (2013) found, parents tended to have aspirations located within the range of perceived possibilities.

## 5.4 Undesirable housemates

Lastly, for many of the parents there was one shared living arrangement that was undesirable. Living with a peer was problematic if that choice entailed a girlfriend, boyfriend or

partner.  While many of the parents acknowledged the importance of interpersonal relationships and love for their family member and some of the older parents already do facilitate their family member by providing transport and being supportive of their relationships, parents had reservations:

> …*we support them in the relationship as best we can without introducing the awkward situation, like you said yourself it's hard to say these things out but you know.  We have never let them in a position that they would be able to have sex and I don't intend to let that happen.* (Pauline, FG2)

In the main parents worried about pregnancy and then support: 'that's two to mind and at that stage parents are getting older anyhow' (Pauline, Interview).   However, it appears that it is not just about support; a few of parents indicated that seeing their son or daughter as a parent was something they were just not comfortable with. In addition, some of the participants feared abuse, as Valerie explained: 'you just wouldn't want your daughter to be taken advantage of…' (Valerie, Interview). In contrast, for some a relationship that was mutually consenting and appropriate was not as daunting, as Deirdre noted: 'it

wouldn't probably scare me as much' (Deirdre, Interview). In the end though, for most, it was not a priority or aspiration but at the same time all of the parents wanted to see their family member happy:

> *I would much rather her have a someway decent job now than a wedding … But then again you wouldn't deny her either would you.  You wouldn't deny her either that's the other side of it* (Marion, Interview).

It is also worth noting that without the support of parents, many adults with Down syndrome will be denied the opportunity to have a consenting relationship.  Firstly, as mentioned in chapter 2, it is currently illegal for two adults deemed to be 'mentally impaired' to have a mutually consenting sexual relationship outside of marriage (LRC, 2006, CDLP, 2011) and secondly, there is evidence to suggest that service providers actively discourage such relationships (Kelly et al., 2009).   Sheila noted: I mean you are allowed have a girlfriend, you are allowed hold hands probably in the service but in school you don't hold hands" (Sheila, Interview).  As Shakespeare points out, for many disabled people, in segregated institutions, 'sex was never on the agenda, and wasn't seen as being part of the story" (Shakespeare, 2000,

p.161).   In addition, Sheila also explained that at school or at a service provider may be the only opportunity to meet since they may not reside in the same community (Sheila, Interview). Therefore, the opportunity to express or develop an interpersonal relationship and a valuable source of friendship is often lost.

## 5.5 Conclusion

This chapter has examined parents' aspirations for their family member to have access to friendships and their aspirations for living arrangements. For many of the parents in this study, congregated settings in the community appear not only to have the potential to facilitate peer relationships but also provide security and support that is perceived to be cost effective and significantly a plausible possibility.  However, some of parents in this study also feared that congregated settings were institutional and promoted exclusion but for those parents the only perceived alternative was family support. Therefore, when parents were asked about their aspirations for their family members' living arrangements, the data suggests that parents' aspirations were closely in line with the levels of support and services perceived to be potentially available.  Lastly, while shared or close-by living arrangements with peers were desirable for many parents, less

desirable were shared living arrangements which included

partners.

## Chapter 6: The CRPD – "It's not worth the paper it's written on".

### 6.1 Introduction

This chapter first focuses on research questions 2 and 3 by examining parents views of Articles 12 and 19 of the CRPD; whether participants' aspired to their family member having choice, control and an independent life with any necessary supports and if parents believed the CRPD would be realised. Next, research question 4 is addressed by assessing parents' views on support provision, in order to ascertain if parents believe changes in support provision could realize independent living. Before doing so it is worth briefly mentioning parents' awareness and knowledge of the CRPD prior to the focus group.

### 6.2 Parents Awareness of the CRPD

As mentioned in Chapter 3, the focus groups provided an opportunity to introduce the CRPD and give participants a brief overview of Articles 12 and 19 of the convention. Just two participants were aware of the existence of the CRPD and only one had any actual knowledge of the convention and Ireland's current status on the convention, this knowledge was gained through further education at university level. Jolly's (2010) pilot

study, focusing on disabled people and non-disabled peoples'
knowledge and views of the CRPD,  found that 42% of
respondents believed that they had did not have enough
information on the CRPD. However, Jolly's study also indicated
that participants' actual knowledge may have been even less than
participants recognized themselves. The participants in this study
indicated that overall they had little awareness and knowledge of
the CRPD. While this study includes only a very small sample of
ten participants, it may indicate that there is possibly a general
lack of awareness and knowledge of the CRPD among parents
with a disabled child or adult in Ireland.

## 6.3 Choice – "It depends on…"

> *I think somebody responsible for them would have to be*
> *sure it was the, you know, the correct decision* (Treasa,
> FG1)

Many of the participants expressed reservations concerning
articles 12 and 19 of the CRPD.  To begin with some participants
questioned whether or not people with Down syndrome would
have the capacity to choose and make the right decisions.  Some
of the participants indicated that capacity to choose, as set out by
Article 12 (United Nations, 2006), should be conditional on a

person's 'intellectual ability' or the level or category of 'intellectual disability' that they had been assigned:

> *I mean, if a disabled person has a mild intellectual disability and can make a decision yeah that's and it's safe and there you know that's fine.  But I think you can't just say 'disabled person', it is very individual, it depends on their level of disability* (Valerie, FG1).

For many of the parents, at the centre of their concerns regarding decision making was safety.

However for most, it was society that posed the greater threat to choice and control rather than individual capacity to choose:

> *It is general society that would worry me nearly more than him living on his own, because society is not fair and as Sheila said there some people are very cruel* (Pauline, FG2)

Parents' fears are not unjustified. Choice can involve degrees of risk and sometimes unwanted outcomes (Quinn, 2011). Mainstream society cannot only be lonely for an person labelled with an 'intellectual disability' (Tiplady, 2008) but even more troublingly, as research in the UK indicates, a place where people labelled with an 'intellectual disability' can sometimes be

subjected to hate crime (DH, 2007).  While Quinn (2011) recognizes how difficult it is as a parent to let go, he also recognizes the human necessity to take risks and maintains that the denial of choice and inevitable exposure to levels of risk is a denial of personhood. As Zola (1982) maintains then:

> '… *to design an environment or device to prevent any kind of risk may go too far. It may not produce a real life but a mirage of one. There is human dignity in risk. There can be dehumanizing indignity in safety'* (p.7).

Additionally, institutional abuse has occurred within the walls of segregated settings in Ireland, places without choice (CICA, 2009; IHRC, 2010).

However, choice was perceived not just to be restricted by 'intellectual inability' to make safe choices in a sometimes hostile society, for others the right to choice is inherently linked to an individual's apparent social competency*:*

> *It all comes back to how you are and what your ability is you know, can you do your shopping and pay your bills and you know make sure your mortgage is paid, you know all the things that we as adults do* (Marion, Interview)

Many of the participants tended to view independence in terms of "the successful transcendence of structural dependency on others" (Priestley, 2003: 119). For some of the parents then, choice and autonomy were seen as a right for those who were capable of looking after themselves; fulfilling the 'adult role' (Priestley, 2003, p.119). For Barnes and Mercer (2005), western societies tend to afford status of 'personhood' to those in 'adult employment' (p.5-6) In contrast, the independent living movement defines independent living as choosing where and how you live, where you work, who you spend your time with and having and controlling the necessary supports to achieve these choices (Finkelstein, 1996, Jolly, undated). As discussed in the previous chapter, for many disabled people, particularly those perceived to have greater impairments or perceived to be less able-minded, the prospect of unemployment and then socially created dependency is ever increasing. Therefore, the opportunity to fulfil the 'adult role' (Priestley, 2003: 119) and have choice is increasingly unlikely for people with Down syndrome.

However, one participant stated that parents like society need to respect family members' right to choose: '

*We can't have it both ways, we can't want them to have a*

*vote and want them to be treated equal and then say no*

*hang on a second now their intellect* (Judy, FG1)

Furthermore, a few parents did indicate that perhaps parents can be too controlling: "We are going to react differently anyway [to other family members' choices]… we are guilty ourselves of keeping our children (Ciara, FG1). For Morris (1997) and Evans (2004) the role of carer often distorts intra-family relationships. While it has been acknowledged that families can have a positive role in disabled peoples' lives (CPSD, 1997, Dean, 2003, Evans 2004, Weafer 2010a,) families have also been identified as oppressing (Morris, 1997, Evans, 2004, Weafer 2010a). Families can be 'overprotective' and sometimes constraining towards their disabled family member, which can result in disabled people being 'institutionalised' within their own family (Evans, 2004: 3). But ultimately for most of the participants the lack of choice and control for the family member came down to a lack of support.

## 6.4 'I have to live in the real world'

For most of the parents the overriding barrier to choice and autonomy and community participation was support. They

believed support, as defined in Articles 12 and 19, would never be fully funded by government. While nearly two thirds of Jolly's (2010) participants did not believe that the CRPD would bring about any changes or 'not very much' change in one year, not one of the participants in this study had any confidence that the CRPD would be effective in the immediate future. Most of the participants in this study, eight out of the ten, had little hope that the CRPD would make any tangible difference in the lives of people with Down syndrome: 'It's not worth the paper it's written on in reality' (Treasa, Interview). All of the parents indicated that in the absence of support; inevitably the available choices for disabled people would be limited and their son or daughter may be reliant on other family members:

> *I am not sure if it can be totally up to them [family members with Down syndrome] really if it doesn't suit everyone around them. I don't know if they should have a right to choose* (Treasa, FG1).

Participants' experiences to date and their perceptions of the cost of independent living to the state led them to believe that the state would never fully commit to Articles 12 and 19: 'I don't see the will, I don't see the money, I don't see anything' (Deirdre,

Interview). Nearly all of the parents believed that the political will to realize the CRPD did not exist due to their varied and numerous experiences to date of being denied early intervention services, resources in education, support services in the workplace, on-going reductions in disability welfare allowances and the current shortage of residential places for people labelled with an 'intellectual disability'. Eileen's comments illustrate this point:

> *Perhaps they would do it but then they were awash with money they really didn't do it either. There was a huge amount of money there to support people and to facilitate things like this but that is not what they spent the money on* (Eileen, FG2).

In addition, most parents also believed that the right to 'live in the community', with 'whom and where they choose' and avail of the necessary supports to live and be included in the community would never be realized because they believed it would actually cost too much and government would always resist such costs:

> *…it won't be economical and no matter how much we want it. You see I often have this debate with my husband at home, no matter how much a person is entitled to or has the*

*right to if it breaks the government it can't happened or*

*won't happen* (Sheila, Interview)

Independent living, entailing full social and economic inclusion, is believed to be too costly by governments (Zarb, 2003), despite evidence demonstrating its overall cost effectiveness (Hurstfield et al., 2007).  One parent pointed out, similar to Barnes and Oliver (2012), in the absence of political will and funding, for the CRPD to be effective, parents would have to challenge the legality of the inequalities and discrimination experienced and for most parents that is not realistic: "But who will do that? They are such a disadvantaged group anyway you know overall" (Treasa, Interview).

As mentioned in the previous chapter, as Irwin and Elley's (2013) found, parents spoke of aspirations for their family member which were within the range of what they perceived as realistic possibilities: 'So I know I'm being negative Fiona and I find it very hard to see…I have to live in the real world' (Sheila, Interview). For nearly all participants the CRPD did not offer much hope of change.    Yet, when parents were asked if in an ideal world people should have the necessary support and right to make choices then, most of the parents indicated in an ideal world they

would like their family member to have choice, control and support.  As Michelle (Interview) explained :

> *Realistically yes because we all get the choice of where we'd like to go and live and who we want to live with and I suppose it should be no different for them. But I couldn't imagine it working because I don't think they would have that facility there at the moment to choose* (Michelle, Interview)

## 6.5 Support Provision

Parents were also asked how support should be organized, funded and managed in order to support day to day living and if direct payments could facilitate independent living and choice. Many of the parents, some younger and older, felt that the current system of service provision needed to be changed because they believed it did not necessarily provide the services actually required and denied choice:

> *being dictated to them that you have to go here on a Monday and you have to go there on a Tuesday, that you mightn't even be interested in what's happening* (Michelle, Interview).

As discussed in Chapter 2, in Ireland, predominately, people labelled with an 'intellectual disability' have been segregated and excluded from every aspect of mainstream society (McDonnell, 2003, Conroy, 2003, CDLP, 2009). Funding is allocated directly to the voluntary sector and then segregated group service provision is controlled by professionals (ERG, 2011, DOH, 2012b) thereby, creating dependency (Oliver, 1986, Barnes, 1991). Calls for revision of this service model (ERG, 2011, DOH, 2012b) were echoed by some participants. In addition some parents felt that money allocated to service providers 'doesn't necessarily get to the end to the actual person' (Valerie, Interview) and therefore lacked transparency (ERG, 2011) or effective use of funding (Zarb, 2003; Hurstfield et al., 2007; Jolly, 2009).

However, parents who were critical of the current service provider led system differed on what they perceived would be the best replacement. For some direct payments offered a possible solution. As explained in Chapter 2, direct payments entails disabled people choosing and controlling their own personal assistance through state funding, in order to live independently in the community (Evans, 2004). Direct payments were favoured by some participants because it was believed that funding would be

actually spent on the person 'by cutting out the middle man' (Judy, Interview) and choice would be facilitated:

> *every individual is different and every individual has different needs, so I think the individual it should be the individual and then the backup services that she decides on…*(Michelle, Interview).

However, these parents also expressed concerns about direct payments. Some parents had concerns that the monies might be spent unwisely and not on services which would actually "help them have a better day, a better week, a better life" (Michelle, Interview) and therefore expressed the need for an independent advocate to support decision making and ensure that money was spent appropriately.  For Judy (Interview), an independent advocate would be required to support the individual making decisions to ensure that parents did not usurp decision making or indeed the funding itself . A report by Inclusion Ireland (2003) found: 'In practice, decisions are made on behalf of adults with intellectual disability by parents or by service providers'(unpaged).

In contrast some parents were not entirely comfortable with independent advocates taking on the responsibility of advocacy:

*I think they [advocates] should be part of the discussion*

*…someone who would know exactly they are talking about.*

*But I think in conjunction with the family as well I think the*

*family can't be just side-lined either* (Marion, Interview).

Alternatively, some parents indicated a preference for

'Individualized payments' (Appendix 2**)** over direct payments.  For

these parents, individualized payments appeared to address

some of the concerns regarding people with Down syndrome

making the best decisions.  Valerie explained:

*the broker obviously as a professional with  a lot of experience in*

*the type of services that a person would need and would be able*

*to advise and support and identify where priority areas are, rather*

*than the sole responsibility being left to the individual*  (Valerie,

Interview)

However, not all parents felt that the traditional system of service

provision should be replaced entirely.  Firstly, Pauline and Sheila;

parents with the oldest adults in FG2, were reluctant to move

away from established service providers.  Direct payments or

individualized budgets were seen as elusive and concerns were

expressed about family members being left without adequate

support and then yet again parents having to organize and manage support, particularly as they grew older:

> *It's ok to say in small children, I did sus out schools, Montessori …speech therapy and that myself but they are only very small issues. When it comes to the workplace you need, this is what I feel you need the service provider behind you for that…. If people can choose that's fair enough if they can do that but that wouldn't be suitable for everyone* (Pauline, Interview)

Ultimately though, most of the parents expressed one common concern regarding direct payments, most doubted it would ever be sufficiently funded to actually work:

> *Well, it would be fantastic if you could have a choice in everything but in reality that doesn't happen and the way the climate of today (Pauline, Interview)*

Therefore, while some parents welcomed the idea of direct payments, there were in the main concerns about people's decision making abilities, the need for advocates or alternatively the need for families to have input and the fear that direct

payments or individualized budgets would mean that ultimately it would be parents who would be forced to source and manage services; an unrealistic expectation, particularly as parents age.

## 6.6 Conclusion

Most of the participants believed that the CRPD would not deliver choice, control and independent living for their family member. They believed that government would never commit to the funding required for full inclusion.  While most of the parents expressed some fears about the choices their family member might make due to risk from society and in some cases people with Down syndrome perceived abilities, the principal barrier to making choices and having them realized was the perceived lack of support.   Therefore, this study indicates that parents' expectations were not impacted by knowledge of articles 12 and 19 of the CRPD.  However, most parents did acknowledge that in an ideal world independent living with choice, control, participation and support was preferred.  While some parents believed direct payments could offer more choice and control, most were sceptical that direct payments would ever be sufficiently funded. Finally, though, some parents, in particular those older, the

traditional service provider was seen as least to be tangible and

workable.

**Chapter 7: Conclusion**

This last chapter summarizes the findings of this study and attempts to outline potential areas for future research and policy recommendations**.** Before doing so, it is first necessary to discuss the main limitations of this study.

**7.1 Limitations**

Being a master's dissertation with one researcher without funding within a limited timeframe; this study has had certain limitations. Firstly, the focus groups were segmented by just one age partition: parents with a family member with Down syndrome under or 16 years of age and over.  Then only two focus groups, one per segment, consisting of six and four participants in each group and then ten individual interviews were conducted (Appendix 4). Morgan (1995) suggests holding multiple focus groups for each segment as participants within a single focus group may not encompass all of the experiences and knowledge of a particular segment.  However, given the limited resources, it would not have been possible to conduct, transcribe and analyse multiple focus groups and follow up interviews for each segment (Tight and Hughes, 2010). While the small focus group sizes proved conducive to both stimulating discussion and allowing

sufficient time for meaningful discourse from all participants (Morgan, 1995), with more participants and then greater segmentation, for example family members in pre-school, primary school, secondary school, school leavers and adulthood, more in-depth discussions on the barriers experienced at difference life stages may have been generated. Secondly, in Ireland the level and type of service provision can differ depending on the service provider in a specific location (DOH, 2012b). Therefore, the research findings may be limited due to the single location of participants and then the expected levels of services from particular service providers in Cork. For these two reasons, the findings may only be read as indicative rather than evidential.

Thirdly, adopting a participatory approach meant that participants had the opportunity to establish their own priorities within the scope of the research through the use of semi-structured methods and to reflect upon and amend their contributions, but it was I, alone, who collectivised and analysed the data generated, a weakness of the participatory approach (Stone and Priestley, 1996). Parents with disabled family members are not a homogenous group. I found parents' thoughts and experiences of the barriers disabled people encounter to be complex with both significant and nuances of differences between parents. I have

struggled to adequately represent each of the participants'

experiences and thoughts and I can only therefore claim to have

attempted to include only what I understand to be parents' main

priorities underpinned by the social model of disability.

Notwithstanding these limitations, this research has produced

knowledge that may be valuable.


## 7.2 Knowledge and understanding

This study aimed to understand parents' aspirations for their

family member with Down syndrome in adulthood and the actions

and changes required to realize those aspirations. Parents

expressed aspirations for their family member to have an ordinary

life with a meaningful role valued by society, through actual

inclusion in employment and education.  Parents also aspired to

friendship for their family members with peers and for many

parents congregated or clustered living arrangements facilitated

this aspiration.  For others these arrangements were seen as

segregated and institutional with the only alternative being family

support.  For all of the parents, the limited expected options were

congregated or clustered settings with shared support or family

support. Therefore, in line with the Dean (2003), this study

indicates that parents' aspirations for their family members' living arrangements tend to be within the range of what parents perceived as realistic possibilities.

This study also aimed to understand parents' aspirations for independent living with choice, control and any necessary supports, in the context of parents being cognizant of articles 12 and 19. For most of the parents in this study the CRPD brought no new possibilities. Participants in this study appeared to have even lower expectations of the CRPD than Jolly's (2010) research indicated. Parents appeared not to expect the convention would deliver adequate support that would facilitate independent living entailing choice, control and autonomy and social participation with mainstream society and disabled peers.  Some parents had concerns about articles 12 and 19 of the CRPD; particularly parents expressed reservations about their family member's ability to make safe choices.  However, according to the parents in this study, it is the risks that society poses to their family member and the lack of supported options and alternatives, especially when things go wrong, that are the primary root causes of their fears about choice and risks. Moreover, the parents in this study appeared not to believe that the CRPD would deliver their overriding aspiration; an ordinary life with a meaningful role

valued by society.  Many of the parents indicated that it is a person's perceived economic worth that society values a person by and independent living is achieved through work and then financial independence.  For many of the parents this economic participation, a prerequisite to independence, is not addressed by the convention.  This research then adds to Russell (2002) and Barnes and Oliver (2013) assertion that a rights based approach cannot deliver equality because it does not address the structural barriers within the employment market created by an unequal capitalist society.  In the end, although parents tended to focus on aspirations circumscribed by expectations, for all of the parents in an ideal world with support, acceptance and a valued role, autonomy and participation were desirable.  However, the question of intimacy was for many beyond the final frontier.

This research adopted a participatory approach and therefore will be judged on its ability to build knowledge among participants to facilitate their own self-determination and empowerment. The last aim of this study was then to disseminate the knowledge generated. The planned outputs of this study included a report for parents and an accessible report for adults with Down syndrome, to be submitted to DSI (DSI, 2011) for publication, I plan to begin this final stage in September 2013.

## 7.3 Future Research

This study originally set out to examine the aspirations of parents with family members with Down syndrome and although it was not my intention all of the participants were mothers.  Where family members provide support to a disabled person it is typically the mother who is the primary source of support within the family (Watson et. al., 2004).  Fathers *tend* then to occupy a different role.  Therefore, it would worthwhile to explore fathers' aspirations in future research.

Many of the parents in this study felt that schools, in particular secondary, are increasingly arguing that there are insufficient resources available to include students labelled with 'intellectual disability' and therefore, sending a child with Down syndrome to mainstream school is becoming progressively more difficult and increasingly an unlikely option.  Research to examine the barriers encountered by parents when applying and sending students labelled with an 'intellectual disability' to mainstream schools would be valuable.

In addition, some of the parents in this study believed that while students with Down syndrome may be physically present in a

mainstream school in Ireland, they are often excluded from mainstream teaching and the barriers include both a lack of resources and paradoxically, the presence of resources. Research to examine the level of inclusion/exclusion experienced by students labelled with an 'intellectual disability' in mainstream schools and the barriers to inclusion with a particular emphasis on the role of 'special needs' resources and mainstream teaching practices would also be worthwhile.

Many of the parents expressed concern about the lack of post-secondary courses leading to meaningful qualifications and moreover, actual paid employment. Although, statistics show that people labelled with an 'intellectual disability' are in the main excluded from paid employment (Kelly, 2011), research on the type of courses available to people labelled with an 'intellectual disability' and their success or failure in the preparation for and transitioning to actual paid employment would still be valuable.

## 7.4 Policy Recommendations

Parents in this study, expressed concerns about the risk wider society often posed to their family member labelled with an intellectual disability.  Evidence demonstrating how disabled people are more likely than non-disabled people to experience

abuse (McCormack, 2009, CICA, 2009) and violence (Hughes et al., 2012) exists.  Similar to research in the UK (DH, 2007), research in Ireland is required to examine hate crime directed towards people labelled with an 'intellectual disability' and then legislation to address the issue.

The legal right to direct payments covering the costs of disability and the right to and access to full support in the procurement and managing of services and independent advocacy is required. Payments, support and advocacy need to facilitate and cover all aspects of social and economic participation.

To state the obvious, the established practice of long term *unpaid* work for people labelled with an 'intellectual disability' must stop. It is exploitative and dependency creating (Oliver, 1990). However, replacing this practice with nothing would mean continued dependency. Everyone needs a 'valued' and 'meaningful' role in society (see chapter five); in a capitalist society that means paid employment.  Therefore, legislation which obliges the public sector to employ people labelled with an 'intellectual disability' specifically is required and redress for the years unpaid is required.

## 7.5 Optimism

In the end, though, it is difficult to see how these recommendations would be realized in an age of austerity (Bergin et al., 2011). These recommendations are only attempting to surface cover a systemic problem (Gleeson, 1997; Barnes and Oliver, 2012).  Not everyone can fit into the structure of the workplace (Tomlinson, S. and Colquhoun, 1995) and some will be systematically excluded (Russell, 2002, Barnes and Oliver, 2012). However, Pauline (Interview) said: 'You can't be too pessimistic you have to be optimistic'. I have to then believe that while it may not be possible to alter the social relations of work within capitalism (Gleeson, 1997, Oliver and Barnes, 2012); it has to be possible to replace capitalism with a just and equal system for everyone (Oliver and Barnes, 2012).

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**Appendix 1: Topic guide for the Focus Groups**

The purpose of the first part of this focus group is to try to understand together the difficulties we anticipate adults with Down syndrome will encounter/ are encountering in **adulthood** and then generate ideas together on how our collective problems might be resolved.

1.   **I would like to begin by asking you what difficulties do you believe or anticipate that adults with Down syndrome will experience in adulthood?**

    Possible prompts depending on how the discussion evolves:

    Living arrangements, community participation, employment, further education, interpersonal relationships, financial independence, changes over time?,  might difficulties vary depending on family circumstances: people/ different similar to yourself

    2.  **How might these difficulties be resolved?**

    Possible prompts : support, employment, service provision

### 3. CRPD

3.1 I would like now to discuss with you briefly the United Nations Convention on the Rights of Persons with Disabilities. To begin with, I would like to try to understand how widely known the convention is.

**How widely, do you believe, the United Nations Convention on the Rights of Persons with Disabilities is known?**

**What information/ knowledge do you have on the United Nations Convention on the Rights of Persons? I had no real knowledge of the convention until I began my studies in Disability Studies.**

3.2 Sharing information on the convention.

Ireland has signed and has committed to ratifying the convention (ratification – becomes legal) so, I would like to share some information on the convention. In particular, I am going to focus on two Articles, articles 12 & 19 (Vignette 3.2). Due to the limited amount of time we have available, I have summarized the information on the front page.

At the end of the focus group I am going to give you a copy of the convention for you to take home. This will give you an opportunity to look at all of the articles, if you so wish, and formulate your own priorities.

**3.3 Do you think adults with Down syndrome, given any necessary support, should have the right to make decisions in all matters of their life?**

Prompts: living arrangements, interpersonal relationships, employment, leisure, health,

**3.4 Do you think the right to choose and live independently in the community with any necessary supports will be realized?**

**3.5 What barriers might remain?**

Prompts: employment, funding of services and supports,

**3.6 Who should decide which day to day supports are required?**

**3.7 Who would you like to see providing and controlling the supports in daily living that might be necessary?**

Vignette : 3.7 Supports and Services handed to participants.

# Appendix 2: Vignettes for focus groups.

**Vignette : 3.2 CRPD**

**Overview  of Article 19:**

Article 19 of the CRPD states that disabled people have the **right**

to '**live in the community'**, with '**whom and where they choose**'

and avail of the necessary **supports** to live and be included in the

community (United Nations, 2006: 13-14).

**Overview of Article 12**

Article 12 obligates states to ensure that **everyone enjoys legal**

**capacity** to make decisions and everyone should be **supported**

in making their own decisions

The following proposed principles set how article 12 should be

implemented and includes three levels of support:

a)     the first level is where a person has the ability to **make**

   **decisions with only minimal support** e.g. easy to read

   information,

b)     The second level is **supported decision-making,**

   where a person is supported by someone they trust to

   make a decision, and

c)       the third level is **'facilitated decision-making'** – this is used as a last resort where the person's will and preferences are not known. Here, a representative has to determine what the person would want, based on what they know about that person and on their best understanding of their wishes.

These principles were developed by organisations including: the Centre for Disability Law and Policy at NUIG, Amnesty International, Alzheimers Society of Ireland, Age Action, National Federation of Voluntary Bodies, Shine, Inclusion Ireland, National Institute for 'intellectual disability' at TCD and set out how Article 12 can be achieved through new legal capacity laws in Ireland.

CDLP, et al. (2011) **Essential Principles: Irish Legal Capacity Law** (http://www.nuigalway.ie/cdlp/documents/principles_web.pdf)

(Note: the following sheetdetailing the exact wording articles 12 and 19, and a full copy of the CRPD were given to participants to take home but not read out during the focus group)

**Article 19**

**Living independently and being included in the community**

 States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

 (a) Persons with disabilities have the opportunity **to choose their place of residence** and where and with whom they live on an equal basis with others and **are not obliged to live in a particular living arrangement;**

 (b) Persons with disabilities have access to a range of in-home, residential and other community **support services**, **including personal assistance necessary to support living and inclusion in the community**, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

**Article 12**

**Equal recognition before the law**

1. States Parties reaffirm that persons with disabilities have the **right to recognition** everywhere **as persons before the law**.

2. States Parties shall recognize that persons with disabilities enjoy **legal capacity** on an equal basis with others in **all aspects of life**.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and

undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

**Vignette : 3.7 Supports and Services**

1) Direct payments

   Disabled people choose and control their own support services,

   any required support to manage those supports comes from

   independent advocates or disabled people's organizations.

2)    Individualized payments

3)    Service provider receives the budget

4)    Choice of the above, who decides?

Extract from Expert Report Group (2011);

   'An independent comprehensive assessment of need will shape

   the individual support plan for each person. Individualised

   supports will be used to identify an individualised budget, which is

   a sum of money that attaches to the person and is used to

   provide the supports and services they need within existing

   funding limitations.  The service user (and family as appropriate)

   will have an input into how this individualised budget is used and

   which providers will provide which supports.  A number

   of mechanisms can be used to achieve this, including **direct**

**payments,** where the person administers the budget themselves

[**with support from disabled peoples organizations and/ or**

**independent advocates if required**], or a **broker**

**system [Individualized funding]**, where the person has the

same amount of input into 'designing' their supports and services,

but uses the broker to administer the budget and to commission

supports and services on their behalf' (ERG, 2011, p.80)


Expert Reference Group (ERG) on Disability

Policy  (2011) **Report of Disability Policy Review**, prepared by

Dr. Fiona Keogh on behalf of the Expert Reference Group on

Disability Policy

(www.dohc.ie/publications/disability_policy_review.html)

**Appendix 3: Invitation to Participate in Research, Information Sheet and Consent Form**

**Invitation for Parents to Participate in Research Project**

Dear Parent,

My name is Fiona O'Riordan, I am Isabel XXXXX's Mum and a member of Down Syndrome Ireland Cork Branch. I am undertaking a Masters in Disability Studies by Distance Learning with The University of Leeds. My research dissertation will focus on **parents' aspirations for their family member with Down syndrome in adulthood.**

I would greatly appreciate if you would consider participating in this research project. Please find attached an information sheet, describing the aims of the research and the process, and a consent form should you decide to participate.

Participation involves **one focus group** for 1.5 hour and then, **one follow up individual interview by telephone** for 30 minutes to 1 hour. The focus groups will be conducted in Centre 21, Down Syndrome Ireland Cork Branch, Unit 7 Kilnap Business & Technology Park, Old Mallow Road, Cork, as follows:

- parents who have a family member with Down syndrome aged between 5 and 15 years: Monday 15<sup>th</sup> April @ 7.30 pm.
- parents who have a family member with Down syndrome aged 16 years or over, Wednesday 17<sup>th</sup> April @ 7.30 pm.

If you would like to participate, please contact me by text, telephone (0XXXXXXXX) or email (XXXXXXX) by Friday 5<sup>th</sup> April 2013.

**Please include the following information:**

Your Name

Telephone

Email

Age of your family member who has Down syndrome

Thanking you for taking the time to consider this request,

Fiona O'Riordan

**Information Sheet for Research Dissertation by Fiona O'Riordan:**

**Working Project Title:** The Struggle by Parents for the Rights of People with Down syndrome

Fiona O'Riordan, a student of the University of Leeds, is conducting a Masters research project.  The research aims to build understanding of parental aspirations for their family member with Down syndrome and the social actions required to achieve these aspirations, within the context of knowing the rights of people with Down syndrome.  Your participation in this research would be greatly appreciated and valued.

**Research Aims:**

1. to understand parents aspirations for their family member with Down syndrome in adulthood
2. to share knowledge and understanding on the rights of people with Down syndrome
3. to understand how effective parents believe these rights will be in realizing their aspirations
4. to identify what social policies and actions are required to achieve parents aspirations for their family member

5. to produce a dissertation underpinned by the social model of disability. The social model of disability asserts that impairment does not cause disability; social and economic exclusion, discrimination and oppression cause disability.

6. to produce a report for parents and an accessible report for adults with Down syndrome, to be submitted to Down Syndrome Ireland for publication, to share the knowledge gathered during the research.

**Research Process:**

Each participant (parent) is requested to partake in one focus group and then one follow up individual interview by telephone. The focus groups will last 1.5 hours and will be held in Centre 21, Down Syndrome Ireland Cork Branch, Unit 7 Kilnap Business & Technology Park, Old Mallow Road, Cork, as follows:

- parents with family members with Down syndrome who are between 5 and 15 years of age, Monday 15th April @ 7.30 pm.

- parents with family members with Down syndrome who are 16 years of age and over, Wednesday 17th April @ 7.30 pm.

The individual interview will be by telephone at a date and time of your choice after the focus group and will last approximately 30 minutes to one hour.

Please read and consider the below consent form.  If you decide to participate then you will need to sign the consent form before the focus group commences.  If more than the required number of parents wish to participate, then participants will be selected at random.

**Consent Form for Participation:**

As a participant you will be asked to discuss your aspirations for your family member, the social actions and changes required to realize your aspirations and your thoughts on the effectiveness of the rights of people with Down syndrome.  You will be asked to share your knowledge, experience and thoughts in both a focus group and a follow up individual interview by telephone. You are not obliged to answer any question that you do not wish to answer. The researcher will then analyse this information, placing this knowledge within existing concepts and research, to draw conclusions and findings and then produce a dissertation and accessible reports. You are free to withdraw from the research at

any time without explanation.   There are no anticipated risks associated with your involvement in this research.

The Focus group discussion is estimated to last up to 1.5 hours and will be audio-recorded.  A professional transcribing service provider, who will sign a confidentiality agreement, will then transcribe the recording. Names will be changed on the transcripts and no identifying information will be included.  The actual focus group and interview recordings will not be shared with any other third party and will be securely stored on the researcher's password protected home computer.  As a participant you will be provided with a copy of the transcript and you can choose to amend, delete or add to the information you have shared.

The individual follow-up telephone interview will be conducted at an agreed time and date that suits you.  The interview will be audio recorded and a copy of the recording will be sent to you. Again, you will have the opportunity to amend, delete or add to the information you have shared.  The researcher will only

transcribe the key information.  Your name will be changed and no identifying information will be included.

For the report for parents, you will be sent a draft of the report and invited to validate and provide input if you so wish.  For the report for adults with Down syndrome, an adult with Down syndrome will be employed to critique and provide feedback on the report, to ensure the report is accessible.  Both reports will then be submitted for publication in DSI's quarterly magazine and website and DSI Cork's website, should they so wish.

The research is an academic exercise and does not have organizational or political support to bring about immediate political change.  It does, however, have the potential to begin the process of building knowledge of parental aspirations for their family member with Down syndrome and the social actions required to achieve these aspirations, within the context of knowing the rights of people with Down syndrome.

If you should require any further information or have any concerns regarding the research and your rights as a participant, please do contact me at email: XXXX@XXXX.com or mobile: XXX XXXXXX at any time. If you have an access requirements please let me know.

**Your Consent:**

I understand that I will be participating in the research with the working title "The Struggle by Parents for the Rights of People with Down syndrome".  I have read and understood the above information and am aware of the aims of the research, the process and my rights as a participant.  **I also understand that I am free to withdraw from the research at any time, without any explanation.**

**Please sign here to confirm your consent to participate in this research:**

**Signed by:** _____

**Date**_____

# Appendix 4: Participants

For the purposes of anonymity and confidentiality, names have been changed and the ages of the people with Down syndrome are only expressed as a range.

## Focus Group 1 (FG1):

| | Family Member with Down syndrome | | | |
|---|---|---|---|---|
| **Participants Name** | Name | Gender | Age Range (years) | School |
| Deirdre | Kim | Female | 0 – 5 | Pre-school |
| Ciara | Jean | Female | 5 – 10 | Mainstream Primary School |
| Marion | Beth | Female | 5 – 10 | Mainstream Primary School |
| Judy | Rachel | Female | 5 – 10 | Mainstream Primary School |
| Valerie | Dara | Female | 5 – 10 | Mainstream Primary School |
| Treasa | Tom | Male | 10 - 13 | Mainstream Primary School |

## Focus Group 2 (FG2):

| | Family Member with Down syndrome | | | |
|---|---|---|---|---|
| **Participants Name** | Son/ Daughter's Name | Gender | Age Range | Occupation(s): |
| Pauline | John | Male | 30 – 45 | Paid Employee |
| Sheila | Conor | Male | 20 – 30 | 1.Farmer 2.Unpaid employee |
| Eileen | Eva | Female | 18 – 20 | Secondary School leaver |
| Michelle | Tanya | Female | 18 – 20 | Secondary School leaver |