

# **Adult Siblings of Individuals with Intellectual Disability/Autistic Spectrum Disorder: Relationships, Roles & Support Needs**

For

National Disability Authority

By

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## List of abbreviations and acronyms

ASD	Autism spectrum disorder
DS	Down syndrome
ID	Intellectual disability
NIID	National intellectual disability database
PCP	Person centred plan
PI	Principal investigator
PPS	Personal public service
TCD	Trinity College Dublin
TD	Typically developing
UCC	University College Cork



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## Summary

### Introduction

There has been limited exploration of the experience of siblings who live in family situations where their sister or brother has an intellectual disability (ID) or an autistic spectrum disorder (ASD). Little is known about how adult siblings understand their relationship with their brother or sister, and what understandings they may have about the roles they expect to play in the life of their brother or sister in the future. This study aims to:

- Document the nature and extent of sibling relationships throughout the lifecourse.
- Explore the feelings and understandings of siblings in relation to these relationships.
- Elicit their aspirations and concerns in relation to any future support roles they might play in their siblings' lives.
- Gather their opinions on what resources, interventions etc. could best support adult siblings in determining, negotiating and sustaining the caring/support role at various stages of the lifecourse.
- Analyse examples of good practice which would support adult siblings in whatever roles they play in the life of their brother or sister with ID/ASD in the future.

This study addresses these aims through an international literature review and 25 semi structured interviews with adult siblings of people with ID/ASD.

## **Understanding sibling relationships: what the literature tells us**

- Adult siblings maintain high levels of involvement and emotional connection with their brothers and sisters with ID/ASD across the lifecourse. Adult sibling roles take many forms and frequently change over time.
- Siblings feel a sense of responsibility for the future of their brother/sister with ID/ASD and expect to be involved in supporting them or caring for them in the future.
- Siblings' wishes to provide support for their brother or sister with ID/ASD can sometimes clash with responsibilities they have to spouses, partners, children, their work etc. This can cause tension and guilt for the adult siblings.
- The future roles that adult siblings might play in the lives of their brothers or sisters are rarely formulated into concrete future care plans. There is a reluctance among parents to discuss or engage in futures planning.
- Adult siblings do not systematically consult with their brothers or sisters with regard to what future living or care arrangement the latter might prefer. Only a minority of participants mentioned what they perceived to be the preferences of their brother or sister.
- Support needs experienced by adult siblings include; support with proactive futures planning, counselling services for parents and adult siblings, opportunities for developing support networks, information on services available to brothers and sisters, financial and legal advice and practical and emotional support.

## **Findings from the interviews: sibling childhood experiences**

- Siblings are socialised into 'minding' and 'looking out for' the brother or sister with special needs from an early age.
- As children, the siblings did not experience their family lives as being different from other families. Most felt that having a brother or sister with a disability did not impact negatively on their lives. They accepted the way their siblings were and saw that as part of 'normal' life. They now see how their lives were different and many acknowledge the intensive care work that their mothers engaged in.

- In a small number of families, mothers or fathers struggled to cope with the challenges of having a child with ID/ASD. Participants from these families had some negative experiences. Challenging behaviours by brothers or sisters were reported by a few participants but these behaviours did not make them feel unsafe or anxious at home.
- Many participants stressed how important it was for siblings to receive age appropriate information about their brother or sister's disability at relevant stages throughout childhood.

As children, many participants experienced negative public attitudes towards their brother or sister with a disability. For some, this resulted in conflicted emotions about their brother or sister with ID/ASD. On the one hand, they felt embarrassed by their brothers or sisters and, on the other hand, they felt sorry for them because of their disabilities.

- As they grew older, many participants realised the potential which their brother or sister with a disability had for developing their potential and leading an adult lifestyle.

### **Findings from the interviews: current adult sibling roles and experiences**

- The majority of participants were centrally involved or planned to be involved in supporting their brother or sister with ID/ASD. Most can be described as the 'most involved' siblings in the life of their brother or sister.
- Their relationships with their brothers and sisters were underpinned by bonds of affection and many participants emphasised the pleasure which the relationship brought to them.
- Reconciling the most involved sibling role with other responsibilities, life situations and life aspirations, resulted in complex emotional tensions for some participants, with guilt and, in some cases, resentment, featuring in participants' accounts.
- Activities participants undertook for/with their brother or sister included; keeping in touch through phone or Skype, shared engagement in family and social activities, support with practical care/self-care activities, occasional supplementing of primary care arrangements provided by parents or

residential facilities, facilitating development of self-care and independence skills, monitoring and overseeing service provision, advocacy work with professionals and organisations and negotiating with parents and other siblings in relation to the development of future support plans.

- In some cases, siblings were more focused than were their parents, on supporting their brother or sister with ID/ASD to develop greater independence skills.
- Participants envisaged a range of future living situations for their siblings, including continued residential care, movement into residential care, supported independent living and co-residence with themselves.
- Most participants, whose brothers or sisters are currently in residential care, supported continuation of this arrangement. They perceived that their future role would involve: monitoring the quality of the care service provided; negotiating with service providers to ensure that the needs of their brothers or sisters are being met; and, providing companionship and facilitating family engagement with their brother or sister.
- Most participants noted that there was no definite plan for the future of their brother or sister. In many cases their parents were reluctant to engage in planning.
- Concern for the welfare of their brother or sister in the future and lack of clarity about how, where and by whom they would be supported was a source of anxiety for many participants.
- Most of the participants believed that they would play a major role in organising and/or providing this future support.

### **Findings from the interviews: sibling support needs**

- There are serious gaps in the supports available to siblings throughout the lifecourse.
- Key supports required include; information about disability entitlements and service provision, support with engaging in family discussion of future and transition planning and access to high standard day, respite and residential services for brothers and sisters with ID/ASD.

- Initiatives to promote greater public awareness of ID/ASD and fora that provide ongoing information and support for siblings are also required.
- Siblings are not a homogenous group and their different family configurations, personal circumstances and personality types will influence their perceptions of what supports might be of use to them and their willing and capacity to engage with same.

## **Recommendations**

### **Information and support needs**

- Young siblings need to be supported by parents and service providers from an early age. They need age appropriate information about the impairment experienced by their brother or sister and about how this might impact on their brother or sister's behaviour, appearance and development.
- Siblings need to receive information about their brother or sister's disability throughout their childhood. The information needs to be age-appropriate and should keep siblings informed about changes in their brother or sister's behaviour, health or impairment and changes in the therapies or medication they are receiving.
- Consideration should be given to the best way to provide information. It needs to be age appropriate, provided in a way that is easily accessed and that recognises the level of digital engagement of young people.
- As many students with ID/ASD are now integrated in mainstream schools, there is a need for disability awareness education to be integrated into primary and secondary school curricula. Awareness programmes would assist in educating students from families who do not have the experiences of living with special needs and make it easier for siblings to explain their own personal situations to their peers.
- Information products such as short films or animations would be a useful resource in school settings. The provision of age related fact sheets which could be shared with parents would extend the potential of such school-based awareness initiatives.
- As siblings transition from young childhood into adolescence, there is an increased need for more information regarding the brother/sister's disability. Many participants had searched for information on the Internet

and there is a need to provide easy access to online fora in the Irish context.

- Peer support can be provided through formal groups such as Sibshops (as discussed in Chapter 2), which are suitable for siblings who would benefit from the facilitated sharing of experiences with peers. Sibshops are designed as a time-limited, managed intervention and as such are resource heavy and have a limited applicability. Social or digital networking opportunities for siblings are also required. The online digital resource provided by the UK charity Sibs (<https://www.youngsibs.org.uk/>) and targeted at children between the ages of 7 and 17 is a good model.
- The US based SibTeen, which operates as a closed group on Facebook, is a global online community targeted at adolescents who want to exchange experiences and views about what it is like to be a sibling of an individual with an intellectual or ASD ( [https://www.siblingsupport.org/connect-with-others-sibs/meeting\\_other\\_sibs\\_online/sibteen](https://www.siblingsupport.org/connect-with-others-sibs/meeting_other_sibs_online/sibteen)). The potential for similar fora which reflect the Irish context should be explored.
- Consideration should also be given to the value of providing real-time meeting opportunities for adolescent siblings. Activity- based events and safe meeting places, along the lines of youth cafes, merit consideration.
- Some siblings may need one-to-one support and to talk to someone outside the family about their emotional and practical needs.
- Adult siblings of people with ID/ASD and particularly those moving into the role of advocate or overseer of services for their brother or sister, require support and information. A dedicated Irish resource point to meet the information and support needs of adult siblings of people with ID/ASD would be useful. The Sibs organisation in the UK provides (<https://www.sibs.org.uk/>) a good model.

### **Futures planning**

- Service providers and professionals need to facilitate families in planning for future living, support and care arrangements.
- Future planning dialogue between parents and typically developing (TD) siblings, and where possible the person with ID/ASD, needs to be encouraged as early as possible.



- An awareness raising campaign targeted at parents and adults siblings is required to encourage futures planning. This could occur in conjunction with initiatives such as planning workshops providing information about issues to be considered and resources which would facilitate planning activities. Such resources could be available both electronically and in print format and could provide details about:
  - Assisted decision making and guardianship
  - Wills, inheritance and financial trusts
  - Residential options and elicitation of individuals wishes for the future
  - Entitlements for people with disabilities and carers under the Irish welfare and legal systems
  - Self-reflection resources to encourage siblings to consciously consider what role they want to play in their brother or sister's future
- An activity book/DVD set designed to help families with planning such as the US produced 'My Life Book: Future Planning for People with Developmental Disabilities' (Meyer & Holl, 2014:173) would also be helpful. The set consists of a video, which follows four families attending a future planning class and a related workbook, which provides a location for recording important information about the individual with ID/ASD, about the family and about their wishes and plans for the future
- Siblings moving into the role of advocate or overseer of services for their brother or sister with ID/ASD, require practical information relating to that individual's medical information, entitlement cards, personal public service (PPS) numbers, names and contact numbers for relevant professionals, etc. A hard copy and/or electronic template tailored to the Irish context which, would facilitate the compilation of such information would be very useful.
- Disability awareness programmes, targeted at potential 'natural supports' such as extended family members, friends and members of the local community, and highlighting the role they could play in supporting people with ID/ASD may foster the development of 'natural supports'. To be effective these may need to be supplemented by practical training and information sessions for those who wish to take on such roles.

### **Implications for service provision, practitioners and professionals**

- Professionals and service providers need to recognise the roles that siblings undertake and acknowledge them as active agents in the support

structure within families. Such engagement with siblings as well as parents, is likely to improve the quality of life of individuals with ID/ASD.

- Siblings whose brothers or sisters are in residential services, have varying experiences with staff in these facilities. Their accounts demonstrate that practices applied by services vary significantly. Sibling awareness within service provision organisations, and a more systematic approach to dealing with siblings, would be desirable.
- Reflection on current practices, staff attitudes and possible training needs would be helpful as would the development of national, service level protocols around engagement with siblings. Such protocols would need to acknowledge that sibling roles are different to those of parents and are likely to change as siblings proceed through the lifecourse.
- Person centred plans (PCPs) provide a useful opportunity for exploring sibling connections and considering how sibling contact and support could be facilitated.
- The adoption of a whole family approach by professionals and service providers is desirable.
- Greater consideration could be given by service providers to the potential that siblings have in relation to widening natural supports for people with ID/ASD.

### **Implications for policy**

- Participants in this study describe a variety of living arrangements, which their brothers or sisters are currently availing of, or which they hope will be availed of by them in the future. This diversity makes clear the need for a range of living arrangements, which reflect the wishes of the individual with ID/ASD, their level of ability and the financial and family based supports they have at any given time.
- Where siblings are supporting their brother or sister in the 'community', adequate financial, information and professional supports need to be put in place to facilitate this.
- Individualised models of service provision and personalisation of funding offer individuals with disabilities more decision making input in relation to the design of the care, support and training package that best suits their needs and wishes. However, personalised funding also brings challenges. If

it is not resourced at an adequate financial level, a personalised funding model could potentially increase care and support demands on siblings of people with ID/ASD.

- Many people with ID/ASD are also likely to require support with decision making about how personalised funding is to be spent. It is probable that siblings would be involved in providing this support and they would require information and guidance in relation to this role.
- It is to be expected that some siblings will take on decision-making roles as part of the new arrangements set out in the Assisted Decision-Making (Capacity) Act 2015. In this context, siblings need to be recognised as an identified group and provided with specific information about the terms of the Act, and what it means for decision-making processes involving their brother and/or sister with ID/ASD.

### **Implications for future research**

- Research on sibling relationships in situations where one sibling has a disability, has focused almost exclusively on the sibling without the disability. Irish research which, considers how people with ID/ASAD perceive their relationships with their typically developing brothers and sisters, and on their preferences in relation to the types of roles they would like their siblings to play in their lives, would be useful.
- Research on sibling experiences where one sibling has ID/ASD, has primarily involved individualised analysis of the impact on the TD sibling, of having a brother or sister with a disability. Research which draws on macro-level, material and structural analysis of the socio-economic, legal and policy contexts in which, sibling relationships are constructed would be welcome. Such research should consider policy domains including disability policy, family support policies, care policies, housing policies, welfare provision and legal rights.
- Research to explore the gendered dimensions of sibling relationships is also necessary. Exploration of how and why, women more frequently become the most involved sibling is required. The implications of such roles for women need to be investigated, and consideration needs to be given to how such roles might be more equally dispersed among women and men.

# I Introduction

## I.1 Background to research

A substantial body of social scientific and psychological research has explored the impact of having a disabled child, within the context of the family and family networks (Dobson et al., 2001; Dyson, 2010; McConkey et al., 2008; Paster et al., 2009; Seligman and Darling, 2007). Much of this research has focused specifically on the experiences of parents, and parental roles in terms of care-giving. There has been limited exploration of the experience of siblings, both as children and as adults, in family situations where their sister or brother has a disability. We know little about how siblings understand their relationship with their brother or sister, and what understandings they may have about the roles they expect to play in the life of their brother or sister in the future.

The aim of this research is to document the experiences of adult siblings of individuals with intellectual disabilities/autism spectrum disorders (ID/ASD) with a view to identifying best practices in relation to supporting them in their multiple roles with their brother(s) or sister(s). While there is a significant body of international literature on children's experiences with siblings with intellectual disabilities (Rossiter & Sharpe, 2001), few studies have extended the investigation of the sibling bond into the adult years. The limited research available suggests that adult siblings maintain high levels of involvement and emotional connection with their brothers and sisters with ID across the lifecourse (Orsmond & Seltzer, 2000; Pruchno, Patrick, & Burant, 1996). However, this contact is mediated by factors such as gender, with sisters playing a more supportive role (Orsmond & Seltzer, 2000; Seltzer, Begun, Seltzer, & Krauss, 1991), and diagnostic differences, with more extensive and more positive relationships being found with siblings with Down syndrome (DS) compared to ASD (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007).

Currently we have limited understanding of the extent to which such siblings are involved in their brother or sister's lives, and of how they feel about taking on increased caregiving responsibilities as their parents age and die. The limited research exploring the experiences of Irish families of people with ID focuses primarily on the experiences of parents. Of the 70 family members who participated in the 2013 Family Voices study by Chadwick et al., (2013), only 5 were siblings. Given the role that siblings play in providing care for adults with ID and ASD in later life, documenting their experiences is of crucial importance for Irish disability policy (Hodapp, Glidden, & Kaiser, 2005), particularly in a context where increased emphasis is being placed upon independent and community living, and on the development of 'natural supports' for people with disabilities (Weafer and Weafer, 2012).

## **1.2 Research aims and objectives**

The specific objectives of the research are:

- To document the nature and extent of sibling relationships throughout the lifecycle.
- To explore the feelings and understandings of siblings in relation to these support relationships.
- To elicit siblings' aspirations and concerns in relation to any future support role they might play in the lives of their siblings.
- To gather their opinions on what resources, interventions etc. could best support them in determining, negotiating and sustaining the caring/support role at various stages of the lifecycle.
- To analyse examples of good practice which would support adult siblings in whatever roles they play in the life of their brother or sister with ID/ASD in the future.

## **1.3 Research governance and methodology**

Inclusion Ireland,<sup>1</sup> a national rights-based advocacy organisation, which promotes the rights of people with an ID and their families, partnered with the UCC research team in undertaking this study. The organisation played a vital role in the research process. Fiona Duignan, Policy and Projects manager from Inclusion Ireland served on the Research Advisory Group for the study, which also included Dr Michael Feely from the School of Social Work and Social Policy in Trinity College Dublin and the members of the UCC research team, namely, Dr Máire Leane (PI), Dr Anna Kingston and Dr Claire Edwards. The Research Advisory Group contributed to all stages of the research process including identification of the topic guide for the interviews, discussion of preliminary findings and the development of recommendations.

This research is based on a small-scale qualitative study, which adopted a two-pronged methodological approach. The first element of the research consisted of a literature review which draws on both national and international literature, and explores sibling experiences of having a brother and/or sister with an ID/ASD,

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<sup>1</sup> Inclusion Ireland is a national advocacy organisation promoting the rights of people with intellectual disabilities and their families. It is an umbrella group for over 160 organisations who work and campaign in the field of intellectual disabilities. For further information go to [www.inclusionireland.ie](http://www.inclusionireland.ie)

the extent and nature of sibling caring and support, and initiatives for supporting siblings in caring and support roles.

In reviewing the literature, several social science and health databases were used, including Web of Knowledge, JSTOR and Academic Search Complete. Search terms included "disability", "autism" and "siblings". Several newly published publications were sourced through the UCC Article Finder Alert using the keywords "disability" and "siblings". This search produced different types of literature, including international peer-reviewed academic journals, policy documents produced by statutory agencies and civil society organisations, research reports commissioned by organisations, and 'grey' literature.

The second phase of the research involved semi structured interviews with 25 siblings of people with ID/ASD between the ages of 18 and 45 living in Ireland but also, in some cases, living internationally (where the brother or sister with ID/ASD resided in Ireland). The interviews focused primarily on exploring the nature of the sibling relationship (in both childhood and adulthood), documenting the nature and range of support roles played by siblings, and identifying the types of support which would be of most use to siblings in sustaining them in these roles. Further details of both elements of the methodology are set out in Chapter 3.

#### **1.4 Situating the research: the Irish context**

Despite recent developments in disability policy in Ireland, siblings of people with ID/ASD have received little visibility within the disability policy or research domain. In 2013, 27,691 people were registered with the National Intellectual Disability Database (NIID),<sup>2</sup> with 18,498 of these living at home with parents, sibling, other relatives or foster carers (Care Alliance Ireland, 2015:2/3). The extent to which adult siblings provide care for these people is however unclear. The Irish Central Statistics Office indicate that many adult children provide unpaid care in their family homes, however the figures do not identify who this care is provided to (Central Statistics Office, 2012). It is vital that efforts are made to identify more specifically the dynamics and dimensions of sibling support and care for people with ID/ASD, not least so that statutory and voluntary sector organisations can effectively develop practice initiatives, which facilitate siblings in the support and care of their brothers and sisters with intellectual disabilities/ASD.

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<sup>2</sup> The National Intellectual Disability Database (NIDD) collects data from service providers, Health Service Executive personnel and school principals about people with ID who are availing or waiting for services. This data informs the number of people with ID identified by the NIDD.

Figures on the numbers of siblings who are involved in caring roles are scant. The 2011 Census records that there are 187,112 family carers in Ireland, that is, men, women and children caring for a person with a disability, health problem or long term illness. However there is no disaggregated data regarding siblings' care of their brothers or sisters with disabilities (Central Statistics Office, 2012).

Similarly, the Growing Up in Ireland survey asks a range of questions about health and disability, including whether someone in the child's family has a disability, the relationship of this person to the child, and whether this affects the study child adversely. However many variables remain unaccounted for (including the type of disability), and we are unable to calculate how many children have a sibling with a disability

([http://www.growingup.ie/fileadmin/user\\_upload/Conference\\_2014/conference\\_presentations/session\\_e/the\\_effect\\_of\\_disability\\_on\\_siblings\\_Collins\\_and\\_Doherty.pdf](http://www.growingup.ie/fileadmin/user_upload/Conference_2014/conference_presentations/session_e/the_effect_of_disability_on_siblings_Collins_and_Doherty.pdf)).

Awareness of the needs of siblings, and sibling voices has however begun to emerge in other types of arenas, including the media and parent support groups. The National Parents & Siblings Alliance, for example, provides a link to a booklet for younger siblings published in the 1990s by the Brothers of Charity

<http://www.npsa.ie/content/siblings>. Some limited articles in the media have documented the experiences of siblings, but primarily from the perspective of parents. One article, for example, entitled 'Autism: siblings 'have no idea how hard they have it' recounts a mother's concerns for her three 'typically developing' children<sup>3</sup> and their relationship with their 8-year-old sister who has ASD, not least in terms of the potential negative effects of growing up in a chaotic household, but also future care responsibilities

(<http://www.independent.ie/lifestyle/health/autism-siblings-have-no-idea-how-hard-they-have-it-30012701.html>).

Some local Irish ASD support groups have recognised the support needs of siblings of people with ASD. For example, one Dublin-based group, Harold's Cross Autism Resources, Therapy and Support, addresses future concerns for adult siblings of people with ASD on its website, and makes readers aware of the sources of stress and worries that both children and young adult siblings may have in relation to their brother or sister, including "embarrassment around peers; jealousy regarding amount of time parents spend with their brother and sister" and so on. It also raises the important issue of how young adults may feel responsible for their siblings, which could impact on their decisions to leave

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<sup>3</sup> Typically developing is a term commonly used for research purposes to identify children who have no diagnosis or impairment and are assumed to be meeting normal developmental milestones.

home and live independent lives (<http://www.hxarts.org/siblings.php>). As we document later, some work has also been undertaken in the Irish context in terms of developing and evaluating Sibshops <sup>4</sup>as a support mechanism for siblings (see for example D'Arcy et al., 2005).

In terms of contemporary policy agendas, a number of developments are pertinent for thinking about sibling relationships and roles in the context of people with ID and ASD. In particular, there are two significant legislative and policy trends which may have consequences for siblings who are involved in some form of support role with their brother or sister. The first of these relates to the move towards more personalised, community-based services for people with disabilities; the second concerns proposed changes to capacity legislation, as set down in the Assisted Decision-Making (Capacity) Act 2015.

#### **1.4.1 Moves towards personalisation and community living**

Reflecting international trends, and influenced by ideas emanating from the independent living movement, there has been a move in the past ten years towards supporting people with disabilities to live independent lives in the community, rather than in institutional settings. This agenda has coalesced over the past 5 years in a range of documents published by the government and Health Service Executive, including *Time to Move on From Congregated Settings* (Health Service Executive, 2011), *New Directions* (Health Service Executive, 2012), and *Value for Money and Policy Review of Disability Services in Ireland* (Department of Health, 2012). In all of these documents, there is an assertion of the need to provide more personalised services and individualised types of service provision. However, these may also presuppose the existence of informal community-based and family-based support networks.

While, in the context of this research, the implications of this policy agenda for siblings are not clear (and indeed, siblings are not mentioned specifically in these documents), it would be fair to say that siblings are likely to be seen as part of that network of informal supports which are supposed to more actively engage the person with a disability in social and community activities. This however may be a problematic assumption, insofar as it may not reflect the diversity of sibling relationships, the different types of expectations that siblings may have about

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<sup>4</sup> Sibshops are opportunities for brothers and sisters of siblings with special needs to obtain peer support, education and advice within a recreational context.

[http://stjosephsfoundation.ie/?page\\_id=835](http://stjosephsfoundation.ie/?page_id=835) and <http://www.autismireland.ie/news-events/463/sibshops/>.



their support role, and the nature of contemporary Irish families in which siblings may live abroad or away from their brother or sister with ID/ASD.

## 1.5 Changing capacity legislation

Siblings' support roles also need to be understood in the context of changes to Ireland's capacity legislation, as set down in the Assisted Decision-Making (Capacity) Act 2015

([http://www.citizensinformationboard.ie/downloads/relate/relate\\_2016\\_04.pdf](http://www.citizensinformationboard.ie/downloads/relate/relate_2016_04.pdf).)

The Act replaces the Ward of Court system of the Lunacy Regulation (Ireland) Act 1871, and is built on the presumption that people with disabilities will have access to informal supports such as close family members and friends, in making decisions about different areas of their lives. Under the Act, the person with a disability (the appointer) can choose someone (for example, a parent, a sibling, a close relative or friend), to support them in making decisions where they lack capacity to make such decisions on their own. Three types of decision-making arrangements are provided by the Act, namely, (a) Assisted Decision-Making, (b) Co-Decision-Making and (c) a Decision-Making Representative appointed by the court.

Under the Assisted Decision-Making arrangement, a Decision-Making Assistant can be appointed by a person, who feels her/his capacity is limited and that she/he needs to be supported in making decisions. The function of the Decision-Making Assistant is to **assist the person in making her/his own decisions** in certain areas of her/his life. Under the Co-Decision-Maker arrangement, **decisions are made jointly between the person and the Co-Decision-Maker**. This is the key point of difference with the Assisted Decision-Making provision described above, in which the person makes her/his own decision. Finally, under a Decision-Making Representative arrangement, the court appoints someone to make decisions in certain areas on behalf of the person, after determining that the person lacks capacity to make those decisions.

The Act allows for the roles of Decision-Making Assistant, Co-Decision-Maker and Decision-Making Representative, to be taken on by parents, siblings, close relatives or friends, provided that they are 18 years or older and have a bona fide interest in the welfare of the person requiring support. The Act also sets out who cannot be appointed as there are some restrictions. As such, it is possible that siblings will fill these roles for some people with ID/ASD who need decision-making support.

## **1.6 Structure of the report**

This report is structured into seven chapters. Chapter 2 provides a review of relevant literature. Chapter 3 outlines the methodology underpinning the research. Chapters 4, 5 and 6 outline and analyse the findings from the research. Finally, chapter 7 draws conclusions and makes recommendations for future practice and policy in relation to the recognition and support of adult siblings of individuals with ID/ASD.

## 2 Literature Review

### 2.1 Introduction

In this chapter, we discuss the parameters and findings of international literature which has explored the sibling relationship in the context of ID/ASD. The field of sibling research in relation to *adult* siblings is a relatively recent one; far greater attention has focused on the psycho-social effects of having a sibling with an ID/ASD in childhood, and on child development and adjustment (Tozer and Atkin, 2015; Heller and Arnold, 2010). This interest in childhood psycho-social adjustment came largely from a presumption that having a sibling with a disability could lead to negative social and psychological outcomes for so called ‘typically developing’ (TD) children (Petalas et al., 2012; Meadan et al., 2010). As a result, a significant body of sibling research has tended to explore the relationship in terms of binary categories (that is, positive or negative outcomes). This literature, which has largely been rooted in the discipline of psychology, draws predominantly on quantitative methodologies in which parents, rather than siblings themselves, have been respondents to standardised assessment tools or scales (see for example, Fisman et al., 2000; Benson and Karlof, 2008). While these studies provide a picture of the extent of ‘adjustment’ and the influence of different factors on this adjustment, they are perhaps less able to capture some of the complexities and nuances of sibling relationships which may not be simply positive or negative, but reflect a multitude of constantly changing roles and emotions. To that end, a number of recent studies (many of them drawing on qualitative methodologies) have sought to shed light on how siblings of adults with ID/ASD understand, and make sense of, their roles as sibling, and the sibling relationship (see for example, Hodapp and Urbano, 2007; Davys et al., 2010; Tozer and Atkin, 2015; Tozer et al., 2013). Insights from these studies are particularly helpful in the context of this research.

This chapter explores some of the parameters (and limits) of the sibling research field, and proceeds to focus specifically on literature which enables an understanding and conceptualisation of the adult sibling relationship. In particular, it draws on literature which explores how adult siblings understand the changing nature of their relationship and the types of roles they perform, or in some cases, feel are expected of them, in the context of their brother or sister (Tozer and Atkin, 2015). These roles, and emotional investment, have to be understood in the context of previous childhood experiences and the dynamic nature of family relationships; where relevant, therefore, the review draws on literature which pertains to childhood and/or adolescent sibling relationships, considering them in the context of “lifespan development” (Hodapp and Kaiser, 2005: 336). There are, however, distinct issues that may shape the adult sibling relationship, not least of which is the issue of future planning (Davys et al., 2014, 2016). This is

particularly significant in a context where people with ID/ASD are living longer, and where living arrangements which stress personalisation and independence may involve siblings in planning, and being actively engaged in, their brother and/or sister's support as their parents age, or pass away (Seltzer et al., 2009; Tozer and Atkin, 2015). The chapter concludes by considering siblings' support needs in both childhood and adulthood, and how these might be addressed.

## **2.2 Contextualising sibling research**

As set out above, the emphasis on adult siblings in relation to people with ID/ASD is a relatively recent departure in social science literature. The concern to study siblings – particularly in childhood – was often linked to the assumption that having a sibling with ID, ASD or indeed any disability had negative psycho-social outcomes for the 'typically developing' child. As Heller and Arnold (2010: 16) note, "Much of the early research on siblings pathologized the experience of growing up with a person with a disability", and this pathologization has shaped much of the research which seeks to explore psychological adjustment of the sibling, and the psycho-social outcomes of having a sibling with an ID/ASD. Siblings were typically constructed as a group "at risk" (San Martino and Newman, 1974), with studies suggesting that siblings of children with ASD may be more likely to have psychological and/or behavioural problems and poorer self-esteem. Rossiter and Sharpe's (2001: 76) large scale quantitative review (or 'meta-analysis') of literature between 1972 and 1999, for example, concluded that there is a "statistically significant but small negative effect for having a sibling with mental retardation on the functioning of the typically developing sibling" (see also Bågenholm and Gillberg, 1991; Fisman et al., 2000). This effect has been attributed to a greater level of parental stress and concern focused on the child with ID/ASD; greater social isolation of the non-disabled child from peers and others (including having to deal with feelings of embarrassment), increased caregiving roles and responsibilities within the family; and in cases of ASD, having to deal with violence and aggressive behaviour (Ross and Cuskelly, 2006; Barr and McLeod, 2010; Opperman and Alant, 2003). Other studies have, however, shown the results to be less clear cut (Cuskelly and Gunn, 2006; Hastings, 2007; Heller and Arnold, 2010). For example, while acknowledging the challenges that siblings may face, others suggest that negative effects have been overstated, and that there are many positive outcomes of these sibling relationships, including greater tolerance and empathy in siblings of children with ID/ASD (Dellve et al., 2000; Petalas et al., 2012; Kaminsky and Dewey, 2002).

Historically, many of these 'adjustment' studies, which focus on the positive or negative outcomes (or seek to 'count' positive versus negative outcomes), were based on large scale surveys, and considered outcomes only in relation to children. Many also sought to disentangle the different factors that affect sibling relationships, including the gender of the sibling, type of impairment and age of

sibling and/or position in the family; these are dimensions that we return to later in the chapter (Meadan et al, 2010). There has however been some reflection in recent years on the type of research being undertaken under the rubric of 'sibling research', and discussion about future research agendas. For example, Hodapp et al. (2005) acknowledge the need not just to focus on the sibling relationship in childhood but also the transition into adulthood, recognising the development of relationships over the lifecourse. To that end, there have been a number of emerging studies (from North America, the UK and Australia, in particular) exploring adolescent and adult siblings' experiences and transitions across different stages of their life (Seltzer et al., 2009; Heller and Arnold, 2010; Heller and Kramer, 2009; Hodapp and Urbano, 2007; Orsmond and Seltzer, 2007). Many of these studies have for the first time given voice to siblings themselves, rather than using parents as 'proxy' respondents for children, an approach which characterised many of the early (quantitative) studies.

Others have argued for the need for qualitative research to explore sibling experiences, and complement existing quantitative approaches. Petalas et al., (2012: 304), for example, argue that "Although quantitative research can help us to understand what variables affect sibling adjustment or sibling relationship outcomes, they do little to inform our knowledge of how siblings make sense of their circumstances and attribute meaning to their experiences when they have a brother or sister with an ASD". Qualitative studies have facilitated a focus not just on psychosocial outcomes and behavioural adjustment, but allowed an exploration of how siblings understand their relationship, including some of the tensions which explain the positive and negative outcomes and "mixed findings" (Petalas et al., 2012: 304) presented in quantitative studies (see also Tozer and Atkin, 2015; Dellve et al., 2000). Significantly, they have also facilitated an understanding of how adult siblings often engage at the interface with service providers to act as advocates for their brother(s) or sister(s), and raise questions about how service providers perceive these siblings and the roles they play. It is important to acknowledge also, that while there is some literature which focuses on support mechanisms for children with siblings who have ID/ASD (for example, the development of SibShops), there is little, or nothing, written on supports that may be required for adult siblings.

### **2.2.1 Conceptualising the adult sibling relationship**

In this section, we draw largely on literature which has focused on adult sibling relationships to consider how this relationship has been understood, what type of roles adult siblings play, how they understand their role in future planning (if at all), and what supports they themselves require. As such our focus is less on psychosocial outcomes for adult siblings, although this is something that has been extended from childhood to adult sibling relationships in various studies. For

example, in their review of literature on adult siblings aged over 21, Heller and Arnold (2010: 23) conclude that the reviewed studies “present a mixed, but generally positive picture of the psychosocial outcomes of having a sibling with an intellectual or developmental disability”. One of these studies, a web-based survey conducted with 460 adult siblings of individuals with ASD and DS in the USA, suggested that the majority of respondents reported a positive relationship with their sibling and that “they themselves were functioning well” (indicated by low levels of depressions and self-reported ‘very good’ health) (Hodapp and Urbano, 2007: 1023). However, the study did note some differences between those individuals whose siblings had DS and those who had ASD, an issue we return to in section 2.4.2 below.

Before discussing some of the findings of research in relation to adult sibling relationships, it is helpful to lay out some of the recurring *conceptual* themes which cut across the literature, and which help to inform how the adult sibling relationship can be understood.

**The lifecourse:** a number of studies draw attention to the need to understand sibling relationships across the lifecourse (Seltzer et al., 2009; Hodapp et al., 2005). This means not just acknowledging that sibling relationships are constantly in transition, but that different ages or stages of life may lead to particular dimensions or dynamics in the relationship coming to the fore at different times. For example, Tozer and Atkin (2015) note that adult sibling relationships may be affected by the different roles and responsibilities of siblings in their adult lives. Supporting a brother or sister with an ID/ASD can be more challenging for a sibling who has children, lives far away from the family home, or is juggling other work-life commitments. Meanwhile, siblings can be confronted with feelings of resentment or guilt from earlier life, drawing attention to the need to recognise the influence of childhood experiences in shaping sibling relationships in adulthood (Dellve et al., 2000; Tozer et al., 2013).

**Sibling relationships within the broader family ‘system’:** a range of studies have highlighted the significance of thinking about sibling relationships in the context of the broader family unit. For example, Angell et al.’s study (2012) of the experiences of siblings of individuals with ASD, draws on family systems theory to explore how sibling dynamics effect notions of family cohesion and adaptability, while other studies have suggested that psychosocial outcomes for children with a brother or sister with ID/ASD have to be understood in relation to parents’ behaviours and coping strategies towards the child with ID/ASD (Seltzer et al., 2009; Rossiter and Sharpe, 2001; Smith and Elder, 2010). In short, the sibling relationship cannot be understood in isolation, but as situated within a broader set of family relationships and social networks.

**Constructing sibling roles and relationships in the context of policy and legislation:** thinking about sibling relationships in the context of policy developments and the interface with service provision/providers (for example, around carers and caring, or capacity and assisted decision-making) draws attention to the way in which siblings, and the roles they might play, are constructed and understood by policymakers and professionals (Petalas et al., 2012; Tozer et al., 2013). For example, in Ireland the move towards personalisation in services for people with disabilities, or changes to capacity legislation, may have implications for siblings of adults with ID/ASD who might be supporting their brother or sister around these issues.

These conceptual starting points are helpful insofar as they further recognise the sibling relationship as a dynamic, contingent and multi-faceted entity. Siblings often experience a number of “harmonizing dilemmas” (Dellve et al., 2000: 172) in terms of seeking to reconcile sometimes conflicting emotions and roles. However, it is also important to avoid pathologizing sibling relationships in the context of disability by recognising that all sibling relationships – regardless of whether one sibling has an ID/ASD or not- are subject to different dynamics, including, in many cases, tension and conflict.

### **2.3 Understanding the adult sibling relationship: the influence of previous childhood experiences**

As numerous studies point out, the sibling relationship is a key relationship as it is the first instance of socialization that children experience; siblings also “provide the longest-lasting family relationships and tend to become close as other family members age” (Heller and Arnold, 2010: 16). A key part of understanding the adult sibling relationship involves recognising the impact of previous childhood experiences as a mediating factor in current adult sibling dynamics. These experiences are important as they have been shown to have a long-lasting impact on the siblings and the nature of their relationship. For example, Orsmond and Seltzer’s (2007) US study, carried out with 154 siblings of individuals with ASD and DS, suggests that in the context of ASD particularly, stressful childhood experiences can have long-lasting effects on the sibling and sibling relationship, although they stress that these effects are not solely negative. Similarly, Tozer and Atkin’s (2015) qualitative research, conducted with 21 adult siblings in the UK, found that adult siblings could only make sense of their current relationship by reference to their past experiences from childhood. They noted that half of the sample had sought counselling to understand their childhood experiences and related feelings of anger and resentment (Atkin and Tozer, 2014:231). In many cases, these experiences reflected themes which emerge in the broader literature on the effects of childhood sibling dynamics, including the ways in which “they had to assume additional family responsibilities and accommodate an unpredictable family life” (Tozer and Atkin, 2015: 345).

Literature exploring the effects of growing up as a sibling of a child with ID/ASD reiterates these themes, and highlights some common experiences. These include, for 'typically developing' children, the exercise of trying to 'normalise' family experience in the context of an outside world which could often present disabling barriers, including negative and/or hostile attitudes towards their brother or sister with a disability (Stalker and Connors, 2004; Barr and McLeod, 2010). Barr and McLeod's (2010) Australian study, for example, highlights how siblings could feel embarrassment when out in public with their brother or sister, and experience a lack of understanding from peers regarding their situation, which could impact on their developing friendships (for example, not feeling like they wanted to invite friends home when their brother or sister was there). The literature on growing up with a child with ID/ASD and disability more broadly, is reflective of the emotional conflict which many siblings experience in childhood with regard to their brother or sister (Benderix and Sivberg, 2007; Mascha and Boucher, 2006; Davys et al., 2016). Benderix and Sivberg's (2007: 414) qualitative study of siblings of children with ASD in Sweden, for example, outlines clearly the mixed emotions that siblings feel towards their brother or sister. On the one hand, for example, they could sometimes feel unsafe and anxious in the home due to the physical violence and "frightening abnormal behaviour" that accompanied ASD (see also Duignan and Connell, 2015; Barr and McLeod, 2010; Mascha and Boucher, 2006); on the other, they felt sorry for, and empathy and compassion towards, their brother or sister. Petalas et al's (2012: 307) Welsh study of siblings of brothers with ASD, also notes the frustrations of adolescent siblings and their description of the relationship as "characterised by a tension between their apparent irritation and feelings of empathy and understanding towards their brother". Other studies refer to siblings' recognition of their brother or sister's vulnerability, and the need to protect him or her (Tozer et al., 2013).

Literature then demonstrates that siblings are only too aware of the impact of their brother or sister's behaviour on family life in childhood. Siblings frequently express what Benderix and Sivbeg (2007), refer to as a "precocious responsibility" towards their sibling and family, and often describe feelings of anxiety that they were not helping enough. They also describe taking on more caring responsibilities, partly to support their parents. For example, Tozer et al. (2013: 483) note how adult siblings in their study reflected back on their childhoods, and "remembered playing with their siblings to relieve stressed parents and doing household chores to give their parents a break". Others described "attending appointments or school reviews from an early age". Involvement in these tasks indicates how, even within childhood, siblings are engaged in support and care roles beyond what would be assumed of sibling relationships where there are no children with disabilities or ID/ASD; this involves a form of 'balancing' (Dellve et al., 2000: 175) in which siblings have shown themselves to be aware of the need to make concessions in terms of their



own goals and interests to support the family and their brother or sister. As we will go on to show, these roles and responsibilities often continue to shape sibling relationships in adulthood.

### **2.3.1 Factors affecting adult sibling relationships**

One of the preoccupations of research regarding the sibling relationship (both in terms of children and adults) is the focus on different variables that are seen to affect the relationship in terms of outcomes and nature of the relationship. This has predominantly taken place in the context of large scale quantitative studies, and the most commonly examined of these ‘variables’ are the type of impairment (in particular, DS and ID as opposed to ASD), and the gender of the sibling.

### **2.3.2 The adult sibling relationship and the impact of type of disability**

A commonly reported distinction across studies of adult siblings, concerns the difference in the experience and outcomes of sibling relationship in relation to different types of impairment. For the purposes of this study, the distinction is drawn between ASD and intellectual disabilities such as DS. Some of the most commonly reported findings relating to this distinction are drawn from quantitative large scale surveys conducted in the US by Orsmond and Seltzer (2007) and Hodapp and Urbano (2007). Both of these studies found that adult siblings of individuals with DS were more likely to report fewer health or depressive symptoms, a more positive relationship with their sibling, and greater contact in the relationship than those siblings whose brother or sister had ASD. Orsmond and Seltzer’s (2007) study found that adult siblings of people with ASD were more likely to be pessimistic about the future, and were more likely to say that their relationship with their parents had been impacted (although they often described this impact as a positive, rather than negative, dynamic). The difference in experience and quality of relationship between siblings of individuals with DS and ASD is attributed to a number of factors. Hodapp and Urbano (2007: 1019) suggest that their findings support the existence of a ‘Down syndrome advantage’, an idea which recurs across a number of studies of child and adult siblings of people with disabilities (see, for example, Hodapp et al., 2001), and which suggests that, when compared to families of children and adults with other disabilities, across a number of measures such as stress and coping, families of individuals with DS seem to fare better. Explaining this ‘advantage’ is more complex, with Hodapp and Urbano (2007: 1026) suggesting that it may relate “to characteristics of the person with the syndrome or to such ‘associated characteristics’ as having an older mother (who may also be more experienced as a parent), being diagnosed at or near birth, and having a known condition supported by several parent groups”.

Orsmond and Seltzer’s (2007) study, too, makes some preliminary attempts to explain the differences between impairment. They point to the impact of different

behavioural characteristics associated with the two types of impairment, suggesting, for example that ASD is associated with “social impairment and the presence of repetitive and unusual behaviours” (p.683) compared to DS, in which individuals are often reported to be more sociable. They also suggest that ASD’s genetic component and the existence of the “broader autism phenotype” (693), which may shape the characteristics of siblings themselves, may have an influence on the quality of relationship between siblings. Certainly, in the context of behaviours, a range of studies point to some of the challenges of living in an environment which can be marked by episodes of violence and aggression that characterises the behaviour of some individuals with ASD, and which can contribute to social stigmatisation on the part of the individual and their sibling(s) (Duignan and Connell, 2015; Benderix and Sivberg, 2007). For example, Duignan and Connell’s (2015) Australian study demonstrates how living with an individual with ASD in the context of the home can make the domestic space one of anxiety and disruption for family carers, rather than one of relaxation, intimacy and ease. However, some pieces of research have shown that behaviours associated with ASD may change over time with Seltzer et al. (2009) citing research, which suggests that declining severity in some of the impairments associated with ASD, may in some instances lead to an improvement in the sibling relationship over the lifecourse.

Findings from studies such as these are significant as they point to the ways in which the dynamics of impairment may shape the sibling relationships. However, we would argue that caution needs to be applied in locating the problem of relationships in the inherent characteristics of individuals themselves, without also recognising the social and cultural factors which shape the ways in which these behaviours are perceived and responded to by society more broadly.

### **2.3.3 The adult sibling relationship and gender**

Building into broader debates about the role of gender in care work, a number of studies have sought to explore how far sibling relationships are affected by the dynamic of gender. In a review of a number of studies which explore adult sibling relationships in the context of developmental disabilities, Heller and Arnold (2010) concluded that women were more likely to be involved with, or have a closer relationship to, their brother or sister with a disability than men. Sisters are more likely to be perceived as potential primary care-givers (including after parents have passed away) and have been shown to provide more emotional support than brothers (Greenberg et al, 1999). Some studies have suggested that the gender of the individual with the disability is also significant in this relationship, with Orsmond and Seltzer (2000) suggesting that whilst sisters are close to both brothers and sisters with ID, brothers expressed less positive affect in situations where they had a sister with ID. This observation is also reiterated by Seltzer et al., (2009: 9) in the context of ASD, leading them to conclude that

“women with developmental disabilities, including ASD, may be at risk for social isolation later in life if their only sibling is a brother”.

Other studies have been more circumspect about the influence of gender in the sibling relationship. For example, Orsmond and Seltzer’s (2007:693) study found no significant gender effects in terms of the practical and emotional involvement of adults in sibling relationships where one sibling had an ID or ASD, with their only finding being that sisters with a sister with DS “reported that a greater number of their life areas had been affected...and they used more emotion-focused coping strategies”. This, they suggest, may reflect the expectations on sisters from childhood that they will take on caregiving roles and responsibility for their sibling in the future.

### **2.3.4 The adult sibling relationship: other factors**

A range of studies have explored various other factors that may influence the sibling relationship in the context of individuals with ID/ASD. These include:

**Age of the sibling:** some studies have considered the age of the sibling and their position in the family. For example, Seltzer et al., (2009) found that adult siblings were more likely to engage with their brother or sister with ASD if the brother or sister was younger than them, with other studies suggesting that “the most involved person was more often older than the person with the disabilities” (Heller and Arnold, 2010: 23; Seltzer et al, 1991). This is not the case in all studies, however (see for example, Pruchno et al, 1996).

**Geographical proximity:** geographical location has been shown to be another factor that can influence the nature of the sibling relationship. Closer geographical proximity has been shown to be positively correlated with greater involvement of siblings with their brother or sister with ID and/or ASD (Heller and Arnold, 2010). There has however, been less exploration of how new modes of communication (such as through Skype or Facebook) might affect sibling relationships over longer distances.

## **2.4 Dimensions of the adult sibling relationship**

Research indicates that adult siblings of individuals with ID/ASD tend to maintain high levels of involvement with their brothers and sisters throughout the lifecourse (Doody et al., 2010; Heller and Kramer, 2009; Orsmond and Seltzer, 2007; Hodapp and Urbano, 2007). Understanding the nature and quality of these adult sibling relationship has been a focus of several quantitative studies (Orsmond and Seltzer, 2007; Hodapp and Urbano, 2007; Doody et al., 2010). These studies have focused on the quality of sibling relationships in terms of both instrumental (how often there is contact between siblings, what type of contact), as well as ‘affective’ measures (amount of affection felt toward and experienced

from the sibling). Doody et al., (2010) explored sibling relationships between adults who had siblings with (N = 63) and without (N= 123) intellectual disabilities using an online survey distributed in the UK and Ireland. They found that adult siblings of individuals with ID/ASD usually maintain high levels of involvement with their sister or brother and demonstrate strong affective ties throughout the lifecourse (Doody et al 2010:225). Moreover their findings indicated that adults with a sibling with ID usually lived closer to and had more frequent contact with that sibling than with siblings without an ID (Doody et al., 2010:229). There is also some evidence to suggest that there may be greater stability over time in the closeness of the sibling relationship when one sibling has an ASD (Seltzer et al., 2009). In sibling relationships where there is no disability, closeness in the relationship tends to decrease during adolescence and young adulthood and to increase again in middle and later adulthood (Seltzer et al., 2009).

However, Doody et al., (2010:229/230) also found that siblings with a brother or sister with ID reported less warmth in the sibling relationship with significantly less warmth being identified by participants who had a brother or sister with a severe/profound ID. Similar findings were reported in Orsmond and Seltzer's US study (2007) of 154 siblings of individuals with DS or ASD. They found that siblings of adults with ASD had lower levels of both instrumental and affective involvement with their brother or sister than did sibling of adults with DS. Hodapp & Urbano (2007:1026) refer to this as 'the Down syndrome advantage' and note that their US study of siblings of individuals with DS (N= 284) and with ASD (N=176) revealed a small to moderate difference favouring the siblings of those with DS with regard to the quality of the sibling relationship, number and length of contacts and perceived health and rate of depression. The extent and nature of sibling contact has also been found to be impacted by factors such the gender of the non- impaired sibling, as discussed in 2.3.3 above, the extent of other care responsibilities held by the sibling and the age of the individual with ID/ASD. For example reduced rates of contact were found as the person with the impairment moved into later middle age (Hodapp & Urbano, 2007), while geographical proximity of the sibling was linked with increased involvement (Heller and Arnold, 2010).

Of particular relevance to this study is research which explores siblings' expectations in relation to future involvement in the lives of their brothers and sisters with ID/ASD, their understandings of the types of roles they might perform, and their concerns about the future.

#### **2.4.1 Adult sibling expectations about care and support in the future**

Increased longevity among adults with ID, particularly those with DS, means that parents are unlikely to remain primary carers for adults with ID and ASD

throughout the impaired adult's lifecourse. In the USA, Yang et al. (2002) have identified an increase in the median age of death for individuals with DS from 25 to 49 years between the years of 1983 and 1997. Glasson et al. (2002) writing in the Australian context have identified a life expectancy of 58.6 years for a cohort of people with DS registered with disability services between 1953 and 2000. In the Irish context, 12.4% of individuals with ID are now over the age of 55 which reflects an increase of 60.3% of individuals with ID in this age group between 1996 and 2010 (Care Alliance Ireland, 2015:2). Given this development, it is increasingly likely that siblings of adults with ID/ASD will be involved in providing care for them or in making decisions about care. It must also be acknowledged that individuals with ID/ASD may themselves become carers to older parents with whom they share the family home. Recent work by Care Alliance Ireland highlights the likelihood of this phenomenon of reverse care roles (Care Alliance Ireland, 2015). It notes that while there has been no systematic study of this topic in the Irish context, there is anecdotal evidence, and research elsewhere has identified the issue.

Research indicates that many siblings have a strong commitment to their brother or sister with ID based on their shared history and unique understanding (Tozer & Atkin, 2015:349), feel a sense of responsibility for their future (Ormond and Seltzer, 2007) and expect to be involved in care or support work (Heller & Arnold, 2010; Greenberg et al., 1999). They also express concern and anxiety about the future when their parents are no longer in a position to provide support (Benderix & Sivberg, 2007; Orsmond & Seltzer, 2007). Heller and Arnold's (2010: 23) review of twenty three studies of adult siblings of people with intellectual and developmental difficulties, identified studies in which 19% of siblings expected to co-reside with a sibling and 60% expected to be carers for their sibling in the future. Similar expectations were revealed in a recent survey of 111 adult siblings of people with ASD, aged 40 and older, which was conducted by the National Autistic Society in the UK (Gomez de la Cuesta & Cos, 2012). It found that nearly half of the participants felt that they had no choice but to support their siblings and that discussing the future with parents was sensitive and complex (Gomez de la Cuesta & Cos, 2012). Nevertheless, they were willing to take over the support role out of love, a sense of duty and responsibility (Gomez de la Cuesta & Cos, 2012).

Siblings' expectations of involvement in the lives of their brothers and sisters are however frequently held in tension with concerns about limitations and challenges this might create in their own lives. The qualitative studies by Atkin and Tozer (2015 & 2014) and Davys et al. (2010, 2014, 2016) revealed participants' strong sense of connection and commitment to their brother or sister with ID/ASD, while at the same time highlighting frequent feelings of resentment about the demands made by their brother or sister and guilt about

moving on with their own lives and/or away from the family home. Siblings who have witnessed their parents' ongoing struggle for appropriate supports also express anxiety about facing similar difficulties in the future (Gomez de la Cuesta & Cos, 2012). Concern about the implications of caring for a brother or sister with ID/ASD as their own lives progress, was also commonly expressed. Siblings emphasised how life changes and emergent life stages, experienced by all members of the family unit, including the impaired family member, the non-impaired sibling and the parents, would result in a constant re-negotiation of relationships with impaired brothers and sisters (Atkin and Tozer, 2015, 2014; Davys et al., 2010, 2014, 2016; Gomez de la Cuesta & Cos, 2012.)

#### **2.4.2 Parental and policy expectations about sibling care and support roles**

Parents play a significant role in shaping adult siblings expectations around their future involvement with their brother or sister with ID/ASD. Parental aspirations for TD siblings to live their own lives are frequently held in tension, with expectations that these siblings will be involved in supporting their brother or sister in the future (Davys et al., 2016 & 2010; Davys and Haigh, 2008; Bigby, 1997. There is diversity in parental expectations regarding the future roles they envisage siblings playing, with some siblings reporting that their parents expected them to become an 'over viewer' while others expected co-residence (Davys et al., 2016). Other siblings noted that although their parents had never voiced their preference in relation to future care for the brother or sister with ID/ASD, it was understood by the family that the parents wanted them to remain living within the family (Davys et al., 2014:222).

In terms of expectations which policy regimes create for siblings, Atkin and Tozer (2014), writing in the UK context, argue that whole family approaches in policy making, often fail to acknowledge the potential roles that adult siblings may play in caring for brothers and sisters with ID/ASD (Atkin and Tozer, 2014:226). In a policy context which assumes a degree of family care, and encourages personalisation of care services, individual family members have to negotiate tensions between forging their own biographies, and societal and statutory expectations, that as siblings, they will be involved to some extent with caring for and/or about their adult brother or sister with ID/ASD. It is vital therefore, that policy makers acknowledge, as Atkin and Tozer (2014), note, that family care is contingent and context specific, changing with the varying demands and transitions experienced by family members throughout the lifecourse.

A report by the National Autistic Society in the UK, argues for increased respect and assistance from statutory authorities for siblings who take over the care for their brothers/sisters with ASD (Gomez de la Cuesta & Cos, 2012, p.22). They

emphasise that financial, practical and emotional support is critical in enabling and encouraging siblings' roles as advocates (Gomez de la Cuesta & Cos, 2012).

### **2.4.3 Sibling roles**

Sibling roles take a multiplicity of forms and change and alter throughout the lifecourse. Siblings may act as companions, advocates, mediators, mentors, financial overseers, co-residents and legal guardians. Heller and Arnold's (2010: 22) review of 25 studies of adult siblings of people with intellectual and developmental disabilities between the years of 1970 and 2008, suggests that in families where there was more than one typically developing sibling, there was usually one sibling who took the role of 'most involved sibling'. For example, Bigby's (1997) qualitative study of the informal support networks of older people with ID in Melbourne highlighted the existence of a 'key person', predominantly a sibling, in their lives. Typically the role of 'key person' had been negotiated by parents prior to their death and the supports provided by this person were primarily affective, consisting of expressing interest in and concern for the individual and providing them with companionship, while also undertaking some instrumental tasks such as advocacy or direct assistance with financial or decision-making activities (Bigby 1997:341 & 335). Factors such as life stage and personal circumstances have been shown to impact on the selection of the most involved sibling (Davys et al., 2016). Tozer and Atkin's interviews with 21 adult siblings in the UK, suggest that those who took on advocacy roles and responsibilities in relation to their brother or sister with ID/ASD, were siblings who had a lifelong close relationship with that brother or sister (Tozer and Atkin's 2013: 484). Significantly however, many of the siblings emphasised, that they wanted their relationship to remain a sibling one as distinct from their being reinvented in a 'carer' role (Tozer et al., 2013: 484).

### **2.4.4 Planning for the future**

Future planning in relation to care or support for adults with ID/ASD when their parents die or are no longer in a position to provide such care, is receiving increased research attention, prompted in large part by the increased longevity of people with ID (Bigby, 1997; Davys et al., 2010; 2014 & 2016; Heller & Arnold, 2010; Benderix & Sivberg; Orsmond & Seltzer). Findings in relation to the number of families who have actually engaged in such planning for the future are variable. A US study (Bowey & McGlaughlin, 2007) found that 32% of families had made residential plans, while UK research suggests that approximately half of families had made some plan (Davys et al., 2010, 2016). Davys et al's. (2010) small scale survey of 21 siblings of adults with ID in the UK revealed that just over half of the participants (57%) reported having had a full discussion with their parents regarding the future care of their sibling with ID, with the same amount (57%) stating that there was no clear future plan in place for their sibling. Subsequent research by Davys et al., (2016), which involved interviews with 15 adult siblings

of individuals with ID, indicated a near equal distribution between families who had engaged in future planning and those who hadn't. However, it is noteworthy that even when plans did exist they frequently lacked detail and tended to be verbal rather than written. Plans range from those, which focus on future living plans for the individual with ID, to future plans which consider wider issues such as guardianship, financial planning, and decision making support.

Barriers to families engaging in future planning include, parental reluctance to discuss the issue and limited choice in relation to service provision (Davys et al., 2010: 175/6) with insufficient information and difficult relations with service providers being further barriers for some (Davys et al., 2014:223). Unsurprisingly, support with discussion and arrangement of future plans has been identified as an unmet need in many studies and is discussed further in section 2.7 below.

## **2.5 Supporting sibling in childhood**

The challenges and risks experienced by siblings of children with disabilities and chronic illness are recognised in the literature, as is the fact that such children may benefit from support interventions (Roberts et al., 2015; Granat et al., 2012). However, there is limited research that documents and evaluates childhood support interventions for such children (Granat et al; 2012; Heller & Arnold, 2010:24). Systematic review of the evaluations that are available is difficult due to differences in the interventions. Some interventions focus exclusively on supporting siblings with brothers and sisters with ASD (Kryzak et al., 2015), others included siblings of children with a mix of intellectual and physical disabilities and chronic health conditions (Roberts et al., 2015; Granat et al., 2012; D'arcy et al., 2005). Furthermore, some interventions involved a parallel intervention with the child with the disability/illness (Kryzak et al., 2015).

There is however consistency across interventions in that all focus on addressing risks that can be altered. As such they focus on providing social support, knowledge about the relevant disability/condition, coping and problem solving strategies and advice about mutually beneficial ways of interacting with the impaired brother/sister (Roberts et al., 2015). Angell et al.'s (2012) qualitative study of the experiences of 12 siblings (aged 7 to 15) of individuals with ASD, suggests that these types of support are very relevant. The siblings they interviewed identified time for themselves away from stressful situations, the opportunity to talk to peers who understood their experiences, and awareness of techniques which would assist them in managing their brother or sister's behaviour, as key support needs. Petalas et al.'s (2012:312) interviews with adolescent siblings of individuals with ASD suggest that other support needs may be present in this age group such as a need for 'support in negotiating friendships, informing others and providing explanations, as well as dealing with their own reactions (e.g., anger)'. The need for acknowledgement of and support with



worries that adolescents may have about future care roles for their brother or sister was also identified.

Many interventions reflect the Sibshop model developed by Don Meyer in the US in the mid 1990s. This model is characterised by group-based work with siblings aged 8 to 13, usually comprising of sessions of two to three hours run over six to eight week periods. The groups aim to foster a relaxed atmosphere, include recreational activities and provide opportunities for siblings to meet peers, to discuss the challenges and advantages of having a brother or sister with a disability, to learn about implications of these disabilities for behaviour and to learn how challenging situations might be handled (D'arcy et al., 2005:45).

Evaluations of interventions highlight success in terms of enhanced peer network (Kryzak et al., 2015; D'arcy et al., 2005), increased sibling knowledge about the disability experienced by their brother/sister (Granat et al., 2012; D'arcy et al., 2005), improved emotional and behavioural functioning (Robert et al, 2015) and improved relationships with their brother/sister (Kryzak et al., 2015).

Interventions to improve coping and problem solving skills (Robert et al, 2015; Granat et al., 2012) and to develop self-esteem proved less successful (D'arcy et al., 2005).

Despite such mixed outcomes there is agreement in the literature that peer based interventions, provided in the context of fun activities and providing opportunities for siblings to talk about their feelings, are beneficial (Benderix & Sivberg, 2007). The need for interventions to be adapted to meet the specific needs of individual families has also been identified (Benderix & Sivberg, 2007). Support interventions targeted at the whole family unit, such as summer camps and skiing camps, have also been found to be beneficial for siblings (Liljekvist & Thorneus, 2012). The particular need for support experienced by lone siblings with no typically developing brothers or sister has been identified (Liljekvist & Thorneus, 2012). Finally the absence of material which voices the experiences of now adult siblings who attended Sibshops as children, is a significant research gap.

## **2.6 Supporting siblings in adulthood**

Recent research on the experiences of adult siblings have identified a range of support needs, many of which related to transition planning. These include; support with proactive futures planning, counselling services for parents and adult siblings, opportunities for developing support networks, information on services available to brothers and sisters, financial and legal advice and practical and emotional support. (Meyer & Holl, 2014; Gomez de la Cuesta & Cos, 2012; Davys et al., 2014 and 2010; Heller and Kramer, 2009; Benderiz and Sivberg, 2007). A need that is not frequently identified by siblings when discussing transition planning is information on the future wishes of their brother or sister

with ID/ASD. Davys et al., (2014) noted that among the 15 siblings of adults with ID they interviewed in relation to future planning, only 3 individuals referred to the wishes of their brother or sister with ID.

### **2.6.1 Sibling support from services/professionals**

There is limited research relating to adult siblings experiences with professionals involved in the provision of care to their brothers or sisters with ID/ASD. A recent small scale, qualitative, study in the UK, revealed that most adult siblings felt that practitioners did not always acknowledge or accommodate the sibling role and did little to facilitate it (Atkin and Tozer, 2014:234). Commenting on their childhood experiences, some of the 21 respondents in Atkin and Tozer's study reported feeling ignored and excluded by social workers who visited the family home and engaged almost exclusively with parents (Tozer and Atkin, 2015: 437). In their adult interactions with practitioners working in the services where their brother or sister attend, most felt that staff did not proactively involve them and believed that they were only called on when a crisis arose (Tozer and Atkin, 2014: 235). Some siblings noted their lack of confidence in dealing with professionals and a lack of clarity regarding their legal position in this regard (Atkin and Tozer, 2014:223 & 234), while more noted that they frequently felt judged by service providers who perceived their flexible involvement as a lack of commitment (Tozer & Atkin, 2015:349). Siblings also expressed concern about what they perceived to be ongoing re-organisation of care arrangements and prevailing resource challenges in social care provision (Atkin and Tozer, 2014:234). A relationship in which practitioners would see siblings as 'co-workers' in supporting the adult with ASD, was favoured by the siblings in Atkin and Tozer's study (2014:238). The siblings also advocated that practitioners should support and involve siblings viewing them as 'co-clients' (Atkin and Tozer, 2014:238). It is noteworthy that despite their commitment to maintaining a relationship with their brother or sister with ASD, the participants in this research were reluctant to be perceived in a policy context as formal carers or resources for their brothers or sisters (Atkin and Tozer, 2014:233 &235). The situation of sibling carers in a legal context also lacks clarity with Tozer & Atkin's, (2015) UK research indicating that they were not clear about their legal status or about the extent to which they could legally involve themselves in the lives of their adult brothers or sisters with ID (Tozer & Atkin, 2015:342).

### **2.6.2 Web-based adult sibling support**

Websites where sibling relationships and issues can be discussed provide a useful support for siblings of people with ID/ASD. The US-based SibNet,<sup>5</sup> for example,

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<sup>5</sup> SibNet is an international web based support organisation for siblings of individuals with ID/ASD <http://www.sibnet.com/>

is the first and largest web based groups for adult siblings of people with special, health, developmental, and emotional needs. Since 1996, SibNet has connected tens of thousands of siblings from around the globe with their peers, providing members with information and advice. SibNet is co-hosted by the “[Sibling Support Project](#)” and the “[Sibling Leadership Network](#)”. The aim of the group is to increase peer support and information opportunities for brothers and sisters of people with special needs and increase parents' and service providers' understanding of sibling issues. The stated mission “is accomplished by training local service providers on how to create community-based peer support programs for young siblings; hosting workshops, social network sites, and websites for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, lifelong, and ever-changing concerns through workshops, websites, and written materials” (<http://www.siblingsupport.org/>).

## **2.7 Conclusion**

This chapter has provided a critical overview of the parameters and findings of international literature which has explored the sibling relationship in the context of ID/ASD. The literature suggests that adult siblings maintain high levels of involvement and emotional connection with their brothers and sisters with ID/ASD across the lifecourse, and that adult sibling roles take a multiplicity of forms and change and alter over time (Doody et al., 2010; Heller and Kramer, 2009; Orsmond and Seltzer, 2007; Hodapp and Urbano, 2007; Orsmond & Seltzer, 2000; Pruchno, Patrick, & Burant, 1996).

The literature also indicates that siblings feel a sense of responsibility for the future of their brother/sister with ID/ASD (Orsmond and Seltzer, 2007) and expect to be involved in care or support work (Heller & Arnold, 2010; Greenberg et al., 1999). Such expectations can be a source of tension particularly when adult siblings have conflicting care and support demands relating to different relationships in their lives.

Expectations around future roles of adult siblings are rarely formulated into concrete future care plans with the literature indicating a reluctance among parents to discuss or engage in futures planning (Bigby, 1997; Davys et al., 2010; 2014 & 2016; Heller & Arnold, 2010; Benderix & Sivberg; Orsmond & Seltzer).

Finally, the support needs of siblings of individuals with ID/ASD are acknowledged in the literature. The challenges and risks experienced by siblings of children with disabilities and chronic illness are widely explored, and findings suggest that such children may benefit from support interventions (Roberts et al., 2015; Granat et al., 2012). A range of support needs experienced by adult siblings have also been documented. These include; support with proactive futures planning, counselling services for parents and adult siblings, opportunities for developing support

networks, information on services available to brothers and sisters, financial and legal advice and practical and emotional support. (Gomez de la Cuesta & Cos, 2012; Davys et al., 2014 and 2010; Heller and Kramer, 2009; Benderiz and Sivberg, 2007).

## **3 Methodology**

### **3.1 Introduction**

The core aim of this research was to explore the lived experiences of adult siblings (aged 18 to 45) of brothers and sisters with an ID and/or ASD. In particular the study sought to document the siblings' understandings of and feelings about their relationships with their brother or sister and to explore their expectations and wishes in relation to the future.

Two data collection methods were utilised in this study. A review of relevant literature drawing on both national and international sources was undertaken. This was followed by primary data collection in the form of semi-structured interviews with 25 adult siblings (aged 18 to 45) living in Ireland and abroad. These interviews explored sibling relationships from childhood to the present time and sibling expectations about the future. This chapter will outline the ethical and research governance framework of the research, describe the research design, explain how the sample was recruited, outline the characteristics of the sample<sup>6</sup> and discuss some of the challenges encountered in the research process.

### **3.2 Ethics**

Ethical approval for the research was granted by the Social Research Ethics Committee (SREC) in UCC following a review of all aspects of the study. In line with good practice, all prospective research participants were provided with information outlining the purpose of the research, the type and extent of participation requested from them, the data to be collected and measures for recording, anonymising and storing this data (See Appendix A). Participants were also asked to sign a consent form prior to the interviews and were informed of their rights in relation to withdrawal from the study (See Appendix B). Provision was also made to offer support to any participant who experienced distress in the course of the interview or as a result of same.

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<sup>6</sup> This research only addresses one side of the sibling relationship, namely the perspective of the typically developing sibling. This bias in research about brothers and sisters where one has a disability has been acknowledged and critiqued in the wider literature (see Meltzer & Kramer, 2016).

A number of steps were taken to ensure the anonymity of participants. Pseudonyms were assigned to participants and care was taken to remove any identifying information which might have compromised anonymity.

### **3.3 Research design**

#### **The semi-structured interview**

A face-to-face semi-structured interview was selected as the data collection method for a number of reasons. Firstly, it was felt that personal accounts of the experience of having a brother or sister with ID/ASD could be most safely explored in the context of a semi-structure interview, which provided participants with a safe and private forum for discussing a potentially sensitive topic. Secondly, the dispersed geographical location of the participants would have made focus groups interviews very difficult to organise.

A topic guide with semi-structured questions was devised by the research team and reviewed by the research advisory group in July. It was subsequently revised and used for the interviews (See Appendix C).

### **3.4 Sample recruitment**

A purposive sampling approach was used in recruiting participants. Siblings aged 18 to 45, of brothers and sisters with ID/ASD were invited to participate in semi structured interviews, either face-to-face or via Skype. A call for participants (See Appendix D) was compiled detailing the aims of the research, the criteria for inclusion and the requirements of participants. In mid July 2015 this call was circulated by Inclusion Ireland through its various communication and distribution channels, to both individual and organisational members. These members and organisations may have subsequently circulated it to their networks.<sup>7</sup> These channels included the Inclusion Ireland website, Facebook and Twitter platforms, as well as their July Newsletter. A member of the research team also forwarded the call to the ASD support groups, Shine Ireland<sup>8</sup> and Irish Autism Action<sup>9</sup> as these groups are not members of Inclusion Ireland.

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<sup>7</sup> It was not possible to follow up the dissemination of this call in detail. However, some respondents indicated that they had seen the call on other organisations' Facebook pages

<sup>8</sup> Shine Ireland also known as the Irish Progressive Association for Autism (IPAA) is a Cork based voluntary organisation which works with children with autism and their families. [www.shineireland.com](http://www.shineireland.com).

<sup>9</sup> Irish Autism Action provides information and support for autistic children and adults and their family and friends. [www.autismireland.ie](http://www.autismireland.ie).

The mid July call generated a swift response with 29 siblings making contact within two weeks. Two of these respondents were older than the upper age limit of 45. In two other cases, more than one sibling from the same family responded and following consultation with those involved, one sibling per family was chosen to participate. In one other case, a mother volunteered her adult sons and daughters to participate however subsequent direct contact with these individuals did not yield participants. A further three participants ceased communications after the initial email contact. Thus, after the July call a total of 26 individuals had self-selected by choosing to respond to the call. 24 of these completed the interview or provided a written response to the themes in the topic guide. Two individuals were unavailable for interview.

Analysis of the age and gender profile of these participants indicated a larger percentage of female participants (n=19). It was felt that inclusion of more male participants would be desirable from the perspective of getting as wide an understanding as possible of different sibling experiences. At the end of October 2015, a second call for participants was distributed through the same channels as the first call. This second call looked specifically for male siblings and also for siblings who had participated in Sibshops. This call was again made through the Inclusion Ireland website, Facebook and Twitter pages. A member of the research team also posted the call on the Facebook pages of Irish Autism Action, Shine Ireland and AsIAM.<sup>10</sup> The second call was largely unsuccessful and resulted in only one more participant bringing the total number of participants to 25.

### **3.5 Characteristics of the research sample**

A table outlining participant's age, location, family structure and pseudonym and the age, diagnosis and pseudonym of their sibling is provided in appendix E. Descriptive statistics documenting some key demographic characteristics of the participants are presented below.

#### **3.5.1 Participants' gender and age**

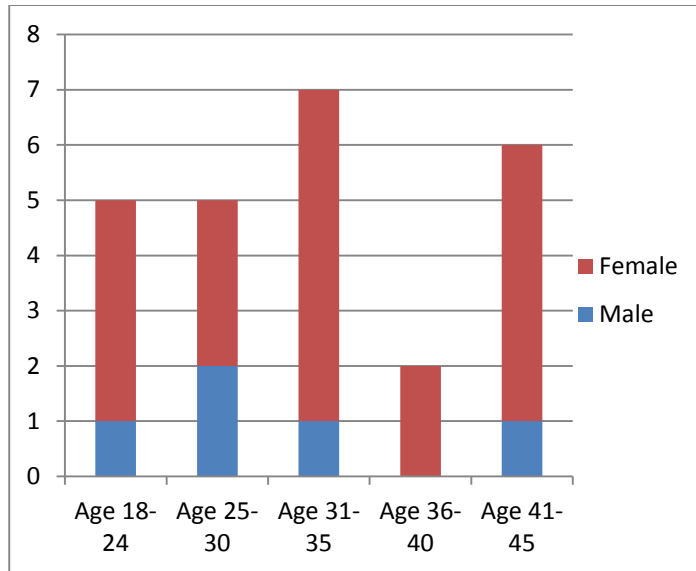
The majority of the participants were female (n=20) and there was a dispersal of participants across all of the age categories. 5 were aged between 18 and 24, 5

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<sup>10</sup> AsIAM is a website which aims to provide a one-stop=shop for the Autism community in Ireland. ASIAM.ie.

were aged between 25 and 30, 7 were aged between 31 and 35, 2 were aged between 36 and 40 and 6 were aged between 41 and 45.

Figure: 3.1 Participants' gender and age

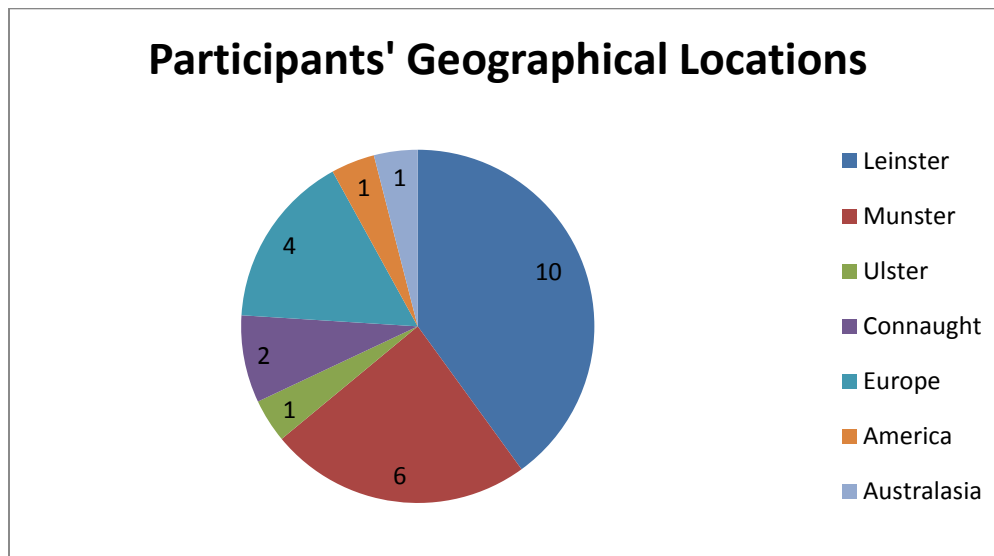


### 3.5.2 Participants' geographical locations

The largest cohort of participants resided in Leinster (n=10), but all provinces were represented in the sample (Munster (n=6), Connaught (n=2) and Ulster (n=1)). Significantly almost a quarter of the participants (n=6) lived abroad. This high self-selection rate from siblings living abroad is interesting. All the siblings living abroad had been notified by their parents about the research and their participation would seem to suggest that concern about a brother or sister with ID/ASD continues when one is abroad. However a larger sample would be required to investigate this hypothesis further.



Figure 3.2 Participants' geographical locations



### 3.5.3 Participants' current occupational/educational and relationship status

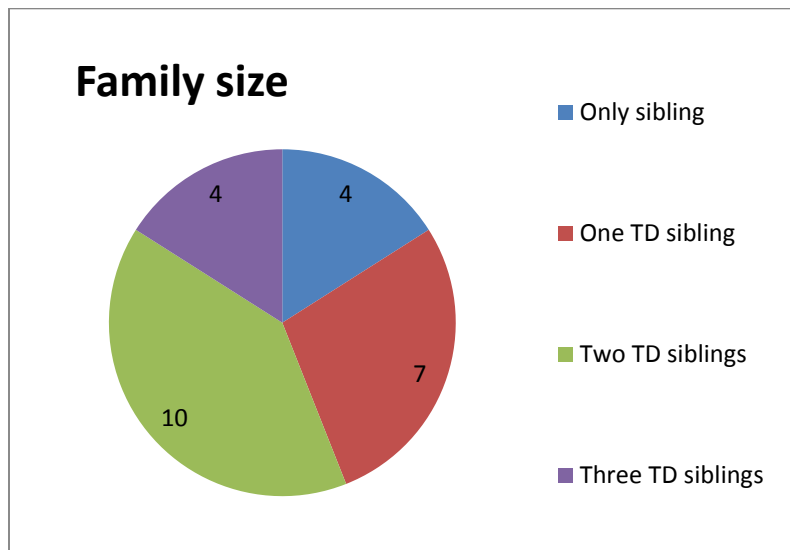
All of the participants had completed or were completing third level education. At the time of interview 19 were in employment, 5 were in education and 1 was working in the home.

The majority of participants (n=16) were single, 9 were married or had partners. A minority of participants (n=6) had children.

### 3.5.4 Number of typically developing (TD) siblings in participants' families

Family sizes varied among the participants, from the participant being the only sibling to the brother/sister with ID/ASD (n=4) to participants having up to 3 TD siblings (n=4). The most common family size was having 2 TD siblings (n=10) followed by having 1 TD sibling (n=7).

Figure 3.3 Number of typically TD siblings in participants' families



### 3.5.5 Participants' location in family

9 of the participants were the oldest in their families, 4 were second oldest in their families, 6 were the middle child in the family, 2 were the second youngest in their families, and 4 were the youngest in their families.

### 3.5.6 Limitations of the research sample

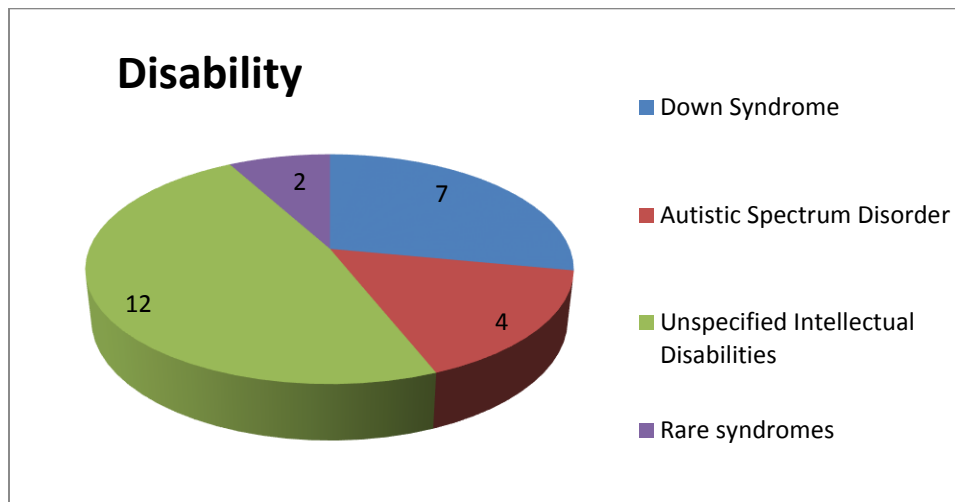
The research sample as discussed above represents a geographically diverse sample from a cohort that is difficult to identify and reach. However the sample has a number of limitations. It is overwhelming female ( $n=20$ ) with a majority of the participants ( $n=15$ ) aged between 31 and 45. All participants had completed or were currently pursuing third level education, which suggests limited diversity in terms of class background. Given the recruitment strategy it is likely that those recruited most likely represent siblings from families who are engaged with the issue of disability rights and policy. Siblings from families who have not engaged with support or campaign organisations are less likely to have received details of this call. Finally, this research only addresses one side of the sibling relationship, namely the perspective of the TD sibling. This bias in research on siblings where one has a disability has been acknowledged and critiqued in the wider literature (see Meltzer & Kramer, 2016).

## 3.6 Characteristics of brothers/sisters with impairment

### 3.6.1 Category of disability of brother/sister

Participating siblings had brothers or sisters ( $n=25$ ) with a range of different disabilities including unspecified Intellectual Disabilities (from mild to severe  $n=12$ ), ASD  $n=4$ , DS ( $n=7$ ) and other rare syndromes ( $n=2$ ).

Figure 3.4 Category of disability of brother/sister



### 3.6.2 Age of brother/sister

The participants' brothers and sisters ranged in age from 15 to 46.

### 3.6.3 Living arrangement of brother/sister

The majority (n=16) of the brothers and sisters lived in the family home with one or both parents. 7 lived in residential accommodation and 2 were living on their own with supports.

## 3.7 Data collection and interview dynamics

Two pilot interviews were conducted in early September 2015 and no changes were made to the topic guide following the pilots. The majority of the interviews were completed between early October and early November 2015. Interviews took place in locations throughout the country primarily in Inclusion Ireland's offices in Dublin. Other interview locations included the participants' homes, TCD, UCC, a participant's workplace and hotels. The average length of interview was 55 minutes.

22 of the participants were either in full time employment or full time third level education. This posed challenges in terms of scheduling interviews to fit around the participants' very busy schedules and the majority of the interviews were conducted in the evenings after work or college. 17 interviews were conducted face-to-face and 5 were conducted using Skype with participants living abroad: UK (n=3), USA (n=1) and Europe (n=1). 1 interview was conducted over the phone as the scheduled face-to-face interview was cancelled due to a family bereavement. In two cases, face-to-face or Skype interviews were not possible,

due to the hectic work schedule of the participants, one of whom lived in Australasia. These participants were invited to email a written response to the themes set out in the topic guide and both availed of this option. 23 of the 25 interviews were digitally recorded and subsequently transcribed.

### **3.7.1 Interview dynamics**

Recounting the story of the relationships and experiences they shared with their brothers and sisters with ID/ASD, was challenging and emotionally demanding for a minority of participants. Two participants wept quietly throughout the interview but both were adamant that they wished to continue with their narrative and neither wanted to avail of a break or any other support.

### **3.8 Data Analysis**

In the first stage of the data analysis the 23 verbatim transcriptions of the interviews, and the two written contributions were read by the three members of the research team and a series of emergent themes were identified. In the second stage of analysis, a number of major themes and sub themes were identified and these provide the framework for the presentation of findings. The data generated under each theme is explored to generate both descriptive and explanatory/conceptual accounts of the key issues identified. Findings are also considered in relation to material in the literature review and recommendations for future policy and practice developments are identified.

### **3.9 Conclusion**

This chapter has outlined the research methodology adopted in this study including discussion of ethics, sample recruitment, research design and data collection, interview dynamics and data analysis. The remaining chapters in the report present and analyse the findings generated by the research.

## **4 Sibling roles and childhood experiences**

### **4.1 Introduction**

This chapter will discuss findings from the 25 narratives which relate to childhood experiences of living with a brother or a sister with special needs. The connection between early childhood experiences and adult sibling relationships, as documented in international research, was reflected in this study (Tozer and Atkin, 2015). Our findings indicate that the vast majority of the participants experienced their childhood as 'normal' and not defined by their brothers' or sisters' special needs. However, emerging themes from the narratives suggest a social conditioning around 'minding' and 'protecting' the brother or sister in childhood. In some cases, where the brother or sister's disability was more severe, participants recall helping their parents (predominantly the mothers) with more hands on practical caring. Other themes discussed are parental attitudes, family dynamics and supports provided to the participants as children.

### **4.2 Learning about the diagnosis**

The participants learnt about their siblings' disabilities at different stages of their lives, depending on the type of disability. In cases where the brother/sister was diagnosed immediately or shortly after birth with disabilities such as DS or severe epilepsy/ID, the participants learnt quickly that something was different. In one case the sister's arrival caused 'family trauma' as the diagnosis included a very poor prognosis. Christine (34) was 17 at the time Fiona (now 17) was born.

I was doing my Leaving Cert at the time and Fiona was born in the January and I was, you know, studious and all the rest. I mean, the whole household just went into panic mode and suddenly my mum was away, Fiona was in hospital, you're hearing bad news. The child was having seizures, they wouldn't stop.

Other participants also had the experience of family life being disrupted due to the sibling going to hospital at an early stage of their lives, or being hospitalised frequently. Annie (aged 45) recalls how her father had to run to a neighbouring couple when her younger brother had a seizure during the night. The man drove her parents and brother to the hospital, while his wife looked after Annie. Carmel (aged 42) and David (aged 32) both had siblings who were seriously ill when they were born. David remembers living with his aunt a number of times

when his sister was extremely sick and describes the experience as ‘a very difficult time’.

The diagnosis of DS, while a sudden initial upset to the family, appeared to have been received more positively and with less disruption to the participants when they were young children. Emma (33) was 11 when her brother was born with DS. She remembers going in to see this new brother after three girls, ‘all the excitement - and my mum called my dad aside and he burst into tears, so I knew something was wrong.’ Other participants recall being told by their parents that their siblings with DS would do everything they did, just a bit slower.

In other cases, participants had brothers and sisters whose special needs were not noticed at birth but later, in some cases not until the brother or sister had started school. In one case, someone outside the family alerted the parents. Ann (aged 44) recalls an aunt advising that Anne’s older brother of two years needed an assessment. In another case, while the parents were aware of their son’s disability, they had not shared this information with their daughter Marion. Marion (aged 32) remembers being around four or five when a next-door neighbour called her younger brother Sean handicapped.

I went in crying to mum...so I’d say she just hadn’t gotten round to telling me or...because they were very open about it, you know. And then all of a sudden she said, ‘Well, yes, he is.’

For the majority of the participants, the news about their siblings’ disabilities did not have any major impact on the sibling relationship. The participants remember loving their brother or sister unconditionally from early days and accepting them as they were. Thus, when asked to support the brother or sister, they were all willing to help.

### **4.3 Family focus on the “special” brother/sister**

Many participants, when asked to reflect back on their earliest memories, remember being told that their brother or sister was ‘special’ and needed to be ‘minded’ and ‘looked after’. Anna (aged 30), whose younger brother Peter was born with DS, remembers that she was told that ‘Peter is special’ from an early age. She also recalls questioning this statement as a child, wondering why her brother was special and she wasn’t. As an adult she reflects on how the naming of her brother as being ‘special’ was also followed with ‘therefore you have to mind him’ and now thinks that ‘it was a lot of responsibility in hindsight to put on a child, but you know no different.’

As young children, all participants remember accepting their parents’ explanations regarding their brother’s or sister’s special needs without raising any questions.

Ann (aged 44), whose only brother George is two years older and diagnosed with unspecified ID, accepted that this was the way her brother was: 'I just kind of accepted that George is different and George is the way he is and George is special. I always got told George is special.' Similarly, Geraldine (aged 39) was told by her parents that her brother Robert, who was one year older than her, 'was special' and that she needed to be 'careful with Robert'. She remembers starting school at the age of four and wondering why her older brother hadn't. As an adult she reflects on the fact that it must have been difficult for her parents to find a suitable place for her brother back in the 1980s.

Younger participants also recall 'minding' their siblings a lot as children. Líosá (aged 22) was very involved in day-to-day activities from an early age 'minding' her sister Aoife who was two years younger and has ASD, 'I was always the one to mind her and make sure she was okay in school and make sure she was okay, like, if we went to the shops'. Líosá has no other sibling and says that her parents now acknowledge that she became a 'third parent' rather than a sister from an early age. Líosá does not resent this 'parenting role' although some of the autistic behaviours of her sister did cause her stress during her Leaving Certificate.

Like around my Leaving Cert now I had to mind her all the time and I was like, 'I can't do this.' And we lived in the same bedroom up until about... until I was 18...I'd wake up at like 3 or 4 in the morning; she'd be sitting up in her bed, like, playing with all the things beside her as a routine. And I was just like, 'Oh, for God's sake.'

In Líosá's case, her parents realised her difficulties and suggested that her sister Aoife move into a room of her own. Líosá reflects on how this move also benefited her sister who became more independent and happy.

Another younger participant, Alan (aged 23), recalls being very patient with his younger brother Gary (21) who was born with DS and ASD. Alan describes himself being closest to his brother in comparison to his other three TD siblings. In particular, he claims that his youngest sister (18) found their brother's autistic behaviours a bit difficult to cope with as a teenager, something that never bothered Alan: 'mum would be saying that I'd always look after him even most out of the siblings, because I would be probably close to him in age'.

#### **4.4 Supporting sister/brother while growing up**

The supports provided by the participants for their brother or sister with ID/ASD mainly consisted of simple tasks, such as looking after or 'minding' them. Some participants, however, recall being involved in more demanding 'caregiving' tasks from an early age. Karen (aged 36), older sister of Kim (aged 33), diagnosed

with moderate ID, who recalls actively helping her mother, described herself as a 'mini mum before my time'.

Yeah. Look, I was caregiving. I assumed caregiving roles from an early age, you know. And it was just something that I assumed. There was no definitive pressure or 'this is what you must do'. I just kind of became my mum, you know, with her and helped her and stuff.

Other participants recall helping out with homework, playing with their brother or sister, reading to them or helping them get to sleep. Anna described playing teacher with her brother Peter during the summer holidays when he would practise his handwriting. She is proud to say that he won awards for his handwriting and still to this day loves writing, 'he'll transcribe chunks of *Inside Soap* or magazines that he likes. But I distinctly remember that and teaching him how to write'. Other participants had much less involvement in their brother or sister's lives. For example, Chloe (aged 31) does not recall much involvement with Diarmuid, who is four years older and has DS. One of the few supports that she and her older sister did provide was help with homework, 'That's about the only thing I remember...trying to do homework with him and little things'.

Common activities which, younger sibling engaged in with their brothers and sisters with ID/ASD, included reading books and helping getting siblings off to sleep at night. Tara (aged 25) recounted reading Harry Potter books to her sister Molly (aged 23) who has a diagnosis of mild ID. Molly's fascination with Harry Potter also included going to Harry Potter movies and Tara went to see every new movie with her sister. Aspects of the sibling relationship such as 'hanging out' together were common emerging themes in families where the siblings were close in age and the brother or sister was able to engage in social activities. Participants frequently recall offering help, rather than being asked by parents to provide it. For example, Bernie (aged 44) would often have gone up to her sister Jackie's bedroom and gone to sleep with her. Jackie, who was four years younger and born with DS, would otherwise take a long time to fall asleep but Bernie recalls that 'I wasn't really being asked. It was just that I probably offered because it was effective'.

Similarly, David (aged 32) described talking his sister Laura, who is three years older, into going to bed when they were young, as this was something she did not like to do. Laura was born with multiple disabilities and was hospitalised frequently the first three years of her life. David recalls that his parents made conscious efforts not to involve him and his older brother in other more difficult and heavier tasks.

I suppose the biggest thing would be her toileting, you know. And that's something that I think my parents kept us away from, you know what I



mean...I don't know whether they thought it wasn't appropriate and... A lot of the physical lifting and stuff like that my dad would have taken charge and all that.

In contrast, Aoife (aged 24) took a very active role in her brother Seamus' (aged 22) life when they were growing up as her father left the family when Aoife was three years old. As the only sibling, Aoife supported (and still supports) her mother in all caregiving tasks involved with her brother who was born with a rare syndrome and in need of help with many daily tasks.

I would say I was very involved in supporting Seamus growing up. It was just me and mum for a long time so she always involved me in decision making around Seamus and took my opinions and views about everything on board. In terms of direct responsibilities, Seamus can't use a toilet so I help out with changing his pads, dressing him, showering him (when the home help guys aren't around), sorting out meals, medicating him etc. I also just hang out with him and watch TV and movies, but this isn't really a responsibility because it's something I like to do.

In other families, the severity of the disability needed all family members to assist with supporting the brother or sister with special needs. It was not a matter of choice, it had to be done. Ann's brother George moved into residential care at the age of 12 as her parents had to work for financial reasons. George came home every weekend and every holiday and Ann had to look after her brother as soon as she was old enough: 'I was probably 12 or 13...I would have to stay at home and look after George. But I didn't mind because it was just... I just had to do it.' Christine (aged 34) whose sister Fiona was 17 years younger and suffered from severe epilepsy from birth, remembers sitting watching her baby sister for hours. She recalls that her two brothers also took turns doing the same so that their 'mum could do something in the house...because she had to be watched because she was going in and out of these seizures'. Kenneth (aged 41) similarly recalls assisting his mother with supporting Heather, his younger sister by eight years who was born with epilepsy and ID, 'When dad was working I assisted my mum more than my brother and older sister ever did with my sister'.

For some participants, subtle demands from their parents to play with or to include their brothers or sisters occasionally became frustrating and interfered with their own plans to play with friends. Marion (aged 32) remembers playing with her friends outside and that her mother occasionally would ask her to involve her younger brother Sean who had a diagnosis of moderate ID, 'Marion, you have to play with him...I really remember going 'What?' you know'. While Marion doesn't think that she was given huge responsibilities for her brother as a child, she reflects as an adult on how her mother probably was 'at her wit's end'

looking for a break and therefore asked her to mind him for a while. Carmel (aged 42) has similar memories of her mother asking her to take her 3 years younger brother Jack, born with severe ID, out in a big buggy. She recalls wheeling the buggy around the estate and on return having a sense that she never stayed out quite long enough.

I suppose that's me in retrospect kind of thinking she was probably dying for that half an hour and I'd be back, you know, like all children after 15 minutes – 'I'm bored and, you know, I don't want to do this anymore.' You know, when she probably really needed the break.

Both participants above reflect as adults on their mothers' needs to have a break from their caregiving tasks, suggesting that they internalised this caregiving which subsequently reinforced future involvement. Carmel in particular refers to the 'psychological territory' of being an oldest child and only girl.

I suppose that's a lot of internalising, not wanting to upset her, because you know at some level as a child that there's something going on, you know, that she has stresses...I mean, I don't know how much of that is to do with being an oldest child and an only girl...I think that kind of goes with the psychological territory for those two. But absolutely, yeah, there would have been a big kind of don't add to their stresses, they've enough going on.

For Carmel the best way of helping out was to look after her own needs rather than add to her parents' stresses.

I was very independent as a child anyway, so I kind of looked after myself so that my parents could mind him more. I suppose I might have been encouraged like that a little bit... It was just if you looked after yourself you were helping mammy and daddy a lot, you know.

A common theme emerging from all narratives is the lack of resentment of expected and assumed supportive roles during childhood. Carmel, for example, never felt any resentment about the supports she provided or about her parents spending more time with Jack than they would have done with her and her other brother 'and my parents would probably say if you asked them that they felt a bit guilty about that...I knew that they were doing their best to make time for us as well. I never felt there was something I couldn't ask them for'.

#### **4.5 Adolescence and changed relationships**

As discussed above, many of the participants had been sharing several aspects of their day-to-day activities during early childhood with their brothers or sisters. As they transitioned from childhood to adolescence, the sibling relationships often changed. One participant, as already mentioned, recalled how her sister's

ASD started to interfere with her studying for her Leaving Certificate. Another remembers added pressure when her sister with high functioning ASD started in the same secondary school. Sarah (aged 22) remembers her father asking her to look out for her younger sister Lisa (aged 20) in school and recalls meeting her Special Needs Assistant before Lisa started. Sarah has memories of eating lunches with her sister in silence in school, as Lisa did not like talking. She reflects on the fact that her parents probably did not intend to cause her any inconvenience by asking her to look out for her sister.

I don't think they meant to, do you know, because they put conscious effort into not doing that. But they did do it anyway sometimes as she got older. I'm very close to her in age – I'm only two years older than her... I suppose I didn't like it...I don't know if it was every day but it was a lot. I think it probably annoyed me an awful lot at the time. Whereas now looking back on it I wouldn't be angry about it, do you know, as an adult. Whereas when you're 15 or so I suppose... Yeah, it was really hard.

In another family, the participant 'opted' out of her sister's life for a while, until she became a teenager and decided to include her in her everyday life again. Siobhan (aged 27) had played a lot with her sister Ailish (aged 30) when they were younger children. As Siobhan grew older, Ailish, born with a rare syndrome, was not able to keep up with the play and at around the age of ten Siobhan did not include her as much in activities. From the age of fifteen, this changed again and Siobhan made a conscious effort to include her sister, 'when I started to drive at 17 I would bring her along with me.'

Carmel recalls her parents becoming increasingly dependent on her skills as a teenager in dealing with bureaucracy and negotiating services. Her parents had no secondary education, and while they were literate and bright, they had left school at 14 to work. She remembers being around 15 and going with her mother to get the domiciliary allowance and accessing other supports that needed completion of forms.

So as soon as I was able I was the one filling out the forms. Like *with* them. It was never I was on my own doing it. You know, when he'd gone to bed we'd be off – right, we have to do this form tonight...

For other participants, looking after their brothers and sisters with special needs became more frequent in their teenage years. Linda (aged 22), the oldest of four siblings, started minding all three, including her youngest sister Louise (aged 15) born with DS, around the age of 13 or 14 'just like if they [*parents*] needed to run out and do something, or if they were gone for an hour to two at a meeting or something'. Karen, second oldest of four siblings, also 'minded' her sister Kim and

her youngest brother during summer holidays when her parents were working. However, when Karen was around 16 or 17 she felt the need to get another job outside the family, in a local shop or in the local restaurant.

I remember discussing it with my parents and them feeling, yeah, that I needed to kind of get away from the family thing. But financially it really helped that I was looking after them, so I did it for one more year. I think actually I was going on 17 and I got a job in a restaurant.

Karen's parents eventually understood the need for Karen to lead her own life separately from the family and her sister with special needs. Her role as a 'mini mum', however, has continued into her adult life where she still takes a greater responsibility for her sister in comparison with her two brothers.

#### **4.6 Parental attitudes and family dynamics**

Family dynamics changed for many of the participants after the arrival of a sibling with disabilities. Two mothers became very depressed which had a huge impact on participants. Christine (aged 34), as already mentioned, was doing her Leaving Certificate when her sister (aged 17) was born with severe epilepsy. She remembers how her mother went into deep depression and how the rest of the family struggled to get on with their lives: 'It was very difficult...a very, very difficult time.'

Two other participants remember how their parents could not cope at all with their sons' disabilities. In Annie's case, her mother took out her anger and resentment on her:

Because mum was very – well, not was – still is – very angry and resentful and bitter and critical, and instead of being angry at the person she's angry at, which is maybe a psychologist or a speech therapist or somebody that she can't get to, she'd be angry at me if she could get to me.

In another case, a father's negative reaction reinforced an already strained family dynamic. Amy (aged 41) recalls her father's inability to cope with her 10 years younger brother Philip's seizures and his 'running away' when Philip had to go to hospital. Amy witnessed how her mother needed help in order to support Philip, but her father opposed respite or supports from outside the family although he himself 'wasn't stepping up to the mark'.

So that's the way I would have viewed it when I was growing up, you know. I suppose going back to how my parents would have dealt with it...that was the difficult part. And they ended up separating in the end, you know.

#### 4.6.1 Families split in two

Another change in family dynamics involved splitting families in terms of activities outside the home. Many families were divided into two, where fathers spent time with the typically developing children and mothers took care of the children with special needs. Annie (aged 45) remembers, how her brother James who was 4 years younger, was always kept separate from Annie and her sister.

It was like my mum abandoned us and stopped parenting us. She left that to my dad. And so it was always dad and the girls, and mum was always with James, so much so that she would be at home with James all the time and she didn't really go out much at all...When we were younger we went to Irish dancing myself and my sister. My dad took me to all of that, took us learning music and everything, so much so that the other children in our dancing class thought our mum was dead.

Similar parental divisions of labour were described by other participants. Siobhan (aged 27) recalls how she and her sister Ailish (aged 30 and born with a rare syndrome) had parents 'allocated' to them: 'so my dad, when I was small, was like my parent and my mum was Ailish's parent'. This family division was taken for granted and anything outside this norm became a memorable experience. For example, when she spent one day with both her parents on her own:

I was about maybe 6 or 7... I remember spending the day with my parents alone without Ailish, and that is the only memory I have of being alone with my two parents without Ailish being there. Oh yeah, I was delighted with myself. This was the best day ever. I was getting all the attention. Because usually I only got attention from one at a time, but today was the day that I would get attention from both at the same time. So that was really unusual...So Ailish and myself loved to watch Darina Allen, the cookery programme. So mum and dad asked me what I would like to do, when I was about 6, and I said I wanted to go to Darina's house. So we went off to Ballymaloe for the day and, sure, I was delighted with myself.

Similarly, Carmel (aged 42) reflects on the very few occasions that she went out with the whole family as a child. Her father took Carmel and her typically developing brother out occasionally, while her mother stayed at home with her younger brother Jack born with severe ID.

There are some photos of us all out as a family at the seaside or whatever, but they're very rare, and there was never any question that we would go away somewhere...we didn't have a car as well, which made things more difficult. So if we were going, it was all of us on the bus with the big buggy and, you know, all of that...it probably hugely impacted my parents' social

lives as well because there weren't many people willing to babysit a disabled baby.

Lack of services, then, such as respite care or other supports, impacted hugely on family dynamics and on some of the participants' social lives growing up. Family outings involving the whole family were rarely, if ever, a possibility. The theme of supports for siblings and families will be further discussed in Chapter 6.

#### **4.6.2 Challenging behaviours**

For a minority of participants, the nature of their brother's or sister's disabilities prevented them from bringing friends home. Christine (aged 34) remembers how her sister Fiona (aged 17) would scream before seizures.

I think the biggest thing – and I've talked to my brothers about it – is that we could never bring anybody home...I never remember us having friends over because Fiona...she has horrendous screaming. It's like a seizure activity – before a seizure – and she can scream for hours. And you just wouldn't bring someone home, like, you know. It was very difficult...we'd meet them somewhere else. That was definitely one thing that kind of was affected.

Another participant, Alan (aged 23), remembers how his social life was restricted because of his younger brother Gary's disabilities (DS and ASD): 'We couldn't have huge big birthday parties because Gary would be there'. Alan also reflects on how he thought it was unusual to see ornaments or flowers on tables when visiting other people's houses, as this was something that they could not have in his own house due to his brother's behaviour.

While participants in this study recall some negative childhood experiences of living with a brother or sister with special needs, there are strikingly few accounts of challenging behaviours reported. However, two participants do remember rare occasions of feeling upset or afraid due to their brother's or sister's outbursts. Kenneth (aged 41) remembers that his sister Heather (aged 33) used to have severe outbursts when she didn't get what she wanted. She also insisted that the whole family would go to bed at the same time as she did otherwise she would start throwing things at Kenneth and his other siblings.

I could see it terrified my mum and so she agreed. I recall some nights myself and my brother would sneak back into the lounge to watch TV and if my sister heard a noise she would come down and check; many times we would hide behind the couch so she could not see us and then come back out when she returned to bed. Looking back now it was scary if she caught us as she was unpredictable.

Mary (aged 34) recalls one upsetting time, when her brother Paul (aged 38) who has Asperger syndrome, hit their mother hard across her face and she started crying: 'I remember we were all sent to our bedrooms and all that kind of stuff and we could hear her crying'. Both Mary and her brother were teenagers at the time and she remembers her father becoming very cross with Paul.

I remember that time I felt sorry for him because my dad got very angry with him actually and I was very much like, God, you know, he shouldn't have done it but it's not his fault kind of thing.

Mary's reaction is typical of the 'mixed emotional' experience many siblings of brothers and sisters with disabilities have growing up. On the one hand, they dislike the behaviours associated with the disability and on the other hand they empathise with their brother's or sister's difficulties and defend their actions as being part of their condition. Many participants thus realised at an early stage the importance of the need for intervention and therapies.

#### **4.7 Therapies, treatments and care arrangements**

Many participants remember the various professionals and therapeutic interventions involved in supporting their siblings with special needs and in many cases they would have been brought along to these therapies. Annie (aged 45) recalls the whole family having to go to meetings with professionals as her mother would not take her brother James (aged 41) on her own.

We'd be like ducks going off. We had to go to [Eye Hospital] and to this hospital and that hospital. And we never knew why; we just knew it was a big stressed thing and that mum was really stressed.

Similarly, Alan (aged 23) remembers accompanying his mother and younger brother Gary to professionals. Gary, born with DS and also diagnosed with severe ASD, became very agitated in waiting rooms, so Alan would have taken him out while his mother spoke to the doctor, 'he'll start screaming and kind of self-harming'.

Anna (aged 30) also went along to 'at least a dozen speech therapists' with her younger brother Peter, born with DS. She also recalls doing the same therapies as Peter as he then was 'far more manageable...and didn't feel he was being singled out'. Tara (aged 25) remembers going to the children's hospital with her mother as her sister Molly (aged 23) started doing speech therapy and other therapies.

So I remember when we came back [from living abroad] finding it really hard, because we'd go to all the different therapies and we'd have to sit in

the foyer and do our homework. So I remember finding that really hard and annoying. Like besides the whole like coming home business, do you know – like that massive change - it was a complete change. We went from going swimming after school to sitting in the foyer of a boring therapist.

While Tara experienced her sister's therapies as 'boring', Amy (aged 41) was traumatised by the treatment regime for her younger brother Philip who has severe ASD. It was a physical intervention involving the whole family and Amy and her siblings had to do it every morning for half an hour before school.

And it's where you take his arms and legs and you do this kind of movement...And then he had this breathing bag and then he had to climb on this climbing frame and claw... Anyway, that traumatised me, traumatised me - and it still does, like... he was crying the whole way through it. It was traumatic. And we used to have to do it... We'd be up at 6 or 7 in the morning to do that before we went to school. And it was obsessive on my father's side more than my mother's and it was just... It wasn't right in my mind, you know. But they were doing it for the right reasons, you know.

Although the above case appeared to have been an extreme intervention, common for all participants was the fact that therapies and meeting professionals became part of family life.

Other upsetting memories referred to by one participant, concerned her brother's transition to residential care. Ann (aged 44) who grew up in the UK remembers her brother George's (aged 46) move into residential care at the age of 12 as being very traumatic. Ann's parents both had to work, so residential care was the only option. Ann remembers as a child how her brother hated going back to residential care after being home over the weekend.

I always remember him going back on a Sunday evening. He hated it. He didn't like going back. And mum would always give him a bath before he went and he'd always have his clothes that he wore from residential that he would wet. But not wet as in urinate - he'd put it in the sink so it would be wet, so he knows he wouldn't have to put them on. So that was George's way of saying 'don't bring me back'. And that was heart-breaking. That was really hard... they'd [parents] have tears in their eyes but they'd try not to show me.

#### **4.8 Sibling dynamics**

The participants' tolerance towards their brothers or sisters with disabilities was tested at times during their childhoods. Some participants reflecting on their childhood behaviours towards their sibling acknowledged that some behaviours



were not entirely positive. Mary (aged 34) recalls how she and her brothers used to provoke their brother Paul (aged 38 and diagnosed with Asperger syndrome).

So sometimes, yeah, we'd like to get a reaction and then, you know, he'd... I remember, like, he was really scared of knives, and we thought it would be really funny to walk into the room with a knife and things like that. And he'd start screaming, you know...It sounds so cruel!

Similarly, Henry (aged 30) remembers how he and his other brother teased their sister Jill (aged 32) and diagnosed with mild ID. As an adult, Henry reflects on his behaviour as being part of 'normal' sibling rivalry 'just because that's how boys are with their sisters' and that children can be cruel sometimes. Another participant, Bernie (aged 44) also remembers the occasional fights four sisters close in age would have had during childhood, including their sister Jackie (aged 40) born with DS.

While the overwhelming majority of participants in this study describe their sibling relationships as being part of 'normal' life, it is important to acknowledge different family sizes. Four of the participants in this study were the only sibling of a brother/sister with disabilities. As such most participants were able to share their experiences with other typically developing siblings. In families where the participant were the only sibling of the brother or sister with special needs, the lack of other typically developing siblings was sometimes felt. Ann (aged 44) and only sibling of George (aged 46) recalls how as an adolescent, she reflected on the fact that she did not have other siblings that she could talk to or share her experiences with.

Actually I do remember feeling resentful when... I was probably 18, I think. My two cousins were home from Ireland....and they're brother and sister. And then my other two cousins in London that are both brother and sister. I remember the five of us being out together and it was then I realised God, I wish my brother could be out with us and, you know, have the craic with us and...It was only kind of then that I realised that oh God, you know, I do miss that...someone that I could talk to. Because I had a sibling - George is my sibling - but I could never talk to him.

Ann's narrative resonates with the loneliness identified by only siblings in other international research (Barr and McLeod, 2010:168, Meyer and Holl, 2014).

#### **4.8.1 Conflicting emotions in the public gaze**

All participants in this research were very protective of their brothers or sisters in public and would have stood up for them if needed. Anna (aged 30) for example remembers how her brother Peter (aged 29) born with DS came with her parents to collect her after a basketball class.

And Peter took a basketball and tried to play basketball. And I remember the kids there mocking him and laughing at his attempts and I never went back. I refused to go back. So it was almost like if you didn't accept Peter you weren't accepting me and I'm going to reject you before you have a chance to reject me. And I've always been kind of his protector and I didn't want to put him in a situation... Probably I didn't want myself in that situation, but I really didn't want them to be mocking him and belittling him.

Similarly Emma (aged 33), whose brother James (aged 22) has DS, remembers an incident in school. She was in sixth class and one of the children in her class called her 'a capper and I absolutely lost my reason'. Emma's reaction was not only to the use of the word itself, but the fact that her friend knew that she had a sibling with DS: 'and I just saw red. That's one of the things that sticks out most for me: sticking up for James'.

Aoife (aged 24) and only sibling of Seamus (22) born with a rare syndrome, used to be very bothered by people staring at Seamus in shops when they were children.

I used to give them dirty looks and stare back at them until they noticed and got uncomfortable. Childish curiosity has never bothered me, kids ask questions and are interested to know why someone looks different, uses a wheelchair, acts differently, and mum and I will always answer their questions – often to the embarrassment of their parents who find the whole thing very awkward – but it would be when older children and adults stared at him that it really bothered me, because I was always afraid Seamus would get freaked out by people looking at him, or feel uncomfortable, or wonder why they were staring, because I don't know if he knows that he is a bit different.

Bernie (aged 44) and sister to Jackie (aged 40) and born with DS also stared back defensively if strangers looked at Jackie. Similarly, Kenneth (aged 41) remembers feeling uncomfortable if people stared a lot at his 8 years younger sister, Heather, born with ID.

Other participants recall being embarrassed by their siblings' behaviours in public. For example, Siobhan (aged 27) and only sibling of Ailish (aged 30) born with a rare syndrome, recalls not wanting her sister coming in the car with her to school on one occasion when she was very young.

I didn't want Ailish to come in the car, probably because I didn't want her to be banging on the windows and waving at everybody. And I remember dad asking me: 'Are you embarrassed by your sister?'...and I must have been, but I was more embarrassed that he had noticed that.

Marion (aged 32) remembers going to outings such as a pantomime where her brother Sean (aged 29) who has moderate ID would start screaming 'so my mum would have to bring him out and...I was really embarrassed by him actually'. Other participants, whose siblings had high functioning ASD, also recall being embarrassed by their behaviours. Mary (aged 34) was in the same school as her four years older brother Paul who has Asperger syndrome.

I was kind of probably embarrassed by him for a long time, because we would have been in the same school at certain times. I remember sometimes, like, he would be incontinent at school and things like that...He went through a lot of that as a child. You know, and I'd be very embarrassed by it. And in the schoolyard he'd be on his own, walking around, you know, doing the typical autistic hand gestures.

Sarah (aged 22) remembers her younger sister Lisa's tantrums in public but does not recall being particularly embarrassed by them when she was younger. However, as she was getting older, the socially inappropriate behaviours caused by Lisa's ASD, began to annoy her even though she is aware that her sister doesn't realise how inappropriate her behaviour is.

And as I've gotten older things like that I'm like oh my God I can't believe she's doing that...Like she'll start picking her nose and I'm kind of there going, 'Lisa, stop!' And then she jumps and she gets a fright and it's kind of – I don't know – it's weird. She doesn't realise.

Similarly, Mary recalls how her feelings towards her brother with Asperger Syndrome changed from embarrassment to empathy as she grew older. While initially feeling very embarrassed by his autistic hand gestures, she gradually became more conscious of his exclusion having frequently seen him alone in school the assembly area.

I actually started to feel sorry for him at that stage. I used to think, okay, he's spent a lot of time on his own, he stands out, he's obviously being ignored by the school. So, yeah, I probably started changing my feelings at that stage from the embarrassment to more for like sympathy and 'this is wrong and he needs more help than this' kind of thing, yeah.

Mary's changed reaction from embarrassment to empathy during adolescence, is commonly reported by siblings in other qualitative international adult sibling research (Benderix and Sivberg, 2007; Mascha and Boucher, 2006; Stalker and Connors, 2004; Barr and McLeod, 2010; Davys et al, 2016).

## 4.9 Conclusion

International research has highlighted the importance of recognising childhood experiences in order to understand adult sibling relationships (Heller and Arnold, 2010, Hodapp and Kaiser, 2005; Petalas et al., 2012; Atkin and Tozer, 2014; Davys et al., 2016). The childhood journey of siblings of individuals with ID/ASD therefore merits research attention. This journey varies depending on a range of circumstantial and emotional variables such as parental coping, family dynamics, the type of disability and where the sibling's life is situated emotionally and physically during childhood and adolescence.

Analysis of the 25 narratives in this study suggest an early socialisation into 'minding' and 'looking out for' the brother or sister with special needs. The level of supports for the brother or sister with special needs varied depending on the severity of the disability. In cases of moderate to severe intellectual disabilities, participants reported a high level of hands on involvement. Participants with siblings with mild intellectual disabilities or high functioning ASD would also have provided support, in particular as they transitioned from childhood to adolescence. These findings resonate with other studies suggesting that siblings assume additional caring responsibilities at an early stage (Tozer and Atkin, 2015).

Family dynamics and parental coping capacities had major implications on how the siblings experienced growing up with their brother or sister with ID/ASD. Thus, in families where mothers became depressed or withdrawn, participants' experiences were negative. A majority of participants also recall how families were split in two, where mothers spent most of the time with the brother/sister with special needs, and fathers with the typically developing siblings. It is important to acknowledge that the majority of the participants as young children did not experience their family lives as being different from other families: this was the way their siblings were and it was part of 'normal' life. However, reflecting back on their childhood experiences, they now see how their lives were indeed different. In particular, many acknowledge the intensive care work which their mothers engaged in.

These findings mirror experiences documented in international literature exploring the effects of growing up as a sibling of a child with ID/ASD. The theme of emotional conflict also resonates with other studies, where participants on the one hand felt embarrassed by their brothers or sisters and on the other hand felt sorry for them because of their disabilities (Benderix and Sivberg, 2007; Mascha and Boucher, 2006; Davys et al., 2016, Tozer et al., 2013).

Challenging behaviours, although reported in a few cases, did not make participants in this study feel unsafe or anxious at home (Duignan and Connell, 2015; Barr and McLeod, 2010; Mascha and Boucher, 2006). This can perhaps be

explained by the fact that only four out of the 25 participants have siblings with a primary diagnosis of ASD, a disability more commonly associated with challenging behaviours (Ross and Cuskelly, 2006; Barr and McLeod, 2010; Opperman and Alant, 2003).

In sum, the participants' childhood experiences, did shape their roles and expectations for the future. The next chapter will discuss participants' sibling roles as adults.

## **5 Sibling roles and expectations for the future**

### **5.1 Introduction**

This chapter explores findings from the 25 narratives in relation to participants' understandings of the role they play or intend to play in the lives of their brothers and sisters with ID/ASD. A key theme is the assumption of the 'most involved sibling' role (Heller and Arnold, 2010: 22). Related themes include, motivations for assuming the role, concerns and tensions surrounding the role and challenges in reconciling the role with life changes and other responsibilities. The issue of future planning and the extent to which this has been undertaken in participants' families is another key issue. The reluctance of parents to engage in planning, lack of legal clarity about the potential roles which siblings can hold, and the difficulties of getting service providers to recognise siblings as advocates are explored. Finally, the supports which participants identify as enabling their roles as siblings are discussed.

### **5.2 Assuming the 'most involved sibling' role**

The role of 'most involved sibling' described in Heller and Arnold's (2010: 22) work was clearly evident in this research. Most of the participants are currently acting as most involved sibling for their brother or sister, have done so in the past or expect to do so in the future. In most cases this role evolved from childhood and is frequently explained by reference to a close relationship with their brother or sister and a sense of being best suited to supporting them. Most participants began to think about the future needs of their brother or sister during adolescence and while most do not feel obliged by their parents to assume responsibility for their sibling, some express mixed emotions regarding the implications of such a role for other aspects of their lives.

#### **5.2.1 Motivation for assuming the most involved sibling role**

The strong connection which many siblings have to their brother or sisters with ID was evidenced in the narratives. The high level of involvement which many participants described having with their adult brothers and sisters with ID/ASD, reflects the findings of Doody et al., (2010). They found that adult siblings of individuals with ID/ASD, usually maintain high levels of involvement with their sister or brother and demonstrate strong affective ties throughout the lifecourse. Similar to other research (Tozer & Atkin, 2015:349) this study found that these ties are based on a shared history and a feeling by the participants that they have a unique understanding of their brothers and sisters and of their needs. For the

most part, the participants are motivated to take on the role of most involved sibling out of affection for their brother or sister and a concern for their future welfare and happiness.

Very strong emotional attachments to sisters and brothers with ID/ASD were described by a number of participants. Anna (aged 30), considers her brother with ID who is 17 months younger than her, to be her best friend. She describes an affectionate and inter-dependent relationship in which 'he's a safety blanket for me rather than I'm minding him. He's minding me.' Emma (aged 33) recalled that she 'absolutely adored' her brother James (aged 22) from the start: 'From the second he was born I just loved him so much. I always thought he was the cutest kid.'

Carmel (aged 42) believes that her relationship with her brother Jack (aged 39) who has ASD is:

...closer to a parental bond than a standard brother/sister bond would be. I've always felt responsible for him. ... I would never have emigrated. I would never have worked abroad because I didn't want to break that relationship, any more than I would leave my child.

Other participants described a childhood in which they were the sibling who engaged most with their brother or sister with ID/ASD and they frequently related this to aspects of their personality. Mary (aged 34), realised in her late teens that she would probably be the sibling most involved with her brother with Asperger's syndrome: 'I was the one closest to him and kind of understood him the most and spent a lot of time with him.' Sarah (aged 20), has already self-identified as the sibling likely to be most involved with her younger sister with ASD. She frequently worries about her sister's future but doesn't believe that her older sister thinks about it.

I think I make more of an effort with her [sister with ADS] than my older sister does... I would be a really empathetic person...whereas my older sister... she'd be much more emotionally removed from it.

Similarly Tara (aged 25) believed that it was she, rather than her older sister, who would most likely be the key person who would assume responsibility for her sister Molly (aged 23) with mild ID.

I'd be closer to her than my older sister... I'm just a bit, I don't know how to put it. My older sister, she's just a bit scattier. She probably wouldn't be as well able to take care of her as I would... And I'd earn more money than she would, so I'd be better able financially to take care of her.

Linda (aged 22) is the eldest of three siblings, with the youngest Louise (aged 15) having DS. She is conscious that her parents are 'exhausted' from the 'constant battle over everything' that is required for Louise. Despite this she is willing to take on the role of most involved sibling, partly because she is very close to her sister and partly because she doesn't believe her other siblings would assume the role.

I don't feel forced into it at all. I think it's probably an eldest thing to feel like you have to take it on, but I actually don't feel forced into it.

A minority of siblings described their assumption of the key sibling role in terms of duty or responsibility. Harry (aged 27) and brother to Tom who has an ID has thought about his brother's future since he was a teenager and felt that he would 'probably have some duties in it'. He envisages being involved in his brother's life as an organiser or overseer. Currently he sees his brother every few weeks when he comes home from college for a weekend and is not actively involved in his life. He believes his future role will reflect a similar level and type of involvement best described as caring about more so than caring for.

From my perspective maybe I don't want Tom to be literally under my wing...I can tag in organisationally and see him as often as I see him now.

A similar understanding of her future role was expressed by Chloe the 31 year old sister of 35 year old Diarmuid who has mild ID. She described having very little involvement with her brother growing up and she now sees him about six times a year. Diarmuid has lived happily in a residential setting since he was 20 and Chloe does not envisage a need for either she or her sister to be more involved in his life. She did expect to 'sort of up the ante and see him more' when her parents are no longer alive but doesn't believe that she will 'have any constraints on my life because of Diarmuid'.

Participants who are only siblings all report that they intend to be very closely involved in their brother or sister's future. They also report that their parents have not put any pressure on them to assume this role. In all cases the only siblings are motivated by bonds of affection and concern for the wellbeing of their brother or sister. Líosá (aged 22) and an only sibling to Niamh who has ASD, is adamant that she will take care of her sister in the future.

I don't want her, do you know, going to a place every single day and staying overnight there...I wouldn't be happy with that... I just want to protect her and make sure she's okay and so on.

She perceives her decision as a choice: 'my parents have always said I have a choice and I was like, "No, no argument, I'm doing this".' Ann (aged 45) and also



an only sibling described the 'very special unique relationship' she has with her 44 year old brother with ASD. From a young age she was committed to being an advocate for him telling her parents that 'no matter what happens I'll always be there for him.' Siobhan (aged 27) and only sibling to a sister with a rare ID also began wondering and worrying about her sister's future from a young age but didn't raise the topic with her parents as any mention of the future made her mother cry. She is very clear that her parents have encouraged her to have her own life and is motivated to be involved her sister's future care out of love.

### **5.2.2 Negotiating roles with other siblings**

In most families where there is more than one typically developing sibling, there appears to be unspoken agreement between siblings about who will take on the most involved sibling role. Referring to the future of Peter, her brother with ID, Anna notes that she 'will get him' and acknowledges that 'I think there's just been this unspoken agreement that this will happen.' She does not expect to get help from her two older siblings. Her brother who lives nearby is much older and has no relationship with Peter and her sister who lives in the UK is described as 'a kind of shadow in the distant background'. Mary (aged 34) who has three typically developing siblings raised the question of what would happen to their brother with Asperger's syndrome in the future. Her older brother responded that the other siblings assumed that she would be the future carer but he offered to help out financially if that was required.

Most participants were accepting of the role of most involved sibling, however a minority have challenged their other siblings to take on some responsibilities. Annie who is single, childless and in her mid 40s, always assumed that she would be the most involved sibling for her brother James who has ASD and whom she expects to co-habit with her when her mother is no longer in a position to care for him. This assumption was shared by Annie's sister. Their mother's recent frailty and illness has prompted Annie to have some difficult discussions with her sister in relation to future care for James. This has become a cause of dispute and tension between them. Annie has told her sister (a teacher) that James can live with her [Annie] during the school year but she expects her sister to take James to live with her during school holiday time. Her sister who is married with children doesn't believe this will be possible and hasn't spoken to Annie since the discussion about future care. Annie believes however that the issue will be resolved and is determined that the responsibility will be shared.

Harry (aged 27) believes he is best placed to be the sibling with most responsibility for his brother with ID, but notes that his older sister might not agree with this. He asserted that he '...would carry that responsibility better than my other siblings, simply put.' His belief in his suitability for the role is based on his assumption that he is likely to be the most financially stable of his siblings in

the future 'maybe I see those with financial security as having greater responsibility, which I think is fair enough.'

A minority of participants described a more equal distribution of care and support roles between the siblings in their families. Bernie (aged 44) who has three typically developing siblings felt that they 'would all have an equal responsibility' for their sister Jackie (aged 40) who has DS. Angela a 32 year old single and childless woman and sister to Patrick who has mild ID, explained that Patrick would be closer to her than to their two other siblings. She noted that when troubled or stressed he would talk to her and that he would do anything for her. However, she emphasised that her other brother and her sister were also involved in supporting Patrick to more or less the same extent as she was, although in different ways. As such she did not identify herself as the most involved sibling. A similar distribution of care work was described by Christine, the 34 year old sister of Fiona who has severe ID and complex medical and care needs, which are currently being cared for by a combination of professional and family care within the home. Christine (aged 34) a doctor, is more involved than her two brothers in interactions with medical and other professionals, as her medical expertise makes her an effective advocate. However, she noted that her brothers were 'very, very, very, good. I might do a little bit more, but they're very present as well and they're not typical boys.' Alan (aged 23) and brother to Gary (aged 21) described himself as the sibling who would always 'look out' for Gary and observed that growing up, he tended to be the one who tried to make Gary laugh while his older sister adopted roles in relation to training and teaching Gary. Alan emphasised however that he believed his three other typically developing siblings were open to providing financially for Gary in the future and to having him come and stay with them for visits.

### **5.2.3 Tension and ambivalence in assuming the most involved sibling role**

Some participants indicated the complex emotional tensions that surrounded their decision to be actively involved in the lives of their brothers and sisters. Mary (aged 34) found it difficult to decide if she had chosen the role of key sibling. She explained that part of her motivation for taking on the role was that she couldn't 'trust the others to do it the way I would want them to do it'. However she does believe that she could walk away from the role and that as such it was essentially a choice she had made. The significance of feeling that one had a choice, was mentioned by a number of participants. Annie a single woman in her 40s acknowledged that up to recently she felt 'trapped' and believed she had no choice but to take on the care of her brother with ASD. Discussions about this with her GP and an alternative therapist have helped her realise that she does want to take on the role but only with some involvement from her sister who lives nearby. Similarly, Angela (aged 32) has felt 'bogged down' by

responsibilities to her brother Patrick (aged 30) who has mild ID. She found counselling very helpful in enabling her to recognise that she has a choice about involvement and to reconcile her own needs with her sense of responsibility and connection to her brother.

...I do have a choice and I do at times when I need to take a step back and stuff like that for my own happiness and wellbeing... I could never just walk away.

A number of participants experienced what Delleve et al., (2000:172) have referred to as “harmonizing dilemmas” where they struggle to reconcile sometimes conflicting emotions and roles. Anna (aged 30) for example has felt some occasional resentment toward her brother with DS who has caused her to be somewhat tied down but she describes this as fleeting and believes that ‘I’ve gotten more from him that he has taken from me.’ Christine (34) who continued to live at home until she was 27 so that she could help to care for her sister Fiona who has profound ID and complex medical and care needs, continues to struggle with the sense of duty she feels. She believes that her brother who is married and also involved in caring for Fiona, feels a similar sense of duty to be involved, although their parents never asked them to do so.

It wasn’t that anyone expected me to do it. ... It was just never spoken about. ... But I felt a duty. .. And it’s the sense of duty, the sense of responsibility. The wanting to do it, it’s not that you don’t want to, but it’s very hard then when that comes into conflict with the other relationship.

A similar conflict is evident in Sarah’s narrative. Aged 22, Sarah has a younger sister Lisa with high functioning ASD and one other typically developing sister who is 24. Sarah is conscious of the very demanding role her mother plays as primary carer for her sister and would prefer to avoid taking on that role in the future. However she believes that her sister who is training for a demanding career won’t take responsibility for Lisa in the future and as such the role will fall to her.

She [typically developing sister] wouldn’t really feel guilty about it, I don’t think, whereas I probably would. I’d find it really hard... I just couldn’t put her [Lisa] in a care home here. Like I just couldn’t do that.

Geraldine (aged 39) was also conflicted. She is tempted by international career opportunities which would require her to move and not be near the residential home where her brother Robert (aged 40) lives. While she feels she has the choice to do this, she doesn’t feel she could live with herself if she was not nearby and closely involved in Robert’s life, particularly as both of her parents are

dead and her only other sibling lives in another part of the country and is not closely involved with Robert.

I have tied myself down here with this. And is that willingly or what? But you know, there is still a huge amount of love there for your brother. There's a huge amount of guilt and part resentment too.

Guilt was also expressed by a number of other participants. For some the guilt relates to their limited availability to participate in their siblings' lives. Henry (aged 30) who lives in Europe has limited opportunity to visit or be involved with his sister Jill who has ID: '...I do feel guilty being here and not helping out.' Similarly David, who works very long hours and lives some distance from the residential community where his sister Laura lives, feels guilty about how often he sees her.

How often do I see her now? I mean not as often as I should ... it comes down to how I work, it's once every couple of months. I try, but I know I should be better.

A minority of participants describe the guilt that has surrounded their decisions to step out of a very involved care role with their siblings. These participants perceived, as have participants in other research, that parental aspirations for siblings to live their own lives are frequently held in tension, with expectations that non-impaired siblings will be involved in supporting their brother or sister in the future (Davys et al., 2016 & 2010; Davys and Haigh, 2008; Bigby, 1997). Marion (aged 32) has been very actively involved in supporting her brother Sean with ASD. Recently she told her parents who are now in their 70s that Sean cannot live with her in the future as he is disturbed by the noise and unpredictability of children.

But I just had to sit them [parents] down and say 'If I take Sean I can't have a family of my own. I think they were so shocked. They were like, 'Oh my God, we would never do that and we didn't expect it.' But I think that deep down they hoped... Like I really feel guilty about that. A lot of people do.

Amy (aged 41) played a central role in caring for her brother Philip throughout her childhood and when she reached 18 she took the decision to move far away from her family as she could no longer cope with the situation.

I felt I had to leave. And I had to leave. ... I had to leave. I had to be gone. I had to move out. I mean far away. And that's what I did... But that was more because of the dynamic, what was going on in the family as opposed to Philip. And I felt I'd let him down.

Amy also described the anxiety she experienced around support issues in Philip's residential placement. An alternative residential place has been provided by the service provider but it is very unsatisfactory. As the mother of 5 children living at the opposite side of the country to her brother, Amy is in no position to provide him with an alternative to attending the service and she and her mother are in constant negotiation with Philip's service provider to improve the service he is receiving.

The fact that their brother or sister was in residential care proved a source of guilt for other participants. Despite acknowledging that residential care was the best option for her brother Jack who has severe ID, and that neither she or her parents had ever thought that she would be a carer for him, Carmel still felt guilty when he moved into residential care: 'But I suppose I felt guilt about it because ... I don't want to be a full-time carer. I've seen what it did to my parents, you know, they're exhausted.' Similarly Geraldine acknowledged the guilt she felt when her brother Robert entered residential care. Geraldine and another brother took the decision to seek a residential placement for Robert who has ASD having spent three years as his primary carers following the death of their widowed mother. Combining this role with full-time employment proved extremely difficult but the decision remains a source of guilt for Geraldine.

It's easy to say, you know, what your parents would want you to do is for you to look after your brother... and in some way I really would like to do that because no one will look after him as well as his own family ... and you want to care for him but it's so draining...It can be so isolating, ... you can find somebody to mind your children. Nobody wants to mind a challenging needs adult. ... And there's that level of guilt that you will have, you know, that I have this place, couldn't he stay here?

Henry (aged 30) also drew attention to how lonely he finds it when he spends long periods of time on his own with his sister Jill (32) who has ID and expressed his admiration for his mother and other sister who spend more time with her.

Jill came to visit me actually here in X [European city]... just for a weekend. And it was lovely, it was great. But sometimes it can be almost a little bit lonely as an experience because she just ... there's no conversation at all, you know. I'm so impressed with mum and Nora and how they manage.

The complex emotional tensions which many of the participants identified clearly indicate the strain which the sibling role can entail at various points in the lifecourse. The participants' narratives also highlight the isolation which siblings who are involved in caring can experience and the limited supports which are available to them in this role.

### 5.3 Sibling roles across the lifecourse

The contingent and transitional dimension of the sibling role highlighted in the literature (Tozer and Atkin, 2015; Seltzer et al., 2009; Hodapp et al., 2005), is emphasised in the narratives of a number of participants. Sibling relationships are constantly in transition and different stages of life lead to particular dimensions or dynamics in the relationship coming to the fore. The uncomplicated vision that Líosá (aged 22) had of her future role in her sister's life has been challenged by the complexity of life changes she is currently experiencing. She is increasingly conscious of potential limitations on her life including the fact that it is unlikely that she can live abroad.

Originally before I went to college, I was like great, I'm going to go home, going to mind her for the rest of my life. A husband – that's fine- we'll put that in there. But now I don't know what's going to happen because, do you know, I've kind of realised, like, you know, she's have to come down here. So she'd have to move or I'd have to move and I don't know how she'd feel about that, would she be stressing out and stuff. So I'm not really too sure about what's going to happen now.

Many siblings expressed concerns about how their future roles and responsibilities in relation to their sisters or brothers might impact on their life choices. Aoife, (aged 24) and only sister of Seamus (aged 22) who has a rare syndrome, was very concerned about how she would reconcile her own needs and those of her brother in the future: 'I worry about how I can best look after Seamus and make sure he lives his best life, while also having one of my own.' Linda (aged 22) and a medical student feels that she has to consider the potential financial needs her sister Louise (aged 15) might have in the future. She anticipates a career path that will allow her to earn enough to provide financially for Louise who has ID.

...I need to do something that I'm going to have the kind of money that she [Louise] might need to have ... things that she [Louise] wants to do or the services that she wants to access.

Furthermore, Linda believes that decisions about where to live will have to take Louise into account: 'I wouldn't have a problem with moving away for a short time, but I feel like I'm never going to fully move away, of if I move away, like, Louise will be coming with me.' Christine (aged 34) is involved with the physical care of her sister Fiona, who has ID and complex medical needs, and also assists her mother in arduous negotiations with professionals and service providers. She combines this with a busy career and is very conscious that she may not be able to reconcile these responsibilities with the added responsibility of motherhood.

...I do someday want to have a child. But how would I do both? How would I do okay by her [Fiona] and by a child... So yeah, that would be a worry for me. And the guilt.

Sarah (aged 22) voiced the same concern. She envisages that her sister Lisa who has high functioning ASD will live with her in the future but expressed concern about whether or not she could reconcile that with having a family of her own. In contrast, Anna who is 30 and currently single, believes that as her brother is very gentle and good with kids, his co-habiting with her in the future would not be incompatible with her having children.

A number of younger participants who foresaw themselves being the most involved sibling in the future and who are currently single, indicated that any decisions they would make about future partners would have to include consideration of their responsibilities to their sister or brother. Most were adamant they would not consider a partner who was not accepting of their sister or brother and of their responsibilities to them. Liosa (aged 22) Linda (aged 22), Sarah (aged 22), Alan (aged 23), Tara (aged 25), Anna (aged 30), David (aged 32), Emma (aged 33) and Geraldine (aged 39) all noted that their partners would have to accept their sister or brother and the responsibilities that came with that. David (aged 32) for example, explained that acceptance of his sister would be a 'prerequisite' for any relationship.

Like my sister is part of my life. She's an amazing person. If someone couldn't accept that or found it difficult I'd have huge problems with that, you know.

Sarah (aged 22) felt that any potential partner she had would have to accept that her sister with ASD would be living with her and she acknowledged that 'it's a massive ask to put on someone else and sometimes I don't know if it's fair. So I don't know what way that'll go.' Geraldine (aged 39) also believed that the additional demands and stress of having a sibling (Robert) with ID makes her cautious about engaging in a relationship with a partner.

I've sheltered myself away from opportunity. I can't blame Robert. But it does obviously play a big part in it... It's so stressful, the last thing you want to do is put up with somebody else coming in who has their own needs and expectations.

Six of the participants had children and some described the challenges of reconciling parenting and care roles. Ann (aged 44) is actively working to develop activities that her four year old son can share with his uncle George who has ID.

I'm trying to build up the relationship with him (George) and Seamus (son) because George was never used to babies. ... He's kind of getting used to him now.

Emma (aged 33) who is a full time student and single mother to a school going son, related that while her son and her brother James who has DS get on well together, she finds it very difficult to find time to spend with her brother. Similarly Amy, a 41 year old mother of five children living at the other side of the country to her brother Philip (aged 31) who is autistic, spoke of trying to balance the conflicting needs of her brother and her own children.

...that's been very difficult because a lot of my time's spent helping my mother with Philip and then it takes up an awful lot of time and it's pulled away from my own kids... And they understand it to a point. But it's getting to a point where they're pulling. So I'm kind of stuck in the middle and it's kind of hard trying to get a balance on that.

Carmel who has a 20 month old son identified the guilt she experiences about being able to spend less time with her brother Jack who has severe ID since her son was born: 'I was always much more hands-on... I'm aware of that and I'm aware that I don't want that to be the long term.' She also noted that she was moving into a three bedroom house with a view to being able to have her brother come and stay overnight, something which her partner was very supportive of 'My partner is great.. there's never been any issue with him.' However Karen (aged 36) who is married with an infant son, highlighted the conflict that can ensue when her sister Kim who has ID and challenging behaviour comes to stay for a weekend.

She is rather demanding, so like we do need to plan around her coming. And obviously with Vincent (husband) working full-time and, you know, weekends now are family time with Andrew (son)....So there's a bit of I guess conflict there around the over protective sister and then Vincent... If I'm talking about a scenario at home he might say, 'yeah, but come on, like, she really is able to do that'.

The concerns and challenges identified by participants in relation to life changes and emergent life stages, emphasise the likelihood of constant re-negotiation of the roles they play in the lives of their brothers and sisters with ID/ASD. Such changes also have implications for other family members and professionals involved with the care and support of the individual with ID/ASD. This ever-changing dynamic of the adult sibling relationship identified by participants, and the challenges that are part of it, are widely



acknowledged in other research (Atkin and Tozer's, 2015, 2014; Davys et al., 2010, 2014, 2016; Gomez de la Cuesta & Cos, 2012.)

## **5.4 Roles currently played by siblings**

Similar to other findings from the literature most of the participants in this research expressed a sense of responsibility for the future of their brothers and sisters (Ormond and Seltzer, 2007) and expect to be involved in care or support work (Heller & Arnold, 2010; Greenberg et al., 1999). The participants currently play a range of roles in relation to their siblings. These vary from roles in which siblings are directly involved in support, advocacy and at times practical care activities relating to their brother or sister with ID/ASD, to roles where they supplement the care role undertaken by parents.

### **5.4.1 Active support/care & advocacy roles**

Some participants are actively involved in the lives of their sister or brother and engage in advocacy, monitoring, care and coaching activities. In some cases siblings are gradually taking over the key carer role previously held by the parent, usually the mother, and becoming the key support person for their brother or sister with ID/ASD. For example, Karen (aged 36) and married with an infant son continues to support her mother, attending her sister's day care review meetings and taking her sister for weekends to give her parents a break. Karen has been identified as next of kin with the day service her sister attends and when her parents are out of the country she is responsible for her sister. Similarly Anna (aged 30) is already doing most of the care and support work in relation to her brother Peter and taking him to most of his appointments. Alan (aged 23) who lives in another city and goes home for occasional weekends, provides regular hands on support with his brother Gary (aged 21) who has DS and ASD. Gary is in five day residential care with one residential weekend per month and on weekends when both Alan and Gary are home, Alan helps with care tasks and also engages in social activities and outings with Gary. Alan took a month's leave from work to care for Gary during a crisis period before a day service place became available for him and he frequently attends Gary's hospital appointments with his mother.

Carmel (aged 42) who has one typically developing sibling notes that apart from her parents she is the primary support for her brother Jack who has severe ID and lives in a community based residential home: 'in terms of the day to day practical sort of future planning, at the moment to all intents and purposes it's me'. She sees her role as that of keeping an eye on the quality of service Jack receives and on his health care and medical needs while also engaging in one to one social activities with him, seeing him every second weekend when he comes home to her parents and having him to stay with her own family. She has a positive working relationship with the staff in the residential house where her

brother lives and is included in discussions and updates about his health and progress.

Ann's (aged 44) brother George (aged 46) has been in residential care for much of his life and she identifies her role as providing advocacy and emotional support: 'I'll always be there for him. I'll always be advocating for him. I'll always be his sister, I'll always bring him up for a visit.' Currently Ann sees George every other weekend when he comes home to her mother and she engages in close monitoring of his residential service and his activities there. As a social care worker herself she is very involved in discussing his needs and supports and is satisfied with the working relationship she has with staff in his facility.

But because I am in social disability services I'm constantly advocating for George. I'd be on the phone once a week at least.... I'd be questioning, constantly questioning. And I went in with the attitude that I really don't care what you think of me, I'm here for my brother.

Geraldine (39) is closely involved with her brother Robert who is in residential care. He comes to stay with her for a night every second weekend and they are in daily phone contact. Mary (34) visits her brother Paul (aged 38), who lives with their widowed mother, a few times a week and identifies herself as directly involved with her brother's day-service and included in all meetings. She is currently lobbying for individualised funding for Paul which, would allow him more independence outside out of the options available from his current service provider. She believes that the service have agreed to engage with her because they acknowledge that she is the closest sibling to their client. Annie (aged 45) has recently asked her brother's service provider to put the information they relay to her elderly mother into a letter to her and her sister, as her mother was finding it difficult to remember the details. She believes that the service will do this in the future as she has recently challenged them about what she perceived as a lapse in her brother's care and she believes they are 'a bit afraid now'. In contrast, Amy (aged 41) who supports her mother as an advocate for her brother Philip (aged 31) who is in residential care, is not recognised by the service provider. Philip recently had a negative care experience which resulted in a move to a different living situation. Amy and her mother have been negotiating with the service provider to address concerns about quality of care. Amy contacted the Complaints Officer about a care issue she witnessed but the service refused to engage with her: 'I got an email back saying that the person that was dealing with it the manager, was going to contact my mother. They only wanted to deal with my mother. .. they know the vulnerabilities of my mother.' Amy finds this situation to be extremely frustrating. Christine (aged 34) has also found dealing with service providers to be challenging and exhausting but takes

on this role to support her parents and because as a doctor she is well placed to negotiate such situations.

These accounts suggest mixed experiences in relation to engagements with staff in service provision contexts. Most participants in a UK study of siblings of people with ID felt that staff did not proactively involve them and believed that they were only called on when a crisis arose (Tozer and Atkin, 2014: 235). Some siblings in that study also noted their lack of confidence in dealing with professionals and a lack of clarity regarding their legal position in this regard (Atkin and Tozer, 2014:223 & 234).

Other siblings who continue to live in the family home with their brother or sister with ID/ASD are involved in their lives in very practical ways. Aoife (aged 24) lives full time with her mother and her brother Seamus (22) who has a rare syndrome. She is involved in personal care tasks like toileting, showering and dressing, on days when there is no home help support. Linda (aged 22) undertakes both caring and coaching tasks with her sister Louise (aged 15) who has ID and lives at home with Linda, her two other sisters and her parents. She assists Louise with showering and washing her hair and socialises with her every weekend. Linda uses these interactions to help develop Louise's skills for independent living: 'I guess I try to do more things ... like trying to kind of repeat activities that she might be able to do on her own soon.' Sarah (aged 22) who lives at home with her sister Lisa (aged 20) who has ASD, also seeks to support Lisa to become more independent and to develop skills to manage the severe social anxiety she experiences.

#### **5.4.2 Supplementary support/care and advocacy roles**

In other cases siblings play supplementary, support, care and advocacy roles in situations where their parents are very much the key carers. Angela (aged 32) and sister to Patrick (aged 30) who has mild ID emphasised the supplementary nature of the role she plays. Patrick lives with his partner who also has a mild ID and their two children. His parents are very involved in the care of the children having moved house to live near them. Angela who lives some distance away is largely involved in providing financial and social welfare advice to her brother and having him to stay with her for occasional weekends when they socialise.

As much as possible I treat it as that my mother is the project manager and I support my mother and that is the end of it all, for the moment the buck stops with her.

A number of participants act as locum carers who stand in for their parents to facilitate them taking a weekend break or a holiday. Tara (aged 25), Emma (aged 33), Henry (aged 30) and Sarah (aged 22), have all undertaken this role at various times. Tara and Emma also socialise on a regular basis with their brother or sister

with ID/ASD. Popular pursuits include attending the cinema and shows, going bowling and going for coffee. Many of these participants envisage taking key responsibility for their brothers and sisters when their parents are no longer in a position to do so.

#### **5.4.3 'Normal' sibling roles**

A minority of participants engaged with their sister or brother with ID/ASD in ways which are very similar to the relationships between typically developing siblings. Harry and David who live in Ireland both see their sibling five or six times a year and have intermittent phone/Skype contact with them in between visits. Neither of them are currently involved in advocacy, coaching or care roles and they are not engaged in providing support to their parents in relation to their caring roles.

#### **5.4.4 'Distant' sibling roles**

Participants living abroad played a range of roles in the lives of their sisters and brothers with ID/ASD. These ranged from very involved to limited involvement and reflected the participants' life styles and the extent to which other support was available at home for their brother or sister. Siobhan (aged 27), living in the UK described her efforts to stay actively in the life of her only sibling Ailish who has a rare syndrome and lives at home with her parents: 'right now I'm trying to be as active as I can while at a distance and get home more often, you know, things are changing, are going to change so much.' Siobhan comes home on a regular basis, is constantly seeking information about her sister's rare condition and keeps up to date with changes in her sister's service use. Similarly Marion (aged 32) who has recently moved to work in the UK, continues to play a very involved role in the life of her brother Sean who has ID. She visits regularly, continues to monitor and adapt the training system she developed for her parents to use with Sean, encourages her parents to work out a future care plan for him and has taken compassionate leave from work to come home and assist them during a crisis period. Bernie (aged 44), who has lived abroad for the past 21 years, has always been in regular contact with her sister Jackie (aged 40) who has DS. Bernie who now lives in the US, comes home to visit two or three times a year and talks to Jackie on Skype at least once a week. Jackie visits Bernie regularly in the US and is part of her life there 'She knows my friends well, she knows the land in x [US city]. She knows my apartment. It's kind of a home away from home'. Bernie is familiar with Jackie's service provision and is involved in family discussions about future care.

In contrast, Henry (aged 30) who also lives abroad reported that he has very little contact with his sister Jill as he doesn't get home much and knows very little about her service provision. However, he believes that this is something he will become more involved with in the future when his parents are no longer around.

At present his mother and his sister in Ireland are the main people who support Jill.

I mean mum is really the person who's doing all of that at the moment. And I suppose I need to be more involved and to ask her more and stuff, be more aware of it, because ultimately that'll be something that I'll have to deal with later on.

Henry's sister visited him in his home abroad and on one occasion he cared for her at home when his parents went on holidays. Kenneth who lives abroad with his partner and 3 children has only seen his sister Heather once in the past 10 years. However he Skypes Heather, who has ID and cerebral palsy, every two months and offers his mother advice and support around Heather's care as he himself works in the disability sector. Despite his limited direct contact with Heather in recent years, he emphasised that: 'I am willing to be a trustee for my sister and to move her here to [name of country] should she ever need or want to come here when my parents die. .. I always worry where she will end up and if she is ok.' Chloe who lives in the UK sees her brother five or six times a year, is not currently involved in any aspect of his life and has no great sense of having any responsibility for him in the future other than to perhaps visit him more often in his residential community when her parents are no longer alive.

The diversity of roles played by siblings living abroad indicate that care, advocacy and support activities can be undertaken even when siblings live some distance away.

#### **5.4.5 Distinguishing the sibling role from the maternal role**

Many siblings see a clear distinction between the role currently played by parents or in most cases mothers, and the role they currently play or intend to play in their brother's or sister's life. While all participants acknowledged and praised the Trojan work their mothers do, and the struggle many of them engage in to acquire services, ten of the participants are critical of what they perceive to be the over involved and protective role that their mothers play in the lives of their brothers or sisters with ID/ASD. These participants believe that their brother or sister would benefit from the opportunity to undertake more self-care and independent living tasks and feel that the level of care provided by their mothers is inhibiting their potential in this regard. Many are adamant that in the future when they are the primary carer/supporter for their brother or sister, they will foster greater independence and encourage their brothers and sisters to do as much as possible for themselves.

Karen (aged 36) describes her sister Kim (aged 33) who has moderate ID as being 'disabled by all the care she's had and the cocoon she's been in' and describes herself as 'the harsher mummy' who expects Kim to do some chores

when she comes to stay with her. Similarly, Annie (aged 45) is adamant that she will not become a replacement for her mother who has devoted her whole life to the care of Annie's brother with ASD and is angry and resentful as a result. Annie believes that her brother is capable of all self-care activities and expects him to care for himself when he comes to live with her. Harry (aged 27) also expressed the view that the sibling role should not be the same as that of the parent, and he firmly believes that the very hands on care that his mother provides for his brother (aged 24) is unnecessary and should not continue into any future care arrangement. Siobhan (aged 27) believes that her role as a sibling will be different to that of a parent. Siobhan feels that her mother is too protective of her sister Ailish (aged 30) and is hampering her independence. In contrast she hopes that 'In the future I'll be able to support Ailish and make the decisions just as well but not with the same maternal attachment, because I think that that's almost damaging at times with my mam.'

The struggle which mothers might experience in allowing their adult children with disabilities to move away from sheltered and protected routines, was acknowledged by other participants. Kenneth (aged 41) observed that 'Mum struggles to let my sister go independent' while Sarah (aged 22) believes that her mother is so anxious about her sister Lisa (aged 20) who has high functioning ASD, that she hinders her independence:

... she stops her from doing things she's able to do, you know... and I think it's good for Lisa to spend time with me in that sense in that I'd be much more relaxed and I'd be like, 'Okay, off you go. Like you have your phone. Text me if you need me.'

One participant identified his father as being a barrier to his sister's independence as he 'will kind of almost treat her like a child' but noted that his mother was more aware of his sister's capabilities.

The belief amongst some participants that their brother or sister was capable of greater independence, suggests that the dynamic of the care/support relationship that they will have with their sister or brother will be different to that which, their parents/mothers shared with them. Tozer et al., (2013: 484) found that many siblings in their research wanted their relationship with their brother or sister with ID/ASD to remain a sibling one as distinct from being reinvented as a 'carer' role. The accounts discussed above also suggest that our participants see their future roles in relation to their brothers and sisters as different to that played by their parents. However, many envisaged future roles involving support, advocacy and care dimensions. Indeed a few participants noted that notwithstanding their very real awareness of the difficulties their mothers experienced in negotiating services and in providing direct care, they planned to

continue in a similar vein. Emma (aged 33) speaking about the plan that she and her sister have in relation to providing care for their brother James (aged 22) in the future observed ‘...because we have seen her [mother] over the years doing so much for James it just comes naturally to us to do the exact same.’ Emma was also conscious of the strategies employed by her mother to take care of herself. These include availing of respite and taking regular breaks with female friends and family members.

## **5.5 Sibling aspirations for brother/sister’s future living arrangements**

### **5.5.1 Co-residence**

Many siblings, whose brother or sister is still living with a parent (s) in the family home, envisage a future role in which they are closely involved in the day to day life of their brother or sister. 6 of the 25 participants in this study hope to co-reside with their brother or sister with ID/ASD in the future. This figure is similar to that found in Heller and Arnold's (2010, 23) review of twenty three studies of adult siblings of people with intellectual and developmental difficulties, which identified studies in which 19% of siblings expected to co-reside with a sibling.

Líosa (aged 22), Sarah (aged 22), Tara (aged 25), Anna (aged 30), Emma (aged 33) and Annie (aged 45) envisage a co-habitation arrangement, in which their brother or sister with ID/ASD shares a house with them or lives in a small self-contained unit next-door. Líosa who is single and in her 20s believes her future role will involve direct caregiver and co-residence with her sister– ‘I feel hopefully we’d live in the same house or something like that... ’ She is hopeful that her sister may be capable of supported independent living in the future but would not envisage her every being in a fully independent setting. Even if this were to happen, Líosa envisages herself being in the background ‘maybe have a kind of a separate house really attached to another house and have her own, do you know, space and stuff to do her own thing, but I’m always kind of in the background’. A similar arrangement is envisaged by Tara (aged 25) for her sister Molly (aged 23) who has mild ID: ‘I’d probably have her living with me and maybe someone helping me with her part-time. ... I’d like her to still have kind of her independence, so like maybe her own room or kind of area of the house.’

Annie (aged 45) who is a single woman without children, has bought a house with a downstairs bedroom to facilitate her brother moving in with her when her mother is no longer able to care for him. From Annie’s perspective this arrangement provides the best quality of care.

...him living with me is the right thing, because it’s safe in that he will be cared for and cared about and not just by someone who’s paid to sit in the

same room as him or whatever and knocks off at a certain time and goes home to their own family. I just think it's different.

Anna who is 30, single and has no children, also expects a co-residence arrangement with her brother in which she would build a granny flat for him attached to the current family home where she would live. She believes this is what her brother wants as he has expressed this view to service based professionals who have spoken to him about it. She feels that he is capable of semi-independent living under these circumstances and notes that she would 'love to be able to give him that.'

Sarah (aged 22) foresees that her sister Lisa (aged 20) who has ASD will live with her in the future, however, she is very worried about what this will mean for her life chances. Sarah feels that she has no option other than to support Lisa in a co-habitation arrangement as she has grave reservations about the quality of residential care available in Ireland and was adamant that: 'I couldn't put her in a care home here. Like I just couldn't do that.' She is conscious that having Lisa live with her will be very demanding as she is aware of how curtailed her mother is in her role as Lisa's current carer.

### **5.5.2 Small-scale community based living arrangement**

Other participants favour future living arrangements in which their sibling is living in a small-scale community based facility. Siobhan (aged 27) who currently works in London, is an only sibling to Ailish (aged 30) who has a rare syndrome. Siobhan aspires to a small-scale, supported, community based living arrangement for her sister, but envisages that she herself would live nearby and be very involved in her sister's life, seeing her a couple of times a week. Marion who also lives in the UK has a clear vision of the type of residential care she would like for her brother Sean who has moderate ID.

...a house of people his own age... My hopes would just be, that he's in a good place where they do stuff with them. I know he needs occupation, you know, and just a good level of independence and some choices in his day, you know.

Sean does not interact well with small children, but Marion hopes that at a later stage in her life, Sean will be able to spend more time with her: 'I would envisage if I was older with an older family, for example, I don't see why he couldn't come and stay with us and bring him on holiday and do things like that'. Marion also outlines a monitoring role which she envisages she will play in Sean's life in the future and is adamant that she will 'need authority on like his medical care or things like that'. She would like an arrangement where either she or one of her two siblings would visit him at least one weekend a month and believes that this would facilitate monitoring and would ensure that he was happy. Karen also plans



to be involved in the future of her sister Kim who has ID and who is keen to live in a residential home where she currently goes for respite. Karen believes that for this to work effectively, there would need to be 'significant family involvement' and she is happy to take on this role, noting 'you'd want to do it anyway for your sister because you'd want to see her.' Amy's brother Philip who has ASD, is the only resident in a small community based house, however she is very dissatisfied with the arrangement as he has no day service and he rarely gets to leave the house. She is very distressed about the situation and is actively lobbying to improve the service her brother receives.

It's very difficult to support him when he's nothing happening for himself. Like he's in a house in the community with no community and he hasn't been out in the community in months. ... It's heart breaking, heart-breaking.

Harry (aged 27) also favours a non- institutional, supported living arrangement for his brother who has ID. He believes that his brother needs support with living but not full time care, 'a non- institutional house where a few of them could live together with, I don't know, 8, 12, 16, 24 hour assistance and not care.' Harry sees a future role in which he would see his brother every few weeks.

### **5.5.3 Supported independent living**

Mary who is single, childless and in her 30s, would like to see her brother Paul who has Asperger syndrome continuing to live in the family home when her mother is deceased. This is also Paul's wish and she believes he has the capacity to look after himself. Mary is actively supporting Paul to develop skills for independent living, has arranged cooking lessons for him and encourages his continued use of public transport. Bernie (aged 44) also envisages that her sister Jackie (aged 40) will continue to live in the family home when her widowed mother is deceased. However she is not sure what arrangement might facilitate this.

I think the idea would be for Jackie to stay within her home and maybe have some support within the house or for our house to become a community house.

Kenneth who lives in Australasia also believes that supported independent living with 'one to one support and peer supervision' would be a desirable option for his sister Heather (aged 33) who has ID. Linda (aged 22) and sister to Louise (aged 15) who has ID has a clear sense of the type of future living arrangement she would like for Louise: 'Like the way I have it envisioned is that she's kind of living very close to me'. Linda believes that she and her two other siblings would provide financially for someone to support Louise in this living arrangement but sees herself as the main person providing support.

#### 5.5.4 Residential living

The brothers and sisters of 7 participants currently live in residential settings outside of the family home. In most of these cases the family member with ID/ASD entered residential care as a young adult and at a time when their parent (s) were very much in charge of decision making. Carmel (aged 42) recalled that her family was always 'sort of unified' about what would be the appropriate care plan for her brother Jack (aged 39) who has severe ID. Jack has lived in a community based residential house since he was 25 and attends an adult day service. He initially came home every weekend but now that Carmel's parents are older, he comes home for one day every second weekend and also at holiday times. Similarly Ann (aged 44) who lived in the UK as a child, always anticipated that her brother George, who has ID and was in residential care since he was twelve years old, would be in a residential service as an adult. Ann married an Irish man and moved to Connaught and her parents retired to Ireland some years ago. After a few years of living at home with his parents, George secured a place in a residential facility. Other participants with siblings in residential care highlighted their satisfaction with the service. Chloe (aged 31) and David (aged 32) both have a sibling living in a residential community and they and their families are very happy with the quality of service provision and their siblings are very content in their communities. David's sister Laura, who has epilepsy and ID, was 16 years old when she moved into residential care and David was 13 years old at the time.

I remember it being quite traumatic at the time for her when she went there. But I remember going up there and seeing their way of life....my parents felt very passionately about where they wanted Laura to live and this was the kind of community they wanted her to live in.

Similarly, Alan's brother, Gary (aged 21) (born with DS and later diagnosed with severe ASD) accessed respite from the age of 10, one weekend every six weeks. When Gary was 20 his parents made the decision to move him into residential care during the week.

They're [service provider] very good. They really reassured mam and dad. I can remember mam being very upset about the whole idea of kind of packing him off. But we were trying to console her, saying this is the right thing to do.

Strong feelings of guilt about availing of residential care were expressed by one participant. Geraldine (aged 39) recalled the stress and sense of isolation she experienced after her mother's death when she was caring for her brother Robert (aged 40) who has ASD and mild ID. Robert was attending a day service but no plan was in place for his future and Geraldine

and another brother, who were both in full-time employment, were supporting Robert in the family home. The difficulties associated with this led them to take the decision to seek residential care for Robert and after much persistence they secured a place. However, this decision is a continuing source of guilt for Geraldine and her wish is that Robert could live with her and that a carer would 'do the caring part of it and I could just be his sister, that would be ideal'.

Having a sibling in a residential settings does not however address all future care and support issues. For example Amy (aged 41) is very dissatisfied about the quality of care her brother Philip (31) is receiving in his current residential placement. She is working actively with her mother to improve the situation, however negotiations with the service provider are very difficult and she believes that they resented being challenged about the care arrangement. Amy was adamant that it could not continue and that she would have to make alternative arrangements if the situation could not be resolved.

## **5.6 Future planning**

Concern and anxiety about the future when parents are no longer in a position to provide support has been expressed by siblings in previous research (Benderix & Sivberg, 2007; Orsmond & Seltzer, 2007). Similar findings were found in this study. Most participants reported that while they attempted to raise the question of future planning, often from a young age, their parents for the most part, refused to engage with the topic and reacted to it with anxiety and distress. Concern about how change will be received by the family member with ID/ASD, fear about the quality of care they will receive and feelings of guilt, can all be barriers to families taking proactive steps toward transition to alternative care arrangements.

### **5.6.1 Avoidance of future planning**

The data suggests that in some families, planning for the future is the responsibility of particular members rather than being something that all members engage in. Mothers were more likely to discuss future plans than fathers, as in some cases, fathers have limited engagement in care practices and decisions and are unfamiliar with services and other available options. It would appear that mothers as primary caregivers, are also key gatekeepers in relation to discussions about the future. Anna (aged 30) has always helped her mother care for her brother with ID as her father was largely uninvolved, believing it to be his wife's responsibility. Her mother is distressed by discussions of the future and her father has not engaged in any discussion around the topic other than to remark that he does not believe that Anna can care for her brother in the future given that she has a chronic illness. Kenneth (aged 41) and brother to Heather

(aged 33) who has ID and Cerebral Palsy, also emphasised the key role his mother plays in decision making about Heather's future and what he perceived as her reluctance to allow Heather greater independence. Kenneth who lives in Australasia worries about 'where she [Heather] will end up' as there is no plan in place and his mother refuses to discuss the situation.

My mum is very in charge of my sister's support, my dad has no say in any decisions. If my mum is confronted by any family members then she puts her guard up until we give in.

Similarly Karen (aged 36), whose parents are in their late 50s, described her father as being 'a little bit on the outside' in terms of involvement in the care of her sister and in terms of planning for her future. Sarah (aged 22) reflecting on the dynamic in her family, perceived that 'it's mam's decision and dad kind of just goes along with what mam says.' Henry, Angela and Amy made similar observations about the more peripheral role their fathers played in future planning.

Parental/maternal disinclination to engage in future planning is a source of frustration for many participants. Mary (aged 34) raised the issue of future planning with her parents when she was in her late teens and several other times in subsequent years, but they refused to discuss the issue which Mary found very frustrating. Her mother's attitude is 'we'll cross that bridge when we get to it'. Her other siblings do not involve themselves in any future planning and her mother who is now widowed has not made a will or any other type of care plan.

Líosa (aged 22) and an only sibling, is trying to push her parents to discuss the future but notes that 'they kind of just want to ...put it on the long finger'. She feels that her parents are trying to protect her by not engaging with her about what her future role might be and believes they are 'a little bit worried that I would take on something so big, like more or less minding another person for the rest of my life.' Sarah a 22 year old sibling of a younger sister (Lisa) with ASD, is also very anxious to discuss the future with her parents despite the fact that they are quite young. She finds their refusal to engage with her very upsetting.

It's just not talked about. I think it's too stressful kind of to talk about... I mean, maybe it would help to talk about it. You know, maybe it would make it a bit less stressful for everyone if it was acknowledged.

Sarah acknowledges however that part of the reluctance to discuss the future is Lisa's fear of it and notes that: 'She's terrified of the future, absolutely terrified. So we don't mention the word 'future' like not around her.' Bernie (aged 44)

made a similar observation about her sister Jackie (aged 40) who despite being very articulate refuses to talk about the issue of future plans.

Siobhan (aged 27), an only sibling raises the issue of the future with her parents, despite the fact that it distresses her mother.

I make it my business to talk about the future now. And at this stage, yes, my mother will get upset, but really I don't care anymore if she wants to cry through the whole conversation, because it needs to be addressed.

The question of whether one could legally be a guardian for an adult sibling with ASD was raised by Amy (aged 41).

... even if it's in a will there's no guardian for an adult. So in legality it really doesn't mean anything.... The grey area for me is around the sibling role going forward, really what that role actually means in legalities.

Lack of clarity in relation to other legal matters was a source of frustration for David (aged 32). He expressed great annoyance at his parent's reluctance to make a will, identifying himself and his brother as wanting to be legally responsible for their sister Laura (aged 35) who has ID and lives in a residential community.

Now, the one thing I know is that I don't ever want my sister to be a ward of state. .. So I've been on to my parents for three, four years now to – sorry – but fucking sort it out like. ...And they're humming and hawing... I've put them in contact with lawyers to sort this out.... This is something myself and my brother categorically agree on. ... We need to ensure that that's all boxed off.

Tozer & Atkin's UK study (2015:342) also found that some participants were not clear about their legal status or on the extent to which they could legally involve themselves in the lives of their adult sibling with ID.

### **5.6.2 Proactive future planning**

A number of participants in this study were aware of plans which their parents have put in place for the future of their sibling with ID/ASD. In a minority of cases participants were aware of an inheritance or financial arrangement. Anna's parents have willed her the family home, in which her brother with ID lives, on the condition that she will co-habit with her brother. Marion (aged 32), Tara (aged 25), Angela (aged 32) and Alan (aged 23) are aware that their parents have put financial plans in place for their brothers and sisters with ID, which will guarantee them financial security.

Other participants noted changes in living arrangements which their parents had made or were making, to ensure accommodation security and easier access to services for their sibling with ID/ASD. Henry's parents are in the process of building a small house for his sister Jill who has a mild ID and is currently living alone in rented accommodation: 'They're hoping that that will then provide her with some sort of security... because they're paying rent for the current place.' Tara's parents are moving to a more central location which will allow her sister Molly (aged 23) who has a mild ID, direct access to a bus which will take her to her day service. Bernie's mother has made a similar move and now lives in a house from which her sister Jackie (aged 40) can walk to her day service and where they have better access to bus routes. Bernie perceived that in proactively planning for Jackie's future care her mother was trying to reduce future responsibility for Bernie and her siblings.

I think my mother's concerned that we would take on more responsibility that we should and she wants to ensure that there's provision made in terms of infrastructure for Jackie without disrupting any of our lives.

Bernie's mother has also begun discussions with a local service provider with a view to 'laying the groundwork for maybe a plan for Jackie'.

In other cases families have put in place, or are planning, alternative or additional care supports for the individual with ID/ASD. Emma (aged 33) highlighted how satisfied she is with the respite services her brother James (aged 22 with DS) accesses, one week every second month: 'it's a break for my mam and dad – as well as him...and he loves it, loves going away'. Marion has recently persuaded her parents to put her brother's name on a waiting list for residential care following a deterioration of his behaviour and the inability of her ageing parents to care for him at home. Karen's sister, Kim (aged 33), is also on a waiting list for residential care and is very excited about the prospect as she already attends the service for respite. However, Karen (aged 36) acknowledges that her mother may not be ready to let Kim go. Linda (aged 22) reported that she and her parents have been actively focusing on extending the social network of her sister Louise (aged 15) who has ID with a view to increasing the number of people who could help to support her.

We've been thinking the last few years just about her having a wider support network than just us and having people who would kind of like go and see her or take her out or whatever. It's kind of becoming more important to like build that network.

For Aoife (aged 24) and her mother, the decision to allow Seamus (aged 22) who has a rare syndrome to attend respite was a significant milestone in terms of accepting that a wider system of support would be positive.

When he was younger we were often offered respite breaks for Seamus but mum and I weren't inclined to send him because we weren't really sure if he would like it ...Eventually through talking to his social worker and visiting the houses with Seamus we decided to take the plunge by building up to it gradually, and he really loves getting away and spending time out in X [service name] so we don't feel guilty about dropping him off.

### **5.6.3 Sibling involvement in future planning**

A minority of participants indicated that parents have engaged directly with them in terms of future planning for their brother or sister with ID/ASD. Aoife (aged 24) who is an only sibling to Seamus (aged 22), described how her mother, who is parenting alone, has always included her in decision making regarding Seamus.

It was just me and my mum for a long time so she always involved me in decision making around Seamus and took my opinions and views about everything on board...I want to be involved in decision making about his future, which I will be, and oversee that he is getting the right care that he needs.

Alan (aged 23) described the consultation that his family engaged in prior to a recent decision to seek a residential placement for his brother Gary (aged 21). Alan's parents are in their 60s and both are in full time work as are two of his siblings with a third being a full time college student. As a family they took the decision to seek a residential place for Gary believing that it was better to 'get him used to living in a residential home. Because he would have been used to living in a residential at weekends'.

However Linda (aged 22) acknowledged that in terms of Louise's (aged 15) future she and her parents have only ever had 'a few conversations about it, but I've always said to them obviously that I'll look after her'. Her parents have a vague idea that in future years Louise would: 'kind of live with them in some kind of apartment that is separate to their house of that she will have some kind of space that is her own.' Emma's family have always been very open in discussing issues about James who has ID, but despite this, she noted that there was no formal plan for his future care, rather there was a 'spoken agreement' between her and her sister that they would 'automatically take over the running of James'. She believes that James, who is 22, is unlikely to outlive her (she is currently 33) but was clear that if he did she would not want her son or niece to be responsible for his care and noted: '...so at that stage it would be, I don't know, residential care maybe. But that's way down the line.'

Overall however, there was limited evidence of siblings being involved in any systematic discussion of future plans for the care and support of brothers and sisters with ID/ASD. In many cases the issue of future plans had been a concern

of siblings since an early age but parents were in the main reluctant to discuss the issue. Participants attributed this reluctance to parent's not wanting to burden them with care responsibilities, and to parents not being willing to engage with the realities of what the future might hold, despite the fact that this was frequently perceived by participants to be a huge source of distress and fear for their parents.

Irish families are not unusual in this reluctance to make plans for the future of a brother or sister with ID/ASD. Bowey & McGlaughlin's (2007) US study found that only 32% of families had made residential plans, while UK research suggests that approximately half of families had made some plan (Davys et al., 2010, 2016). Similarly Davys et al's. (2010) small scale survey of 21 siblings of adults with ID in the UK, revealed that just over half of the participants (57%) reported having had a full discussion with their parents regarding the future care of their sibling with ID, with the same amount (57%) stating that there was no clear future plan in place for their sibling. Clearly there is a great need for a range of support which would help families to engage with transition and future planning in relation to their family member with ID/ASD.

What also emerges from this research is a question about the extent to which, adult brothers and sisters with ID/ASD are consulted about their wishes for the future. While there was no question in the interview schedule that directly asked participants if their brother or sister had been consulted about their wishes, one would have expected some discussion of this topic when the issue of future planning was being considered. The research suggests that siblings engage in very little consultation with their brothers or sisters with regard to what future living or care arrangement the latter might prefer. Only a minority of participants mentioned what they perceived to be the preferences of their brother or sister. This finding is not surprising as recent work by Davys et al., (2014), found that among the 15 siblings of adults with ID that they interviewed in relation to future planning, only 3 individuals referred to the wishes of their brother or sister with ID. Communication and comprehension difficulties, and the stress that questions about the future might cause for adults with ID/ASD, are obvious challenges in addressing the future living preferences of this cohort, but notwithstanding these barriers, there would appear to be a need for greater consultation in this area.

## **5.7 Conclusion**

The majority of the siblings who participated in this research were centrally involved and/or planned to be involved in supporting the life of their brother or sister with ID/ASD. In this regard most can be described as the 'most involved' siblings in the life of their brother or sister. This relationship was in the main underpinned by bonds of affection and many participants emphasised the pleasure which the relationship brought to them. However, reconciling the key sibling role



with other responsibilities, life situations and life aspirations, also resulted in complex emotional tensions, with guilt and in some cases resentment, featuring in participants' accounts.

The participants outlined a range of activities they undertook in relation to the wellbeing of their brother or sister. These included peripheral activities like keeping in touch through phone or Skype; shared engagement in family and social activities; support with practical care/self-care activities; occasional supplementing of primary care arrangements provided by parents or residential facilities; facilitating development of self-care and independence skills; monitoring and overseeing service provision; advocacy work with professionals and organisations and negotiating with parents and other siblings in relation to the development of future support plans.

Participants envisaged a range of future living situations for their siblings, including continued residential care, movement into residential care, supported independent living and co-residence with themselves. Most of those whose brothers or sisters are currently in residential care supported continuation of this arrangement perceiving their future role as being one of monitoring the quality of the service provided, negotiation with service providers in relation to ensuring that the needs of their brothers or sisters are being met and providing companionship and facilitating family engagement with their brother or sister. Most participants however noted that there was no definite plan for the future of their brother or sister and highlighted that their parents were in many cases reluctant to engage in such planning. Concern for the welfare of their brother or sister in the future and lack of clarity about how, where and by whom they would be supported, was a source of anxiety for many. Significantly, most of the participants appeared to accept that they would play a major role in organising and/or providing this future support.

## **6 Supports for siblings across the lifecourse**

### **6.1 Introduction**

Siblings of individuals with ID/ASD experience challenges related to this role at various stages of their lives. This chapter explores the range of challenges identified by participants in this research and provides insights into the supports that they believe would be useful and effective.

### **6.2 Sibling support experiences and needs through the lifecourse**

None of the 25 participants received any specific supports from service providers when they were growing up. Within the family, the main focus was on accessing supports and services for the brother or sister with special needs. It is not surprising then, that a strong theme emerging from this research, is the need for TD siblings to have information about their brother's and sister's disabilities, and about the supports and services that are available to their brothers and sisters as they grow older. The other key theme emerging, is the need for siblings to have opportunities to share their experiences of being a sibling with other siblings who understand what that entails.

#### **6.2.1 Information and awareness about disabilities**

Mary (aged 34) whose brother Paul was diagnosed with Asperger syndrome at the age of 12, remembers wanting to learn more about ASD as she got older.

I do remember going to a local meeting where the principal of the local special school gave a speech about autism and what it's like. And she was very detailed and it was really interesting...and it really probably changed everything for me actually that time.

Líosa (aged 22) similarly recalls looking up ASD on the internet aged 15-16 and realising that everyone on the spectrum is different. This reassured her as she was worried about her sister at that time, 'I kind of calmed down a bit ... because I thought she was very bad at the time and then I saw that and I was like, okay, she's fine!' Anna (aged 30) also educated herself about her younger brother's disability until she fully understood DS. She believes that her parents were of an older generation and did not fully understand the disability themselves, thus could not explain it to her.

Sarah (aged 22) found it hard not having words to explain to others about her younger sister's ASD. Her mother did not want a label so the diagnosis of ASD was not talked about when the sisters were younger. Henry (aged 30) believes

that he would have had more understanding of his sister's difficulties if he had been more aware of her abilities despite the diagnosis of mild ID. Thus, it was as he and his other siblings grew older that they realised that Jill (aged 32) had potential to move on with her adult life, the same way that they had.

Several participants expressed a need for disability awareness training to be part of the curriculum in both primary and secondary schools. Anna emphasised that this training needed to be age appropriate.

Just have age-appropriate explanations of what DS is, what ASD is, what special needs is in general. Because with more kids going to mainstream schools, more SNAs being in the schools, they're [children with ID/ASD] not as hidden as they used to be.

Furthermore, Anna identified the need for members of the public to become familiar with people with ID/ASD and she believes that practices such as locating day services in mainstream rather than isolated settings are important in this regard. Sarah was also highly critical of what she understood as a lack of public awareness and public concern about the rights of people with disabilities.

...like very few people actually care... I think it's hard to care about something that you don't understand. So people who don't have anyone in their family with a disability I just feel like they don't care.

She believes that public awareness campaigns and school based education programmes, are required to raise awareness and advise people how to promote inclusion. Sarah also feels that people with disabilities should be involved in a disability pride event to draw public awareness to their existence and their rights.

### **6.2.2 Peer based sibling support during childhood and adolescence**

Most participants, when reflecting back on their childhood, would have welcomed some form of support as children. Very few of them had heard of the concept of Sibshops (as discussed in chapter 2). However, Christine (aged 34) had attended a Sibshop session organised by the service provider.

I do remember when I was about... 18 maybe at this stage or older - even 20 – they put on this thing called a Sibshop and it was like one afternoon. I remember myself and my brother went and it was specifically for the siblings...It was more people talking about their experience, about how it had affected their lives.

Christine remembers finding this information useful and welcomed any type of supports offered, although at this stage she was an adult. Líosá (aged 22) also recalls receiving a letter in the post when she was 18-19 offering supports for

siblings and commenting 'where was this when I was younger?' As an only sibling, Líosá would have welcomed the opportunity to share her experiences with another typically developing sibling. Siobhan (aged 27) and only sister to Ailish (aged 30) born with a rare syndrome felt a similar need for someone to share experiences with. She thinks that a forum such as a Sibshop, where siblings can discuss their experiences would have been helpful to her.

It's incredibly hard on the sibling...and it's really important to have other people they can relate to...just having someone that...understands you, that you can kind of have a little complain, a little moan about your sibling, that they understand why you're doing that.

Siobhan feels that society in general, and support systems in particular, forget about siblings, especially the younger ones. The particular need for support experienced by lone siblings with no typically developing brothers or sister has been identified in other studies (Liljekvist & Thorneus, 2012).

The difference between parent support networks and sibling support networks was emphasised by other siblings. Many participants reported that their parents were involved in support and advocacy networks (Sarah, Anna, Harry, Marion, Siobhan, Emma, Alan, Bernie) but this did not automatically mean that the siblings in the family were supported. Emma (aged 33) commenting on her parent's involvement in the Down Syndrome Association, noted that, 'it's parents focused. Siblings are kind of just in the background until something goes wrong with the parents.' Anna (aged 30) highlighted the need for the organisation to specifically address the needs of siblings.

...there should nearly be a branch within that, that's specifically for siblings, to explain to them what things are, what is expected.... You learn from your peers more so than sitting in a classroom... they can learn from each other... and there needs to be a social aspect.

Amy (aged 41) pointed out that networks do not naturally occur between siblings and she highlighted the need for a community of interest between adult siblings. She believes that this should be cultivated through the organisation of family events or sibling events when siblings are children. This would allow siblings with a brother or sister in the same service, to be in contact and build up a support network. She also believes that it would challenge what she perceives as a fear among families of complaining about service provision, and would undermine the sense of isolation and individualisation, which breeds competition between families for scarce resources.

### 6.2.3 Peer based sibling support during adulthood

A number of participants noted that as adults, they would welcome an online fora as a means of sharing experiences with a community who would understand, and could potentially advise, on how to deal with some of the issues which adult siblings experience. Líosá (aged 22) sees potential in having a Facebook chat room 'like a support chatline'. Siobhan (aged 27) accessed supports on an internet forum when her sister Ailish's behaviour became very difficult. She appreciates this forum describing the response she got to a question she posed as 'just incredible'. She believes that such fora stop siblings feeling alone and give them the opportunity to voice their feelings and experiences without fear of judgement or excessive sympathy. Emma (aged 33) also sees the potential for an online forum at transition points, such as when siblings are taking over greater responsibility for their brother or sister with ID/ASD.

... if you could click online and talk to someone it'd be super, it really would. Even for them pointing you in the right direction. They might say 'well this didn't work for us. It might work for you.' ... Even to know that there's options would be brilliant.

Amy (aged 41) engages with a number of online fora but finds them to be 'very impersonal' and would prefer more localised support groups for siblings. She believes that service providers should be more proactive in facilitating the development of support networks between the families associated with their services and believes that this would provide useful community based support to siblings, and would in turn support the service to meet needs in a responsive way.

You know people in one residential unit, the families should know each other...and by the families knowing each other then the siblings get to know the siblings...That has to come from the provider... 'You know, how can we improve things here?' And the families need to know each other. A natural thing.

However it is important to acknowledge that given the diversity of sibling experiences, roles and outlooks, siblings will not automatically perceive each other as supports. For example, Marion (aged 32), who also explored online fora, found them distressing as they make her feel guilty about her decision not to live with her brother in the future.

I just see how involved a lot of them [siblings] are and how it seems to like totally all consume them. And instead of thinking I'm glad I'm not like them, I feel guilty...

Marion has also met siblings, whom she perceives as resentful about the caring and support responsibilities they have, and this discourages her from connecting

with them: "...so I don't really have anyone like that's in the same boat that I relate to actually.' Aoife (aged 24) while acknowledging the value of peer support groups for some siblings, felt strongly that she would not find them useful. She rejected such groups on the grounds that she 'wouldn't really want to be defined by my brother's disability by meeting up with people based solely on that fact'. Aoife also rejected what she perceived as some sibling's tendency to 'play up to being the amazing big brother or sister' and registered her dislike of awards which give 'a pat on the back' to siblings of people with disabilities.

### **6.3 Informal and formal supports outside the nuclear family: sibling experiences and needs**

The contribution and value of informal supports was emphasised by some participants with members of the extended family, primarily grandparents being the greatest source of support.

Líosa's grandparents helped out with homework for both Líosa (22) and her sister Niamh (aged 20) who has ASD and they worked systematically to challenge Niamh to develop a range of skills: 'so they kind of taught her everything. They taught her how to walk, running, and spelling as well.' Harry's (aged 27) grandmother also took on the role of homework supervisor for his brother Tom (24) who has ID. Aoife (aged 24) who grew up with her mother and her brother Seamus (aged 22) who has a rare syndrome, described her grandparents who lived nearby as being 'very involved in our lives'. Similarly, Alan (23) recalled that his grandmother who lived on the family farm helped out a lot. Interestingly both Aoife and Alan drew attention to the fact that their grandparents who were previously providers of care, are now at an age where they themselves require care from the family unit. This highlights the care crunch which many parents and possibly siblings of adults with disabilities can experience at particular life stages.

Tara (aged 27) described the supportive role her aunt has undertaken providing both practical and emotional support to Tara's mum. David (aged 32) remembers going to live with his aunt when his sister was hospitalised and Alan (aged 23) recalls an occasion during childhood when his aunt looked after his brother Gary (aged 21) while the family took a week's holiday. Sarah's uncle has provided significant financial support to her sister Louise (15) for whom he has set up an educational trust. This has provided for a private tutor who has worked with Louise fulltime after school since she was 7 and also covers costs such as books, an ipad and speech therapy.

However, such family support cannot be taken for granted and depends on a range of factors including proximity of the wider family, ages of the grandparent, and severity of the family member's disabilities, to name but a few. Geraldine's

(39) extended family offered help when her widowed mother passed away leaving Geraldine and another brother to care for their brother Robert (40) who has ASD. She acknowledged however that without having a close understanding of Robert's behaviour or needs there was little that her relatives could do to help. This point was reiterated by a number of participants who emphasised that lack of knowledge, fear, and the challenging needs of some people with ID/ASD, made it difficult for others to help out with care. For example, Christine whose sister Fiona was born with severe epilepsy and ID, recalls her grandparents supporting the rest of the family so that her mother could focus on Fiona. Her aunts, however, kept a distance.

I don't think it was intentional, but it was like they didn't know how to cope with epilepsy and they definitely didn't know how to cope with, you know, this very bad prognosis for this child.

Neighbours, friends, and in one case, a paid carer were also identified as sources of support but to a much lesser extent. Amy (aged 41) who identified her family as very private, noted that they received no family support, but her mother was supported by a woman who was 'involved in volunteering with people with disabilities' who 'would have come out and looked after him [brother with ASD] for a few hours or whatever.' Siobhan (aged 27) reported that the family childminder and the childminder's family became like a second family to her.

This lady I still refer to her as my second mother even now...her and her family really welcomed me as one of their own and that has huge impact because it gave me this whole other family that I could experience. And that was a huge support, I think, because I didn't feel so alone.

Carmel (aged 42) remembers the local neighbourhood kids calling to their house to see her father and her brother Jack (born with severe ID).

We lived in [housing estate] on the north side of the city and we lived on a square, and my dad in the summer evenings used to sit with him out on the front step to let him get a bit of fresh air when he couldn't walk, and all the kids from the area would just cluster to come and talk to my dad and Jack. So there'd be a gang of kids around our front door yapping.

Similarly, David (aged 32) grew up in a small housing estate within a very close community where the neighbouring children would join his sister Laura's (aged 35) birthday party.

And that was through till she was 17, 18, stuff like that. All the kids came in there and they all kind of grew up around it. And even like today when, say,

friends come in, they're always coming in and they're all very engaging. They all know her, her whole life, you know.

This community spirit reported by Carmel and David was not evident in the other narratives. This could perhaps be explained by the fact that many of the participants grew up in rural areas and thereby were more isolated in the family home.

A few participants drew attention to current sources of support which they draw on. It would appear however that such supports are very much supplementary and are not utilised on a regular or systematic basis. Aoife's (aged 24) description of the support system that she and her mother could draw on highlights this.

Mum has a couple of close friends that are always there if we need something and while our neighbours don't know Seamus all that well, if anything did go wrong or there was an emergency there are a few we could count on.

Some participants noted that their friends provided a form of social connection for their sibling. Carmel (aged 42) noted that her friends were always very comfortable with her brother Jack (aged 39) who has ID and that he 'adores one of them in particular.' Linda (aged 22) is hopeful that her friends, who get on very well with her sister Louise (aged 15), will begin to take her out socially from time to time as Louise really values the opportunity to socialise with someone outside her family. Linda also highlighted that Louise who went to mainstream school has a cohort of school friends who continue to play a positive role in her life and with whom she has ongoing social contact.

Siobhan (aged 27) has family friends she can call on for support, when she is looking after her sister on her own while her parents are on holidays.

I might have a family friend come in for a few hours a day. I might have a couple of my friends just being around... because it can be quite intense to be with Ailish on your own for that long.

Mary (aged 34) has also established a support network among supporters of the local football team, who now give her brother Paul (aged 38) who has ASD lifts to matches.

I kind of tried to start friendships with other supporters from the local area that travel a lot to matches. And they were very helpful and they said 'oh, we're going to Cork. We'll bring him'. ... So he's got lots of different 'crews' as we call them. ... He has their mobile numbers and he will ring



these people...they have their own little relationships built up now, you know.

These informal networks are clearly a very valuable source of both practical support and social connection for people with ID/ASD and their siblings. However it cannot be assumed that such supports are naturally occurring and always available, indeed this research would suggest that they are quite limited.

Formal support such as respite care, was identified by a number of participants as a great source of support to the wider family unit. Carmel (aged 42) drew attention to the respite care provided by a volunteer scheme, which involved a family taking her brother Jack (aged 39) who has ID, for a holiday when he was a child. This arrangement continued into adulthood and led to a strong and ongoing relationship between Carmel's family and the family who provided the respite for Jack.

We've reached a point with A [family who provide respite for Jack] where if there was something specific coming up like a family wedding or something we could contact them through Z [name of service provider] and they would be the ones to give him the respite.

#### **6.4 Future and transition planning: sibling experiences and needs**

Future and transition planning was a key area in which participants identified unmet support needs. Two key support needs were identified. The first was the need for factual information about; welfare entitlements, care and educational services, and legal and financial arrangements. This need was articulated very clearly by Linda (aged 22) and sister to Louise (aged 15) who has ID.

The practical education about like what kind of things they're going to have access to or what kind of supports they're going to have or like how much is going to be available... that's what I would feel like I need now.

This practical information is required at various points across the life course. Speaking about the dearth of such information Marion recalled that her parents had been unaware that her brother Sean who has ASD was entitled to a state allowance 'it was years later that my mother realised he was entitled to a disability allowance. And then they got a solicitor and got back pay.' Liosa highlighted the challenge her family experienced when her sister Niamh (aged 20) who has ASD turned 18 and moved to adult services.

When she turned 18 all the service just went, everything, and we're just fighting ever since, the medical card, her travel card, trying to get the, what's it called, the disability allowance and all that.

Emma (aged 33) and sister to James (aged 22) with DS, identified a similar need for information when brothers and sisters reach adulthood, and decisions are being taken about adult services and future care.

I'd love to go to a workshop with other people what have siblings with Down's syndrome or autism or any sort of a disability because we're at the next stage now of his life. .. So I think it would be great to have even an information day about, you know, what should we be doing now, or even about, the living will or, you know writing a will for James. All that kind of stuff I think now would be great.

The second key support required in relation to planning, is assistance with the process of engaging family members in discussing, developing and implementing plans for transition and future care. The challenges which families experience in addressing this issue have been identified in Chapter 5. Marion (aged 32) believed that an information pack, or set of guidelines which could facilitate family discussion of the issue would be very helpful.

But I think a pack around that... yeah I mean if there were guidelines then it wouldn't have to come from me. .. If it says ... 'these are the steps, this is what you're supposed to do' ... then it becomes objective. You learned it from somebody else. That would really, really help people. ... Any support that can be given for whole families to talk about this and to have these conversation and say 'Well, what do you want for him [brother with ASD]?'

When discussing future and transition planning it is important to acknowledge that the reluctance of parents to plan is impacted by factors such as the limited availability of adult services, which in turn means that service providers are not proactive in facilitating future planning. Some participants noted the challenges their parents experienced in negotiating day and residential services. Emma (aged 33) recalled the difficulties her mother encountered when trying to secure an appropriate adult day service for James (aged 22).

There's been a few times where she's been very frustrated with services and there was one time where they didn't know if James was going to have a service... you know that took a lot of out of her.... There were other people that he went to school with, that were in his class, they grew up together, that didn't automatically have the service. So not only is my mother worrying about James, she's worrying about those people because they're friends.

The desire by parents for their typically developing children not to be burdened by care responsibilities for their sibling with Id/ASD is a further barrier to parents

engaging in discussions around planning. Amy (aged 41) is very conscious of this but believes that parents need to be challenged on this perception.

What I'm hearing a lot in these forums (parent and sibling fora) is that parents don't want the siblings to be really taking any responsibility. They want to keep them protected. ... I'm very shocked by it because that's wrong for the person they're looking after, that's totally wrong for the siblings because they want to be part of that person's life, and that person is part of their life... So it has to be talked about like as a real thing.

Amy believes that families should be engaging with the issue of future planning from a very early stage and that siblings should be involved in such discussions in an age appropriate way from as early as possible. This she believes would facilitate siblings having the knowledge and skills required to be advocates for their brothers and sisters in the future.

## **6.5 Conclusion**

This chapter has highlighted a range of support needs experienced by siblings of individuals with ID/ASD at various points in the lifecourse. As children, siblings need age appropriate information about their brother's and sisters' disabilities and would appreciate acknowledgement of their needs by professionals and opportunities for discussion of their experiences with other siblings. Greater understanding and awareness of disability among their peers, and indeed the wider public, would also support young siblings.

Siblings' needs as adults, centre on a need for information and a need for help with transition planning. It is clear from the findings that there are serious gaps in the supports available to adult siblings in this regard. Information about disability entitlements and service provision, support with engaging in family discussion of future and transition planning and access to high standard day, respite and residential services for brothers and sisters with ID/ASD, are key requirements. Initiatives to promote greater public awareness of ID/ASD and fora which provide ongoing information and support for siblings are also required. However, siblings are not a homogenous group and their varying family configurations, personal circumstances and indeed personality types, will influence their perceptions of what supports might be of use to them and their willing and capacity to engage with same.

## **7 Observations and implications for policy**

### **7.1 Introduction**

The aim of this research was to document the experiences of adult siblings of people with intellectual disabilities and/ or autistic spectrum disorders (ID/ASD) in Ireland. This is the first study of its kind in Ireland and adds to the existing, relatively small, knowledge base of international research which gives a voice to adult siblings (Orsmond and Seltzer, 2007; De la Cuesta and Cos, 2012; Tozer, Atkin and Wenham, 2013; Davys, Mitchell and Haig, 2015). This research is important as the majority of previous research on siblings, has focused on individual psychological impacts of having a brother or sister with ID/ASD, to the neglect of wider and more nuanced explorations of the sibling experience in this context. This has resulted in a failure to consider the sibling experience from a more structural or political perspective, which considers common experiences between siblings and explores the policy, welfare and service provision contexts within which sibling experiences are shaped (Meltzer & Kramer, 2016).

25 siblings aged 18-45, living in various parts of Ireland and abroad, participated in the study, either through face-to-face interviews, Skype interviews or through written contributions. Three overarching themes were explored in the study, concerning childhood experiences, current adult sibling relationships and hopes and aspirations for the future.

The findings demonstrates that siblings play a significant role in the lives of their brothers and sisters with ID/ASD and indicates that service planning and policy making could benefit from greater attention to their perspectives, experiences and needs. Systematic integration of a sibling focus in policy and practice would benefit individuals with ID/ASD by enabling, supporting and enhancing the roles of siblings in their lives. The following discussion considers the insights to be gained from consideration of sibling experiences, the ways in which such insights can inform policy and service enhancement and the specific support needs of siblings as a group.

### **7.2 Childhood**

The research revealed the strong bonds of affection and loyalty that participants felt for their brother or sister with ID/ASD. For most of the participants, childhood was largely a positive experience and having a sibling with ID/ASD did not impact hugely on everyday family life. Family dynamics depended on various factors, including the nature of the siblings' disabilities, parental coping strategies and family size.

As children, the siblings were conscious that their brother or sister was 'special', but for the most part, they perceived their families as 'normal', with behaviours and practices associated with their brother or sister, being an accepted and integral part of their family life. The narratives revealed a process in which siblings were socialised into the role of 'minding' and looking after their brother/sister. This occurred even in families where parents did not directly ask for practical help and support.

Many participants reflected on how their families became divided with mothers usually focused on meeting the needs of siblings with special needs, while fathers took responsibility for the activities and outings of the TD children.

None of the participants, growing up in the 70s, 80s and 90s, received any supports addressing their roles as siblings of an individual with ID/ASD. The child with special needs was the focus of parental and professional attention. Information about the nature of their brother or sister's disability was also very limited. As participants transitioned to adolescence, many began looking for information regarding the disability of their brother or sister. Many also began worrying about their brother or sister's future and some became aware that they were likely to be the sibling most involved in their brother or sister's life. Siblings who did not have other TD siblings to share their experiences with, felt particularly lonely and worried about the future.

### **7.3 Current sibling relationships and roles**

The current roles that adult sibling play in the lives of their brothers or sisters with ID/ASD are varied, are subject to change and depend on what is happening in other areas of the sibling's life. The roles they play depend on a range of factors including; the participants' personal life situations, their geographical location, the involvement of other siblings, the current residential and care arrangements of their brother or sister and the nature of their brother or sister's disability. Participants who have brothers and sisters with severe disabilities are involved in more hands on support, especially if their brother or sister is still living in the family home. Others provide social support and companionship for brothers and sisters who are living relatively independent lives. Advocacy roles are also common, in particular for those participants who work within the social care, disability or medical sectors and are familiar with policies and services. Participants living abroad find it harder to take on care or support roles but the majority want to remain involved in their brother or sister's life to the extent that is possible, and all maintain contact with their brother or sister.

Although the majority of participants describe their sibling relationship as loving and affectionate, some negative experiences are evident in the narratives. Challenging behaviours caused stress for some participants as their brother/sister

reached adolescence and adulthood. Furthermore, emotions of guilt and resentment are expressed in relation to the limitations of life style choices which participants experience, due to support commitments for their brother or sister. Six of the participants have sought counselling at some stage during their lives and two became emotional during the interviews. These findings are in line with other international studies on adult siblings, suggesting the need to pay attention to siblings' emotional and psychological well being while supporting families with members with special needs (Atkin and Tozer, 2014).

#### **7.4 Future involvement and planning**

All participants propose to be involved in the lives of their brothers and sisters in the future. However the expected degree of involvement varies between participants. The contingent and transitional dimension of the sibling role was highlighted, with some participants describing changes in the nature and extent of their involvement with their sibling, due to other care or work/study responsibilities. Other participants fear future 'harmonizing dilemmas' (Dellve et al., 2000: 172) where changes in their lives may call for a restructuring of their sibling role.

Participants envisage a range of future roles. Some envisage living with their brother or sister, either in the same residence or nearby. Others plan to be financially involved, or to play an advocacy and support role for a brother or sister living in supported or residential care. Many participants, particularly younger participants living at home with parents, are concerned about their parents' reluctance to discuss the future. Some are also critical of what they perceive as parental, or more commonly, maternal, over protection of their brothers or sisters, whom they believe have the potential to gain more independence.

Most participants acknowledge their parents' (predominantly their mothers') struggles to secure appropriate services and were expecting to take on similar roles as strong and vocal advocates for their brothers or sisters. However some participants are frustrated at the lack of legal clarity regarding their rights as siblings vis a vis engagement with service providers and in terms of the possibility of their having oversight of the welfare of their brothers or sisters. This was particularly evident in cases where siblings perceived elements of service provision to be less than optimal.

## **7.5 Implications for policy and service provision**

### **7.5.1 Implications for supports at different stages of the lifecourse Information and support needs:**

Young siblings need to be supported by both parents and service providers from an early age. They need age appropriate information about the impairment experienced by their brother or sister and about how this might impact on their brother or sister's behaviour, appearance and development. Information giving needs to be an ongoing process reflecting; the age of the sibling, changes in their brother or sister's behaviour, health or impairment and changes in therapies or medication. Consideration should be given to the best way to provide such information. To have maximum impact it needs to be age appropriate, and medium appropriate, and to be easily accessible. Digital media provide innovative and impactful ways to deliver information that is age appropriate and recognises the level of digital engagement of young people.

As many children with ID/ASD are now integrated in mainstream schools, there is a need for disability awareness education to be integrated into primary and secondary school curricula. Awareness programmes would assist in educating students from families who do not have the experiences of living with special needs and would make it easier for siblings to explain their own personal situations to their peers. Information products such as short films or animations would be a useful resource in school settings. The provision of age related fact sheets which could be shared with parents would extend the potential of such school-based awareness initiatives.

As siblings transition from young childhood into adolescence, there is an increased need for more information regarding the brother/sister's disability. Many participants had searched for information on the Internet and there is a need to provide easy access to online fora in the Irish context.

Peer support can be provided through formal groups such as Sibshops as discussed in Chapter 2. These are suitable for siblings who would benefit from the facilitated sharing of experiences with peers in similar situations. Sibshops are designed as a time-limited, managed, intervention and as such are resource heavy and have a limited applicability. The therapeutic orientation of Sibshops may also be negatively appraised by some adolescents and some participants in this research indicated that they would not have participated in Sibshops even if they had been available to them. As such there would seem to be a need for additional social or networking opportunities for siblings which are not therapeutic in orientation. Digital networking opportunities have potential in this regard. The online digital resource provided by the UK charity Sibs

(<https://www.youngsibs.org.uk/>) is targeted at children between the ages of 7 and 17 and provides both information and support. It contains sections on; disability types, difficult situations, family life and feelings. It also supports an interactive chat forum where young people can raise issues and get responses from others. The US based SibTeen, which operates as a closed group on Facebook, is a global online community targeted at adolescents who want to exchange experiences and views about what it is like to be a sibling of an individual with an ID or ASD ([https://www.siblingsupport.org/connect-with-others-sibs/meeting\\_other\\_sibs\\_online/sibteen](https://www.siblingsupport.org/connect-with-others-sibs/meeting_other_sibs_online/sibteen)). The potential for similar fora, which reflect the Irish context, should be explored.

Activity based events and the provision of safe meeting places along the lines of youth cafes should also be considered for adolescent siblings, given that adolescents appreciate opportunities for congregating in unstructured settings.

Some siblings may need one-to-one support and to talk to someone outside the family about their emotional and practical needs. At present the individual with the impairment is perceived as the client by service providers and professionals, and there appears to be little engagement with the wider family outside of the parents. This engagement is very much needed in families where challenging behaviours are posing a risk to family members, including siblings.

Adult siblings of people with ID/ASD and particularly those moving into the role of advocate or overseer of services for their brother or sister, also require support and information. At present there is no dedicated Irish resource point to meet the information and support needs of adult siblings of people with ID/ASD. The Sibs organisation in the UK provides dedicated support and information to adult siblings (<https://www.sibs.org.uk/>). A similar model in the Irish context would be desirable.

Futures planning:

Service providers and professionals need to facilitate families in planning for future living, support and care arrangements. Such discussions may be difficult for parents who are reluctant to burden siblings, or fearful about the limited options that the future seems to hold. The shortcomings of some residential care facilities (<https://www.hiqa.ie/social-care/find-a-centre/disability-services>), long waiting lists and dissatisfaction with the limited living and residential options available, are disincentives to futures planning.

Future planning dialogue between parents and TD siblings, and where possible the person with ID/ASD, needs to be encouraged to begin as early as possible. Given that many TD sibling(s) experience concern for the future of their brother or sister from adolescence onwards, it is important that they are kept informed



from an early age of developments relating to their brother or sister's condition and future plans for their support.

Such planning requires a number of supports. An awareness raising campaign targeted at parents and adults siblings is required to encourage consideration of the issue of planning. This should occur in conjunction with initiatives such as planning workshops providing information about issues to be considered and resources which could help in this regard. Such resources should be available both electronically and in print format providing details about:

- Assisted decision making and guardianship.
- Wills, inheritance and financial trusts.
- Residential options and elicitation of individuals wishes for the future.
- Entitlements for people with disabilities and carers under the Irish welfare and legal systems.
- Self-reflection resources to encourage siblings to consciously consider what role they want to play in their brother or sister's future. Resources to stimulate reflection on personal aspirations, responsibilities and commitments, time and resource capacities and required supports for various roles, would also be desirable.

An activity book/DVD set designed to help families with planning such as the US produced 'My Life Book: Future Planning for People with Developmental Disabilities' would also be helpful. The set consists of a video, which follows four families attending a future planning class and a related workbook, which provides a location for recording important information about the individual with ID/ASD, about the family and about their wishes and plans for the future (Meyer & Holl, 2014:173.)

Finally, siblings moving into the role of advocate or overseer of services for their brother or sister with ID/ASD, require practical information relating to that individual's medical information, entitlement cards, PPS numbers, names and contact numbers for relevant professionals, etc. A hard copy and/or electronic template tailored to the Irish context, which would facilitate the compilation of such information would be very useful. Parents and adults siblings need to be encouraged to update this template on an ongoing basis and to ensure its storage in a safe and accessible location, known to all of the TD siblings. The availability of this information would help siblings who are assisting ageing parents with advocacy and would allow siblings to assume a key support role with minimal disruption if this was required in an emergency situation. Sharing of this information template between all siblings might also facilitate wider engagement of siblings and lessen the likelihood of one sibling being seen as the holder of knowledge and responsibility in relation to their brother or sister with ID/ASD.

To summarise, parents, professionals and service providers need to become more 'sibling aware' in order to understand the complexities involved in sibling relationships over the lifecourse. Future supports for people with ID/ASD depend on a social care model, which includes and acknowledges the important role that siblings play. Disability awareness programmes, that highlight the contribution that extended family, friends and members of the local community could play in supporting people with ID/ASD and those supporting them, might also increase the potential for 'natural supports'. To be effective these may need to be supplemented by practical training and information sessions for those who wish to take on such roles.

### **7.5.2 Implications for service provision, practitioners and professionals**

The findings from this research indicate a range of sibling experiences in relation to service providers, practitioners and professionals. As children, the participants reported being largely ignored by professionals. Yet it is clear from their accounts that many of them undertook direct care tasks for their brother or sister and almost all provided some form of support, which helped their parents with care tasks. It is also evident that as children, the participants were very familiar with the likes, dislikes, routines, needs and challenges of their brothers and sisters with ID/ASD. This would suggest a need for professionals and service providers to recognise the roles that siblings undertake and acknowledge them as active agents in the support structure within families. Recognition of sibling roles and engagement with siblings from an early age, would facilitate futures planning in a gradual way and would set the foundations for subsequent beneficial, collaborative and cooperative, sibling relations with professionals and service providers.

Siblings whose brothers or sisters are in residential services, have varying experiences with staff in these facilities. Their accounts demonstrate that practices applied by services vary significantly. Sibling awareness within service provision organisations, and a more systematic approach to dealing with siblings, would be desirable. Reflection on current practices, staff attitudes and possible training needs would be helpful as would the development of national, service level protocols around engagement with siblings. Such protocols would need to acknowledge that sibling roles are different to those of parents and are likely to change as siblings proceed through the lifecourse.

PCPs provide a useful opportunity for exploring sibling connections and considering how sibling contact and support could be facilitated. The adoption of a whole family approach by professionals and service providers would be desirable. This would require a shift in professional and institutional practice and the provision of additional resources, but it would be fruitful in terms of the

identification of emerging issues, the provision of timely support and the facilitation of futures planning within the family.

### **7.5.3 Implications for policy**

Recent policy discussion around disability services in the Irish context, acknowledges the need to move toward de-institutionalised forms of living and more individualised models of service provision (Health Service Executive, 2011; Health Service Executive, 2012; Department of Health, 2012). A move toward community based, de-congregated living (Health Service Executive, 2011) is to be welcomed. However siblings in this study describe a range of living arrangements, which their brothers or sisters are currently availing of, or which they hope will be availed of by them in the future. This diversity in opinion as to what constitutes the best arrangement for particular individuals with ID/ASD, makes clear the need for a variety of living arrangements, which reflect the wishes of the individual with ID/ASD, their level of ability and the financial and family based supports they have at any given time. The variety and context-specific nature of these arrangements needs to be recognised, and where siblings are supporting their brother or sister in the 'community', adequate financial, information and professional supports need to be put in place to facilitate this.

Individualised models of service provision and personalisation of funding, undoubtedly offer individuals with disabilities more options in designing the care, support and training package that best suits their needs. They also facilitate flexibility and responsiveness to changing circumstances. In this regard, a budget personalisation approach may help address the issue of lack of power, which people with disabilities have experienced in relation to determining their own life agendas. It also provides an alternative to the potentially negative dimensions of centralised care and support initiatives. However, personalised funding also brings challenges.<sup>11</sup> If it is not resourced at an adequate financial level, a personalised funding model could potentially increase care and support demands on siblings of people with ID/ASD. Many people with ID/ASD are also likely to require support with decision making about how personalised funding is to be spent. It is probable that siblings would be involved in providing this support and they would require information and guidance in relation to this role.

With regard to the issue of legal capacity, it is also to be expected that some siblings will take on decision-making roles as part of the new arrangements set

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<sup>11</sup> Inherent in this approach is a commodification and privatisation of care and support arrangements. Private, commercial care usually occurs in un-regulated domestic settings, is poorly paid and frequently reinforces gender and racial exploitation, see Mahon and Robinson, 2011).

out in the Assisted Decision-Making (Capacity) Act 2015. In this context, siblings need to be recognised as an identified group and provided with specific information about the terms of the Act, and what it means for decision-making processes involving their brother and/or sister with ID/ASD.

#### **7.5.4 Implications for future research**

Research on sibling relationships in situations where one sibling has a disability, has focused almost exclusively on the impact on the sibling without the disability. The marginalisation of the voices of those with disabilities within the sibling research context is striking. Some recent studies have addressed this omission (Serdity and Burgman, 2010; Kramer, Hall & Heller, 2013; Petalas et al. 2013). Research in the Irish context, focusing on the perspective of those with ID/ASD would be welcome. A focus on their perceptions of their relationships with their TD brothers and sisters, and on their preferences in relation to the types of roles they would like their siblings to play in their lives, would be useful.

Few studies have provided collective, politicised consideration of experiences that siblings of individuals with ID/ASD might have in common. Research which draws on macro-level, material and structural analysis of the socio-economic, legal and policy contexts in which, sibling relationships are constructed would be useful. Such research should consider not only disability policy but related policy domains such as family support policies, care policies, housing policies, welfare provision and legal rights.

Research to explore the gendered dimensions of sibling relationships is also necessary. This study, like many others (Orsmond & Seltzer, 2000; Seltzer, Begun, Seltzer, & Krauss, 1991), has highlighted that sisters are more likely to be the siblings who are most involved with a brother or sister with a disability. Gendered analysis of women's accounts of their childhood experiences, and of their assumption of sibling care and support roles in adulthood, is required. This will allow insights into how and why, women more frequently become the most involved sibling. The implications of such roles for women need to be explored and consideration needs to be given to how such roles might be more equally dispersed among women and men.

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## **9 Appendix A**

### **Exploring Adult Siblings' Experiences of their Relationships with their Brothers/Sisters with Intellectual Disabilities/Autism**

#### **Information for Research Participants**

##### ***What is the purpose of the research?***

The aim of this research is to document the experiences of siblings of individuals with Intellectual Disabilities (ID)/Autism. The specific objectives of the research are:

To document the nature and extent of sibling relationships

- To explore the feelings and understandings of siblings of brothers and sisters with ID/Autism
- To document their aspirations and concerns in relation to future relationships and supportive roles they might play in their sibling's lives
- To gather their opinions on what resources, interventions etc. could best support these sibling relationships at various stages of the lifecourse
- To analyse examples of good practice relating to sibling relationships

##### ***Who is carrying out the research?***

This research is a small study supported by a grant from the National Disability Authority (NDA). The research will be carried out by Anna Kingston, Máire Leane and Claire Edwards from the School of Applied Social Studies UCC, in collaboration with Inclusion Ireland (a national umbrella organisation representing support groups of people with Intellectual Disability (ID)).

The steering group overseeing the research project also includes Michael Feely (Social Studies, Trinity College Dublin) and Fiona Duignan (Policy and project manager, Inclusion Ireland). The project adheres to ethical guidelines outlined by the UCC Social Research Ethical Committee as well as ethical codes promoted by the NDA and Inclusion Ireland.

##### ***What would my participation in the study involve?***

The study will involve face-to-face interviews with adult siblings (aged 18 to 45) who have a brother or sister with ID/Autism. The interviews will focus primarily on documenting the relationships between siblings, and the nature and range of support played by siblings, and in identifying the types of support which would be of most use to siblings in helping them in these roles.

Due to the nature of this research, there is a possibility that the interview might cause distress for the participants and the researchers will endeavour to provide necessary support if this happens. For example, offer a break from the interview or reschedule it. Inclusion Ireland will also be available to provide support should it be needed. If you agree to participate in the study you would be asked to do a face to face interview or Skype with one of the researchers. This interview would be audio recorded and would take between 40 minutes to an hour to complete. It would take place at a location that is convenient to you.

It is envisaged that the findings from this study will contribute to the development of policy and practice initiatives to sustain life long relationships between siblings.

***What will happen to the information collected at the interview?***

The information recorded at the interview will be typed up into a document and information from it may be used in the final report compiled by the researchers. Direct quotations from your interview may be used but they will be anonymised so it will not be clear who provided the quotations. The research team will do its utmost to ensure that no clues to a participant's identity will be included in the final report. The data will be stored in a locked filing cabinet in UCC and on a password protected computer. The data will be destroyed within 7 years of completion of the research.

***What will happen to the results of the research?***

The information collected in the interviews will be analysed and results will be produced. The results will be presented in a research report which will be available on the National Disability Authority website. They will also be presented at a seminar to which you will be invited. The results may also be published in an academic journal.

***For more information or any other queries regarding this research please contact Anna Kingston on [a.kingston@ucc.ie](mailto:a.kingston@ucc.ie).***

## **I0 Appendix B**

### **Exploring Adult Siblings' Experiences of the Relationships with their Brothers/Sisters with Intellectual Disabilities/Autism**

You have been contacted to take part in this interview because you previously self-selected to participate in this research as a response to a public call for participants.

I, \_\_\_\_\_, have been informed of the purpose of this National Disability Authority commissioned research being conducted by Dr. Máire Leane, Dr. Claire Edwards and Dr. Anna Kingston from the School of Applied Social Studies at UCC. I understand the aim of the research is to explore the experiences of adult siblings of individuals with Intellectual Disabilities (ID)/Autism with a view to identifying best practices in relation to supporting them in these sibling relationships.

Please tick as appropriate:

1. I consent to participate in the research and share my experience of my relationship with my sibling with ID/Autism  
YES       NO
2. I consent to the interview being audio-recorded  
YES       NO
3. I consent to excerpts from the tape being referred to or quoted in the research and I understand that these will be anonymised  
YES       NO
4. I consent to the material from my interview being used in the report produced for the National Disability Authority and possibly for further publications  
YES       NO
5. I understand that I can withdraw my participation in this research at any stage up until two weeks after receipt of the transcript of my interview. There will be no negative repercussions for me to withdraw and data collected will be destroyed  
YES       NO

I would like to have access to the material I contribute to the research and/or to the report produced for the National Disability Authority through the researchers:

- a) Providing me with copy of the transcript of the recording of my interview  
Yes: \_\_\_\_\_ No: \_\_\_\_\_
- b) Providing me with access to the National Disability Authority report  
Yes: \_\_\_\_\_ No: \_\_\_\_\_

Signed \_\_\_\_\_

Date \_\_\_\_\_

## **II Appendix C**

### **Building Capacity among Adult Siblings of People with Intellectual Disabilities/Autism**

#### **A. Demographics**

- Age, where they live, living circumstances (do they still live at home, near their family, away from their family, urban/rural);
- Where does sibling live?
- Place in family (in relation to other siblings), how many siblings, parents' ages.
- Education;
- Employment; where working, if working.
- Family of their own?

#### **B. Growing up with a sibling who has ID/Autism**

1. How and when did you find out about your sibling's disability?
2. Can you think of any particular event/story about you and your brother/sister that reflects your childhood experience?
3. Did growing up with your sibling impact on family and social life? If yes, how did you make sense of this experience?
6. To what extent were you involved in supporting your sibling growing up? What kind of responsibilities have you had as a sibling?



7. Did you ever feel that it was hard to have a sibling who is different? If yes, what situations were hard? How did you feel then?
8. Did you talk to your peers about your sibling growing up? How did you experience their views and comments?
9. Where there any advantages having a sibling with a disability growing up?
10. Did you receive any support as a sibling growing up? If yes, what kind of support and how did this work for you (for example Sibshops)?
11. What was your relationship with your parents and other siblings growing up?
12. Was there anyone who was helpful in supporting the family?
13. Did you have any particular worries about the future?

### **C. Current relationship with sibling**

1. Has your relationship changed with your brother/sister over the years? If yes, was there at a particular point that your relationship changed or was it gradual?
2. What is your relationship with your sibling now?
3. What is rewarding and what is difficult?
4. How often do you see your sibling and in what context?
5. To what extent are you involved in activities with your sibling?
6. How do you view your sibling role?
7. Are you currently involved in supporting your sibling? Is this support shared with others in the family? If yes, in what way? If no, why not?
8. To what extent were you/are you involved in decisions about your sibling's support?
9. How do you feel about being involved in supporting your sibling?
10. To what extent do you feel you have a choice in supporting your sibling?

11. Has having a sibling with ID/Autism made a difference to your adult life?
12. How do you feel about your parents' support of your sibling?
13. What is your current relationship with your parents and your other siblings?
14. How would you describe the relationship of extended family, friends and neighbours with your sibling?
15. How do you experience that others react when you tell them about your sibling? Positively? Negatively?

**D. Future supports for sibling relationships with people with ID/Autism**

1. What do you hope for your sibling's future?
2. What role would you like to have in this future?
3. Do you have any concerns about the future?
4. How do you anticipate you might be involved in supporting your sibling in the future?
5. Have you had experiences involving support services (e.g. community, statutory services) for your sibling as an adult? If so, can you tell us a bit about your experiences with these services? Can you give an example of a particular successful relationship?
6. What improvement would you like to see in current provision?
7. In your view, are there sufficient supports in place for siblings? If not, what support services do you think would be helpful? What would be the best way to deliver these services (e.g. through blogs, internet-based, face-to-face peer support, professional support)?

8. Are there any other issues that you think it is important for us to address?

## I2 Appendix D

### **Call for research participants**

Are you a sibling of someone with an intellectual disability and/or autism? Are you aged between 18 and 45? We are looking for participants for an Irish study who would like to share their experiences of having a brother or sister with ID/Autism in Ireland. The aim is to document these sibling relationships and gather a wide range of views and perspectives on how siblings feel about the issue of providing/not providing support, the expectation that siblings should/will provide support and the factors which encourage or inhibit the provision of support.

The research is a partnership between University College Cork and Inclusion Ireland and funded by the National Disability Authority. We hope to conduct 25 face-to-face interviews beginning in September and would like to hear from adult siblings from all walks of life. You don't have to live with your brother/sister with ID/Autism and you don't even have to live in the same country as we can conduct interviews via Skype.

***For more information or any other queries regarding this research please contact Anna Kingston on [a.kingston@ucc.ie](mailto:a.kingston@ucc.ie).***

## I3 Appendix E

### Demographic details of participants and their brother/sister

<b>Participants</b>	<b>Siblings</b>
<b>Líosa</b> Aged 22, Munster No other siblings	<b>Niamh</b> Aged 20, ASD At home with parents
<b>Harry</b> Aged 27, Munster Two TD siblings	<b>Tom</b> Aged 24, DS At home with parents
<b>Annie</b> Aged 45, Munster One TD sibling	<b>James</b> Aged 41, ID (unspecified) At home with mother
<b>Anna</b> Aged, 30, Munster Two TD siblings	<b>Peter</b> Aged 29, DS At home with parents
<b>Siobhan</b> Age 27, UK No other sibling	<b>Ailish</b> Aged 30, Rare syndrome At home with parents

<p><b>Mary</b></p> <p>Aged 34, Connaught</p> <p>Three TD siblings</p>	<p><b>Paul</b></p> <p>Aged 38, Asperger syndrome</p> <p>At home with mother</p>
<p><b>Ann</b></p> <p>Aged 44, Connaught</p> <p>No other sibling</p>	<p><b>George</b></p> <p>Aged 46, ID (unspecified)</p> <p>Residential</p>
<p><b>Karen</b></p> <p>Aged 36, Leinster</p> <p>Two TD siblings</p>	<p><b>Kim</b></p> <p>Aged 33, ID (moderate)</p> <p>At home with parents</p>
<p><b>Sarah</b></p> <p>Aged 22, Leinster</p> <p>One TD sibling</p>	<p><b>Lisa</b></p> <p>Aged 20, ASD (high functioning)</p> <p>At home with parents</p>
<p><b>Christine</b></p> <p>Aged 34, Leinster</p> <p>Two TD siblings</p>	<p><b>Fiona</b></p> <p>Aged 17, ID (severe) &amp; epilepsy</p> <p>At home with parents</p>
<p><b>Alan</b></p> <p>Aged 23, Leinster</p>	<p><b>Gary</b></p> <p>Aged 21, DS &amp; ASD</p>

Three TD siblings	Residential
<b>Marion</b> Aged 32, UK Two TD siblings	<b>Sean</b> Aged 29, ID (moderate) At home with parents
<b>Angela</b> Aged 32, Munster Two TD siblings	<b>Patrick</b> Aged 30, ID (mild) In own accommodation
<b>Chloe</b> Aged 31, UK One TD sibling	<b>Diarmuid</b> Aged 35, DS Residential
<b>Bernie</b> Aged 44, US Two TD siblings	<b>Jackie</b> Aged 40, DS At home with mother
<b>Amy</b> Aged 41, Ulster Three TD siblings	<b>Philip</b> Aged 31, ASD (severe) Residential

<p><b>David</b></p> <p>Aged 32, Leinster</p> <p>One TD sibling</p>	<p><b>Laura</b></p> <p>Aged 35, ID &amp; epilepsy</p> <p>Residential</p>
<p><b>Linda</b></p> <p>Aged 22, Leinster</p> <p>Two TD siblings</p>	<p><b>Louise</b></p> <p>Aged 15, DS</p> <p>At home with parents</p>
<p><b>Henry</b></p> <p>Age 30, Europe</p> <p>Two TD siblings</p>	<p><b>Jill</b></p> <p>Aged 32, ID (mild)</p> <p>In own accommodation</p>
<p><b>Geraldine</b></p> <p>Aged 39, Munster</p> <p>One TD-sibling</p>	<p><b>Robert</b></p> <p>Aged 40, ASD (high functioning)</p> <p>Residential</p>
<p><b>Tara</b></p> <p>Aged 25, Leinster</p> <p>One TD sibling</p>	<p><b>Molly</b></p> <p>Aged 23, ID (mild)</p> <p>At home with parents</p>
<p><b>Carmel</b></p> <p>Aged 42, Leinster</p> <p>One TD sibling</p>	<p><b>Jack</b></p> <p>Aged 39, ID (severe)</p> <p>Residential</p>



<p><b>Emma</b> Aged 33, Leinster Two TD siblings</p>	<p><b>James</b> Aged 22, DS At home with parents</p>
<p><b>Aoife</b> Aged 24, Leinster No other sibling</p>	<p><b>Seamus</b> Aged 22, Rare syndrome At home with mother</p>
<p><b>Kenneth</b> Aged 41, Australasia Two TD siblings</p>	<p><b>Heather</b> Aged 33, ID &amp; epilepsy At home with parents</p>