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# *"I don't care anymore if she wants to cry through the whole conversation, because it needs to be addressed":* Siblings' without disabilities experiences of the dynamics of future care planning for brothers and sisters with developmental disabilities


## ABSTRACT

In families with a member with a developmental disability (DD), future care planning is limited (Brennan et al., 2018; Davys et al., 2016, 2014 & 2010; Bowey and McGlaughlin (2007). However, most siblings without disabilities (SWD) expect to be involved in the future care of their brother or sister with DD (Gomez de la Cuesta and Cos, 2012; Heller and Arnold, 2010, Benderix and Sivberg, 2007). Based on qualitative interviews with 25 SWD in Ireland, this article explores how SWD experience future care planning. The findings indicate that they experience care planning as an ongoing, fluid and emotionally charged process. Parental fears about a future care landscape that they do not control and about passing intergenerational care responsibilities to their children without disabilities, emerge as key factors inhibiting planning. Attention to the highly emotive nature of care concerns and to the tentative pace of planning that is comfortable for families will help professionals provide optimum planning support.

## 1 INTRODUCTION

Future planning in relation to care for adults with developmental disabilities (DD) when their parents are no longer in a position to provide this care, is receiving increased research attention (Power and Bartlett, 2018; Brennan et al. 2018; Davys et al., 2016, 2014 & 2010; Pryce et al. 2015; Bibby, 2012; Burke et al., 2012; Taggart et al., 2012; Gomez de la Cuesta and Cos, 2012; Heller and Arnold, 2010 & 2009; Bowey and McGlaughlin, 2007; Barron, McConkey and Mulvaney, 2006; Benderix and Sivberg, 2007; Orsmond and Seltzer, 2007; Bigby, 1997), prompted in large part by the increased longevity of people with DD (Coppus, 2013; Emerson et al., 2012; Fujiiura, 2010; Hog et al., 2000). In the context of neo-liberal politics of austerity, decreased funding for disability services (Taylor-Gooby et al, 2017; Power and Bartlett, 2018) and policy moves toward de-congregated living and personalised budgets (Mansell and Beadle-Brown et al, 2010) the question of who will provide support and care for adults with DD when their parents can no longer do so is increasingly urgent. In Ireland where the research reported in this article was conducted, the majority (69.0%) of people with DD live with family members, including almost one third (31.6%) of those aged 35 years and above (Hourigan et al., 2017:12; Egan

and Dalton, 2019). The phenomenon of ageing parents providing care to adults with DD within the family home is replicated internationally (Coppus, 2013; Emerson et al., 2012; Hogg et al. 2000). Yet, the limited literature available consistently indicates that in families with a member with DD, future care planning is inadequately addressed or not addressed at all. Davys et al's. (2010) small scale survey of 21 siblings of adults with intellectual disability in the UK revealed that just over half of the participants (57%) had a full discussion with their parents regarding the future care of their sibling with intellectual disability, 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), involving interviews with 15 adult siblings without disabilities (SWD), indicated a near equal distribution between families who had engaged in future planning and those who had not. In the US, Bowey and McGlaughlin (2007) found that only 32% of older parents with an adult offspring with intellectual disability had made residential plans. Recent Irish research with 8 siblings of adults with Autism Spectrum Disorder (Noonan et al, 2018) found that no concrete future plans were in place, while Brennan et al's. (2018) research with 17 family members of people with intellectual disability who were aged over 40, revealed that only 2 families had a future care plan. Barriers to families engaging in future planning include, parental reluctance to discuss the issue

due to concerns about changing the existing relationship with the person with DD (Bibby, 2012; Taggart et al. 2012; Bowey and McGlaughlin, 2005), reluctance to pass a care burden on to siblings (Rawson, 2010), limited choice in relation to available care options (Brennan et al., 2018; Pryce et al. 2015; Davys et al., 2010: 175/6), insufficient information about care options and difficult relations with service providers (Davys et al., 2014:223).

Notwithstanding the lack of planning for future care, research with SWD consistently reveals an expectation of involvement in care or support for their brother or sister (Gomez de la Cuesta and Cos, 2012; Heller and Arnold, 2010, Benderix and Sivberg, 2007; Ormond and Seltzer, 2007). Heller and Arnold's (2010:22) review of 25 studies of adult siblings of people with intellectual disability, found that 60% of siblings expected to be carers for their brother or sister in the future and that there was usually one sibling who took the role of the 'most involved sibling.' SWD sometimes perceive an implicit parental expectation that the individual with DD will remain living with a family member (Davys et al., 2014) and parental expectations around SWD future involvement with their brother or sister with DD, appear to be significant in shaping sibling's expectations about care (Davys et al., 2016, 2014 & 2010; Davys and Haigh, 2008; Bigby, 1997). However, there is also a wealth of research which indicates that many siblings are motivated to care for their brother or sister with DD due

to strong and enduring affective connections (Leane, 2019; Doody et al., 2010; Rowland, 2010; Orsmond and Seltzer, 2007; Hodapp and Urbano, 2007; Doody et al., 2010). This desire to care frequently coexists with SWD' feelings of having limited choice and with tensions around forging their own biographies in the face of familial and societal expectations that they will be involved to some extent with caring for and/or about their adult brother or sister with DD (Leane, 2019; Atkin and Tozer, 2014; Gomez de la Cuesta and Cos, 2012).

The literature thus highlights a disjuncture between high levels of sibling desire to care and low levels of future planning within families. This tension is reflected in research findings that identify support with discussing future plans as a frequently reported unmet need reported by adult siblings of people with DD (Davys et al. 2016, 2014 & 2010; Atkin and Tozer, 2015 & 2014; Meyer and Holl, 2014; Gomez de la Cuesta and Cos, 2012; Heller and Kramer, 2009; Benderiz and Sivberg, 2007). Key questions then are how do SWD experience and understand the dynamics which surround family future care planning? And why are many families of adults with DD not engaging in the discussion and development of future care plans? Based on qualitative accounts from 25 SWD in Ireland, this article explores how family members experience, engage with and make sense of the dynamics of future care planning. The data was collected against the backdrop of a policy and service landscape dominated by

austerity measures that have severely strained public services. The implications for adult services for people with DD include an unmet need for 2,179 new full-time residential placements (Hourigan et al., 2017), reduced homecare supports (Inclusion Ireland, 2018 and 2020) and acutely worrying reports on standards of care being provided in residential facilities (Irish Times, 2016). As such decisions about future planning take place in a context where there is a scarcity of residential options and limited public funding for services for people with DD. Of significance also is the historically limited engagement of the Irish state in providing care and the tradition of high levels of family engagement in the provision of care, with women bearing the burden of this work (Conlon et al., 2014). This combination of austerity, heavy reliance on unpaid family care and a policy agenda prioritising deinstitutionalisation and community living (Department of Health, 2012; Health Service Executive, 2011, 2012) renders future care planning an issue of crucial concern in the Irish context.

## 2 METHOD

This article draws on data gathered from 23 in-depth interviews and 2 written narrative accounts provided by SWD. Ethical approval for the research was

granted by the Social Research Ethics Committee (SREC) in UCC. Written consent was provided by participants and all data was anonymised.

## 2.1 Sample and Data collection

A purposive sample was generated through a call for participants issued in July 2015 through the communication networks of three Irish NGOs providing support to individuals with ID and or ASD and their families. These were Inclusion Ireland[1], Shine Ireland[2], Autism Action[3] and AsIAm[4]. Inclusion criteria for participation were that they were aged between 18 and 45,[5] had a sibling with DD and were willing to engage in a one to one or skype interview. In some instances, details of the research call were passed to potential participants by their parents, while in others, the participant saw it themselves. No incentive to participation was offered.

[1] 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

[2] 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.

[3] Irish Autism Action provides information and support for autistic children and adults and their family and friends. www.autismireland.ie.

[4] AsIAm is a website which aims to provide a one-stop=shop for the Autism community in Ireland. ASIAM.ie.

[5] The upper age limit of 45 was determined by the National Disability Authority (NDA) who funded the research. Another research team funded by the NDA was focusing on family care for an older cohort of people with developmental disabilities who would have older siblings. See Brennan et al. (2016).

25 participants were recruited and their demographic details along with those of their brothers and sisters with DD are provided in Table 1. The majority of the participants were female (n=20) and there was a dispersal of participants across the age range. 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))[6]. Almost a quarter of the participants (n=6) lived abroad. At the time of interview 19 were in employment, 5 were in education and 1 was working in the home. The majority were single (n=16) and 9 were married or had partners. A minority of participants (n=6) had children. The participants' brothers and sisters had a range of disabilities including unspecified Intellectual Disabilities (ID) (n=12), Down Syndrome (DS) (n=7), Autistic Spectrum Disorder (ASD) (n=4) and rare syndromes (n=2).[7] They ranged in age from 15 to 46 and had a variety of living arrangements (see Table 1).

The interviews, conducted between September 2015 and April 2016, included 17 face-to-face interviews, 5 Skype interviews with participants living abroad (UK (n=3), USA (n=1) and Europe (n=1)) and 1 phone interview. In 2 cases where face-to-face, Skype or phone interviews were not possible the

[6] Ireland is divided into four provinces, Munster, Connaught, Leinster and Ulster and all would have a mix of urban and rural communities.

[7] Details of the nature of the rare syndromes identified by the participants were not collected. In each case the disability was present from birth and presented similar support needs to ID and ASD.

participants were invited to email a written response to the themes set out in the topic guide and both availed of this option. As such 23 of the 25 interviews were digitally recorded and transcribed and two were provided in email format. The average length of interview was 55 minutes. Participants were offered a copy of their transcribed interview for review and correction and were advised that they could withdraw it from the research process within two weeks after they received it. 11 participants asked for a copy of their transcription and none asked for corrections or withdrew from the research. Participants were offered a copy of the completed report but were not asked to comment on interpretation or analysis. 19 participants asked to receive the report.

## 2.2 Data collection and analysis

This study was informed by a phenomenological approach being concerned with exploring how SWD made sense of their experiences of being a sibling of a PDD. Data were collected through one to one interviews conducted using a semi-structured topic guide (see Table 2) and a life course or life history approach (Miller, 2000). The decision to take a life course approach was informed by a desire to understand siblings caregiving in a way that considered care

connections and practices across the arc of the participants' life course rather than focusing on an atomistic account of their current care practices or intentions. As such the participants were asked to reflect on their relationships with their brother or sister when they were children, their current relationship and engagement and their aspirations for the future. The interview began with questions about their early memories of their brother or sister with DD and participants were asked to describe when, how and by whom their brother or sisters' disability was explained to them, what family care practices were like when they were children, what role they played in them, how they felt about these practices as children and how they felt about them in the current time. They were then invited to discuss their current relationship with their brother or sister, to reflect on how they feel about their engagement in support or caregiving and to speculate on how they thought their roles as supporters and carers might develop in the future. A narrative approach was adopted to elicit a contextualised account of siblings' understandings and feelings about their ongoing relationships and care connections with their brother or sister as mediated by the changing and evolving contexts of their own lives and families.

The data were analysed following Braun and Clarke's (2006) guide to thematic analysis and involved both open and axial coding. In the first stage of the data analysis open coding was undertaken. 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, axial coding was applied with a number of major themes and sub themes being identified along with relationships between themes. This researcher triangulation was employed to establish credibility in relation to the fit between participants' accounts and our representations of them (Guba and Lincoln, 1989). One major theme related to the issue of future planning and the extent to which this has been undertaken in participants' families. Three inter-related sub themes were identified. The first (discussing and sharing care) relates to the care planning which has occurred in families. The second thematic area (devolving, deflecting and deferring care conversations) explores participants' understandings of parental reluctance to engage in future care planning. The final thematic area (assuming, ascribing, contesting and sharing care) considers participants' experiences of negotiating care responsibilities with their other SWD. The data generated under each theme were explored to generate both descriptive and explanatory/conceptual accounts of the key issues identified.

# 3 RESULTS

## 3.1 Discussing and sharing care: developing future plans

Only 4 of the 25 siblings who participated in this research indicated that they have had open and engaged discussions with their parents about future care plans for their brother or sister with DD. Aoife (aged 24) who is an only sibling to Seamus (aged 22 with a rare syndrome), 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.*

An inclusive and consultative approach to care planning was also described by Alan (aged 23 and brother to Gary aged 21 with DS and ASD) whose parents and three other SWD all engaged in discussion prior to a decision to seek a residential placement for Gary. As a family they were comfortable with the idea of residential care as Gary was "… used to living in a residential [home] at weekends." Emma's (aged 33) family have always been very open in discussing issues about James (aged 22 with DS), 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.” Similarly, Linda (aged 22 and only sibling of Louise aged 15 with DS) explained that although she and her parents have only ever had “… a few conversations ...” about future care she had made it clear to them that she planned to “…look after” Louise. The conversations about future care which Emma and Linda describe can be understood as groundwork for the development of care plans in the future. As we will see in section 3.2, the open consideration of care issues in these families, contrasts with the dynamics in other families where SWD’s attempts to discuss care are thwarted.

The existence of plans which address certain elements of care such as financial provision or accommodation plans were reported by 12 participants. Marion (aged 32), Tara (aged 25), Angela (aged 32) and Alan (aged 23), reported that their parents have financial plans in place for their brothers and sisters, which will guarantee them financial security and Anna’s (aged 30) parents have willed her the family home, in which her brother Peter (aged 29 with DS) lives, on the condition that she will co-habit with him. Seven 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 DD. Henry’s (aged 30) parents are in the process

of building a small house for his sister Jill (aged 32 with a mild ID) who is currently living alone in rented accommodation. He understands this as a strategy his parents are employing to provide care into the future, "They're hoping that that will then provide her with some sort of security… ." Tara's parents are moving to a more central location which will allow her sister Molly (aged 23 with a mild ID), direct access to a bus to her day service. Bernie's (aged 44) mother has also moved house and now lives in a location from which Jackie (aged 40 with DS) can walk to her day service and access a wider range of bus routes. Bernie's mother has also begun discussions with a local service provider with a view to "laying the groundwork for maybe a plan [residential plan] for Jackie."

In other cases, families have put in place, or are planning, alternative or additional supports to extend the care network of the individual with DD. Marion (aged 32) has recently persuaded her parents to put Sean (aged 29 with ID) 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. Linda (aged 22) and her parents have been actively focusing on extending the social network of Louise (aged 15 with DS),

*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.*

Respite services frequently serve as starting points for the emergence of future care plans. 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." Karen's (aged 36) sister, Kim (aged 33 with ID), 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 acknowledges that her mother may not be ready to let Kim go. For Aoife (aged 24) and her mother, the decision to allow Seamus (aged 22 with 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.*

Establishing financial or accommodation supports, facilitating greater independence for the individual with DD and negotiating and accepting occasional care supports from people outside the immediate family are core elements of future care planning as described by participants. The findings above suggest that these initiatives are usually negotiated in gradual ways, frequently in consultation with SWD and in one case with the support of a social worker. A key challenge for parents in this negotiation of future care is allowing other parties, be they siblings, wider family members, local community members or professionals, to assume or share some care and support tasks for the adult child with DD. Karen and Aoife's accounts above highlight how emotionally challenging it can be for parents to entrust care responsibility to others, particularly to non-familial, professional care providers. Their narratives also draw attention to the way in which care plans may evolve in tentative ways characterised by a gradual and iterative laying down of care connections between familial and other care providers.

### 3.2 Devolving, deflecting and deferring care conversations: understanding parental reluctance to engage in future care planning

The parental openness to considering and engaging in future care planning described by participants in the previous section, contrasts sharply with accounts from other participants which highlight strong parental or more specifically maternal reluctance to discuss the topic. Many siblings reported that while various family members engaged in care practices, mothers had primary responsibility for organising and providing care, reflecting prevailing gendered inequalities in care work (Lynch, 2009). Unsurprisingly then, mothers were identified as the family member with most influence in shaping family dynamics in relation to future care planning. Sarah (aged 22) reflecting on the decision-making dynamic in her family, perceived that "… it's mam's decision and dad kind of just goes along with what mam says." Henry, Anna, Kenneth, Angela, Karen and Amy made similar observations about the more peripheral role their fathers play in care and their tendency to devolve decisions about care to their wives. The centrality of mothers as both caregivers and care organisers in many families, resulted in their being identified by some participants as gatekeepers to discussions about future care planning. Anna (aged 30) reported that her mother is distressed by discussions of future care plans for Peter (aged 45 with DS) and deflects all attempts at detailed discussion of the issue. Kenneth (aged 41) and brother to Heather (aged 33 with ID and Cerebral Palsy), emphasised the combative, emotionally charged

and stressful nature off interactions he and his siblings have with their mother in relation to future plans for Heather,

> *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.*

The majority of participants began to think about the future care needs of their brother or sister with DD during adolescence and for some of them, future planning was a long term and ongoing source of worry and exasperation. Mary (aged 34 and sister of Paul aged 38 with ASD) has occasionally raised the issue of future planning with her parents since she was in her late teens but her mother defers the issue adopting the attitude of "We'll cross that bridge when we get to it". This makes Mary very anxious and frustrated as her mother who is now widowed has not made a will or any other type of care plan for Paul. The highly emotive and distressing nature of the dynamic which can emerge between SWD and their parents in relation to care planning is poignantly evidenced in Siobhan's (aged 27 and an only sibling to Ailish aged 30 with a rare syndrome) narrative,

> *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.*

Participants attribute various motivations to maternal or parental reluctance to discuss future care. Parental concern about the intergenerational transfer of care responsibilities was perceived by a number of participants as a reason for their reluctance to discuss future care plans. Líosa (aged 22 and an only sibling to Niamh aged 20 with ASD) believes that her parents' refusal to discuss the future is based on their concern that she will feel obliged to take on care responsibilities, "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."

Bernie (aged 44 and sister to Jackie aged 40 with DS) perceives her mother's proactive planning for Jackie's future as a strategy to reduce the care responsibilities that would be passed on to Bernie and her siblings,

> I *think my mother is 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.*

Interestingly, Emma (aged 33 and sister to James aged 22 with DS), expressed a similar concern about passing on intergenerational care to her son or niece. She explained that she and her sister were committed to looking after James, but was adamant that if James outlived her and her sister, she would not want her son or niece to be responsible for his care, "So, at that

stage it would be, I don't know, residential care maybe. But that's way down the line."

Such concerns about the intergenerational transfer of care spotlight the power of cultural expectations about responsibility for care while also underlining the potential tensions between relatedness and autonomy that may underpin care situations (Albertson Fineman, 2008/9; Tronto, 1993). The strong relational attachments that siblings have to their brothers and sisters with DD were clearly articulated narratives of all but a minority of participants and were reflected in their aspirations to care for them into the future. Amy (aged 41 and sister to Philip aged 31 with ASD) vehemently asserted a relational understanding of care and emphasised the affective dimension of the relationship which many SWD have with their siblings with DD and was highly critical of parental reluctance to allow SWD to assume greater care responsibilities,

*What I'm hearing a lot in these forums [online 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 [sibling with ID], 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.*

Having a legal right to involvement in decisions being made by and/or about their siblings with DD in the future was a concern for some siblings who were anxious to ensure that they, as distinct from a statutory body, would have primary decision making power in relation to the welfare of their sibling. Similar concerns have been expressed in other studies with siblings, highlighting the complexity of the issue of guardianship in the context of adults with DD (Rowland, 2010; David (aged 32 and brother to Laura aged 35 with ID) expressed great annoyance at his parent's reluctance to make a will, identifying he and his brother as legally responsible for Laura,

*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.*

Some participants drew attention to the tension they experienced in trying to find a balance between their desire to be involved in the care of their

brother or sister while also managing other competing desires and responsibilities in their own lives. While no participants reported being directly asked by their parents to care for their sibling in the future, a minority acknowledged that they perceived a sense of parental hope or expectation in relation to assumption of future care. Christine who lived at home until she was 27 so that she could help to provide daily care for Fiona (aged 17 with severe ID and epilepsy) continues to struggle with the sense of duty she feels in relation to providing care. She believes that her married brother who is 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."

Similarly, Marion (aged 32 and sister to Sean aged 29 with ID) believed that, when she told her parents that Sean could not live with her in the future, they "… were shocked." Despite their protestations that they would not expect her to become a fulltime carer for Sean, she felt that "… deep down they hoped." Christine and Marion's accounts draw attention to the powerful and nebulous ways in which the unspoken or that which is not brought into conversation, can nonetheless impact profoundly on siblings' experiences of the dynamics of family care planning.

A final reason that participants identified for parental reluctance to discuss future care is the potential distress which talking about the future, or changes in care arrangements, can cause to adults with DD. Sarah (aged 22 and sister to Lisa aged 24 with ASD), is very anxious to discuss the future with her parents and she finds their refusal to engage with her very upsetting. She acknowledges however that part of their reluctance to talk about it is their awareness of Lisa's fear, "She's [Lisa]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 with DS) who despite being very articulate, refuses to talk about future plans. As such avoidance of care planning may represent another aspect of the moral practice of care in which parents avoid situations that they know will be experienced as challenging or disconcerting by their adult child with DD.

### 3.3 Assuming, ascribing, contesting and sharing care: negotiating care roles with other siblings

The accounts off the participants suggest that SWD do not engage in systematic discussion about future care plans. Participants' expectations about the roles they would play in the future of their brother or sister were frequently based on unspoken assumptions rather than concrete or even tentative plans agreed in consultation with siblings. Most participants believed that they would most likely be the sibling with greatest care responsibilities in the future while a minority flagged the possibility of future care being shared between siblings. In some cases, they described current shared care roles undertaken by siblings which reflected diverse types and levels of care involvement and in a minority of cases the conflict and tension associated with the assumption or ascription of sibling care roles was identified.

The four participants who are the only SWD in their families all expected to be closely involved in future care for their brother or sister but asserted that their parents have not put any pressure on them to assume carer roles. Rather, their narratives suggest a willingness to assume future care responsibilities which is motivated by bonds of affection and concern for the wellbeing of their brother or sister. Líosa (aged 22 and only sibling to Niamh aged 20 who has ASD) perceives her decision to be involved in future care for Niamh 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) described the "very special unique relationship" she has with her 44 year old brother with ASD and noted that 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 Ailish aged 30 with a rare syndrome) was also adamant that her parents have encouraged her to have her own life and emphasised that her motivation to be involved in her sister's future care is based on love.

The narratives of participants in families with more than one SWD, revealed the complexities and tensions which can surround future care planning in these contexts. In some families there appears to be an unspoken expectation between siblings about who will take on the 'most involved sibling role' (Heller and Arnold (2010). Some participants believed that their SWDs perceived them to be the sibling who would take primary responsibility for care in the future. Referring to the future of her brother Peter (aged 29 with DS) Anna (aged 30) notes that she "will get him [James]" 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 she describes her sister who lives abroad as “a kind of shadow in the distant background.” The dynamics of the interplay between siblings ascribing future care responsible to a particular sibling, and that sibling’s acceptance of the responsibility was revealed in some narratives. Mary (aged 34 and sister to Paul aged 38 with ASD) who has three SWDs raised the question of what would happen to their brother in the future. Her older brother responded that the other siblings expected that she would be the future carer, but he offered to assist financially if required.

Most participants who identified themselves as the ‘most involved sibling’ were accepting of the role, however a minority challenged their other siblings to take on some responsibilities. Annie (mid 40s brother James aged 41 with ASD) always assumed that she would be the most involved sibling and expects James to live with her when her mother is no longer able to care for him. 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. Annie told her sister who is a teacher that James can live with her during the year but that she expects her sister to take him to live with her and her family during school holiday time when. Her sister doesn’t feel that this will be possible and hasn’t spoken to Annie since that discussion. Annie believes however that the issue will be resolved and is determined that the

responsibility will be shared. The potential for conflict with his siblings was anticipated by Harry (aged 27 and brother to Tom aged 24 with DS) who believes he is best placed to be the sibling with most responsibility for Tom. He notes that his older sister might not agree with this but asserts that he "would carry that responsibility better than my other siblings, simply put." This belief is based on his perception 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." As such Harry perceives that future care responsibility should be determined by the financial capacity of siblings to pay for care as distinct from level of relational attachment. A minority of participants described equally distributed but differentiated care and support roles that they share with their other SWD. Bernie (aged 44 and sister to Jackie aged 40 with DS) who has three SWD felt that they "would all have an equal responsibility" for Jackie. Similarly, Alan (aged 23 and brother to Gary aged 21 with DS & ASD) described himself as the sibling who would always 'look out' for Gary who is currently awaiting a residential place. However, he believes that like him, his three SWD are open to providing financially for Gary in the future and to having him come and stay with them for visits. Angela (aged 32 and sister to Patrick aged 30 who has mild ID), explained that while Patrick

would be closest to her, her other brother and her sister were involved in supporting him to more or less the same extent as she was, although in different ways. The differentiated types and levels of care work undertaken by siblings was also described by Christine (aged 34) whose sister Fiona (aged 17) who has severe ID and complex medical and care needs, which are currently being met by professional and family care within the home. Christine, 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 notes that her brothers are, "… very, very, very, good. I might do a little bit more, but they're very present as well and they're not typical boys."

Future care planning among siblings would not seem to be a usual or systematic, rather the participant accounts suggest that care plans, in as much as they exist, emerge or evolve, influenced by factors such as the composition of the family, the relational history between the SWD and their sibling with DD and the varying resources and capacities off the individual SWD.

## 4 DISCUSSION AND CONCLUSION

This research provides a range of useful insights into the ways in which SWD experience and understand the dynamics of future care planning for their

siblings with DD. These coalesce around three analytical themes, (1) the emotive nature of care planning, (2) the complex factors that inhibit engagement in planning and (3) the fluid, incremental and emergent nature of care planning and indeed caregiving as it relates to adults with DD.

### 4.1 Acknowledging the emotive nature of future care planning

Similar to previous research, (Gomez de la Cuesta and Cos, 2012; Heller and Arnold, 2010, Benderix and Sivberg, 2007; Ormond and Seltzer, 2007) the findings reported here indicate close relational connections between SWD and their brothers and sisters with DD. They also indicate strong commitment among most participants to be involved in providing care and support to their brother and sister in the future, notwithstanding the concerns which some participants had about how caregiving might be reconciled with other responsibilities and aspirations. As the participants self-selected in response to a call circulated through support groups for families it is to be expected that siblings with an interest in caring were likely to come forward. What is of interest is the finding that while most participants had been considering, and in some cases, worrying about care giving since their early adolescence, most reported that they had not been involved in any significant familial discussion about it. Although this is a small scale qualitative study the extent of reported discussion of future planning would appear to be low in comparison to that

found in other international studies which indicate that between a third (Bowey and McGlaughlin, 2007) and a half (Davys et al., 2016 & 2010) of families have discussed future care. It is however, consistent with recent Irish findings (Noonan et al., 2018; Brennan et al., 2018) which also indicate very low rates of planning.

A key contribution of this research is the light it sheds on the emotionally fraught nature of the family dynamics surrounding the issue of care planning. This emerged clearly in the accounts of many participants with anxiety, exasperation and conflict being evident in descriptions of exchanges between SWD and their parents and between the SWD themselves. Mothers, as primary care organisers and care providers emerge in the participants' accounts as also holding roles as care gatekeepers who frequently seek to avoid or prohibit future care discussions. The tension and distress which this creates within families was poignantly articulated in the narratives of some participants. Conflict between siblings about distribution of care responsibilities was much less frequently articulated and, in most cases, there was little reported sibling contestation in relation to who held the 'most involved sibling' role whether this role was ascribed by the wider sibling group or assumed by the individual sibling themselves.

What also emerges from this research is a question about the extent to which, adult brothers and sisters with DD are consulted about their wishes for the future. There was no question in the interview schedule that directly asked participants if their brother or sister had been consulted about their wishes, however, one would have expected some discussion of this topic when the issue of future planning was being considered. While a small number of participants mentioned what they perceived to be the care preferences of their brother or sister, the narratives suggest that few SWD engage in conscious consultation with their brothers or sisters with DD with regard to what future living or care arrangement the latter might prefer. Rather, it would seem that their wishes are inferred by their parents or their SWD, something which has also been highlighted in other research (Davys et al., 2014; Jecker-Parvex and Breitenbach, 2012; Ward, 2012).

These findings suggest that care planning is complex and emotive and that any support to families will need to recognise this, as well as acknowledging the challenges involved in bringing all parties, parents, SWD and most importantly the family members with DD, into discussions of future care.

## 4.2 The complex factors that inhibit future care planning

The two key factors inhibiting engagement in future care planning which emerge from the participants' accounts are, parental and particularly maternal fears, about a future care landscape that they do not control and about passing intergenerational care responsibilities to their typically developing adult children. The participants' accounts frequently describe how mothers have assumed key caregiving responsibility, constructing care regimes which are comprehensive and protective. Maternal resistance to relinquishing control of care and passing responsibility on to others has been identified in other research (Rowland, 2010) and can be understood in terms of moral dilemmas of care as described by Tronto (1993). Tronto's (1993) ethics of care perspective understands caregiving as based on five key ethical values including attentiveness which is described as awareness of the needs of others and competence which refers to the capacity to provide good care supported by adequate resources. Mothers' concerns about future care provided outside the family, as perceived by the participants in this research, relate to fears about the attentiveness of other carers as reflected in their abilities to discern the needs and desires off the person with DD and their competence or capacity

to respond adequately to these needs. This resonates with Power's (2008) finding that parents of adults with intellectual disabilities in Ireland perceived community-based services to be lacking in terms of both availability and quality with engagement with services being experienced as non-supportive. Degeneffe's (2017) US based work also highlights the influence of the caregiving context on family caregiving expectations. He found that parents and siblings had greater expectations of caregiving involvement in relation to siblings with acquired brain injury as compared to siblings with intellectual disabilities and identified poorer quality community support services for people with acquired brain injury as a factor influencing this difference. The paucity and quality of community care options for adults with DD in Ireland (Hourigan et al., 2017; Inclusion Ireland, 2020 and 2017; Irish Times, 2016) and the challenges of engagement with service providers (Power, 2008) undoubtedly serve as barriers to greater family engagement in future care planning.

The ethical value of responsibility conceived by Tronto (1993) as a value grounded in implicit cultural expectations, is also useful in making sense of both parental dis-inclination to pass care responsibilities on to SWD and indeed parental expectation or hope of same. Some participants felt that their parents were countering cultural care expectations by shielding them from

assuming too much care responsibility while others felt that their parents hoped that they would take on the mantel of care. Conlon et al.'s (2014) exploration of intergenerational care expectations among a cohort of 52 Irish women aged between 18 and 102, also found differences in expectations about receiving and providing care however these were largely related to socioeconomic status. Women from lower socioeconomic groups expected greater interdependency and reciprocity in terms of giving and receiving care within the family. In contrast, women from higher socioeconomic groups were re-scripting traditional family care expectations and both the younger and older generations expected more freedom from care responsibilities through the sourcing of formal, paid, help and support. This would suggest that while cultural expectations about family caregiving are changing, these changes may be unevenly spread across family groups and that awareness of class impacts may need to be factored into future explorations of family decision making about care for people with DD and into professional engagements with families.

The emotional challenge for both parents and SWD, in entrusting care responsibility to others, particularly to non-familial, professional care providers, was evident in the accounts. In this context, guardianship and parental and external acknowledgement of the legitimate role of siblings as

carers and advocates for their brothers and sisters with DD were emotive topics for some participants. The moral dimensions of care, the emotions associated with care decisions and practices (Leane, 2019) and the challenges of negotiating and accepting shared care with those outside the family, need to be acknowledged in any intervention being provided to families. It is vital that professional engagement with families is sensitive to the need to support all members of the family in making sense of the complex feelings, emotions and concerns that surround care planning.

### 4.3 The fluid, incremental and emergent nature of future care planning

The descriptions of care planning provided by participants in this research suggest that it is not experienced as progression through a set of pre-defined or sequential stages. Rather, it is constructed as an ongoing, fluid and emotionally charged process in which the moral practice of care is intricately entwined with its concrete and material delivery. When asked about care planning, participants rarely referred to specific, static or definite blueprints for action. For the most part they described tentative and emergent plans for transitions and devolutions of caregiving. When describing emergent care plans, participants described “laying the groundwork for maybe a plan” (Bernie) and of “building up to it gradually” (Aoife) and spoke of their parents availing of respite, putting their brother or sister’s name on a waiting list for

residential care or facilitating opportunities for them to walk or travel independently to a day service. These actions suggest that future planning is incremental and evolves in iterative layers which reflect a gradual extension of alternative care supports to those previously provided by parents. In the few instances where participants identified concrete, plans for the future, these related to financial supports which parents had put in place. Paying attention to how care plans emerge, is vital for professionals and services that are working to engage families in transition and future care planning. Our findings suggest that many SWD want to be involved in the future care of their brother or sister. However, families need to be sensitively supported to address the challenges involved in transitions of care. Attention to the highly emotive nature of care concerns, to the complex reasons why parents are reluctant to plan and to the tentative pace of planning will help professionals to provide such support.

**LIMITATIONS**

The participants in this research represent 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 the majority of participants (n=15) aged between 31 and 45. Given the recruitment strategy of

contacting participants through organisations who advocate and provide support to people with disabilities and their families, it is likely that those recruited most 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 SWD. This bias in research on siblings where one has a disability has been acknowledged and critiqued in the wider literature (see Meltzer and Kramer, 2016).

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**REFERENCES**

Atkin, K. and Tozer, A. (2015). Personalisation, family relationship and autism: Conceptualising the role of adult siblings. *Journal of Social Work,* 14, 341–351.doi.org/10.1177/1468017313476453.

Atkin, K. and Tozer, A., and Wenham, A.M. (2014). My brother likes meeting new people, but don't ask him any direct questions': involving adults with autism plus learning disability in a qualitative research project. *British Journal of Learning Disabilities*, 4, 292-300. **doi.org/10.1111/bld.12073.**

Barron, S., McConkey, R. and Mulvany, F. (2006). Family Carers of Adult Persons with Intellectual Disabilities on the Island of Ireland. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 87–94. **doi.org/10.1111/j.1741-1130.2006.00059.**

Benderix, Y. and Sivberg, S. (2007). Siblings' experiences of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families. *International Paediatric Nursing*, 22, 410 – 418.

DOI: 10.1016/j.pedn.2007.08.013

Bigby, C. (1997). When Parents Relinquish Care: Informal Support Networks of Older People with Intellectual Disability. *Journal of Applied Research on Intellectual Disabilities,* 10, 333-344. **doi.org/10.1111/j.1468-3148.1997.tb00028.**

Bibby, R. (2012). 'I hope he goes first': exploring determinants of engagement in future planning for adults with learning disability living with ageing parents. What are the issues? A literature review. *British Journal of Learning Disa*bilities, 41, 94-105. **doi.org/10.1111/j.1468-3156.2012.00727.**

Bowey, L. and McGlaughlin, A. (2007). Older carers of people with learning disabilities confront the future: issues and preferences in future planning. *British Journal of Social Work,* 31, 39-5. doi.org/10.1093/bjsw/bcl052.

Braun, V. and Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3, 77-101. doi.org/10.1191/1478088706qp063oa.

Brennan, D., Murphy, R., McCallion, P., Griffiths, M. and McCarron, M (2016). *Understanding Family Strategies that Enable Long Term and Sustainable Home Environments for Older People with an Intellectual Disability*, (Final Report), Dublin, National Disability Authority. http://hdl.handle.net/2262/79120.

Brennan, D., Murphy, R., McCallion, P. and McCarron, M. (2018). "What's going to happen when we're gone?" Family caregiving capacity for older people with an intellectual disability in Ireland. *Journal of Applied Research in Intellectual Disabilities,* 31, 226–235. doi.org/10.1111/jar.12379.

Burke, M. M., Lounds Taylor, J., Urbano, R. and Hodapp, R. M. (2012. Predictors of Future Caregiving by Adult Siblings of Individuals With Intellectual and Developmental Disabilities. *American Journal on Intellectual and Developmental Disabilities*, 117, 33-47. doi.org/10.1352/1944-7558-117.1.33.

Chadwick, D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A. and Harrington, G. (2013). Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities,* 26, 119-132. DOI:10.1111/jar.12003.

Coppus, A.M.W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews,* 18, 6 - 16. DOI:10.1002/ddrr.1123.

Davys, D. and Haigh, C. (2008). 'Older parents of people who have a learning disability: Perceptions of future accommodation needs. *British Journal of Learning Disabilities,* 36, 66-72. **doi.org/10.1111/j.1468-3156.2007.00447.**

Davys, D., Mitchell, D. and Haigh, C. (2010). Future planning, parental expectations and sibling concern for people who have a learning disability. *Journal of Intellectual Disability*, 14, 167-183. DOI:10.1177/1744629510385625.

Davys, D., Mitchell, D and Haigh, C. (2014). Futures planning: Adult sibling perspective. *British Journal of Learning Disabilities*, 43, 219-226. **doi.org/10.1111/bld.12099.**

Davys, D., Mitchell, D. and Haigh, C. (2016). Adult Siblings Consider the Future: Emergent Themes. *Journal of Applied Research in Intellectual Disabilities*, 29, 220-230. DOI:10.1111/jar.12172.

Degeneffe, C.E. (2017). Future planning among parents and siblings of adults with acquired brain injury: a comparative analysis with intellectual disability. *Journal of Rehabilitation,* 83*,* 31-40.

Dellve, L., Cernerud, L. and Lillemor, R.-M. Hallberg. (2000). Harmonizing dilemmas: siblings of children with DAMP and Asperger Syndrome's experiences of coping with their life situations. *Scandinavian Journal of Caring Sciences,* 43, 172-178. DOI: 10.1080/028393100750018797.

Doody, M.A., Hastings, R.P., O'Neill, S. and Grey, I.M. (2010). Sibling relationships in adults who have siblings with or without intellectual disabilities. *Research in Developmental Disabilities***,** 31, 224-231*.* DOI: 10.1016/j.ridd.2009.09.007.

Egan, C. and Dalton, C. T. (2019). An exploration of care-burden experienced by older caregivers of adults with intellectual disabilities in Ireland**.** *British Journal of Learning Disabilities,* 47, 188 – 194. **https://doi.org/10.1111/bld.12273**.

Emerson, E., Glover, G., Turner, S., Greig, R., Hatton, C., Baines, S., Copeland, A., Evison, F., Roberts, H., Robertson, J. and Welch, V. (2012). Improving health

and lives: the learning disabilities public health observatory. *Advances in Mental Health and Intellectual Disabilities*, 6, 26-33. doi.org/10.1108/20441281211198835.

Fujikura, G.T. (2010). Ageing families and the demographics of family financial support of adults with disabilities. *Journal of Disability Policy Studies,* 20, 241-250. doi.org/10.1177/1044207309350560

Gomez de la Cuesta, G. and Cos, M. (2012). *We exist too: Valuing the contributions of siblings.* UK, National Autistic Society.

Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., and Krauss, M.W. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services, 5*, 1214–1219. doi.org/10.1176/ps.50.9.1214.

Guba, E. G., Lincoln, Y. (1989). *Fourth Generation Evaluation.* Newbury Park, CA, Sage.

Heller, T. and Arnold, C.K. (2010). Siblings of adults with developmental disabilities: psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities,* 7, 16-25. **doi.org/10.1111/j.1741-1130.2010.00243.**

Hodapp, R.M. and Urbano, R.C. (2007). Adult siblings of individuals with Down Syndrome versus with Autism: Findings from a large-scale US study. *Journal of Intellectual Disability Research,* 51, 1018-1029. DOI:10.1111/j.1365-2788.2007.00994.

Hogg, J., Lucchino, R., Wang, K., Janicki, M.P., and Working Group (2000). *Healthy Ageing & Social Policy.* Geneva, World Health Organisation.

Hourigan, S., Fanagan, S. and Kell, C. (2017). *HRB Statistics Series 37 Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings.*

Inclusion Ireland. (2018). *Deinstitutionalisation in Ireland: a failure to act.* http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1655/deinstitutionalisation-ireland-failure-act.pdf

Inclusion Ireland. (2020). HSE Service Plan 2020: our analysis. http://www.inclusionireland.ie/content/news-items/1791/hse-service-plan-2020-our-analysis

Jecker-Parvex. M. and Breitenbach, N. (2012). Tracking an elusive population: family carers of older adults with intellectual disabilities in Romandy (Switzerland). *Journal of Policy and Practice in Intellectual Disabilities.* 9, 175-184. **doi.org/10.1111/j.1741-1130.2012.00351.**

Leane, M. (2019). Siblings Caring for Siblings with Intellectual Disabilities: Naming and Negotiating Emotional Tensions. *Social Science and Medicine,* 230, 264 - 270. doi.org/10.1016/j.socscimed.2019.04.022.

Lynch, K. (2009). Affective Equality: Who cares? *Development,* 52, 410–415. doi:10.1057/dev.2009.38

Mansell, J. and Beadle-Brown, J. (2010). Deinstitutionalisation and community living: Position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities**.** *Journal of Intellectual Disability Research,* 54, 104-12. **doi.org/10.1111/j.1365-2788.2009.01239.**

Matson, J.L. and Kozlowski, A.M., (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 418–425. doi.org/10.1016/j.rasd.2010.06.004.

Milligan, C. and Power, A. (2010). The Changing Geography of Care, in Brown, T. McLafferty, S. and Moon, G. (eds) *A Companion to Health and Medical Geography*. UK, Wiley/Blackwell. DOI: 10.1002/9781444314762.ch29

Orsmond, G.I. and Seltzer, M.M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research,* 51, 682-699. DOI:10.1111/j.1365-2788.2007.00954.

Power, A. (2008). 'It's the system working for the system': carers' experiences of learning disability services in Ireland. *Health and Social Care in the Community* 17, 92–98. doi: 10.1111/j.1365-2524.2008.00807.x

Power, A. and Bartlett, R. (2018). Ageing with a learning disability: care and support in the context of austerity. *Social Science & Medicine*, 231, 55-61. doi.org/10.1016/j.socscimed.2018.03.028.

Pryce, L., Tweed, A., Hilton, A. and Priestly, H.M. (2015). Tolerating uncertainty: perceptions of the future for ageing parent carers and their adult children with intellectual disabilities. *Journal of Applied Research in Intellectual Disability,* 30, 84-96. **https://doi.org/10.1111/jar.12221**

Rawson, H. (2010). 'I'll be here long after you've gone': sibling perspectives of the future. *British Journal of Learning Disabilities,* 38, 225-231**.** doi/pdf/10.1111/j.1468-3156.2009.00599.

Riessman, C.K. (1993). *Narrative Analysis.* Thousand Oaks, Sage.

Taggart, L., Truesdale-Kennedy, M., Ryan, A. and McConkey, R. (2012). Examining the support needs of ageing family carers in developing plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities,* 16, 217-234. doi.org/10.1177/1744629512456465.

Taylor-Gooby, P., Leruth, B. and Chung, H. (2017). *After Austerity: Welfare State transformation in Europe after the Great Recession.* Oxford University Press, Oxford.

Tozer, A., Atkin, K. and Wenham, A. (2013). Continuity, commitment and context: adult siblings of people with autism plus learning disability. *Health & Social Care in the Community,* 21, 480-488. DOI: 10.1111/hsc.12034.

Tozer, A. and Atkin, K., (2015). 'Recognized, valued and supported'? The experiences of adult siblings of people with autism plus learning disability. *Journal of Applied Research in Intellectual Disabilities*, 25, 341-351. **https://doi.org/10.1111/jar.12145.**

Tronto, J.C. (1993). *Moral Boundaries: A Political Argument for an Ethic of Care.* New York/London, Routledge.

Ward, C. (2012). Perspectives on ageing with a learning disability. Joseph Rowntree Foundation. Retrieved from https://www.jrf.org.uk/report/perspectives-ageing-learning-disability.