**Tolerating uncertainty: Perceptions of the future for ageing parent-carers and their adult children with intellectual disabilities**

 **Abstract**

*Background:* Improved life expectancy means that more adults with Intellectual disabilities (ID) are now living with ageing parents. This study explored older families’ perceptions of the future.

*Materials and Methods:*  Semi-structured interviews were conducted with nine older parents and three adults with ID and analysed to produce an explanatory thematic framework.

*Findings:* ‘Tolerating uncertainty’ was the major theme in participants’ attempts to manage anxieties about the future, encompassing sub themes of ‘accepting the parenting role’, ‘facing challenges’, ‘being supported/isolated’, ‘positive meaning making’, ‘re-evaluating as time moves on’ and ‘managing future thinking’. Some participants expressed preferences for their future which were in contrast to their parents’ views, and provide a unique perspective that has often been neglected in prior research.

*Conclusions:* This research has found commonalities in how families tolerate the uncertainty of the future, but also unique differences that require tailored interventions and prospective action by services

**Introduction**

Improvements in health and social care over the past 20 years have led to improved longevity for the general population, including people with Intellectual Disabilities (ID) (Emerson *et al*., 2012). Alongside this is the recognition that parent-carers are also ageing. It is estimated that approximately 29,000 people with an ID live with a family member over the age of 70 in the UK (Foundation for People with Learning Disabilities, 2012). Similar trends in the growth of this population are also seen at an international level (Hogg *et al*., 2000). This represents a significant challenge, as service providers must respond to the needs of these older families in order to reduce psychological distress and avoid crisis care situations when the parent-carer becomes no longer able to provide care.

            Research into family caregiving highlights that stress and burden is central to the caregiving experience. Older parents’ experiences of depression, stress and anxiety in their caregiving role can be mediated by the high levels of satisfaction associated with caring for an adult-child with ID (Dillenburger & McKerr, 2010; Hill & Rose, 2009; Rowbotham *et al.,* 2011; Yoong & Koritsas, 2012).  Other factors affecting the psychological well-being of older parents include availability of support networks, cognitive appraisals of their caregiving roles (Hill & Rose, 2009), taking on additional caregiving recipients (Perkins & Hayley, 2010), and the challenging behaviour of the person with ID (Unwin & Deb, 2011).

            Despite having significant anxieties, research consistently demonstrates that most parents do not make explicit plans for the future (Taggart *et al*., 2012). Failure to plan for the future may lead to a crisis situation, when a parent dies and the person with ID is moved to new accommodation (Bowey & McGlaughlin, 2007). Thompson and Wright’s (2001) report highlights how crisis management can compound the trauma of bereavement through inappropriate placement, with long-term consequences on quality of life.

            Research has begun to explore ageing parents’ reluctance to relinquish their caregiving roles (Bibby, 2012; Gilbert *et al*., 2008). Parents may ignore the inevitability of their own mortality in order to protect their children. They may have difficulties in letting go of their loved ones as it could increase loneliness and a reduced sense of purpose in later life. The existence of mutually supportive relationships may mean that neither the parent nor their son/daughter want to relinquish it (Bowey & McGlaughlin, 2007). Thus, future planning can become even more problematic as the older parent may rely on the person with ID for support. This is despite government attempts in recent years to support older families and avoid the emotional impact of crisis care (Department of Health, 2001, 2008, 2009).

            Parents who do make plans usually rely on non-disabled offspring for the future care of their son/daughter but they do not expect them to replicate the hands-on caregiving role that they provide (Heller & Arnold, 2010). Often future plans are not openly discussed within the family.  Siblings may take on this assumed caregiving role unwillingly, potentially leading to family breakdown. Moreover, the person with ID is rarely consulted in future plans (Ward, 2012), militating their involvement in important decisions about their life.

            Most research in this area has focused on the perspective of parents rather than adults with ID. Those few studies that have explored the experiences of adults living with older parents found that they were aware of the likelihood of an end to family care and had significant anxieties about this. They also expressed preferences about future support (Bowey & McGlaughlin, 2005; Jecker-Parvex & Breitenbach, 2012). Ward (2012) argues that services should allow people with an ID to have a meaningful involvement in plans for the future well before the need arises. Further qualitative investigation is warranted to explore the experiences of adults with ID living with their older parents and their perceptions of the future.

*Rationale and aims for current study*

            This study aims to address limitations in previous research by uniquely exploring both the experiences of older parents and adults with ID about being a life-long caregiver/care-recipient and their perceptions of the future. The aim is to develop a thematic account of these experiences, as an aid to guiding professionals in meeting the needs of older families and helping them plan for the future. This may also avoid crisis care and family breakdown. Older carers and adults with ID represent vulnerable groups in society and will otherwise continue to be marginalised if these issues are not addressed.

**Materials and Methods**

*Design and ethical approval*

.While the entire project was initially approached from a constructivist Grounded Theory perspective (Charmaz, 2006), due to its applicability to explore topics where there is little pre-existing knowledge, the approach was adapted for the population under study. While grounded theory principles informed the interview format and content, the analysis and selected findings in this paper are presented thematically in accordance with Braun and Clarke’s (2006) guidelines. The decision to include both caregivers and care-recipients within the design reflects a focus on the phenomenon of interest (perceptions of the future), rather than the characteristics of participants. Hence the group was viewed as homogenous in relation to the phenomenon, allowing analysis of the data as a whole. Ethically, this also represents a desire to treat the views of people with ID as equal to others, affording them the same status in the production of the thematic framework as the caregivers. The study was approved by University and NHS ethical committees.

*Participants and recruitment*

            Participants were recruited from a Community Learning Disability Team within the United Kingdom using purposive sampling. Families who met the eligibility criteria were identified by professionals in the team. Potential participants with ID were screened to determine their cognitive ability to participate in a semi-structured interview using visual aids. This was done using the clinical judgement of clinicians who knew them well.

            Potential participants were sent an invitation letter and information sheet about the study. These documents were also presented in an easy-read format, following Department of Health (2010) guidelines. Participants were asked to return the opt-in slip attached to their invitation letter or contact the gatekeeper directly.

            Recruitment took place from November 2013 to April 2014. 12 participants (nine older parents and three adults with ID) were recruited from six family units. All participants were interviewed separately. Older parents comprised six mothers and three fathers, aged between 65 and 85 years (mean age = 76 years). Adult-children included two males and one female (mean age = 45 years, range = 38-57 years) and all had a mild ID, as described by the clinicians involved in their care.  All older parents were married except one who was widowed. All identified themselves as White British.  The vignettes in Table 2 summarise the older families’ experiences and situate the data in context of their lives.  Pseudonyms are used to protect confidentiality.

*Procedure*

            Prior to the interview taking place, participants were provided with written and verbal information about the study. Participants were made aware that responses were anonymous and that they could withdraw at any time. Each participant completed a consent form and demographic questionnaire.

*Interviews*

            All participants were interviewed in their own homes. Participants from the same families were interviewed separately.

            Semi-structured interview schedules were used for both older parents and adults with ID, exploring experiences of caregiving and perceptions of the future (see Appendix 1). Interview questions were based on relevant literature relating to experiences of caregiving.  The interview schedule was used flexibly and participants were encouraged to talk about topics they felt to be most important in their experiences of being a parent-carer/care-recipient and their perceptions of the future.  Due to the small sample size and ability of the participants with ID, this approach was believed to be the best means by which to focus on the research topic, whilst also allowing exploration of related areas. Interviews lasted approximately one hour for parents and approximately 30 minutes for adults with ID.

*Data analysis*

            Interviews were audio-recorded and later transcribed verbatim. This process allowed the principal researcher to become immersed in the data and absorb content and meaning from the material.

            The first stage of data analysis involved systematic initial coding to identify as many potential codes as possible, using code labels close to and grounded in the data. The next stage was to collate data identified by the same code and then to sort the different codes into potential themes. This more focused coding enabled identification of the broader level of theme and sub-themes, which were given more abstract labels. This process was facilitated with written memos to define each theme’s properties and to identify gaps in the data. Visual diagrams were also produced to aid the analysis. New codes and themes were continually compared with existing data to fully develop the thematic framework.

Keeping a reflexive diary and supervision in which the rigour of the analysis was checked helped the primary researcher to consider different perspectives whilst acknowledging her interpretations were integral to the resulting framework and not separate from it.

 As the sample size was small, the principle of theoretical sufficiency (Dey, 1999; cited in Charmaz, 2006) reflects the research undertaken. It also recognises that the quality of the data provided by participants enabled the development of a thematic framework which could serve as a starting point for future research to be built upon.

**Results**

Findings are illustrated in Table 1:

*Insert table one here:*

The major theme of ‘tolerating uncertainty’ captured participants’ attempts to manage their anxieties about the future. The inter-connected sub-themes of ‘accepting the parenting role’, ‘facing challenges’, ‘being supported/isolated’, ‘positive meaning making’, ‘re-evaluating as time moves on’ and ‘managing future-thinking’ were all related to ‘tolerating uncertainty’ The ways in which parents handled uncertainty across the lifespan determined their ability to manage their caregiving role over time, and their children’s ability to manage their anxieties about a future without their parent(s). The views of individuals with ID are captured within the majority of the themes. However, these are presented more tentatively as fewer people with ID were involved in the study than parents.

*Main theme: Tolerating uncertainty*

            This theme represents how parents and individuals with ID attempted to manage their anxieties about the future from the early years to the present day. Most parents described *“living one day at a time” (Nancy).* This sentiment was echoed by Oliver, an individual with ID: “*I just take each day as it comes”.*

            By focusing on the present, parents were able to manage the uncertainty of the continuing challenges caring for a child with ID presented. Older parents avoided or minimised thinking about their own mortality, ill-health and what might happen when they were no longer able to care for their son/daughter. Similarly, most adult-children also avoided contemplating a life without their parents.

            ‘Tolerating uncertainty’ was typically a passive process characterised by: *“waiting and seeing what happens” (Mary)* and *“taking things in your stride” (Jack).*   Sometimes having a strong faith or religion meant participants did not feel it was necessary to plan for the future. This enhanced their capacity to cope with daily uncertainty. At times, participants had to move from passivity to activity, particularly when a life event (e.g. ill health) brought the uncertainty of the future into sharp focus. This is further discussed in the category ‘managing future thinking’.

*Sub-theme 1: Accepting the parenting role*

This sub-theme describes how parents came to accept their roles as caregivers for their children with ID and how they grieved for the loss of the child they had expected.

 Sometimes caring for a child with ID triggered memories of losses of earlier children: *“It was devastating really…I lost a child very early on and then we were so delighted when we were going to have Anthony and we thought things were going to be alright and unfortunately they weren’t.” (Barbara)*, illustrating a move from a position of relative certainty to one of uncertainty as expectations about the future had to change. Nancy talked about how the experience of losing a child created a fear of losing her son with ID: *“Well the fact that I’d lost one son, I knew that sons could disappear*.” Nancy’s earlier experience of loss had placed her in a position of uncertainty about the future as she contemplated the possibility of losing her second son.

            All of the parents fully accepted and embraced their role as caregivers for their children.  Parents described this as *“a way of life”* and *“like a job”.* All experienced strong feelings of unconditional love towards their children. This helped them to integrate their roles of carer and parent: *“We’ve just got on with it being parents. You just say, well I’m her mother and that’s it!” (Susan).*

*Sub-theme 2: Facing challenges*

            Participants continued to experience pressures and challenges in their roles as care-givers/care-recipients. These challenges centered around three areas: the changing nature of their child’s condition, their child exhibiting challenging behaviours and being restricted in the ways to manage this.

            Oliver discussed how his experiences of anxiety had begun from when he had been bullied about his ID in the past. He talked about the physical relief of *“pulling [my] hair out”* as a way of managing emotional pain. His parents commented on the impact that these behaviours have had on them: *“Over the last month he has been taking all the skin off his fingers, these are things that you don’t like to see, they’re very distressing.” (Eileen).*

            Parents described how their son/daughter’s health problems added additional complexity and uncertainty that had to be tolerated. For example, parents whose son/daughter had epilepsy used words such as *“frightening”, “unpredictable” and “distressing”* when reflecting on their experience.  The complexity of their son/daughter’s difficulties affected parents’ ability to cope and in many cases parents felt restricted in all aspects of their lives:

*“We’ve got two shadows, we’ve got ours and we’ve got Oliver’s… That‘s one of the problems because where we go Oliver has to go because he doesn’t like to stay in the house by himself. We’re not missing out but it would be nice I suppose to do things on our own” (Liam).*

Theresa spoke of adjusting her employment to “*centre around the needs*” of her daughter.  Mary spoke of “*being restricted by time constantly”*.  Nancy felt *“stuck in a routine”* that had governed her life for many years. For these parents, their lives had been consumed by their caregiving role.

*Sub-theme 3: Being Supported/being isolated*

Participants’ experiences of informal and formal support were polarised between ‘being supported’ and ‘being isolated’. How much families were supported determined their ability to cope with challenges. All parents described how support from wider family systems helped them to cope within their caregiving role. Individuals with ID also valued the support they received from family members. Kate’s parents helped her with *“cooking and cleaning”* and Ian valued his parents “*taking him out”* to places he enjoyed visiting. Oliver described the emotional support he received from his family: *“I go to my mum and dad if I’m worried about something and they help me…they look after me wonderful [sic].”*

Individuals with ID expressed how support from services was helpful: *“I have an anxiety problem, so I have carers to take me out and it sometimes helps.” (Oliver).* Many parents also felt that formal support was crucial inallowing them to cope within their caregiving role: *“She goes to day services everyday like. I couldn’t cope if she had to be at home, I’d have a nervous breakdown!  (Susan).*

Some individuals with ID were fearful that the limited formal support that they found valuable might not be available in the future and how this created further uncertainties that needed to be tolerated. Ian spoke passionately about the potential closure of the day services: *“My centre is closing! [shakes head] no, no, not happy!” (Ian).*  Parents also anticipated the loss of services that they found helpful, which led to more uncertainties for the future: *“Having the day centres’ has helped an awful lot. But that looks as though it’s coming to an end unfortunately.” (Theresa).*

Whilst some participants had found services helpful and feared losing them, others felt *“disappointed”* with the professional support offered to them. Some individuals with ID felt let down by the formal care they had received:

*“I have carers but the last few weeks they have let me down something rotten… they go off sick so I have different people.  And I don’t like change so I’d rather have the same people.” (Oliver).*

Some parents felt services were *“inflexible”* to their needs and spoke of how managing challenges alone with limited support had made them feel isolated: *“He doesn’t get much support really and I think this is unfortunate that we have tended to become a bit isolated, the family is it basically.” (Jack). Similarly, Eileen said: “You just have to get on with it by yourself because there’s not really anybody else to help and it’s not fair to put onto others.”*

The differences between supportive and isolating experiences of parents and individuals with ID were noticeable in the interviews. Kate and Ian felt a greater connection with services and had not experienced the isolation described by their parents.

*Sub-theme 4: Positive meaning making*

Finding positive meanings allowed participants to cope with the daily challenges they faced. Individuals with ID described experiences of living with their parents in positive ways: *“My mum and dad take me to the garden centre.  I like it there.” (Ian).*

            Despite the challenges of the caregiving role, parents found satisfaction and fulfilment in caring for their son/daughter:

*“There’s nothing better when I take Oliver down to the sea and he has a smile on his face. That makes us happy.  As long as he is happy, then we are satisfied.” (Liam).*

Some parents described how caring had given them *“a purpose in life”* *(Michael)* and a motivation to look after themselves as they entered into old age:

*“Well for one thing, I know every day I’ve got to cook a meal at night don’t I? And if I lived on my own I wouldn’t bother (laughs) and so we always have a dinner at night which is good for me because it makes me do it” (Barbara).*

Many parents felt a sense of pride when they compared their ability to cope with others. This enabled them to develop a greater sense of control over the challenges they continued to face: *“When I sometimes think back I think how on earth did I cope?!...you know, things other people can’t believe even you deal with.” (Nancy).*

*Sub-theme 5: Re-evaluating as time moves on*

Participants assessed their positions as a carer/care-recipient at different points across the lifespan.  All parents acknowledged they were unable to care forever: *“But there again we’re not young are we? We don’t last forever.” (Jack).*  Many parents discussed how their deteriorating physical health impacted on their ability to sustain the level of caregiving that they were accustomed to:

*“As I’ve got older I’ve had some health issues, my tolerance in support of Oliver is slightly not as good as it used to be because I can’t do physical things as I used to and he can’t seem to understand that.” (Liam).*

Some parents had acquired additional caregiving roles, which added additional strain.  For example, Jack and Mary also cared for their sons when their spouses became unwell. Similarly, individuals with ID had re-evaluated their position as care-recipients and had considered becoming more independent in order to tolerate the uncertainty of the future. For example, Kate felt her plan to move into supported living accommodation was best for herself and her parents: *“I thought about it myself. I want to move out and they want to be on their own.”*

*Sub-theme 6: Managing future-thinking*

This was a complex process involving multiple means of dealing with anxieties about the future. At times, coping involved avoidance, but future-thinking was often brought into sharp focus by life events such as ill-health. Within this concept, participants differed most widely into how they managed future-thinking and tolerated uncertainty.

As parents were faced with ill health, the future felt more uncertain. They all spoke of profound anxiety and fear about what might happen to their son/daughter when they become no longer able to care for them:

*“I do worry that he won’t be happy and that he won’t be looked after but I hope that he will, I hope that there are still people that will do that but you can’t do anything can you?” (Barbara).*

Individuals with ID offered contrasting perspectives about the future. Ian and Oliver felt that an independent future without their parents to care for them was *“bad”* and *“scary”.* However Kate expressed *“feeling excited”* about moving into her own flat.

Minimising or avoiding thinking about the future allowed participants to live in the present and allay their fears, thus helping them to tolerate difficult feelings of uncertainty. Whilst many parents found this a helpful strategy, it prevented some of the adults with ID from exploring the possibility of a different future. Ian found it difficult to consider the prospect of not being cared for by his parents and spoke passionately about *“wanting to stay at home forever.”* His parents described the future being a background worry they hadn’t discussed with him: *“It’s something that is in the background really, I think about it but we don’t talk about it I suppose.”  (Michael).*

Oliver described how talking about the future was difficult: “*If you think about the future it’s scary so I just take each say as it comes…sometimes when people ask me about the future it can push my buttons and make me a bit cross.” (Oliver). His parents echoed this same view: “When we’ve tried to talk to Oliver he gets very defensive, saying ‘do you want me to move out?’ so we just avoid talking about it.” (Eileen).*

Most parents believed that they would continue to care until they were no longer physically able: *“As long as I am alive I will look after him.” (Mary). Barbara said: “I’ve made the decision to carry on caring for as long as I can.  That’s my way.  I mean, he is my son and he is my care isn’t he?” (Barbara).*

*A different perspective*

Susan represented a different perspective in the analysis. She had decided to let go of her caregiving responsibilities after experiencing physical health difficulties. She described how this decision was made easier as her daughter expressed a desire to move into supported living accommodation.  Susan spoke of her attempts to prepare Kate for this transition: *“I’ve tried to teach her such a lot in the last few years to make her more independent.”*   Kate described how she was looking forward to practicing these independent skills: *“When I have my own place I can do more like cooking, and ironing.  Mum does all that now.”*

Susan described the difficulty of ‘letting go’ psychologically: “*I shall worry all the time but I’ve got to learn that Kate has got to start doing things without me.”*  Kate did not share the same concerns, she said: *“[moving home] was an easy decision, I’d thought about it myself.”* Through open conversations about the future, Kate had been able to generate new possibilities and become more independent.

*The perspective of adults with ID*

Adults with ID did not appear to experience the same feeling of hopelessness about their potential future care as their parents did. This is a unique finding. Kate was looking forward to developing a greater sense of independence. Oliver described how seeing friends move out had given him a positive view of supported living: *“[Friend] lives in a flat. The carers seem nice.”*  Previous conversations about the future helped individuals to generate new possibilities and ideas. Ian found it difficult to feel hopeful about a future without his parents in it. How parents tolerated their own anxieties influenced their children’s ability to envisage a different future. Adopting a position of *“living one day at a time” (Nancy)* allowed the majority of parents to maintain balance and protect their children from experiencing uncertainty.

**Discussion**

This study presents a thematic framework exploring the processes involved in being a caregiver and a care-recipient, and perceptions of the future. Analysing the full data set as a homogenous group (i.e. members of a family) enabled the researchers to afford equity of value to the experiences described, as well as to examine the nuance between parents and children and between individuals. ‘Tolerating uncertainty’ was the major theme, encompassing six sub-themes:  ‘accepting the parenting role’, ‘facing challenges’, ‘being supported/isolated’, ‘positive meaning making’, ‘re-evaluating as time moves on’ and ‘managing future thinking.  How much participants reported being supported and gave positive meanings to their role as a care-giver/care-recipient determined their ability to cope with day-to-day challenges and the uncertainty of the future.

Most parents were not seeking alternative future care arrangements whilst they could still manage to care.  However, in some cases, this position was one of passive acceptance rather than active choice. Many felt hopeless when they considered what the care services might offer their children and looked towards the future with profound anxieties and fears. ‘Living one day at a time’ allowed parents to minimise or avoid thinking about the future, thus protecting their son/daughter from uncertainty. However as parents were ageing and facing ill-health this became a much more difficult task.

Avoiding talking about the future prevented adults with ID from developing ideas about a different future. Despite this, some individuals positively expressed desires and preferences and did not experience the same feelings of hopelessness as their parents did about future care. This provides a new perspective, not previously highlighted in the literature.

The main theme of ‘tolerating uncertainty’ encompassed all of the sub-themes. Mason’s (1993) concept of ‘certainty’ which assumes that nothing is fixed and everything is in a state of flow, might explain how parents coped with the changing demands of the caregiving role. However as parents’ age and face ill-health the uncertainty of the future may become intolerable. Many felt their options were now limited, leading them into a position of ‘unsafe uncertainty’, described as ‘the sense of being overwhelmed by the complexity and enormity of the problems and not knowing where to go or what to do.’ (Dallos & Draper, 2010, p.176). In contrast, participants who had made active future plans were able to adopt a position of ‘safe uncertainty’.

The sub-theme of ‘accepting’ captured how parents managed the discovery that their child had an ID before fully accepting their role as a caregiver. These findings reinforce findings of a previous study where the parent carers reported making a decision to take on the responsibility of caring for a child with a learning disability described under the theme ‘taking it on’ (Cairns et al, 2012). Systemic literature recognises an association between loss and protection. Families who strive to protect the person with ID from the perceived consequences of their disability may restrict the individual as they mature into adulthood (Goldberg *et al*., 1995; Pote *et al*., 2011). In the current study, parents engaged in strategies to protect their child from the perceived dangers of unfamiliar care; for example, many rejected opportunities of respite care for fear that carers would not be as responsive to their child’s needs.

The parents in this study faced many challenges, leading them to feel restricted in their personal, social and working lives. This finding resonates with previous research suggesting that parents may experience depression as a consequence of their caregiving role. Chou et al (2010) found that the main factors associated with carer self-reported depressive symptoms were carer physical health, social support and caregiver burden. Parents and adults with ID found support was invaluable in helping them to overcome the challenges they faced. However, some expressed frustration that the support was inadequate and made them feel isolated, identifying with findings from previous literature in which parent-carers reported having a lack of confidence in present and future provision and felt that their own standards of care could not be met by anyone else (Bibby, 2012). In contrast, adults with ID did not report these concerns to the same extent as their parents did and instead reflected more positive experiences of services. The meaning of support for parents and individuals with ID may be very different.  An activity experienced as meaningful by the person with ID may not offer support or a break to the parent and vice versa.

Todd & Shearn’s (1996) concept of the ‘perpetual parent’ may explain the parents’ feelings of isolation. ‘Perpetual parents’ limit social contact and doubt other’s capacity to care for their children. Most parents in this study could be viewed as ‘perpetual parents’ since they described having limited social contact with people outside of the ID context and few opportunities for time alone or quality time with their spouse. Many felt their individual identity had been overshadowed by their identity as a carer.

Complementing the ‘perpetual parent’ is the notion of the ‘eternal child’ (Todd & Shearn, 1996), referring to how parents may view their adult-child as remaining in infancy or adolescence stages. While it was clear that parents had their son/daughters’ best interests at heart, most cast them in the role of an ‘eternal child’.  For example, in parent interviews, the ‘voice’ of their adult with ID was often missing. There was little recognition that their son/daughter may have desires or wishes about the future, or indeed that these might be different to their own desires. Two individuals with ID in the study did in fact express aspirations for the future and a desire for independence, connecting with findings from a previous study which found that participants had clear preferences about their future options. However, these participants also showed extensive concern for their family carers and this often impacted on their willingness to plan for the future or move to alternative housing (Bowey & McGlaughlin, 2005). For one individual with ID, discussing the future was an unfamiliar concept. Avoidance of this topic by parents held implications for their adult-children who are not given the opportunity to develop new ideas and possibilities. Allen (2011) notes that the wider system (family and services) can ‘unwittingly stifle movement towards independence if it remains unaware of the shifting needs of adults’ (p. 30) as they mature into adulthood.

The category ‘positive meaning making’ captured how participants’ appraisals of their ability to overcome challenges and adversity affected their ability to cope.  Parents gained tremendous satisfaction and pride from their caregiving role, which enabled them to continue in their caregiving role and cope with the uncertainty of the future. Deriving satisfaction from the caregiving role is a consistent finding in the literature. For example Yoong and Koritsas (2012) found that caring had a positive impact on quality of life by enabling participants to develop relationships and receive support, participate in leisure activities, achieve a sense of personal satisfaction and enable a more positive appraisal of their lives.

Most parents and adults with ID in this study expressed anxieties about the future in the concept ‘managing future thinking.’ Parents grappled with the dilemma of relying on formal services for future support for their son/daughter whilst at the same time having little faith in the services offered. They expressed hopelessness about the future and anticipated loss of services owing to the financial cuts to services.  Existing literature supports the finding that distrust and dissatisfaction in services is an obstacle to future planning (Cairns *et al*., 2012).

In contrast to previous research, which suggests that many parents have desires for their non-disabled offspring to take over the future care of their son/daughter with ID (Heller & Arnold, 2005), this study did not find this.   Most parents felt that passing over this role would be unfair.

Previous studies have frequently demonstrated how barriers to future planning have centered on parents’ fears of letting go and anxieties around the care not being good enough. For example, Taggart *et al* (2012) found that the majority of carers did not want their relative to move into an older people’s residential/nursing facility. A minority preferred their relative to move into the home of a sibling, although some favoured the person move to a residential facility with other people with ID. Avoidance, lack of guidance and a lack of appropriate residential provision were cited as obstacles to making future plans compounded by the emotional upset experienced by carers in thinking about the future. A striking finding in the current study was that despite these barriers, some parents were willing to explore alternative options for the future if their son/daughter initiates this request. Kate and Susan represented an example of where this had happened. The onus on the individual to initiate decisions about their future potentially creates difficulties in family systems which utilise a strategy of avoiding thinking about the future, perhaps stifling the person with ID to be able to generate ideas about a different future.

*Strengths and limitations*

This study includes the voices of both mothers and fathers. The experience of fathers is often neglected in caregiving research. However, the small sample size makes it difficult to meaningfully explore gender differences between mothers and fathers, and make comparisons between the perspectives of parents and adult-children. The study also offers the unique perspective of individuals with ID. While the sample size was small, the researchers believe the findings have theoretical sufficiency in order to be transferable to other similar groups of older caregivers and care-recipients with ID.

Meeting with individuals with ID on only one occasion may have been a hindrance to gaining rich interview data. Building rapport with participants is good practice when working with seldom-heard groups (BILD, n.d). Whilst attempts to meet communication needs were made, meeting the individual beforehand may have allowed the researcher to become more familiar with the person’s preferred methods of communication and make adaptations accordingly. Regardless of these methodological constraints, the three individuals with ID that did participate provided three unique experiences and perceptions of the future.

*Limitations and directions for future research*

All of the participants were white British. It is possible that families who have been exposed to different cultural norms, the transition to becoming an older parent/adult with ID may be very different. Furthermore, all participants had involvement with formal services. The voice of families not known to services is therefore missing. Their experiences may represent the use of different coping strategies.

A further limitation is through the use of purposive sampling. Families who chose to participate may have extreme positive/negative views, making the findings difficult to generalise to other older families. Recruiting people via their family inevitably meant that parents decided whether their adult-child participated. This was coupled with a professional’s judgment about the cognitive ability of a person with ID to participate. Although consent from adults with ID themselves was gained, they may have been open to suggestibility from parents and professionals. Approaching adults with ID directly, perhaps thorough an advocacy service, may have empowered individuals to make informed decisions about whether or not to take part.

Future research could include participants from a wider range of backgrounds in order to determine the influence that such factors have on the experience of an older parent. For example, examining potential differences between; (i) younger and older parent subgroups (e.g. 60-year-old parents and 80-year-olds); (ii) older parents from minority ethnic groups and (iii) older parents with an adult-child with specific ID/additional diagnoses (i.e. Down syndrome or autism). Further qualitative investigation into the views of both older parents and their son/daughters with ID who have successfully made the transition to leave the family home would be helpful in informing practice on how to best support families considering this transition in the future.

Ethnographic methods could be considered as a possible alternative to interviews. Longitudinal research is needed to represent variations in experiences of families with ID over time.

*Clinical implications*

Professionals need to be mindful of the needs of older families and therefore training is key. Some families in this study did not feel that they had been listened to and felt that they had no choice but to cope on their own. Empathic listening of professionals in understanding the needs of older families, involving all members would allow their voices to be heard.  It is crucial that interventions are tailored to meeting the needs of these older families in order to reduce psychological distress, enhancing their well-being and quality of life.  It is important that professionals pro-actively review future planning across stages of the life cycle. This will help ease anxieties about the future and avoid crisis care situations.

The findings also revealed that older families lack support, information and practical resources, despite policy improvements over the years to better support their needs. More importantly, many families had lost trust in services. The implications of these findings are that a holistic approach to service delivery is needed, working within and external to the family in enabling people to consider different future possibilities. Health and social care professionals should (re)build levels of trust by listening to families concerns and signposting to sources of advice. Tailored psychosocial interventions may be beneficial in enabling older parents to continue within their caregiving role. Systemic therapy may be useful in helping families with the transition to becoming older parents/adult with ID and moving towards positions of safe uncertainty, where options about the future can be explored and discussed openly. The need for such tailored interventions is supported by recent UK government policies which highlight the difficulties faced for ageing families of people with intellectual disabilities. For example, The White Paper ‘Caring for our Future: reforming care and support’ (2012) set out a long term vision to promote wellbeing and independence at all stages to reduce the risk of reaching a crisis point, and so improve the lives of individuals with ID and their families.

**Conclusions**

The thematic framework produced showed how families with ID tolerated uncertainty about the future. How families were supported and gave meaning to their role as a caregiver affected their ability to cope with the challenges they were faced with and would continue to face as they aged. Many families expressed profound anxieties and fears about the future.  Uniquely, adults with ID were able to express desires for a different future in the context where the topic was discussed openly within the family system. More research is needed that directly engages adults with ID. It is important that services support such families in planning for the future so that crisis care responses to changing life events are avoided and individuals with ID are able to process loss in a healthy and effective way.

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Tables:

*Table 2: Participant vignettes*

|  |  |
| --- | --- |
| Family 1 | Jack and Nancy are in their eighties and live with their son, Mark who is 57. Mark has additional physical health problems including epilepsy. Mark attends a day centre and requires support from his parents with regards to personal care and daily living tasks.  Nancy has begun to experience memory difficulties, meaning that Jack assumed responsibility for the majority of the caregiving tasks. Mark was unable to be interviewed in his study due to his level of ID. |
| Family 2 | Susan is in her late sixties. She lives with her husband, Robert, and her daughter, Kate who is 44. Robert is Kate’s step-father. Susan has recently experienced some physical health difficulties, impacting on her caregiving role.  Kate has an additional diagnosis of autism.  She has recently expressed an interest in moving out of the family home. Kate and Susan have been exploring supported living environments for Kate.  |
| Family 3 | Mary and Michael are in their late 70’s/early 80’s.  They live with their son, Ian who is 53.  Michael has recently been undergoing treatment for bowel cancer.  Mary cares for both Michael and Ian at home, despite her own health problems.  Ian has an additional diagnosis of autism. Ian’s parents provide help with daily living, financial and emotional support.  Ian’s views are included in this study. |
| Family 4 | Barbara is in her mid-eighties and lives with her son, Anthony, who is 54.  Barbara’s husband died seven years ago. Until recently, Barbara provided full time care for Anthony but he now receives support from paid carers in the community three days per week.  This was due to deterioration in Barbara’s physical health.   Anthony was not interviewed for this study due to his level of ID. |
| Family 5 | Theresa is in her seventies and lives with her husband, Brian and daughter, Jessica, who is 52.  Brian is Jessica’s step-father.  Jessica suffered a stroke at the age of six resulting in severe physical and intellectual disabilities. Jessica requires a high level care from her parents and support from paid carers.  Jessica was not interviewed for this study due to her level of ID. |
| Family 6 | Eileen and Liam are in their mid-sixties.  They live with their son, Oliver.  Oliver has a rare genetic syndrome which contributes to his experiences of depression and anxiety. Eileen and Liam support Oliver emotionally and provide help with daily living tasks.  Oliver also receives support from paid carers in the community.   Oliver’s views are included in this study.  |

**APPENDIX 1:**

**Interview Schedule**

For parent-carers

1. **Can you tell me about your experiences of caring over the years?** *(prompts: how have you found being a carer over the years? When son/daughter was first born, what was it like?… as they were growing up?…now?)*
2. **What has been the advantages of caring?** *(prompts: what has been enjoyable, what aspects of caring for your son/daughter do you like? Have there been any positive impacts of caring on other aspects of your life?)*
3. **What has been the disadvantages about caring?** *(prompts: what has been difficult about caring? What aspects don’t you like? Have there been any negative impacts of caring on other aspects of your life?)*
4. **What care/support do you provide…each day?** *(prompts: what kind of support – e.g. personal care/daily living/ transport/ emotional /physical/ financial/social etc.)*
5. **Does your son/daughter provide help/support for you? If so, what?** *(prompts: physical support ie.help with domestic chores etc, emotional support? Social support?)*
6. **Does your son/daughter have any form of support from social services or other providers?** *(prompts: e.g. Day care/respite/support worker/direct payments/short term breaks?)*
7. **What support do you/son/daughter have from others?** *(prompts: e.g. Family, neighbours and friends?)*
8. **What hopes do you have regarding the future of your son/daughter?**
9. **What fears do you have regarding the future of your son/daughter?**
10. **What do you think would happen to your son/daughter if you were no longer able to care for him/her at home?**
11. **Are you aware of what options could be available to you in these circumstances?**
12. **If you had the freedom to choose, what sort of accommodation and support would you want for your son/daughter if you were no longer able to provide care at home?**
13. **How could services support you more in planning for the future?**

**Interview schedule**

For adults with learning disabilities:

(Visual aids using photo symbols will be used during the interview)

1. **Can you tell me about your experience of living with mum and dad?**
2. **What things about living with your parents do you enjoy/like?**
3. **Are there any things that you don’t like about living with your parents?**
4. **Can you tell me what support your parents give to you on a daily basis?** *(prompts: eg. with money, shopping, getting around, keeping safe, looking after yourself, cooking meals, taking to appointments, washing, dressing, with worries….)*
5. **What help or support do you give your mom/dad?**
6. **Can you tell me about support that you receive from others?** *(prompts: support workers? Relatives/friends etc? what kind of support?)*
7. **What hopes do you have about the future?**
8. **What fears do you have about the future?**
9. **Have you ever thought about living somewhere else in the future?**
10. **If you could no longer live with mum and dad, what do you think will happen?**
11. **Have you ever thought about living somewhere else in the future?** *(prompts: has anyone ever talked to you about the future?)*
12. **If you could choose where you would like to live in the future, what would this look like?** *(prompts: e.g own place, with others, with friends, with other family....)*
13. **How could services help you to plan better for the future?**