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Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability

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ABSTRACT
The number of older parents ageing in tandem with their adult children with intellectual disability (ID) is increasing. This unique situation calls for greater research that investigates how older parents experience this extended care-giving role, including the extent to which they are engaging in futures planning. Participants were recruited via disability service providers in South Australia. Using the theoretical perspective of hermeneutic phenomenology to understand lived experiences, semi-structured in-depth interviews were carried out with older parents (N = 17, mean age 70 years). Six offspring were living in the family home while the remainder were in supported accommodation. Main themes to emerge from the data were: (a) perpetual parenting, (b) costs and rewards and (c) planning to plan. Parents were providing care across a range of areas, regardless of whether their offspring lived at home or in supported accommodation. While aware of the need to plan for the future, most did not have a firm plan in place. Parents are providing a high level of support to their adult children with ID regardless of whether they live in supported accommodation or the family home. While some have started to think about future care arrangements, most appear unclear over what the future holds.

KEY WORDS – care-givers, everyday support, families, intellectual disability, qualitative.

Introduction

The majority of research on care-giving in late life has focused on the care provided by an older adult to their spouse or care provided by adult children to their ageing parents (Abramson 2015). In Australia, while the majority of older carers provide care to their partner or spouse, around 9 per cent are caring for an adult child with disability (Australian Bureau of Statistics 2012). The prevalence of intellectual disability (ID) is estimated

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to be 1.3 per cent of all live births (Petterson *et al.* 2007), with Down syndrome the most common cause. Due to improvements in medical technology and social conditions, life expectancy for people with ID has increased dramatically in the last 30 years, with many now living to middle and old age (Hole, Stainton and Wilson 2013; Thompson, Ryrie and Wright 2004; Torr *et al.* 2010). The increased longevity of people with ID now means that carers – typically parents – are ageing in tandem with their adult offspring with ID (Ryan *et al.* 2014).

While the demands of caring for young children with disability are well documented, comparatively little is known about the care-giving dynamics for older parents who care for adult offspring with life-long disability such as ID (Abramson 2015). These older parents have recently been labelled the 'Panini Sandwich generation' (Abramson 2015); an expansion of the well-documented 'sandwich generation' analogy (Miller 1981) relating to middle-aged care-givers 'sandwiched' between caring for children and ageing parents. The term 'Panini Sandwich generation' refers to those who may, in addition to dealing with their own ageing, be caring for spouses, grandchildren and/or adult children with disability (Abramson 2015).

One area which has received growing attention is the conundrum parents face over who will provide care for their son or daughter once they need to relinquish care (Pryce *et al.* 2015). A number of studies have highlighted older parents' trepidation or inability to engage in so-called 'futures planning' around such things as living arrangements, guardianship, financial planning, future vocational and recreational desires, and general lifestyle choices (Heller and Caldwell 2006). A range of factors have been found to underpin such apprehension, including scepticism about alternative accommodation services and a general lack of information about how/when to plan (Bibby 2012). Currently, in countries such as the United States of America, Canada, Australia and the United Kingdom, programmes which aim to support ageing carers to make future plans for their adult offspring with ID exist only on an *ad hoc* basis (*e.g.* ASLaRC 2011). In Australia, there is a lack of co-ordinated efforts between federal and state governments to provide information, support or services to enable ageing carers to plan for the future, which leaves them without firm pathways or guidance for the future care of their offspring. It is important to note that much of the research on family care-giving for adults with ID to date has been conducted with those providing care in the family home (Walker and Hutchinson 2017), with the realities of those parents whose offspring live in out-of-home care less well-documented (Baumbusch *et al.* 2017).

Despite the issue of futures planning being well-documented as a key burden associated with caring for an adult child with disability in late life, an emergent body of research is seeking to expose the positive as well as negative dynamics associated with this care-giving relationship. While early theories on family care-giving in late life (Aneshensel *et al.* 1995; Braithwaite 1992) and care-giving for dependants with ID in particular (Raina *et al.* 2004; Singer 2006) have tended to focus on the stress associated with this role, Grant (2007) and others (*e.g.* Soottipong Gray *et al.* 2016) have recognised the need to acknowledge the 'flipside' of family care-giving roles and, in particular, called for a re-conceptualisation of the role which equally focuses on 'strengths and resources' rather than burden *per se* (Grant 2007; Nolan, Grant and Keady 1996). Grant (2007) calls the less-visible and 'taken-for-granted' care that family care-givers provide adults with ID 'invisible care', in that it tends to be undervalued by services and the community in general in comparison to the financially remunerated care provided by paid support workers. This might include providing advice around intimate relationships, finances and ensuring their adult child has on-going contact with other family members. He argues that far from being a burden on parents, this role may be rewarding both at an intrapersonal *and* interpersonal level, but argues that more research is needed to elucidate these dynamics further (Grant 2007).

The current study therefore aims to address these gaps in the literature by exploring the care-giving dynamics and perceptions of futures planning among ageing carers of adult offspring with ID living in the family home *and* in supported accommodation. This study examines the current care-giving concerns and experiences of these parents within the context of care-giving burden (Aneshensel *et al.* 1995) but also draws on Grant's (2007) re-conceptualisation of care-giving to explore the benefits and strengths that might be derived from this role for the older person. Therefore, the study aimed to:

1. Explore older parent's day-to-day experiences of caring for adult offspring with ID – both those whose adult offspring live in the family home and in supported accommodation.
2. Determine future plans for care and accommodation that older parents are considering for their adult offspring with ID.

Methods

Recruitment

Eligibility criteria included being a parent (aged 55+) of an adult child with ID who lives either in the family home or supported accommodation (defined as community-based accommodation for people with a disability). A range of disability service providers and associations supporting people with ID and their families in South Australia were approached to assist with recruitment. Of these, four organisations agreed to support recruitment. In addition, colleagues and contacts in the disability sector were also sent a recruitment flyer to forward to potential participants known to them. Twenty-one potential participants agreed to participate. Of these, five were siblings rather than parents, and therefore ineligible for the study, and one person left contact numbers but could not subsequently be contacted following three attempts. The participants recruited came from seven different recruitment sources (two service providers, one association and four professional contacts).

Participants

There were 17 participants in the research: two couples, ten mothers and three fathers. As can be seen in Table 1, three of these were foster parents (one couple, one mother). Parents ranged in age from 55 to 86 years (mean = 70 years); the majority (N = 9) were married, four were divorced and two widowed. Six of the participants had their offspring living in the family home, while nine had moved to supported accommodation between 11 and 30 years prior to the study. Three participants were born outside Australia, though only one came from a non-English-speaking background. The majority of parents (N = 10) were retired. The ages of the adult offspring with ID ranged from 22 to 53 years (mean = 40 years). Nine of the 15 adult offspring with ID were male (Table 1).

Approach

The research was qualitative and adopted an interpretative or hermeneutic phenomenological approach (Cohen and Omery 1994). In this approach, researchers seek to make sense of and look for hidden meanings embedded in narratives of the experiencing person(s), focusing 'on what humans experience rather than what they consciously know' (Lopez and Willis 2004: 728). This interpretative approach is appropriate where researchers are making use of an orienting framework to sensitise them to the data (Lopez and Willis 2004), as was the case in the present study in relation to theories of care-giving. Interviews were semi-structured with a schedule to guide discussion. This schedule was developed following a review of the literature on futures planning for adults with ID. The flexibility of the semi-structured format allowed interviews to unfold in a unique way to capture individual experiences. This format also ensured that interesting avenues of information that presented themselves during the course of the interview could be explored in detail (Rapley 2004).

TABLE 1. *Sample demographics*

Participant/carer	Age and marital status of carer	Gender and age of person with ID	Diagnosis	Living situation	Years out of home	Supported employment/day options
1. Barry	69 years, divorced	Male, 32 years	Down syndrome	Community	11	Supported employment
2. Meredith	66 years, widowed	Male, 38 years	ASD	At home	–	Supported employment
3. Ben	71 years, married	Male, 43 years	ID	Community	21	Supported employment
4. Jan and Phil[1]	67 years, 69 years, married	Male, 34 years	Williams syndrome	Community	10	Supported employment
5. Veronica	85 years, widowed	Male, 49 years	ASD	Community	20	Supported employment
6. Colette	69 years, divorced	Male, 40 years	Lujan-Fryns syndrome	Community	19	Supported employment
7. Susanna	64 years, married	Female, 40 years	Sotos syndrome	Community	16	Neither
8. Mary	74 years, divorced	Male, 50 years	ID	Community	30	Supported employment
9. Lillian	76 years, married	Female, 53 years	Tuberous sclerosis	Community	10	Supported employment
10. Kath and Bob	68 years, 73 years, married	Female, 41 years	ID	Community	20	Supported employment
11. Marion	69 years, married	Male, 40 years	Fragile X	At home	–	Supported employment
12. Jack	86 years, married	Female, 53 years	ID	At home	–	Neither
13. Alice[1]	68 years, married	Male, 42 years	ASD and FAS	At home	–	Day options
14. Tina	55 years, married	Female, 22 years	Pitt-Hopkins syndrome	At home	–	Day options
15. Lucy	64 years, divorced	Female, 22 years	Down syndrome	At home	–	Day options

Notes: All names are pseudonyms. 1. Foster parent(s). ID: intellectual disability. ASD: Autism Spectrum Disorder. FAS: Fetal Alcohol Syndrome.

Procedure

Potential participants were contacted and provided with an overview of the study aims and details of what participation involved. All participants who could be contacted, and were eligible for the study, provided their formal written consent to participate. Thirteen of the interviews took place in participants' homes. Of the remaining two interviews, one took place in a meeting room at a service providers' worksite and the other was conducted via Skype. The semi-structured interviews lasted on average one hour and, with the exception of one interview, all were conducted by the same researcher (CH). All interviews were audio recorded with participants' consent and transcribed verbatim using a professional transcription service.

Analysis

Grant's (2007) theory of 'invisible contributions' informed the analysis of data. In particular, data were analysed to identify the tangible but also less-tangible forms of care that older parents may be providing to their adult children. Interview transcripts were analysed concurrently using constant comparison in line with grounded theory techniques (Ezzy 2002; Strauss and Corbin 1998). Data analysis commenced with line-by-line coding of all interviews or 'open coding', which allowed for examination of data to identify similarities and differences in experiences. After devising a list of initial codes and collating them with data extracts, potential higher-level themes and sub-themes were then developed using the next level of analysis – 'axial coding'. The final level of analysis – 'selective coding' – involved abstraction of these themes into the three core themes described in the next section. To ensure rigour, both researchers independently analysed transcripts to identify, discuss and reach agreement on themes. This acted as a cross-checking of coding strategies and any disagreements or differing insights assisted in refining the final coding framework.

Results

Perpetual parenting

All of the parents were highly involved in supporting their son or daughter in wide-ranging ways. Somewhat surprising, however, was the degree of support being provided for those living out of home, despite the majority of offspring having lived in supported accommodation for over a decade. This included shopping and managing food intake, advocacy, personal care, supporting ties with friends and family, maintaining finances, and arranging and attending medical and dental appointments. One set of parents had decided to arrange, pay for and deliver frozen meals to their son, largely because they could not justify him paying for a meal service that he did not need:

> He used to go to the dining room but in fact he was hardly ever there for meals because he was out and about. He was doing bowling and that sort of thing … and then he'd eat McDonald's, which is what kids of that age group do, but I'm thinking 'oh you've just paid a fortune for a meal you haven't eaten' and so in the end we got him [the frozen meals]. (Jan, 67 years)

The same couple reported that they also take responsibility for their son's doctors' visits; something they saw as 'easier' for them to do rather than abdicate responsibility to the accommodation provider who they felt was short-staffed and under-resourced.

> Mother: We take him to the doctor all the time and all that sort of thing.
> Father: A lot of that too is just to free up [provider] because if they have to take him to the doctor that's one of their staff that's out of action for a couple of hours or whatever.
> Mother: Yes, but we're quite happy to do that. (Jan and Phil, 67 and 69 years)

As can be seen below, this notion of needing to be a 'perpetual parent' was closely associated with general perceptions of inadequate service provision. For example, one father, who also happened to have a terminal illness, described how he felt it was his responsibility to provide hair-cuts and general maintenance of his son's facial hair when he came home to visit. He pointed out that the service provider did not tend to prioritise this level of personal care and nor did his son:

> Normally I just give him a number one over the top for a hair-cut so I don't have to worry about him. At the moment I think he's about into a four- or five-week growth and he's into about a three-week growth around here. It ain't pretty. He's a ginger nut so if you've got ten red hairs coming on one side and five red hairs on the other side and six across the top of your lip, it's better if you have the shave and smarten up but he doesn't do it. (Barry, 69 years)

Similarly, one of the oldest participants, an 85-year-old mother of a son aged 49 living in supported accommodation, described the range of activities she had primary responsibility for in relation to her son:

> Well, I'm responsible for his money. I have power of attorney over his affairs and have had for years. I'm responsible for arranging holidays. I'm responsible for paying for things like Holiday Explorers, getting him there to meetings and back again, and that's getting to be a problem because I don't drive anymore. I'm also responsible for shopping to a large degree because … [when he comes home at the weekend] – he goes back with a bag of fruit every week, something like 15 pieces to 16 pieces of fruit. It's better for him to have fruit, which he's

> used to, than it is for him to have a high amount of carbohydrates. (Veronica, 85 years)

When asked why she felt she needed to take on this range of responsibilities, Veronica mentioned that one reason was to alleviate some of the responsibility for the accommodation provider. She also suggested that the provider 'wouldn't do this sort of thing because money was tight'; in essence, suggesting that her son would have more opportunities for social engagement and a healthier diet and so forth if she took it upon herself to arrange these things rather than rely on service providers who are constrained by their modest budgets.

Needing to advocate for their adult offspring was an experience described by several participants. Susanna, a parent of an adult daughter with ID who lived in supported accommodation, spoke of how she was unhappy with the amount of oversight the accommodation provider was having over the well-being of residents who lived semi-independently in shared group homes. She felt that the staff-to-resident ratio was too low and consequently some residents, including her daughter, lived in at times unhygienic environments or did not keep up with their own personal hygiene:

> I've raised the issue and had a number of meetings, and I need to have another one with them, about the state of the house and M's bedroom. The three girls are lazy and if they can get away with it they don't do their housework. On occasions I've gone into the bathroom when I've been dropping M off or picking her up. Sometimes I go in, and the toilet's filthy, the hand basin's dirty, the shower hasn't been cleaned and the kitchen floor's sticky, just they've dropped cordial or something and nobody's – just they need to be doing a weekly clean. M, with her anxiety and depression, had dropped the ball basically, wasn't showering, wasn't cleaning her teeth. (Susanna, 64 years)

Costs and rewards

When focusing on both the negatives and positives of the care-giving role for older parents, it became apparent that there were a number of what might be deemed 'costs' associated with the role. One parent of an adult daughter with ID who lived in the family home described how the demands of her care-giving role had at times resulted in her neglecting other family members:

> I seen a picture of a tree on Facebook, you know, Christmas tree and I said 'oh that's beautiful' and [my daughter] had said to me 'yeah, that's our Christmas tree'. I'd never seen it. Make me cry now; I'd never seen it. Yeah that makes me cry. I don't get to go visit them. It's never just that 'let's go and have a coffee' and when we are free to do that it's sort of not comfortable because you always think '[damn], I've got to go. I've got to go and get B'. We're on a time-frame so if anything brings a tear, yeah, it's that. (Tina, 55 years)

A further potential 'cost' for parents was the sense of co-dependency or over-reliance on their adult son or daughter with ID, such as that expressed by Meredith whose son lived at home with her. Meredith became very emotional during her interview and described how she could not see a future for herself without her son:

> Well, I've often said if anything does happen to him – because we've had a couple of near misses actually – 'don't bury him in a hurry because I'm going with him'. I said 'if I die first you keep my ashes and when he goes you put us together'. It's been only me and my son for 27 years. (Meredith, 66 years)

Some parents were becoming aware that one 'cost' associated with their ongoing care-giving role was their own ageing, or diminishing capacity to continue to fulfil their care-giving role to the level they did currently. Barry, whose son lived in supported accommodation, was very heavily involved in on-going care for his son which he had recently had to juggle with his own ill-health:

> Normally, [I look after his hair-cuts]. I haven't been able to see him for about three weeks because I had an angiogram, two stents put in and I was in hospital for a week. When I came out I was a bit [nervous] about doing things so I just took it easy for the next couple of weeks. The first time I saw him at bowling was last week and he looked a bit scruffy then but not too bad. (Barry, 69 years)

Similarly, Lillian, whose daughter lived in supported accommodation, was contemplating relinquishing some of her on-going care-giving duties to the disability service provider; particularly as she was aware that her own ageing would potentially interfere with her capacity to maintain such levels of care:

> I want to discuss [with the accommodation provider] their availability to take over [my daughter's] medical issues when I can no longer drive all over [the place]. (Lillian, 76 years)

When focusing on the positives associated with the care-giving role, parents did, however, seem to derive a degree of purpose and pride in describing the range of activities and areas in which they supported their son or daughter. Lucy described that while she was aware that she may prioritise the needs of her daughter over her own interests, she was willing to accept that this was something she was comfortable with:

> Yeah, my life does revolve around her and that may or not [be a good thing] – it's healthy for her, that's good for her. It may not be so healthy for me but on the other hand I think well, it's given me a whole lot of purpose that I may have had a real hole in my life had she not been here. (Lucy, 64 years)

Parents whose offspring lived in the family home also described that a valuable aspect of their care-giver role was the mutual support associated with it.

This included not only being the provider of support but also the *recipient* of support from their adult child with ID; as Alice, whose son lives with her in the family home, described:

> As long as I'm here he stays with me, as long as I'm able, and I don't see that I'm not going to be able. I mean my eyesight's probably the only thing that's going to be a problem and he would be a good help in that because he's physically able and, you know, he can follow instructions and things. And he does things for [my husband – who is physically disabled] that he can't do. (Alice, 68 years)

Planning to plan

Overall, both sets of parents (with offspring living at home or in supported accommodation) were conscious of the *need* to plan and were at the very least 'planning to plan'. It was evident that taking part in the interviews and being asked about their plans for the future prompted some to acknowledge that they were lacking firm plans for when they need to relinquish care. For those whose adult children were living in supported accommodation (N = 9), the majority (N = 5) anticipated that their child would remain in their current accommodation so had not made any alternative plans. However, in raising this, some of these parents seemed to realise they had an almost 'blind faith' in service providers prompted by taking part in the interview. Another two parents had no plans at all and two did have plans in place involving seeking alternative accommodation as their child aged and health needs changed. For those whose adult children were living in the family home (N = 6), the majority (N = 4) tended to describe aspirational plans or verbal understandings between family members, while only two had firm plans in place involving relinquishing care to other family members.

As can be seen in the comment below, Jan and her husband did not have a firm plan in place but were expecting their foster son could remain in his current accommodation. They were happy to support their son while they were alive, however, did not expect their daughters (one biological, one adopted) to take over care:

> I'm assuming we won't be here then anyway [when their foster son is 60–65 years] so then I'm just assuming someone like the Public Trustee will [take over] – I'm not expecting our daughters to do it; no, I'm not, not at all. (Jan, aged 67)

Another couple who anticipated their daughter would be able to remain in her supported accommodation became quite troubled during the interview when prompted to think about the future. They realised that they had no plan in place and that they probably needed to have a discussion with their two sons about their sibling's future:

Mother: I don't know [whether she can stay at the accommodation she is currently at]. That sort of stuff just makes me feel anxious. I can't answer that. But I don't see what other options there are.

Father: I'm quite confident of it. I think the – it's a little bit difficult, the fact that the next generation for us, you know, the two boys, one's in Hong Kong, the other one in Melbourne. They will have some responsibility, they know that. We haven't really discussed with them what that responsibility means, it's sort of more implied than explicit, but they haven't really stayed close to H over the years, which is, I suppose, a bit of a disappointment. (Kathy and Bob, 68 and 73 years)

An example of an aspirational or informal understanding rather than a firm plan *per se* was evident in the experience of a mother whose son lived at home. She had verbally agreed with two of her daughters that they will share her son's care when she dies or becomes incapacitated. Her daughters shared their mother's view that he should remain with the family and not move out into the community (even though he has already expressed a desire to).

Oh they've made up their minds. My middle daughter has worked in a lot of the big homes and 'no, he is not going in that place' … that's just something we agreed on. (Meredith, 66 years)

One of the few parents who did have more of a firm or written plan in place was the participant who had a terminal illness and whose son lived in supported accommodation. This participant had made a will and set up power of attorney for his son who was set to inherit a share of his father's estate, which will be held in trust to fund his ongoing care and lifestyle activities, *e.g.* holidays. Any change to his accommodation was to be agreed between his daughter and lawyer (joint power of attorney) and his son's current place of residence. This participant was confident that there were provisions in place to move his son to higher-level care as needed.

If they [the residents] need more than what they can get now, like they might need high care, then they would put them into a nursing home and he would be looked after. I won't be around to see that so I don't worry about it … Once I go my youngest daughter will be the obvious one that'll take over because she's in town. (Barry, 69 years)

Discussion

In families of children who have life-long disability, the process of care-giving and the dependent relationship between parent and child may be life-long, as illustrated in the current study. This study suggests that by the time parents of adult children with ID reach late life, they are not only dealing with their own ageing but continuing to provide a wide range of support (both emotional and instrumental) to their adult offspring with

ID, regardless of whether they live at home or in supported accommodation. They are also aware of the need to plan for the future, but many are relying on current accommodation providers or family members to take over care when the time comes, rather than having firm plans in place.

When focusing on the range of support parents provided and their justification for doing this, a number of factors seemed to be at play. For parents of adult children in supported accommodation, in particular, there was an underlying lack of trust in services, particularly to provide the 'invisible care' (Grant 2007) such as socio-emotional and instrumental care. This scepticism about the ability of formal services to provide such care has been reported elsewhere (Cairns *et al.* 2013). Notably, in the current study, parents of adult children living in supported accommodation continued to see themselves as primary care-givers and, for most, this provision of a high level of support resulted in strong feelings of purpose and continuity of a valued role. At the same time, the capacity for adult children with ID living in the family home to reciprocate care for their older parents was also demonstrated; notably in the case of Alice who saw her son as being able to provide assistance to herself and her husband as they aged. These positives associated with providing care for a relative with disability reinforce the work of Grant (2007) and others (Pryce *et al.* 2015) but what is unique from this study is how even those parents whose offspring live out of home derive positive reinforcement from the ongoing parental role.

Not all participants in this study were living with their spouse, with six participants either divorced or widowed. In terms of their parenting capacity, however, regardless of their marital status, all were providing high levels of support to their adult children. When looking at the extent to which parents whose offspring lived in the family home were using services or involving professionals in the care, there was a mix of experiences. Two of the six families did not have any contact with formal services (one family was of non-English-speaking background and one had never felt the need to), however, the rest had accessed services including respite care, support to access community activities such as camps, as well as in-home support with personal care. Interestingly, it was very rare for any of the parents to report explicitly feeling over-burdened or exhausted in their role; potentially because they have become accustomed to the role over a long period and it is one to which they are heavily devoted. That is not to suggest that this care-giving role does not have the potential to be associated with negative health and wellbeing outcomes, just that parents may develop coping styles over many years to adapt to their role. Iacono *et al.* (2016) recently conducted a study with carers of people with ID (including parents but also other family members and friends) which sought to identify how the caring role was perceived and whether it was associated with parents' health and wellbeing. The authors found that carers differed in terms of whether, at one end of the spectrum, they felt resigned or 'captive' to the caring role (feeling that there was no one else to do the job) or whether the role was one they preferred. Such different orientations or 'loci of responsibility' were found to be related to more negative and positive health and wellbeing outcomes, respectively. The authors argued that the mechanisms involved may be associated with the fact that those who see care-giving as their role may have developed coping strategies and 'activity-oriented' and adaptive coping strategies which protect against the stress and strain of the role. This finding also confirms the work of Grant (2007), who suggests that care-giving can be associated with positive 'cognitive coping' strategies among older people which enhances a sense of mastery and self-belief.

In line with previous studies (Bibby 2012; Dillenburger and McKerr 2011; Knox and Bigby 2007), this research has found that few parents have firm future plans in place. Parents seem to know that they need to make plans and while some have formulated aspirational or verbal plans, these are not necessarily being voiced to other family members nor the person with ID, or are being left as vague 'understandings' between family members. Similar findings were demonstrated in a recent Irish study where parents seemed to be relying on informal conversations with other family members and lacked certainty over whether plans would actually be carried out (Brennan *et al.* 2017). Interestingly, the two parents who were quite adamant that their non-disabled adult children would *not* be involved in future care were both foster parents of their adult child with ID. While their broader experiences did not differ markedly from birth parents, they did seem to have firmer preferences for, or expectations that, siblings would not take over care. Another important consideration is that none of the parents of adult children living in supported accommodation mentioned that service providers had instigated conversations about future care arrangements of their sons/daughters. As it currently stands in Australia, there are no formal procedures or processes in place that dictate that service providers need to discuss futures planning with parents, however, resources do exist for family carers (Australian Government Department of Social Services 2014).

What this research has emphasised is that parents experience diverse drivers (the push and pull factors) regarding the need to plan for the future. Participants in this research were aged over a fairly broad age span, from 55 to 86 years, so the immediacy of needing to plan also varied. Overall, however, there seemed to be a complex interplay between their own health and stage of life, satisfaction with available services or current accommodation arrangements, their degree of contact with other family members and their own sense of identity as a carer for their son or daughter with ID. Nevertheless, our findings suggest that while the high level of care-giving that older parents are providing both in the family home and in supported accommodation can be accompanied by certain 'costs', this relationship is also associated with a number of positives for the older person. From a family lifecourse perspective, this finding is in accordance with the notion of 'linked lives' (Elder, Johnson and Crosnoe 2003; Greenfield and Marks 2006), *i.e.* the suggestion that interactions between parents and children can extend throughout the lifecourse and that older parents' wellbeing can be affected by the circumstances of their adult children, even when they do not reside in the family home (Walker and Ward 2013). Assisting or encouraging parents to put some firm plans into place for the future may help to alleviate the emotional and practical day-to-day demands they face as ageing carers, and be beneficial for their family member with ID in the longer term by avoiding decisions at a time of crisis. At a practical level, however, services need to avoid a 'one-size-fits-all' approach to supporting older parents to make future plans and instead take into account the fact that parents will be at different stages and have different priorities around the best way to negotiate their future plans. While some may be keen to relinquish some of their care-giving roles, others may want to retain some aspects of care that are compatible with their capacity and values as care-givers and their plans will need to incorporate these preferences. As has also been previously mentioned (Walker and Ward 2013), the important role of siblings also needs to be integrated into the planning.

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