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Parent, carer, person: Future plans and the identities of parent carers for people with disabilities

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Points of interest

- Parent carers have a significant role in future planning, particularly in relation to housing. However, little is known about their own future aspirations, and the relationship of these to planning for their child.
- In understanding this planning, parents' identities may be significant. However, little is known about the ways in which parents' identities are related to their planning.
- Interviews with parent carers and planning service staff highlighted that planning is complex and issues involved in making planning choices are interrelated.
- Analysis identified three identities – carer, parent, and person – which interacted with each other. Each identity affected – and was affected by - planning.
- These findings are important for developing an holistic understanding about planning that considers the parents' own needs and aspirations as part of the planning process.

Abstract

Parent carers are often central in futures planning for their children with disability; however, little is known about the implications of planning for parents' futures and aspirations. In understanding this, parents' own identities are important, but how these identities intersect with their planning is not well understood. This study explored how parents were positioned in discussions about planning. Interviews with parents and planning service staff highlighted three positions among parents- carer, parent, and person- representing multiple, intersecting identities. These impacted on and were impacted by planning in particular ways. Understanding these processes may assist programs to support parents more effectively.

Keywords

Parent carers, Planning, Identity

Background

For adults with disabilities living in the community and supported by their parents, long-term planning has been highlighted as important for the achievement of enhanced well-being and participation (e.g. Chou, Lee, Lin, Kröger & Chang, 2009; Gorfin & McLaughlin, 2004; Jokinen & Brown, 2005; Prosser, 1997). With the emergence of social and rights based models of disability, frameworks of care and planning are required to respond to broader issues of inclusion, citizenship and self-determination (Jenkinson, 2008). In particular, the emergence of frameworks embracing person-centred care and planning, which “is fundamentally about sharing power and community inclusion” (Sanderson, 2000, p.2), has also pointed to the centrality of the family contexts of care in achieving the power shifts to which the approach aspires. This, in turn, is likely to affect the resources that carers need to bring to their role, raising issues concerning the roles they play in future plans for the person with disability, and the practicalities of their own planning.

Importantly, this planning can have significant long term impacts on carers through its implications for their own trajectory in fields such as employment, health, education, and community life. For example, achieving and maintaining employment can have beneficial outcomes for carers’ finances, social connectedness, health, and wellbeing (Broady, 2015). The realisation of such outcomes requires that carers consider their future aspirations and needs. Planning for the needs of the individual with a disability, however, may both facilitate and hinder planning for the carer’s own future (Hafen & Sorensen, 2008). Therefore understanding carers’ aspirations and plans, and how these plans are shaped, is essential in identifying and providing appropriate supports for an holistic approach to planning. This paper reports on a qualitative study which sought to enhance understanding of the ways parent carers position themselves with respect to their roles in planning and their participation beyond the care role.

We first turn to review research on the mechanisms of identity that are central to the way parent carers understand and negotiate planning for their future. This review sharpens the focus of

the study in terms of the positions that parent carers can adopt as a key foundation for planning. The paper then discusses the approach to data collection and analysis best suited to identifying and analysing this positioning. Finally, the paper reports on and discusses the identities parent carers employ in engaging with their future.

The dynamics of identity and the carer role

Evidence regarding parents' aspirations for themselves from use of services suggests that the parent carer's own identity and role are significant. For example, this research has suggested that their aspirations were focused, among others, on achieving a balance between parenting and caring roles, maintaining their personal identity through work, interests and personal relationships, and maintaining family life including their relationship with their spouse (Beresford, Rabiee & Sloper, 2007). Caring has been described as identity-defining in the way it changes the carer's life (Holland & Blood, 2008) and some parents have described losing parts of their identity, with the parent-carer dominating, and identified redeveloping aspects of their identity as a personal aspiration (Beresford et al., 2007). The parenting role has been identified as potentially overwhelming other aspects of self-identity, even to the point of becoming an overwhelming, or even sole source, of self-meaning (Todd & Shearn, 1996a). Therefore how parents view themselves and their roles, and how these roles intersect and may conflict with each other, are central to understanding parent's perspectives on their own lives and their aspirations for their own futures.

Studies with carers in various relationships with care recipients, however, have identified multiple and often simultaneous identities, which may be implicitly or explicitly designated separately from that of carer, including spouse, parent, friend or individual person (e.g. Holland & Blood, 2008; Hughes, Locock & Ziebland, 2013; Todd & Shearn, 1996a). Indeed, as Hughes et al. (2013) argue, the identity of carer is variable and fluid and may for some be explicitly rejected as an inadequate description of the relationship. Henderson (2001) similarly emphasises the inadequacy of the identification of 'carers' and 'cared for' in understanding the relationships sitting alongside,

and beneath, caregiving. It has therefore been suggested that the term 'carer' may simply be inadequate. It has been argued that it became a social identity distinct from the other, often familial, relationships between the carer and cared-for, through relatively recent processes of social construction (Bytheway & Johnson, 1998). A failing of services has been in their inability to separate the different aspects of identity for carers, failing to respond to any but the parent-carer role (Todd & Shearn, 1996a). It is also of note that much literature conflates the parent and carer roles in particular, rather than treating these as separate self-identities with separate implications.

Importantly, a number of studies have suggested that identity is shaped for parents over time, through the experiences and transitions of their roles. For example, the formation of the parental identity – and aspirations for future identity – are challenged and influenced by the diagnosis of an impairment (Rix & Paige-Smith, 2008; Bosteels, Van Hove & Vandebroek, 2012). However, transitions, both physical and emotional, continue to occur throughout time (Ytterhus, Wendelborg & Lundeby, 2008). These transitions occur for all families; however, for parents of adult children with disability, they are experienced differently, often representing greater physical and emotional challenges than those experienced by other families (Ytterhus et al., 2008). At certain turning points, such as their child's adolescence and adulthood, the normalising strategies used by parents are no longer as successful, with the particular challenges of their family situation brought into stronger focus and challenging parents' self-identity (Todd & Shearn, 1996a).

The ongoing revisions of identity that occur through these transitions over time highlight the struggle between the expression of multiple self-identities (Todd & Shearn, 1996a). Broader identity theory recognises the shifting nature of identities and the potential for two or more identities to exist simultaneously; when these are in opposition, this may result in dissonance, and shifts in or changes in the relative salience of the identities, and the individual withdraws from the associated relationships (Burke, 2003). In the parent carers literature, the self-identities of parent and individual person are often highlighted, with a life beyond parenting seen as aspirational and

often unobtainable (Todd & Shearn, 1996a; b). Todd and Shearn's (1996b) research differentiated between 'captive' and 'captivated' parents; that is, parents who experienced parenting as restrictive and desired the lifestyle of their peers, and those who gave up their personal aspirations and ambition towards achieving their peers' lifestyle, finding positive meaning in their role as parents. Walden, Pistrang and Joyce (2000) further suggested that this may be a continuum, but similarly emphasised the contrast between these identities and the struggles between them.

However, the development of different identities for parents may also be influenced by other relationships and life events. For example, the social role may be connected with that of spouse, making widowhood directly challenging to development of a social personal identity; therefore the links between different identities can be instrumental in parents' willingness or perceived ability to develop roles outside of parenting (Todd & Shearn, 1996a). Therefore understanding parents' roles and identities beyond those of parent or carer is essential in developing an understanding of their future aspirations, and how they can be supported to plan for their future.

Therefore, in exploring parents' own aspirations, considering their self-identities and the ways in which they are expressed in relation to each other is central. How these parents understand and enact their positions may have significant implications for the planning process. Importantly, how those assisting families with planning understand these positions and identities has implications for the ways in which programs support parents to plan beyond their child's individual future. It is important, then, to consider how these roles are played out in relation to planning for self. However, despite research exploring the importance of and mechanisms of identity among parent carers, knowledge about how identity shapes, and is shaped by and through planning by parents for their own futures, is limited.

The aim of this study was therefore to explore the issue of planning among a group of parents who were already engaged in futures planning for their child with disability. The study placed a particular focus on how parents were positioned in discussions about their aspirations

regarding their own housing and other aspects of their future and that of their children. This was explored among clients and staff of planning programs in Queensland. Analysis focused on the role of the care relationship in their future planning for their own needs and the roles and identities that were made implicit or explicit within their discussion of these issues.

This is achieved through the use of positioning theory. According to this theory, people occupy (either take up or are positioned by others) different 'subject positions' in the way that they speak about a topic (Davies & Harré, 1990). Positions are dynamic, fluid and constantly renegotiated, rather than predetermined and static as roles are seen to be (Harre & van Langenhove, 1999). In this sense they resonate with the ways in which identity has been described by caregivers in previous studies, and indeed it is for this reason that positioning theory has been used in previous studies to explore identity in caregiving (e.g. O'Connor, 2007). This analysis examined what positions parents took up in relation to the subject of planning specifically, rather than caregiving generally; that is, rather than exploring a caregiver identity, the analysis reported here used positioning theory to open up questions of the role of positioning and identities within long term planning by parents.

Methodology

As a study about the subjective lived experience of parent carers, the research used a qualitative approach, which enabled carers' voices to be heard in an inclusive way. In keeping with a qualitative, theory building approach, the research was based on concepts that 'sensitised' the investigation to the central relationships of interest (Blumer, 1954; Charmaz, 2003; Bowen, 2006): those that were central to carers' sense of positioning and identities in relation to planning. Other dimensions of the data are reported elsewhere (Petriwskyj, Franz and Adkins 2016).

The project involved a series of semi-structured interviews with parents of people with disability, and staff of planning programs. This provided rich data based in present lived experience. Staff were included to explore the broader context of parents' planning, including staff reflections

on common themes or patterns among the families with whom they worked. The research received ethical clearance from The University of Queensland. Families and staff were recruited from a number of planning programs in Queensland, as well through organisations' newsletters. The information sheet provided to all participants detailed the aims and purpose of the study, details about data collection, assurance of confidentiality and anonymity and freedom to withdraw. All participants provided written consent.

Data collection

Interviews were conducted at the respondents' homes, workplaces, or by telephone. Twenty interviews involving 21 people were conducted based on an interview schedule. Interviews lasted between one and one and a half hours. Questions explored issues for the parents relating to their long-term planning and future housing for themselves and their children, and their experiences with disability organisations and their planning and housing programs; for staff, questions focused on their experiences and perceptions of these issues for carers. While the focus of the interviews was on housing, the interconnectedness of planning issues meant that discussion encompassed a broader range of dimensions than housing alone.

Participants

Respondents included 20 women and one man aged between 39 and 72 ($M = 54.5$ years). Of the total sample, 17 were parents, 2 were staff only, and 2 both parents and staff. Staff were in a range of roles including quality assurance, project worker, and planning co-ordinator. Staff were employed in three different organisations, with one of the staff employed by two of these organisations simultaneously. Of the 19 parents interviewed, nine were in part-time employment, and three were in fulltime employment. Two were from non-English speaking backgrounds. In order to gauge family circumstances and support, parents were asked about their marital status and care arrangements; 11 were married or in a de facto relationship, two were divorced, two were widowed, and two were single.

Family circumstances varied considerably. The type or level of disability experienced by the son or daughter of interviewees included intellectual and physical conditions, with some experiencing multiple disabilities or co-morbid conditions. Conditions included Cerebral Palsy, epilepsy, chromosome deletion, austio dystrophy, spine bifida, autism, and varying degrees of intellectual impairment. Care needs ranged from mild needs with the potential to live without a carer later in life to high care needs with constant and ongoing supervision required, and 24/ 7 care required into the future. The son or daughter for whom respondents provided care were aged between 10 and 41 (M = 19.7 years), with the majority in their teens at the time of the interviews.

The level of shared care varied; a third of participants identified as sole carers, however most shared care, often (although not always) with their spouse. Shared care was also often unevenly distributed, as for many carers their partner travelled often for work or worked long hours. Extended family and friends also provided support in the caring role, particularly other teenaged or adult children.

Analysis

Interviews were recorded and transcribed verbatim. Data were analysed with the help of qualitative data management program NVivo 10 (QSR, 2012), to draw out themes and patterns relating to the research aims. The data presented in this paper were thematically analysed by exploring for themes relating to the families' experiences with planning including the catalysts for planning, key influencing factors and concerns and aspirations. These broad topic areas represented the key questions guiding the research study of which this data forms a part, and provided a broad framework for understanding the parents' narratives.

An iterative coding process was used to identify concepts and distil themes relating to these areas (Strauss & Corbin, 1998). This coding process involved open coding on the data to identify initial ideas or codes, which were re-examined and categorised into themes. These themes were reviewed and refined to ensure that they accurately, and fully, represented the data. Within each

theme, sub-themes were identified. At this level of analysis, the focus was on parents' experiences of future planning. Two overarching categories relating to parents' aspirations and balancing of needs were formed, which reflected personal aspirations, independence, relational aspirations, social and lifestyle benefits, and emotional needs, and balancing familial, financial, care, and emotional needs with those of their children. These themes were then used as a vehicle through which to explore the positions adopted by parents in their discussions of planning. Positioning theory was employed to 'sensitise' (Blumer, 1954; Charmaz, 2003; Bowen, 2006) the investigation to the relationships likely to expose aspects of identity central to the study.

Rigor

A number of strategies were employed to ensure rigor in the research and analysis process (Shenton, 2004; Lincoln & Guba, 1985; Braun & Clarke, 2006). Direct quotations from the interviews were used to ensure that participants' meaning was captured and their own words were adequately represented, and a semi-structured interview schedule was used to help provide consistency. The inclusion of data from participants in diverse circumstances including as sole or shared carers, employed and not employed, parent carers and staff, and providing care for individuals with a range of disabilities helped to provide diverse perspectives against which to check findings.

Regular debriefing and reflective appraisal was also undertaken throughout the research and analysis process. A reflexive process was vital, given the nature of the analysis; the ways in which parents positioned themselves in their discussion about planning could be influenced by the interview process, and the ways these positions were perceived could be influenced by the researchers' own positions and experiences. Discussion and interpretation of data involved the three authors, who had varying backgrounds and personal circumstances, including varying experience of both parenting and disability.

Results and Discussion

What housing and care options are families considering?

As part of their planning for future housing, families reported a wide range of options. For some families, both the parents and their son or daughter were planning to leave the current home, whether together to a new family home, together to a nursing home or retirement village, to separate homes, or to separate but connected homes such as a duplex or apartments in the same block. Others preferred that both the parents and the son or daughter stay in the family home or connected through a granny flat. The majority of parents expressed a preference to stay in their own home, although some chose to relinquish the home for the benefit of their child. Some were planning to move to a new home to downsize, or to a retirement village or aged care facility. For the families in which the son or daughter was planning to move, plans included a unit or apartment nearby to the home, sharing with peers, or specially developed living options such as a farm development. Some parents were looking at multiple options in a staged approach to provide a more gentle transition for their child.

Contributing factors to parents' planning

A number of different aspects or dimensions of planning for housing were discussed. These included legal, financial, social and employment issues for both the parents and their son or daughter. Discussion highlighted the complexity of planning and the range of interrelated issues that both inform and present challenges to planning. The factors that affected plans for the parents were slightly different from those that affected plans for the son or daughter's housing future, however they were strongly interconnected. In considering options for their own future housing, parents considered these on their merits in relation to whether they afforded a range of benefits or outcomes for them. Two dimensions were identified to the experience of planning: the aspirations and planned future benefits that the plans would facilitate, and the balancing of needs that occurred both implicitly and explicitly throughout planning.

The dynamics underlying this process were complex, with a range of issues to be weighed up and traded off, and a diverse range of factors impacting on the planning experience and the plans themselves. Further, planning was related to care, lifestyle, social outcomes, employment, and continuing education among other aspects, all impacting on each other and on the housing being considered.

Positioning of parent-carers

The data were analysed to examine what positions parents took up in relation to planning. Analysis revealed that parents simultaneously positioned themselves as carer, parent, and person, each identity intersecting with the others and each impacting on the planning process and on the plans made.

Carer

The first of these, the position of carer, was reflected strongly throughout the discussions. This position was most evident in discussions about the emotional, financial and practical challenges of caring, and was implicit throughout the discussions in the tension between the child's and parent's planning. Planning for these parents is made more complex by its inextricable relationship with their child's plans. Often the plans reported by parents were nebulous ideas that would be significantly impacted by their plans for their son or daughter. In addition, existing plans were largely contingent on the plans for their child coming to fruition; parents' planning for themselves was deeply interwoven with planning for their child, sometimes subjugated to their child's needs. This suggests a tension between the development of aspirations for parents' 'possible future selves' and those of their children (Rix & Paige-Smith, 2008).

Parents identified emotional, financial and practical challenges in implementing their plans for themselves. For example, some parents, while financially capable of implementing their plans

for their child, found that the affordability of their own housing and care would be compromised.

Not all had considered how to manage this:

I don't have a lot of financial support anyway, I just paid off this house and that's all my money ... when I'm older and you go to a nursing home, you have to put the money towards the nursing home or something ... so maybe I have to sell this house. I don't know, I'm really scared when I think those things (Mother, 54, of 18 year old son)

It was very common for respondents to report that their strategy was to remain well indefinitely, because they did not have the capacity or think about, or implement, plans for their own future in addition to those of their child:

Too interested in thinking about his care; I just hadn't thought about it. ...I just thought I would go on forever and stay here. What is it, ten foot tall and bullet proof? That's me, hopefully. (Mother, 64 of son (age unknown))

Indeed, the majority of interviewees had not given much thought to their own future health or care needs and how their plan for their son or daughter might impact on this. There was a sense from many of these parents that it is hard to plan for unknowns or for what they could not control. For others, their own planning was made possible by having arrangements in place for their child, but was secondary:

...we have our needs met because her needs are being met. So we can be a little bit more selfish about what we do and how we have our needs met because hers are being taken care of... (Mother, 63, of 26 year old daughter)

Some parents, however, were planning ahead to ensure they retained control over their own futures:

That was one decision, that we're not so focussed on [son]'s needs that we are almost putting ourselves at risk, you know we're funnelling everything into a trust or into [son]'s name or something and we can't access that in an emergency, so we tried to keep it flexible ... so that was the idea to provide for [son] without having too big an impact on our lives. (Mother, 50, of 14 year old son)

One parent described how this planning for her own care was an essential part of planning for her son:

... because if I'm supported, he can be supported. And if I'm not, or don't do anything about it, well then I feel I've failed him because I've left him stranded. That's how I feel and I don't want to do that, I'm thinking, planning or hoping that I can have something in place for us, to both have support, for him after I've gone, or me after he's gone, whichever happens... (Mother, 65, of 33 year old son)

For this mother, the very act of planning for her own future was an act of caregiving for her son.

One reason for this interconnection of planning described by program staff was to ensure physical proximity, suggesting that continuation of the caring role affected parents' plans despite the establishment of physical separation and establishment of alternative care arrangements:

... they'll always be a few doors away or in the same suburb at least, or definitely in close proximity ... So they're definitely intertwined, their plans and the plans of the young person. I think that's all happening together; they're doing that planning altogether. (Planning program staff)

Therefore priority was usually given to the son or daughter's needs; however, some parents were spending the time on planning looking for synergy between the two. For some that was serendipitous, with the parents and child having similar preferences.

I'm surprised...we both do want very similar things and like very similar things though [daughter] is very stubborn and she does know what she wants but luckily it's things that we're sort of wanting as well. (Mother, age unknown, of 17 year old daughter)

For others, finding synergy took work and there was an element of self-sacrifice which was sometimes distressing for parents.

... he is first, I will just fit around it, I'm not important. (Mother, 54, of 18 year old son)

Some parents also highlighted the overwhelming nature of the daily challenges in providing care and of negotiating services, explaining that planning for their own future was an extra consideration they did not have the capacity to engage with.

...it's really hard to think about that when you're managing day-to-day and you're saying but I don't want [daughter] to be separate from us yet ... (Mother, 53, of 15 year old daughter)

This mother also highlights the difficulty for some parents, also highlighted in staff interviews, in moving into a phase of life where they were not a primary carer. Some felt a reluctance to hand over responsibility for care. However, it should be noted that this was by no means a universal experience.

In these quotes, while talking about their own futures and their own planning, parents positioned themselves as carers foremost, in that the caregiving role and responsibilities dominated their positioning of themselves in relation to planning. This position was, at times, related to traditional tasks of care, such as everyday provision of physical support or to ensuring physical proximity in order to continue oversight. However, it was also reflected in the prioritisation of planning for their son or daughter, sometimes at the expense of their own future wellbeing, as a

form of 'caring'. Therefore in these discussions, the identity of carer was most salient, through the emphasis on present, and future, caregiving responsibilities as central to future planning. Previous research has suggested that caregiving can be identity-defining or dominating (Beresford et al., 2007; Holland & Blood, 2008), potentially becoming the sole source of meaning (Todd & Shearn, 1996a). In much the same way that diagnosis may influence the formation of parents' identities (Rix & Paige-Smith, 2008; Bosteels et al., 2012), the process of planning may also emphasise, or make more salient, the carer identity (Burke, 2003).

However, research has also suggested that carers may have multiple and often simultaneous identities, including spouse, parent, friend or individual person (e.g. Holland & Blood, 2008; Hughes, Locock & Ziebland, 2013; Todd & Shearn, 1996a). While the caregiving role for these parents dominated their approach to planning, it was not the only dimension of their identity evident. Indeed, even while strongly identifying as carers, the respondents also, often simultaneously, identified as parents, and as individuals beyond either of these roles.

Parent

Respondents – implicitly or explicitly – separated the role as carer from that of parent. For example, as one mother explained:

...eventually she will become more and more separate from us and we will become more and more mum and dad, and less and less full-on doing everything with her (Mother, 63, of 26 year old daughter).

Statements such as this one explicitly reflected this separation of roles. This was also reflected in the notion of planning for others to take over care and support later in the parent's life. Further, this quote represents the connection between physical separation – through a move to separate living situations – and a separation from the caring role.

The parental role was also often reflected in frequent references to other children in the family, and the parents' responsibilities to those children, or grandchildren, which sometimes conflicted with responsibilities to the child with a disability. Planning was seen as a way of facilitating the separation of roles, and also a way of fulfilling responsibilities to other children, such as by ensuring they were not required to provide support either for their parent or their sibling.

...I'm not going to be a parent who sits in my big house and says to my kids, you have to look after me... (Mother, 52, of 23 year old son)

For the most part, respondents were concerned about the impact on their other children and planning was a strategy to address this. In this sense the tension between identities emerged in response to the specific and conflicting needs of their children in relation to their child's disability. However, family circumstances varied. Some did not have other children, and one had a difficult relationship with their other adult child, in which part of their care role was in protecting the interests of their child with disability in relation to their sibling. For this mother, the role of carer was central, highlighting the impact that relationships with other children may have on the tensions between, and prioritisation of, different identities.

In some cases, parents also explicitly described their efforts to ensure that their caregiving responsibilities was not reflected in differential treatment of their children. In this way they prioritised the role of parent, implicitly rejecting the prioritisation of caregiving in response to disability and challenging the assumed salience of this role. This deliberate separation of roles reflected a normalising approach to disability. It also reflected a conscious attempt to circumnavigate relational tensions.

This separation of the parent and carer roles and the explicit reference to a desire to spend more time as a parent reflected the findings of other research, which has, for example, found that parents desired a greater balance between caring and parenting, including among their children (Beresford et al., 2007; Holland & Blood, 2008). Thus planning represents a transition in which the

separation of these self-identities becomes more stark (Todd & Shearn, 1996a), providing an opportunity to place greater emphasis on the parental identity rather than that of carer.

However, the findings also reflect a deliberate prioritising of the parent identity over that of carer, rather than simply a transition. This finding is particularly important in light of the tension in the literature, identified earlier in this paper, between the terminologies used to describe parents' self-identities. It has been noted that the label of carer is contentious, and the literature often refers simply to 'parents' and to the 'parenting identity', even when the issues at hand are those specifically relating to caregiving. Indeed, O'Connor (2007) found that adoption of a caregiving identity is not automatic and the activities of care are often viewed within the family relationship rather than as tasks of caregiving. Caregiving may be seen as a separate and even rejected position (O'Connor, 2007; Hughes et al., 2013). What these findings highlight, however, is that for some parents, recognising these separate dimensions of identity is valuable in identifying and articulating their own aspirations for themselves and for their relationship with their children.

Individual

In parents' planning and the factors they identified as important were also reflected issues relating to parents as individuals with aspirations, other (non-caring and often non-parental) relationships, and individual needs that could be met by specific planning choices. This position was often implicit in discussions about the practicalities of housing. It was also explicit in the choice of housing as an emotionally-based decision that fulfilled psychological or emotional needs, and in explicit separation of their needs from those of their child.

Fulfilled self

Parents reported making planning choices that would fulfil their needs and aspirations, and provide desired social and lifestyle outcomes for them as individuals or as a couple. Some aspects

of lifestyle respondents identified were generally related to location, and positioned these parents as choosers or shapers of a lifestyle that suited their preferences:

I suppose because we've got used to living out on acreage, the peace and quiet, we don't really like the idea of moving into a very dense area, densely housed area. ... And I think we'd like a place that was a smaller community or a beachside area... (Mother, 52, of 19 year old son)

The respondents, through planning, constructed a future biography for themselves that revealed, or created, a number of identities including as travellers, workers and students. For example, parents and staff talked about aspirations for the future that arrangements for both parents and their child would afford: the ability to engage in study and paid work, or the ability to travel.

“... we'd like to travel, we'd like to pack up in a camper van and tour around Australia and do some of those fun things, you know? (Mother, 50, of 14 year old son)

This future biography of the separate individual was also constructed as independence. This independence was seen as happening in different ways, for example: as time for the parents to live separately from their children; time for parents as a couple; an opportunity for the parents and their child to have separate but connected lives, rather than dependent ones; freedom to take time for themselves (e.g. weekend away); and separation from the responsibilities of care. In this way the individual is positioned as 'separate', whether physically or more abstractly in relation to lifestyle.

The aspiration of the fulfilled self as distinct from the role of parent carer reflects previous research, in which work, personal interests and personal relationships have been found to be salient to parent carers in maintaining their personal identity (Beresford et al., 2007), in the caring relationship in which some parents report a 'loss of self' and a lack of a life of their own (Holland & Blood, 2008. p. 25). It reflects the separation of the self from the carer (Holland & Blood, 2008;

Hughes et al., 2013; Todd & Shearn, 1996a), demonstrating the fluidity of this identity (Hughes et al., 2013). This separation is facilitated by planning, which focused these parents on their own aspirations and concept of fulfilment.

Physical self with health needs

For some parents, planning ensured the future opportunity to have a ‘break’ and take care of their own health.

I think some of those more elderly parents, their need now is more to have a break.

That’s the future that they can see, I’ll have a break from this...not planning to go travelling or to do anything else, but just not to be in that full-time role and to probably take care of their own health a bit more. (Planning program staff)

In this way parents were positioned as individuals with health needs that differed from those of their child. Although many had not considered their own future health and care needs, for others their own health or their potential future need for care was an important factor in their decision about the type of housing or living situation that would suit. A few parents, for example, stressed the importance of avoiding a move to a retirement village or aged care facility, noting such details of planning as the intention to move to a low-maintenance property.

I don’t ever visualise living in one of those gated communities with lots of other older people. That doesn’t appeal to me at all ... I certainly would never want to end up in a nursing home. ...I’d rather you shot me first rather than that. (Mother, 63, of 26 year old daughter)

These lifestyle plans also extended to the design of the home. A convenient location close to amenities and transport, quality of the housing and property, and the design of the house including the level of maintenance required were all important factors.

...a big house needs maintenance; this doesn't even need lawn mowing... we've purposely chosen a smallish house that we don't need to be over-burdened with the maintenance part. We chose the location so that it's convenient even to the stage when both of us cannot drive, we'll still be okay. We could have picked a single storey house but at this point in time it's not an issue. So we haven't got plans to move. (Father, 62, of 13 year old son)

For those parents who had made such plans, these were conscious choices about housing location, design, and quality that were intended to make the home suitable for the long term. In this way the respondents positioned themselves as independent individuals with the capacity to care for themselves, or in some cases, access care services in order to retain this independence. Planning was a way of securing this position, and made explicit this identity around physical independence into the future. It is notable that some parents, in this way explicitly rejected a future identity as 'cared for'.

Emotional self

Some of the interviewees discussed the emotional ties and memories attached to the house or area they were in, explaining that these ties made it difficult to consider moving or that they created an attachment to the home.

*I'm staying right here (laughing)...not moving. My husband and I built this house ...
I'm not moving anywhere; this is where I'm staying. (Mother, 64 of son (age unknown))*

This reflects the connection between different identities, and their relationship with planning (Todd & Shearn, 1996a). For this mother, for example, her identity as a spouse and her shared history with her husband is central to her planning.

Security and stability were also important, with one parent describing the importance of home ownership providing a sense of security about having somewhere to live.

I want it to give me security and stability ... and I own the house, so that's one thing and I just want to be able to say this is where I can lay my head down every night really, I don't want much more than that. (Mother, 65, of 33 year old son)

The choice of home therefore represented the fulfilment of emotional needs as well as physical or practical ones. In these quotes, the respondents positioned themselves as people with emotional needs and emotion-laden histories, which guide their planning choices.

Spouse or partner

Implicit and explicit within such discussions was also the position of spouse or partner. Many respondents referred to aspirations that were shared with their partner, or related to their marriage or partnership.

We were going to get married last year but we had to put it off ... Because I can't see how it's going to happen until I've got all this into place. ...But I'm hoping that within the next 5 years, so I'll be 70, he'll be nearly 80 and I'll get married and go and live with him... (Mother, 65, of 22 year old son)

In this quote, the positions of carer and spouse can be seen as existing in tension, and it is the transition allowed by planning that allows the spouse to emerge (Todd & Shearn, 1996a), in both abstract and practical terms. For this mother, the tension between these identities highlights the finding of previous research that through comparison with their peers, and challenges to their self-meaning, parents can experience a struggle between competing identities and may see life beyond parenting as unobtainable (Todd & Shearn, 1996a; b).

This position of partner was also sometimes implicit in discussion about future selves that were framed as shared rather than individual biographies.

I guess because we have invested so much into creating that community connection, that it would be quite difficult I think for us to ...we do plan to travel and everything, but it would be difficult for us to start off again somewhere else because we've put so much effort into making sure that that little community is there for our son and us. (Mother, 47, of 14 year old son)

Plans for the future, and consideration of preferences and needs, were often framed in terms of the couple's shared history, shared vision, or shared wishes. This reflects the ways in which identities and roles can be connected (Todd & Shearn, 1996a). For these parents, for example, the independent individuals, separate from carer and parent, existed in a couple with shared visions and plans.

Social self

Similarly, a number of parents spoke about the social benefits that were or would be afforded by their chosen housing situation. For example, proximity to friends and the opportunity to spend time with friends and family, the ability to stay in the community they like, and the opportunity for social interaction were of great significance. In this way the respondents positioned themselves as social beings and members of a dynamic community. This was both directly related to existing social networks, for example *...just being able to spend more time with my friends and family (Mother, 52, of 16 year old son)* and also to deliberate choice of housing that facilitated social interaction:

... I don't see myself as being precious about living in my own home. ... I guess that I'm looking for somewhere where we can still have the social interaction on a day-to-day basis. (Mother, 65, of 41 year old daughter)

Tensions and fluidity between positions

In some cases tension was evident between parents' positions within their talk about planning. At times, this tension was explicit, such as in discussion about balancing their child's

needs with their own, or balancing their child's needs with other family relationships including spousal and parental relationships. This resonates with previous studies which have found that in caregiving more generally, tensions arise between positions such as those of spouse and carer for those who care for a spouse (Hughes et al., 2013) and between positions as a person or 'human being' and carer (Holland & Blood, 2008), including as a person with their own needs, which could become a source of guilt (O'Connor, 2007; Ytterhus et al., 2008; Todd & Shearn, 1996a). Indeed, in O'Connor's study, some carers used a caregiving position or 'storyline' rather than a familial one to create space between themselves and the care-recipient. Todd and Shearn (1996a; b) particularly highlighted the tension between the expression of different identities, particularly the struggle to realise the aspirational identity of an individual person beyond the parenting or caring role. This tension was certainly evident in our findings; for some parents, their identity as a fulfilled self was largely aspirational, prevented for the foreseeable future by practical, particularly financial, constraints.

Identity theory suggests that when identities are in opposition, the individual may experience dissonance, and as the associated relationships shift, the relative salience of these identities also changes (Burke, 2003). Hughes et al. (2013) reported that the identities of carer, son, daughter, spouse and so on may be fluid depending on the salient needs or the condition of the care receiver at the time. They reported that carers assumed multiple identities at any one time, sometimes hierarchically but without contradiction. The importance of recognising multiple self-identities has been highlighted, and recognised as a failing of services, which have been limited in their approach to parents (Todd & Shearn, 1996a). In the present study particular identities were not necessarily rejected because of the tensions between them; the respondents moved between them, and at times adopted them simultaneously. For some, the identities often presented as problematic – those of carer and individual – were symbiotic, or at the least synergistic - in the way they facilitated planning.

Further, this study found that parent carers' identities were not necessarily overwhelmed by those of 'caregiver' and their needs were not always superseded, as has been suggested in some previous studies (Holland & Blood, 2008). Certainly for some of the parents, this was evident in comments such as '*I don't know, I don't think of myself a lot*'; however, for others there was a recognised importance, and even deliberate strategies, to ensure this did not occur. In this sense the deliberate separation and articulation of positions – particularly those of carer and person or carer and parent – allowed the parents to strike what they saw as a better balance between competing needs. In this sense the recognition and separation of self-identities by parents was a tool they used to create and articulate aspirations for their futures. Thus the respondents in this study used explicit separation of identities, such as those of carer and parent, or those of carer and fulfilled self, to make sense of and also guide their future planning.

Previous research has demonstrated how identity is shaped for parents over time, through their experiences of their roles (Ytterhus et al., 2008). Parents have been described as undertaking ongoing revisions of identity (Todd & Shearn, 1996a), shaped by competing pressure and tensions between roles. This process is reflected in our findings, with transitions between identities taking place through the process of planning. For example, the 'fulfilled self', who was represented by the traveller, worker, or student, was made possible by the success of planning in diminishing the salience of the position of 'carer'. The individual would then be able to transition to an individual free to pursue other interests. Similarly, planning was seen as a way to transition from 'carer' to 'parent', a role that was presented as carrying less responsibilities and more freedom, perhaps akin to those of their peers with adult children. In some cases these transitions related to more specific identities. For one respondent, for example, planning was expected to facilitate the transition from 'carer' to 'spouse'. Therefore as well as highlighting different aspects of parents' identities, future planning provided a pathway to identity transition.

Limitations

In interpreting the findings, some limitations of this study must be acknowledged. First, the sample was small and the number of staff in particular was limited. The inclusion of a larger sample including more staff would provide a useful opportunity to explore the convergence and divergence between parent and staff perspectives, which was beyond the scope of this study.

Second, as initial exploratory research, this study was not able to explore issues such as cultural differences or gender differences in the positioning that occurred. This would provide a valuable next step in exploring the diversity of parents' experiences, as these are significant aspects of identity that may have had an impact on these findings. For example, fathers may report different experiences from mothers. In this study, only one father volunteered to participate, and he was interviewed as part of a couple; the majority of the data reported here was from mothers. In this regard the identities that were not evident in these discussions are also worthy of note. For example, positioning in relation to gender or culture did not seem to occur, although one parent did discuss their experience of migration to Australia. This may indicate that in talking about future planning, other aspects of identity are more salient, particularly since cultural influences on planning were not explicitly addressed; alternatively, it may be an artefact of the sample.

Finally, as a result of the small sample, although there was some diversity in the conditions and specific disabilities among respondents' children, there was a relatively limited range. Research that incorporates parents who are responding to a broader range of disabilities would allow for some comparison of experiences for different severity or level of need, or different types of impairment.

Conclusion

Little attention has been given to the dynamics of long term planning in the context of the parental carers' own future needs, and the implications this has for how parents understand themselves and are understood by practitioners and researchers. While the diverse academic and

practice discussions agree on the importance of parents' involvement in planning, this focuses on their role in supporting planning for the future of their child. This study has explored in some depth the experience of planning for their own needs, from the parents' perspectives. Planning by these parent carers is multidimensional and reflects the interconnected nature of different domains of life. Importantly, it is impacted by a broad range of needs and aspirations held by parents for their own futures, which reflect social, emotional, familial, and practical needs and desires. Perspectives on these needs and desires are diverse and demonstrate the different perspectives on independence, fulfilment, and self.

Importantly, however, the positions adopted by parents in their descriptions of planning reveal a fluid and multi-layered set of identities that at times manifest as tensions, but at others support parents' planning for their own futures. Planning was shaped by parents' self-identities; it, in turn, created opportunity for, reinforced, and shifted these identities. Identities existed in tension, but could also be synergistic or even symbiotic; they existed simultaneously and could be interwoven, but were also deliberately separated by parents to facilitate, and articulate, future plans.

Some implications for planning programs can be identified from these findings. An holistic focus on planning that is inclusive of the future for the parents as well as the individual would provide a useful additional support. While planning programs appropriately focus on the person with a disability, these programs have an opportunity to support the parents in a way that facilitates their own planning. Given the implications of planning for the parents, it is of concern that there is limited planning among parents for their own future. In the context of schemes like the National Disability Insurance Scheme (NDIS) in Australia, these findings demonstrate that giving a central role in planning to parent carers can create challenges and tensions, if planning does not also incorporate the future needs and aspirations of those carers in addition to the person with a disability.

Understanding the multiple layers of identity that parent carers adopt and may move between, rather than assuming a salient caregiver or parent identity in relation to parents' own plans may assist planning programs to support the needs of these carers beyond planning for their child's future. The use of identities to articulate aspirations and share planning experiences, as well as an understanding of the ways identities, and the relationships between them, shape parents' planning, is important. Recognition of the multiple self-identities for parents, and the ways these identities affect, and are affected by, planning over time and across transitions and changes for families, is central to supporting parents in the planning process.

References

- Beresford, B., Rabiee, P. & Sloper, P. (2007). *Outcomes for parents with disabled children*. Research Works, 2007-03, Social Policy Research Unit. York: University of York.
- Blumer, H. (1954). What is wrong with social theory? *American Sociological Review*, 18, 3-10.
- Bosteels, A., Van Hove, G. & Vandebroek, M. (2012). The rollercoaster of experiences: becoming the parent of a deaf child, *Disability & Society*, 27(7), 983-996.
- Bowen, G. (2006). Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods*, 5(3), 12-23.
- Broadly, T. (2015). The carer persona: Masking individual identities. *Persona Studies*, 1(1), 65-75.
- Burke, P.J. (2003). Relationships among multiple identities. In: P.J. Burke, T.J. Owens, R.T. Serpe & P.A. Thoits (ed.s) *Advances in Identity Theory & Research*, pp. 195–214. New York: Kluwer Academic/Plenum.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Bytheway, B. and Johnson, J. 1998. The Social Construction of Carers. In *The Social Construction of Community Care*, edited by A. Symonds and A. Kelly, 241-53. London: MacMillan.
- Charmaz, K. (2003). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies for qualitative inquiry* (2nd ed., pp. 249-291). Thousand Oaks, CA: Sage.
- Chou, Y.-C., Lee, Y.-C., Lin, L.-C., Kröger, T. & Chang, A.-N. (2009). Older and younger family caregivers of adults with intellectual disability: factors associated with future plans. *Intellectual and Developmental Disabilities*, 47(4), 282–294.

- Davies, B. & Harré, R. (1990). Positioning: The discursive production of selves. *Journal for the Theory of Social Behavior*, 20(1), 43-63.
- Gorfin, L & Mclaughlin, A. (2005). Planning for the future with adults with a learning disability living with older carers. *Housing, Care and Support*, 7(3), 20-24.
- Hafen, M. & Sörensen, S. (2008). Preparation for future care needs by parents providing care for their adult offspring with disabilities. *Illness, Crisis & Loss*, 16(1), 37-51.
- Harre, R. & van Langenhove, L. (1999). *Positioning theory*. Malden, Mass: Blackwell.
- Henderson, J. (2001). 'He's not my carer—he's my husband': Personal and policy constructions of care in mental health. *Journal of Social Work Practice*, 15(2), 149-159. DOI: 10.1080/02650530120090601
- Holland, K. & Blood, R. W. (2008). *Carers' perspectives on caring: A qualitative analysis of open-ended responses to the Carer Health and Wellbeing Index survey 2007*. Deakin, ACT: Carers Australia.
- Hughes, N., Locock, L. & Ziebland, S. (2013). Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Social Science and Medicine*, 96, 78-85.
- Jenkinson, S. (2008) *Disability: Local, National and International Trends*. Western Australia: Disability Services Commission.
- Jokinen, N. S. & Brown, R. I. (2005). Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research*, 49(10), 789–793.
- Lincoln, YS. & Guba, EG. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.
- QSR International (2012). NVivo qualitative data analysis software, Version 10. QSR International Pty Ltd.

- O'Connor, D. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*, 21, 165-174.
- Petriwskyj, A. M., Franz, J. and Adkins, B. 2016. Parents, services and system: An exploration of power dynamics in future planning among parent carers for people with disability. *Disability & Society* 31 (8): 1081-1097.
- Prosser, H. (1997). The future care plans of older adults with intellectual disabilities living at home with family carers. *Journal of Applied Research in Intellectual Disabilities*, 10(1), 15-32.
- Rix, J. & Paige-Smith, A. (2008). A different head? Parental agency and early intervention, *Disability & Society*, 23(3), 211-221.
- Sanderson, H. (2000). Person-centred planning: Key features and approaches. Available online at www.familiesleadingplanning.co.uk/.../pcp%20key%20features%20and%20styles.pdf.
- Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63–75.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.
- Todd, S. & Shearn, J. (1996a). Struggles with Time: The careers of parents with adult sons and daughters with learning disabilities. *Disability & Society*, 11(3), 379-402.
- Todd S. & Shearn J. (1996b) Time and the person: the impact of support services on the lives of parents of adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 9, 40-60.
- Walden, S., Pistrang, N. & Joyce, T. (2000). Parents of adults with intellectual disabilities: Quality of life and experiences of caring. *Journal of Applied Research in Intellectual Disabilities*, 13, 62-76.

Ytterhus, B., Wendelborg, C. & Lundeby, H. (2008). Managing turning points and transitions in childhood and parenthood: Insights from families with disabled children in Norway. *Disability & Society*, 23(6), 625-636.