"Futures planning - adult sibling perspectives"

Summary

15 adult siblings of people who have a learning disability were interviewed in relation to their future wishes and expectations of care giving. Interpretative Phenomenological Analysis (IPA) was used to analyse transcripts from the interviews where it was demonstrated that futures planning remains an area of difficulty for families of learning disabled people. The range and degree of plans in place were variable across the families and overall, plans tended to lack detail and clarity. Various factors were cited as hindrances to the futures planning process such as parental anxiety, difficulty with service providers, superstition, attitude, assumption and life stage. Futures planning presented as a transitional process and further research into how best to support families and individuals who have a learning disability to develop long term yet flexible plans is indicated.

Introduction

Planning for the future tends to be a topic that is avoided as individuals may accept that decline and dependency take place but generally do not apply this to themselves (Weinstein 2003). From a previously published literature review (Davys et al 2011) however, it is apparent that futures' planning is an area of concern within the field of learning disability. Older parents and carers may have specific concerns such as the level and quality of care available from service providers (Gilbert et al 2008), and worry about the role of siblings (Taggart et al 2012). Adult siblings are similarly concerned about the future, specifically when parents are unable to provide previous levels of support (Orsmond and Seltzer 2007). Some siblings have expressed pessimism about the future and concern about their ability to provide a similar level of support to that provided by parents. They have also raised concern about managing the care needs of the disabled person, financial and legal responsibilities (Economic and Social

Research Council 2011), the needs of their own families and a lack of appropriate services (Davys et al 2010).

Presence of futures plans:

According to the literature, the number of families who have made plans for the future is variable. Plans may relate solely to where people will live (residential plans) or consider wider aspects (futures plans). Heller and Kramer (2009) report that only 32% of families in the USA had made residential plans. Jokinen (2008) noted that there was disparity in the level of futures planning between families from a Canadian perspective, whilst within the UK, Bowey and McGaughlin (2007) reported that around 50% of families in this position had made a futures plan. Dillenburger and McKerr (2010) claimed that most families did not have a plan and similarly low proportions of plans were reported by Davys et al (2010). Where plans have been seen to exist, the degree of depth and detail has been inconsistent (Taggart et al 2012).

Perceived barriers to futures planning

A range of factors may affect futures planning, the first being that some families do not feel ready to plan or believe that support will be provided as required (Dillenburger and McKerr 2010). Other impediments include a lack of information on issues such as guardianship, legal matters, housing options, finance, support networks and advocacy (Arnold et al 2012). Joint working between families and service providers can also be problematic due to perceived or real lack of co-operation between family members and care providers (Bhaumik et al 2011). It has also been claimed that some older carers have been reluctant to relinquish a parental role and that some services providers hold negative opinions of families of people who have a learning disability viewing them as selfish (Smith and Tobin 1993), motivated by financial gain (Grant 2001) and as impediments to independence (Scelles 2002).

Even when future plans have been discussed within the family, evidence of inter-family diversity and confusion is present. Krauss et al (1996) demonstrated that in 22% of American families where siblings expected the person with a learning disability to live with them, their parents had also put the name of the disabled adult on a waiting list for residential services. This could indicate divergence of opinion within the family or a desire on the part of parents to have a contingency plan.

In addition to the impediments already cited, some individuals with a learning disability lack awareness of changes in their health and social situation which makes it difficult for them to make an informed choice for their future. Some family carers claim that individuals may not want to move away from the family home and a further complexity is that some may support an older carer (Heller 2000). In studies where people with a learning disability have discussed options for the future, plans have tended to be vague, although a preference to stay in the local area near family and friends has been expressed (Bowey et al 2005).

Rationale

The need to address futures planning within the field of learning disabilities has been raised at national level in documents such as Family matters: counting families in (Department of Health (DoH)2001) where the unique and complex nature of caring between family carers and adult who have a learning disability was presented. Similarly the Valuing People Now: Summary Report March 2009 – September 2010 (DoH2010) refers to the need for alternative accommodation and choice for individuals who have a learning disability and their families. At an individual level, adult siblings of individuals who have a learning disability commonly expect some degree of future care giving. Of particular concern however is the life stage when older carers are not available (Benderix and Sivberg 2007; Orsmond and Seltzer

2007) and there seems to be an expectation within families and wider society that siblings will take on some degree of support in parental absence hence the need to study this topic. It is important to understand barriers to futures planning so as to better facilitate the process of transition and avoid inappropriate placements which are likely to cause significant distress to all family members.

Method

Semi-structured interviews were carried out with 15 adult siblings of people who have a learning disability. All interviews were audio-taped and an interview guide was used to focus questions on growing up with learning disability, current context and the future. Manchester Metropolitan University and Sibs, the UK charitable organization for people who have grown up with a disabled brother or sister provided ethical approval for this study.

Participants

Learning disability self help organizations in the North West distributed study information sheets and individuals who were interested in taking part contacted the lead author. The necessary criteria were that participants were an adult sibling of a person who has a learning disability and were aged 25 or over. Three men and 12 women were interviewed; their ages ranged from 30 to 64. 14 participants had white British ethnicity and one was Asian. Written consent was gained and the research aim reiterated before starting each interview. Two participants lived with the person who has a learning disability for 12 months or more following parental death, two continue to cohabit with the individual and expect this to continue in the long term, and one participant lived with her brother until his death.

Data analysis

Data was analysed using an Interpretative Phenomenological Analysis (IPA) approach (Smith and Osborne 2008). Following transcription, superordinate themes and corresponding subthemes were identified. The presence of themes were identified and recorded in theme and evidence charts using participant quotes which were then checked by the research supervisors for credibility. The following superordinate themes emerged from the data; Impact upon sibling lives, Family, Impact upon person with a disability, Social response, Transitions, Services, The future and Sibling needs and advice. This paper only presents the theme “The future”.

Within the analysis and reporting of these results, pseudonyms were used to maintain anonymity.

Results

The superordinate theme “The future” appeared in all interviews and incorporates subordinate themes of futures planning; future expectations and wishes; and concerns for the future.

Futures planning

Five respondents claimed that futures plans were discussed overtly within their family, although on deeper exploration, planning tended to be partial and cover financial issues rather than be comprehensive. A further five interviews stated that futures plans were not an open topic for discussion. Reasons for this were varied but included fear of the future and parental belief that only they were able to provide the appropriate level and quality of care. Superstition that open discussion of the future may pre-empt parental death or would cause distress to parents were other reasons for non-discussion.

11 participants referred to the existence of futures plans which took different forms: a verbal understanding of future care was noted in six interviews; an end of life plan; a financial or advocate plan; an unspecified written plan; and a five year unspecified plan. Two participants said that both they and their parents were clear that the demand upon services will increase over time rather than the parent or sibling resuming care:

> *"I think we (mum and respondent) are both aware, that as time goes on, ... she (person with a learning disability) almost relives her life backwards ...she started fully staffed and has almost got less and less support - that as time goes on, she will have to have more support. But we are very clear that she will do that: she won't come to us and then try and get somewhere... as things happen, the sliding scale will have to happen." Rachel P22 line 2*

The final comment above could suggest that although plans may be conceptualised at a given time, futures planning is a transitional process which is supported by the fact that eight respondents indicated that their plans were unclear. Overall, there was a lack of detail regarding futures plans. Some rationale as to why plans were not fully formed was given, such as siblings reacting to situations as they arose. Others assumed that someone within the family would provide care, or said that they did not know who to approach. Life stage for example working full time or having children at home was cited as a rationale for lack of planning as was siblings being unsure about their future wishes.

Future expectations and wishes

Three respondents claimed that although parental wishes were not verbalised, there was a clear understanding that parents wanted the person with a learning disability to remain with the family. Ten participants stated that overt verbal discussion about the future had taken place with their parents. Parental expectations were variable as was the degree to which parents expected siblings to be involved. Some parents wanted the disabled person to live with a sibling after their death, yet others expected that although the non-disabled siblings would provide support, co-residence was not assumed. Although parents may expect siblings to provide future support they also anticipated increased input from services.

Two siblings claimed that they had been given an explicit understanding in childhood that their mothers did not expect future co-residence. This understanding however, was perceived to change as parents aged:

> *"...she (mum) always says that she'll haunt me if I do things (for the disabled sibling) but she says it less and less, the older she gets ... I'd say as when we were kids... I'd say, 'Oh Amy will have to come and live with me', and she said, 'Well if she did, I'd haunt you' ...." Rachel P2 line 27*

For certain respondents there was no expectation of change from their current situation, whether this involved co-residence or not. Alternatively, some expected their future level of care to increase significantly and intended to incorporate change, such moving house or take on a parental role, as presented by Helen:

> *"...if my parents can't do that (sort out services) then somebody's going to have to......so I would do that, and if that meant moving home, working part time, so be it - that's what I would do...." Helen P10 line 21*

Other anticipated support roles included financial management and general responsibilities for example dropping off groceries, providing transport to and from appointments and acting as an advocate.

Although some siblings said that they expected to be more involved in the future, they did not plan co-residence and gave different reasons for this. Rachel felt that her sister would destroy every important relationship in her life; Kevin felt that the toileting needs of his sister and work commitments were a barrier; whilst Fran claimed her work commitments and outdoor lifestyle would prohibit cohabitation. Maali and James wanted increased input from services in the future; whilst others wanted increased family support. Some participants however, were unclear about the future; which may link back to the concept that futures planning is transitional.

> *"...will I move back to be near Fiona one day... It's hard cos I can't make my mind up which way I see it." Steven P 23 line 11*

Sometimes respondents gave a conflicting impression of family wishes and expectations of future care which further supports the notion of ongoing transition.

Two participants noted conflict between their wishes for the future and parental wishes**.** Claire described how her parents expected her brother to live with her after their death however she wanted him to be supported in the community. The rationale given for difference in expectation was that parents had grown up in a different era. Helen outlined the opposite situation: her parents wanted her to have an independent life yet her stated wish would be to take on their role in the future:

> *"I think their idea would be...I'd have the same level of involvement as I do now ... not changing anything in my life specifically because of him... and that's not the way I see it (laughs)... They don't want my life to be dictated by him;... but if push came to shove, I couldn't do it (laughs) - I couldn't live with it." Helen P10 line 10*

Her rationale for wanting to take over the parental role was that her brother has always been part of her life however the final part of the quote may suggest that guilt could also be a motivating factor. Nine other respondents reported alignment between their future wishes and parental wishes which could infer that overall, sibling and parental wishes concur.

Three siblings made reference to the future wishes of the person with a learning disability. James and Carol claimed that their siblings were happy to continue living with them, whilst Janet thought that her brother would want the same as her, which is for them to be neighbours.

Concerns for the future

All participants made reference to their own worries and parental concern regarding the future. Parental concerns voiced by Steven and Carol presented a generalized fear about the future whilst Kath described her mother`s concern that no one else could provide the same standard of care. Only one sibling had no particular concerns about future care as she felt confident in her brother's care package. Participants worries related to service provision, funding and parental death. Siblings were also worried about how they would cope without their parents and increased care demands. Additionally there was concern about how the disabled person would respond to maternal death and divided loyalties between family members. Health concerns for the disabled person and siblings own health and ability to provide a care role caused further distress whilst Val suggested that her anxiety was caused by a lack of planning and information on available resources:

> *"I've only just started thinking about that (future care) and I've not done anything about it yet but it has been on my mind... I never made a will because I don't know who would have Phil and so I tend to bury my head in the sand; I certainly wouldn't want him to go into a home ...and quite honestly, I don't know who I'd ask." Val P 16 line 9*

Discussion

Impact of learning disability upon the future

The findings of this study and earlier research (Davys et al 2010) demonstrate a fairly equal division between families where futures planning is openly discussed and those where it is not, providing some contrast to other findings (Dillenburger and McKerr 2010) and therefore drawing attention to the multiplicity of family response to futures planning. The results presented here demonstrate that futures plans tended to be verbal rather than written. Different types of plan were reported and although five respondents claimed that futures planning was not an open topic of conversation, many voiced a clear understanding of parental expectation which may be associated with family culture. The lack of detail in futures plans could also provide evidence for the view that this is a transitional entity.

The reasons why open discussion around futures plans had not taken place were varied. Participants referred to parental fear and distrust of services which add to the view that futures planning is stressful for parents as endorsed by previous research (Taggart et al 2012).

One theoretical perspective that may explain the apparent unwillingness of older carers to engage in futures planning is that of unrealistic optimism (Weinstein 1980, 2003). This theory suggests that individuals may generally accept that decline and dependency occur, but tend not to accept this for themselves. This could lead to an overestimation of the carer's ability to provide support and evidence for this theory within learning disabilities is provided by Gilbert et al (2008) who identified that one of the reasons carers gave for not making futures plans was the feeling that they were still coping.

The literature refers to insufficient information and difficulty with service providers as barriers in planning (Heller 2000). It could be that changing policy and resource contexts such as the "Personalisation agenda" may affect family willingness to engage in futures planning however this study presents barriers of a laissez-faire attitude, superstition, and the assumption that 'someone' in the family would provide care. Additional reasons included life stage, living in the present or next anticipated life stage, and not yet being sure about future wishes which further illustrates the view that futures planning is a developmental process.

The results of this study present sibling perception of parental wishes; sibling wishes and expectations; and sibling perception of the wishes of the person with a learning disability in some cases. Parental wishes and expectations were varied, some expected the typically developing sibling to take on the role of over viewer; others expected co-residence, whilst others again expected non-residence. Previous studies have demonstrated mixed results regarding parental expectations of sibling support in this situation (Dillenburger and McKerr 2010; Taggart et al 2012) and some participants in this study perceived parental expectations of sibling involvement increased with age.

In terms of sibling wishes and expectations, some expected no change and appeared content with existing care arrangements whether this involved co-residence or not. Others expected to increase their level of involvement in the future, for example moving house, and many expected financial involvement. Some siblings did not want co-residence for reasons that included life style, work, gender and conflict in relationships. At times, participants were unclear about what sort of support they would offer in the future, which reinforces the premise that futures planning is a transitional entity.

Previous studies point to a variety of sibling wishes and expectations regarding future care which may be linked to variables such as proximity, life circumstance and life stage (Kramer 2008; Burke et al 2012). The significance of life stage and expectation to provide care has been highlighted by Burke et al (2012) who found that siblings had a greater expectation to provide future care when parents were able to provide support, however this expectation diminished with parental decline.

Reasons that may help understand why siblings commonly provide support can be reviewed from various theoretical perspectives. In Bowlby's life-span attachment theory (1969), one sibling role noted is the maintenance of family tradition and knowledge. Further theoretical perspectives include the symbolic interactionist view of negotiation (Finch 1989; Finch and Mason 1993) which claims that roles and responsibilities are influenced by factors such as relationships, gender, class and ethnicity, whilst the hierarchy compensatory model (Cantor 1979) states that siblings may provide support in the absence of other support networks.

The convoy model of social support (Antonucci and Akiyama 1987) could explain why futures planning is a transitional process as here networks of support are seen as constantly changing. This could explain the difference between actual and anticipated support as well as variation in levels of support over time and gives further strength to the view that futures planning is a transitional entity. Due to variation in family culture, values, individual life stage and circumstance however, it remains difficult to apply one theoretical framework to explain the impact of learning disability upon futures planning.

When comparing and contrasting siblings wishes and expectation for the future with parental expectation, most respondents reported close alignment, although two participants stated that their wishes were opposite to parental wishes. Alignment of wishes could be attributed to the impact of family culture and parental attitude (Scelles 2002). In contrast, dissension between parental and sibling wishes was found by Knox and Bigby (2007); yet the view that family values and roles need to adapt over the lifecycle was upheld. This shift in sibling roles over time further highlights the changeable nature of futures planning and care giving (Hodapp and Urbano 2007), whilst perceived change in parental wishes over time and lack of clarity regarding future plans adds further weight to this perspective.

Only three respondents referred to the future wishes of the individual with a learning disability. This could indicate that siblings are not aware of what the individual wants, have not been involved in futures planning, or that the needs and wishes of people who have a learning disability are overlooked; as indicated within the literature.

Having outlined sibling wishes and expectations for the future it is clear that most respondents, (and their parents), were worried about the future. Siblings claimed that parents were concerned about service quality and availability, whilst siblings themselves were concerned about service provision and financial issues which echo earlier studies (Orsmond and Seltzer 2007). Death was also a worry as was increased care demands, divided loyalties between siblings' own lives and the disabled person, and issues regarding siblings' own health and that of the disabled person.

Limitations

It is acknowledged that family culture, values, and structures are diverse as is the range and impact of learning disability upon individuals and families. 15 participants provide a small sample however as a methodology, IPA is ideographic (Yardley 2008) and the themes generated are acts of interpretation on the part of the researcher. It may also have been useful to compare the issues of futures planning between those people who have a learning disability and those who do not, to consider the impact of changing policy and resource contexts and any association between level of independence and sibling levels of engagement within futures planning however this lay outside the remit of this paper. To support credibility interviews were transcribed verbatim, participant quotes were used extensively to provide evidence for themes and were checked for congruence by the research supervisors.

Conclusion

The results presented here add to the knowledge that futures planning is an area of difficulty and complexity within learning disabilities. Futures planning was said to be an open topic of conversation in certain families but not in others. Where futures plans did exist, they tended to lack depth for reasons that included: assumption of care by others, a laissez-faire attitude, superstition, siblings not being sure what they want and life stage. Parental expectations of siblings' future involvement were vocalised in some instances yet where they remained unspoken, siblings often noted a tacit understanding. Parental expectation of co-residence was mixed yet overall parents expected increased levels of sibling involvement in the future and some participants noted increased parental expectation over time. Siblings' wishes regarding future involvement were equally inconsistent, all of which supports the view that futures planning is a developmental entity. Although there was some difference between sibling and parental wishes for the future, they were often aligned. Most siblings were concerned about the future and in particular service provision, finance, increased responsibilities after parental death and health issues. Due to the transitional nature of futures planning, the anxiety this topic engenders and the potential for harm that inappropriate placement may cause, a clear practice implication is that new and innovative ways in which to engage and support families in futures planning are urgently required. Statutory and voluntary service providers need to involve siblings in futures planning from early adulthood and imbed this within policy and practice. In addition, a long term perspective of futures planning is required that will consider the needs and wishes of siblings within this process and adjust plans to reflect family life stage, context and events. Services also need to provide advice and support to siblings over the life course and in particular when parental ability to provide support declines.

Conflict of interest

This study was undertaken as a doctoral study from Manchester Metropolitan University by the first author. There is no conflict of interest or financial gain for any of the authors.

Participant	Age and gender	Living situation	Ethnicity
1 (sister to participant 15)	53 (f)	Participant lives with husband. Brother with a learning disability lived with participant 15 until his death.	White UK
2	50 (f)	Participant lives with husband and children. Brother with a learning disability lived with her for over 12 months following parental death and now lived in community supported accommodation.	White UK
3	30 (f)	Participant lives alone. Brother with a learning disability has shared care between parents and a community based home.	White UK
4	49 (f)	Participant lives with partner. Sister with a learning disability lives in supported community accommodation.	White UK
5 (sister to participant 11)	56 (f)	Participant lives with husband. Sister who had a learning disability lived in various institutions and supported community living until her death.	White UK

6	43 (f)	Participant lives with partner. Brother who has a learning disability lives in the family home with their mother.	White UK
7	38 (f)	Participant lives with husband. Brother who has a learning disability lives in the family home with their mother.	White UK
8	36 (f)	Participant lives with children (husband living abroad and participant due to join him in near future). Sister who has a learning disability lives with husband (without a learning disability) and child in the community.	Asian
9 (sister to participant 10)	64 (f)	Participant lives alone * Sister who has a learning disability lived with her for 12 months following parental death but has now moved to supported community accommodation.	White UK
10 (brother to participant 9)	49 (m)	Participant lives with partner. Sister who has a learning disability lived with his sister (participant 9) for 12 months following parental death but has now moved to supported community accommodation.	White UK
11 (sister to participant 5)	65 (f)	Participant lives with husband. Sister who had a learning disability lived in various institutions and supported community living until her death.	White UK
12	34 (m)	Participant lives with partner. Sister who has a learning disability lives in 24hour supported accommodation in the community.	White UK
13	68 (m)	Participant lives with sister who has a learning disability since parental death.	White UK
14	61 (f)	Participant lives with husband and brother who has a learning disability since parental death.	White UK
15 (sister to participant 1)	48 (f)	Participant lives with husband and brother who had a learning disability until his death.	White UK

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