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Older parents of people who have a learning disability : perceptions of future accomodation needs

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Title Page

Short title:

Older Parents of People who have a Learning Disability – Perceptions of Future
Accommodation Needs.

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The Perceptions of Older Parents of Learning Disabled People on the Future
Accommodation Needs of Their Adult Children.

Key words:

Learning disability, older parents, futures planning, parental concerns, accommodation
needs, parental role

Summary

The aim of this qualitative study was to provide an insight into the perceptions of older parents of learning disabled people on the future accommodation needs of their adult children. Semi-structured interviews were used to seek parental awareness of residential options available, concerns in relation to future accommodation and the preferred accommodation options for their offspring. Four couples who shared the family home with an adult who has a learning disability took part in the study and data was analysed using a step by step form of content analysis as described by Burnard (1991). Emergent themes from transcripts were then organised into main categories

The results of this study suggest that older parents are dissatisfied with both statutory and private services, that they have concerns for their non-disabled children and their own ageing. Being a parent to a person who has a learning disability is seen to be a difficult

task and yet parents may want to provide support at home for as long a possible. Of the parents who participated in this study, three couples wanted to maintain their adult child at home for as long as possible and the parents who were actively seeking accommodation outside the family home expected to be involved in all aspects of their daughter's care for the long term future.

Word count 218

Accessible Abstract

- This study looked at where parents think people who have a learning disability may live when parents are not able to give support at home.
- The study showed that parents were not satisfied with services and that they worry about the future and getting older.
- Parents feel that supporting a son or daughter who has a learning disability is a difficult job but they want to give support for as long as possible.
- Parents are worried about what the brothers and sisters of people with a learning disability may have to do in the future.

This study is important to people who have a learning disability because parents will not always be here to help.

Introduction

Parents of adults who have a learning disability are growing in number due to advances in health and social care (Dowling and Hollins 2003). As a nation, we are dependent upon the support provided by these families and finding accommodation for this group of learning disabled people is now considered a priority as outlined in the government white paper Valuing People: A New Strategy for Learning Disability for the 21st Century (Department of Health 2001). Within this paper, local authorities were charged with the need to identify and support carers over the age of seventy and according to Morgan and Magrill (2005), there have been improvements in services and support to older families at local level but such improvements are variable and influenced by short term funding. Other policy initiatives such as the National Service Framework for Older People (Department of Health 2001) and the National Health Service Plan (Department of Health 2000) call for services to work in partnership with older people whilst Our Health, Our care, Our say : A new direction for community services (Department of Health 2000) calls for the extension and promotion of carer's rights. Alongside Valuing People (Department of Health 2001) and the National Service Framework for Older People (Department of Health 2001), this paper supports the co-ordination of services across health and social care and promotes the use of Personal Health and Social Care Plans by 2008 for those people who have enduring health and social care needs. The aim of this study was to provide an insight into the perceptions of older parents of learning disabled people on the future accommodation needs of their adult children. Parental views were sought regarding awareness of residential options available, concerns in

relation to future accommodation and the preferred accommodation options that parents want for their offspring.

Literature Review

Many parents may presume that as their children become adults, they will ultimately live away from the family home. For the parents of someone who has a learning disability, this expectation may be more difficult to realise as the need for care and support may be both ongoing and long-term (Mencap 2002). The extended carer role of these older parents has significant dimensions and implications for their lives as well as the lives of their adult children and finding appropriate accommodation for this group of people is now considered to be a priority by the government within the White Paper Valuing People (2001) and relevant organisations such as the British Institute of Learning Disabilities (BILD 2005) and The Foundation for People with Learning Disabilities (2005).

Parents of dependent adult children are not easily able to remove themselves from concern regarding the future care of their offspring. Grant (2000) supports this view, claiming that parents of learning disabled people have an on-going parent / carer role and that they often continue to provide a home and support. As such, it is difficult for these parents to have the “typical” lifestyle of parents of a similar age and therefore they may harbour fear and anxiety regarding the unfinished business of parenting and worry about the future.

From an historical perspective, it is clear that real and significant tensions exist between parents and service providers. According to Thompson (2001) older parents of learning disabled people have been alienated and had their needs and wishes ignored by statutory services despite providing a lifetime of care and support. As a generalisation, there appears to be a lack of trust in services; for example, Burke et al. (2001) found that families felt services ignored their intimate knowledge of their sons/daughters. Other reasons why parents preferred not to use services included a lack of consistency, high turnover of staff within learning disability services and difficulty in accessing services at times that met carer needs.

Proactive planning is a fundamental requirement for families where a person has a learning disability and will require carers to have a comprehensive list of options. Such planning may take years or months to achieve rather than weeks or days and is understood to be a stressful process for both parents and the adult child (Jokinen and Brown 2005). This stress may be compounded by the fact that older parents tend to have fewer plans for the future in place, which Thompson (2001) attributes to a lack of available information, isolation from services, not having a named key worker and lack of services available to minority ethnic groups. It is possible that such issues add to the existing tensions between parents and service providers.

Research carried out by Burke et al. (2001) contradicts the findings of studies by Small et al. (2003) and The Sharing Caring Project (1997) by claiming that as parents age, they do want arrangements to be made regarding the future care of their children before they become too frail or ill to be involved. Parents do, however, want plans to be appropriate and they are concerned about the limited options available, especially where people have more care needs. Parents also want increased access to community based services that would allow them to remain actively involved and maintain a positive relationship with their offspring. The wish to maintain an on-going role was seen as significant to parental health and wellbeing, and was linked with parental sensitivity to the vulnerability of their child.

Aim of the Research

The aim of this study was to provide an insight into the perceptions of older parents of learning disabled people on the future accommodation needs of their adult children.

Ethics

Before any part of this research was undertaken, ethical approval was gained from the university and local social services. All participants were asked to provide written consent and were informed of where and how the research results may be disseminated. Parents were assured that the identity of participants would be kept confidential (Polit et al. 2001).

Method

Semi-structured interviews were used to collate the data. An interview schedule with specific questions was drawn up which focused upon the research aims (the interview questions can be found in Appendix 1). Four couples participated in the study and were interviewed in their own home. One parent in each couple was aged at least 65. Three couples were interviewed about their birth child and one set of parents was interviewed about their foster child who had lived with them since he was fourteen months old and who they regarded as their own child. Parents provided varying degrees of support and in two families, adult children were dependent on their parents for all personal and domestic activities as well as behaviour management. The interviews lasted for approximately one and a half hours and were audio-taped. Brief notes were taken throughout the interview in order to record key points and were read back to the interviewees at the end of the session for verification and as a method of triangulation. Respondents were offered a copy of the final research paper on completion.

Analysis

A step by step process related to content analysis and similar to that described by Burnard (1991) was used to analyse the data from this study. Emergent themes from the transcripts were organised into main categories. These categories were discussed with the research supervisor and then further refined.

Results and Discussion

From the transcripts, six key themes were generated and occurred in at least three of the four interviews. The themes “Dissatisfaction with Services”, “Siblings Issues”, and “Financial Issues” arose from all four interviews, whilst the themes “The Difficulty of Being a Parent to a Person with a Learning Disability”, “Providing Support at Home for as Long as Possible” and “Parents being Aware of their Own Ageing” were generated from three of the four interviews. Other themes were generated from the interviews but are not presented due to time constraints and the wish to present the most commonly occurring themes. Although the sample group is small and may not be generalisable to the wider population of older parents, Polit et al (2001) condone the use of a small sample size within phenomenological studies. The results of this study will serve to contribute to the existing body of knowledge in this area and explain the concerns of a small group of parents regarding the provision of care that is outside parental control.

Dissatisfaction with Services

This was the strongest theme across the four interviews with regard to how many times this topic came up during the conversations. Dissatisfaction incorporates a number of elements and includes anger at service providers, a sense of having to fight to get what you want, distrust of services, a sense of parents and service providers being on opposing sides and a feeling that services provided are not what parents want and lack quality.

The parents in interview A demonstrate a number of these elements when they describe how they think social workers view them

“...they think we’re a load of hassle and we are a load of hassle because we do complain and we do complain at the right place and they certainly find out what it is that we are thinking about..”

Such dissatisfaction would appear to support the view that historical tensions have existed between parents and service providers as described by Beail (1999).

Although there is clear evidence to suggest that the parents within this study were dissatisfied with service providers, this has not led to a lack of futures planning as suggested by Thompson (2001). All of the parents interviewed within this study had carefully considered the future and had plans and wills in place, apart from the family in the foster care situation who had been advised not to do so legally.

Sibling Issues

Issues related to siblings were raised throughout all interviews and took two main sub themes, firstly that siblings (all non- learning disabled) need to have their own lives but secondly, that these siblings would have an ongoing involvement in the lives of the adult who has a learning disability for the long-term future. Within interviews A and B, the parents acknowledge both themes within the same sentence. From interview A the statement is made

“I’ve got to consider our daughter, cos over the years... we’ve worked very hard not to pile the problem onto her own back, she has her own life and I’m happy

that she has made a good life for herself, but we know that she is going to be restricted to a certain degree because we know that she will do the job of (son) well when we go..”

A recent study by Jokinen and Brown (2005) echoed the results of this study in that one of the main concerns highlighted by older parents was the role of siblings when parents are no longer available. This study found that siblings often take on care giving and support roles for their learning disabled brothers and sisters when parents are no longer able to provide care, but it was also found that not all non-disabled siblings are willing to take on this role and equally, not all learning disabled siblings wished them to do so.

In reference to the role of siblings in futures planning, McCallion and Kolomer (2003) claim that this is an area of research which is both unclear and under-developed. A study carried out by Heller (2000) found that of families who had futures plans already in place, nearly half wanted family members to provide accommodation in the future. In contrast, research carried out by Rimmerman and Raif (2001) found that of those families with futures plans in place, approximately one third intended to co-reside with their learning disabled sibling whilst two thirds intended to live apart.

Financial Issues

Financial considerations cover a range of sub-themes that include the fact that parents have to pay for services they receive, and there is a link between what parents may feel that they need and what they are able to afford. Redmond and Richardson (2003)

demonstrate that caring for a child with a disability can lead to a negative impact upon the financial situation of the whole family. There may be the financial costs of specialised equipment, transport, clothing and higher laundry costs, but in addition to this, the care needs may affect the parents (especially mothers who commonly have the main carer role) ability to take up paid employment. The family capacity to generate money therefore is reduced in a situation where there are increased financial demands. Elements of this concept can be seen within this study from interview A when the mother says in reference to her work life

“...mine has been limited from a work point of view ...I have had to give up certain things to be here...”

and within interview C, the mother says of the father

“... he had to turn down no end of higher up jobs and to concentrate on what was going on at home...”

All parents within this research raised the issue of money in different ways which would suggest that this is an important concern. It may also be the case that finances form part of the ongoing tension in the relationship between parents and service providers as parents feel that the services they receive are not of the required quality and level they desire.

The Difficulty of Being a Parent to a Person who has a Learning Disability

Three of the four interviews raised this theme which embraces a range of beliefs including:

- the view that only other parents of learning disabled people can truly understand their unique perspective
- that parents have an extra sense of responsibility and concern for their learning disabled child compared to non disabled children
- that caring for a person who has profound and multiple needs which incorporates challenging behaviour, is hard work both physically and mentally

The mother (foster) in interview D outlines some of the demands made upon her in the night

“...he starts banging or if he’s not tired, he gets out of bed and we have to put him back. He puts his head between his knees and bangs, and he makes himself bleed so we have to try and stop him from doing that which is very hard as he’s so intent on doing it...”

Parental anxiety is a facet which can be considered in tandem with this theme. Both Burke et al. (2001) and The Sharing Caring Project (1997) identify that parents become increasingly concerned about the future of their children and the word “worry” was used directly in two of the four interviews within this study when parents were talking about a future when they are no longer available to provide support or oversee service provision. Heller (2000) claims that parents in this situation have to confront both their own mortality and attempt to disengage from their lifelong role as carer.

Providing Support at Home for as Long as Possible

Three out of the four sets of parents wanted to maintain their current situation of supporting their adult child at home for as long as possible. This was their stated ideal scenario and had some links with wanting to avoid sons and daughters being forced to move several times which parents believed would be distressing and upsetting for their offspring. Of these three sets of parents, all presented a vision of remaining at home with their adult child and having support come into the home either in the form of external services or family in the event of their being unable to provide direct support. One parent commented

“..we plan to look after (foster son) as long as we are both able to or even if one of us can't do the lifting, we've got our son next door to help...”

It may be possible that this desire to provide care for as long as possible and involve family members is linked to the barriers, lack of trust and dissatisfaction that is seen to exist between families and service providers as demonstrated within the first theme. According to Smyth and McConkey (2003) over half of the parents in their study stated that they would like to see their child living in the family home in the future and where this was not possible, the next most popular option was for their child to live with a family member.

Parents Aware of their Own Ageing

Within this theme the physical impact of ageing is one component that is brought to the fore. The mother in interview A states

“...I mean we look healthy and I suppose we are, but sometimes you wake up in the morning and you very much feel 70 odd...”

Two out of the three parents who demonstrated an awareness of their own ageing still asserted their wish to continue in their role as care providers for as long as possible. This may again link back to the issue of distrust and general dissatisfaction with service providers and the belief that only the family are able to provide the most dedicated care (Smyth and Mc Conkey 2003).

Limitations

As this is such a small group of respondents and the study is set within a phenomenological frame of reference the results cannot be considered as generalisable to the wider population of older parents who live with their adult children who have a learning disability (Seal and Barnard 1998). Despite this, Polit et al (2001) support the use of a small sample size within phenomenological studies. In order to improve the generalisability of this study, a cross sectional design could have been used to consider the perceptions of older parents of learning disabled adults across England (Holloway and Wheeler 2002) whilst a longitudinal study may have presented the evolution of parents perspectives over a period of time (Polit et al. 2001). All participants interviewed presented as having a white English ethnic background and therefore older parents from a different ethnic background may have raised alternative concerns and perspectives. It is also acknowledged that all interviewees had a partner which may affect the results as the perceptions of older carers who are single may be different to those represented.

Furthermore, this study provides a focus solely on the perceptions of older parents and not people who have a learning disability.

Qualitative research is considered to have increased rigour through the use of reflexivity (Coneeley 2002) and as such the researcher accepts the likely impact of personal behaviour, values and biases upon the results of this study (Finlay 1997) and that both quality and rigour would have been enhanced by spending more time with respondents (Hammell at al. 2002). Attempts at maintaining quality and credibility, however, were made by checking key points with each interviewee immediately after the session, the use of a research diary, and cross checking between transcripts and the research diary to ensure that themes reported in the results were present in both places.

Conclusion

This small scale qualitative study aimed to provide an insight into the perceptions of older parents of learning disabled adults on the future accommodation needs of their sons and daughters. Dissatisfaction with services was the strongest emergent theme across the interviews and appears to be woven throughout the other emergent themes. As there was such a low response rate, however, it may appear that futures planning for people who have a learning disability is an anxiety provoking and sensitive area for older parents. Within this scenario, parents may have to contemplate a future when they are no longer able to continue their life-time's role as carer and rely upon services that they do not trust, yet equally, they wish to avoid placing a perceived burden their non-disabled offspring.

Parents highlighted some of the difficulties in being a parent to a person who has a learning disability. Parenting is a hard task, both physically and mentally and whilst parents are aware of their own physical ageing, they affirm their desire to remain actively involved in the carer role for as long as possible, even where accommodation is sought outside the family home.

All parents raised the issue of finance in different contexts which would suggest that finance is a significant matter and may further contribute towards the ongoing tension between service providers and parents as they feel that they are having to pay for services that are not of the quality and level they require.

Implications for the future

The results of this study suggest that despite changes in government policy, and the recommendations of agencies involved in learning disability and older people's services, some parents have significant distrust and concerns about future accommodation and, therefore, wish to maintain control for as long as possible by providing ongoing support in the family home. Even where a move away from the home is sought after, parents may wish to maintain control of what happens in all areas of their son or daughter's life. For older parents in this situation, it would appear that concern arises from internal issues, such as wanting to avoid placing a perceived burden upon siblings and adapting to their own physiological ageing. External pressures also exist such as social ageing, tensions with service providers and government policy. Recent policy recommendations and good

practice guidelines promote co-operative working and education between all stakeholders in both learning disability and older people's services. The results of this study would suggest, however, that policy makers and providers require a significant degree of understanding and sensitivity of these issues and the ability to acknowledge the wider human dimension and concerns of older parents in this situation so as to gain their active co-operation in futures planning which will consequently support the needs of people who have a learning disability.

Recommendations for future research:

It is suggested that further research may be indicated in areas such as comparing the results of this and similar studies with parental perceptions where adult children who have a learning disability have moved away from the family home. Also of value would be consideration of the difference that government initiatives have made to parental choice and options, and the impact of Fair Access to Care policy regarding carer support and preferences.

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3409 words from introduction to acknowledgements

Appendix 1

Questions asked within each interview:

1. Can you tell me your date of birth and that of your son/daughter?
2. How long have you lived at this address?
3. Who owns the property?
4. Can you tell me how long you have cared for your son/daughter at home?
5. How much care/support do you give your son/daughter on a daily basis?
6. Do you or your son/daughter have any form of support from social services or a voluntary agency e.g. day care or respite care?
7. Do you have any particular concerns regarding future accommodation for your son/daughter?
8. Are there any plans set up for the future if you are no longer able to provide support at home?
9. What do you think would happen to your son/daughter if you were no longer able to care for him/her at home?
10. Are you aware of what options could be available to you in these circumstances?
11. If you had freedom to choose, what sort of accommodation and support would you want for your son/daughter if you were no longer able to provide care at home?

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