

Older Carers and Adults with Learning Disabilities: Stress and Reciprocal Care

Valerie Gant ¹

¹ Edge Hill University

Older Carers and Adults with Learning Disabilities; Stress and Reciprocal Care

Valerie Gant

Abstract

People with a learning disability have an increased longevity. The majority of adults with a learning disability live with their parents which means that many of these parents are themselves elderly people. For the first time more adults with learning disability are outliving their parents. This paper presents some of the findings of a qualitative case study using interviews and focus groups with 24 carers and 14 adults with learning disabilities. It explores older carers' perceptions of stress and experiences of the longevity of care giving, together with the views of people with learning disabilities about their relationship with their parents. It shows that there is often mutual or co-caring between the older carer and their relative with a learning disability, and that the amount and quality of mutual caring is frequently overlooked by service providers and professionals alike. The findings highlight the complexity of ways that older carers make sense of, and develop strategies for, dealing with the effects of the longevity of care-giving, and their ambivalent relationship with social work and other professionals.

Key words: Learning Disabilities, Older Carers, Reciprocal Care.

Introduction

Although there is a considerable body of research regarding care-giving in general terms, little is known about the needs of older carers, their perceptions and experiences. One element of the research discussed in this paper is qualitative interviews held with 24 older family carers, also focus groups held with 14 adults with learning disabilities. There is a need to research, understand and record the perceptions of adults with learning disabilities about their relationships with their older carers. Traditionally, people with learning disabilities have been, 'Tested, counted, observed, analysed, described, and frequently pathologised.' (Walmsley, 2001 p.188) although their views have rarely been ascertained (Northway, 2003). As well as interviewing older carers this research study sought the views of adults with learning disabilities regarding life with their elderly parents. The shifting patterns of family life brought about in part by changing demography, alters the picture of informal care-giving. At one time thought to be the premise of unmarried daughters, the most frequent pattern of care-giving in England is now an older couple, both with care needs, engaging in reciprocal care. In a turn-around in roles within the household, adults with learning disabilities are now providing care for their elderly parents (Grant, 1986; Parker and Clarke, 2002; Prosser, 1997; Walker and Walker, 1998). Thus, the traditional patterns of care-giving and receiving are being questioned and the role and response of the local authority is ambiguous.

Study Design / Method

A methodology was sought for collecting data which would allow the lives of older carers to be structurally positioned in the remit of the local authority, and which would respect the sensitivity of the research issues and their impact on the participants. The methodology for the research project was framed around the existing literature on older carers of adults with learning disabilities. This reflected a high level of mistrust and reluctance to engage with formal support services (Bigby, 2004; McCallion and Tobin 1995; Walker and Walker 1998), and a feeling of being in conflict with professionals (Nolan and Grant 1989; Magril et al.,

1997; Qureshi and Walker 1989; Twigg and Atkin 1994; Williams and Robinson 2000). In light of this, a qualitative approach to data collection was seen as paramount. The sensitive nature of the research, coupled with the documented distrust of professionals meant that qualitative interviews were the only way to encourage people to tell their own stories. This method was chosen to allow older carers and adults with learning disabilities to vocalise their personal experiences of care giving/receiving and to address in some way the dearth of research from the perspective of adults with learning disabilities. Attempts were made to contextualize these perceptions and experiences, recognising the multiple reciprocal relationships that exist between older carers and adults with learning disabilities. To this end a multi-stranded qualitative approach was used. Use of focus groups for adults with learning disabilities living with older carers, and documentary analysis, has highlighted some of the personal and professional dilemmas to do with the effect of care on people's lifestyles. As Walmsley (1996) suggests, research to do with both learning disability and caring is rarely grounded in people's biographies. The same is true with care giving contextualized with support from local authorities.

I believe that it is an important principle in social work research to have a good knowledge of the context for your research. The uniqueness of my position as a social worker, researcher and mother of a child with a severe learning disability provided the necessary knowledge for the context of the research.

For the qualitative interviews the target population was people over the age of 60 who were carers for adults with learning disabilities living in the community. It was fundamental that people were participating from a position of informed choice. To enable this to happen I wrote to all older carers' giving copious information about the research project and about my background as a social work practitioner and carer of a child with a severe learning disability. In addition, a carer's link worker gave out information in person to older carers' she visited. The letters were followed up by a telephone call to establish willingness to participate, to further explain the research and answer any questions.

From those eligible to participate 25 expressed an interest/willingness to be interviewed; one later withdrew from the process stating lack of time as the main reason. A pilot study was carried out by a random selection of five participants from the 25, to test the interview process and identify any problems in the methodology. Following the pilot study no changes were required to the identified methodology.

Focus group participants were selected from a group of adults with learning disabilities who attended local authority day centres. Local knowledge makes it much easier to recruit for focus groups (Bunningham and Thrush, 2001). Using information held by the day centres it was possible to identify adults who lived with carers over the age of 60. The difference in my role of researcher as opposed to that of social worker was emphasised at all times, this was necessary as I had been visible at the day centre in my capacity as a social worker, prior to the present research.

A primary reason for holding focus groups at the day centres, and asking for participation from the attendees there, was that people who attended the day centres had experience in group work in various areas including advocacy. I felt that these experiences, combined with their familiarity with each other, would mean they were less likely to acquiesce and more likely to discuss their experiences and perceptions of the subject area. I felt this was important as adults with learning disabilities are rarely in a situation of power and have had little opportunity to express their views.

The participants were identified following suggestions by staff members at a day centre owned and managed by the participating local authority. The research aims were discussed

with staff who in turn asked for volunteers who they knew lived with older carers. Day centre staff were able to give prospective participants an explanation of the research aims to enable them to make a decision regarding their possible involvement; it was emphasised that prospective participants had a choice to be involved, and that their care would not be affected by their participation or otherwise. Staff at the day centre suggested prospective participants who they felt had the capacity to understand the research focus, and who were able to communicate verbally. This had obvious drawbacks for the representativeness of adults with learning disabilities. Issues remain about empowering adults less able to communicate to participate in research projects. I remain concerned that by only including adults with a reasonably high level of cognition and verbal skills I was perpetuating years of research 'about' adults with learning disabilities rather than 'with' adults with learning disabilities. I did not want the focus groups to be seen as a token inclusion in the research project, however, nor did I want to coerce unwilling participants to become involved in a process in which they had little control or understanding. This issue was discussed with the intermediaries at length; however, I eventually felt their opinion on participants' willingness and ability had to be respected. Given the timescale involved with the research project, and the resources available, I had no other way of accessing sufficient numbers of adults with learning disabilities. Whilst the views and opinions of those who participated in the focus groups were valid and pertinent I remain disappointed that these groups could be seen as unrepresentative of adults with learning disabilities who live with older carers.

Signed consent was obtained from people who chose to participate.

Generation of Concepts and Themes

Permission was obtained from participants to audio record the interviews and focus groups. I began this process by listening to the audio tapes several times until I was familiar with them. Notes were made of any areas that I considered to be interesting or significant. These themes were identified and marked. As the themes began to emerge I returned several times to the transcripts to ensure that my interpretation linked in with what the participant had said during the interview. I was then able to draw up a list of themes. Descriptive categories such as how they came to their caring career were separated from conceptual ones such as how they felt about their lives and their perceptions of themselves as carers.

It is considered good ethical practice to share with participants the findings and possible outcomes of a research project (Finlay and Ballinger, 2006). Within this research transcripts were checked by participants, and all participants have been informed of the main findings, with an option to read the final draft if they so desired. Continued dialogue between myself and supportive colleagues enabled me to check ethical principles were being adhered to during the research process, also ethical approval was obtained from the participating local authority.

Results

From the qualitative interviews 18 Initial themes were identified; associations were sought among initial themes, and, where suitable, initial themes were grouped together in an attempt to create major themes. Five major themes were recognised in this way. That is:

- A high degree of stress, mainly due to (but not limited to) behaviour of the individual, lack of continuity of services, transition periods, for example leaving school at age 19 and on assessments which were said to be repetitive and did not result in any increase in services.

- How much the lives of older carers revolved around their son or daughter, frequently above that of their other offspring.
- Support given to them by the adult with learning disability, this includes practical support as well as companionship.
- Reluctance to use respite services, this was linked to carers previous experiences and perceptions of services for themselves or their children.
- Not defining themselves as carers, instead they see their parenting role as a permanent one; this can lead to difficulties with professionals as there are differences of opinion regarding the ability of the adult with a learning disability.

Due to limitations of space, this article focuses on the major finding from the research project namely that older carers were experiencing high levels of stress. This corroborates other research (Department of Health, 2001; Evandrou, 1999; Hayden and Goldman, 1996; Williams and Robinson, 2001), although the originality lies in its association with local authority involvement. The complexities of decades of caring mean that the causes of carer stress vary. Within this research it was noted by older carers that the attitude of professionals, and support from the local authority, was influential in determining their levels of stress. As Mencap (2006 p3) states: 'It's not caused by caring - it is caused by caring without the right help'. Frustrations due to support services and organisations not functioning as promised causes carers to feel let down and obstructed. Research by Williams and Robinson, (2000) found that many older carers reported that their relationships with professional services were more stressful than years of providing care for their son or daughter with a learning disability. In a similar vein, research by Todd and Jones, (2003) highlighted the problematic dealings with professionals experienced by mothers of children with learning disabilities. The mothers in their study felt that any meetings regarding their learning disabled child were based on conflict and that their abilities as mothers were being persistently analysed. The current research corroborated Williams and Robinson's (2000) findings, namely how older carers of adults with learning disabilities describe their relationship with such services using the language of war:

We've always had to fight for what we need. (Female aged 72).

It's a huge battle to get anyone to listen, let alone do anything useful.
(Male aged 78).

The conflicts I've had over the years with social workers have worn me out, but you have to have these confrontations in order to get anywhere, it's sad but true, those that shout loudest get listened to-eventually. (Female aged 79).

In the research study, some older carers expressed reluctance to 'shout loudest' for fear that it would undermine their role as parents and make them appear selfish. Other reasons for not challenging social workers' decisions, with which they disagreed, were explained as concerns that any services might be reduced, or if the professionals thought that they couldn't cope, then their son or daughter would be taken away from them. All of these reasons add to the stress experienced by older carers as they internalise the anger they feel at professionals' perceived lack of understanding about their current situation.

The other major significant factor related to characteristics of the adult with learning disabilities. A high incidence of behavioural difficulties such as aggression, self-injury, destructiveness and non-compliance is seen as more challenging than disability type. However, poor physical health and high physical dependency all contribute to greater stress

levels experienced by older carers (Floyd and Gallagher, 1997; Hayden and Goldman, 1996; Heller and Factor, 1993; Seltzer and Krauss, 1989). The research study corroborated earlier literature as some carers described difficulties they had managing the challenging behaviour of their offspring.

Well, he used to shout and swear in public, I don't know how he got to know such words, but he'd swear at people wherever we went. He didn't really mean anything by it but he's a big fella and people would be frightened by it. For years I felt like we could only go out when it was quiet, never on Saturday that's for sure, it used to be so embarrassing and it'd worry me to death in case he ever got hold of someone. He's calmed down quite a lot now but for years he was bad like that. (Female aged 78).

Fewer initial themes were apparent from the focus group interviews than the individual interviews. This may be because less people were involved (14 as opposed to 24 interviewees) and the very fact of such a group discussion highlights similar issues. 11 initial themes were identified. After grouping together it was possible to see 5 major themes identified. That is:

1. The high level of concern the adults with learning disabilities had regarding their parents welfare.
2. The amount of practical and emotional support given to their parents by the adults with learning disabilities.
3. Restrictions placed on their lives, either by their parents or self-imposed so their parents would not be left on their own.
4. The lack of planning for the future. Participants in the discussion did not seem to be aware of planning for the future. That is to say plans may have been made for their future care, however in practice only 2 participants out of 14 were able to describe with any degree of certainty what would happen to them if their parents were not able to continue to care for them.
5. Linked closely with theme 4 was the apparent lack of knowledge adults with learning disabilities participating in the focus groups had regarding available options. This included options for major life changes, as well as smaller day to day issues like how you joined various groups or how some people had a support worker and others didn't.

Discussion

Recording interviews verbatim allowed a narrative analysis to be utilised. The older carers interviewed articulated what it was about their experiences and perceptions of care giving that was important to them and what they felt able to discuss at this point in their lives. Obviously within this, ideas about absolute and objective fact (D'Cruz and Jones, 2004) are superfluous. However, what these stories do is to inform us and provide insights into everyday experiences of inequality, powerlessness and oppression, experienced as a direct result of being a carer for a son or daughter with a learning disability. As reported non disabled people are disadvantaged and excluded as an indirect result of impairment or disability (Shakespeare, 2006). That this frequently goes unchallenged by older parent carers is noteworthy. The internalisation of decades of such oppression and unequal treatment may be an unconscious strategy to enable the older carers to survive and to continue in their caring role. The profoundly negative impact on their lives may be seen as a by product of an autonomous society, one in which individuality and freedom are strongly prioritised (Shakespeare, 2006). For older carers involved in the research project comments regarding lack of employment, and leisure opportunities that would fit in with their caring role, were frequent. This shows the implications of long term care giving in a negative light. It has been possible to contradict that with the emotional responses of older carers to their sons or

daughters existence. The positive perceptions expressed by many older carers, regarding the development of their son or daughter, highlights a dichotomy expressed by Atkin and Hussain who found in their study regarding disability and ethnicity that:

There is a constant tension in the parents narratives as they try and make a sense of their own sadness at having a disabled child, while at the same time wanting the best for their children (Atkins & Hussain 2003 p166).

The research corroborated earlier studies in that it highlighted how other major life events have the capacity to cause stress to older carers - for example, their own health problems, divorce, widowhood, or other bereavements. Kim et al., (2003) found that the age of the carer was a predictor of depressive symptoms; the older the carer the more likely they were to experience stress due to many of the reasons listed above. In addition, other causes of carer stress include having to balance the needs of their son or daughter with a learning disability with the needs of other family members (Twigg and Atkin, 1994). In some families there is more than one person with support needs. This obviously means more needs to meet, but may also mean that the carer is dealing with more than one support agency.

Of course, causes and reasons for carer stress are not static. In a study by Haveman et al., (1997) it was noted that the needs of parents fluctuate, depending on the age of their son or daughter. For adults with learning disabilities, parents found that information from physicians was needed, as was information and help to make, and follow through, plans for future care, particularly with regard to accommodation. Comments from the older carers in this study indicated similarities to this.

Well we weren't too worried about things when he was younger, I think we only took it one day at a time you know with him being so poorly, now he's older its all about where will he live when we aren't around, as well as the health needs he's got, you know, will his epilepsy change again, that sort of thing. (Female aged 65).

Having a learning disability limits the extent to which a person can live independently in the community without support (Kim, et al., 2003). The research study highlighted the concerns of older carers about the continuation of suitable care once they themselves are unable to offer support (Perring et al., 1990).

The main thing now is the future. Realistically, we have got more years behind us than ahead of us and we'd both like to see our Michael settled. The trouble is he is too comfortable here and doesn't want to go anywhere. To be honest with you, now his Mum's not so good he's a great help to me keeping her company and the like. (Male aged 77).

When accommodation is secured for their son or daughter with a learning disability, older carers are unsurprisingly still concerned and experience stress. McDermott et al., (1997) found no significant differences between carers of adults with learning disabilities living at or away from the family home. There were no statistically noteworthy disparities between carers of either group in terms of social and emotional problems, objective worries and gratifications. It can be seen, therefore, that parental stress is for many an enduring feature of having a son or daughter with a learning disability. The 'eroding nature of this level of stress' (Read et al., 2006 p42) cannot be taken too lightly. This continues even after the person with a learning disability has left the family home. The research findings indicated that for carers, despite finding alternative accommodation for their offspring, there was no evidence to suggest that they would be any less involved in their lives when they eventually

moved out of the family home and indeed, it may cause more stress, as one carer explained;

It'll be lovely seeing him settled, don't get me wrong, the thing is I'll be going up to see him every day just to make sure he's alright. I have to get two buses to get there as well so it's more work for me, but it's what he wanted for a long time, so I couldn't stop him. (Female aged 79).

The research has corroborated some details of earlier studies, which for example indicated the interdependence between adults with learning disabilities and their older carers (Grant, 1986; Parker and Clarke, 2002; Prosser, 1997; Walker and Walker, 1998; Williams and Robinson, 2001). That people with learning disabilities frequently assume a caring role for their ageing parents is seldom recognised by policy-makers (Williams and Robinson, 2001). This was apparent throughout the interviews when it became evident that the relationship between carer and cared-for is distinct in that interdependence is frequently established. Similarly, Walker and Walker (1998) found that one of the most significant factors in older carer families is the mutually dependent relationship that exists between the adult with a learning disability and their older parent carer. The current research found that reciprocity of care takes on a more significant role as the carer becomes older. This interdependence took many forms, not least practical physical support, for example, hanging out washing and emptying bins. One older carer explained how he had his shopping delivered each week but relied on his son to:

Go to the bookies and put my bets on, he takes the money and I fill in the slip before he goes. I make sure if I win I get a taxi to go and pick them up myself though-that doesn't happen often! (Male aged 77).

For another carer the physical ability of her son was a distinct advantage.

He always does the garden, he can do the grass, and he digs the borders over, then he will put all the rubbish out. It's handy having him so strong. Oh yes and he gets the Christmas tree down from the loft as well. (Female aged 72).

Emotional support, for example keeping the older parent company and providing companionship, was mentioned as a key feature of their relationship by most of the respondents. For one older carer the support she received from her daughter with a learning disability was invaluable, as she explained:

Sometimes, see, I even keep our Pauline off from the centre to help me. I know I shouldn't really but when I'm taken bad with this (asthma) I need her to stay with me and get me a drink and help me to the bathroom, that sort of thing. (Female aged 69).

The same carer described how she is a wheelchair user and is only able to go out if her daughter pushes her chair. In this instance, the carer recognised the support that she received from her daughter. However, there were discrepancies between the amount of care supplied and older carers' perceptions of such. Interestingly, for some carers, it appeared that talking about the issues made them realise just how much they depended on their son or daughter. When initially asked if they received support, several said no, then later on discussed certain tasks that their son or daughter did to help them. It may be that changes in their relationship were so imperceptible that they did not realise just how much they were reliant on the support, or it may be that they did not want to recognise their own support needs which were increasing as they aged. Literature shows that as the carer becomes older the reciprocity of care becomes an important feature of the relationship (Department of

Health, 2001; Prosser, 1997; Walmsley, 1996). Research by Grant (1986) noted how the needs of older carers and their sons or daughters became so entangled that interdependence and mutual helping became the norm as opposed to the exception. Overall, reciprocity between older carers and their sons or daughters with learning disabilities is a little researched area.

In the discussion, I have alluded to the impact of physical, emotional and practical reciprocal care. However, there is also an economic element. Financial interdependence also occurs; state benefits, for example, disability living allowance paid to the adult with a learning disability, become part of the general household income and it becomes impossible to separate them out. This has implications for the adult with a learning disability moving on as carers may become dependent on the joint income in order to survive. When the research was carried out certain organisations, for example, the Independent Living Fund (ILF), a body set up to provide funding for extra care for people with disabilities - required a payment of half the care component of disability living allowance. The research noted the reluctance of some families to apply for ILF for additional support for their son or daughter as this significantly reduces the household income. Additionally, anecdotal evidence suggested that some families were reluctant for their sons or daughters to move out of the family home because of the drop in level of household income that would bring about. The loss of an income, which has been part of the household budget for decades, would negatively affect the future lifestyle of the carers (Magril, 1997) and would plunge older carers into greater poverty.

Changes which affect one family member impact on the other. The scenario of care-giver and care-recipient is not mutually exclusive. Care is not a situation where an active care-giver performs an activity on a passive dependent recipient. The majority of people involved in the research project appeared to adopt both care-giving and care-receiving roles; the needs of both carers and service- users must be taken into account when planning for the future. This reciprocal relationship often denotes one of the most sizable barriers to potential arrangements (Bowey and McGlaughlin, 2007).

Sometimes he'll say he wants to move out, but I don't really think he knows what it means. He'd never manage on his own, and I don't think I'd manage without him here. (Female aged 79).

This is a complex area for recommendations for policy, where the needs of both parents and their adult children must be balanced and sensitive support provided on an individual family basis:

Caring is a relation in which carer and cared for share an interest in their mutual well being. (Held, 2006 p. 35).

The changing nature of older carers' relationships with their adult children, demonstrated by the reciprocity of care-giving, means that planning for the future of the person with a learning disability becomes difficult. One of the features that distinguished older carers from their younger counterparts, the duration of care-giving, means that for many families their own lives cannot be separated from that of their son or daughter, thus an atypical social model develops, with parents seeing themselves not as a couple, but as part of a threesome (Wertheimer, 1981). This has implications for future care of the adult with a learning disability as they could be held back from greater independence as the needs of their elderly parent increase. This issue was touched upon in the focus group of adults with learning disabilities when one participant expressed his wish to live with his girlfriend. He acknowledged, however, that this would mean leaving his Mother alone at the age of 77 and he did not feel able to do that.

She has done such a lot for me ... when my Dad died I said that I would look after her. (Male aged 44).

Evidence provided by the focus groups held with adults with learning disabilities again highlighted reciprocal or mutual care giving, although there was no reference made to stress. Adults with learning disabilities in the focus groups spoke with pride of things they did to make their parents' lives easier:

I get up in the morning for the centre, then get everything ready, take Mum a cup of tea and her pills, and when I've finished my breakfast I clean out the birds..... Make the beds and always swill out the yard, and put the bin bags out. (Female aged 44).

I get some shopping; I always go with my Mum and carry it for her. She needs me to help her; she's 73 now you know. (Male aged 33).

The significance of reciprocal care to the adults with learning disabilities enabled me to recognise features that occurred throughout the study. Although some literature makes reference to mutual or interdependent care (Walker and Walker, 1998; Williams and Robinson, 2001), this was a highly significant part of the identity of the adults with learning disabilities who participated in the focus groups. It became clear that one of the major characteristics of the relationship between older carers and their sons or daughters is one typified by reciprocal care to a greater or lesser degree:

Me and my Dad do our house work together on Thursdays. I help. We do everything together me and my Dad, I do everything. We go shopping on Friday. I do the cleaning and set the table, my Dad cooks, I like that. (Female aged 41).

I like to cook as well; sometimes I lay the table and wash up. I do the polishing at home and wash up every day. It's good to have responsibility towards your Mother. When my Father died I promised him I would take care of my Mother and I think I have done that. (Female aged 40).

The adults living at home with older carers who participated in the focus group discussions carried out a wide range of supportive tasks, which they perceived as making life easier for their older parents. The focus groups sought to encourage adults with learning disabilities to give their views on a range of topics that impinged on the lives of their older carers. In highlighting the intricacy in comprehension and experience, I am not suggesting that I represent the 'real' voices or perceptions of the adults with learning disabilities in this research. Rather, by sharing the experiences of the fourteen adults with learning disabilities who participated in the study, I endeavoured 'to hear more of their voices, and understand more of their perspective' (Mauthner and Doucet, 1998 p140).

Conclusion

Caring takes place in a relationship and within that relationship there will be examples of mutual care; however, this is rarely recognised by service providers. This lack of recognition adds to stress experienced by older carers. This paper provides a snapshot of a moment in time for a particular group of people and by doing so, enriches understanding of the longevity of care-giving. Care-giving as an activity needs to be addressed inwards as well as outwards to others; at some stage in their life everyone is likely to be either a giver or a receiver of care. This research, by including the perspectives of adults with learning disabilities, addresses the imbalance of research concerned with care-giving that focuses

solely on the care-givers in a traditional sense. The research makes a valid contribution to the development of policy and practice concerned with older carers and their sons or daughters with a learning disability. In addition, it offers an interesting grounding for future research projects.

References

- Atkin, K. & Hussain, Y., 2003. *Ethnicity, Disability and Young People* in Watson, N. (ed) *Disability, Culture and Identity*, Pearson Education, London,
- Bigby, C. 2004. *Ageing with a Lifelong Disability*: Jessica Kingsley, London.
- Bowey, L. & McGlaughlin, A. 2007. 'Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning', *British Journal of Social Work*, 37. 1: 39-54.
- Burningham, K. & Thrush, D. 2001. *Exemplar: The Environmental Concerns of Disadvantaged Groups*. In Gilbert, N. (ed) *Researching Social Life* (2nd edition): Sage, London.
- Care Services Improvement Partnership. 2007. *Commissioning for Adults with Learning Disabilities: A Tale of Two Nations*, July 2007:
- D'Cruz, H. & Jones, M. 2004. *Social Work Research: Ethical and Political Contexts*: Sage, London.
- Department of Health. 2001. *Valuing People: A New Strategy for Learning Disability For the 21ST Century*: Department of Health, London.
- Department of Health. 2002. *Fair Access to Care Services; Guidance on Eligibility Criteria for Adult Social Care*, LAC (2002) 13, Department of Health, London.
- Department of Health. 2004. *Carers (Equal Opportunities) Act*: The Stationery Office, London.
- Evandrou, M. 1999. *Unpaid Work, Carers and Health* in Blane, D. et al (eds) *Health and Social organization*: Routledge.
- Finlay, L. & Ballinger, C. (eds). 2006. *Qualitative Research for Allied Health Professionals: Challenging Choices*: John Wiley, London.
- Floyd, F. & Gallagher, E. 1997. *Parental Stress, Care Demands, and Use of Services for School Age Children with Disabilities and Behaviour Problems*, *Family relations* 46 (4), 359-371.
- Grant, G. 1986. *Older Carers, Interdependence and the Care of Mentally Handicapped Adults*: *Aging and Society* 6, 333-351.
- Haveman, M., van Berkum, G., Reijnders, R., & Heller, T. 1997. *Differences in Service Needs, Time Demands and Care-Giving Burden Among Parents of Persons with Mental Retardation Across the Life Cycle*. *Family Relations: Interdisciplinary Journal of Applied Family Studies*, 46(4): 417-425.
- Hayden, M.F., Goldman, J. 1996. *Families of Adults with Mental Retardation: Stress Levels and Need for Services*: *Social Work* 41(6): 657-667.
- Held, V. 2006. *The Ethics of Care*. Oxford University Press, Oxford.

Heller, T; Factor, A. 1993. Support Systems, Well-Being and Placement Decision Making Among Older Parents and their Adult Children with Developmental Disabilities. In Sutton, E., Factor, A., Hawkins, B.A., Heller, A. and Seltzer, G.B. (eds) *Older Adults with Developmental Disabilities: Optimising Choice and Change*: Baltimore, M.D., and Paul H. Brooks.

Heller, T; Caldwell, J; Factor, A. 2007. Aging Family Care-Givers: Policies and Practices: *Mental Retardation and Developmental Disabilities Research Reviews* 13: 136-142.

Herring, J. 2007. Where are the Carers in Healthcare Law and Ethics? *Legal Studies*, Vol. 27 (1): 51-79.

Kim, H.W; Greenberg, J.S; Seltzer, M.M; Krauss, M.W. 2003 The Role of Coping in Maintaining the Psychological Well-Being of Mothers of Adults with Intellectual Disability and Mental Illness: *Journal of Intellectual Disability Research*, Vol 47: 4/5 313-327 May/June 2003.

Magril, D. 1997. *Crisis Approaching: The Situation Facing Sheffield's Elderly Carers of People with Learning Disabilities*. Sharing Caring Project, Sheffield.

Mauthner, N; Doucet, A. 1998. in Ribbens, J. & Edwards, (eds) *Feminist Dilemmas in Qualitative Research, public knowledge and private lives*. Sage, London.

McCallion, P; Tobin, S. 1995. Social Workers' Perceptions of Older Adults Caring at Home for Sons and Daughters with Developmental Disabilities. *Mental Retardation* 33, 153-162.

McDermott, S; Valentine, D; Anderson, D; Gallup, D; Thompson, S. 1997. Parents of adults with Mental Retardation Living In-Home and Out-of-Home; Care-Giving Burdens and Gratifications. *American Journal of Orthopsychiatry* 67(2): 323-329.

McLaughlin, J. 2006. Conceptualising Intensive Caring Activities: The Changing Lives of Families with Young Disabled Children. *Sociological research on line*, 11:1 <http://www.socresonline.org.uk/11/1/mclaughlin.html>.

Mencap 2006. *A Report on the Continuing Problem of Caring Without a Break for Children and Adults with Severe and Profound Disabilities in Oxfordshire*. www.mencap.org.uk

Nolan, M; Grant, G. 1989. Addressing the Needs of Informal Carers: A Neglected Area of Nursing Practice. *Journal of Advanced Nursing*, 14, 950-961.

Northway, R. 2003. Participatory Research. In Jukes, M. and Bollard, M. (eds) *Contemporary Learning Disability Practice*. Quay Books, Wiltshire.

Parish, S; Seltzer, M.M; Greenberg, J.S. 2004. Economic Implications of Care-Giving at Midlife: Comparing Parents With and Without Children who have Developmental disabilities. *Mental Retardation* 42: 413-426.

Parker, G; Clarke, H. 2002. Making the Ends Meet: Do Carers and Disabled People have a common agenda? *Policy and Politics*, 30(3): 347-359.

Perring, C; Twigg, J; Atkin, K. 1990. *Families Caring for People Diagnosed as Mentally Ill: The Literature re-examined*. HMSO, London.

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.

Qureshi, H; Walker, A. 1989. *The Caring Relationship: Elderly People and their Families*. Macmillan, London.

Read, J; Clements, L; Ruebain, D. 2006. *Disabled Children and the Law: Research and Good Practice*. Edition 2nd ed. /, Imprint, London: Jessica Kingsley, 2006.

Seltzer, M. M; Krauss, M.W. 1989. Ageing Parents with Adult Mentally Retarded Children: Family Risk Factors and Sources of Support. *American Journal of Mental Retardation* 94: 303-312.

Todd, S; Jones, S. 2003. 'Mum's the Word!': Maternal Accounts of Dealings with the Professional World. *Journal of Applied Research in Intellectual Disabilities* 16(3): 229.

Twigg, J; Atkin, K. 1994. *Carers Perceived*. Open University Press, Buckingham.

Walker, C; Walker, A. 1998. *Uncertain Futures. People with Learning Difficulties and their Ageing Family Carers*. Pavilion, Brighton.

Walmsley, J. 1996. Doing What Mum Wants me to. *Journal of Applied Research in Intellectual Disabilities*, 9(4): 324-341.

Walmsley, J. 2001. Normalisation, Emancipatory Research and Inclusive Research in Learning Disability. *Disability and Society*, 16(2): 187-205.

Webb, R; Tossell, D. 1999. *Social Issues for Carers (2nd edition)*. Towards Positive Practice. Hodder Arnold, London.

Wertheimer, A. 1981. *Living for the Present: Older Parents with a Mentally Handicapped Person Living at Home*. Enquiry Paper 9. Campaign for Mentally Handicapped People, London.

Williams, V; Robinson, C. 2000. *In their Own Right; The Carers Act and Carers of People with Learning Disabilities*. Policy Press, Bristol.

Williams, V; Robinson, C. 2001. He will Finish up Caring for Me: People with Learning Disabilities and Mutual Care. *British Journal of Learning Disabilities*, 29(2):56-62.