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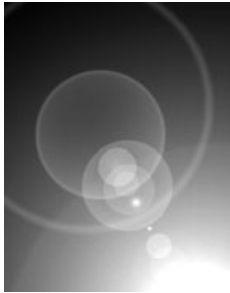
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'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities

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Accessible summary

When sons and daughters with disabilities live with their parents all their lives, this can sometimes be difficult for the parents as well as the sons and daughters. We asked the parents what they like and dislike about having their sons and daughters living with them and what makes it easy and what makes it difficult. The parents who took part in this study told us that

- They loved their sons and daughters very much and had much fun living together;
- Sometimes they had difficulties getting help or services;
- They worry a lot about the future and what will happen when they can no longer look after their sons and daughters with disabilities;
- It is really important that families plan ahead so that everyone knows what will happen when parents get older and can no longer look after their sons and daughters with disabilities.

Summary

Research-informed policy and practice is needed for older caregivers of adult sons/daughters with disabilities. These caregivers are often under tremendous stress because of failing health, financial pressures, bereavement and worry about the future of their sons/daughters. Twenty-nine older parents/caregivers of 27 adults with intellectual and/or developmental disabilities were interviewed to explore their views and experiences regarding long-term care and service arrangements, health and psychological needs and 'future planning'. Findings show a severe lack of support, respite care and future planning which causes high stress levels for caregivers. Policy makers and researchers working in this field need to take into consideration the needs of older caregivers when making future plans for adults with disabilities.

Keywords *Adults with disabilities, early intervention, older carers, services and education*

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Social change and better health and social care have lead to improved longevity in general and increased parental age at birth, and growing numbers of children diagnosed with disabilities show that more people are caregivers well into their old age (Minnes & Woodford 2005). For 82% of adults

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with disabilities, the main support comes from an informal caregiver who lives in the same household (ABS, 1999; Argyle 2001). 'Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability' (Carers Northern Ireland, 2002, p.6). This article reports on a study of parents/caregivers of adult sons/daughters with disabilities, which was carried out in Northern Ireland. Following a brief review of local, national, as well as international literature, caregiver voices are heard through phenomenological reports about issues, such as relationships, social support and future planning. The interpretative discussion is based on behaviour analytic interpretations of ageing and caring. Practice recommendations are offered.

In the United Kingdom, more than 24.6% of women and 17.9% of men (aged 50–59) provide unpaid care, while many of them are also in paid employment and/or suffer from ill health themselves (Fisher 1994). Unpaid carers frequently provide 50 or more hours per week of care, and Buckner & Yeandle (2007) estimated that they save in excess of £87 billion for the UK economy, a sum that exceeds the total expenditure on the NHS.

Kenny & McGilloway (2007) found that little is known about the actual experiences of parents who care for their children with disabilities in Ireland. Their research suggested that while caring for a child with learning disability is both rewarding and challenging, the key to coping lies in the appropriateness and effectiveness of support services for these parents and their children. Similar results were found in siblings of people with intellectual disabilities (Egan & Walsh 2001). Recent reports on parenting children with disabilities confirm the history of tension between parents and service providers (Kearney 2001) and identified a severe lack of adequate services offering early behavioural intervention and the failure to provide appropriate planning for the future as particular causes of stress (Keenan *et al.* 2007). Parents expressed the need to increase awareness of issues faced by them now and in the future, especially as they and their children grow older.

There are many worries and challenges for older parents of adult sons and daughters with disabilities related to learning, physical, sensory, mental health or a combination of these (Scott & Donnelly 2008). One of the most stressful is this question: 'What will happen when we become unable to care for our child ourselves?' (Freedman *et al.* 1997; Hollins & Esterhuyzen 1997; Stokes 1977). Intra-family solutions include siblings or other relatives who act as caregivers; however, while siblings may be willing to become caregivers in the future, parents may be reluctant to burden them with care-giving responsibilities (Griffiths & Unger 1994). Sheltered housing or residential accommodation are options (Walsh *et al.* 2001); however, frequently there is little provision, lack of information and practical support, and a

sense of marginalisation for older parents (Gilbert *et al.* 2007). It is clear that appropriate interventions and treatments provided routinely at an early age can go a long way in alleviating worry about the future, because they lead to enhanced skills levels and independence for the person with disabilities (DOH, 2007; Keenan *et al.* 2000). However, ultimately there will be the need for alternative accommodation and care, and these families may require professional help with planning for their son/daughter's future (Sherman 1997; Smith & Tobin 1989; Smith *et al.* 2000).

This situation has implications for families, policy makers, politicians, professionals, researchers, and ultimately, every taxpayer (Johnston & Martin 2005). While postponed parenthood may have a positive effect on socioeconomic status of the family, caring for a child with disability commonly has a negative effect on family finances (Census, 2001; Keenan *et al.* 2007; Knapp *et al.* 2007); e.g., the cost of caring for a child with disabilities is estimated to be three times that of caring for a typically developing child (Järbrink *et al.* 2003). In addition, caring is related to elevated divorce rates (in the region of 82%; National Center for Autism Research and Education, 2008), high rates of single parenthood (1/3 of families with a child diagnosed with autism spectrum disorder (ASD) are headed by a single parent; Bromley *et al.* 2004), major challenges for education and employment of family caregivers (Russell 2007); and stress related to ageing, such as physical and emotional tiredness, deteriorating health, and increasing anxiety over who will care for their child after they die (Australian Family and Disability Studies Research Collaboration, 2004).

Given that Northern Ireland is one of the most deprived areas in the United Kingdom (Social Disadvantage Research Centre, 2001), these effects are compounded. However, while families who have spent a lifetime caring may feel disenfranchised by professionals and the service system (Robinson & Williams (2002), by-and-large these families are characterised by strong self-reliance and a reluctance to ask for help (Australian Family and Disability Studies Research Collaboration, 2004; Bigby 1997; Kearney 2001).

Only recently, more emphasis has been put on the views, rights and experiences of people with disabilities and their families (Freedman *et al.* 1997; Grant *et al.* 2005; Miltiades & Pruchno 2001). Their entitlement to human rights to freedom, respect, equality, dignity and autonomy are now acknowledged in the law (Joint Committee on Human Rights, 2008; Russell 2007). However, many of the laws that aim to protect caregivers and persons with disabilities are neither well known nor widely applied (Robinson & Williams 2002). In England, *Caring about Carers* (DOH, 1999) and the *Carers and Disabled Children Act* (2000) regulate the relationship between local Councils, caregivers, and disabled children. In Northern Ireland, equivalent legislation includes the *Carers (Recognition and Services Act) 1995*; the *Carers and Disabled Children Act 2000*; and the *Carers*

(*Equal Opportunities*) Act 2004. Most recently, the Carers' Strategy (DOH, 2008), underpinned by £255 million, sets out the Government's agenda and vision for support of carers. However, already there are worries that some of these moneys do not reach carers directly (BBC, 2009).

In England, Bowey & McGlaughlin (2007) explored the views of older caregivers (70+) of adults with a learning disability with regard to planning for the future. Among these caregivers, 55% had not made future plans, because they either did not have a sense of need since they still had their spouse, they failed to understand the timescales involved in arranging alternative housing for the looked-after individual, or they lacked confidence in the options available and therefore were unwilling to hand over the caring role. However, it is also likely that the relationships with their son/daughter were mutually supportive to the extent that neither caregivers nor sons/daughters wanted to relinquish it. Kaufman *et al.* (1991) confirmed that in United Kingdom over 50% of parents had no firm future plans, in USA Freedman *et al.* (1997) found similar rates, and Prosser (1997) put this figure up to 71% of parents who had made no future plans. Walker & Walker (1998) are cautious, however, not to lay blame onto older family caregivers who are not doing the planning, instead they found that 'many family caregivers do have serious misgivings about their relative leaving home... [due to]... dissatisfaction with the range and quality of care available, their belief that their relative does not want to leave, and their own inter-dependent relationship with their relative for companionship or practical or financial support'.

Parents who made future plans mostly rely on sibling or other family members to care for their son or daughter with disabilities; only few make plans including formal residential care or support in the present family home (Bowey & McGlaughlin 2007). Parents with a close informal network of friends and family seemed to be less likely to have plans (Kaufman *et al.* 1991). Ultimately, Bowey & McGlaughlin (2007) asserted, 'If service-users are to have real choice and control over how and where they live in the future, then they have to be fully involved in planning well before the need arises for any change to take place' (p.52).

There is little research on future planning internationally (Llewellyn *et al.* 2003; Miles 1996). HelpAge International (2003, 2007) provides some examples that describe the difficulties of families where parents died as a result of HIV/AIDS, and grandparents have to take over the care for their grandchildren. In Sudan, Oliver, aged 65, lives with his wife, six children, and two orphaned grandchildren, aged 4 and 7, explained: '*The children are in poor health and one has malnutrition. I can't provide the needed care because I have no money and none of my relatives or friends help me. Sometimes... I've felt I just wanted to leave*' (quoted in HelpAge International, 2003, p.11).

In Northern Ireland, given the history of civil conflict and the subsequent lack of focus on issues other than the *Troubles*, heavy reliance on family and kinship networks have developed (Dillenburg 1992), specifically in poorer and ghettoised areas (Hillyard *et al.* 2003). Historically social services have been difficult to access in some areas (Darby & Williamson 1978). The effects are still felt in many areas. Little is known about the reality of caring for adults with disability in Northern Ireland, and even less about future planning of older parents who care for their adult sons/daughters with disabilities (Krauss & Seltzer 1993). Therefore, the research reported here aimed to explore issues related to caring and future planning in Northern Ireland and to give a voice to of older caregivers.

Methodology

Ethical approval

Queen's University of Belfast School Research Ethics Committee granted ethical approval for this study.

Participants

A convenience sample of 29 caregivers (20 mothers, eight fathers, one sister) were recruited through community self-help groups. They cared for a total of 27 adult dependants, including 15 sons, 11 daughters and one sister with disabilities. Seventeen participants were interviewed on their own (two of them were caregivers of two sons/daughters), while 12 participants took part in couple interviews (two couples caring for two sons/daughters; four couples caring for one son or daughter). The average age of participants was 65.17 (range 47–84). The average age of sons and daughters was 33.48 (range 12–59) (Table 1).

Research tools

A semi-structured interview schedule using open-ended questions enabled participants to tell their stories in their own words, introduce new topics and add their interpretations of events, experiences and views. The interview schedule was modelled on the Carers' Assessment of Difficulties Index and Carers' Assessment of Managing Index (Llewellyn *et al.*, 2002). Furthermore, the General Health Questionnaire (GHQ-12; Goldberg *et al.* 1996) was used as a validated measure to give reliable quantitative data on psychological health. According to Goldberg *et al.* (1996), respondents who score above threshold score of four out of 12 points were classified as *cases*, i.e., likely suffering levels of tension, anxiety and depression that require full psychological assessment.

Table 1 Composition of research participants

| | Caregiver | Age | Relationship | Cared for | Age | Disabilities |
|---|-----------|-----|--------------|-----------|-----|---------------------------------|
| Single interviewee; one son/daughter/sister with disabilities | | | | | | |
| 1 | Mrs T | 76 | Mother | Female | 35 | Learning disability, depression |
| 2 | Mrs D | 62 | Mother | Female | 28 | ASD; LD, nonverbal |
| 3 | Mrs C | 74 | Mother | Male | 41 | Learning disability |
| 4 | Mrs E | 61 | Mother | Female | 29 | LD, limited speech/mobility |
| 5 | Mrs K | 74 | Mother | Male | 42 | Learning disability |
| 6 | Mrs S | 47 | Mother | Male | 18 | ASD, learning disability |
| 7 | Mrs M | 79 | Mother | Male | 47 | PKU, epilepsy |
| 8 | Mrs F | 60 | Mother | Female | 38 | LD, mental health |
| 9 | Mrs B | 60 | Mother | Male | 33 | ASD, epilepsy, depression |
| 10 | Mrs O | 75 | Mother | Male | 44 | Down Syndrome |
| 11 | Mrs G | 80 | Mother | Female | 54 | LD (not diagnosed) |
| 12 | Mrs Q | 60 | Mother | Male | 13 | Down Syndrome |
| 13 | Mr A | 84 | Father | Female | 52 | Cohen's Syndrome |
| 14 | Mr S | 61 | Father | Male | 32 | LD, cerebral palsy |
| 15 | Mrs H | 66 | Sister | Female | 59 | Down Syndrome |
| Single interviewee; two sons/daughters with disabilities | | | | | | |
| 16 | Mrs G | 60 | Mother | Male | 28 | Down Syndrome |
| | | | Mother | Male | 24 | Down Syndrome |
| 17 | Mrs Y | 70 | Mother | Female | 34 | Stroke, aphasia, epilepsy |
| | | | Mother | Male | 29 | Down Syndrome |
| Single interviewee; two sons/daughters with disabilities | | | | | | |
| 18 | Mrs E | 62 | Mother | Male | 41 | Muscular dystrophy |
| 19 | Mr E | 68 | Father | Female | 12 | PKU, cerebral palsy |
| 20 | Mrs Q | 60 | Mother | Female | 23 | Deaf, blind, cerebral palsy |
| 21 | Mr Q | 66 | Father | Female | 28 | Learning disability |
| Couple interviewees; one son/daughter with disabilities | | | | | | |
| 22 | Mrs K | 60 | Mother | Male | 30 | Prader-Willi Syndrome |
| 23 | Mr K | 61 | Father | | | |
| 24 | Mrs L | 60 | Mother | Female | 25 | Microcephaly, cerebral palsy |
| 25 | Mr L | 60 | Father | | | |
| 26 | Mrs V | 60 | Mother | Male | 40 | ASD, wheel chair |
| 27 | Mr V | 65 | Father | | | |
| 28 | Mrs Z | 59 | Mother | Male | 25 | ASD, challenging behaviours |
| 29 | Mr Z | 60 | Father | | | |

ASD, autism spectrum disorder; LD, learning disability; PKU, phenylketonuria.

Procedure

A convenience sample of participants was recruited from charities, and support groups identified using Duffy's (2008) list of contacts and additional personal contacts. Interview dates were arranged by telephone, and interviews lasting 45–60 min were held at locations identified by participants, either in the premises of the support group or in the houses of the participants. The majority of interviews were recorded on a small digital voice recorder and later transcribed verbatim. In cases where recording was not acceptable to interviewee ($n = 9$), notes were taken during the interview, and full accounts were written up immediately following the interview. Each caregiver completed the GHQ-12 after the interview was completed. Where necessary, e.g. in case of reading difficulties, the researcher read out the questions of the GHQ-12 and scored the reply.

Analysis of findings

Interpretative Phenomenological Analysis (IPA; Smith 1996) was used for the analysis of verbatim accounts of participants' idiographic experiences (Smith *et al.* 1999), considering the dynamic processes involving the researchers (Brocki & Wearden, 2006) and balancing experiential claims against detailed and open interpretative analysis (Larkin *et al.* 2006). Both authors read the phenomenological interview transcriptions independently before common themes were drawn out. Interpretation was based on behaviour analytic concepts of ageing (Gallagher & Keenan 2006) and caring (Dillenburger & McKerr 2009).

IPA's two complementary commitments were used to structure the results section. (i) Verbatim, phenomenological accounts are reported to 'give a voice' to participants. This is underpinned by some basic descriptive statistics to illustrate the relative weight of particular findings. (ii) Interpretative

analysis based on behaviour analytic concepts is offered to 'make sense' of the findings, by providing conceptual and contextual commentaries and locating the phenomenological descriptions within this theoretical framework.

Phenomenological accounts: 'giving a voice'

Socio-demographics

Forty-one percentage ($n = 12$) of the participants were over 65 years of age (mean 65.17; range 47–84), and all of the sons and daughters with disability were under 65 years of age (mean 33.48 years; range. 12–59 years). The age of participants has to be viewed in the context of life expectancy in the United Kingdom, for men 75 years and for women 80 years (National Center for Health Statistics, 2006).

Most of the participants owned their own home (93%; $n = 26$), while others lived in rented accommodation (7%; $n = 3$). Although data were not available for all participants, there was some bias towards those who lived in rural environments (34%; $n = 10$) vs. those who lived in urban areas (14%; $n = 4$). The average home size was 4.2 bedrooms (range 3–6).

Some participants had made no alterations to their homes to cater for the needs of their son or daughter with disabilities (24%; $n = 7$), while most had made alterations (76%; $n = 22$), such as fitting an extra bathroom, shower or en-suite, fitting ramps and handrails or fitting a wheelchair hoist. 'We had some renovations done about 12 or 14 years ago and we always intended to do some other things... Those are on hold now... Now prices have shot up.'

Respondents had an average of 3.9 offspring (range 1–9); 88 sons and daughters in the sample total. The average age of neurotypical sons and daughters was 34.7 (range 12–55). Most of the participants lived with their spouse (76%; $n = 22$), while a quarter of them lived alone with their sons/daughters with disabilities (24%; $n = 7$).

Everyday positives and everyday challenges

Many participants expressed that the most positive things in their lives was their family and their sons and daughters (51%; $n = 15$). 'Just, you know, that we still have [name of son] really... [name of son] is there, we're here and it's our job to look after him you know...' Others mentioned health, work, sport, social support and general attitude to life (48%; $n = 14$). 'Being able to cook, being able to walk as well as I am, I'm thankful not in a wheelchair, I'm able to do as much as I can do which is quite a bit.'

The greatest challenge in life for many participants were their son/daughter's care requirements, the need to keep them occupied and difficulties in dealing with behavioural problems (48%; $n = 14$). 'When [name of husband] was working I'd have been a 24-hour carer except at weekends but

whatever happened with [name of son] during the day was over. [name of husband] would say how did things go and I'd say 'Oh grand', though he might have seen there was two windows boarded up... So he knew everything wasn't grand but there was no point me saying 'Oh wait 'til I tell you the day I had today' and I hadn't the energy to go over it again anyway. Anyway, he never really showed that bad behaviour to his daddy. So by the time I twigged this on, he had me wrapped round his wee finger. I was the problem and I had to teach him to behave when I'm there.'

Caregivers' physical and psychological health

Most caregivers described their own health as good or fair (76%; $n = 22$), despite the fact that they were suffering from various health problems. '[my health is] quite good, I'm on lots of tablets but only normal ones you know, for my age... you couldn't be perfect at 75...' A number of participants stated that they suffered ill health. 'I have to use a stick but I can still drive which I'm very happy about.'

The average GHQ-12 score was 3.61 (data missing, $n = 3$); 35% of participants scored over 4, the threshold for 'cases' and recommend for further psychological assessment. A recent large-scale study in Northern Ireland resulted in 17% of participants scoring over the threshold of 4 (ARK, 2006), as such, older caregivers in this sample were more than twice as likely to experience psychological ill health than the general population.

Family, social and agency support

For many participants, family support played an important role in caring for their son/daughter with disabilities. Participants generally reported to have very good family relationships. Most were happy with their spousal relationships and care arrangements. '[name], my husband's very easy going, God love him... you know what pressure you're under.' Participants generally described their relationship with their son/daughter with disabilities as very good. 'Ach, well goodness me, I've a good... well I love him. It's a loving relationship and he can communicate with me without words, I usually know what he's saying without him saying anything.'

Among the participants, 69% ($n = 20$) received support from bothers, sisters, sons and daughters, and in-laws, and even their own parents; however, quite a few of the participants did not have any family support (31%; $n = 9$). 'Oh yes, I have a sister and her husband would come and let us out... again we'd be back early, we wouldn't be staying out late.' Only a very small minority of participants received help from friends or neighbours (14%; $n = 4$), although this was partly because they did not ask for help. 'I'm sure they would, if we asked them... but we've never needed any occasion to ask them because if we're going out we would usually take

1 [name of son] with us and if we were going away on our own for
2 a week or that, we would use respite.'

3 In fact, some of the participants set up their own support
4 groups to help with care and social support needs. 'Four or
5 five years ago I did take the step of creating a circle of support... I
6 learned for the first time, instead of bearing it all myself, to
7 go out and say, 'Can you help'. So my sister, and sister-in-
8 law and Nanny became involved with [name of son]'s care
9 and if we want to find out what he's thinking, we would bat things
10 off them... He has very close communication with all of
11 them, so it doesn't just depend on me, but I did set that up...
12 out of desperation...'

13 For the most part, support with day-to-day supervision
14 was considered helpful, so as to allow main caregiver to go
15 shopping or go out for a few hours. 'If I wasn't home for
16 [name of daughter] coming home at 3.30, all I have to do is ring
17 the school and say, would the bus driver leave her off at Auntie
18 [name]'s this evening. They know on Thursdays to leave her
19 down with the other friend. Everybody is busy. Except they're paid
20 for looking after someone, no one does this any more. The extended
21 family is over.' Day care and respite care seemed to be the
22 biggest help for most participants. 'It would be [name of day
23 care centre], she loves going over, she loves company... and the
24 respite is a big help. A lady looks after [name of daughter] in
25 her own house.' However, four participants did not receive
26 any day or respite care.

27 The biggest challenges included general supervision and
28 medical care. 'He has a lot of tummy [skin fold] and he would
29 come back [from respite] red raw because they don't dry him
30 properly in the shower, and he wouldn't know to say. His feet
31 would need attention too. When he had the other catheter that was
32 a problem too. His peripheral nerves aren't good, and he doesn't
33 realise if he is in pain.'

34 Futures planning

35 The vast majority of participants had not made long-term
36 plans for the future care of their sons or daughters with
37 disabilities (72%; $n = 21$). 'I know I should be thinking about
38 it... Any one of his two siblings would take him but I have a
39 thing about that. From they were born they have already
40 shared that life with him and it wasn't easy when they were
41 youngsters, you couldn't take [name of son] every place. They
42 were curtailed and they never ever complained. So I think it's a
43 terrible burden to ask them now to go back and even ask their
44 youngsters to share... the old 'handicapped' uncle.' Only few
45 who had made plans were clear about what would happen
46 to their son or daughter when they were no longer able to
47 provide care. 'I've it sorted out that [name of daughter] would
48 take the house and look after [name of son].'

49 Others worried about future planning (10%; $n = 3$) and
50 their own health and well-being (24%; $n = 7$). 'Our biggest
51 problem, as far as both [name of son and daughter] are
52 concerned, is how long are we able to go on? We think a lot about

that... and we haven't come up with an answer. Because,
our health could change, overnight.' Some were so desper-
ate that they considered their son/daughter's early death
preferable to being taken into care. 'I really don't want him in
a home, so I just hope that God will take him before he takes us,
but that's not always the way, so you have to think of these
things.'

Participants had not discussed futures planning with
their son/daughter with disabilities. 'I can say right away
that I have never said to him... but I have heard him saying
what would happen if mother went and he had this look
of panic on his face.' Most participants had not discussed
future provision with social services (66%; $n = 19$), while
those who did found advice helpful. 'I don't see them or
know anything about them. I know they are there but someone
said it's pretty hard even to get your social worker, so I haven't
bothered.'

Some of the participants had ensured future financial
security for their son or daughter with disabilities (28%;
 $n = 8$). 'We just made a will last year and our oldest daughter said
that she would look after her.' However, most had not
considered making financial arrangements for the future
(72%; $n = 21$). 'Not at all, I know we should be thinking about
it...' The importance of futures planning was apparent to
most participants, and they generally thought that plans
should be made as early as possible. 'You know we keep
saying we should do something, but it seems awful to have to face
it... You think, oh God maybe if you ignore it something
will just happen and it will all get taken care of.' Advice to
parents of young children with disabilities was mostly
related to future planning. 'Do not always depend on social
services... they often let you down. Look at all the options
available and request that social worker provides more than
one option.'

52 Discussion and interpretation: 'making 53 sense'

54 This section moves from phenomenological descriptions to
conceptual and contextual interpretation. IPA is inevitably
subjective to the extent that different researchers may not
interpret the same phenomenon in the same way. Although
this issue is not specific to IPA, intellectual honesty
demands that this complexity is explicitly acknowledged.

As with all research, the researchers cannot be divorced
entirely from the research process. They form an integral
and reflexive part of the research questions that are asked,
the methodology that is used, the data that are collected,
and the subsequent analysis. The first author was a Senior
Lecturer in Inclusion and Special Educational Needs at the
Graduate School of Education, Queen's University Belfast
(QUB), a clinical psychologist and Board Certified Behav-
iour Analyst-Doctoral, who designed the research question
and methodology and was the grant holder. The second

1 author was research assistant on the project and conducted
 2 most of the interviews. She is an anthropologist and
 3 archaeologist with much experience in interviewing older
 4 research participants and has a teenage son diagnosed with
 5 Asperger's Syndrome.

6 Findings reported here support behaviour analytic concepts
 7 of ageing (Gallagher & Keenan 2006) and caring
 8 (Dillenburg & McKerr 2009) in which behaviour is
 9 viewed as the intersection of person and environment,
 10 rather than interpreting behaviour as being caused by
 11 some hypothetical internal or cognitive factors (Keenan &
 12 Dillenburg 2004). This approach ensures that blame for
 13 difficulties in coping and planning is not laid at the foot
 14 of the individual, but is found in the contingencies to which
 15 the individual is exposed (Dillenburg & Keenan 2005).
 16 This study illustrates the difficult contingencies to which
 17 older parents who care for adult sons/daughters with
 18 disabilities are exposed. An explanation for their stress and
 19 difficulties is to be found in these contingencies, and
 20 consequently, solutions for the problems they face are to be
 21 sourced from within the social, cultural and political
 22 environments in which they find themselves (Dillenburg
 23 & Keenan 1994/2001).

24 The behavioural concept of supply and demand (Hurst
 25 1984) illustrates particularly well how in situations of high
 26 demand and low supply, conflict and stress are inevitable.
 27 This research confirmed the low level of supply of social
 28 support, suitable alternative accommodation and help with
 29 future planning leads to high stress levels for parents. The
 30 lack of suitable accommodation, respite and support services
 31 should not be news to service providers. Numerous
 32 reports have pinpointed this deficit (e.g., Bamford 2006;
 33 Keenan *et al.* 2007; McConkey 2004). It seems that while
 34 society relies on older parents and informal caregivers to
 35 take full caring responsibility, and thereby making substantial
 36 savings, the situation is unlikely to change. Inadvertently,
 37 the huge amount of high quality care given freely and
 38 willingly by the parents unintentionally reinforces
 39 (Grant & Evans 1994), thereby increasing the future
 40 probability of, inactivity of service providers.

41 Consequently, older parents are expected to carry the
 42 full responsibility for care and futures planning against a
 43 backdrop of severe shortage of provision and networks.
 44 This research revealed that necessary networks to break
 45 this vicious cycle of low supply/high demand include
 46 extended family, friends, financial security, accommodation,
 47 statutory bodies, employment and day care. Figure 1
 48 offers an overview of the necessary support network that
 49 would alleviate unnecessary stress for parent/carers of
 50 adult sons/daughters with disabilities. It shows that if
 51 the family (parent/child) is placed at the centre of the
 52 network of adequate support while they are able to care
 53 for their loved one, this network of support will hold
 54 even when the parents are no longer able to care. As such, the main

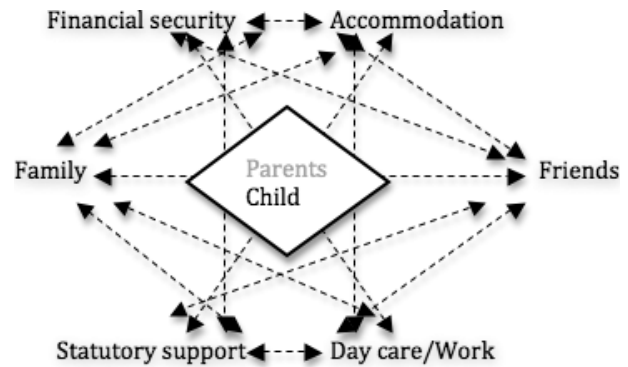


Figure 1 Illustration of parents/child at the centre of network of support. 12

stress, i.e., the worry about *how long can we go on*, is alleviated.

These mutual interrelated relationship networks cannot be built overnight or in a crisis situation, they require planning and long-term partnership between all participants, including parents and sons and daughters with disabilities, to ensure that eventually when the need arises, sons/daughters with disabilities will be included in a safety net of support. In Northern Ireland, the need for reform and modernization of the health and social care system has been recognised some time ago (McGimpsey 2008) and should be based on theoretical implications of research reported here.

Two recent major Government spending initiatives in the United Kingdom aimed at going some way to deal with the situation. In the White Paper 'Valuing people: A new strategy for learning disability for the 21st Century' (DOH, 2001) resources of over £300 million were invested to improve the accessibility of mainstream schools and to improve provision for children with special educational needs more generally with the explicit commitment to: *improving early identification and early intervention; supporting parents and carers; improving the SEN framework; developing a more inclusive education system; developing knowledge and skills; working in partnership*. Research reported here shows the importance of including policies on early intervention and early planning. These and similar findings (cf, Keenan *et al.* 2007) should be used to enable governments to spend resources wisely.

More recently, the Carer's Strategy (Department of Health (DOH) 2008) has identified the importance for carers to be afforded short breaks for respite, supporting carers to enter or re-enter the job market, and improving support for young carers. However, despite the fact that the Carer's Strategy was underpinned by £255 million, recent reports allege that, for example, much of the £150 million that were to be spent towards planned short breaks for carers, seemed to have been 'lost into the general budget of primary care trusts' (BBC, 2009). Research reported here

shows that these funds should be freed and commitments implemented so as to reach the populations for whom they are intended.

Recommendations

1. A new theoretical approach or scientific jump-start (Lipsitt 2005) is necessary to help parents who care for their sons/daughters with disability now and in the future.
2. Support nets should be set up and maintained well in advance of the crisis situation in a way that includes the whole family in future planning at regular points along the life cycle.
3. Future care and accommodation needs should be calculated on the basis of the number of children born with impairments and the number of people who experience impairments later in life. This way, reasonably accurate predictions about future provision needs can be made and resourced.
4. Early intensive behavioural intervention should be offered routinely once a child is diagnosed with a disability (cf. Ontario IBI Initiative, 2002).
5. Resources that are allocated to this client group should reach their intended targets and not be buried in bureaucracy.

Conclusion

The study reported here explored issues faced by older family members who care their sons/daughters with disabilities. Although utilizing a relatively small sample and conducted within a specific cultural context, data reported here identified a range of generalisable issues for policy makers and practitioners. These concerns must be addressed urgently, particularly in the face of increasing population longevity.

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