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Research Article

Echoes of the Future: Adults with Disabilities Living at Home with Their Parents

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Abstract

Almost 90% of all adult sons and daughters with disabilities live at home with their parents. Consequently, they have life experiences that are atypical for most of their adult peers and their aging caregivers are under stress due to failing health, financial pressures, bereavement, and worry about the future.

Adults with intellectual disabilities and aging parents took part in focus groups and interviews. Results show a loving and caring home environment but evidence a lack of effective life skills development and futures planning. The paper draws attention to the inevitable crisis that occurs when ageing caregivers are no longer able to care. The urgent need for skill development and timely futures planning is outlined.

Keywords: Learning Disabilities; Early Behavioural Intervention; Adults; Ageing

Background

Recent reports on educating and parenting children with learning disabilities call for a better understanding of the needs of these young people and their families. This is particularly pertinent for educational research and interagency, joint-up thinking, because as children with learning disabilities grow older so do their parents and all too often service provision is inadequately [1,2]. Therefore, many adults with disabilities remain in their parental home long after their typically developing peers would have left and set up independent living and working arrangements amongst peers [3-5].

For the purpose of this paper the definition of learning disabilities includes individuals who experience a 'significantly reduced ability to understand new or complex information, to

learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development' [6]. Estimated prevalence figures are difficult to pin down and differ across countries. In the USA, there are an estimated 59.4 million individuals with learning disabilities, of whom approximately 11.6 million have long-term care needs, 9 million are children, 34.2 million are working-age adults, and 16.2 million are older adults [7]. An estimated 985,000 people in England have a learning disability (about 2% of the population) (Foundation for People with Learning Disabilities, 2009) and in Ireland the estimated prevalence figure for persons with learning disabilities is 25,613 [8]. In Northern Ireland, 18% of individuals in private households experience some kind of disability (21% of adults and 6% of children) [5].

The increasing longevity in developed countries (from 1900 to 2003, life expectancy for men increased from 48 to 75 years and for women from 51 to 80 years) means that people with learning disabilities also can expect to live longer than ever before [9]. The ratio of people who reach retirement age and have surviving parents or other very old family members nearly doubled in the past 50 years; in 1950 for every 100 persons aged 50-64, there were 2 persons over 85 years, in 2000 there were 4 persons over 85 years, and by 2050 this number is expected to triple [10]. Robinson and Williams (2002) found that 89% of adults with learning disabilities lived in the community, supported by unpaid members of the family who lived in the same household. 25% of these carers were over the age of 70 and were virtually unknown to services until there was a crisis.

It is now well established that disabilities, such as Autism Spectrum Disorders are on the rise, although the reasons for this are unclear and both environmental as well as genetic factors are considered in the literature [11,12]. Individuals with learning disabilities are more likely to experience other health related issues, such as epilepsy, diabetes, and are more likely to experience mental health problems. For example, Bhaumik, et al. (2008) [13] identified a total prevalence rate of 33.4% for psychiatric disorders in their study population of nearly 3000 adults with learning disabilities. Behaviour disorders (19.8%) and autistic spectrum disorders (8.8%) were the most frequent diagnosis in men and schizophrenia, depression, and organic disorders were more frequent in women.

A number of recent UK governmental papers, including Independence, well-being and choice [14] and Improving the life chances of disabled people [15] point out the importance of futures planning. Clearly, assessments should be carried out in a timely manner and undergo regular review in order to allow for proactive planning. To-date, despite the introduction of Person-Centred Planning (PCP) [16] the failure of services to meet the needs of adults with learning disabilities is endemic and crisis management is prevalent [17].

Unresolved issues of family involvement, education, work, separation, and independence prevent many families from preparing appropriately for future transitions [3]. Lack of future planning inevitably is stressful for the individual with learning difficulties, especially if they are unable to fully grasp the implications of necessary transitions due to limited intellectual capacity. Of course, parents also experience transitions as stressful because they have to prepare to give up their active parenting role [18] and adjust to life without their offspring, often after long-term care [19,20,21].

In the UK the shift from institutional to community care in the 1990s has led to more people with learning disabilities living with elderly parents than in the past [22]. Parents frequently feel that the needs of their sons or daughters are not fully tak-

en into account by service providers and that they themselves are required to take on the role of advocate. Concerns about the quality of care in alternative accommodation cause additional trepidation [17] and all too often it is assumed that ultimately a sibling will take responsibility without detailed plans or discussion [23].

Valuing People [6] requires service providers to 'secure a plan for all service-users with learning disabilities living with older carers and promises them and their families more choice and control over how and where they live' [24]. The UK Government's vision for people with learning disabilities across a range of services is based on the four key principles of rights, independence, choice, and inclusion [6]. In addition more recently, the Governmental paper Valuing people now [25] identifies five priorities for action: personalisation, what people do during the day, better health, access to housing, and making sure that change happens.

Although Putting People First (2007) stated that 'We agree that there is a need to explore options for the long term funding of the care and support system, to ensure that it is fair, sustainable and unambiguous about the respective responsibilities of the state, family and individual' (p.1), the experience of many families is still negative [24]. Similarly, independent living schemes are often seen as leading to less support mainly because individuals with learning disabilities may not be able to communicate their needs appropriately [24].

The significant factor in the relationship between sons/daughters with learning disabilities and their caregivers is the mutual dependence of the relationship [19,26]. However, interdependence is not a static state; rather it is a dynamic process that changes over the lifetimes of both. The ageing process of sons/daughters as well as that of their caregiver plays an important part in this interdependent relationship. With failing health many of the caregivers themselves may require care. With increasing age, many of the sons/daughters may assert their rights for independence and inclusion in peer networks. Despite the fact that over the years a range of governmental papers [6,14,25,27] outlined key principles, set priorities for action, emphasized the importance to secure futures plans, and aimed to offer more choice and control, this message has not permeated service provision [21].

Services and support systems

Voluntary and statutory organisations provide a range of services that intend to help individuals with learning disabilities to remain in the family home as long as possible. Where a parent can no longer provide the care necessary, or the son/daughter has chosen to live outside the home, there are a number of alternatives to home-based services. Ultimately, as detailed in the Chronically Sick and Disabled Person's Act (1978)

and its subsequent amendments, provision of health and social care services for individuals with disabilities should be negotiated between the provider, the caregiver, and the care user. Care may be delivered through statutory or voluntary agencies, or through informal care, or a combination of these. Care users can access these services through their key worker, usually a social worker or a nurse, who should co-ordinate the care package. The care user may be living in the family home, in supported living accommodation, in residential accommodation, or in a specialist unit that offers nursing care. The system is complex because individuals may need to access a combination of these options to meet their needs depending on their circumstances over time.

In Northern Ireland, the issue of adequate domiciliary care is complicated through lack of registration. The Regulation and Quality Improvement Authority (RQIA) is the regulatory and inspection body for day care and domiciliary services for adults with disabilities, however, registration uptake is slow [28]. Not surprisingly then information on suitable accommodation, education, support, and day care is very hard to come by.

Day care or day support for adults aged 19 or over is frequently used to alleviate family stress and facilitate normalising activities [29,30]. Day care centres aim to provide a range of social, educational, and leisure activities tailored to the needs of the individuals, as well as specific therapies. Despite acknowledged utility, McConkey, Slevin, and Barr (2004) [2] noted that, 'the evidence does suggest that centres under-perform in terms of the outcomes they offer to people with a learning disability'.

Respite care or short breaks offer a temporary break in caring for families. This can take place outside the home in a residential setting or scheme provided by registered host families in their home, i.e., Home- from-Home, or as a Sitting Service, where a respite worker will stay with the care user in the family home while the parent (or parents) can leave the house for several hours at a time [22]. The Caring for Carers report [31] acknowledged that breaks from caring are essential, yet, only one in five individuals with learning difficulties benefit from short break services [32] and concerns are noted about the lack of age-appropriate respite care in Northern Ireland [33]. Consequently, improving respite care remained a target area for Health and Social Care providers [34].

For many carers, there are concerns about the quality of care in alternative settings as well as problems of availability. The degree of differences in the quality of education and care and the costs can be noticeable to the extent that 'for a significant minority of people, their quality of life is relatively indistinguishable from the quality of life of people in hospital' [35]. In view of this, the research reported here had the following aims:

- To elicit reflections on life-experiences of adults with learning disabilities who live at home with their parents;
- To identify factors involved in planning for the futures;
- To offer a theoretical framework and make recommendations.

Methodology

•Ethical approval

This research was conducted in line with Queen's University of Belfast Research Governance Procedures. Data reported here were derived from a larger study; findings regarding theoretical and caregiver issues are reported elsewhere [19,20,21].

• Participants

37 adults with disabilities (males n= 15; females n= 12) were included in this study; they all lived with either one or both of their parents, except one who lived with her sister. In most of the families they were the only sibling with learning disabilities, while 1/4 lived at home with another adult sibling who also had disabilities.

Findings are based on focus group discussions with adults with learning disabilities and caregiver (mainly parents) interviews.

Nine participants (four women and five men) took part in the service user focus group. They belonged to a self-advocacy group for young people with learning disabilities, that was facilitated by a voluntary sector organisation. They were aged between 19 and 29 years (average age = 23.5 years). Group members were drawn from across Northern Ireland. Table 1 details the age and place of residence of participants.

Table 1. Service users- Participant details in Focus Group.

Gender	Age	Place of residence	Accommodation shared with
Female	26	At home	Parents
Female	28	At home	Mother + brother
Female	22	At home	Mother + grandmother
Female	24	At home (on housing waiting list)	Parents + 2 brothers
Male	29	At home	Parents
Male	19	At home	Parents + brother
Male	22	At home	Parents
Male	20	At home	Parents + 2 brothers + sister
Male	22	At home	Parents

Caregiver interviews (n=29) illustrated the lives of sons/daughter with disabilities who were unable to take part in focus groups or interviews; 17 of the caregivers were interviewed individually while 12 were interviewed as couples. The average age of the caregiver was 65.17 years (range 47-84 years). Their average age of their sons/daughters was 33.48 years (range 12-59 years) (Figure 2).

Table 2. Sons and daughters represented by caregiver interviews.

	Gender	Age	Impairment
1	Female	35	Learning Disability; depression
2	Female	28	ASD; Learning Disability, non-verbal
3	Male	41	Learning Disability
4	Female	29	Learning Disability, limited speech/ mobility
5	Male	42	Learning Disability
6	Male	18	ASD, Learning Disability
7	Male	47	PKU, epilepsy
8	Female	38	Learning Disability, Mental health
9	Male	33	ASD, epilepsy, depression
10	Male	44	Down Syndrome
11	Female	54	Learning Disability (not diagnosed)
12	Male	13	Down Syndrome
13	Female	52	Cohen's Syndrome
14	Male	32	Learning Disability, cerebral palsy
15	Female	59	Down Syndrome
16	Male	28	Down Syndrome
17	Male	24	Down Syndrome
18	Female	34	Stroke, Aphasia, Epilepsy,
19	Male	29	Down Syndrome,
20	Male	41	Muscular dystrophy
21	Female	12	Phenylketonuria (PKU), cerebral palsy
22	Female	23	Deaf, blind, cerebral palsy
23	Female	28	Learning Disability
24	Male	30	Prader-Willi Syndrome
25	Female	25	Microcephaly, cerebral palsy
26	Male	40	ASD, Wheel chair
27	Male	25	ASD, Challenging behaviours

Keyword: ASD: Autism Spectrum Disorder.

• Research tools

Service user focus groups

The focus group format was chosen and the questions were selected so as to elicit responses on general themes identified from the research question. The questions regarding participant profiles reflected the perspectives of the service users (i.e., sons/daughters), i.e., it was a self-advocacy forum engaged in regular meetings and social activities over a number of years and therefore participants knew each other very well. The questions focused on themes such as activities, home life, relationships, and independence.

Caregiver interviews

Where the adult with disabilities was not able to 'speak for themselves', a semi-structured interview schedule using open-ended questions was used to enable caregivers to talk

freely about their observations and experiences. Questions addressed issues such as demographics, life circumstances, challenges and opportunities, level of support, and futures planning, and advice to others. A full version of the interview schedule developed for this study has been included in the American Psychological Association's new PsycTESTS database (PsycINFO, 2010).

• Procedure

The focus group lasted just over one hour and took place in a specially hired hotel seminar room. The group was familiar with the rooms, and the discussion was tape-recorded. Notes were taken by one of the researchers while the other researcher conducted the focus group. The agency group facilitator attended the young person's focus group and facilitated communication for some of the group members. Following an 'ice breaker', the focus group was carried out as an open discussion with minor input from the facilitator.

Interviews with caregivers took place face to face either in the premises of the group/organisation or the family home (whichever was preferred). Interviews lasted 45-60 minutes and were tape recorded (where possible) and transcribed.

• Data analysis

Interpretative Phenomenological Analysis [36] was used to focus on understanding participants' idiographic observations and experiences and to allow for an interpretation from a theoretical framework.

Results

Young adult service users: Focus group findings

The participants in the focus group were young adults with learning disabilities, including Down's syndrome. Notwithstanding their age (between 19 and 29 years; average age 23.5 years) all of these young adults lived at home with their parents. Four also had siblings living at home, and one individual lived with her mother and grandmother. In addition, they were all involved in services outside the home, such as the support group run by a voluntary organisation and work and leisure activities.

Home and family life

Talking about how they spent time at home, most said they helped with household tasks, and some considered this both a very positive responsibility and an accomplishment they could take pleasure in.

I would call myself the golden girl because I'm always helping

out my mum because I'm always ironing and I'm always doing house chores. 'Cos ironing is a job that I'm really good at, I enjoy it, and I help my mummy.

However, helping out around the house was not a priority for all:

I help out my mum and my dad sometimes, helping to make the dinner or sometimes clean the house- only sometimes but I don't try a lot, but only sometimes and I play the guitar, and practice a lot.

All of the participants had a very active interest in new technologies; all had access to a computer at home and some had personal cable or satellite televisions in their rooms. When asked how they spent the time when they weren't helping out, the most frequent responses related to social network sites and television. However, they were also very much engaged with sporting and social activities.

I go out line dancing three nights a week, sometimes there's a competition.

I'm not usually in the house at night 'cos I like to go out; clubs like Drama, gymnastics and tag rugby.

Living at home was seen as a positive experience for most, and they expressed that they had acquired a sense of independence and confidence about their skills.

Having independence, and be able to have the ability to look after yourself and to know that you have the responsibilities of making sure that the house is tidy...

They also valued having their own space within the home, and looking after their room was seen as a responsibility (with certain benefits):

It means you can get away from your parents!! [General laughter]

There was only one negative response to living at home, where the individual felt that the other adults were noisy, especially with appliances like the television and radio, and this was an irritation:

The problem in our house is that ours is a bungalow and our walls are a bit like paper and I can hear them ...

Services and support outside the family

The focus group members were all very active socially and were involved in educational, employment and leisure activities that took them outside the home on a regular basis.

All group members lived at home and they nearly all enjoyed holidays or short breaks throughout the year; these were not just local, but involved holidays in England and abroad. For many, these were not 'respite' in the strictest sense, they were family occasions.

I go with my friend. We went for a trip to Australia! [Friend's name]'s mum and dad and family come too.

Some of these breaks were linked to other leisure activities such as sports or social groups, and some involved a degree of commitment to community involvement and social awareness on the part of participants (as well as a sense of adventure).

Well, I'm also a member of the [name] Association for people with learning disabilities and they do residential holidays. You get away to, Spain, or sometimes to the [name] Centre but that's only for the younger group but the older ones go to Spain.

Having a disability was not seen as a barrier for the young people in the group; they were very involved in local politics, in lobbying for disability rights and (as with many other people of their age) interested in becoming involved in projects that improved the lives of people in developing countries:

Have you heard of a thing, [name of charity]. Well they went through the Association and they're taking a group away over to, I think it's South Africa or something like that, to build houses for people who are in need of care.

Respite stays or short breaks through statutory agencies were a less common form of holiday for the group, and only one member actually reported going to an organised residential setting. One individual had not been away, either as part of a group or in the family.

My respite is in [name of town] gives my mum a break from me. Sometimes I go for a week or so, it all depends.

Parents who participated in individual interviews for this study reported a lack of social networking for their children with disabilities, and this was seen as a distinctive disadvantage for sons and daughters (of all ages) and in terms of allowing parents a break in caring responsibilities. The focus group, however, reported many opportunities linked to sports and social activities, and this had been actively sought out and supported by their parents, often when they were younger.

I go out too. Mum's never seen me all weekend! My mum took me down for my snooker tournament, in my snooker team every Saturday. My Mum leaves me down at the snooker hall, she leaves me there and Mum goes back home again. I look after myself. My Mum doesn't stay, all my friends in my snooker team look after

me, everybody in my snooker team knows me.

In one instance, a group member had helped found a social club that had expanded to include younger members, and others had been creative within existing groups, running special events to highlight sporting activities and raise funds.

I go to drama on Mondays, at night, and we're putting a show on. Anyway [name] is going to Athens and we're doing this thing, it's like a charity thing, for the Special Olympics.

However, since many of the group were in their mid-twenties, they felt that the clubs and activities were becoming less age-appropriate.

The thing about youth clubs, there's not enough for older people. Most of the clubs are up to a certain age.

When asked what kinds of activities they would prefer for over 25s, there was a general consensus that activities such as bowling, snooker, or trips to the cinema, which involved groups of friends, would be more appropriate for their age group. Some of the participants acknowledged that their parents had a major say in organising these activities; for some, it was totally up to parents, while for others, it was a process of negotiation. A growing awareness of a need for more independence (as with looking after the household tasks) was evidenced by many of the group. For others, they had already taken the first steps towards social independence in a new relationship.

[Name] and I are a couple, we go out on dates.

Access to social groups however was still dependent on parental support with transport; only one group member used public transport (the bus) occasionally for evening activities, and one other group member drove his own car.

Well, my two brothers drive, my parents drive and my sister drives. I'm the only one in the family who's not driving- my younger brother just passed the test.

All of the group members had occupations that took them out of the house on a regular basis during the day, and this varied from five days a week to three days a week; 77% (n=7) were employed and/or in college and two individuals attended day centres.

I'm at the day centre too, but I'm in a different day centre to the one he's in. I do three days a week, I mean catering two days a week I'm in the kitchen and we cook break and lunch for everybody else and then on a Friday I'm in the computers.

The college placements offered a range of qualifications, and most of the group were ambitious in terms of improving their educational experiences through obtaining national qualifications, such as NVQs, although some were sceptical of the quality of other awards.

When I'm in college I'd like to improve my skills so it means you can help out at home and cook dinner for your family I'd like to improve my skills. I'm leaving school and in September I'm going to [name], the same college as [name], on a course.

Those who worked most of the week had jobs in retail, either in major multinational stores, or local shops, which were limited in terms of time but which were flexible enough to allow some group members to carry out two part-time jobs.

My dad or sometimes my mum would maybe make my breakfast and I go to work around half twelve in the café. I work in a different café on a Wednesday.

When asked about acquiring new skills that would improve their opportunities, there was consensus around wanting to learn to drive a car, a skill that would offer independence, both in terms of social activities and work. The drawbacks, i.e., the cost of running a car, and the work involved in passing the theory test, were also considered, although only a few of the participants seemed discouraged by these aspects.

I know, I'd like to drive a car but my head's not focussed sometimes. I'd learn lots of theory and there's all the money it's dear.

Young adults planning for the future

All members of the focus group lived in the family home with their parents. Only one young person was on a housing list, but the consensus was that independent living was something to aim for. The reasons for living at home were fairly evenly divided between a feeling that they themselves needed more time to get ready for the move or that they were needed at home, and perceived unwillingness on the part of their parents to let them be more independent.

No, I'd like to go, but my problem is that my mum isn't ready to let me leave.

I don't want to leave the house, I know it's to be decided, but there's things you have to do around the house.

However independent these young adults hope to become, the majority will almost certainly want to access services to support them in their future lives. In the next section, the life of adults with disabilities will be examined from the perspective of the parents and caregivers.

Caregiver interviews

For the most part, the relationship between family members was described with love and affection (79%; n=23). Although, some difficult relationships were also described (14%; n=4).

"Difficult at the moment, was better in the past, a lot has changed since [his father] died."

There was evidence of severe lack of adequate services in almost all interviews in almost all services sectors, including health, education, and social care.

"When his depression developed, I went to his community nurse and I said, 'Look, he's not eating'. He went completely anorexic. I was convinced there was something wrong with his stomach, for he really loves his food. [name of son] wouldn't be very emotional as long as someone is there, it doesn't matter, so I didn't think he could have depression."

• Living at home

Most parents identified a range of positive aspects about their adult son/daughter with disabilities living at home, such as enjoying each other's company, spending time together, and going out (79%; n=23).

"I think he has become very contented with his lot, and he's relatively easy... once he goes to bed that's it and he sleeps right through the night."

Some participants could not see an positive side for their son/daughter mainly due to lack of support, while others found the support they received had a positive impact on their son/daughter with learning disabilities.

"Find it very difficult to get someone outside my immediate family who can manage [name of daughter] even for a short period of time. It takes a long time for them to get to know her."

• Challenges

The greatest challenges were educational and behavioural issues, including physical aggression, and meeting social needs (86%; n=25).

"He can be a bit of a maverick... He could strike out on his own in situations where it could be dangerous. We've had situations where he's gone walking, or taken taxis to places. He's very high functioning at that level and he could talk people into doing anything for him, so that to me is the danger..."

• Self-care skills

Caregivers reported on sons and daughters with disabilities

showing a considerable lack of self-care and life skills:

"You would actually have to get into the shower and have to end up doing it. He would have a wee go but he would just sort of rub and then you would say 'what about under your arms'. And the same with brushing the teeth, he'd just sort of sit there with the brush, so you'd take the brush. Constant supervision or constant prompting, you know? He wouldn't have any idea of cooking or making meals, or travelling, going out on his own or coming back on his own, you'd have to be with him... he has no speech... [name of son] has absolutely no speech."

"Both boys require 24hr supervision; personal care... dressing, personal hygiene; meals prepared, medication administered and monitored; clothing washed; activities organised. Similar to the type and level of care a 3-4 yr old requires."

At the same time, many of the adult sons/daughters required supervision and guidance regarding appropriate activities.

"For [name of daughter] more of supervisory care... companionship maybe when you consider her friends; she has a few friends from her school days, and those are her friends now. A lot of them left her after she had the stroke and dysphasia, she wasn't speaking and they cleared off because they couldn't hack it, but she has three, maybe four good friends and of course her best friend died of cancer about a month ago...and that took a lot of getting round."

• Social life

With regard to appropriate social life, the demands of sons and daughters changed across the life span.

"He's getting more independent, his needs for going to places, to youth clubs and going out. ...but he maturing slowly, developing slowly but getting more independent."

• Leaving home

Eventually, leaving home becomes an issue to be addressed by adult sons and daughters with learning disabilities. However, parent caregivers expressed concern about safeguarding and wellbeing for sons/daughters when cared for away from home. Related to this was a worry about what will happen once parents are no longer able to care.

"[name of son] came home after this holiday... he was away about four or five days and the young fella on the bus said 'I don't think [name of son] enjoyed his holiday'. He was bruised all down when I took off his shirt.... He had cuts... what happened, he had fallen out of the wheelchair and his leg was also hurt... we phoned [name of day centre] and our GP phoned, but we couldn't find out..."

• Retrospective

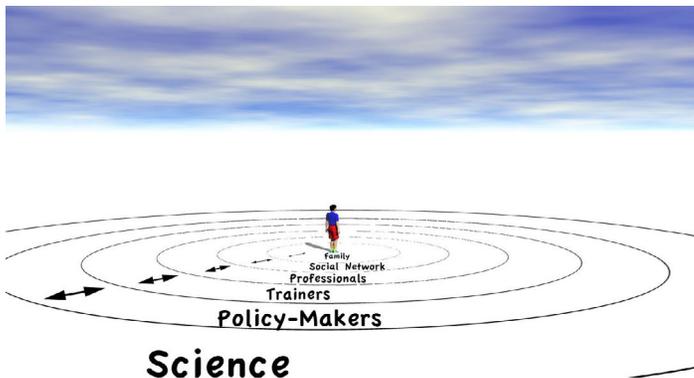
A number of issues were mentioned when caregivers considered what they wish they had known during the process of raising a child with learning disabilities.

“Goodness me... if the child can't communicate... you would really need to plan it around what the child wants. The child would need to be compatible with the person that's caring for them... no point in setting up something where they aren't compatible with the person that's being cared for.”

Discussion

This study illustrated reflections on the life experiences of adults with learning disabilities who live at home. Figure 1 illustrates the strata of relationships involved in their lives that include family, social networks, professional education and service providers, trainers, policymakers and that should be underpinned by a scientific understanding of best practice.

Figure 1. Strata of relationships involved in lives of individuals with disabilities.



(Reprinted from Keenan et al., 2007, [1] with permission)

Overall, sons and daughters with learning disabilities experience a loving and caring environment within the family and were valued, however, there was a severe lack of social and self-care skills indicating that they had not benefitted from early behavioural intervention aimed at extending their skills levels and behavioural flexibility [37-39]. Children with learning disabilities who benefit from effective early behavioural intervention have more behavioural choices and consequently are able to lead more independent adult lives than the sons and daughters in this study [40-42].

The theoretical framework outlined by Gallagher and Keenan (2006) [43] contrasts traditional psychological approaches with a behaviour analytic perspective. This means that instead of relating age as the independent variables to developmen-

tal milestones as dependent variables, thus concluding that certain behaviours are determined by being a certain age, environmental events are identified as independent variables, while behaviour (publicly observable as well as private behaviour) is considered the dependent variable. This kind of contingency-based explanation of behaviour offers new inroads to understanding how the behavioural repertoires of individuals with learning disabilities develop and become inter-dependant with those of their caregivers [19,20].

This analysis should inform future policy-decisions and research directions. Recently the Promoting Social Inclusion Working Group on Disability [4] outlined their vision of a 'future where disabled people contribute to and benefit from the cultural, social, political and economic life of Northern Ireland on an equal basis with others' (p.10) and the Northern Ireland Survey of People with Activity Limitations and Disabilities [5] identified 'barriers to employment, education, transport, housing, access to information and lifelong learning for disabled children and adults' (p.9) and made recommendations for wider policy developments. The reflections on the life of adults with learning disabilities reported here point clearly to a new research agenda with regard to effective and evidence based early behavioural interventions.

Summary

A study of 37 adults with learning disabilities was carried out. Focus group discussion with service users and in-depth interviews with their parent caregivers showed a highly complex picture of interdependent relationships. Overall, adult sons and daughters with disabilities experienced loving home environments; however, better early behavioural interventions aimed at improving life and self-care skills would increase quality of life and generally enhance social capital.

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