Living in Sandwell: An Exploratory Study into the Key Issues and Challenges that Affect a Small Group of People with Mild Learning Disabilities

Liz Tilly[1]

[1] Freelance trainer and facilitates Building Bridges Trainers, a training group of people with learning disabilities

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Abstract

This paper is concerned with a small group of people with a mild learning disability; who they are and what their lives are like. This group is not typically known by the label of mild learning disability in research, social policy or in service provision, due to a lack of suitable assessment or identification methods. This small study, using focus groups as a data collection method and undertaken as a pilot study for further research, has shown this group experienced wide ranging social disadvantage, and difficulties and challenges in daily living due to their learning disability. These included travel, shopping, parenting, lack of IT skills, plus experiencing local anti-social behaviour on a regular basis. Lack of recognition and appropriate support can leave them vulnerable to a range of difficulties and issues including social isolation and harassment.

Keywords: Mild learning disability; focus groups; social exclusion; anti-social behaviour, eligibility criteria

Introduction

The experience of most people with learning disabilities is generally reported as them having a poor quality of life, i.e. excluded from mainstream life, communities, employment, social and political participation and inadequate income for their basic and disability related needs (Bach, 1994 Department of Health, 2001). Valuing People, the Government's key strategy for people with learning disabilities, however, has social inclusion as a key principle;

> 'Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community' (Department of Health, 2001:24)

Inclusion means people being able to: participate in, benefit from and contribute to society; claim full human and citizenship rights, access the same opportunities, use the same facilities as other people for education, housing, employment, health and leisure and having the support to do so (Bradley, 2005).

This principle is reiterated in the government consultation paper Valuing People Now:

> 'The aim is to support people with learning disabilities to live an ordinary life in the community alongside their fellow citizens as described by human rights legislation and the Disability Discrimination Act' (Department of Health, 2007:10).

Who are People with Mild Learning Disability?

Valuing People (Department of Health, 2001:14) defines learning disability as follows:

'learning disability includes the presence of:
• A significant reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with:
• A reduced ability to cope independently (impaired social functioning);
• Which started before adulthood, with lasting effect on development.'

Similarly the British Psychological Society (2001:4) defines three core criteria for learning disability;

• Significant impairment of intellectual functioning
• Significant impairment of adaptive functioning
• Age of onset before adulthood

The label 'learning disabilities' is used to describe a very wide group of individuals, covering the continuum from those who have profound learning disabilities and have very low levels of functioning and very high level of care needs, through to severe learning disabilities, to those who have only mild learning disabilities. There are no clear dividing lines between people with mild learning disabilities and the general population, and there is no clear cut off point, so the prevalence rate can vary. Most people with a mild learning disability can communicate using spoken language and reasonable skills to live independently with appropriate support (British Institute of Learning Disabilities, 2007a). People with a mild learning disability are frequently ineligible to access learning disabilities services (Learning Disability Commission, 2007), they frequently experience social exclusion from the wider community (Simons, 2000).

Prevalence of severe and profound learning disability is fairly uniformly distributed across the country and socio-economic groups, whereas mild to moderate learning disability is associated with poverty. Rates are higher in socio-economically deprived and urban areas and clusters in families, and has an identifiable cause in only 50% of cases, as opposed to 80% in severe learning disability (Mackenzie, 2005). Higher rates in some social classes suggest that factors such as large families, overcrowding and poverty are significant. It is usually caused by a combination of restricted learning and social opportunities, plus a high rate of low-average intellectual ability and learning disability in close relatives (See 'Contact a Family' website)

There are many difficulties in coming to a definition of this label; people with a mild learning disability are those who have an IQ of 50 to 70, theoretically 2.23% of the population (Whitaker, 2003), with 71 to 130 IQ considered to be within the normal range (Department of Health, 2001). The IQ of 70 is a benchmark simply because it is two standard deviations from the mean IQ of 100.

Whitaker (2003) suggests the major reason for identifying who has a learning disability is in order to provide a specialist service, but questions the reliance of identifying learning disabilities by IQ alone. The measure of IQ 70 is arbitrary and is not an indicator of whether someone can cope with daily living. The relationship between measures of IQ and adaptive social behaviour is described as moderate and is not a good predictor of adaptive behaviour and therefore also

need of a service. Whitaker (2006) reports that his experience of 25 years of administrating IQ tests has demonstrated that an IQ level of 70 is not a good indication of ability to cope and therefore need of services, and that the term learning disabilities is demeaning to the people to whom it is applied, confusing to professionals and researchers and fails to describe the group of people who receive a specialised service.

There is a continuing shift to supporting all people with learning disabilities through non-specialist mainstream services, (Department of Health, 2001; Department of Health, 2007), so inevitably people become less identifiable and are potentially vulnerable and 'fall through the net' (Simons, 2000), and so the label mild learning disability is not well known or used outside of the field of learning disability. People who may be described as having a mild learning disability are often an invisible group in policy and academic research, as most research is focussed on either those with more severe learning disabilities who use specialist services, or research on social exclusion, but not those labelled or recognised as those with a mild learning disability. For many years the focus of research has been on the medical and psychological analysis of needs, rather than on social needs and using an inclusive research method (Walmsley, 2005).

It has been suggested that research undertaken in relation to people with learning disabilities has been slow to involve them directly in the research process (Kiernan 1999). However this group are echoing the demands of women and minority ethnic groups for equal say and opportunities (Beresford et al, 1993), and from the late 1980s there has been a continuous development of participation, citizenship and empowerment, and the rights and responsibilities that go with it. People with learning disabilities are taking an increasingly active role in both research and consultation (Ward, 1997; Atkinson, 2000; Carr, 2004). It is now widely accepted that they have opinions and the right to express them (Stalker, 1998; Simons, 1999) and furthermore that they are the best informants concerning their experiences (Chappell, 2000). The methodology selected for this study sought to enable people to communicate their own stories and experiences.

People with a Mild Learning Disability and their Use of Support and Services

As local authority budgets become overstretched, people with a mild learning disability are increasingly less eligible to receive support and specialist services, as they are deemed to be too able and therefore do not meet access criteria, yet receive minimal support from other mainstream services.

They are often outside of the employment market and, after leaving special schools, become lost from formal services until crisis situations such as being the victim of crime, a perpetrator of crime, debt, illness, neighbour disputes, bereavement, homeless, pregnant or other situations requiring professional intervention (Simons, 2000; Care and Repair England, 2008; Easterbrook, 2008).

Fair Access to Care Services, the Department of Health (2003) guidance on the eligibility criteria for adult social care, was developed to establish fairer and more consistent eligibility decisions across the country. The framework is based on individuals' needs and associated risks to independence, and includes four eligibility bands - critical, substantial, moderate and low.

In November 2007 the Learning Disability Coalition (2007a) reported on the withdrawal of services to people with learning disabilities and it revealed that an increasing number of local authorities are rationing support by only providing social care to those people with very high levels of need.

During 2007 the member organisations of the coalition gathered information on local authority funding cuts to learning disabilities services, both those provided in house and by the independent sector. They reported Government spending on social care for people with learning disabilities had increased by 7.2%. However the level of funding from central government had not kept pace with a population that is growing at about 1% per year (Learning Disability Coalition, 2007b). In 2007, 80% of local authorities said their budgets for learning disabilities were under pressure, 70% would only support people whose needs are said to be substantial or critical and 80% of councils planned to tighten their eligibility criteria (Learning Disability Coalition 2007b).

The study took place in March 2008 in Sandwell, a metropolitan borough council, the most deprived borough in the West Midlands and, based on the average ward deprivation scores, is the 16th most deprived in England (National Statistics, 2006) therefore a particularly relevant geographical area to undertake such research given the link between levels of deprivation and numbers of people with a mild learning disability.

Using prevalence rates based on entire populations (as compared with people known to services) and applying these across the Sandwell population indicates that locally, there should be approximately 1,698 people with severe learning disabilities and 8,490 with mild learning disabilities in the borough, which is a significant section of the community   (Gaughan et al., 2005).

Between 2005 to 2008, Sandwell MBC only funded services to people who would be assessed as being in the substantial band (Learning Disability Commission, 2007a). People who have a mild learning disability are therefore highly likely to be excluded from services provided by funding from the local authority.

Design and Method

Focus Groups

Focus groups were the method chosen to gather relevant qualitative data to draw out and explore the participants' life experiences, key issues and challenges. They have become increasingly popular since the 1980s initially in marketing and now also in social research.

> 'Focus groups clearly have potential for research questions in
> which the process through which meaning is jointly constructed is
> likely to be of particular interest' (Bryman, 2004:359).'

Focus groups involve intensive discussion and interviewing of small groups on a given focus or issue (Scott et al., 2005). The aim in this study was to use open questions to stimulate and generate discussion 'and thereby understand through subsequent analysis the meanings and norms which underlie those answers' (Bloor et al., 2001:43). They elicit information in a way which allows researchers to develop an understanding about *why* people feel the way they do in addition to

their opinion; to find out why an issue is salient as well as what is salient about it (Gibbs, 1997).

The method was chosen because of the recorded benefits to the participants; people may feel empowered, feel the benefit of meeting with others who are similarly situated and report the benefit of being listened to (Fay, 1987; Gibbs, 1997; Options for Life 2007). They also provided an opportunity for participation in the research process and gave the participants a chance to be valued as experts (Gibbs, 1997).

The study sought to explore 'what do a group of people with mild learning disabilities living in Sandwell consider to be the key issues and challenges that affect their daily lives?' and was a pilot study to inform further research.

Participants

The criteria for participation in the focus groups were that people:

- Lived in Sandwell
- Were aged over 18
- Lived independently with up to five hours 'of individual formal support
- Described themselves as having a mild learning disability i.e. that they need support to live independently, and have difficulties in numeracy and literacy and sustaining education or work
- Identified they had limited formal and informal support networks

The participants were all contacted through a Supporting People 'floating support' service delivered by a voluntary sector provider. People were invited to participate by a third party, their support worker, who also identified that the person met the criteria. The support worker was asked to explain that participation was voluntary. This non-direct approach was chosen to enable them to decline more easily than if invited directly by the researcher.

Ten people were invited, seven responded and six were able to attend each session, each person attending at least twice. The group comprised two men and five women; five were also parents, with two of them having had children removed by the courts.

There were a range of issues and challenges to be considered and overcome in working closely with people with learning disabilities, who had no or limited prior experience of research participation (Ham. et al. 2004; Walmsley, 2005; The Learning Disabilities Research Team. 2006), and understanding gained from a previous research project (Options for Life, 2007) resulted in the following practical arrangements being taken which contributed to the success of the focus groups:

- All written information was translated into a more accessible format
- Transport arrangements were made for people who could not travel independently
- Participants were telephoned to remind them beforehand
- The groups were held in a room at a local voluntary organisation which was accessible and held at an appropriate time for those attending
- Refreshments were provided

- Each session began with an icebreaker, such as 'what is your favourite memory' to enable the participants settle down before the group discussion
- The pace was appropriate to those attending and the discussion questions were within their range of skills and levels of ability in the areas of verbal communication, literacy skills and memory. Appropriate simple language without jargon was used
- Careful facilitation and questioning was used to overcome a tendency to respond compliantly
- Due acknowledgment and reward were given to those who participated, by thanking them, providing a certificate of participation, and they were promised an easy-to-read version of the final report.

Participants were encouraged to share their thoughts, feelings and experiences on three themes in order to give the sessions a focus for the discussion around the research title:

- my life and home and health
- my community
- relationships, help and support

Some topics were considered inappropriate to explore using this research method, such as where sensitive information is required, and there could be potential issues concerning confidentiality from other group members (Gibbs, 1997). The topic guide therefore avoided sensitive subjects such as money and debt.

Issues concerning anonymity and confidentiality were considered carefully, including the possibility that in a group setting people may disclose more sensitive personal information than they may have expected to which may leave them vulnerable, referred to as 'over-disclosure' (Bloor et al., 2001). This was overcome establishing clear ground rules at the beginning of each session with an emphasis on confidentiality and participants were reminded throughout that they could withdraw at any point.

Each session began with introductions and thanking people for coming, outlining the goals of the research, the reasons for recording the session and the format of the focus group and agreeing the ground rules. After the focus groups, the findings were written up in an easy-to-read format and circulated to the participants. They were sent via a third party, their support worker, for support with reading them, to ensure people were free to respond and not feel under pressure to comply. They were asked if they were satisfied that the record of their discussion was accurate and to check again they were willing for their data to be used.

Data Analysis and Results

The raw data from the three groups was analysed under the following broad headings, and then further analysed to those topics that the group talked about:

- Experiences and issues which could affect anyone living in Sandwell
- Experiences and issues due to having learning disabilities
- Personal strengths and coping strategies
- Formal and informal support

Housing and their Local Area

Although all the participants lived in accommodation which met their needs, they all shared the experience of previously having been accommodated in poor housing stock; four participants having lived in properties which have since been demolished, and most having experienced moving house several times in recent years.

Local anti-social behaviour was a serious issue experienced by the entire group, both in terms of it happening in the participants' locality and in them being first hand victims. Some of the examples given from both their past and current experience were having eggs thrown at windows (two participants had experienced this), leaves pushed through letter boxes, seeing people urinate outside, young people hanging about, having windows broken deliberately, drunken neighbours being insulting and neighbours' children 'running riot' with their parents not taking any action.

In addition to anti-social behaviour by local youths, all the participants had experienced problems with harassment and intimidation from at least one and often more neighbours which significantly affected their daily lives. It made people feel angry, afraid, annoyed, upset or harassed.

As with many people living in deprived communities (Home Office, 2008), one of the main issues reported was the level of anti-social behaviour in their local areas, and a specific concern was the intimidation experienced when using local shops of young people requesting that they bought them alcohol and cigarettes. Intimidation was also experienced when using public transport.

Use of Community Facilities and Local Shops

These were limited to those which were less expensive such as visiting local shopping areas, the library to borrow books for themselves or their children and to use the internet, and attending the local church. Only one person attended a keep fit class. People frequented places free to enter, such as museums and the park. Almost everyone used the local take-away regularly but only one person went regularly to the pub.

People only occasionally used and did not like the local shops as they lacked variety, were too expensive, and they felt they were being rushed, watched and followed. A major issue that everyone shared was being approached by young people outside the shop and being asked to buy alcohol or cigarettes. This happened very regularly to all the participants. Everyone said they refused to buy for the young people but that this was difficult, and the younger participant said she had bought for the young people when she herself was younger.

Supermarket Shopping

Everyone shopped regularly at a supermarket; some of the difficulties reported were that special offers could be very confusing; it was hard to know what the best buy was, and to understand the labels in order to check the ingredients or the fat content. Selecting the right items was difficult and 'just choosing things can be hard sometimes'. Other issues related to basic numeracy; for example, some people found it difficult to know if they had sufficient money to pay for everything at the checkout and work out how much they could afford to buy. One

woman 'felt stupid' at the checkout to discover she did not have sufficient money but that 'having a smile helps'.

In the supermarket four people regularly asked the supermarket staff for help, which was beneficial. Shopping was generally seen as quite a challenging chore and having either informal or formal support was very important to all the participants.

Reasons for not Using Community Facilities More

These were due both to issues with the venue or facility; some facilities like swimming baths were considered scruffy and dirty, places are not always family friendly like social clubs. Lack of money was also an issue and those with children also said it was hard to find child care. Some did not do more because they had no one to go with and 'felt lonely' if they went by themselves, and also did not like to walk to places on their own. Some had even been excluded by people they thought of as friends, from joining in social and leisure activities with them.

Communication and Access to a Landline, Mobile Phone, Computer and the Internet

Only one person had a landline; three others had one previously but had been cut off following problems with paying the bill. Some would like one so they could have internet access at home. Everyone had at least one 'pay–as-you-go' mobile phone, with most claiming to have several. Everyone used their phones to make calls only, as texting was reported to be difficult, despite this being an increasingly common method of communication. Three people had a computer at home but only one was currently connected to the internet.

Three of the group did not know how to use a computer, this caused a problem for those with children doing their homework but people did use the facilities at the local library. Only one person had used the internet for shopping and no one had or wanted to use a computer for either study or 'social networking'. People were quite limited in who they could go to for help and support with any problems using a computer or the internet. Generally people used a computer for leisure use such as playing games.

Local Travel

Everyone travelled locally using public transport, as no one had their own transport. The main problems reported were that it was hard to find out how to get to new places; knowing which bus to catch and what time it leaves; the difficulty of getting back from places late at night or travelling outside of the local area, 'it can make you nervous using the train'. People also said they had experienced anti-social behaviour on the buses, e.g. young people smoking, including smoking drugs and playing loud music.

Other Experiences which were Reported During the Three Focus Groups

Everyone had experienced a wide range of very challenging and difficult personal circumstances and all showed a high level of personal strength, coping skills, resilience and resourcefulness to survive. Experiences included:

- Being bullied at school
- Losing a wife to cancer
- Difficult marriages
- Having children removed by the courts
- Being wrongly accused which resulted in eviction, being homeless and living in a hostel for a time
- Frequently moving house, and living in inadequate homes
- Frequently changing relationships with partners
- Bringing up children without a partner
- Friends letting them down
- Difficulties in parenting teenagers
- Postnatal depression
- Being raised by foster parents
- Poverty and debt
- Long term unemployment

Experiences and Issues due to Having Learning Disabilities

One of the main issues for people was literacy difficulties, which presented problems in a range of daily tasks, including obtaining information about the local area and travel, difficulty reading letters, and especially relating to shopping and reading the text on food tins and packets. Other difficulties reported, due to finding reading difficult, were reading and understanding prescriptions, reading to their children, following the instructions for assembling new things and reading adverts to find out what is on. Completing forms such as for dental or medical treatment, applications for housing benefit, school letters and job applications were also difficult.

Most people commented that newspaper advertisements and other information were described as being too small to read, and, it is assumed, this also meant difficult to understand.

There was no embarrassment within the group about discussing literacy difficulties; however, there seemed to be some reluctance in letting others know, as people did not want to be thought of as 'thick'. No one expressed directly any problems with numeracy except one participant who shared how she was not always sure she would have enough money to pay for the groceries she selected in the supermarket. Others reported problems with phone bills which may have been due to difficulties in budgeting as well as insufficient money to pay the bill. The lack of IT skills was a main issue for the parents who were unable to support their children with homework.

Did the Participants Think Others are Aware that they have a Mild Learning Disability and Does it Help if they do Know?

There were mixed opinions regarding how much they thought people knew of their learning disabilities and the extent to which it helped if people did know.

The participants gave a mixed response; sometimes it is difficult to request help as although sometimes people are helpful sometimes they 'don't want to know' and people might think you are 'thick', and you can 'feel embarrassed'.

They reported that while some people treated them better when they did know, others did not. Others said that they felt that people worked it out 'if you ask

questions or ask for help'. Sometimes people found it hard to ask for help, especially when they would prefer to be able to 'do it themselves'. Someone felt that their GP knew and another felt that her social worker was more sympathetic having found out that she has learning disabilities.

Personal Strengths and Coping Strategies

The participants were all able to cite the source of their personal strength or a reason for their abilities to cope and survive. These were an attitude of self determination; 'I can do it' and 'I will get through this'; thinking of one's children; faith in God and the support of friends. No one mentioned intervention of paid staff.

They also used others as a source of information and help, including people on the TV and supermarket staff. Those with children identified them as a source of help with literacy problems. People had also developed strategies to overcome literacy problems including: looking at the pictures (e.g. with instruction guides), asking their children, using their memory, asking other people and using trial and error. They identified larger font and illustrations as helpful to being able to understand text.

The Level and Type of Support Available

Everyone had formal weekly support from a worker funded through a Supporting People service, support tasks included paying bills, shopping, sorting out letters, making appointments and some also had help with grocery shopping.

Although the question was not put to the group directly, no-one expressed that they needed or wanted to have more support from a paid worker. Everyone needed support to shop and received this from either informal or formal support. The majority of the group members' friends also had a mild learning disability. Support staff were not needed except for help making an appointment or going with them for the first time. Additional help they identified was for support in parenting and shopping, and for some DIY and decorating.

The participants agreed that they needed the support of the facilities' staff, especially at the supermarket, when using community facilities. In most cases this was reported as helpful although some reported incidents where there had been altercations with staff, so it identified the importance of front line staff being aware of the needs of this group of people.

Discussion

The study considered the effects of social deprivation and exclusion experienced by a group of people who have a mild learning disability. It was found that they had limited social networks and informal support mechanisms, few identified role models or people to turn to for advice. Their lives are also influenced by other factors such as the level of formal support from services and the level of anti-social behaviour in their neighbourhood. All the group had experienced a range of very difficult and some traumatic experiences in their past, yet this group of people were only receiving a few hours of formal support a week. The findings suggest that proactive support is very important and also there is a need for signposting and advice services.

As with the general population, this study found that anti-social behaviour was a major issue affecting lives and contributing to their social exclusion, and being a personal victim of anti-social behaviour was exacerbated by a breakdown in relationships with neighbours.

Their experience is typical of many people in Sandwell; the Local Area Agreement Evidence (Research Sandwell, 2008) reports that the perception of anti-social behaviour in Sandwell has risen considerably from 2003 to 2006, which is considerably higher than the national average and second highest in the seven West Midlands districts. Anti-social behaviour was also a key issue reported in Making Voices Heard (Options for Life, 2007). People with a mild learning disability, however, can be considered to be especially vulnerable, as this study reports, they have reduced skills to deal with it, both emotionally due to limited support networks, practically as they report not having the skills or resources to report it, and may even be especially targeted if they are perceived by the perpetrators as being different in some way. Whilst tackling anti-social behaviour continues to be a major focus in government policy, the 2003/4 British Crime survey found that 76% of the population perceived anti-social behaviour to be a problem, and that living in deprived areas such as Sandwell, gave predictions of perceiving anti-social behaviour four times higher than wealthier areas. This frequency of incidence was noted to result in serious emotional impact and affect quality of life (Wood, 2004).

These findings suggest that Local Authority and police interventions in tackling this problem, especially the reporting of incidents, should take into account the specific needs of this group; they are less likely to be able to report it by letter, phone, text or email. It suggests that better advice on community safety advice and support in an accessible format would be useful for this group of people.

The study has also highlighted the importance of identifying people with a mild learning disability and therefore targeting support to their unmet needs. Some particular areas of support this group identified were in shopping, and especially using the supermarket, support in parenting, computer use and travel training to enable them to have full community inclusion. The findings also suggest that frontline staff need to be aware of the needs of this group of people, who may not initially present as having a learning disability, and how they might need support due to their literacy difficulties or lack of using facilities on an initial visit. It has highlighted a need for further research to look into the accessibility of community courses in literacy and computer skills, and advice and guidance services for this group of people, to ascertain if this group of people are using them and if they are of value, and if not what the barriers are.

Although not explored specifically, poverty and low income also affected the group, especially their leisure time. They seldom used the pub and were restricted to free to enter places, which would have an impact on their inclusion in the local community.

The value of informal networks and friends in the use community facilities, as identified in other studies (Beart et al., 2001), was highlighted, and shows how this group can be vulnerable to social isolation if they do not have a circle of friends and informal support. Finally, it has shown how important it is to enable people with learning disabilities to be direct informants of the pertinent issues in their lives, and how, by employing an appropriate method, they are able to share their experiences.

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