

Research paper

‘I ain’t been bothered to go’: managing health problems in people with a learning disability who live without support

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What is known on this subject

- People with a mild learning disability who do not use services are the largest group within the learning-disabled population.
- This group are often a hidden population post school years, and frequently are not known by mainstream services as having a learning disability.
- Learning disability and poverty are both associated with poor mental and physical health.

What this paper adds

- Limited social capital and poverty mean that people with a mild learning disability have limited access to good role models that might help them to access healthcare.
- This group of people with mild learning difficulties had a wide range of avoidable health problems.
- This group had difficulty in accessing health services, attending appointments and understanding health advice.

ABSTRACT

People with a mild learning disability, who live independently without support from services, make up the largest group within the learning-disabled population. An inclusive project enabled a small group of seven people with a learning disability to take the lead in exploring their own lives. It used a grounded theory approach, enabling the group members to take a lead in the direction of the research. The aim was to explore the strategies they used to cope with day-to-day living, their experiences of poverty, and the support they received from their social networks. The research also explored issues of identity and labelling and enabled this socially excluded group to have a voice. The

findings revealed multiple challenges in many aspects of day-to-day living. These challenges included a wide range of avoidable health problems and difficulty for a number of reasons in engaging with health services and health advice. This was exacerbated by having poor role models and limited social capital. Their health problems had a major impact on their lives, and many avoided diagnosis and treatment out of fear.

Keywords: grounded theory, hidden population, inclusive research, mild learning disability, poverty, social capital

Introduction

People with a mild learning disability make up approximately 85% of the learning-disabled population (Emerson and Hatton, 2008b). They are known

to have difficulties with a wide range of skills that severely hamper their chances of obtaining employment. Those who do work tend to be in unskilled, low-

paid occupations. Unemployment and lack of access to education or training that might improve their skills mean that many depend on welfare benefits and live in poverty (Emerson and Hatton, 2008a; Tilly, 2008; Emerson *et al.*, 2009; Department of Health, 2010b). This situation is exacerbated by limited social networks and social capital, particularly if other family members also have a mild learning disability (King's Fund Centre, 1988; Simons, 2000). Consequently, they may have difficulties with issues such as housing and managing relationships (Simons, 2000; Easterbrook, 2008), civic and public engagement (Emerson *et al.*, 2009) and caring for their children (Craft, 1993; Booth and Booth, 1997; McGaw, 1997; Department of Health and Department for Education and Skills, 2007; Working Together with Parents Network, 2009). People with a mild learning difficulty also suffer from an above average incidence of health problems which are often related to diet and lifestyle and related to inter-generational patterns of health behaviours (Flynn *et al.*, 2002; Options for Life, 2007; Emerson *et al.*, 2009; Cabinet Office Social Exclusion Taskforce and Department of Health, 2010). After leaving the education system, people with a mild learning disability may have little or no engagement with formal services. They tend to fall between service and agency responsibilities and consequently receive little or no attention unless or until a crisis situation arises (Simons, 2000; Myers, 2004), such as being the victim or perpetrator of crime, as well as debt, illness, neighbour disputes, bereavement, becoming homeless, and becoming pregnant or having children (Simons, 2000; Care and Repair England, 2008; Easterbrook, 2008).

This paper draws on the findings of a research project that focused on enabling a group of seven people with a mild learning disability, who did not receive any support from services, to explore their own lives. They were not considered eligible to receive support from local-authority-funded adult care services as they did not have 'critical' or 'substantial' need (Department of Health, 2003, 2010a). The initial plan did not include an exploration of health and well-being in any great depth but, as the group members chose to share their experiences, it became evident that this aspect of their lives contributed to difficulties in coping from day to day and affected their overall quality of life. This paper focuses on how contact with health services and medical professionals created a series of challenges, including difficulties in making medical appointments, reluctance to attend appointments on their own due to problems with communicating symptoms or understanding what was said to them, and complying with medical treatments (NHS Service Delivery and Organisation, 2004; Disability Rights Commission, 2006; Mencap, 2007; Michael, 2008).

Methodology

An inclusive research methodology was essential for enabling a group of people with mild learning disabilities to have a voice and take a leading role in how the research developed, rather than just contributing to the data collection (Walmsley and Johnson, 2003; Townson *et al.*, 2004). A grounded theory approach (Glaser and Strauss, 1967) was selected because it was considered to be organic, flexible and compatible with inclusive research and a person-centred approach (Sanderson, 2000; Tilly, 2011). Grounded theory has been used in previous studies about people with learning disabilities. For example, Llewellyn and Northway (2008) used it to examine experiences of advocacy. Grounded theory has been used to analyse life stories as 'it offers a well-established approach to ensuring that the ideas and recommendations which the researcher develops and makes emerge *from* the data, [and] are *grounded in* what key group members have contributed through their words and experiences' (Goodley *et al.*, 2004, p. 119; italics in the original).

Grounded theory is described as a voyage of discovery, starting with no fixed ideas (Denscombe, 2007). It is an iterative process in which the researcher and group members create a shared understanding of the issues that they are considering (Fyson and Ward, 2004). As the analysis in the present study proceeded, themes (e.g. health appointments) emerged which then prompted re-examination with the group members. Data collection and analysis were linked through the members' involvement.

Ethical approval for the research was given by the University of Bristol, and consent forms and information sheets were developed in an easy-to-read format for the research group members. The latter were recruited through previously known contacts of the researcher, and they were all initially asked if they would like to participate through a third party.

The fieldwork took place from 2010 to 2011. Close involvement between the researcher and the research group members continued throughout the project. The group continued to undertake other roles, such as dissemination, contributing to analysis and contributing to journal articles. Data were collected using multiple methods that included 10 focus groups, unstructured interviews, and notes from observations and reflections. Seven people (four women and three men) with a mild learning disability agreed to take part. They were all living independently without support from any services. They were all in their early forties and typical of the wider population of people with a mild learning disability. They were all white and had attended special schools followed by vocational services, after which they became permanently unemployed.

Each member of the group was found to have at least one ongoing health problem, such as high blood pressure, high cholesterol level, diabetes, asthma, gallstones, skin conditions, toothache, arthritis or mild depression that affected their quality of life. Typically, people with a learning disability have a higher rate of such problems compared with the general population (Kerr, 2004; Mencap, 2004; Kerr *et al*, 2005; Disability Rights Commission, 2006; Emerson *et al*, 2009). Ill health contributes to a decline in socio-economic status, thus increasing social exclusion and limiting opportunity (Emerson *et al*, 2009).

Relevance of social capital

The notion of social capital was important in the analysis of this research. Social capital is understood as 'the value of networks of social interaction and support which reside in these relationships' (Spicker, 2007, p. 46). It can be defined as a collective resource based on accumulated relationships, connections and social networks between people and organisations in a given neighbourhood, and is strongly linked with trust (Pierson, 2002; Rapley, 2003; Field, 2008). It is concerned with community cohesion, including the level of activism in civic organisations, the degree of political involvement, the vitality of local institutions such as places of worship (Pierson, 2002, p. 167), and community well-being (Productivity Commission, 2003). Although social relationships are valued in their own right, they are noted to be particularly important in hard times and in enabling people to achieve their goals (Bartkus and Davis, 2009). High levels of social capital have strong correlations with economic prosperity, civic life and social cohesion because social capital creates 'connections amongst individuals – social networks and the norms of reciprocity and trustworthiness that arise from them' (Putnam, 2000, p. 19). Social capital is therefore an important concept when considering the full inclusion and contribution of people, including people with a learning disability, to their community. It also has relevance to considering informal support from other community members.

Putnam makes a distinction between two types of social capital, namely bridging and bonding. Bridging social capital is the connection to others outside one's immediate community, across to other diverse social connections (Bates and Davis, 2004). This is similar to the concept of 'weak ties' (Granovetter, 1973), which often bring a range of benefits and opportunities that are not available through bonding social capital. They can be described as exclusive links to external assets. Bridging social capital is needed for information diffusion and is formed from the connections between people who have less in common but may have an overlapping interest (e.g. neighbours, colleagues or

different groups in the community) (Gilchrist, 2009). It is considered valuable as it enables connections to people who are acquaintances but who move within different social circles. Bonding social capital refers to close supportive relationships and networks, that is, the strong ties between people who share a common bond. This type of social capital is inclusive. It reinforces social identities and maintains homogeneity by supporting enduring relationships between similar people with strong mutual interests (e.g. friends, family and close-knit groups) (Gilchrist, 2009). All members of the group benefited from strong bonding social capital from family and close friends, but they lacked bridging social capital to people outside their social networks, and this affected their ability to access and use health services.

Access to health services

One of the founding principles of the NHS was to improve health and prevent disease. From the late 1960s, the Health Education Council and the then Department of Health and Social Security started to launch national health promotion campaigns about issues such as smoking, AIDS and HIV. These were intended to inform and motivate people to change their behaviours and manage their own health. The White Paper, *Health of the Nation* (Department of Health, 1991), identified five areas for improvement, namely coronary heart disease, cancer, mental health, AIDS, HIV and sexual health, and accidents. From this, a strategy for people with a learning disability was produced which addressed their particular needs within these areas. It specifically mentioned people with a mild learning disability as being a significant group (2%) that 'need support because they have not learned all the skills to live independently, especially in times of crisis' (Department of Health, 1995, p. 4).

Once a Day (Lindsey and Russell, 1999) was issued to promote good practice in enabling people with a learning disability to access and receive good-quality services from primary healthcare teams. *Valuing People* (Department of Health, 2001) emphasised the importance of proactive health support, such as health action planning, for people with a learning disability (Department of Health, 2002a,b; McCoubrie *et al*, 2002), and introduced new nursing roles such as that of health facilitator. *Valuing People* also required GPs to keep a register of patients with a learning disability.

Equal Treatment: Closing the Gap (Disability Rights Commission, 2006) and *Healthcare for All* (Michael, 2008) revealed that people with a learning disability do not access mainstream health services as much as the general population, and are more likely to:

- fail to understand information given about symptoms

- fail to recognise and communicate their symptoms
- need support with medication management
- have limited support networks
- be without someone who can check that they are OK.

A recent study in Oxford found that only one in four people with a learning disability had a health check, and that the extent of these checks varied greatly (Michell, 2012). Health behaviours are heavily influenced by each individual's social network (Emerson *et al*, 2009). In the project discussed here, members of the group had poor role models in terms of healthy lifestyles, particularly with regard to adequate exercise and healthy diet.

Findings

Health problems of the research group

Despite both general health campaigns and initiatives specifically aimed at people with a learning disability, the group members in this project showed poor understanding about health conditions and difficulties in communicating symptoms, as the following exchange between group members illustrates:

What's wrong with your hand? Is it arthritis?
 No I've got um ... a germ in it.
 Yeah, arthritis.
 But it isn't catching.

This demonstrated how it was difficult for them to communicate symptoms clearly to their GP, which then impeded a correct diagnosis.

One group member had been diagnosed as having a high cholesterol level, a condition he did not understand and which he concluded was cancer. He became very anxious as he did not understand the nature of this condition or the fact that, with medication and a change in eating habits, it could be rectified. Another group member had a wide range of debilitating health problems, constant pain and mobility problems caused by arthritis which had a severe impact on her quality of life. During the course of the project she reported no progress by the GP to move the diagnosis and treatment forward. She also found it very difficult to give a clear explanation of her symptoms:

Yeah. Like yesterday I was trying ... I walked to the doctors. It was killing me. He said it's just crumbling arthritis. And it's all like in all my tissues and ... That it's from ... right from there but that's going all the way up to here.

One group member talked about health problems as a way to gain attention, for example, by interrupting conversations and the focus groups to talk about her

medical symptoms. She was waiting to have a hip replacement, but was considered too young:

How can I bend if I'm disabled? I can't bend down. ... They think it's my heart now. Yeah, it's my spine now. No, they says, they says to me I was too young before ... I was too young again, they says I'm too young now. I said I need it doing cos my hip's completely gone.

She also mentioned having allergies, a heart problem, an ulcer and problems with her knee:

My knee's playing up at the moment and my back. Look ... look ... that one's gone now; I'm gonna have the operation shortly ... cos it's doing ... it's doing my back in now. I've got a hearing aid but I've got to take it back to get it fixed – but never worn.

She was afraid to have an operation because her father had died following a stay in hospital:

I hate hospitals ... for a fact. ... Cos I don't like it ... yeah my dad died in there ... no thank you!

Her self-image and identity were of an ill person with many impairments and someone needing health treatment and medication. This is in stark contrast to the increasing awareness of many people with disabilities that they are equal citizens and community members able to live fulfilled lives. This woman was looking to the health services for the solution to her health problems, but this was complicated by her fear of hospitals and medical procedures. This preoccupation with her ailments and the way that it dominated all of her conversations was noted to present barriers to developing relationships with others, as it alienated her from her peers and other people in the community, and so had the effect of limiting both her bonding and bridging social capital.

Another participant talked often about his back problems, and despite ongoing pain had not been to see the doctor:

Keep having like pains across my shoulder. Very sharp pains but I don't know what they are.
 So have you told the doctor?
 No, not yet ... I just ...

Health issues also gave a purpose to days that were otherwise very restricted due to poverty and lack of other more constructive opportunities. For example, one couple would go to the Emergency Department on average once a fortnight, for treatment for minor ailments. When the husband was suffering from toothache and an infected skin rash on his legs, which he explained was caused by scratching flea bites from pet cats, he chose to go to the Accident and Emergency department to have treatment for the infected bites, rather than make an appointment to see his GP. This pattern of behaviour reflected the couple's desire for immediate attention and their frustration with the difficulties of making a GP appointment. No one in

the group had anyone to support them to access the healthcare they needed or to comply with treatment, such as taking the correct dosage or medicines. Consequently, some initially minor health conditions could, if untreated, develop into more serious illnesses.

Complying with treatment and attending appointments

Although many members of the group had prescription medicines, they found taking the right dose at the right time a challenge, often because of the lack of routine in their lives. For example, one individual took his blood pressure tablets all at once:

Four times ... four times ... a day I take two in a morning ... one in the morning, one at night ... and two I'm supposed to take 'em together ... I don't ... muck around with ... You mean you're now taking one in the morning and one at night, but you're taking them together?
Yeah, and I ain't took none today.

Literacy difficulties were also an obstacle to following dosage instructions. Another participant showed me a bag of eight medicines that she had been prescribed following a visit to the Emergency Department, which referred her to her GP. She seemed confused about what all the medicines were for:

Um I forget what this is ... um ... two ... one to be taken ... taken twice a day.
Do you know what they'll do for you?
To hide everything.

Group members agreed that they found it hard to understand what health professionals said to them, especially if they used medical jargon. They often missed health appointments because they were unable to read letters, did not want to attend, or were too frightened to go. Sometimes they did not have the bus fare, or had problems finding the right place, or wanted to avoid hearing bad news. Several members of the group seemed to be exercising some control over their lives by choosing not to go:

I had a letter from the hospital about having a scan on my back ... and I did not go to it. ... I was supposed to go last month ... I ripped the letter up.

When asked why he had done this, he said:

Don't know ... probably because I did not want to go up. I'm like Maureen, I don't like hospitals. I had the letters the beginning of February, and I ... and I ripped the letters up didn't I? ... I ain't been.

I agreed to accompany him, to encourage him to attend. He said he wanted someone to wait for him in the waiting room:

Wait in case he gives me some bad news about my back. I'm scared in case I have to go into hospital or anything.

He also confessed he would not attend if he had no one to take him:

I won't come if nobody takes me. Nobody takes me I don't go do I? It scares me cos ... my back.

Another participant was seeing a range of healthcare professionals, including physiotherapists, podiatrists, and incontinence, neurological and gastrointestinal specialists. She could not read letters and did not keep a calendar or diary, so relied on other people to remind her of important dates. There was considerable confusion over support for appointments, largely because the organisation which provided a pop-in visit as her tenancy support said it was not responsible for accompanying her to appointments, and had not taken the initiative to coordinate with her informal support network and/or her voluntary work placement to ascertain whether someone else could accompany her.

In the following dialogue between a married couple, the wife showed her confusion and fear about a forthcoming appointment. Her husband tried to allay her fears:

They want to keep me in till Sunday – I went 'no chance' – I said goodbye ... cancelled it.
No, she did not go at all – I cancelled it.
They wanted to keep me in till Sunday ... come out Monday ... no talking.
No ... Wednesday.
Well, why wouldn't you stay in?
Don't like hospitals. No – because my mate ... right ... had something down her ... had the camera down ... and he cut all her inside ... no thanks.

Dental care

Most members of the group had not seen a dentist since they were at school, over 20 years ago, in many cases due to fear and the lack of a supportive person to accompany them. One person described being 'struck off' from the dentist's practice because they said she owed money for missing appointments, so she had to go to the local dental hospital:

They've refused me in every dentist. Cos they say I owe a fiver and I don't owe a fiver, cos I missed my appointment.

Another person just said 'I ain't been bothered to go.' Another had several front teeth missing and spoke of severe toothache several times during the project. He was persuaded to make a dental appointment but did not attend because he was too afraid.

Access to health information

Members of the group had limited access to health information, and this contributed to their health inequalities. They had no computer skills, no home

computers, did not know how to use the Internet and had difficulties with reading. In addition, they were not in touch with services or support networks that could introduce them to some of the excellent easy-to-read health publications and websites that are produced especially for this group, such as Easy Health (www.easyhealth.org.uk).

Discussion

These findings show how ill health and preoccupation with health problems affected the lives of group members. They missed appointments due to fear of being given bad news, or inability to communicate their problems clearly or understand what was said to them. They felt that it was important to have someone to accompany them to hospital for emotional support, to help them to understand the medical terminology and advocate on their behalf. The provision of transport and help with navigating large buildings or new environments were additional factors that contributed to their failure to keep appointments. Thus they experienced multiple inequalities in accessing and using health services. They seemed to frame themselves as 'ill patients', and talked about health services with a sense of frustration as they could not obtain the appointments they wanted or the cures they needed. They complained about communication problems and difficulties understanding medical jargon. However, they did not seem to relate their health problems to their lifestyles, and there was an absence of any kind of responsibility for their own health. All members of the group seemed keen to talk about their health problems, possibly due to the lack of people in their lives available to actively listen to them and show an interest in their concerns, which suggests that health services may also need to learn to listen to people such as these group participants on their own terms. Despite a raft of good practice guidance about working with people who have a learning disability, it seems that some primary healthcare workers do not have the necessary skills to communicate at the right level with their patients.

What could help?

Some simple low-cost solutions could be put in place to support people with mild learning difficulties in order to improve their health. It is essential that GPs and staff in healthcare settings can identify which patients have a mild learning disability, and ensure that they are skilled to work with this patient group. Excellent advice can be easily obtained from the

General Medical Council's website (www.gmc-uk.org/learningdisabilities).

All members of the group stated clearly that they wanted staff in mainstream services to recognise their learning disability so they would receive better support. This suggests the need for a system whereby health professionals are notified that an individual has a learning disability and either has or does not have formal or informal support in accessing health services. Better use could be made of tablet dosage dispenser packs for people with learning disabilities, especially those who have trouble remembering dosage instructions or have difficulty reading instructions. Appointment cards could be produced in an easy-to-read format to remind people of their next appointment. Examples are available free from the Easy Health website (www.easyhealth.org.uk). Hospital letters could be produced in a similar format with illustrations to help with both navigating to the correct department and identifying the individual staff member(s) whom they will be meeting. These simple low-cost suggestions could contribute to increased engagement with health services and produce far better outcomes for people with a mild learning disability.

The research group wrote their own report, *Money, Friends and Making Ends Meet*, which was published in September 2011 (Money, Friends and Making Ends Meet Research Group, 2011). Further information and a PDF file of the report can be obtained by emailing admin@building-bridges-training.org. The research group is continuing as the *Building Bridges Research Group*, and is now researching the impact of the welfare reforms on their lives.

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CONFLICTS OF INTEREST

None.

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