



The Sainsbury Centre

for Mental Health

**A formal investigation into health inequalities experienced
by people with learning difficulties and people with mental
health problems - Area Studies Report.**

Report to the Disability Rights Commission (DRC)

by

**Chiara Samele, Linda Seymour, Brigid Morris,
Central England People First, Alan Cohen, Eric Emerson**

EXECUTIVE SUMMARY

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Introduction

The growing evidence surrounding the increased risk of mortality from natural causes and medical co-morbidity in people with learning difficulties and those with mental health problems is notable. There has also been a simultaneous shortfall in the receipt of adequate and sufficient primary care services for physical health problems and the prevention of poorer lifestyles in these groups. A number of government policy initiatives have sought to tackle the physical health needs of these groups, with an emphasis largely on people with mental health problems.

Despite these government efforts there remains a considerable need to a) implement the current policy recommendations, and b) find practical solutions to improve access to health care for those with mental health problems and those with learning difficulties.

The Disability Rights Commission launched in December 2004 a Formal Investigation to examine the existing health inequalities concerning health outcomes and access to primary care for these target groups with the primary aim to examine and identify solutions to these disparities. The Sainsbury Centre for Mental Health, in collaboration with the Health Research Institute at Lancaster University, was commissioned primarily to:

1. examine access to primary care services for the target groups of interest with reference to their physical health;
2. identify the ways in which primary care services attempt to address the physical health care needs of the target groups.

Additional aims included building a profile of access to primary care services offered and the uptake of these by the target groups by exploring:

- target groups' experiences of primary care services;
- problems encountered;
- the provision of health promotion, health education or interventions;
- the views of target groups, primary care practitioners and other relevant secondary health care professionals on improving access

to primary care services for physical health problems and health promotion;

- how GP practices identified the target groups; and
- a range of groups from within the target groups such as younger and older people, Black and ethnic minorities, those with multiple impairments, etc.

Methods

We applied a multi-method approach using two main sources of data to carry out the project. This involved a) a quantitative study of GP clinical data sets to examine questions relating to the identification of the target groups and access to primary care services for physical health problems; and, b) a qualitative study to explore the questions regarding the difficulties encountered by the target groups when accessing services for physical health problems.

We selected three Primary Care Trust (PCT) areas in England (from the South East, North West and London) and one Local Health Board (LHB) in Wales using a number of criteria relating to geographical location, provision of health care services and population. GP practices were recruited via the PCTs and LHB. We collected data from:

- GP practice databases/registers;
- a postal survey of the target groups registered at participating GP practices;
- focus groups and interviews with the target groups recruited from voluntary organisations and statutory health services; and
- interviews with key managers, health care practitioners and advocates from primary, secondary and voluntary sector services.

Collection of clinical data from GP practice database registers was performed by the Primary Care Informatics Team at St George's Hospital Medical School. All interviews with the target groups were carried out by mental health service user researchers and Central England People First where relevant. Interviews with service professionals and managers were conducted by other members of the research team. The project was granted Local Ethics Committee approval.

Findings from GP clinical datasets

Introduction

Twenty two GP practices across the four local area sites agreed to take part in the project. A total of 150,181 people were included in the combined GP dataset. We identified 864 people with a severe mental health problem (SMI), defined as someone with a diagnosis of schizophrenia or bipolar affective disorder. This gave a prevalence of 5.75 per 1,000 patients or 0.6% for people with a SMI. We also included a group of people with depression in our analyses. There were 15,186 people diagnosed with depression giving a prevalence of 101.1 per 1000 patients or 10.1%. We identified 753 people with a learning difficulty with a prevalence of 5.01 per 1,000 patients or 0.5%.

Medical co-morbidity in the target groups: prevalence and clinical care

We examined the prevalence and clinical care (including health care, treatment/management, health education/prevention advice or interventions) of four major diseases in the target groups. These included: ischaemic heart disease (IHD); stroke; diabetes mellitus; and chronic obstructive pulmonary disease (COPD). They were chosen because of previous evidence showing increased risk of these in the target groups. We were also interested in other diseases like hepatitis and HIV/AIDS, however, the numbers identified were too few to analyse.

Ischaemic heart disease (IHD)

The prevalence of IHD in people with a SMI was 5.4%. It was 6.4% in people with depression. The comparison group for the mental health groups had a lower prevalence of IHD at 3.9%. The prevalence in people with a learning difficulty was very low at 0.7%, and much higher in their comparison group at 4.2%.

The extent of clinical care through recorded health checks for people with IHD was significantly lower for those with a SMI regarding total and LDL cholesterol, but higher for current smoking. Recorded health checks for people with a learning difficulty and IHD were lower than the mental health groups and the remaining population. People with a SMI and IHD were significantly less likely to receive lipid lowering therapy, but received much more advice concerning smoking. People with a learning difficulty and IHD were even less likely to receive health advice/treatments than the other groups.

Stroke

People with a SMI had a higher prevalence of stroke than those with depression or a learning difficulty. The prevalence for this group was 5.1%. The total prevalence for people with depression was 3.4% while that for the remaining population was 1.9%. The overall prevalence for people with a learning difficulty was 1.2%. Stroke was more prevalent in older age groups.

Recorded blood pressure checks were very high in people with a SMI and depression, but lower in people with a learning difficulty. The results of all recorded blood pressure for each of the target groups were within normal limits. Smoking advice was greater for those with depression or a learning difficulty and the same for those with a SMI compared with the remaining population.

Diabetes mellitus

The prevalence of diabetes mellitus in people with a SMI was 8.8%, and higher in women (10.2%) than men (7.6%). In people with depression the prevalence was lower at 4.7%. Both prevalence figures were higher than that of the remaining population (3.2%) and the differences were statistically significant ($P < 0.001$). The overall prevalence for diabetes in people with a learning difficulty was 2.4%, which was considerably lower than all other groups.

Recorded health checks for blood pressure and body mass index (BMI) in all the target groups with diabetes was very high, but less so for urine checks, particularly for people with learning difficulties. The results of recorded health checks showed that people with a learning difficulty and diabetes were more likely to be obese. We also found that the control of diabetes was better among the target groups than the remaining population. Dietary advice was provided around 80% of the time for both mental health groups, but slightly less so for those with a learning difficulty.

COPD

For people with a SMI the overall prevalence for COPD was 20.1%, and for those with depression 23.0%. These prevalence figures were significantly higher than those of the remaining population (14.7%, $P < 0.001$). In people with a learning difficulty the prevalence of COPD was 19.8% and again significantly higher than that of the remaining population (15.5%, $P < 0.001$).

We had limited data on certain health checks for COPD and are only able to report on current smoking status and relevant advice/interventions. People from the mental health target groups were more likely to be current smokers and so received more smoking advice. The learning difficulty group, who were less likely to be current smokers than the mental health groups and the remaining population, were less likely to receive smoking advice.

People at increased risk of medical co-morbidity

We examined data referring to a series of recorded health checks in the target groups without one of the four diseases described above, as well as in the sample as a whole. Included in these analyses were mammography, cervical screening, total cholesterol, urine analysis, current smoking, body mass index and blood pressure. People in the mental health groups as a whole were more likely to have these recorded health checks than the remaining population, and significantly so for the majority of checks. The complete inverse, however, was found for people with a learning difficulty, who were far less likely to receive the above listed health checks.

Smoking, obesity and total cholesterol were the most prominent of the risk factors found for the target groups. The overall prevalence of smoking in all people with a SMI was 49.6%, and for those with depression 45%. For the remaining population it was 22.3%. The prevalence of obesity in all those whose BMI was recorded was 28.5% for those with a SMI, 24.0% for people with depression and 19.8% for the remaining population. In all those with a learning difficulty the prevalence of obesity was 28.3%.

Health prevention advice/interventions in the target groups

As with the previous section we examined the receipt of health prevention services in those without one of the four diseases listed above and in all people in the target groups. Flu and tetanus vaccinations, dietary advice, advice on smoking, smoking therapy and referral to smoking cessation services were the health prevention services analysed. People with a SMI were significantly more likely to receive a flu jab, smoking advice and smoking therapy of some kind, but less likely to have a tetanus vaccine. People with depression were more likely to receive flu vaccination, smoking advice and smoking therapy compared to the remaining population. Similar percentages for dietary advice were found for those with a mental health problem and the remaining population. Those with a learning difficulty generally,

however, were much less likely to receive dietary and smoking advice compared to the remaining population.

The postal survey

We report few findings from the postal survey due to the extremely low response rate received. Generally respondents were very positive about accessing their GP and the care they had received. Some, however, mentioned wishing to see their own GP rather than others based at the practice; needing more information about their medical condition; and wanting additional time with their GP.

Key themes from focus groups and interviews with the target groups

The key themes arising from the focus groups and interviews with the target groups were as follows:

- there appears to be a lack of knowledge and awareness among reception staff, GPs and physical health specialists about the needs of people with learning difficulties, if people with mental health problems and of their carers when using their GP surgery;
- the diagnosis of a learning difficulty and particularly a mental health problem often appears to overshadow a person's physical health issues;
- people with mental health problems often feel that they are treated with less respect than other people at their GP surgery due to having a label of a mental health diagnosis;
- the current way in which primary care operates, particularly with regards to the lack of time that can be spent with each patient and the financial implications of each referral or service provided, means that those who 'shout the loudest' get the most out of the system. People with learning difficulties often have difficulties in communicating their needs to others. People with mental health problems frequently have low self esteem and sometimes find it difficult to be assertive in GP consultations. Carers of people with learning difficulties spoke of how they sometimes felt that they were *bothering* the GP practice yet again with the problems of the person they cared for;

- people with learning difficulties and mental health problems are often on many types of medication, frequently on a long-term basis. It is essential that the complex interactions of drugs are always considered in prescribing decisions and that long-term medications are comprehensively reviewed in order to prevent physical damage to patients;
- people with learning difficulties and people with mental health problems often are on benefits and so have fewer financial resources with which to choose and pay for alternative health care interventions such as osteopathy or acupuncture. These groups of people also have less money to spend on healthy eating and on opportunities to exercise;
- due to the constraints experienced by GP surgeries, practices appear to work within a culture of crisis management rather than active health promotion;
- the voices of people with learning difficulties are often perceived to be hard to hear as they frequently require substantial time and skilled support to enable them to fully communicate their needs. Great effort and care needs to be taken in the future to ensure that the views of people with learning difficulties are elicited, heard and taken into account in primary care. Only in this way can their needs begin to be fully met when they are visiting their GP practice.

Key themes from interviews with health professionals and senior managers

Access issues

Information systems to identify both groups of service users accurately were extremely variable. We had examples that ranged from utilising Read Codes by GPs to *'just knowing when someone is disabled'* from practice staff.

There was a clear reliance on carers – both formal and informal – as primary care access enablers for people with learning difficulties and also for people with enduring mental health problems who lived in supported housing. Carers were thought to need training to recognise when someone they are supporting needs to see the GP for physical health problems.

The physical fabric of buildings was clearly an issue for both target groups. Some GP practices are in buildings which do not allow for disabled access. There is often insufficient space to allow for the privacy that some service users would value.

Specialist health staff such as learning disability (LD) nurses or community psychiatric nurses (CPN) also played significant roles in enabling access for the target groups. The specialist LD posts tended to be short-term contracts or funded through non-recurring monies such as Health Action Zones, whereas the CPN posts are integral to and embedded within psychiatric services. The disparity between the two demonstrated the need for the extension of specialist learning difficulty expertise.

Staff attitudes

The subtext from the interviews with primary care staff and practitioners was a mix of fear, anxiety and some impatience combined with paternalism and kindness. Even though some of the interviews described the provision of awareness training in both mental health and learning difficulty, there was still a sense that patients from these groups were like time bombs ready to go off at any moment.

Time available to see patients once they had an appointment was a recurring issue. Carers and advocates mentioned the speed with which people were seen and treated, which did not allow for proper understanding or getting to the root cause of a physical health problem.

Doctors talked about '*heart sink*' patients from these groups, but there were also compassionate comments that acknowledged that people attending primary care should not have their lives made more difficult by that experience. Some practice staff expressed bewilderment as to why there should be any issues for people with mental health problems or learning difficulties in getting their needs understood.

There are many champions among GPs and other primary care staff, who are prepared to '*go the extra mile*' for patients from these groups. In the main, these champions have one common trait – they all seem to have personal experience of either mental health problems or learning difficulties in their families or from within their social networks.

Physical health issues

In the view of those outside primary care services, diagnostic overshadowing was a significant obstacle to people with learning

difficulties or mental health problems getting their physical health concerns taken seriously in primary care.

Most of the discussions about people with learning difficulties were skewed towards more severe or complex needs. It was acknowledged that people with more mild learning difficulties might be able to get access to services, for example health promotion information. But as practices' abilities to identify this group were so under-developed, it was difficult to know if and when the practice would know they had such a person attending for care.

There was a realisation among primary care practitioners that they did not have the specialist skills in learning difficulties or enduring mental health problems. However, in the former instance, low prevalence was given as a reason for not acquiring the knowledge and skills – they might never be used.

The most recurrent theme to emerge in learning difficulties is the demographic trend toward this population living on into later life. In the view of many of our sample, the social and service implications of this trend have not even begun to be addressed.

Services & treatments for physical health issues

In almost all interviews with primary care staff we heard about patients from these groups who don't follow advice as given, don't attend for appointments and who cannot cope with the implications of the advice they have been given. There did not seem to be any strategies in place to support these groups to follow any advice or guidance they might have been given.

Some of the good practice described went beyond individual practices. For example, clinical support networks on relevant themes or Local Strategic Partnerships that included active service user involvement or drop-in centres run by local voluntary organisations seemed not to make as much of an impact on individual practitioners as discrete clinicians like specialist nurses.

Interface between primary and secondary care

By far the majority of interviewees said quite categorically that primary care should be first port of call for these groups of people when they have concerns about their physical health. But there was also an understanding that primary care is faced with a plethora of demands from all of its patients. That, combined with lack of specialist skills and

confidence working with these groups, meant that in many cases primary care was quick to offload onto specialist services.

From their perspective both specialist mental health and learning difficulty services were happy to both provide services and also to enable their clients to get access to primary care. In addition we heard about partnerships between specialist statutory and voluntary services.

However, structural change within primary care was perceived as both undermining of good practice and as threatening to established links.

Closing the gap

There is a clear-cut perception gap. Primary care practitioners and staff have a sense from individual interactions with their patients that they are providing as good a service as possible. Yet patients, their families and specialist service providers think that primary care services could be much improved, even when allowing for multiple demands on them.

Communication was one of the most significant issues. GPs and practice staff do not always have the skills or time to find out what people's needs and concerns are.

It is incumbent that primary care acquires some specialist knowledge on the health risks of these groups and effective lifestyle advice.

As a minimum, primary care practices could avail themselves of local knowledge on good practice in mental health and learning difficulty through their own management structures such as Professional Executive Committees. On a more national level websites such as www.networks.nhs.uk exist to provide easy access to online discussion groups on a range of topics with relevance to these groups.

What emerged clearly from the data was the importance of local champions: specialist LD nurses, GPs with experience of mental health issues, service user involvement on partnership groupings. Publicising good practice through relevant local arrangements and sharing process, input and outcomes can go some way towards alleviating understandable concerns about overload.

Primary care managers also have an important commissioning role for services for these groups. Partnerships between primary care practitioners and their own colleagues, for example in public health or social inclusion, have the potential to not only improve service design

and delivery but also to enhance the interface between practitioners and their patients who use mental health or learning difficulty services.

Conclusion

A focused approach leads to positive results. This is no less true for addressing the physical health care and health prevention needs in people with a learning difficulty and those with a mental health problem. Good communication skills, the provision of appropriately formatted and accessible information, taking the time to understand the person's requirements, listening, and exercising sensitivity are especially important for these groups. Good practice examples show how championing the cause of people with a mental health problem or a learning difficulty can have an enormously beneficial impact on the physical health needs of these groups. Making these positive examples both permanent and widespread is the next challenge.

Main recommendations

- GP practices should consider developing a **protocol** for supporting people with learning difficulties and people with mental health problems to get the most from their GP practice.
- GP practices should ensure a system is put in place where people with learning difficulties and people with mental health problems are encouraged to attend regular preventative health checks, perhaps every six months or a year.
- GP practice staff, including reception staff, GPs and nurses, should receive **learning difficulty and mental health awareness training**, ideally from trainers who have learning difficulties themselves, mental health service user trainers and carer trainers.
- Staff should also be made aware of the ways in which the physical health problems of these two groups of people are frequently overshadowed by their learning difficulty or mental health diagnosis.
- GP practices should consider more effective health promotion advice and refer to appropriate interventions to improve dietary habits and encourage smoking cessation.

- For **guidance** to be provided to people with learning difficulties and people with mental health problems, and those who accompany them, to enable them to get the most out of their visits to their GP practice.
- People with learning difficulties, people with mental health problems and their carers should consider ways in which they can be more active and assertive in ensuring that their GP practice meets their health needs or those of the person they are caring for.

Keywords: Formal investigation; Health inequalities; Learning disabilities; Mental health