

Equal Treatment - Closing the Gap

Final Report from the Welsh Centre for Learning Disabilities to the Disability Rights Commission

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EXECUTIVE SUMMARY

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Background

This summary includes the key findings from a number of strands of research in Wales:

- a literature review of the health problems experienced by people with learning disabilities, their access to primary care, healthcare policy and health checks;
- a study of the health of 181 adults and 79 children with learning disabilities in 40 general practices across Wales, and the results of health checks;
- a study of unmet need among 75 people at a subsequent check, their frequency of contact with services, and access to health promotion;
- focus groups with 63 people with mild learning disabilities;
- new data from Mencap Cymru's Treat Me Right campaign, based on questionnaires completed by 178 adults with learning disabilities or their carers;
- questionnaires and telephone interviews with members of 22 primary care teams;
- questionnaire responses from 12 of the 22 local health boards (LHBs) in Wales.

Findings

1. The literature review is included in the main report. It examines the health and healthcare needs of people with learning disabilities.
2. The health checks showed that people with learning disabilities had a higher rate of diabetes (9%) than the general population (4%) and a much higher rate of obesity (35%, compared with 22%); obesity among women with learning disabilities was particularly high at 40%. Rates of smoking, alcohol usage, hypertension and asthma were all lower.

Of the 181 people who had health checks, 93 (51%) had new health needs identified and 8% had serious health problems such as breast cancer, diabetes and high blood pressure.

Health promotion uptake:

- 13% of eligible women had cervical cytology compared with 84% in practices as a whole;
- 26% had mammography, compared with 71% in practice populations as a whole;
- 42% had blood pressure measurement, compared with 46% in general population;
- For the above three measures, uptake was highest for people with mild learning disability and lower for those with moderate or severe disability.
- There were low rates of weight recording, height recording, smoking history recorded, drinking history, cholesterol measurement, urine testing, and immunisations.

Contact with primary care:

- People had an average of between 3.6 and 6.9 contacts a year with general practice staff (averages are for different sub-groups within the sample): this is higher than consultation rates for the general population. However, given a consultation rate in the general population of 18.5 per year for people with diabetes, it would seem that the number of consultations by people with learning disabilities may be lower than expected.

3. At a subsequent health check around a year later, 68% of 75 people had new health needs identified, and 11% had serious problems. The results suggest that annual health checks are justifiable.

Problems with take-up of subsequent health checks:

- Time and resources are needed. There was a 1 in 3 drop-out rate of practices.
 - 80% of people who lived independently did not have a second check.
4. The focus groups highlighted variability in the process of making an appointment, the attitudes of professional staff, time available to discuss problems, and extent of explanations provided. Participants were aware of healthy food, the need for exercise, and threats to health of smoking and being overweight. Some had been helped by GPs to access free exercise facilities. However, many lacked practical support to adjust diet, take up exercise regimes or give up smoking.

Although many of the problems they identified are common to other people using primary care, people with learning disabilities may have less confidence and be less persistent. Those in the focus groups were more articulate than people with more severe learning disabilities. Primary care professionals need to adjust the typical appointments and consultation experience to meet the needs of people with learning disabilities, and be more proactive in identifying symptoms that people may find hard to describe.

5. The Treat Me Right questionnaire elicited a generally high level of satisfaction with primary care services, including the rating of the consultation as a whole, understanding of what was said, time provided, information both generally and specifically about medication, and responses of reception staff, nurses and GPs. Differences from the findings of the focus groups may be due to: carers completing some of the questionnaires, the general tendency of satisfaction questionnaires to be skewed towards positive assessments, and the focus group method allowing a greater airing of problems. However, there was some consistency in the nature of problems experienced: having to wait, being or becoming anxious, not having the autonomy to consult the

doctor in the way people preferred (e.g. doctor insisting that a carer be present), difficulties with receptionists, communication problems with doctors, and insufficient time in consultations.

6. Questionnaires and telephone interviews with primary care staff focused on obesity, sensory difficulties, take-up of health promotion, cervical cytology and mammography. Problems relating to health promotion included difficulties in communication, shortage of time, focus on other medical problems, and the stress of waiting at a surgery. Respondents suggested a range of solutions, such as broader health promotion within the general population, better assessment of sight and hearing, promoting access to community activities, education and support for families and carers, and more time for appointments. Consent and the anxiety caused by invasive or intimate procedures were highlighted as problems in relation to cervical cytology and mammography, and respondents noted that there were no easy solutions. Respondents were from practices that had participated in the two research studies: they had been involved in training and health checking and expressed support for both. Their awareness of inequality and the need to make primary care more effective may not be typical of primary care practitioners more generally.
7. Some LHB responses mentioned the need for health checks. They indicated some initiatives in their areas to address the health problems of people with learning disabilities, such as courses for people with learning disabilities or awareness-raising sessions for GPs. Overall, though, LHBs had either only just begun to respond to the problems or were in the process of planning to respond.

Keywords: Health inequalities; Learning disabilities; Wales