Identifying people with learning disabilities in general practice

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Key points

■ *Valuing People* expects that general practices and learning disability services will work together to identify people with learning disabilities on practice lists.

■ Coding of learning disability in electronic patient records in general practice is not of high enough quality to meet the demands made of NHS/primary care information systems.

■ Coding of learning disability in general practice is not solely an IT problem.

■ Successful implementation of Valuing People health targets in primary care requires improvements in joint working.

■ Incentives may be needed to improve the identification of people with learning disabilities and quality of care.

Introduction

The Centre for Research in Primary Care at Leeds University was commissioned by the Department of Health to evaluate the impact of health facilitation on the health care experience of people with learning disabilities.

To evaluate whether *Valuing People* targets were being met, the study aimed to establish the population of all people with learning disabilities in Leeds and, more specifically, assess the extent to which general practitioners (GPs) could identify their patients who have a learning disability. This led to an exploration of the relationship between the identification of patients with learning disability in general practices and the coding of learning disability on their computer systems. This article aims to inform professionals in learning disability services about identification of people with learning disabilities in primary care.

It is evident that some health and social care agencies struggle to implement health facilitation. In a recent workshop, hosted by the research team, people from voluntary and statutory services and people with learning disabilities met to consider obstacles to the implementation of health targets. The article also outlines the recommendations from this workshop.

Community learning disability teams in general practice

■ People with a learning disability have greater health needs and poorer health outcomes than the general population.

■ Despite this, they experience shortfalls in the provision of and access to health care.

It was in response to these findings that, in 2001, a Government White Paper, *Valuing People: A New Strategy*

for Learning Disability for the 21st Century, set out a commitment to ensure that people with learning disabilities receive equal access to health services, based on the broad principles of rights, choice, inclusion and independence (Department of Health, 2001). The Government's strategy for the reform of health service development and delivery identified primary care as the main focus for improving the health care experience of people with learning disabilities.

> *'…the primary care team will play a key role in providing health care for people with learning disabilities and in ensuring that people with learning disabilities can access the full range of health services…'* (Department of Health, 2001, p63).

The White Paper included a specific expectation that, by June 2004, all general practices would have identified all people with a learning disability registered with the practice. It was envisaged that staff from the local learning disability team would act as 'health facilitators' to provide support to all general practices trying to meet this target.

> *'Health facilitators will help general practitioners and others in the primary care team to identify their patients with learning disabilities, in collaboration with colleagues from social services, education and health.'*

> *'We expect that all general practices, with support from the health facilitator and in partnership with specialist learning disability services, will have identified all people with a learning disability registered with the practice by June 2004'* (Department of Health, 2001, p64).

There was a further expectation in the White Paper of collaborative working between the community learning disability team, again in their role as health facilitators, and clinical staff in general practice in order to meet another specific target of *Valuing People*:

> *'All people with a learning disability to have a health action plan by June 2005.'*

> *'The Government expects each individual with a learning disability to be offered a personal Health Action Plan (HAP). Responsibility for ensuring completion of the HAP will rest with the health facilitator in partnership with primary care nurses and general practitioners.'* (Department of Health, 2001, p64).

In order to provide health facilitation and health action plans it is essential to be able to identify people with learning disabilities from existing systems in general practices.

Identifying people with learning disabilities in general practice

Various government policy statements advocate standardised data on learning disability in primary health care to enable effective monitoring, auditing and evaluation of service provision, resource management and strategic planning.

Valuing Health for All (Giraud-Saunders *et al.*, 2003) advises primary care trusts and primary health care teams to:
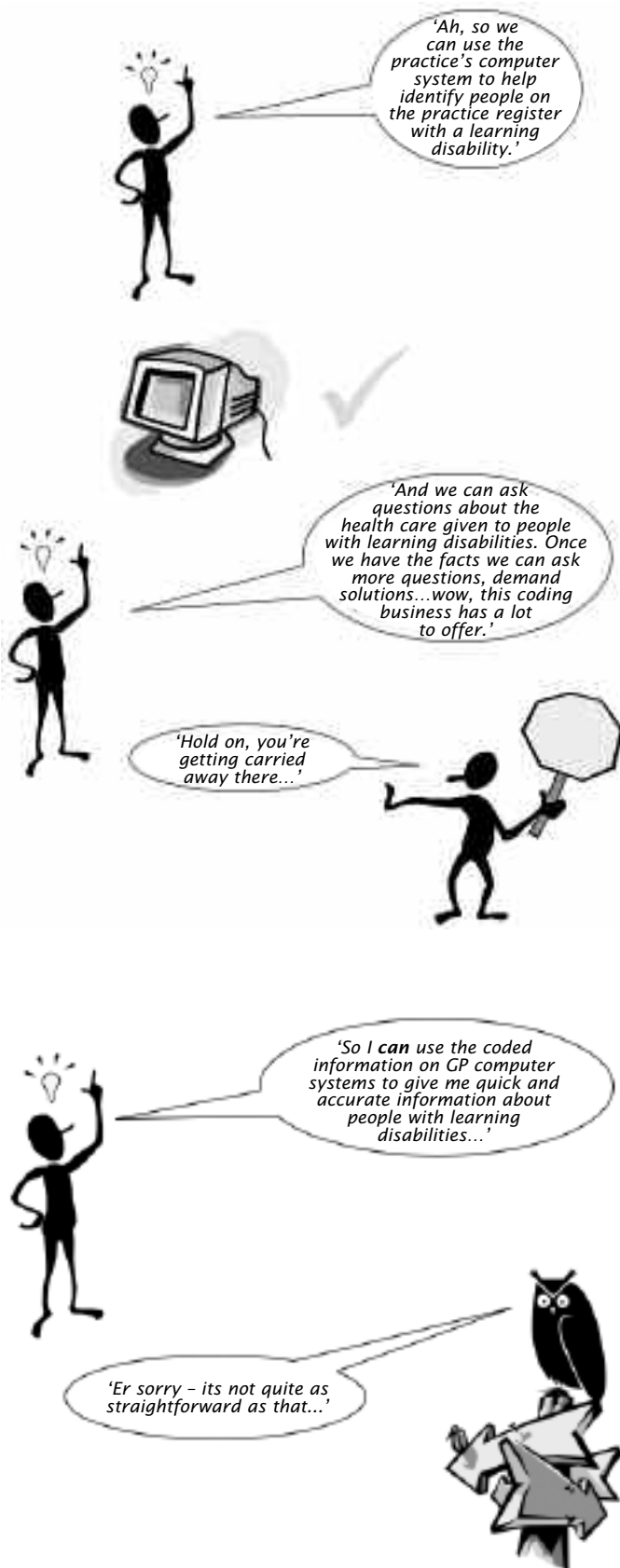
> *'Check that the development of information systems (such as practice registers) includes appropriate coding of learning disability... so that better data on health and access may be collected for future use'*
> and
> *'Ensure that practice …information systems capture information on the health of people with learning disabilities, combining clinical data … with Read code[1]…'*

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[1] Read code classification is a coded nomenclature of clinical terms used in GP computer systems.

'Ah, so we can use the practice's computer system to help identify people on the practice register with a learning disability.'

'And we can ask questions about the health care given to people with learning disabilities. Once we have the facts we can ask more questions, demand solutions…wow, this coding business has a lot to offer.'

'Hold on, you're getting carried away there…'

'So I *can* use the coded information on GP computer systems to give me quick and accurate information about people with learning disabilities…'

'Er sorry – its not quite as straightforward as that…'

There seems to be an assumption that, with the widespread use of computer systems to record medical information, the identification of people with a learning disability is a relatively quick and straightforward task.

Good quality data comes from practitioners recording information that is accurate, up-to-date and consistent.

The study has highlighted many aspects of record keeping in primary care that prevent the retrieval of accurate identification on people with learning disabilities. The main obstacles are:

■ not all paper medical records have been summarised and coded electronically

■ where practices continue to use both paper and computer records there is not always a system in place for ensuring the capture of current information on computer systems after the summarising of historical records

■ with no national or local targets requiring an updated/concurrent assessment and identification of people with learning disabilities, the quality of coding is based on the nature of historical data and individual judgements about medical information contained in the paper records

■ a coding of learning disability may well be based on information contained in a patient's medical records from many years ago – usually there will be no indication in the summarised computer record of the source of this information or the definition of learning disability used

■ there is no way of knowing from the primary care information systems if the identification has been verified recently, using the DoH criteria for learning disability.
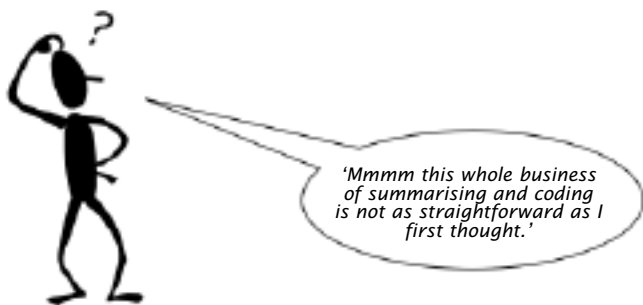
The transfer from paper to electronic patient medical records started in the mid 1990s. At this time 'historical' medical information was summarised and entered onto the computer but there was no set process for this. There were no rules as to the format of the information and the amount and content varied from one surgery to another.

Often the information in medical records about a person's 'disability' was indirect and descriptive. There may be a description of the behaviour, intellectual ability, motor

and language skills and overall development. The professional writing the medical record did not always attach a condition or diagnosis or label from his clinical assessment of the patient with learning disability.

The codes ascribed to people with learning disability are broadly of three kinds.

■ Codes that relate to diagnoses, for example PJ0 for Down's syndrome and F23 for cerebral palsy. Of course, not all people with some of these diagnoses will have a learning disability.

■ Codes that relate to ability, which is a description of a level of intelligence and social functioning. These are codes based on terms used in medical records, such as mental retardation, mental handicap, learning disorder, learning disability, learning difficulty, mental deficiency, mental sub-normality, mental impairment, global delay, developmental delays, development problems. Again some of these codes, especially those relating to a difficulty, delay or problem, do not necessarily indicate a learning disability.

■ Codes relating to referrals or learning disability assessment. Again caution needs to be exercised against assuming a learning disability.

'Mmmm this whole business of summarising and coding is not as straightforward as I first thought.'

It is a lot easier to identify and code a biomedical illness such as hypertension or cerebral palsy than it is for a socially constructed condition such as learning disability. At the moment there is no baseline information about the number of people with learning disability on practice registers locally, regionally or nationally. It is impossible to assess whether the primary care services are currently reaching all those who are potentially included in the *Valuing People* health targets.

There has been little incentive for practices to identify people with learning disability and develop practice registers. GPs are focusing on data required by the Quality Outcomes Framework (QOF), which are linked to payment for practices. Learning disability does not appear in any of the ten disease areas of the QOF, nor has learning disability featured in any national incentive-related scheme.

There has been no obligation, guidance or funding for practices to develop systems to identify those patients in their practice with learning disability. Although the onus appears to be on primary care to provide standardised information on learning disability there are as yet no firm guidelines on what kind of information should be recorded on the GP computer system.
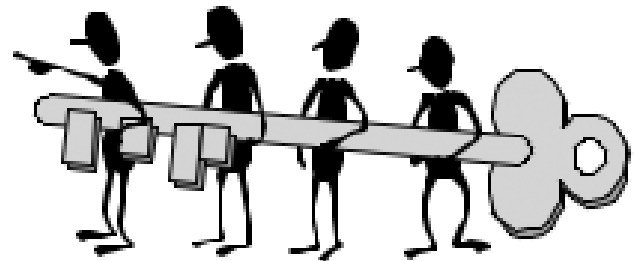
In an attempt to bridge the gap between aspirations for the health care of people with learning disabilities and what is actually happening at practice level a consultation document, entitled *The Better Metrics Project*, proposes more clinically relevant measures of performance (Crump & Whitty, 2005).

Finding information about people with learning disabilities on the practice list is often a difficult and lengthy process. To avoid repeating this process every time information is required about the health status of people with learning disabilities and their access to health care, *Valuing Health for All* advocated the consistent use of a single Read code for learning disability. Providing the primary care assessment of patients with learning disabilities and the information requirements are both based on the same definition of learning disability this would appear to be a straightforward solution. However the term 'learning disability' has the Read code Eu81z-1. This is a sub code of Eu81z, which stands for 'development disorder of scholastic skills unspecified'. It is not always possible for GP computer systems to do a search on sub codes and clearly the higher level code is not synonymous with learning disability. Recognising this problem Valuing People recommended the use of the read code E3.

However many people find the E3 code, used to signify 'mental retardation', a difficult one to accept. Furthermore, it would appear that many people, both service users and service providers, prefer the term 'learning difficulties' to learning disability. However the code for learning difficulties includes many people with specific learning difficulties who do not fit into the criteria for learning disability as defined in Valuing People.

The Valuing People Support Team has since recognised a reluctance to use the E3 code. Their advice to those who want to use a consistent code, but who do not wish to use E3, is to come to a local agreement with the Primary Care Information Service (PRIMIS), to enable local auditing of access to health care. PRIMIS, funded by the NHS Information Authority, is a free service to primary care organisations to help them improve patient care through the effective use of their clinical computer systems.

The 'Better Metrics' project recognises the need to link targets with GP computer systems. The project aims to share the metrics with the National Programme for IT (NPFIT) to further the development of electronic patient records. This will enable the metrics to be measured routinely in the future.

Conclusion

'Oh dear it all feels like we are going round and round in ever widening circles... local and national targets, national and local solutions. All these interconnections – terms like inter-agency working/collaboration tie everyone in knots and nothing seems to get done.'

If the two stage process of identifying and coding patients with learning disability becomes a priority for the future it will require contribution from and collaborative working between all interest groups: service users, GP practices, learning disability services, PRIMIS/IT support systems, primary care trusts and strategic health authorities.

Recommendations from the research workshop highlighted elements of an overall strategy to help enable this process:

- detailed targets and outcomes in the strategic plan relating to (a) joint work between community learning disability teams and GP practices (b) training and support for health practitioners and service users to enable them to collaborate effectively
- inclusion of people from all stakeholder groups on the Partnership Board Health Subgroup
- financial incentives at local level to motivate GPs to identify people with learning disabilities and perform annual screening linked to health action plans
- national action by the Department of Health to tie in *Valuing People* targets with the Quality and Outcomes Framework through which GPs receive payment.

A further research workshop will take place in the fieldwork area in June 2006 to assess progress on these recommendations. Clearly, the national and regional action called for will have a bearing on the extent of progress achieved.

References

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health.

Giraud-Saunders A, Gregory M, Poxton R *et al.* (2003) *Valuing Health for All: Primary Care Trusts and the Health of People with Learning Disabilities*. London: Institute for Applied Health and Social Policy Kings College.

Crump B & Whitty P (2005) *The BETTER METRICS Project*. Version 6 www.osha.nhs.uk.