characterised by frequent short admissions and a history of violence to themselves or others and appear to be more akin to those referred to as "revolving door" rather than former long stay.

Case management provides a means of delivering services to a specifically targeted group with long-term mental illness. The group of clients had many disabilities that needed individual packages of care to be developed. Thus, while the main emphasis was on direct work with the client, case managers also had to give a high priority to negotiating care from other agencies. This suggests that a joint health authority and social services purchasing strategy is needed with case management as a central tool. Case managers can then co-ordinate and provide care so as to comprehensively meet social and health needs.

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A learning disability register – how accurate are the psychiatric data?

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Registers on people with learning disability are widely held (Cubbon & Malin, 1985). They have been set up in a variety of ways, hold differing types of data, and are put to various uses. Service planning and management is a common function for which register data may be required. However, a literature search revealed that no accuracy studies had been undertaken on such registers, apart from a reliability study on the Wessex Mental Handicap Register developed by Kushlick *et al* (May *et al*, 1982). In Wandsworth, an inner city health authority, the Register for People with Learning Difficulties is jointly funded and managed by the health authority and local social service department. The register holds data on just under 1,000 people who use services for people with learning disabilities, and the data are updated annually by questionnaires sent out by the register organiser. The questionnaire includes enquiry into demographic information, functional ability and service use. It also notes the presence or absence of additional complications, including psychiatric disorder and behaviours presenting specific management problems. This article describes a pilot study of the accuracy of the psychiatric and behaviour problem data held on the Wandsworth Register.

The study

Thirty-two of the clients, aged 18 or over, registered or updated within the previous three months, were contacted by the researcher, and consent by the subject (or agreement by the subject's relatives when the subject was not capable of giving informed consent) was given to participate in the study. A psychiatric assessment was made by the researcher, which included an interview with the subject and the primary carer, who was a relative when the subject lived at home, or a key nurse when the subject lived in an institution. Psychiatric disorder was diagnosed, using ICD-9 codes, as this was the classification system used by the register. The diagnostic interview was not standardised but based on the guidelines for psychiatric interview used in the Division of Psychiatry of Disability, St George's Hospital Medical School (Anness *et al*, 1991). An assessment of inter-rater reliability was made on ten subjects for psychiatric diagnosis, and in nine cases, the researcher's opinion regarding presence or absence of psychiatric disorder concurred with an independent psychiatric assessment by the second rater, a senior colleague in the psychiatry of disability.

During the interview the researcher also made an assessment of any behaviours which presented specific management difficulties. The Maladaptive Behaviours domain (Part II) of the Adaptive Behaviour Scales (ABS) was used by the researcher on each subject at the end of each interview. Part II of the ABS is designed to assess behaviours which cause management problems. As the study progressed, the

TABLE I
Comparison of presence or absence of psychiatric disorder between the register and the researcher's assessment

		Register data		
		Present	*Absent*	*Row totals*
Researcher diagnosis	Present	6	9 (false negatives)	15
	Absent	0 (false positives)	17	17

Sensitivity = 6/15 = 40%.
Specificity = 17/17 = 100%.

TABLE II
Comparison of presence and absence of behaviour(s) presenting a specific management problem between the register and the researcher's assessment

		Register data		
		Present	*Absent*	*Row totals*
Researcher diagnosis	Present	18	4 (false negatives)	22
	Absent	8 (false positives)	2	10

Sensitivity = 18/22 = 82%.
Specificity = 2/10 = 20%.

researcher found that strict adherence to the ABS Part II was distressing for family members and sometimes for subjects during clinical interviews with subjects living at home. The ABS Part II was therefore only completed on subjects living in institutional environments, in which the key worker acted as informant for the purposes of clinical assessment. For the remaining subjects, an assessment of the impact of behaviour problems was made clinically by the researcher. Inter-rater reliability of this assessment approach led to 100% agreement in ten cases assessed independently by the second rater for presence of behaviour problems posing a specific management problem.

Findings

Of the 32 individuals who were assessed for psychiatric disorder, the register and researcher agreed on six having a psychiatric disorder (Table I). In addition, the researcher diagnosed nine more individuals as having a psychiatric disorder, who were not known to the register. Analysis showed that the register had a 100% specificity (no false positives) but low sensitivity of 40% (a high proportion of false negatives). These results show the register estimates psychiatric disorder in the sample population at one quarter to one third less than that estimated by the researcher.

A similar 2 × 2 table (Table II) has been constructed to compare presence or absence of a behaviour or behaviours which presented as a specific management problem. Here, the register produced an extremely low specificity of 20%, but a higher sensitivity of 82% (a large proportion of false positives and a smaller proportion of false negatives). The ABS Part II, completed on 18 subjects, was not analysed due to small numbers.

Comment

In spite of the small sample size, these findings question the accuracy of the register data concerning

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psychiatric disorder and behaviour posing a specific management problem. The register appears to under-diagnose psychiatric disorder to a significant extent. Those diagnoses which had been missed include diagnoses which had not been made, and those diagnoses which had been made, but had not been conveyed to the register organiser's assistant during her initial or annual information-gathering. This study is not able to separate the two types of error. However, three cases of autism were not included on the register, in spite of the diagnosis appearing relatively clear-cut to the researcher, and apparently recognised by the care-giver in each case. Care-givers who fill out the register questionnaire may not consider autism to be a psychiatric disorder, while being well aware of the condition's presence.

Just under half of the missed diagnoses, (four out of nine) belonged to the category of neurotic disorders. In contrast to the postulated situation with autism, this may represent true under-diagnosis, complementing community surveys of the prevalence of psychiatric disorder in the non learning disabled population. These show a significant proportion of psychiatric disorder remains undetected, in particular depression and anxiety states (Skuse & Williams, 1984; Tylee & Freeling, 1989) at the community level.

A third possibility which might account for the under-recognition of psychiatric disorder by the register is that the disorder is not present at the time of the annual information-gathering. One case of schizophrenia was diagnosed by the researcher and not known to the register, possibly reflecting the time-lag between onset of the illness and annual data collection. However, such a case should be on the register at the next data collection and this type of error would be unlikely to account for the large proportion of subjects whose psychiatric disorder was undetected.

The results showed a high level of behavioural problems. The researcher and the register agreed with 18 out of 32 (56%) exhibiting one or more behaviours presenting specific management problems. However, the register and researcher disagreed on 12 out of 32 subjects (37.5%) suggesting that the register may inaccurately include some individuals as presenting management problems, while others whose behaviour was perceived by the researcher to present management problems were not included. The total number of subjects viewed by the register and researcher, together and separately, as having behaviour which presented a specific management problem was 30. This represents 94.5% of the total sample. It is probably unwise to draw specific conclusions as the abandonment of the standardised instrument for measuring behaviour problems (the ABS Part II) would make such conclusions unreliable. However, the reliability and accuracy of using an unstandardised, subjective measure of whether or not behaviours present a management problem in a register of this sort might be considered by those using these data.

A further larger study is required to answer the question as to whether these findings reflect true inaccuracies in the register. A larger study should also attempt to assess at what stage inaccuracies, if any, in the register data occur, from the stage closest to the registered client, involving assessment, through the annual filling out of the questionnaire to the final stage of transfer of questionnaire data onto the computerised data bank of the register.

Pending further examination of the accuracy of register data, those using data from this register should bear in mind the possibility of data inaccuracy. This is of particular relevance for service provision when, for example, a significant underestimation of mental disorder may result in serious defects in the service provided. As registers of this type are a widely used information source, it is suggested that further studies on the accuracy of the data held on registers for people with learning disability should be carried out. This may be of importance for any register data used as part of assessment procedures engaged in by purchasers of health and social care for service users with learning disability.

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