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Learning disability psychiatry – the future of services

Distinctions between mental illness and learning disability have existed since the last century (Pinel, 1801; Ireland, 1877). The conditions have been accepted as coexisting in the same individual since the beginning of this century (Kraepelin, 1902). More recent papers have investigated the frequency of their coexistence and concluded that most psychiatric disorders are more common in those with learning disability than the general population (Turner, 1989).

Historically, the functions of institutions for those with learning disability included the provision of assessment, education, occupation, housing, health, social and psychiatric care. General health care was provided by doctors employed in these institutions, accessing specialist medical services when necessary. Psychiatric care was provided by learning disability psychiatrists in institutions, general psychiatrists with modest training in learning disability psychiatry or was unprovided.

Psychiatric services for people with learning disabilities today

Community care has resulted in the fragmentation of services for people with learning disability. With alterations in the provision of health and social care for people with learning disability, there has been debate regarding the need for specialised psychiatrists for this population. People with learning disability are invariably found, in methodologically sound studies, to suffer from psychiatric disorders more frequently than the general population (Gillberg *et al*, 1986). The expected rates of various specific psychiatric disorders are reported in Table 1.

The prevalence of any disorder depends on the population studied, the criteria for diagnosis and data recorded. Some studies are based on reports from case registers and are dependent on the criteria for case register inclusions. Other forms of selectivity may also lead to bias in reporting the prevalence of the disorder in question.

Accepting bias, other factors also lead to under diagnosis of mental illness in those with learning disability. One factor is inadequate provision of appropriately trained and qualified psychiatrists in learning disability. Historically, the speciality has been regarded as a 'Cinderella' speciality within psychiatry, and there has been difficulty in recruitment of suitably trained medical staff. This has resulted in failure of training of medical staff in learning disability psychiatry, leading to under-diagnosis, misdiagnosis and inappropriate management of those with psychiatric and behavioural difficulties with coexisting learning disability. This has in some areas led to an increasing number of people with learning disability and psychiatric disorders being treated on an extra-contractual referral (ECR) basis (O'Brien, 1990). Recom-

mendations for services for those with learning disability vary, but there is clear evidence that there is a need for specialist psychiatric provision for patients with learning disability.

A local experience

Recently, the author accepted an appointment as consultant in learning disability psychiatry in an area where community care developments within learning disability were considered advanced (Buckley *et al*, 1988; further details available from the author upon request). People living in institutions were re-housed in community placements and the learning disability institution closed. Moves to community care were accompanied by 'de-medicalisation' of the service. There was an expectation that primary care and ordinary psychiatric services would provide medical and psychiatric care for people with learning disability. There was little training in learning disability psychiatry offered to general psychiatrists. At about the same time, medical staffing in learning disability psychiatry reduced, through retirement and failure to recruit and retain medical staff in the service. This resulted in a provision of only one consultant in learning disability psychiatry, for a total catchment population of nearly 550 000 for nearly five years (until 1996). This was supplemented by a series of locum and temporary appointments – with variable training – to provide psychiatric care for those with learning disability.

The rates of psychiatric diagnosis as recorded in the local Learning Disability Case Register – which is provided to keep updated data on those with learning disability are shown in Table 1 and are compared with the nationally expected figures. However, case register data have limitations. Cooper & Fearn (1998) showed a significant disparity between case register data and morbidity survey estimates of those with dementia, and it is probable that such a disparity would extend to those with learning disability.

It is suggested that either there is something specific about the learning disabled population in the area leading to less mental illness, not previously discovered, or there is an under-diagnosis of mental illness in this group.

Given the under provision of psychiatrists in learning disability the author assumes the latter to be the case. One consultant for over half a million population is clearly a gross under-provision, particularly when compared with the recommendations of the Royal College of Psychiatrists (one consultant in learning disability psychiatry per 100 000 population) and the national figures reported below. In these circumstances it becomes difficult to offer anything except an emergency referral system. This excludes those disorders which are

**Table 1** Prevalence of psychiatric disorders in those with learning disability in Sheffield using case register data – compared with nationally expected figures

Disorder	Prevalence (Nationally expected rates in the learning disabled population)	Local rate
Schizophrenia	3–5% (Fraser & Nolan, 1994)	1.2%
Affective disorders	8–12% (Sansom <i>et al</i> , 1994)	2%
Dementia	2.7% in those 64 years or younger, 21.6% in those aged over 65 years (Sansom <i>et al</i> , 1994; Cooper, 1997)	0.05% (all adult ages)
Neurotic disorders	28% (Day, 1983)	1.2%
Obsessive–compulsive disorder	3.5% (Vitiello <i>et al</i> , 1989)	0%
Personality or behaviour disorder	25–30% (Reid <i>et al</i> , 1987)	3.5%

more insidious – and those without serious behavioural difficulties. I believe that there is a large unmet need for psychiatric services in the population described.

A recent survey of all the trusts in England and Wales (Bailey & Cooper, 1997) who provide services for those with learning disability reported the following staffing levels – compared with that which is provided within our trust (see Table 2).

With the exception of unqualified support workers and psychologists, the trust is poorly staffed when compared with national figures. Although funded, medical posts continue to be filled by locums and temporary staff. Although recruitment in the speciality is a nationwide problem, the local situation is worsened by the fact that prospective consultants would be expected to care for a high population with few trained staff or facilities. The figures presented also suggest an excess of unqualified staff, but this reflects local contracting arrangements. The trust employs large numbers of unqualified support workers to support people living in community-based houses supplied by housing associations. Were all of these contracts moved to the housing associations the figures would be more reflective of (if still in excess of) national norms.

A recent review (further details available from the author upon request) of staff conducted locally suggests that there are almost 500 staff employed who care for 293 people with learning disability. This gives an average of 1.7 staff per person. Of these, less than 20% are qualified nurses. Overall, staff dissatisfaction is high and patients' needs are, judged by the staff caring for the patients, inadequately met in almost 50% of cases.

Within the community learning disability teams, there is an acceptance that caring for people with mental illness and learning disability is part of the role of the team. However, with the exception of learning disability psychiatrists, there is only one other staff member with any substantial training in mental illness. The expectation that staff with little or no training in mental illness can competently provide such a service seems naive at best.

Service requirements for those with psychiatric disorders and learning disability

Day (1993) suggests that psychiatric service provision for the population with learning disabilities should include

facilities of high security such as special hospitals, medium secure facilities at regional level, and sub-regional facilities. He suggests that a sub-regional level there should be (per million population):

- (a) 30 acute mental illness beds;
- (b) 30 chronic mental illness beds;
- (c) 60 day hospital places;
- (d) 40 in-patient facilities for those with behaviour disorders;
- (e) 40 rehabilitation facilities;
- (f) 30 forensic facilities.

He also suggests a need for specialist learning disability teams, the composition of which depends on other local services. Clearly not all of these facilities are required by every trust, however, all areas should have access to these facilities.

Reid (1994) described a service for those with learning disability – covering a population of 400 000 in Tayside. He reports:

- (a) 12–15 bedded unit for assessment and treatment of mental illness;
- (b) one 10-place low security unit for those with severe learning disability and behaviour problems;
- (c) one 10-place unit for those with mild learning disability and behaviour or personality disorders;
- (d) a day hospital provision for those living in the community requiring the above;
- (e) one 10-place residential unit for those with mild learning disabilities who are less disturbed, but still difficult to manage – in conjunction with a further 10-place day hospital facility;
- (f) all of the above are complemented by multi-disciplinary community learning disability teams.

Reid concludes that in Tayside, the psychiatric aspects of the service which were peripheral are now central, and that the service is unrecognisable compared with 25 years ago. There are no patients treated from Tayside on an ECR basis, compared with the service described in this paper where ECRs have to be used regularly, due to lack of local facilities.

Having reviewed the literature the author concludes that a comprehensive service for those with learning disability should include:

- (a) Adequately trained multi-disciplinary community learning disability teams, employed in sufficient

**Table 2 Staffing levels in trusts who provide services for people with learning disabilities**

Staff	National levels	Local trusts ¹
Psychiatrists	1.1 per 100 000 population	1 per 236 000 population
Learning disability community nurses	3.1 per 100 000 population	2.8 per 100 000 population
Unqualified support workers	4.7 per 100 000 population	83 per 100 000 population
Psychologists	0.9 per 100 000 population (including psychology assistants)	0.87 per 100 000 (excluding psychology assistants)

1. As at June 1996.

numbers to be effective, with access to continuing professional development.

- (b) In-patient services (with appropriately trained staff) for the assessment and treatment of mental illness and behaviour difficulties in those with learning disability.
- (c) Rehabilitative and long-stay hospital facilities for a small number of patients, lack of which results in chronic bed-blocking of acute facilities.
- (d) Psychogeriatric services are also necessary, although are not generally provided as a specific service. The prevalence of dementia is higher in the learning disabled compared with the general population, services offering screening and management of dementia are necessary. With the development of cognitive enhancers this need is likely to increase. This service is being developed in the trust described above.
- (e) Day care provision – should be provided by both health and social services. Day hospital facilities may reduce the need for admission to hospital, while occupation, monitoring and supervision are essential parts of psychiatric care of the learning disabled population.
- (f) Services for children with learning disability and psychiatric or behavioural difficulties are also necessary.
- (g) Respite care is usually necessary for some people with learning disability. The nature and extent of such provision varies, and may depend on other service provision.
- (h) Forensic and secure facilities for those with learning disability also need to be provided. Lack of such provision usually leads to treatment on an ECR basis, which is expensive and often inconvenient.
- (i) General medical care for those with learning disability is necessary, and is increasingly provided in primary health care settings with varying degrees of success.

There are differences in opinion regarding the exact extent of service provision in any of the above facilities. Clearly none can be provided in isolation, and the number of beds or day places will depend on other facilities available.

Conclusions

There are lessons to be learned from our local experience, which have implications for future service development. Clearly, primary and secondary health care services for those with learning disability need to be improved.

The expectation that general practitioners can take on the care of people with learning disability with no extra training or resources is unrealistic at best, and unsafe at worst. Psychiatrists in learning disability are more than advocates and advisors and their primary role is not to ensure adequate social care – but to diagnose and treat mental illness in those with learning disability. They also have a major role in teaching and training staff, as well as in research. However, services must be provided for them to fulfil their core function – to treat mental illness in those with learning disability.

Health care for people with learning disability is a continuing cause for concern in some areas. Moves to community care have, for some people, lost previously available medical, nursing and occupational therapies. There seems little incentive for their re-provision. While the majority have probably had improvements in the quality of their physical surroundings, the lack of appropriate health care in some services must lead one to question whether there has been an overall improvement in the quality of life of the people we aim to serve. While institutional care was never ideal, caution against 'throwing the baby out with the bath water' must be exercised. Psychiatric services for those with learning disability must be planned by learning disability psychiatrists and managers working together. Exclusion of psychiatrists from the planning process, for whatever reason, is likely to lead to costly mistakes, including inadequate, inappropriate service provision, which can be avoided.

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