Secure in-patient services for people with learning disability: is the market serving the user well?

Medium-secure care services developed in England following the Butler report (Home Office & Department of Health and Social Security, 1975). They were established to address the major gap in provision between high-secure and local mental health services. However, the development of special secure services for offenders with a learning disability has largely been neglected (Snowden, 1995). People with learning disability who require secure in-patient care are often placed in remote and costly units because suitable local facilities do not exist. Such placements do not usually accord with user and carer wishes.

Since the early 1990s, successive UK governments have sought to dismantle the state monopoly in the provision of publicly funded healthcare. Secure care for people with learning disability has been in the vanguard of those policies, with the independent sector providing 20.4% of state funded care (Healthcare Commission et al, 2006). In this paper, we ask whether this model best serves people with a learning disability.

The market for secure care services

The Count Me In census (Healthcare Commission et al, 2006) found that 940 out of the 4609 in-patients with a learning disability in England and Wales (20.4%) were placed in 49 different independent provider units. Some of the remaining in-patients are likely to be ‘old long-stay’ patients, since 15% of all National Health Service (NHS) in-patients had been in hospital for longer than 20 years. Another survey of independent learning disability in-patient units (Healthcare Commission & Valuing People Support Team, 2004) identified the average distance from home for clients of such units to be 74 miles, with the furthest placement 385 miles from home. A quarter of the in-patients for whom data was available (198 out of 794) were detained under forensic sections of the Mental Health Act 1983.

Independent secure care out-of-area placements can be expensive. In 2005, Selby and York Primary Care Trust studied funding required for medium- and low-secure independent units for people with learning disability (National Development Team, 2004). They identified 144 patients from 22 different providers nationally. The average cost for these placements was £20.2 million for the full year (about £153 000 per patient per year).

There are other costs generated by too great a reliance on out-of-area placements. State run NHS medium-secure units tend to provide a range of services beyond the core in-patient provision (Maden, 2001), which can be lost, however, when services are located outside the local area. These include:

- provision of advice to general psychiatric teams on risk management
- providing a similar role in relation to the probation service and specialised hostels for offenders with mental disorder, and
- providing community treatment and supervision for sex offenders, and for those with personality disorders.

Service users and carers have said that accessibility and availability were important qualities when asked of their expectations of both mental health services (Lelliott et al, 2001) and learning disability services (Foundation for People with Learning Disabilities, 2004). We have reported service users with a learning disability who have found being far away from their relatives and friends distressing (Yacoub & Hall, 2008).

Challenges for secure out of area placements

First, ‘home leave’ is difficult to execute and needs to be awarded for a couple of days (e.g. over the weekend) at a time to justify the journey. Consequently, it is a rarity despite patients making adequate progress for it to be granted. Second, it is difficult for the home community teams to become involved in patient care. As aftercare/community outreach services are not usually offered by the units, the responsibility for future community supervision is often disputed. This delays discharge and leads to the ongoing segregation of patients from their community. Third, independently run out-of-area placements are relatively costly, which may drive commissioners funding placements in debt. Also, the high cost of such services may inhibit the development of local services (Mcmillan, 2006) as trusts are unlikely to invest in setting up new services which initially increase their already existing debt.
However, the flexibilities for foundation trusts may help address this issue, particularly by improving access to capital. Finally, quality of care and cost-effectiveness can be difficult to monitor for each individual case owing to the units’ remote locations from the referring services. For example, the unit’s security or clinical profile may no longer be available to cater for a patient’s needs. This can lead to a worsening in behaviour due to a sense of not moving on (Healthcare Commission, 2006). There is a possibility that if there are not enough patients in a unit, there are financial disincentives to discharge patients, which may impede a move to a more appropriate placement for some patients.

Regulation

Poole et al (2002) state that admissions to inadequately regulated units often follow lengthy spells in acute wards and prisons, and even where care in the independent units exceeds standards in the NHS, this is offset by severe difficulties in integrating people back into reluctant community services. This has not gone unchallenged. Sugarman et al (2002) point out that the Care Standards Act (Department of Health, 2000) offers a framework of standards and inspection for the independent sector, while Hughes (2002) argues that regulation comes from the National Care Standards Commission, the King’s Fund Health Quality Service (independent charitable foundation seeking to improve healthcare), the Mental Health Act Commission and private medical insurers. In Keen’s view (2000), the government missed an opportunity to regulate the private sector properly when the Care Standards Bill was passed in 2000. He argues that the bill focuses on inspection of premises, implicitly assuming they are a reasonable proxy for the quality of care provided in them.

The impact of out-of-area placements on the evidence base

The evidence base for forensic learning disability practice remains sparse. Low prevalence rates, limited research funds, ethical restrictions, and the diversity of service provision have militated against large-scale surveys of this population (Johnston & Halstead, 2000). Although some independent sector providers have an interest in research or links to universities, training posts or academic departments, many do not.

Poole et al (2002) argue that independent units ‘have developed at a distance from purchasers’, without policies to protect long-term interests of patients. As a result, patients are vulnerable to niche market changes (i.e. when funding is diverted to a more potentially profitable facility). This makes long-term outcome studies difficult, and in any case such research is not likely to be a commercial priority.

Challenges in setting up secure services in the public sector

It is a clear objective of public policy that people with learning disabilities should be cared for in units located as near as possible to their homes and families, and only placed under such level of security as is justified by the danger they present to themselves and others (Department of Health, 2001; 2004). However, when there is a shortage of such services, setting up a new service is a complex process that presents a number of challenges. These include:

1. Identification of the client group. Cohen & Eastman (1997) comment that it is particularly complex to undertake health needs assessments in mental health planning, partly due to the difficulty in defining client groups. The Department of Health & Home Office report (1992) broadened the concept of mentally disordered offenders to include those with ‘challenging behaviour’, antisocial behaviour or those ‘difficult to place’. Questions for learning disability services include what level of intellectual functioning to cater for, inclusion of people with Asperger syndrome, and whether to support those with clear forensic histories alongside those without.

2. Commissioning skills. Cooke & Carpenter (2002) argue that social services have been seen as the main commissioners of care for people with a learning disability with no evidence of them having the knowledge, strategic vision, will, or staff to ensure that the private sector provides a comprehensive local service. They claim that no provision has been planned for the longer-term care of detained patients, patients who require forensic psychiatric treatment or rehabilitation by skilled staff.

3. Geographical issues. Unit costs for health and social care services are variable throughout the country (Netten et al, 1998), partly because of differences in the labour and property market. This perhaps explains the dearth of independent sector in-patient units for people with learning disability in London.

The Tough Times project (National Development Team, 2004) aims to raise the profile of adults with a learning disability placed in secure care, and has developed a number of recommendations that may help overcome the challenges outlined above. Some of these include:

- Local services should complete a forensic needs analysis to inform them of the needs and risks of people in all secure care, in contact with the criminal justice services or at risk of offending.
- A forensic learning disability strategy needs to be written to steer local service development or adapt it to meet local needs.
- There has to be more effective information sharing, involvement and partnerships between local services, and priority should be given to support those services to meet local needs.

It has proved possible to reduce the reliance on independent providers for people without learning disability, at least in one metropolitan area. Bartlett et al (2007) found that:
there was a 37% expansion in medium secure beds in the state sector in London over the past 2 years
- the number of out-of-area low and medium beds in independent hospitals has reduced by 30% over the past 3 years
- most of the medium-secure units were involved in local commissioning, gate-keeping and follow-up of out-of-area placements.

These would make good aspirations for forensic learning disability services. The integration learning disability and general adult mental health services generated favourable responses from carers (Samuels et al, 2007), and integrating learning disability and forensic services may be a way of improving secure learning disability provision, and making it more centred on the patient (Department of Health, 2001).

Conclusion
Psychiatrists can help in the development of better local services for people with learning disability by clearly defining the client group and their needs, involvement in the process of commissioning such services, and learning from colleagues in other service areas such as forensic psychiatry. This should help enable people with learning disability with very high needs to have similar access to services as others have.

Declaration of interest
None.

References
BARTLETT, A., JOHNS, A., JHAWAR, H., et al (2007) Report of the London Forensic Units Benchmarking Project. In press.

COHEN, A. & EASTMAN, N. (1997) Needs assessment for mentally disordered offenders and others requiring similar services. Theoretical issues and a methodological framework. British journal of Psychiatry, 171, 412–416.

COOKE, L. B. & CARPENTER, P. (2002) The NHS, the private sector, and the virtual asylum. No lessons have been learnt. BMJ, 325, 1300.

HOME OFFICE & DEPARTMENT OF HEALTH AND SOCIAL SECURITY (1975) Mentally Abnormal Offenders: interim Report from the Committee on Mentally Abnormal Offenders. Cmd 6244. TSO (The Stationery Office).

DEPARTMENT OF HEALTH (2000) Care Standards Act. TSO (The Stationery Office).

DEPARTMENT OF HEALTH (2001) Valuing People: A New Strategy for Learning Disability in the 21st Century. CM 5086. TSO (The Stationery Office).

DEPARTMENT OF HEALTH (2004) Commissioning Services Closer to Home: Note of Clarification for Commissioners and Regulation and Inspection Authorities. Department of Health.

DEPARTMENT OF HEALTH & HOME OFFICE (1992) Review of Health and Social Services for Mentally Disordered Offenders and Others Requiring Similar Services: Final Summary Report (Reed Report). Cm 1988. TSO (The Stationery Office).

FOUNDATION FOR PEOPLE WITH LEARNING DISABILITIES (2004) Green Light for Mental Health. Part A: the Guide. Foundation for People with Learning Disabilities (http://www.learningdisabilities.org.uk).

HEALTHCARE COMMISSION & VALUING PEOPLE SUPPORT TEAM (2004) The Private and Voluntary Healthcare Survey of Independent Mental Health Hospitals for People with Learning Disabilities. Healthcare Commission.

HEALTHCARE COMMISSION, MENTAL HEALTH ACT COMMISSION, CARE SERVICES IMPROVEMENT PARTNERSHIP, et al (2006) Count Me In: Results of the 2006 National Census of Inpatients in Mental Health and Learning Disability Services in England and Wales. Healthcare Commission (http://www.healthcarecommission.org.uk/db/db/documents/CountMeIn-2006.pdf).

HUGHES, J. C. (2002) The NHS, the private sector, and the virtual asylum. Misconceptions are naïve. BMJ, 325, 1300.

JOHNSON, S. & HALSTEAD, S. (2000) Forensic issues in intellectual disability. Current Opinion in Psychiatry, 13, 475–480.

KEIN, J. (2000) Private health-care: modernisation stops here. BMJ, 320, 202.

LELIOTT, P., BEEVOR, A., HOGMAN, G., et al (2001) Carers’ and Users’ Expectations of Services — User version (CUES-U): a new instrument to measure the experience of users of mental health services. British Journal of Psychiatry, 179, 67–72.

MADEN, A. (2001) Medium secure care and research in forensic psychiatry. British journal of Psychiatry, 178, 5–6.

MCMILLAN, I. (2006) Patients stranded by out of area placements in independent sector. Learning Disability Practice, 9, 5.

NATIONAL DEVELOPMENT TEAM (2004) Tough Times: Raising the Profile of Adults with Learning Disabilities ‘Stuck’ in the Secure Care System. (http://www.ndt.org.uk/projectsN/secure.htm).

NETTEN, A., DINNER, J. & KNIGHT, J. (1998) Unit Costs of Health and Social Care 1998. Personal Social Services Research Unit, University of Kent.

POOLE, R., RYAN, T. & PEARSELL, A. (2002) The NHS, the private sector and the virtual asylum. BMJ, 325, 349–350.

SAMUELS, S., HALL, I., PARKES, C., et al (2007) Professional staff and carers’ views of an integrated mental health service for adults with learning disabilities. Psychiatric Bulletin, 31, 13–16.

SNOWDEN, P. (1995) Facilities and treatment. In Seminars in Practical Forensic Psychiatry (eds D. Chiswick & R. Cope). Gaskell.

SUGARMAN, P. A., DUGGAN, L. & GEOF, D. (2002) The NHS, the private sector and the virtual asylum. BMJ, 325, 1300.

YACOUB, E. & HALL, I. (2008) The sexual lives of men with mild learning disability: a qualitative study. British Journal of Learning Disabilities, in press.