NHS beds for people with learning disabilities

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A questionnaire was completed by 135 of the 161 (83.9%) National Health Service (NHS) trusts who provide specialist health services for people with learning disabilities in England and Wales. From these, cumulative frequencies were calculated to describe the current level of provision of NHS beds. Results vary in different parts of the country, but the majority of NHS trusts provide assessment and treatment admission beds, long-stay beds (including those NHS trusts who have completed their resettlement process) and respite care beds. A half of NHS trusts directly manage NHS day places. The high response to questionnaires indicates the current high level of interest in this issue.

Health services for people with learning disabilities have undergone considerable change in recent years. These changes have been politically driven, and follow changing public opinion and concepts such as normalisation and social role valorisation (Wolfensburger, 1983). The large institutions of the past are closing, with the current focus of care being on the provision of quality care in the community. The literature regarding the research outcomes of deinstitutionalisation of people with learning disabilities has been recently reviewed, and shows trends towards improvements in quality of life on many measures (Emerson & Hatton, 1994).

The existing provision of specialist health services in England and Wales is diverse, with many areas finding solutions to meet local needs. However, it is of interest to compare the provision of services in an existing area against national 'normative' data, as a means of benchmarking, both in terms of keeping pace with the process of resettlement, and also in terms of quantity of services provided. However, as no such register of services exists, this study was undertaken in order to provide an overview of existing NHS bed numbers for people with learning disabilities, against which health purchasers and providers can compare their own locality.

The study

A record of all NHS trusts providing specialised learning disabilities health services was compiled, by combining information from the National Association of Health Authorities and Trusts with that contained in the *Health Services Yearbook* (1994). No 'directly managed units' were identified. A questionnaire was sent to the Chief Executive of each NHS trust requesting her/him to delegate it to the appropriate manager for completion and return. A letter was also sent to the Clinical Director/Lead Clinician of each NHS trust, together with a copy of the questionnaire, for information. The questionnaire enquired about the number of specialist NHS beds and NHS day care places, provided and managed directly by the NHS trust. It also enquired about the total population size served by the NHS trust. Both children and adults were enquired about, although the country's provision of NHS beds for children with learning disabilities is minimal. After a period of six weeks, non-responding NHS trusts were recontacted by a second letter to the Chief Executive, again requesting the enclosed questionnaire to be delegated to the appropriate manager for completion and return.

Findings

Of the 166 NHS trusts in England and Wales to whom questionnaires were sent, six were subsequently determined not to serve people with learning disabilities. A further NHS trust was identified during the course of this process. Hence, a total of 161 trusts were identified. In no case did the Chief Executive or Clinical Director/Lead Clinician actively decline to participate. Replies were received from 135 NHS trusts (83.9%). Three NHS trusts did not identify the size of their target population, and so these results could not be included in the cumulative frequency tables. However, their results are included in the comment on the number of NHS trusts who have specific types of beds. The remaining 132 NHS trusts served a combined population of 39 883 920, which represents 81.4% of the total population of England and Wales (based on 1991 census data).

All results were standardised to the equivalent for a population size of 100 000 prior to further calculations. Cumulative frequencies

were employed as all distributions were skewed to the right. Table 1 reports the cumulative frequencies for the bed numbers of different types managed by the 132 NHS trusts. It can be seen in the table that 60.7% of NHS trusts no longer have any institutional beds, reflecting that they have completed their resettlement process. The NHS trusts were also asked in the questionnaire to identify their priorities for service developments. This revealed that an additional 32 NHS trusts were in the process of developing specialist assessment and treatment admission beds. This will bring the total number of NHS trusts with such beds up to 127/135 (94.1%). Further NHS respite care services were being developed by 24 trusts, which will mean that 107/135 NHS trusts (79.2%) provide such services.

Comment

This study has focused on the current bed provision for people with learning disabilities who require NHS care: the provision of specialist learning disabilities health professionals working in the community has previously been described (Bailey & Cooper, 1997), as has the relationship between learning disabilities psychiatrists and specialist learning disabilities health services (Cooper & Bailey, 1998). There was a high response rate to the questionnaire (83.9%), which indicates a high level of interest in this subject by the NHS trusts.

With the closure of the institutions, social care for people with learning disabilities has been largely moved away from the NHS, which has focused on providing health care largely in the community. The NHS has, however, in many areas, reprovided long-term beds for people with learning disabilities who have additional health needs e.g. profound learning and multiple physical disabilities; severe challenging behaviour/enduring mental illness. This study has purposely examined NHS beds and NHS day places managed by NHS trusts directly, rather than those managed by social services and other private/voluntary sectors, or beds established by trusts but providing social care roles. This excludes arrangements whereby NHS trusts provide staff to assist people living in their own homes, or to assist registered care homes and nursing homes. These figures also exclude social care provided (non-NHS, and therefore charged for) through a sister wing of the NHS trust.

Health services are disparate across the country. This is reflected in the results when one considers the total number of long-stay beds provided by NHS trusts. The 'average' NHS trust (i.e. the trust at the median point) manages 10.3 long-stay beds per 100 000 (combined figure for number of long-stay beds in an institution plus long-stay beds in small NHS managed community homes: excluding social care beds). However, 20% of NHS trusts now have no long-stay NHS provision at all for people with learning disabilities; presumably having resettled individuals from the institution into private sector/voluntary/charitable or social services care, or to out of county placements. A small number of these NHS trusts had developed a style of provision whereby people were discharged from

Table 1. Cumulative frequencies for NHS learning disabilities bed numbers per 100 000 population provided by 132 NHS trusts in England and Wales

Centile (%)	Assessment/ treatment	Day places	Total long stay	Institutional long stay	Small homes long stay	Respite care
20	0.0	0.0	0.0	0.0	0.0	0.0
25	0.0	0.0	0.9	0.0	0.0	0.0
30	0.2	0.0	1.9	0.0	0.0	0.0
35	0.7	0.0	4.6	0.0	4.0	0.0
40	1.2	0.0	6.2	0.0	7.0	0.7
45	1.4	0.0	8.1	0.0	10.0	1.2
50	1.8	0.0	10.3	0.0	12.0	1.5
55	2.0	0.7	14.8	0.0	15.8	1.7
60	2.1	1.8	17.6	0.0	18.0	2.0
65	2.7	3.3	21.8	2.9	25.0	2.4
70	3.2	6.0	27.1	8.0	32.2	2.6
75	3.5	7.7	32.1	13.1	40.0	3.1
80	4.1	12.0	40.0	18.4	52.2	3.4
85	4.9	17.2	46.8	27.1	69.0	4.0
90	5.9	22.8	52.2	40.0	77.2	5.7
95	8.0	39.6	72.9	57.2	107.2	7.3
100	60.0	268.4	426.7	373.3	240.0	12.6

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NHS care, but NHS employees provided a service to staff the homes that they lived in (these are not included in the figures presented in this paper). On one hand, this may be seen as 'true' community care, but on the other hand, it can cause difficulties both in determining lines of responsibility and accountability, and in the development and operation of policies and guidelines, thereby limiting professional practice. A further 40% of NHS trusts had completed their resettlement process, but retained NHS long-stay beds, having reprovided these as small community units directly managed by the NHS trust. Hence a large variation exists across the country, but the majority of NHS trusts (two-thirds) who have completed their resettlement have retained long-stay beds, although in a different style (in keeping with the principles and spirit of community care).

The majority of NHS trusts provided assessment and treatment beds (acute admission beds). With the closure of the institutions, the need for such beds increases. The likelihood is that people will move in and out of NHS care, requiring admission at times of greatest need e.g. when acutely psychotic, but living at home in the community for the majority of the time. This is in contrast to the previous style of care when people move into the institution, and then just stayed there. Included in this figure are both beds on specialist learning disabilities units, as in the model of care described by Day (1993), and also beds on general psychiatry units which are designated for use by people with learning disabilities, as in the model of care described by Bouras *et al* (1995). A few NHS trusts provided assessment and treatment beds and long-stay beds on a regional or national basis (e.g. forensic beds funded through extra contractual referrals): this accounts for the high figures at the 100 percentile.

Respite care beds will continue to be required after the closure of the institutions. The results show a great difference between NHS trusts in terms of the number of such placements that they manage. In part this may reflect local arrangements with social services departments. Assessment and treatment facilities require a high profile of qualified, multi-disciplinary health professionals in order to achieve the required tasks, but the skill mix of staff required for the provision of NHS respite care services is likely to include a higher proportion of staff who do not hold health qualifications. Hence the distribution of respite care placements between the health and social services may vary in different areas. However, NHS respite services appears to be an area that many NHS trusts are developing, in keeping with the recognised increased lifespan of people with learning disabilities.

Just over half of NHS trusts did not provide NHS day care. On the basis of the information collected, it is not possible to say whether this reflects a deficit in service provision in these NHS trusts, or a tendency for care to be delivered in different ways in a given locality. Of those NHS trusts that do provide NHS day care, the questionnaire was not detailed enough to distinguish between day care provided on a long-term basis (to people with enduring health needs) or short-term day care used in an assessment and treatment model.

Menolascino (1989) reported the need for 8–19 acute/sub-acute beds (to provide assessment and treatment services to people with acute/sub-acute illness or challenging behaviour) for a population in the USA of 482 000 (equivalent to 1.66–3.94 per 100 000). The results of this study for assessment and treatment beds in NHS trusts in England and Wales falls within this range (with a median of 1.8 per 1000 000). Day (1993) described bed needs in terms of provision at national, regional, sub-regional and district levels. In addition to national and regional beds (special hospitals and medium-secure units), and local community learning disabilities teams and day placements, he reported the need for 150 beds per 500 000 population (equivalent to 30 beds per 100 000), in specialist learning disabilities psychiatric units. This definition is comparable to the combined long-stay, respite and assessment and treatment beds reported in this England and Wales survey of NHS trusts, which demonstrated the NHS trust at the median level to have 13.6 beds per 100 000: a lower level than that identified to be required by Day (1993).

It is important for the appropriate balance to be struck between the provision of locality-based services for people with learning disabilities, together with supra-specialist services (e.g. forensic services). Most NHS trusts, including those which have completed their resettlement programme, provide long-stay homes for the minority of people with learning disabilities who have extensive health needs (e.g. enduring mental illness/challenging behaviour or profound learning and multiple physical disabilities), and the majority also provide local assessment and treatment beds (for the diagnosis and treatment of mental illness, challenging behaviour or diagnosis of change in behaviour). In the past, facilities such as NHS respite care and assessment and treatment admission beds would have been provided by the institution, and therefore lost upon its closure unless specific provision were made. However, it appears from this study that the necessity for such services has been recognised, with the majority of NHS trusts either meeting the provision already or indicating their intention to do so.

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