

# Survey of services for adults with learning disabilities

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Questionnaire data are presented from a national multi-professional survey. Only 12% of respondents had local quantitative data on adults with learning disabilities (LD) and mental health needs (MHN). More described local provision as part of specialist LD services than integrated with generic mental health services. LD services were rated as more accessible and more available than generic mental health services. Clinicians agreed about the important elements of psychiatric assessment, treatment and their preference for using the ICD-9 and ICD-10 diagnostic classifications. The planning, delivery and evaluation implications for psychiatric services for adults with LD are outlined.

Government policies have encouraged the hospital resettlement of people with learning disabilities (LD) and their community support. Many have complex health and social care needs related to their physical disabilities; sensory impairments, epilepsy, behaviour problems, autism, psychiatric disorders, offending and ageing (Department of Health, 1995a). The development of local services should reflect such needs or problems with availability, accessibility and adequacy will occur (Gravestock, 1997). There are difficulties for local services responsible for the 25–50% adults with LD who also have mental health needs (MHN) arising from psychiatric and behavioural disorders (Bernal & Hollins, 1995). Local confusions are more likely when adults with LD and MHN also present with 'challenging behaviours' (Bouras *et al.*, 1995a; Department of Health, 1995a). If a coherent accessible local psychiatric service model is not operated, unmet mental health and social care needs will occur, resulting in reduced social functioning and quality of life and crisis presentations (Gravestock & Bicknell, 1992).

## The study

A questionnaire was developed to gather local service planning and utilisation data about adults with LD and MHN. The clinical issues data section of the questionnaire was only to be completed by 'clinicians' (those undertaking patient-orientated clinical work). All 15 consul-

tant psychiatrists in the local LD services of the former south east Thames Region completed the pilot questionnaire in 1993, and identified senior psychology, nursing and manager colleagues in their health and local authority LD services to whom it was sent (Gravestock & Bouras, 1995).

Using the College Membership List, the questionnaire was sent to a further 75 consultants in the psychiatry of learning disabilities and their identified local service colleagues. The national survey aims were: (1) to broadly assess local service provisions for adults (aged 19–65 years) with LD and MHN, and (2) to consider how local services could be improved.

As the 'normalisation' philosophy underpinning some LD services promotes access to generic mental health services, the study also compared generic and specialist psychiatric services for adults with LD and MHN. Given the advanced stage of the SE Thames Region hospital resettlement programme, different views about service issues were expected from these respondents compared with those from other regions (Gravestock & Bouras, 1995).

## Findings

### Responses

One hundred and sixty-three replies from 330 represents an overall 49% return rate, with 54 out of 75 returned from the SE Thames region and 109 out of 255 from the other 16 regions (range 1–16; median 7 per region). The 163 respondents were 67 (41%) psychiatrists, 48 (29%) LD service managers, 24 (15%) psychologists and 24 (15%) nurses. They worked in services with a median total catchment area population of 232 500 people (range 1000–1 000 000).

### Care planning

One hundred and nineteen (73%) respondents reported the operation of case registers of adult LD service users and 67 (41%) could provide data on the number of adults with LD in their local service area. While 103 (63%) said local services operated case or care management systems, only

19 (12%) could provide quantitative data on those with MHN. Views about which service should coordinate care were mixed: 81 (50%) health authority LD service; 43 (26%) multi-agency; 21 (13%) variable arrangements; 8 (5%) local authority; and 6 (4%) generic mental health services.

#### *Service models*

Respondents provided services to adults with mild (IQ 50–69), moderate (IQ 35–49) and severe (IQ <35) LD and MHN. Most (125 (77%)) also served adults with borderline intelligence (IQ 70–80) and MHN. One hundred and seven (66%) described most local provisions for adults with LD and MHN as part of specialist LD services rather than integrated with generic mental health services (37 (23%)).

Most confirmed a mixed local care economy; the main service providers were community LD teams, local authority day and residential services, the independent (private and voluntary) sector and the LD hospitals. One hundred and one replies (62%) reported the local establishment of specialist services for adults with LD and MHN. The main types were clinical assessment, treatment and community support services and staff training programmes.

#### *Availability, accessibility and adequacy*

More respondents rated the availability (101 (62%) *v.* 60 (37%),  $P=0.0001$ ) and accessibility (110 (67%) *v.* 31 (19%),  $P=0.0001$ ) of LD services as good than generic mental health services respectively. Most regarded much of the local service provision for adults with LD and MHN as less than adequate including: respite care, day care, day hospital, residential care, secure unit, generic mental health hospital and community LD team services. One hundred and ten (67%) rated psychiatry of LD clinics as adequate.

#### *Clinical assessment and treatment*

When clinicians ( $n=115$ ) rated elements of the psychiatric assessment of adults with LD, the following rank order of diagnostic utility emerged: history taking (most useful), observing interview behaviour, physical examination and investigations, behavioural analyses and checklists, mental state examination, medication trials, psychiatric admission, psychometric assessment and psychopathology rating scales (least useful).

Seventy-four (64%) clinicians used ICD–9 or ICD–10, 14 (12%) DSM–III–R and 27 (23%) neither. Concerning treatment, 55 (48%) agreed that psychotropic medication was generally indicated; 74 (64%) considered medication as effective as for adults without LD; 84 (73%)

thought that other treatment interventions were also required to maintain functioning; 84 (73%) indicated that medication did not inhibit the complementary therapeutic benefits of behavioural, environmental or psychotherapeutic interventions.

#### **Comment**

Given the different response rates of regional and professional groups, the findings are suggestive rather than definitive about the national service ecology for adults with LD and MHN. Few differences emerged between the views of SE Thames Region respondents and those from other regions. The differences were expected given the few remaining LD hospital beds and usage of local generic mental health beds in the region (Gravestock & Bouras, 1995).

Most respondents favoured specialist LD health and social services over generally less available, accessible and adequate generic mental health services. Despite various local mental health service models for adults with LD, the data indicated that most localities have multiple unmet health and social care needs. The findings reflect service systems in transition between health authorities concerned with hospital re-settlement, local authorities trying to coordinate community care and neither having fully implemented the Care Programme Approach for adults with LD and MHN.

Central initiatives have encouraged coordinated interdisciplinary and multi-agency care planning, delivery and monitoring for psychiatric patients, including adults with LD and MHN (Department of Health, 1995b). However, this study demonstrated a dearth of reliable local care and service planning data with diverse views about responsibilities for care coordination. In some localities, service responsibilities need to be clarified for adults with borderline intelligence and MHN, adults with LD and MHN also presenting with challenging behaviours and offending, adolescents and ageing adults with LD and MHN.

Clinicians thought that the psychiatric assessment of adults with LD should be similar to that of adults without LD. Adults with LD usually present with changes in behaviour and functioning and several have communication impairments. Successful psychiatric assessment requires more time and greater reliance upon informants, communication facilitators and behaviour monitoring (Bouras *et al.*, 1995b). Psychometry and psychopathology rating scales were seen as less useful, given their variable reliability and validity. Despite similar concerns about using unmodified diagnostic classifications, clinicians using the ICD–9 or ICD–10

probably facilitate service management data returns (Sturmev, 1993).

Crisis or brief psychiatric admission may not show the usual functioning, behaviour and needs of adults with LD and MHN. Behaviour observations and interdisciplinary interventions are more naturalistic in usual care environments involving usual carers and staff. Local multi-disciplinary LD health services with consultants in the psychiatry of LD have continuing specialist advisory, clinical care and staff training roles. Access to psychiatric assessment and treatment beds is also essential to support community LD services (Royal College of Psychiatrists, 1992; Gravestock & Bicknell 1992; Department of Health 1995a; Bouras *et al.*, 1995b).

Future research should further evaluate specialist and generic mental health service models for adults with LD and MHN, including hospital campus, community based and integrated services (Day 1993; Bouras *et al.*, 1995a). To better evaluate service user outcomes, standardised multi-axial and inter-agency need assessment systems could be further developed (Farmer *et al.*, 1994; Gravestock, 1996).

Service purchasers and providers should ensure that the health and social care needs of local adults with LD and MHN are quantified and responsibilities for meeting complex needs agreed. The data support the coordinated development and evaluation of hospital and community based specialist health, local authority and independent LD services. This would improve the range, volume and quality of local service provisions for adults with LD and MHN. Then individualised service delivery, as envisaged in the Care Programme Approach, could result in positive health and social outcomes for adults with LD and MHN and their carers.

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### References

- BERNAL, J. & HOLLINS, S. (1995) Psychiatric illness and learning disability: a dual diagnosis. *Advances in Psychiatric Treatment*, **1**, 138-145.
- BOURAS, N., HOLT, G. & GRAVESTOCK, S. (1995a) Community care for people with learning disabilities: deficits and future plans. *Psychiatric Bulletin*, **19**, 134-137.
- , MURRAY, B. & JOYCE, T. (1995b) *Mental Health in Learning Disabilities: A Training Pack for Staff Working with People who have a Dual Diagnosis of Mental Health Needs and Learning Disabilities*. Brighton: Pavilion.
- DAY, K. (1993) Mental health services for people with mental retardation: a framework for the future. *Journal of Intellectual Disability Research*, **37** (Supplement 1), 7-16.
- DEPARTMENT OF HEALTH (1995a) *The Health of the Nation. A Strategy for People with Learning Disabilities*. Oldham: HMSO.
- (1995b) *Building Bridges: A Guide to Arrangements for Inter-Agency Working for the Care and Protection of Severely Mentally Ill People*. Wetherby: DoH.
- FARMER, R., ROHDE, J., BONSALE, C., *et al.* (1994) Towards the development of a multi-axial classification of people with learning difficulties. *Journal of Intellectual Disability Research*, **38**, 587-597.
- GRAVESTOCK, S. (1997) Individual community care packages for adults with learning disabilities and mental health needs. In *Commissioning and Providing Services for People with Learning Disabilities* (ed N. Bouras). Brighton: Pavilion (in press).
- & BICKNELL, J. (1992) 'Emergency' referrals to a South London community mental handicap team (CMHT). *Psychiatric Bulletin*, **16**, 475-477.
- & BOURAS, N. (1995) Services for adults with learning disabilities and mental health needs. *Psychiatric Bulletin*, **19**, 288-290.
- ROYAL COLLEGE OF PSYCHIATRISTS (1992) *Mental Health of the Nation*. London: RCPsych.
- STURMEY, P. (1993) The use of DSM and ICD diagnostic criteria in people with mental retardation. A review of empirical studies. *Journal of Nervous and Mental Disease*, **181**, 38-41.

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