

Foreign report

Developmental disabilities services in New York State

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Following a visit I made to New York State in November 1992, this paper describes developmental disabilities (DD) services and compares these with UK learning disabilities (LD) service systems. The State has a multicultural population of 18 million and its Office of Mental Retardation and Developmental Disabilities estimates that 300,000 people have developmental disabilities (DD) i.e. severe and chronic mental handicaps or physical handicaps, or both, present before 22 years of age, including mental retardation, autism, cerebral palsy, epilepsy and related neurological impairments (Bouras, 1987).

Through 20 district offices with a \$1.75 billion budget, the State provides or purchases support, daycare, work programmes, respite care, crisis intervention, community and institutional residential services for 100,000 people with DD. Their 6,000 clients remaining in institutions (14 developmental centres) will be resettled to intermediate care facilities, community residences and supported living schemes by the year 2000. Several private, voluntary and carer organisations provide similar community services.

State resources and priorities are publicised through district offices and the independent Planning Council. Contracts with all DD service providers are subject to complex federal, state and third party funding and quality regulatory systems. The Departments of Social Services are mainly concerned with administration of benefits, including the publicly funded Medicaid health insurance; child protection and adoption; and services for homeless people. DD services emphasise active rehabilitation for all clients. The quality of service environments, management, information systems and staff contrasted with the limited psychiatric input for those with 'dual diagnosis'; i.e. mental retardation and psychiatric disorders, autism or challenging behaviours.

Medical and psychiatric care for people with DD may be obtained from family physicians, private or state clinics and hospitals. Several providers are unwilling to serve people with DD, regarding them as time-consuming, costly and high-risk cases. Health care insurance schemes use complicated eligibility criteria and standard treatment algorithms to determine third party reimbursements. Thus, most public

and private schemes do not account for providers serving people with DD and complex continuing health care needs.

The Westchester Institute for Human Development (WIHD) and County Medical Centre provide tertiary health care services for 2.1 million people in the lower Hudson Valley Region (4,554 square miles). With an annual budget of \$8.2 million, WIHD serves 3,500 people with DD. Most clients have mental retardation and 66% represent ethnic minorities. WIHD aims to improve the quality of life for people with DD by acting as a specialist resource centre and enabling access to quality education, work, health and social services (Bambrick, 1991). It provides a range of multidisciplinary primary and specialist health care, social work and case management services. WIHD also receives federal, state and local grants to replicate quality community services through professional training programmes, consultation and research dissemination. Its transitions planning, enhanced primary care and positive approaches to challenging behaviours programmes interested me.

Psychiatric consultations for people with DD emphasise investigations, diagnostic and medication issues but continuity of care is problematic. Again the funding and organisation of services do not reflect the chronicity of mental health needs or value of clinical monitoring. WIHD is developing its specialist clinic and consultation services to increase follow-up contacts, community visits, outreach training and access to generic psychiatric services.

The generic crisis intervention team, intensive care ward, child and adolescent units at the County Medical Centre are impressive and occasionally serve people with DD. Opportunities to discuss service systems, psychotherapy and medication included visiting the high-powered State Institute for Basic Research into DD.

Comparisons with UK service systems

General rather than detailed comparisons are appropriate, given the complex structure of USA services and broader range of DD service users. USA service

systems monitor and publicise complex data on met and unmet needs. By contrast, our UK pilot study found that services had no specific data on adults with LD and mental health needs using or requiring health and social care services (Gravestock & Bouras, unpublished report).

USA carer, civil rights and advocacy organisations strongly influence the resources allocated to DD services (Braddock, 1992). Quality monitoring systems with legal accountability then maintain the high funding and standards of social care services. However, difficulties of accessing affordable health care have increased the pressure to reform insurance systems (Kastner, 1992). UK primary and specialist health services for defined catchment areas currently allow greater and continued access to less complex community and hospital care for people with LD and similar health needs.

The skills development philosophies of some DD services seem to overshadow consideration of unmet psychiatric and nursing care needs. Most USA psychiatrists receive little training experience of people with DD and their mental health needs. Consequently, clients are often excluded or underserved by generic mental health services while many DD services are unable to recruit interested psychiatrists (Bouras, 1992). Psychologists and social workers in the USA perform service managerial, consultative and direct care roles including behavioural therapies, individual, group and family counselling.

Psychiatrists and neurologists in the USA prescribe a wider range of psychotropic medications for children and adults with DD. Stimulants, serotonergic antidepressants, beta blockers, clonazepam, sodium valproate, clonidine or naltrexone are used as adjunctive therapy for challenging behaviours. Medication trials are often accompanied by behavioural interventions and monitoring by psychologists. State regulations and fear of litigation about tardive dyskinesia restrict the use of long-term

neuroleptics to diagnosed psychotic disorders. USA service providers and carers were impressed by UK specialist psychiatric training schemes, community nurses and the broader responsibilities of local authorities. They valued the community team and outreach clinical work, audit and management activities of consultants in LD services. UK specialist services could learn from WIHD's approaches to defining and then meeting the complex needs of service users and related service systems. Consumers are involved in monitoring unmet needs at all system levels while interventions are tailored to usual service environments. Given the finite resources of both service systems, comparing the impact of UK and USA health care reforms should also prove useful.

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