

*Developmental Disabilities Service in California**

N. BOURAS, Department of Psychiatry, United Medical and Dental Schools, Guy's and St Thomas's Hospitals, London Bridge, SE1

The roots of the modern mental retardation service can be traced to the federal legislation introduced by President Kennedy in 1963. Shortly after he took office in 1961, he appointed an expert panel to study the issues and problems and to propose a plan of action. This signified complete separation between mental health and mental retardation services.

The recommendations of the panel were based on the main principle that "each individual State should develop a comprehensive provision of services for people with mental retardation as close as possible to the local communities".

The Developmental Disabilities Services and Facilities Construction Act of 1970, adopted the term 'Developmental Disabilities' (DD), revamped the initial programme, diversified the purposes and expanded the target population. The definition of 'Developmental Disabilities' included mental retardation, cerebral palsy, epilepsy, as well as 'other neurological conditions'. The new Act marked the beginning of a move towards an emphasis on similar service needs, rather than clinical categories.

The definition, however, permitted varied interpretations, making difficult planning and programme priorities. To some, the definition was interpreted as to include all individuals in the specified clinical categories, regardless of the degree of severity; but many were more restrictive. There was concern that scarce resources were not being focused on those most in need of services, and that many with limitations and service needs similar to the developmental disabilities population, were not being serviced.

This led to a new functional approach of the problem by defining developmental disability as a severe chronic disability of a person which:

- (a) is attributed to mental or physical impairment or combination of both of them;
- (b) is manifested before the age of 22;
- (c) is likely to continue indefinitely;
- (d) results in substantial functional limitations in three or more of the following areas of major life activities: (1) self-care; (2) receptive and expressive language; (3) learning; (4) mobility; (5) self-direction; (6) capacity for independent living; (7) economic self-sufficiency.
- (e) reflects the person's need for multidisciplinary or multi-agency involvement in treatment, or other services to plan for life-long or long-term needs requiring individual co-ordinated plans.

*This report is based on a personal experience from a recent Sabbatical as a visiting Associate Researcher to University of California, San Francisco.

The system in California State

California State with a population of about 21 million introduced the Community Care Facility Act (1973) to initiate community service developments and to establish a co-ordinated and comprehensive state-wide service system for children and adults who were mentally ill, developmentally disabled, and physically disabled.

California was already planning services based on its own operational definition of DD, as referring to "individuals with a substantial handicap whose diagnosis was mental retardation, epilepsy, cerebral palsy, autism, and other neurological conditions, resulting in similar service needs and who became disabled prior to the age of 18".

The adoption of the federal definition of developmental disability would have resulted in a reorientation of the DD target population because the largest representative group would have been the physically disabled (58%) followed by the mentally retarded (29%). Services have continued to operate on the state definition.

The department of developmental services (DDS)

The California State service for developmentally disabled people is administered by the Department of Developmental Services (DDS), which is part of the Health and Welfare Agency. The DDS administers directly the eight state hospitals; has service contracts with the 21 local Regional Centres; and liaises closely with other state departments which provide services to the developmentally disabled population, such as Social Services, Health Services, Mental Health, Education, Employment, Rehabilitation, and Transportation.

Regional Centres

Regional Centres were established in California by the Lanterman Mental Retardation Services Act in 1969. By 1977 there were 21 Regional Centres serving every county in the State, and in January, 1985 the Regional Centres had approximately 73,200 clients. Of these clients, about 90% live in their own homes or community residential facilities and about 10% in the eight state hospitals.

The Regional Centres are private, non-profit-making community agencies, which have contracts with the DDS to provide assessment, diagnosis, programme planning, and co-ordination of the delivery of service to individual clients and their families. They can also provide prevention services such as public information, health and nutrition education, and genetic screening and counselling. Also the Regional Centres are responsible for controlling admissions to state hospitals and for securing community services for persons discharged from them. They are the only entry point into the service delivery system, apart from clients being admitted to state hospitals on court orders.

The Regional Centres do not provide any other direct service to clients but in order to meet their contractual obligations, they purchase programmes from individual or agency contractors (vendors).

Any California resident who is believed to have a developmental disability could be referred or apply for service to his/her local Regional Centre. On referral to the Centre, the person is assessed by a multidisciplinary team. This involves review of existing medical and psychological information, social assessment, and specialised assessment as necessary. Assessment is followed—if the client is accepted by the Regional Centre—by a meeting to set an Individual Programme Plan (IPP). The IPP is a written plan of action which contains the goals and objectives designed to meet the individual's needs and identifies the persons and programmes necessary to meet the objectives. The development of the plan requires the participation of the client, family, regional centre staff and other community agencies who may be involved with the client's care. The IPP should clarify the roles and responsibilities, the funding sources, and the services required for the client.

After the initial assessment, the local Regional Centre will assign a member of staff to serve as the client's case manager (usually a social worker). The case manager has overall responsibility for the client, is in regular contact with the family, assists in finding appropriate community programmes and resources, and provides counselling and support. The case manager keeps records, including medical information, and progress reports from professionals, agencies and programmes. Client progress is evaluated not less often than once a year, and the IPP is reviewed annually or more frequently if necessary.

The Regional Centres have to meet the needs and objectives listed in the Individual Programme Plan either by referring the client to generic services, or by purchasing services from vendors. The vendors are directly accountable to Regional Centres as they are contracted to and reimbursed by them. Some examples of purchasing services from vendors are: short-term care (respite service), day-care programmes, behaviour modification programmes, physiotherapy, speech therapy, and even medical and psychiatric treatment and care, if not available through the generic services.

State hospitals

State hospitals provide the institutional care and treatment for the developmental disabilities services, clients being admitted upon referral by a Regional Centre or by Court Order. All hospital residents are Regional Centre clients, but each hospital functions with autonomy and tailors programming specific to each resident. The internal function and operation of the hospital is divided into different programmes and a Programme Director is identified for each of them. The overall responsibility for the resident lies with his/her Programme Director who may be a clinical psychologist, or a social worker, or a doctor. Physicians and psychiatrists respond usually to referrals and their clinical responsibility is concentrated on this involvement.

State Council on Developmental Disabilities

The State Council on Developmental Disabilities is an independent body federally funded and authorised under federal and state laws, with responsibility to plan and co-ordinate resources as required to protect and advocate the civil, legal and service rights of people with developmental disabilities. To achieve these aims, the State Council sets policy directions for services to people with developmental disabilities through the State, and these are reviewed and monitored by 13 area boards.

There are, also, several major parent/family organisations which were born in the 1950s as advocacy groups and are largely responsible for the creation of the current publicly funded service and advocacy system. In recent years consumers have also begun to organise themselves in other groups such as those based on ethnicity, for example, and become advocates for themselves.

University Affiliated Facility for interdisciplinary training in developmental disabilities (UAF)

The University of California in Los Angeles (UCLA) was the first in the country to be awarded federal support for both a UAF and its companion programme, the Mental Retardation Research Centre in the early '60s. The two operate with a unified administration in the Neuropsychiatric Institute part of the UCLA Centre for Health Services. The programme provides a high standard of developmental disability training for professionals in administration, community liaison, nursing, special education, child psychiatry, etc.

The Mental Retardation Research Centre conducts several research projects for the study of early childhood psychosis, etc.

A clinical inpatient and outpatient service is also offered at the UCLA to developmentally disabled people suffering from psychiatric problems.

Comments

California State is considered to have developed over the last two decades a comprehensive Mental Handicap Service.

I visited various facilities, such as Regional Centres, Day Centres, and residential placements, mainly in the Bay Area and Central California. I also visited the Department of Developmental Disabilities and the State council and my overall impression was of a highly efficient and well organised service system.

I thought that the main contributors to the success of the service are (a) clarity of operational roles with legislative cover; (b) one State service provider; (c) accountability; (d) flexibility and (e) relatively adequate financial provision.

The operational definition in spite of some difficulties is a useful framework for the definition of roles and responsibilities. The extended definition of developmental disabilities is an interesting concept for planning on the basis of similar service needs, and can be useful, provided that it attracts new funds and does not facilitate the diversion of scarce resources to an expanded target population.

The most important factor is, probably, that the responsibility of the service provision lies with only one state agency, the Department of Developmental Disabilities, through the Regional Centres. The Social Service Department has no direct responsibility for services to developmentally disabled people, which avoids separate planning, unnecessary confusion, and split roles.

Accountability appears also to be clear as the Regional Centres receive their annual budget from the Department of Developmental Disabilities and they in turn contract vendors on annually reviewed contracts to provide 'treatment and care programmes' not available from the generic services. The function of the Regional Centres is also defined as they offer assessment-diagnosis, IPP and case management without being involved in direct treatment and care. This mode of working is fundamentally different to British models of community mental handicap teams, which are expected to be primary clinical service providers including sometimes even psychiatric care.

There are, of course, different models of community mental handicap teams emerging from health districts which perceive their role differently. There is, however, a tendency for them not to define their boundaries, roles, and clinical responsibilities, either in relation to social services or to other service agents.

Problems and difficulties

Some of the problems experienced by the Californian service are:

- (1) The increasingly high cost of purchasing programmes and services from vendors. Some of the Regional Centres are under considerable pressure to fulfil the role of meeting the needs of their clients within a tight annual budget. Since 1978/9 there has been a budget increase of 68.6% for the state hospitals and 124.4% for the Regional Centres. But the State Hospital population has been decreased from 8,995 in 1978 to an estimated 7,000 in 1985, while the population serviced by Regional Centres has been increased from 54,549 to 74,184 during the same period of time.
- (2) The major problem, however, appears to be the clients with 'dual diagnosis', that is developmental disabilities and psychiatric or emotional disorders. It seems that when the two services of mental retardation and mental health were separated, no provision was made for those people who would be needing both of them. There is a tendency now for each service to consider the other one to be responsible and, as a consequence, clients may

receive service from neither. Developmental Disabilities Services believe that their clients should have access to generic services, including mental health. But psychiatric services argue that most of the symptoms manifested by these clients are due to their mental retardation and not to treatable mental illness. Such demarcation disputes are only too familiar in Britain.

A 'task force' has been formed by interested parties to study the problems and propose action. In spite of two years work, the study has not yet been completed, and the provision of beds for crisis admissions presents continuing problems. Local arrangements known as 'interim working agreements' are in force in some places and relieve some of the pressure temporarily. The role of the psychiatrist is focused on the assessment/diagnosis and psychiatric care of those in need of them. Generally psychiatrists are reluctant to attend non-medical facilities or go on domiciliary visits as they are not reimbursed by the complicated medical insurance system. These problems create various obstacles and the British system is undoubtedly superior in this respect, terms and conditions of service making it easier for doctors to work in community settings.

- (3) Some other long-term problems for planning are (a) the impact on the service when all people eligible for service become known and (b) the increasing ageing population with developmental disabilities.

The provision of a comprehensive and well co-ordinated service for mentally handicapped people is a difficult and complex task. I think that the characteristics of the Californian system tend to alleviate some of the difficulties and complexities and contribute to a successful service which can (a) provide long-term or on-going case management for Regional Centre clients as they move through developmental life transitions, and (b) provide some of the most important services which are necessary to maintain clients in the community.

I was also much impressed by their computerised data information system available for both service and planning purposes. This and the highly developed multiprofessional training programme would not be available without the active involvement of an academic unit with relevant interests and expertise.

The continuing reduction of the long-term hospital population and the successful maintenance in the community of the great majority of the clients, provides strong evidence that community care can be successful in mental handicap, but efforts must continue to improve the quality of life of all the clients and especially those with special needs.

Family Courts

The Family Court's Campaign has recently responded to the Lord Chancellor's Inter-Departmental Review of Family and Domestic Jurisdiction in its publication

A Court Fit for Families, which is available from the Family Courts Campaign, 66A Eaton Square, London SW1W 9BH, price £2.95 (covered), £1.50 (uncovered).