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Developmental psychiatry and intellectual disabilities: an American perspective

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Summary

The Natalie Cobbing Travelling Fellowship gives the opportunity to medical professionals trained in the Psychiatry of Intellectual Disabilities to gain experience in their field from centres overseas. This article concentrates on specialist work settings and the practice in developmental disabilities in Boston, USA. The authors conclude that such training opportunities not only are important educational milestones but also help in creating a network of professionals who can work together to improve standards of research and clinical practice across different cultural and ethnic divides.

Keywords

Developmental psychiatry; education; intellectual disabilities

Introduction

The concept of development in Psychiatry emphasizes the important link between the genetic determinants of behaviour and the impact of the environment on the final outcome. It is an ongoing process, which involves not only the young child but also the adult, given that behaviour, adaptive mechanisms and illnesses in later life have their roots in early experiences and biological events (Rutter 1980); p. 1; Harris 1998; p. 167).

Munir & Beardslee (1999) argued persuasively that the developmental perspective is paramount to the understanding of psychobiology and psychopathology within an interdisciplinary framework. They further suggested that the adoption of a developmental perspective in the diagnosis of mild symptoms might lead to early or preventive treatment where developmental mechanisms are involved. In the field of intellectual disabilities, the issue of 'nature or nurture' is of particular importance as professionals see the same individuals over several years and predictions about the developmental achievements of children with cognitive impairments in later life can confound many clinicians (Hollins 2000).

However, the terms developmental disabilities and intellectual disabilities or mental retardation denote different types of problems although there is an overlap between the two

groups. For example, people with intellectual disabilities who also meet the criteria for developmental disorders are those likely to require life-long support by services.

As the recipient of a travelling fellowship in 2000, the author (A.H.) chose to spend 6 weeks at the Developmental Medicine Centre, Division of General Paediatrics, Children's Hospital, Boston, Massachusetts. The clinical and research programme was of particular interest first, because of its focus on the early years of children with intellectual disabilities and developmental disorders, second, because training in childhood developmental disabilities is lacking in the UK, and third, because this is an established clinical and research centre of excellence, prominent in policy development and the international literature. Also, there would be exposure to service delivery for adults with intellectual disabilities and mental health problems within the state of Massachusetts. Limited access to service users was available at outpatient clinics and during visits to specialist centres (Fig. 1).

Developmental Medicine Centre

Historically, the programme at Children's Hospital has been established since the inception of federal support for intellectual disabilities beginning with the President Kennedy's *Panel on Mental Retardation* that developed a national strategy in the early 1960s, thus marking the era of early childhood intervention in the United States. In 1968, Public Law 90-538 marked the Handicapped Children's Early Education Assistance Act to '*stimulate the development, evaluation, refinement and dissemination of model demonstration projects for the education of disabled infants, preschoolers and their parents through federal grants*'. By 1986, the Public Law 99-457 Education for All Handicapped Children Act amendment further strengthened the services dubbing it the '*most important legislation ever enacted for developmentally vulnerable children*' (Shonkoff & Meisels 1990).

The Mental Health and Developmental Disabilities Programme is therefore based and resourced within the Division of General Paediatrics and the Developmental Medicine Centre at the Children's Hospital, which runs the following specialist clinics.

Pervasive developmental disorders clinic

It provides interdisciplinary assessments of youngsters with pervasive developmental disorders. Children and their families attend a half-day of assessments at the end of which they are provided with a detailed written report about the diagnosis and management recommendations. Developmental psychiatrists, paediatricians, psychologists and other therapists gather together at the end of the assessments to arrive at a consensus diagnosis and treatment plan, which is then communicated to the parents in a 'feedback' session by one or two of the team members. Further consultation may also be obtained, based on need, by speech and language therapists, paediatric neurology or genetics. Among the children seen in the clinic, several had been receiving early intervention services (EIS) under the auspices of the Department of Public Health (DPH). In Massachusetts, EI programmes are the preferred method of service delivery to children in the first three years of life with either (i) *established risk or established developmental delays* or (ii) *at risk for developmental delays*. They provide a range of services, including occupational, physical and/or speech and language therapy, and include an Individual Family Service Plan (IFSP) with home and EI

programme-based service components. Annually, approximately 8000 referrals are screened statewide for coordinated EIS. A major group of referrals includes children with established risk or established developmental delays, among which are those with autism and pervasive developmental disorders spectrum disorders. A smaller proportion comprise children at risk for developmental delays because of abnormal patterns of maternal or family care, poor health and nutritional care and other social factors (Prizant & Rubin 1999).

Specialist Down syndrome clinic

This specialist interdisciplinary clinic provides follow-up of babies and toddlers with Down syndrome. The clinic benefits from the presence of an advocate who advised parents on available resources and state or federal financial and service entitlements. Medical students and other trainees are given the opportunity to become *buddies* with a family accompanying them around up to six assessment stations during appointments. This particular exercise gives professionals in training a perspective from the consumer point of view in dealing with the hospital system, handling a distressed child with developmental delay and informs them of the parents' concerns and fears.

Other clinics being offered include the 3–6-year team and the lipidoses/mucopolysaccharidoses team, which are run by paediatricians who refer on to child psychiatrists in necessary.

The Commonwealth of Massachusetts: Department of Mental Retardation

The Commonwealth of Massachusetts has a population of 7000000 residents (including the Wampanoag Indian tribe; US Census Bureau, 2000) with an estimated prevalence of developmental disabilities around 4.3%. The rate is higher than that expected because in the United States, developmental disabilities include individuals with intellectual disabilities, pervasive developmental disorders, brain injury and other neurological conditions presented before the age of 22 years and likely to run a chronic course (Developmental Disabilities Assistance and Bill of Rights Amendment Public Law 100-146, 1987).

The state Department of Mental Retardation (DMR) has 29 regional and area offices responsible for running and managing a range of services available to 28500 individuals who are eligible to receive assistance. The departmental budget is approximately \$825 million and supports thousands of employees, 1700 small community residences and 7 developmental centres across the state.

One of the ongoing challenges facing DMR, which has led to lawsuits in federal and state courts, is the wait list for individuals who require social care or community assistance. The number of adults requiring residential care has been steadily increasing over the past 10 years, i.e. from 1769 in 1992 to 3371 in 1998. The increase is mainly because of elderly caregivers being unable to look after their adult children and the increasing numbers of young people leaving special education. Additional ring-fenced budgets for those in the wait list and the school leavers have begun to provide some solution to the complaints and frustration experienced by the service users and their families.

Mental health services for adults with intellectual disabilities

Most psychiatric care is community based but remnants of a custodial past are shown in the presence of the Fernald Centre, which is the oldest publicly funded institution for people with intellectual disabilities established in 1848. Currently, it serves 336 adults with intellectual disabilities.

The recently opened Adult Neuropsychiatric Disabilities Unit based at the University of Massachusetts Medical Centre, Worcester, is a 10-bed locked in-patient unit, which accepts acutely mentally ill patients with intellectual disabilities over 16 years of age for assessment and treatment. Like other in-patient psychiatric units, which are under the influence of medical review by health insurance or Health Maintenance Organizations (HMO) and despite funding support by the state Department of Mental Retardation, is principally focused on acute treatment and short admissions. In order to be admitted, a patient must have an identifiable mental health disorder. Reported problems with this model of inpatient care are repeated hospitalizations (about 6% of readmissions within 30 days), difficulty of the community resources to follow detailed treatment plans, postdischarge and bed blocking (Charlot *et al.* 2002).

A similar privately run unit is now based at the McLean Hospital, Belmont, affiliated with the Massachusetts General Hospital and Harvard Medical School. The establishment of this unit reflects the market need for privately funded services that can conduct evaluation and treatment of patients in the community.

Institute for Community Inclusion (ICI) and the university affiliated programmes (UAPs)

The UAPs were first proposed in the 1962 Report of President Kennedy's *Panel on Mental Retardation*. These federally funded programmes established the creation of interdisciplinary professional training, developed systematic research and recruited scientific manpower aiming at prevention and educational and vocational rehabilitation services for persons with developmental disabilities. There are currently 61 UAPs across the USA.

The ICI based at the Children's Hospital (Harvard Medical School) and affiliated with the University of Massachusetts, Boston, is one of the two UAPs in the state, the second being based at the Eunice Shriver Centre in Waltham.

The ICI has a research budget of over \$20 million focused on projects that explore the conditions of participation of individuals with developmental disabilities in the social system.

It provides high quality training for professionals, offers services to individuals and their families and assists organizations in their efforts to provide better supports to people with developmental disabilities. The ICI has established formal links with many colleges, universities and training programmes that aid the wider dissemination of research findings and interdisciplinary projects. It offers culturally sensitive services to address a broad array of concerns from schools, families and community programmes (Helm 2000). Its unique

focus is on integrated employment services, which assist individuals with developmental disabilities in obtaining and sustaining employment. Job development and onsite supports are a critical goal in creating a match between the individuals with developmental disabilities and their prospective employers.

Comments

The United States has provided significant lead in the community management of people with intellectual disabilities over the past 30 years (Bouras 1987). The Travelling Fellowship has offered A.H. the possibility of visiting facilities for the treatment and for management of developmental disabilities to exchange ideas with colleagues in the field and to attend research and academic seminars at a centre of excellence. The range of facilities available to the children and their families was rather impressive. However, given the system of medical cover existing in the USA, services may be inaccessible to those aged over 3 years who may lack medical insurance. Parents and patients alike were welcoming and willing to discuss their problems. It was interesting to see that parents of very young children would seek help in finding out about the diagnosis of their child.

The Portage system, a comparable home-based early intervention package for parents and preschool children with special needs has been introduced in the UK for many years. However, its use is not as widespread as that in the USA and where one lives may influence the type of services that are available (Sturmey *et al.* 1992; Cameron 1997).

The authors concede that at times there was an uneasy coexistence between the department of developmental psychiatry and its partners in Child Psychiatry, the ICI and paediatrics. This confusion is probably inherent in all services that deal with very young children who have complex needs and their families as their interests are served by many different professional agendas. However, the most important omission appeared to be that of specialists trained to treat and manage adult people with intellectual disabilities, although some with autistic spectrum disorders were followed up by their child psychiatrist.

The differences and similarities between the USA and the UK mental health service systems for people with intellectual disabilities have already been well documented (Gravestock 1993; Bouras & Szymanski 1997). Some of the gaps reported in earlier articles are still present today. For example, there continues to be a lack of trained psychiatrists in intellectual disabilities, and where such expertise is available, training capacity for junior trainees is limited. Efforts are currently being made to consider a change in the use of the term mental retardation, which many service users, advocates and parents or carers find offensive (US Department of Health and Human Services Administration for Children and Families 1999).

Inclusive opportunities for work and leisure and social networks for people with intellectual disabilities were more readily available and embedded in the local service culture. This process is still in its infancy in the UK.

Training of other health professionals, i.e. psychologists, OTs was a particularly strong point within the ICI with many postgraduate students gaining further qualifications within the *Interdisciplinary Leadership Education in Neurodevelopmental Disabilities* course.

The US Department of Health and Human Services has set up an International Committee comprising ‘eleven States, 10 Native American Tribes and two political units from England and Scotland’ with the aim of building robust policies that promote ‘full and life-long community inclusion’ (US Department of Health and Human Services Administration for Children and Families 1999).

The authors believe that international training and educational opportunities are also significant in their own right. In the intervening period, a 2-week international training exchange for Senior House Officers in Psychiatry has been developed between the Psychiatry of Intellectual Disability at University College London, and its counterpart in Boston with generous support by the Camden & Islington Mental Health and Social Care Trust. The first trainee visited Boston in June 2002.

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- ❑ Department of Mental Retardation → Individualised service coordination
  - Flexible family supports
  - Employment services
  - Day services
  - Residential support
  - Collaboration with other agencies
- ❑ Department of Public Health → Early intervention programmes for 1 to 3 year olds with developmental disabilities

Figure 1.

Executive Office of Health & Human Services Commonwealth of Massachusetts.