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Mental Health Services for Adults with Intellectual Disability

Strategies and Solutions

EDITED BY

NICK BOURAS AND GERALDINE HOLT

**SAMPLE
CHAPTER**



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Introduction

Nick Bouras and Geraldine Holt

This book is concerned with the evolution of services to meet the mental health needs of people with intellectual disability (ID), from early deinstitutionalization plans to the implementation of community care 25 years later. The primary focus is on the ways that theories and policies have been applied to clinical practice.

The first plans for deinstitutionalization started in the USA during the early 1960s with John Kennedy's administration, through enabling legislation in the funding of ID services. Parallel initiatives and policies appeared in the UK during the 1970s when disturbing scandals in some long-stay institutions became widely known.

In 1981, the then Guy's Hospital Health District commissioned a development group to plan for local services for people with ID. This followed the decision of the Regional Health Authority to close Darenth Park Hospital in Kent, a large institution with over 1,000 people with ID, serving a wide area of SE London and Kent. The proposed plan included all the components of a comprehensive community-based service for people with ID based on the principles of normalization and attracted a lot of interest from service planners and providers. Its implementation started in late 1982 with the appointment of a multidisciplinary project group consisting of a clinical psychologist, a nurse, a psychiatrist and an administrator.

The first priorities of the project group were to re-provision Darenth Park Hospital with the development of alternative community residential services based on community supported housing. At the same time strong

ideological and political views for services to support people with ID were prevailing in favour of a social care model. The view was that mental health problems of this population would be reduced when community care programmes were in place. With the implementation of deinstitutionalization, meeting the mental health needs of those with ID proved to be a major issue. Thus it became clear that if the plans for community care and support for people with ID were to have any chance of success, a robust clinical mental health service was necessary to meet these needs. In the meantime the pressure was mounting on the project team to respond to referrals of people with ID with mental health problems living with their families for whom the option of hospitalization to a place such as Darenth Park was no longer available.

Many service planners and providers of community care expected that general mental health services would assume responsibility for the mental health problems of people with ID living in the community. General mental health services were, however, entirely unprepared to respond as they lacked knowledge and expertise on the diagnosis and treatment of the mental health problems of this population. In addition, the funding that had been previously used for their mental health care while in institutions was now diverted predominantly towards social care in the community rather than towards health care.

As community services started to develop, Community (Learning/) Intellectual Disability Teams were created with a multidisciplinary composition and multiple functions, ranging from a variety of social care tasks to highly specialist mental health provision. These teams were not equivalent to Community Mental Health Teams, whose focus was the delivery of mental health care to those suffering from mental illness. Instead the Community Intellectual Disability Teams each consisted of a group of professionals expecting to respond to a variety of problems from social care to primary health care and tertiary mental health care.

The development of a specialist mental health service, Mental Health in Learning Disabilities (MHILD), for people with ID was chosen locally and was fully integrated structurally and operationally with the general mental health services. This model was comparable to other specialist mental health services for older adults, children and adolescents, drugs misuse, homeless, eating disorders, etc. The evolution of MHILD service over the past 25 years is presented in Chapter 1, which presents the significant milestones in the development of the MHILD service with reference to a series of national policies introduced during the 1990s and 2000s in England and Wales.

With the acceleration of the closure of the long-stay institutions, the service gap in meeting the mental health needs of people with ID became increasingly apparent across the UK. There has been a proliferation of

policy documents over the past 15 years. Access to general mental health services has been a steady theme of governmental policy for the provision of mental health care for people with ID. Most recent policies recommended that there should be some additional specialist support when it is required, as presented in Chapter 1. The implementation of policy, however, has been unclear, inconsistent and contradictory, with commissioners overlooking the increasing demand posed by the low volume but high financial cost of addressing the mental health problems of people with ID. The function of the Community (Learning/)/Intellectual Disability Teams offered significant support to local services in meeting the generic needs of people with ID such as physiotherapy, speech and language therapy and some forms of challenging behaviours. With such a wide remit, however, and often lacking appropriate skills and resources, many found it highly problematic to respond to the diagnostic and treatment demands of mental health problems, e.g. psychosis and depression of this population. In addition they often lacked links with general mental health services, which operate from different organizational structures. The notion of providing a mental health service through a Community (Learning/)/Intellectual Disability Team seems to be a historical mistake of transferring an institutional model into community care. This contradiction remains and, coupled with strong ongoing ideological arguments as to what constitutes challenging behaviour vs. a diagnosable psychiatric disorder, has led to considerable fragmentation of services for people with ID. Influential policy documents have mixed up mental health problems with challenging behaviour in an attempt to perpetuate social care models, adding to the confusion of commissioning and providing appropriate services as discussed in Chapter 2.

As a result, a large number of people with ID have been placed outside their local area because of the inability of their local services to respond to their complex needs as described in Chapters 1 and 2. This heterogeneous group of people with ID includes many with challenging behaviours. The most complex group are those with usually mild ID and offending behaviour with a forensic history and sometimes coexisting mental health problems. An increasing number of people are also recognized as having an autistic spectrum disorder, for whom neither general mental health nor specialist ID services have been equipped to respond. The issues involved are discussed comprehensively in Chapters 1 and 2.

The MHiLD service attracted considerable interest nationally and internationally, and Chapter 3 highlights some of the collaborations developed over the years with colleagues and partners in Europe, Australia, Asia and United States. Though different countries have unique historical perspectives, national philosophies, various service systems and funding mechanisms, nevertheless the principles of mental health service provision are rather similar. In addition to the developments described in Chapter 3,

collaborative projects have been carried out in service developments, research and training with several colleagues in this country including the Tizard Centre, the Welsh Centre for Learning Disabilities, Universities of Manchester, Lancaster and Birmingham as well as internationally with Austria, Italy, Greece, Canada, Japan and others. MHiLD has also had a long relationship with the National Association for Dual Diagnosis (NADD) in the USA.

The MHiLD service was strengthened in 1999 by the development of the Estia Centre, a joint research and training initiative of the South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry of King's College London. The concept was to combine services, training and research with increasing service user involvement in all these areas. This is described in Chapters 1 and 8. Several health service research studies have been carried out by the Estia Centre and are critically discussed in Chapters 5 and 7. It is very difficult and complex to evaluate and measure outcomes in mental health services, because most of the mental health care changes and reforms are motivated by political and social purposes rather than evidence-based practice. It is difficult to assess changes until defined systems are in place. Initially descriptive studies were performed to allow greater understanding of the access and delivery of newly developed services as well as of the needs of the local population. Controlled studies including randomized trials followed, and the key results are included in Chapters 5 and 7.

In the past few years remarkable advances have emerged in the diagnosis of mental health problems for people with ID. The development of improved reliable diagnostic instruments and methods that have led to this are described in Chapter 4. Some of these have been used routinely by MHiLD in the assessment of people with ID and mental health problems referred to our service over the years.

Interesting findings have also emerged from neuroimaging techniques, particularly in people with autistic spectrum disorders, in recent years. Extensive collaborative research has been carried out by our colleagues at the Institute of Psychiatry, King's College London, and the main results are highlighted in Chapters 5 and 6. In addition, issues on genetic syndromes relevant to mental health problems of people with ID in clinical practice are incorporated in Chapter 6.

Our understanding and knowledge about the psychopathology of mental health problems of people with ID has also improved considerably, as well as our treatment methods. These are all discussed in Chapter 7.

The availability of specialist staff training for those working with people with ID varies significantly in quality, content and style from country to country and within the same country. Professional training for psychiatrists, clinical psychologists, nurses and other care professionals has been

well established in the UK. Most of these specialist training programmes are unique and through regular accreditation monitoring have reached high quality standards, e.g. specialist training for psychiatrists by the Royal College of Psychiatrists. With community care attention focused on training direct support care staff in residential and day facilities, Estia Centre developed a variety of such training programmes for all levels of staff with an emphasis on the mental health needs and related issues for people with ID. These are presented in Chapter 8 together with some evaluative findings. In addition, several flexible training materials in the form of training packages have been produced by the Estia Centre, which can be used by staff groups in their own settings. In addition to the information presented in Chapter 8 on training developments, more details can be obtained from www.estiacentre.org.

The old institutional model of care represented an inclusive system of care providing accommodation, health care including mental health, social care and activities programmes all in one location. The current provision and delivery of care involves several agencies mostly in different settings. This requires a system of coordination of care that is integrated and person-centred. This is not an easy task for people with ID and mental health needs. All partners involved with commissioning and provision of services should ensure that they are well informed about evidence-based practice and as to what the local needs of the population are so as to determine the delivery of service.

An effective mental health service for people with ID should take into consideration the following components as outlined by Bouras and Holt (2009):

- joint social and health services commissioning
- person and carer participation
- involvement of statutory and voluntary agencies
- a baseline needs assessment of the population to be served
- local and national policies
- preferred outcomes
- service specifications
- purchase of services that have the necessary skills to deliver processes that will provide these outcomes
- high level of awareness of mental health issues by direct support staff in residential and day care services
- high level of awareness of mental health issues by primary care staff
- multidisciplinary composition including psychiatrists, mental health nurses, clinical psychologists, behaviour support specialists, therapists and social workers
- ability to provide consultation, assessment and treatment

- provision of community-based interventions
- access to local specialist and generic community and in-patient assessment, treatment, forensic and rehabilitation facilities
- setting in place of monitoring systems, which may include individual and local outcomes, e.g. complaints and incidents monitoring and scrutiny of statistics.

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