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Foundations

Historical and international perspectives of services

Nick Bouras

Introduction

Over the last 25 years we have witnessed remarkable advances in the diagnosis of mental health problems of people with intellectual disabilities (ID) with the use of reliable diagnostic instruments and methods. Our understanding and knowledge on the psychopathology of this population has also improved together with therapeutic interventions. The first and second edition of this book included comprehensive accounts of the historical context for people with ID and mental health problems (Jacobson, 1999; Cumella 2007). This chapter summarizes critically the main points from the above two chapters and adds newly emerged information. Early services for people with ID are briefly presented, while the main historical issues that led to the deinstitutionalization process are discussed. There is a description of the influence of the normalization concept in the development of modern services. Policy initiatives and applied service models for people with ID and mental health problems internationally are highlighted. Perspectives of current and future challenges for people with ID and mental health problems conclude the chapter.

Historical context

Ancient Greeks and Romans believed that ID was a burden on society. Ancient cultures presumed that demon possession caused ID and, similarly, some cultures thought ID was a punishment by God. Early reference to ID dates to the Egyptian Papyrus of Thebes in 1552 B.C. (Harris, 2006). Societies differed in how they conceptualized ID before the 18th century (Harbour and Maulik, 2010). Some early specialist services for people with ID included the founding of an asylum by St. Vincent de Paul in Austria (Barr, 1904/1973); the establishment of a hospital in Cairo, Egypt, in the Middle Ages; a form of group care in 13th-century Gheel, Belgium; and residential programs in the early 17th century in Thuringen, Bavaria, and Austria (Meyers and Blacher, 1987).

In the early 19th century there were inspirational innovations for people with mental health problems and disabilities. Philipe Pinel from 1793 reformed asylum care in Paris, to provide a safe environment, characterized by humane vigilance, planned treatment, recreation and vocational preparation, and the elimination of abuse, chains, and indignities (Scheerenberger, 1983). Another one was the publication of *The Wild Boy of Aveyron* by Jean Itard in 1801, which described how the author had worked with a "feral" boy found

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running in the woods. Itard described techniques, which succeeded in engaging the attention of this boy and enabling him to learn some basic skills (Murray, 1988). Edouard Seguin expanded upon Itard's work (Meyers and Blacher, 1987) and developed more extensive instructional methodology. In the following decades the establishment of educational facilities for people with ID was promoted in the USA and some European countries (Meyers and Blacher, 1987).

In the meantime the growth of institutional care gained pace with the rapid development of asylums in the USA, the UK, and other countries. Many countries began building large, publicly funded institutions to accommodate the growing number of people with ID. In the 20th century the theory of eugenics based on an extension of Darwin's theories to societies as a whole, which were conceptualized as "races" in competition for survival, became prominent (Jacobson, 1999; Cumella, 2007).

After the Second World War the new political consensus emphasized the universality of human rights (the United Nations "Universal Declaration of Human Rights" and the European "Convention of Human Rights"), explicitly extended to disabled people in the later "Declaration of Rights of Disabled People" and the "Declaration of Rights of Mentally Retarded Persons." Within democratic societies, politics became increasingly dominated by the demands for full social inclusion for racial and ethnic minorities, women, and people with disabilities (Cumella, 2007)

In 1950, the National Association of Parents and Friends of "Mentally Retarded Children" formed in the USA to advocate for children and families. The organization, now known as Arc, still provides services, coordinates research, and lobbies on behalf of children with ID and their families. By the 1950s social attitudes towards people with ID had developed towards tolerance and compassion, and financial support was made available for programs for them. In the early 1960s, President Kennedy established the "President's Panel on Mental Retardation" (now the "President's Committee for People with Intellectual Disabilities"), thereby setting a national agenda for policy, research, prevention, education, and services. The Education for All Handicapped Children Act in 1975 secured a free public education for children with ID. In 1994, the United Nations passed the "Standard Rules on Equalization of Opportunities for Persons with Disabilities," providing international standards for programs, policies, and laws for those with disabilities (Harbour and Maulik, 2010).

The World Health Organization's atlas on ID (World Health Organization, 2007) reported data on 147 countries who responded to a survey on ID. Institutional settings continued to be the most prevalent type of available services for people with ID in half of the countries. Results also showed that about 70% of countries have legislation related to ID across the world.

Deinstitutionalization

The deinstitutionalization movement's main aim was to replace the asylums with community services. The emerging use of effective new treatments in the 1950s, legislative initiatives, Kennedy's "Administration of New Frontier" program in the 1960s, changes in public opinion about those with mental health problems and or ID, and governments' desire to reduce financial cost gave impetus to the movement of deinstitutionalization (Bouras and Ikkos, 2013). Parallel initiatives and policies appeared in the UK in the 1970s when some disturbing scandals became widely known for some long stay institutions.



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The movement gained momentum and spread gradually worldwide when it adopted philosophies from the civil rights movement. Families, professionals, civil rights leaders, and humanitarians saw the shift from institutional confinement to local care as the appropriate approach. Concerns, however, and fears were expressed as well, mostly by psychiatrists but also some patients, carers, and other members of the society. Some historians suggest a combination of social policy, antipsychiatry, and consumer activism contributed to the implementation of deinstitutionalization (Eghigian, 2011).

The last 50 years have seen an increased focus on early intervention, community-based rehabilitation, diagnosis, human rights, and legislation, with particular emphasis on deinstitutionalization (Mansell, 2006; Beadle-Brown et al., 2007). Some of the first clinical effectiveness research in this field found that community-based units had better outcomes in terms of behavior and self-care skills (Raynes and King, 1967). Renewed therapeutic optimism led to the increasing recruitment into services for people with ID of clinical psychologists, educationalists, occupational therapists, and therapists, who had less personal investment in maintaining institutions than medical and nursing staff (Cumella, 2007). Deinstitutionalization of people with ID has been probably the largest social policy experiment of our time. Overall, people with ID and their families have benefited, having a better quality of life and more opportunities.

Normalization

The move from institutional care was also promoted by the "normalization" concept first introduced in Scandinavia (Nirje, 1972). It was Wolfensburger's influential writings emphasizing the need to overcome the social psychology of discrimination of disabled people that influenced the development of services for people with ID (Cumella, 2007). Wolfensburger (1991) noted that disabled people suffer disadvantages not only in the form of overt discrimination but also in an unconscious process of denigration. This confirmed to disabled people their inferior and dependent position in society, which they in turn expressed through their behavior, thereby confirming the initial assumptions of their lower status. He proposed that a key objective of services should, therefore, be to enable disabled people to behave in ways that were socially valued rather than inferior, in order to assert their equal status and achieve acceptance by others in society. This involves living in "normative housing within the valued community with valued people," attending the same schools, and being involved in a valued manner in work, shopping, and leisure activities (Wolfensburger, 1991).

Normalization was implemented in various model services, of which the most influential was that of the Eastern Nebraska Community Office of Retardation (ENCOR), which also became known as the "Core and Cluster" program (Menolascino, 1994). This service was led by the pioneer psychiatrist Frank Menolascino under the inspiration of Wolfensburger who was working with ENCOR at that time. This program carried out the adaptation of ordinary houses to provide staff-supported accommodation for small groups of people with ID. The specialized clinical staff also provided direct teaching to caregivers. The program made use of existing community services, including family support services, and integrated job placements, which had been encouraged through liaison with local industries. In the UK, this model inspired the report *An Ordinary Life* (King's Fund, 1981), which came at the moment when changes in social security regulations inadvertently provided an expansion of public funds for resettling people from long stay hospital care



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(Cumella, 2007). Similar policies were adopted gradually around the world, particularly in North America, Europe, and Australasia. The response and attitudes of different societies to people with ID over time has fluctuated in care practices among nations that are consistent with their cultural history and customs.

ID and mental health problems

Until the second half of the 20th century there was little agreement in the professional literature about whether people with ID were susceptible to mental health problems and whether or how treatment should be offered. Research in this field was probably impeded by the eugenic view that mental health problems and antisocial behavior were an inherent characteristic of people with ID. A series of studies in different institutional populations began to estimate prevalence rates for psychiatric disorders and there was recognition that behavioral problems and impoverished institutional environments were very common (Craft, 1959).

Jacobson (1999) noted that instances of coexisting mental health and ID had been described by Seguin as early as 1866. The development, however, of mental health services for people with ID "is largely a phenomenon of the post-modern period. They reflect growth in the financial resources directed via public policy to support and treat people with ID in developed nations during the second half of the 20th century" (Jacobson, 1999).

Service planners and providers assumed that mental health problems for people with ID would substantially diminish when community care programs had been put in place. With the beginnings of deinstitutionalization and the implementation of resettlement programs in the community, the needs of people with ID and mental health problems became evident. Initial longitudinal research indicated the coexistence of ID and mental health problems was a risk factor for reinstitutionalization (Kearney and Smull, 1992). As more and more institutions were closed, people with ID and mental health problems found themselves moving to less restrictive environments, or remaining longer with their families. In such community settings, it became clear that services from both the ID network and the mental health system were required. The provision of the necessary mental health services for people with ID and mental health problems became a major issue in the USA and the UK as community resettlement plans started being implemented.

Strong ideological and political views for services to support people with ID were prevailing in favor of a social care model. However, it became clear that if the plans for community care were going to succeed, a robust clinical mental health service was required. The expectation was that mainstream health services, including mental health, would assume responsibility for the mental health problems of people with ID living in the community. Mainstream psychiatric services were, however, unprepared to respond to the needs of this population, lacking knowledge and expertise on the diagnosis, treatment, and their mental health needs. In addition, the funding for their mental health care from the closure of the institutions was diverted predominately towards social care.

There was a substantial delay before the awareness of the coexistence of ID and mental health problems was converted into public policy. Although mental health clinics for people with ID were established from 1958, in the USA policy-makers were reluctant



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to accept that people with ID needed more than just a uniform and undifferentiated set of services (Menolascino, 1989).

In the 1960s there were continuing signs of psychiatry's schism with ID services. The American Medical Association (AMA) in 1965 reported that very few psychiatric services were serving people with ID and that these were mostly child psychiatric services (American Medical Association, 1965; Jacobson, 1999). About the same time the American Psychiatric Association (APA) issued a statement on ID (American Psychiatric Association, 1966) advocating for integration of ID with community mental health services. The recommendation was that psychiatry should take the lead in these efforts in collaboration with other organizations to develop standards of care and to avoid establishing duplicative services for people with ID and mental health problems. These recommendations were later to be largely realized in the training sequences for medical and mental health professionals provided by university-affiliated programs (Jacobson, 1999).

Menolascino (1989) recommended that services be provided according to need and be delivered in the context of both ID and coexisting mental health problems, allowing for more appropriate treatment, support, service planning, and development. The result would have been a partnership between the mental health and ID service structures to ensure responsive supports and treatments. The term "dual diagnosis" was first introduced by Menolascino but later became synonymous for people with substance misuse and mental health problems.

Similar issues with the USA were experienced in the UK (Day, 1993). The provision of health services for people with ID should be seen within the context of countries' health systems. The National Health Service (NHS) in the UK is funded by general taxation, while in the USA there are various levels of insurance schemes and state and federal funding systems. Another notable difference between those two countries, and probably from the rest of the world, is that in the UK the Royal College of Psychiatrists has a strong faculty of psychiatrists specializing in people with ID and mental health problems. The Royal College of Psychiatrists in the 1970s debated its involvement with people with ID. The outcome was to focus on the mental health problems of this population with the creation of the subspecialty of "Psychiatry in ID" that has contributed substantially to service developments, training, and research. This development, together with specialization of clinical psychology as well as other professions, has played a decisive role in the development of services in the UK for people with ID.

A government report in 1979 in the UK concluded that people with ID had diverse needs, each requiring an array of specialist services (Department of Health and Social Security, 1979). A series of policy reports in the next two decades (Department of Health and Social Security, 1984; Department of Health, 1993, 2001; Lindsey, 1998) proposed various options for how services could be provided. They identified three overlapping groups of people with ID: those with a mental illness; those with severe antisocial behaviors; and those who have committed offenses against the law. The overall position of governmental policy in the UK has been consistently that people with ID should have access to mainstream health services, but with additional specialist (specifically for people with ID) support when needed (Department of Health, 2001).

The argument for the provision of mental health care for people with ID from mainstream services appeared sound and is supported widely (Bouras and Holt, 2004). Some argued that specialized services leads to stigmatization, labeling, and negative professional attitudes. Others argued that special expertise is required for the diagnosis

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and treatment of mental health problems in this population, because, although it is theoretically possible to train staff in mainstream settings, the relatively small number of cases gives little opportunity for staff to gain or maintain the necessary skills (Day, 1999). Problems arise particularly when admissions to adult acute inpatient units occur, as people with ID often require longer admissions, and may be vulnerable without additional support on the ward. Furthermore, people with ID represent a very heterogeneous group with a varied range of highly complex mental health needs.

A wide degree of variation in locations, service mix, financing options, and staffing patterns has been reported among service responses to meet the mental health needs of people with ID. Moss et al. (2000) provided a framework to conceptualize the factors that influence service development in this field. They proposed a variant of the matrix model first described for non-disabled people with mental health problems by Thornicroft and Tansella (1999). The model is comprised of two dimensions, one determined by the level within the service system (e.g., national, local, or individual), and the other by the point in the temporal sequence of service provision (e.g., inputs to the service, the process of providing the service, and the resulting outcome). Using this model to characterize various approaches to service, it is possible to observe that national priorities often vary from country to country and from culture to culture. These differences guide and influence inputs to the service system and, ultimately, affect the way a consumer is served and the service products and outcomes. They also emphasize that inputs to every system at all levels are affected by the need for trained personnel to staff and administer the service.

Davidson and O'Hara (2007) suggested that the characteristics of comprehensive mental health services for people with ID should address the conceptualization of the service system model, using techniques to overcome barriers when there are both conceptual and operational gaps between service systems by establishing interagency communication across systems. Additional characteristics should include consensus among providers, interdisciplinary approach by a team of professionals who can address biomedical, behavioral, and environmental interventions, case management, and supports to families and service users. Community-based with tertiary psychiatric links are also required for an acute crisis and may be provided on a supra-district or regional basis. Training and stable funding are also of utmost importance (Davidson and O'Hara, 2007).

The most common model of services for adults with ID and mental health problems that emerged in the UK is an ID community-based, multidisciplinary (interdisciplinary) team offering assessment and specialist services to people with ID. Initially, most of these teams were involved with deinstitutionalization, carrying out tasks such as identifying appropriately adapted and staffed houses, matching people with ID to live together, assessing health and social needs, and so on. Most of them have input from clinical psychologists and usually some input from a psychiatrist specializing in people with ID. There have been some variations of this approach, mostly related to the interface of these teams with mainstream mental health services and or primary care (O'Hara et al., 2013).

Despite the input from a psychiatrist, such teams have been experiencing difficulties in meeting the mental health needs of people, particularly those with mild ID and diagnosable mental illness. The problems are extended to people with ID who may have additional forensic problems, autism spectrum disorders, including Asperger's syndrome, and comorbid conditions, such as those with borderline intellectual functioning. Chaplin et al. (2010) referred to this model as a "one-stop shop," just as it was in the institutions. Bouras and Holt (2010) stated that the provision of mental health services



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from a specialist Community Intellectual Disability Team was an historical mistake by transferring into community an institutional model of care. This contradiction currently remains and, coupled with ongoing ideological arguments, as to what constitutes challenging behavior versus a diagnosable psychiatric disorder, has led to a fragmentation of services for people with ID in the UK.

The exception to the Community Intellectual Disability Team has been the development of a specialist mental health service for people with ID (MHiID) (also known as mental health services for people with learning disabilities [MHiLD]), fully integrated structurally, organizationally, and operationally with the mainstream (also referred as generic) mental health services. This model is compatible with other specialist mental health services in the UK, e.g., older adults, children and adolescents, drugs misuse, homeless, eating disorders, etc. The MHiID service is one of the longest services in operation, since 1982, based in South East London, providing secondary and tertiary mental health care for people with ID. The evolution of the MHiID service, which first used inpatient beds in a psychiatric unit in a general hospital in the UK, has been well documented. (Holt et al., 1988; Davidson and O'Hara, 2007; Chaplin et al., 2008; Bouras and Holt, 2010; Chaplin et al. 2010; Hemmings, 2010; O'Hara et al., 2013). Other service developments in the UK have also been reviewed in these just-listed publications.

Current research findings on clinical outcomes of different program models for people with mental health problems and ID is presented in Chapter 23. Hemmings et al. (2014) provided an evidence base showing that the way forward is in developing new ways of coworking ID services with mainstream mental health services, including in-community and inpatient settings.

International trends

There has been a growing interest internationally as to how to address the mental health problems of people with ID. Davidson and O'Hara (2007) and Cain et al. (2010) have provided comprehensive reviews of service developments for this population in different countries. The pace and form of change depends on each country's unique historical perspective and national philosophies about care for people with ID. Internationally the trend has been towards the direction of community integration of specialist community ID services with a different degree of inpatient facilities either from mainstream psychiatric services or not. Variation across continents and between services exists on a number of levels. Disparity of service provision also exists between different regions of the same country where local pressures and resources have dictated service developments. These include, service design, care packages, funding streams, commissioning, staffing patterns, and resources (Cain et al., 2010).

Holt et al. (2000) reviewed services for people with ID and mental health problems in five European countries: Austria, England, Greece, Ireland, and Spain. The most common pattern found was a limited number of specialist centers, with the expectation that people with ID and mental health problems will be admitted to mainstream psychiatric services. In some countries, the historical experience of adverse medically dominated institutions led to reluctance among policy-makers to consider any specialist health services for people with ID (Holt et al., 2000). Where emphasis has been on treatment in the community, there was a growing recognition of the need for additional specialist services as well as help to access services. The review concluded that legislation



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and policy in the five countries tended to separate ID and mental health, resulting in unmet needs remaining largely invisible, to the detriment of people with ID and mental health problems, their families, and carers. Similarly, Weinbach (2004) published a condensed overview of service profiles across Europe (including Belgium, England, Germany, Greece, Spain, Sweden, and the Netherlands) in an attempt to describe the systems of care and support available for people with ID. Dosen has written excessively on services in the Netherlands (Dosen, 1988; Cain et al., 2010) and Salvador-Carulla for Spain (Salvador-Carulla and Martinez-Maroto, 1993; Cain et al., 2010).

Davidson and O'Hara (2007) and Cain et al. (2010) have described several services in the USA that have been providing mental health care for people with mental health problems and ID. Early initiatives for these services in our times were pioneered in the USA by the clinical psychologists Johnny Matson and Steve Reiss and the psychiatrists Frank Menolascino, already mentioned in the development of the ENCOR program in Nebraska, and Ludwik Szymanski in Boston. The development of the National Association for the Dually Diagnosed (NADD) founded in 1983 as a not-for-profit association in the USA by Robert Fletcher acted as a catalyst to promote and exchange ideas, principles, and concepts concerning people having mental health problems and ID. The NADD continues having a strong presence worldwide in the field offering training, publications, and professional, carer, and service user support.

The Rochester Crisis Intervention Model in New York has been one of the well-documented services in North America (Davidson and O'Hara, 2007; Cain et al., 2010). Another well-documented service has been the Greater Boston START Model (Systemic, Therapeutic, Assessment, Respite, and Treatment). The START model was first developed and implemented in Massachusetts in 1989 as a linkage model to overcome disparities in access to mental health care (Charlot and Beasley, 2013). The primary function of START teams is to facilitate collaboration between systems and disciplines in order to improve diagnostic accuracy and treatment outcomes. Service elements include an interdisciplinary clinical consultation team, 24-hour emergency services, planned and emergency therapeutic respite services, and ongoing training in the system of care. There are several START programs in the USA with some state-wide implementation and with more in development. Outcomes associated with START include improved access to appropriate services, reduction in emergency service use, and improvements in the quality of community living (Charlot and Beasley, 2013).

Several other services have been described in the USA over time (Davidson and O'Hara, 2007; Cain et al., 2010) but little is known currently in the literature about their fate. Most of these services appeared in the 1990s led by psychologists, nurses, and social workers, with some involvement from a handful of psychiatrists. There has been a growing interest in recent years to services for people with autism spectrum disorders. One such service is the Autism Speaks Autism Treatment Network (ATN) that has associated a large network of hospitals, physicians, researchers, and families in several locations in the USA and Canada (ATN website: http://www.autismspeaks.org/science/resources-programs/autism-treatment-network). Charlot and Beasley (2013) stated that "In spite of improvements in community systems in the US, change has been sporadic and inconsistent from a national policy perspective. Evidence continues that people with co-occurring ID and mental illness are the last and least served in the community. Recent court decisions with regard to the civil rights of these individuals have helped to motivate states to pay closer attention to the system of care and related outcomes."



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In Australia, the term "Dual Disability" was introduced and there have been some specialist mental health services for people with ID that were also reported in some detail by Davidson and O'Hara (2007) and Cain et al. (2010). There are well-established academic units in Australia, e.g., the Centre for Developmental Disability Health Victoria (CDDHV) at Monash University, Queensland Centre for Intellectual and Developmental Disability (QCIDD) at the University of Queensland, and the Intellectual Disability Mental Health at the University of New South Wales. Service provision is also linked with these academic units. Wurth and Brandon (2014) published a 10-year evaluation of the Australian Capital Territory (ACT) Dual Disability Service (DDS) (recently renamed the Mental Health Service for People with Intellectual Disability -MHS-ID), which has been in operation since 2002. Bennett (2014) of the Victorian Dual Disability Service (VDDS) at the Department of Psychiatry at St. Vincent's Hospital in Melbourne has reiterated the need for specialist mental health services for people with ID. Torr (2013) has reviewed the evidence base on mental health for people with ID including services. Trollor, of the academic unit at the University of New South Wales, has reported renewed support from the Royal Australia and New Zealand College of Psychiatrists to reengage in the area of ID, suggesting "Concerted action by government, policymakers, services and practitioners is required if equity of access to mental health services is to be achieved for people with an ID" (Trollor, 2014).

In Hong Kong the Siu Lam Hospital mental health services for people with ID led by Henry Kwok was established in the early 1990s, providing inpatient and outreach services. Within Asia, a survey of 14 countries found a wide variation of services with the type of service relating to wider economic and social considerations (Kwok and Chui, 2008; Kwok et al., 2011). They also reported encouraging developments for children and adults with ID in China. There was, however, a lack of policy to ensure continuity of care or smooth transition from one service to another across the lifespan. Effective implementation of laws and policies remained difficult. They advocated improved coordination, communication, prioritization, and collaboration among government departments, local governments, families, and non-governmental organizations (NGOs) (Kwok and Chui, 2008; Kwok et al., 2011). Similar issues were highlighted by Jeevanandam (2009) for Asian countries, adding the lack of epidemiological studies and evidence-based practices. The lack of policies, poor implementation of plans, low priority, inadequate service provision for people with mental health problems, and ID have been reported by Mercadante et al. (2009) for Latin America, Njenga (2009) for Africa, Adnams (2010) for South Africa, Girimaji and Srinath (2010) for India, Katz et al. (2010) for Mexico, and Ispanovic-Radojkovic and Stancheva-Popkostadinova (2011) for Serbia and Bulgaria.

The issues and dilemmas of the most appropriate services for people with ID and mental health problems have been the focus of important policy documents in recent years. In Canada, in *Moving Forward: National Action on Dual Diagnosis*, the National Coalition on Dual Diagnosis stated that:

Mainstream mental health services have not welcomed people with a dual diagnosis and have not served their needs well. Further, mental health professionals generally do not have the expertise to diagnose or treat them effectively. Today, mental health and developmental services continue to live in separate worlds with separate cultures (National Coalition on Dual Diagnosis, 2011).

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In Ireland, the National Disability Authority made clear in a detailed report that:

Persons registered with a mainstream ID service provider find it even more difficult or impossible to gain access to appropriate mental health services for assessment, treatment or continuing care. The difference in experience arises mainly because of policy confusion. Service delivery should largely focus on specialist multidisciplinary teams who are dual trained in ID and mental health. Regional units, geographically distributed, must be available to support community teams by providing specialist acute assessment and treatment for the dual diagnosis group. Full consideration to staffing issues is required in order to ensure a stable and sustainable service, supporting the highest standards of care, and providing a rewarding career for those in the services. The need for these services is growing, and provision should be addressed as a matter of urgency (National Disability Authority, 2013).

The Royal College of Psychiatrists (2012, 2013) published documents reiterating that:

Each organization providing ID and mental health services should have protocols or practices in place to meet the mental health needs of adults with mild ID, jointly agreed between services for people with ID, adult mental health services and Local Authorities. Clinical and non-clinical managers of ID services should ensure that the needs of this group are on the agenda of the local bodies responsible for the development of mental health services.

Conclusions

Service models for people with mental health problems and ID have emerged following successful deinstitutionalization programs. The current trends are geared towards community integration schemes with service users' participation at all levels, including design and implementation, with a person-centered approach. Those commissioning services need to determine what services are needed locally and to decide how they should be provided, monitored, and reviewed. This chapter provides an historical overview of service developments within an international policy context. In spite of some progress, services for people with mental health problems and ID remain underdeveloped. There has been considerable debate as to whether specialist mental health services for people with ID services should be established, or whether mainstream mental health services should serve this population. How specialist mental health services are provided has changed along with key developments, including detection and identification of mental health problems, and a better understanding of therapeutic interventions. The need for specialist services has been recognized as it has become clear that mainstream mental health services, particularly inpatient wards, are unable to cater for all of those with ID. Many reasons have been given for this at a clinical level, including complexity of presentation, the need for more detailed or specialist assessment, and issues of vulnerability. Whatever strategy is undertaken, it should be based on high professional standards and the evidence base.

Over the last two decades, people with ID in many parts of the world live outside of institutions, with families in local communities, and with increased expectations. There is an increasingly diverse population of mild ID, with more complex comorbidity and increased age expectancy. This, along with the issues of ethnicity and gender, has meant the need for services to respond to the needs of ever-changing local communities is now greater than it has ever been. It is the view of the author of this chapter that mental health services for people with ID are due for a major reshape as we have entered the "post-community era."