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Psychiatry of Intellectual and Developmental Disability in the US: Time for a New Beginning

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Abstract

Although psychiatry in the United States owes its origins to the treatment of persons with intellectual disabilities (ID), over the past 50 years, clinical services, education of professionals and research in psychiatry of ID have consistently lagged behind other fields in psychiatry. The historical and contemporary reasons for this development are discussed with recommendations for establishment of a fully credentialed subspecialty of Psychiatry of Intellectual and Developmental Disabilities in the United States.

Keywords

Psychiatry; Intellectual Disability; Mental Retardation; Education; Research; Training; United States

Introduction

In the same year that DSM-III was published (American Psychiatric Association, 1980), Julius Richmond, then Surgeon General in the President Carter Administration, reported on the remarkable achievements in addressing the needs of citizens with intellectual and developmental disability (ID/DD) in the United States. Major advances had begun in the preceding two decades, beginning in 1961 with the establishment of the President's Panel on Mental Retardation by President Kennedy at the urging of his sister Eunice Kennedy Shriver. Subsequent benchmark legislation in 1963 led to a further impetus for development of a national plan and programs to fight ID. Richmond observed, "*For the first time in our history, the Federal government committed the resources of the nation on a large scale to enhancing the well-being of some of its least fortunate citizens*" (Szymanski, Tanguay, 1980).

In the intervening 50 years, there has been a dramatic amelioration of the life circumstances of persons with ID/DD in the United States, with improvements in inclusionary education, assisted employment, housing, and recreational opportunities. The National Association for Persons with Developmental Disabilities and Mental Health Needs (NADD), established in 1983, has provided a national and international forum for mental health professionals to exchange evidence-based knowledge on mental health issues. NADD has also recently published a Diagnostic Manual on Intellectual Disability (DM-ID) (Fletcher, Loschen, Stavrakaki, First, 2007) with involvement of key leaders worldwide in order to disseminate more accurate DSM-IV-TR (American Psychiatric Association, 2004) diagnoses in persons

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with ID/DD. Despite these achievements, mainstream interest among psychiatrists in the United States has remained low. For optimal care of persons with ID/DD, psychiatrists need to contribute as members of interdisciplinary teams and dissemination of knowledge in the training of mental health professionals is of paramount importance (Bouras, 1999). Through specific committees, both the American Psychiatric Association (APA) and the American Association of Child and Adolescent Psychiatry (AACAP) have regularly published assessment guidelines and evidence-based practice parameters for the care of persons with ID/DD. There is therefore recognition of the duty of psychiatrists to respond to the mental health needs of persons with ID/DD. There is also consensus on the lack of training in ID/DD. Almost 20 years ago, an important APA Task Force on Psychiatric Services to Adult Mentally Retarded and Developmentally Delayed (1991) had also underscored the shift in care from institutions and the importance of training psychiatrists to address the needs of persons with ID/DD in their community. Nevertheless, the status of practice, training and research in psychiatry of ID/DD remains unplanned, especially compared with the current situation in the UK, Ireland, Canada and Australia, each with formal Sections on Psychiatry of ID/DD with credentialing requirements for subspecialty training and regionalized community care.

The existence of separate service structures in mental health and ID/DD in the United States presents important challenges in addressing the mental health needs of persons with ID/DD. Responsibilities remain diffuse, resulting in fragmentation and deficiency in services (Freedom Commission, 2006; Fletcher, 1999; Leismer, 1989). The prospect for establishing formal subspecialty training track in psychiatry of ID/DD in the United States, at best, is a work in progress. The residency training programs currently provide part-time rotations in ID/DD predominantly to help build capacity and confidence among trainees and to satisfy overall certification needs by the Accreditation Council for General Medical Education (ACGME). When exposed to persons with ID/DD, the trainees consistently value their clinical experiences as being formative, yet many are unable to pursue post-residency practices involving persons with ID/DD (Ruedrich et al, 2007).

First, I discuss the historical development of two mutually exclusive ID/DD and mental health care systems in the United States beginning with the Kennedy era reforms. Second, I consider a number of historical and contemporary contributing factors that maintain the status quo for a lack of an organized training in psychiatry of ID/DD. Underlying historical legacy include lack of interest and training in ID/DD, view of ID/DD as being static, and influence of psychoanalysis in psychiatric training. Underlying contemporary factors include the lack of a developmental perspective in DSM-III, difficulty in integrating psychiatry within an interdisciplinary framework, difficulty in integrating psychiatry within a fragmented care system, and lack of incentives for training of psychiatrists in ID/DD. An organized subspecialty in psychiatry of ID/DD can help rectify this lack of convergence.

Renaissance Period in Intellectual Disability

The renaissance of interest by parents and professionals in the 1960s represents a uniquely American era of optimism leading to the establishment of the foundation of programs many of which have endured to this day. The story of this achievement in great part is due to the “love between two sisters and their brother, and a drive to help others” (Dombley, 2009). According to Eunice Kennedy Shriver, it was the influence of her older sister Rosemary that sensitized Jack (who was 3-years old when Rosemary was born) to the problems of “vulnerable and weak people” (Dombley, 2009). Many of his biographers, she argued, had not truly appreciated the impact on the President of being a brother of a person with ID/DD. Eunice led a lifetime of advocacy for those with special needs. The small day camp she established on her Maryland estate eventually led to the establishment of the Special Olympics that now involves the participation of three million athletes in 150 countries (Nilsson, 2009).

Eunice had started her journey by first directly addressing the issue of stigma facing persons with ID/DD in society. In her article published in the *Saturday Evening Post* (Shriver Kennedy, 1962), she wrote: *“We are just coming out of the dark ages in our handling of this serious national problem. Even within the last several years, there have been known instances where families have committed retarded infants to institutions before they were a month old and ran obituaries in the local papers to spread the belief that they were dead. In this era of atom-splitting and wonder drugs and technological advance, it is still widely assumed—even among some medical people—that the future for the mentally retarded is hopeless.”*

Second, Eunice had called into question any similarities between persons with ID/DD and those with mental illness. She wanted to dissipate any fear others may bear in working around persons with ID/DD. *“The vast majority of the mentally retarded are not emotionally disturbed”* she added, *“They simply lag behind in their intellectual and physical skills, usually from birth. They often strike people as odd in their behavior because the mind of a small child inhabits the body of a much older person.”* Again, in Eunice Kennedy Shriver’s words, *“Rosemary was born September thirteenth at home—a normal delivery. She was a beautiful child, resembling my mother in physical appearance. But early in life Rosemary was different. She was slower to crawl, slower to walk and speak than her two bright brothers”*.

Third, Eunice recognized the obstacles not only Rosemary but also all children faced. She spoke of the need for better training, and the opening of job possibilities for mentally challenged adults. She also spoke of the need for a healthy community to address the issue (Nilsson, 2009). *“To our surprise and consternation we found out that most doctors and scientists, like the general public, considered mental retardation a hopeless field for research. Established research scientists saw little connection between their studies and mental retardation. Young researchers wanted to do cancer or heart research and get dramatic results... We decided to bring the mountain to Mohammed by endowing or building research laboratories in places where ‘our’ problem could not be hidden from the Nobel prizewinners, the young researchers or any other men with ideas.”*

Finally, Eunice concluded her article on need for advocacy, *“To transform promise to reality, the mentally retarded must have champions of their cause, the more so because they are unable to provide their own.* The stage was therefore set for a new future that was to involve not only the dismantling of institutions in which persons with ID/DD were then housed (she referred to these as “medieval prisons”), but the recognition of their individual hidden talents, their need for recreation and their ability to hold down jobs.

New Conceptualizations of ID/DD

As also underscored by Frank Menolascino in his landmark textbook on *Mental Illness in the Mentally Retarded*, improvements in the diagnosis, treatment, and management of ID/DD was paramount during this era of national commitment to service, research, training, as well as social and educational policy (Menolascino, Stark, 1984). The gains for persons with ID/DD were multi-faceted. These advances reflected a fresh outlook on conceptualizations of viewpoints such as the concept of normalization (Wolfensberger, 1972), as well as a developmental approach (Zigler, 1969). A foremost achievement was the establishment of programs and legislative supports to endorse every child’s “right to education” and extension of that right specifically to children with ID that explicitly were to be accommodated (until age 22) in a least restrictive educational environment. This remains as the single most important strength of the care of persons with ID/DD in the United States. These programs were later expanded to include vocational training, achievement of gainful employment, and supports for establishment of independent living.

The Divide Between ID/DD and Psychiatry

Historically, many of the ID/DD services situated within mental institutions were seriously neglected. The reform movement provided a unique political will for establishing new roles and responsibilities of various agencies in addressing the complex interdisciplinary needs of persons with ID/DD; psychiatrists were no longer to play a primary role. There was also a deep divide between educators, psychiatrists and research scientists attracted to the newly established ID/DD centers. The educators viewed the “medical model” as low-quality institutional care mostly under the supervision of psychiatrists who they felt showed little interest in treatment of persons with ID/DD because they considered them incurable (Cooke, 2006). They felt that that many of the problems could be addressed through newly funded educational programs. The dispute between educators and medical professionals almost derailed the reform movement but was resolved with the intervention of Eunice Shriver Kennedy, who also served as honorary advisor to the President’s Panel on Mental Retardation.

In subsequent years, the integration of psychiatry within the medical model in the care of persons with ID/DD remained elusive. The network of national ID/DD centers did not embrace psychiatry, now only represented in a handful of programs. Nonetheless, it was also difficult to find psychiatrists with professional training in ID/DD. A premise of the new framework was to synthesize all available knowledge, skill sets, and techniques to solve problems; the integration of psychiatry within such an ID/DD interdisciplinary model was challenging. To add fuel to fire, legislation treated persons with ID/DD and mental illness separately. However, this was not the entire dilemma in the inability of reform movement to address the mental health needs of persons with ID/DD.

Contributory Factors Hindering Development of an Integration of ID/DD and Mental Health

There were number of other contributory factors that hindered the development of an integrated approach to ID/DD and mental health. First, only a handful of psychiatrists, based on leading centers across the US, were interested in carrying the mental health torch within ID. Second, was the development of a new classification inherent in the DSM-III that coded ID on Axis II and did not emphasize the importance of co morbidity between various mental conditions (axis I) in persons with ID. Lacking a developmental approach, many mental conditions were treated as predominantly occurring in adult years, as acute, episodic, discrete conditions, with disregard of developmental origins (Munir, Beardslee, 1999; Hassiotis & Munir, 2004). Later editions, DSM-III-R in 1987, DSM-IV in 1994, and DSM-IV-TR in 2004, continued this viewpoint in characterizing mental conditions as offshoots of adult ones. Third, has been the emphasis on psychopharmacology as a predominant pragmatic form of intervention in the United States with much less incentives in the public mental health system for such services in the care of persons with ID/DD and therefore less opportunity to interface with them.

Although the DSM-III had worldwide impact, its effects on postmodern origins of psychiatry of ID in the UK, Europe, and Australia was not as paramount. Psychiatry of ID in these countries became a credentialed subspecialty. The influence of DSM-III may have been a contributory factor in blinding psychiatrists to ID/DD problems in the United States, but certainly was neither necessary nor sufficient explanation for the lack of progress in establishment of psychiatry of ID/DD. It is therefore also important to look elsewhere for further explanations as to why a subspecialty in psychiatry of ID/DD could not take root in the United States. As proposed by Szymanski and Bouras (1996), the “*care of persons with ID is a reflection of the society of the time – its values, economic and political climate, and attitudes toward those who are not fully independent.*” The major conceptual advance that involved normalization referred to making available to all citizens with ID/DD “*patterns and norms of everyday life which are*

as close as possible to the norms and patterns of the mainstream of society” (Nirje, 1969). This concept was not intended for those facing discrete DSM-based disorders. The subsequent advance involving inclusion referring to integration of persons with ID/DD in education, employment, and independent living settings, likewise faced a similar category problem. This was not a major concern for psychiatry focused on gaining legitimacy in defining and measuring mental conditions reliably during this period. Many of the gains in the interdisciplinary environment for care of persons with ID were in terms of educational, medical diagnostic, treatment and research programs. Although treatment of mental conditions was to be flexibly accommodated the establishment of divergent tracks between ID/DD and mental health for community programs also led to competition for resources between them, making convergence impossible.

Current Issues

There remains a general lack of psychiatric expertise within the ID/DD systems. Whereas many of these systems would have a psychiatrist as a consultant as a full-time employee, in most states this is no longer tenable. Many ID/DD systems currently do not acknowledge mental health needs of their patients and ascribe most problems to behavioral or intellectual deficits rather than emotional needs such as depression and anxiety. Concomitantly, there is a general lack of knowledge on ID/DD expertise within public mental health systems but more states are developing some local specialized services within mental health providers, although often these tend not to be psychiatrists. Even where mental health clinical services are offered to patients with ID/DD, as with other issues, coordination of care between systems is either very poor or nonexistent.

There is a lack of capacity in mental health systems to provide counseling services to persons with ID/DD. Instead, the both the emphasis and expertise lies in prescribing psychotropic medications or behavioral interventions. With mental health services generally, there is increasing emphasis, if not actual services on community versus institutional care. Again, with mental health services generally, there is increasing emphasis on integration of physical and mental health care but, to date, less focus on this in professional or clinical ID/DD practice, even though it is more likely to be of greater need in the ID/DD population.

There is increasing concern and growing advocacy against use of seclusion and restraint procedures. As with mental health generally, there is increasing emphasis, if not actual change in practice, on engaging family and “natural” supports. There is an important need for greater understanding by mental health professionals working with people with ID/DD, on issues related to transition to adulthood and concomitant need to not practice in a vacuum but in conjunction with school and community resources. With the increasing emphasis on consumer direction and control of health and social services (either through funding control or involvement of service brokers) how do mental health professionals working with people with ID/DD deal with these movements and enhance them as desirable social policy? This requires additional planning in organization of mental health systems.

Future Directions

There is a need for establishment of fully credentialed subspecialty of psychiatry of ID/DD in the United States. First, training in psychiatry of ID/DD has to be bolstered both within general and child and adolescent psychiatry training programs that can offer training tracks in psychiatry of ID, with combined exposures to medicine (or pediatrics), neurology, and genetics. In addition, trainees need to develop expertise in working within the interdisciplinary framework that involves colleagues in psychology, education, speech and language pathology, occupational therapy, physical therapy, audiology, vision, and assistive technologies. In addition, mentored-research experiences can be integrated to such subspecialty training as has

been emphasized by the Institute of Medicine (Abrams, Patchan, Boat, 2003) recommendations for the overall residency training experience. How such training in psychiatry of ID/DD can be configured within the current structures remains to be determined. It is clear that, without the development of an additional subspecialty track, this goal cannot realistically be achieved given the service obligations currently inherent in psychiatric residency training. Nevertheless, irrespective as to when such a subspecialty track in psychiatry in ID/DD can be instituted, there is an urgent need in the interim for a more systematic approach than currently exists in bolstering the expertise of psychiatrists in ID/DD.

Such experiences may require trainees to have more exposure to ID/DD in coordinated medical, genetics, and neurology settings. Finally, especially in the community and natural contexts, psychiatrists need to focus less on impairment and barriers and more on strengths, coping mechanisms, external supports, and self-direction, and self-efficacy in learning to care for persons with ID/DD.

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