

# International Encyclopedia of Rehabilitation

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*This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A050008. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.*

# **History of Intellectual Disability**

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Intellectual disability (ID) or mental retardation is one of the most common disabilities. Braddock and Parish (2002) have defined disability as socially determined interpretation of impairment by others. Thus the whole concept of ID and how to define or categorize people with ID (PWID) has been affected by how people in different cultures and in different periods of time have defined it and understood it. Rehabilitation of PWID has similarly been affected by changing concepts and attitudes. The following discussion of the history of intellectual disability (ID) relies on documents published in English, and consequently focuses more on the history of ID in English-speaking countries – particularly the U.S. – than on that of other regions of the world. Our objective was to describe coherently one populous country's history with reference to other countries' histories, rather to try to describe fully the experience of several countries. Furthermore, historical accounts and policy changes towards PWID are available to the largest extent from the U.S.

## **Early history**

The earliest reference to intellectual disability dates to the Egyptian Papyrus of Thebes in 1552 B.C (Harris 2006). The ancient Greeks and Romans felt that children with ID were born because the gods had been angered. Often children with severe ID would be allowed to die of exposure as infants rather than permitted to grow up. However, the Romans did allow some form of protection to children with ID who were born to the wealthy, by allowing PWID property rights and allowing them to have guardians (Harris 2006). Before the 18<sup>th</sup> century, societies differed in how or whether they conceptualized intellectual disability. Those with mild ID who were socially competent received no special identification or treatment, and those with more severe conditions probably received protective care from their families or in monasteries. Some societies considered people with more severe ID to be capable of receiving divine revelation (Beirne-Smith et al. 2006; Harris 2006).

The first systematic and documented program of intervention for ID was developed in France in 1799. Jean-Marc Itard, a medical doctor, developed a skill-based program for a feral child he named Victor. Eduoard Seguin took Itard's methods further and established a systematic program to educate the "feeble-minded" at Salpêtrière Hospital in Paris. Seguin's program emphasized "physiological and moral education" and some of its elements, like individualized instruction and behavior management, are still practiced. Seguin emigrated to the U.S. and in 1866 published an influential reference book, *Idiocy and its Treatments in Physiological Methods*. Johann Guggenbühl established the first known residential facility for PWID in 1841 in Switzerland. The facility was called Abendberg, and during its tenure it received

international attention, creating a “prototype for institutional care” (Beirne-Smith et al 2006).

### **Early years of rehabilitation & reintegration**

In the U.S., through the early and mid-1800s, optimism prevailed for the chances of rehabilitating, training, and reintegrating PWID into “normal” life. Several reformers influenced the field. Dorothea Dix advocated improving treatment of people housed in asylums, poorhouses, country homes, and almshouses in the mid-1800s. Samuel Howe directed the Perkins Institution for the Blind in Boston, and in 1848 he established the first public training facility in the U.S. for PWID within a wing of the Institution. In the same year, in Barre, Massachusetts, Hervey Wilbur established in his home the first private institution for PWID (Beirne-Smith et al. 2006).

### **Segregation, eugenics, and institutionalization**

As the U.S. population became more urbanized in the latter half of the 1800s, the century’s early optimism about the curability of ID waned. People with more severe ID were less able than those without ID to adapt to an industrializing, urbanizing nation where employment increasingly depended on intellectual ability and less so on physical ability. Furthermore, the progressives’ ideal of training, rehabilitation, and reintegration proved to be disillusioned: people could learn skills but did not attain “normalcy.” The systematic programs that had proven successful were diluted and more residential institutions were established. PWID, called “feeble-minded,” were blamed for the poverty, illness, and crime that accompanied urbanization, and a fearful, alarmist attitude toward PWID developed. Criminal behavior and ID – as well as mental illness, tuberculosis, prostitution, poverty, and slums – were thought to be heritable. Consequently, great attention was focused on eliminating the possibilities for PWID and others to reproduce so as to select out heritable traits that were undesirable (Beirne-Smith et al. 2006; Radford 1991; Reilly 1987).

Sir Francis Galton, a cousin of Charles Darwin, published *Hereditary Genius* in 1869, which established a theoretical basis for the heritability of ID and provided a foundation for the eugenics movement (Beirne-Smith et al. 2006). The eugenicists concluded that nature (not characteristics of nurture, like poverty, education, or nutrition) determined personality and intellect, so breeding must be managed to prevent the degeneration of the human species (Radford 1991; Bachrach 2004). Two popular books reinforced the social myth of heritability and ID. In 1877, Richard Louis Dugdale published *The Jukes: A Study in Crime, Pauperism, Disease and Heredity*, and in 1912, Henry Goddard published *The Kallikak Family: A Study in the Heredity of Feeble-Mindedness*, which presented five generations of family pedigree to prove the heritability of “feeble-mindedness.” Goddard subsequently published a study of immigrants to the US which concluded that many of them were “feeble-minded” (Beirne-Smith et al 2006). Those who supported the eugenics movement felt that medicine interfered with Darwinian natural selection and kept the weak alive. They felt that mentally retarded and mentally ill people were reproducing faster than valuable productive people and that they were responsible for escalating costs of schools, prisons, hospitals, and special homes (Bachrach 2004).

In response to the eugenics movement, several U.S. states enacted sterilization laws, notably Indiana, Virginia, North Carolina, Georgia, and California (Sofair and

Kaldijian 2000). Indiana passed the nation's first sterilization law in 1907 for (among others) "imbeciles" who had been diagnosed as "unimproveable" (Reilly 1987). By 1944, 30 states had sterilization laws (Sofair & Kaldijian 2000). The U. S. Supreme Court upheld the states' sterilization laws in the legal case *Buck vs. Bell* (1927), although subsequent research found that many of those sterilized had not in fact been intellectually disabled (Reilly 1987). Between 1907 and 1944, more than 42,000 people were sterilized in the U.S., over half of them in California, in an attempt to eliminate the presumed genetic sources of diseases including feeble-mindedness (Radford 1991). Another 22,000 sterilizations were performed in 27 states to prevent ID and other conditions thought to be heritable between the years of 1943 and 1963 (Sofair and Kaldijian 2000).

In Britain, the Mental Deficiency Act of 1913 emphasized segregation of males and females over sterilization and remained in effect until 1959. Unlike practitioners in the U.S., British practitioners preferred to implement educational programs for PWID. British practitioners used a social definition of mental deficiency as those people who could not fit in to the modern world, not an intellectual definition based on psychological testing (Radford 1991; Reilly 1987). In Germany, the Nazi government's espousal of eugenics led to the 1933 compulsory sterilization law, under which people with "congenital feeble-mindedness" – a very subjective diagnosis – could be forcibly sterilized (Bachrach 2004; Sofair & Kaldijian 2000).

Beginning in the late 1800s and early 1900s, PWID and others were segregated into institutional settings so as to protect "normal" society from them and to control their reproductive lives. The most common method of controlling reproduction by PWID was segregation in the U.S., Canada, and Great Britain, through limitations on marriage, immigration controls, sterilization, and, most importantly, custodial institutionalization (Joseph 2005; Radford 1991; Reilly 1987). "Custodial institutions were most importantly the means by which the feeble-minded were removed from a society in which they were perceived as a genetic threat and placed in isolated environments, completely segregated by gender" (Radford 1991). "The specialized custodial institutions for the mentally deficient were essentially manifestations of eugenically-driven social policy" (Radford 1991). The "colony house" concept was a type of large institutional agricultural development where patients raised food for consumption within the institution and also for sale outside the institution. Examples of colony houses are Vineland in New Jersey and Howe Farm in Massachusetts (Radford 1991). Within institutions "feeble-minded" men and women were kept strictly apart, and thousands were sterilized. Medical literature supported sterilization in the early 1900s and as late as 1942, some respected medical professionals in the US even advocated "euthanasia" of "idiot" children so as to avoid passing on their genes and to reduce their costs to society (Joseph 2005; Reilly 1987).

## **Psychological testing**

The development of psychological tests beginning in the early 1900s acted as a double-edged sword. While it improved identification of PWID, it also contributed to increased institutionalization. In 1905 Alfred Binet and Theordore Simon developed a test for identifying French schoolchildren who were thought to be in need of special services (Beirne-Smith et al. 2006). Robert Yerkes developed intelligence tests for the U.S. army, which used tests during World War I and II in hopes of efficiently assigning personnel (Radford 1991; Beirne-Smith et al. 2006). Testing made

intellectual disability seem more prevalent, since it identified mildly disabled people who would otherwise not have been given a diagnosis (Beirne-Smith et al. 2006). Psychological testing and research in eugenics spurred the development of qualitative methods in social sciences in Britain and in the U.S. (Radford 1991).

Assessments like the Vineland Social Maturity Scale (VSMS 1935) and the Wechsler Intelligence Scale for Children (WISC 1949) were first developed in the 1930s and 1940s. The eugenists were very concerned to identify “feeble-minded” people who lacked a medical diagnosis or physical stigmata, and child educators had the responsibility to pick them out while still children, before they reproduced (Radford 1991).

## **Research refutes heritability of ID**

In 1928, research by Penrose and contemporaries revealed multiple etiologies for mental illness including ID, refuting the single-cause explanations that had been common and that eugenics sought to eliminate (Radford 1991). In the 1930s and 1940s, non-genetic factors such as metabolic disturbances or PKU (phenylketonuria) and environmental factors, such as infection, trauma, and endocrine disturbance, were recognized as having an association with ID. Studies of institutionalized individuals found that more than half of them had parents without intellectual disability, casting doubt on the heritability of ID (Beirne-Smith et al. 2006). In 1930 neurologist Dr. Abraham Myerson showed that the “feeble-minded” were born in approximately the same proportions in all segments of society, and were not concentrated in the lower classes as the eugenists had suggested (Reilly 1987). A report of the Committee of the American Neurological Association for the Investigation of Eugenic Sterilization in 1935 noted that the increased number of mental patients was related to the improved treatment possibilities available, but did not indicate an increased prevalence of mental illness in the general population. The report also recommended voluntary eugenic sterilization for conditions including familial feeble-mindedness (Reilly 1987; Sofair & Kaldjian 2000). According to the Hardy-Weinberg principle, rare recessive genes cannot effectively be selected out of a population because most of the genes persist within a population who do not express the gene; despite this, many geneticists supported eugenics (Sofair 2000). Social policy “continued to reflect deterministic and largely inaccurate hereditarian views of mental deficiency until after World War II” (Radford 1991). The Catholic Church effectively opposed eugenic sterilization in Germany and in the U.S., and the Holocaust also helped to discredit eugenics practices (Bachrach 2004; Sofair and Kaldjian 2000; Reilly 1987). Institutionalization and sterilization of PWID in the U.S. continued through the 1930s, but by the early 1960s most state sterilization programs had ended (Reilly 1987).

## **Legal protections and services for PWID**

Throughout the 20<sup>th</sup> century, federal and local legislation in the U.S. codified rights and mandated services for disabled people, eventually including the intellectually disabled. Even before the advent of widespread mental testing, a special class for people with intellectual disability was established in Providence, Rhode Island in 1896. In 1911, New Jersey mandated that education be provided for students with intellectual disabilities (Beirne-Smith et al. 2006). The Vocational Rehabilitation Act, passed in 1920 after wounded soldiers returned from WWI, provided training and protected the rights of people with disabilities. The Social Security Act (1935)

signalled a more supportive attitude towards people in need. In World War II mental testing was again employed for military purposes and again people experienced disability as soldiers returned home (Radford 1991; Reilly 1987).

In 1950, the National Association of Parents and Friends of Mentally Retarded Children formed to advocate for children and families. The organization, now known as Arc, provides services, coordinates research, and lobbies on behalf of children with ID and their families. By the 1950s social attitudes towards PWID had developed towards tolerance and compassion, and financial support was made available for programs for them. By 1952, 46 of the 48 states had enacted legislation for educating intellectually disabled children, although severely and moderately disabled children were excluded from these benefits.

In the early 1960s, President Kennedy established the President's Panel on Mental Retardation (now the President's Committee on Intellectual Disabilities), thereby setting a national agenda for policy, research, prevention, education, and services. President Johnson's War on Poverty and establishment of Project Head Start sought to address some of the environmental causes of intellectual disability. In the 1970s and 1980s, legislation and litigation, including the 1973 reauthorization of the Vocational Rehabilitation Act, broadened the extent of services offered and mandated for people with ID. The Education for All Handicapped Children Act (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.

## **Deinstitutionalization and global perspectives**

Around the world, the last four decades have seen an increased focus on early intervention, community-based rehabilitation, definition and diagnosis, human rights, and legislation, with particular stress on deinstitutionalization (Beadle-Brown et al. 2007). Current research on institutionalized PWID finds that institutional settings can dehumanize residents, and that quality of life, adaptive behavior, and choice-making improve when people with ID move out of an institution (Beadle-Brown et al. 2007). The concept of "normalization" was introduced in Scandinavia in the 1950s, and suggests that people with ID should have access to supports so that they can experience patterns and conditions of everyday life that are as similar as possible to those of mainstream society (Beirne-Smith et al. 2006).

Since the mid-1980s, the trend in the U.S. has been for individuals with ID to live in inclusive community settings, with appropriate supports to facilitate their experience. In the 1980s and 1990s, the number of children diagnosed as intellectually disabled has dropped, partly as a result of increased early intervention, and also because of a more cautious professional outlook on definition and diagnosis (Beirne-Smith et al. 2006). The institutionalized ID population has also declined in England, Canada, and Norway, and no one in Sweden lives in an institutional setting. In Australia and Ireland, institutionalization has declined, but both countries still have substantial portions of their PWID housed in institutions (Beadle-Brown et al. 2007). Germany, Spain, the Netherlands, Greece, and Belgium have begun deinstitutionalizing ID but institutional care continues to dominate. Deinstitutionalization is just beginning in countries including France, Poland, Romania, Hungary, and the Czech Republic, and

many PWID live in poor quality group settings (Beadle-Brown et al. 2007). Despite its wealth of trained mental health professionals, Argentina continues to institutionalize a large proportion of its people with mental disabilities including ID (MDRI 2007). Transitioning PWID from institutional settings to community settings requires attention to many things, including appropriate housing and co-residence selection, negotiation of staff needs with service users' needs, organizing a culture of engagement in the home and in the community, and focus on quality of life (Beadle-Brown et al. 2007).

The World Health Organization's Atlas on ID (WHO 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 PWID in half of the countries. Surprisingly, institutions for PWID were less prevalent in low and high income countries compared to the middle income countries of the World Bank income groups. While for high income countries it represents deinstitutionalization, for low income countries it probably is an absence of institutions for PWID in the first place, and involvement of other social welfare and educational setups. It could also represent an absence of specific data. Results also showed that about 70% of countries have legislation related to ID across the world with the African Region having such legislation in only 60% of its countries. Frey (2008) comments that "information on Latin Americans with ID is almost nonexistent." However, legal protections are in place in most Latin American countries. Mexico for example has established community-based services in federal law, although enforcement is lacking (Frey 2008). The Atlas reported that about 60% countries have a national policy on ID. Education, health, disability, and social welfare were the key governmental sectors involved in programs and policies related to ID, though the types of services available or the accessibility of such services for all vary across countries. Services were more widespread in high income countries which reported that almost 90% of them have high levels of access (>75% to governmental services) compared to only 10% of low income countries which reported similar levels of access. Some sectors are still quite under-developed. For example only about half the countries reported having special judicial laws for offenders with ID, and this proportion was similar for both adults and adolescents with ID. Taxes accounted for the largest source of finances for services but this covered only 60% of such services in low income countries compared to 90% in high income countries. This implies a larger out-of-pocket expenditure in low income countries, which adds to the burden.

In conclusion, the diagnosis of intellectual disability developed over time as societies became more complex and psychological testing gained popularity. Beginning in the latter half of the 1800s the eugenics movement attributed ID to heritable traits and spurred efforts to segregate and sterilize PWID. Later scientific advances disproved the heritability of ID and identified environmental correlates of ID, some of which were preventable. Since the mid-1900s, beginning in Scandinavia, more and more countries have sought to deinstitutionalize PWID and to create appropriate community supports and inclusive community care settings for PWID. A lot remains to be done, both from the services perspective and the policy perspective. While attitudes have changed and knowledge about etiology and treatment have improved, PWID still continue to be a neglected community across most countries, especially the resource poor countries, and this adds to the growing burden of ID on the community, in such countries.

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