History of Intellectual Disabilities

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Introduction

The field of intellectual disability (ID) traces its history back to early Egyptian, Greek, and Roman societies. Civilizations around the world interpret mental illness, specifically ID, in a variety of ways. Beliefs regarding ID are influenced by the current stigmas, society's understanding of mental health, and the conceptualization of the cause of ID. Furthermore, the terminology used to identify individuals with ID has paralleled the societal climate of the era. To understand the current literature and perceptions of ID, it is important to first review the history of conceptualization, terminology, research, treatment, legislation, and beliefs in this area.

On the following pages, we provide a timeline to help outline the following information presented in this chapter; however, this highlights the most important aspects of history and does not exhaust ID in its entirety. As societies across history attempted to conceptualize ID, progress toward modern thinking has been nonlinear and often includes periods of backward regression due to the religious, political, or social beliefs of the time. Advocacy groups helped propel this movement forward as they disseminated information on ID and advocated for the rights of individuals with disabilities (Fig. 1.1).

Ancient Perceptions

For much of history, ID was undifferentiated from mental illness—both are poorly understood constructs and often the target of stereotypes and stigma. As such, individuals with ID often suffered from societal injustices due to beliefs that symptoms were a by-product of a number of causes, including the individual or their families being cursed or punished for wrongful acts. The earliest definition and descriptions of ID can be found in writings as far back as ancient Egypt (Scheerenberger, 1983). During this era, ancient Egyptians were focused on developing religious and medical procedures to treat a variety of disabilities and problems (Richards, Brady, & Taylor, 2014). However, in ancient Greek and Roman civilizations, the community negatively viewed all disabilities; specifically, Sparta is infamous for killing those with disabilities (Richards et al., 2014). Ancient Greek philosophers, such as Plato and Aristotle, wrote negatively about individuals with disabilities. More specifically, Plato suggested selective mating, a foreshadowing of

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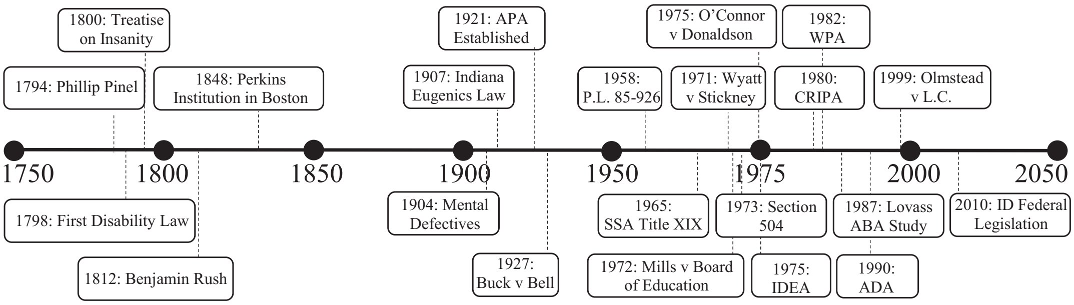

Fig. 1.1 Intellectual disability timeline. This figure illustrates key dates in the history of intellectual disabilities

the eugenics movement (Galton, 1874, 1904; Gillham, 2001a; Richards et al., 2014; Scheerenberger, 1983). Although early Romans pardoned the lives of infants born with disabilities; later Romans returned toward the tendency of infanticide for individuals with disabilities (Richards et al., 2014).

ID during the Middle Ages revolved around religion and superstitions, but Covey (1998) argued that societal response to disabilities varied by the specific disability, its context, and beliefs on etiology. Despite influences of the early Church in eliminating infanticide by providing institutions for individuals unwanted by their families due to disabilities, some argue that Luther's descriptions of the "feebleminded" were excessively negative (Harris, 2006; Richards et al., 2014). However, others argue that Luther's definition of "feebleminded" encompasses spiritual content rather than ID (Andrews, 1998). Nonetheless, during the Restoration period, "idiocy" and general mental illness were associated with immorality resulting in moral punishment (Andrews, 1998).

Philosophy's Influence

History is fraught with many philosophical descriptions and explanations for ID; however, it is important to understand the sociocultural, intellectual, and philosophical foundational contexts did not conceptualize ID as it is now defined (Groce & Scheer, 1990). Historical documentation includes words and phrases asserted to be historical terms for ID (e.g., "fool," "stupidity," and "idiot"), which refer to individuals with a variety of presentations, including mental illness and physical impairments, as opposed to specifically ID (Goodey, 2004). In the late seventeenth century, John Locke was one of the first individuals to differentiate intellectual and mental disabilities from physical disabilities. However, Locke's idea of madness and mental disability truly integrates concepts of intellectual and affective deficits and disorders (Charland, 2010). Furthermore, earlier Renaissance physicians, Paracelsus and Platter, suggested a differentiation between "foolish[ness]," "feebleminded[ness]," and mental illness (Andrews, 1998; Goodey, 2004). In 1664, Willis, another Oxford philosopher and pioneer of brain anatomy, further contributed to the understanding of "stupiditas" and idiocy by describing these states as disease-like and pinpointing various etiologies including heredity, trauma, other diseases, and "animal spirits" (Andrews, 1998; Goodey, 2004).

Asylums

During the seventeenth and eighteenth centuries, despite advances in medical and philosophical understanding (precursors to psychological understanding) of ID, affected individuals still experienced stigma and poor quality of care. They were institutionalized in asylums, hospitals, and prisons during this Age of Enlightenment and Reason. Poor living conditions, neglect, and various forms of abuse were the norm for those who lived in institutions. Furthermore, many believed that basic medical care was not a necessary privilege for individuals with ID. For example, Bethlem Hospital in England rejected individuals deemed "idiots," as they were viewed as outside of the hospital's treatment competence (Andrews, 1998). Toward the end of the seventeenth century, the beliefs of psychiatrist, Philippe Pinel, initiated a paradigm shift in the level and quality of care for individuals with ID and mental illness. Specifically, Pinel advocated for moral treatment of individuals with ID and their release from hospitals and prisons. He was and continues to be renowned for freeing patients from insane asylums in La Bicetre and later La Salpetriere.

By 1794, Pinel published an essay, "Memoir on Madness" that encouraged the study of psychopathology, and by 1798, he published the first edition of his classification of mental disorders (*Nosographie philosophique ou methode de l'analyse appliquee a la medecine*), which served as the first classification of its kind. The *Nosographie* notably differentiated between five disorders, separating ID ("ideotism or obliteration of the intellectual faculties and affections") from dementia, mania, mania without delirium, and melancholia (Pinel, 1806). Pinel's definition of idiotism is not equivalent to modern conceptions of ID. Pinel's student, Jean Marc Gaspard Itard, altered society's perception of how ID was viewed and furthered the potential for treatment and education through an emphasis on humane treatment. The combination of Pinel's work and William Tuke's establishment of humane treatment for patients with mental illness through the founding of the York Retreat for the mentally ill in 1792 served as the foundation of asylums emphasizing moral and humane treatment for patients. Additionally, these institutions began appearing in the early nineteenth century as places of refuge (Dunkel, 1983).

Pioneering the United States

As Pinel and Itard were working in France, a similar movement began in the United States started by Benjamin Rush, a founding father of the country and often considered the father of American psychiatry. Rush also advocated for more humane treatment of mental illness leading to the creation of a separate ward for such patients. In 1812, Rush published *Medical Inquiries and Observations, Upon the Diseases of the Mind*, which served as the first attempt to explain and treat disorders of the mind in the United States. Early nineteenth-century Americans witness the paradigm shift in increased attention to the ideas of mental disabilities and ID. However, at the time, the differentiation of mental disability and ID was not complete; although philosophers attempted to describe it in the past. In the 1930s, James Prichard, another notable psychiatrist, theorized a distinction between ID and mental illness or "intellectual [versus] moral insanity," serving as the foundational definition of this distinction (Carlson & Dain, 1962). Furthermore, advances in awareness of mental illness and general psychiatry significantly relate to advances in understanding and treating ID.

In 1818, the Asylum for the Insane (later the McLean Asylum for the Insane in 1826 and then McLean Hospital in 1892) opened in Massachusetts (Little, 1972) further transforming the quality of care for individuals with ID. Like other asylums of its time, the ideas of "moral treatment" influenced by Pinel and Tuke heavily influenced the model of care for the Asylum (Dunkel, 1983; Pinel, 1806). The McLean Asylum's groundbreaking research and its transition to Belmont, Massachusetts, established the transformation from institutional settings to a more residential environment (Little, 1972). By 1848, Samuel Gridley Howe opened the Experimental School for Teaching and Training Idiotic Children, within the Perkins Institution (a residential institution for the blind), in Massachusetts, serving as the first residential facility for those with developmental disabilities. Now called the Walter E. Fernald Developmental Center, this school became a leader in providing education to individuals with ID. The Experimental School for Teaching and Training Idiotic Children helped change current beliefs to demonstrate that individuals with ID are capable of learning and need to be appropriately challenged. During the mid-nineteenth century, the

Association of Medical Superintendents of American Institutions for the Insane was established, which eventually became the American Psychiatric Association in 1921 (Hirshbein, 2004). This organization was influential in the advancement of science and understanding mental illness and ID.

Eugenics Movement

While the early nineteenth century was marked by the emphasis of humane treatment of those with mental disabilities and ID, the latter part of the century was marked by the eugenics movement, leading to a de-emphasis on ethical treatment and increased stigma against individuals with various disabilities, including ID. The movement was started by Sir Francis Galton who originated the word "eugenics" in 1883. Originally developed from Platonian thought of artificial selection, eugenics occurred as a treatment of individuals with ID and other mental disabilities in early civilizations and medieval times (Richards et al., 2014; Scheerenberger, 1983). However, Galton (1904) conceptualized eugenics as a science focusing on the "improvement" of the species, with emphasis on the influence of nature versus nurture (Galton, 1874). Galton and eugenics were heavily influenced by Charles Darwin's publication, *On the Origin of Species*, in the mid-nineteenth century (Gillham, 2001a). In Galton's distinction between nature and nurture, he indicated that human ability was most strongly influenced by nature. Through this belief, Galton advocated for the heritability of intelligence and cognition (Galton, 1865, 1874; Gillham, 2001a).

As noted above, an era's sociocultural makeup heavily influences conceptualizations of intelligence and ability/disability. Galton's applications of natural selection through the eugenics movement were in opposition to other societal movements of his time during Victorian England (Galton & Galton, 1998). The eugenics movement developed at the same time as societal reforms in England, such as the Anti-slavery Bill, educational acts, protections for the poor, and other social reforms. Galton's work led to the creation of a eugenics register, an arbitrary scale of "worth," and classification of families as gifted, capable, average, or degenerate. However, this measure of intelligence was not available during his time nor proposed by Galton (Galton & Galton, 1998; Gillham, 2001b). Regardless of any scientific merit of Galton's work, it instigated a societal movement that holds significant impact on the treatment of individuals with disability (as well as other socially constructed groups) including sterilization, the restriction of movement, and segregation of individuals with ID.

Twentieth-Century Eugenics and Involuntary Sterilization Laws

Eugenics has existed for centuries, with many influential leaders including Charles Darwin, Cesare Lombroso, Thomas Malthus, Arthur de Gobineau, and Herbert Spencer (Gejman & Weilbaecher, 2002). The eugenics movement gained traction when elected officials focused on ensuring the quality of the population by minimizing and decreasing the number of feebleminded, insane, imbeciles, and idiots (Kendregan, 1966; Stern, 2007). Supporters of eugenics posited that affected individuals were a social burden to the country and should not procreate (Sofair & Kaldjian, 2000). Within the United States, Indiana was the first state to pass a compulsory eugenic sterilization bill in 1907. Thurman Rice piloted sterilization outside of institutions within the state of Indiana. Following Indiana's passing of this legislation, 29 states created their own sterilization laws, including 18 that involved involuntary sterilization (Kendregan, 1966; Sofair & Kaldjian, 2000). Within the first 40 years of these laws, almost 40,000 people underwent sterilization in the United States (Proctor, 1988). Over time, challenges to the constitutionality of these laws occurred. Indiana's sterilization laws were deemed unconstitutional in 1921; however, new legislation (reinstating sterilization) was approved in 1927 (Stern, 2007). The change in beliefs regarding sterilization was not limited to the state of Indiana: consecutive cases on the grounds of constitutionality of sterilization occurred across the United States (Kendregan, 1966; Sofair & Kaldjian, 2000; Stern, 2007).

The Supreme Court case, *Buck* v. *Bell* (1927), served as a monumental shift in the perception of the legality of involuntary sterilization (Berry, 1998; Kendregan, 1966; Siegel, 2005; Sofair & Kaldjian, 2000). The individual who led to *Buck* v. *Bell* (1927) was Carrie Buck, a young woman in Virginia whose mother could no longer care for her (Berry, 1998). Carrie, a teenager, became pregnant as a result of rape. Despite her admission, the courts considered Carrie, her mother, and her infant daughter to be "feebleminded," resulting in Carrie's institutionalization in 1924 when she was 18. The superintendent petitioned to the Board of Virginia Colony that Carrie be sterilized to prevent her from having more children that required further services. The board approved this motion; however, Carrie's lawyer appealed her case to the Virginia trial court, then the Virginia Supreme Court, and finally the US Supreme Court (Berry, 1998). The US Supreme Court ruled in favor of involuntary sterilization. Justice Holmes gave the US Supreme Court's majority's opinion in *Buck* v. *Bell* (1927), claiming that "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind" (p. 207). Prior to the court's determination, 23 states already enacted legislation related to involuntary sterilization (Laughlin, 2009); therefore *Buck* v. *Bell* (1927) confirmed these states' stance on sterilization. One of the largest counterarguments and a descending opinion to this case is that forcing an individual to be sterilized is "cruel and unusual punishment" (Siegel, 2005). In the aftermath of this case, upward of 50,000 Americans received involuntarily sterilization over the next few decades (Berry, 1998). In 1978, the Department of Health, Education, and Welfare altered the requirements for sterilization to include informed consent, therefore, abolishing involuntary sterilization (Title 42, 1978).

Earliest Textbook

In 1904, Martin Barr, MD, published the first textbook on ID titled *Mental Defectives: Their History, Treatment, and Training*. Barr (1904) provided professionals unprecedented information on understanding ID based upon the labels of the time: imbeciles, feebleminded, idiots, and mental deficient. Barr (1904) differentiates between an idiot and imbecile by explaining an idiot "see nothing, feels nothing, hears nothing, and knows nothing," whereas imbeciles have the capacity to understand and reason (p. 18). Furthermore, he stated that differentiating between these two is influential in selecting treatment protocols and assigning realistic prognosis. Through his definitions and classifications, Barr paved the way for others to appropriately differentiate causes and prognoses of those presenting as deficient in some way. Tredgold (1908) expands on Barr's concepts by creating a resource for professionals to educate on appropriate diagnosis, treatment, eligibility for services, and long-term placements. Barr (1904) and Tredgold (1908) provide descriptions of biological, physical, and cognitive differences of those with mental defects. Barr (1904) provides hope for those labeled as mentally defective prognosis by differentiating between disease and defect and argues that regression is preventable through appropriate treatment for those who fall within defect. However, through his classification of idiots and imbeciles, Barr postulates idiots are unable to make any gains and treatment will not result in any improvements; therefore, treatment resembled nurseries. However, treatment focused on those termed as imbeciles' emotions, body, and mind through training them in how to complete daily living activities through step-by-step instructions and avoiding any abstract concepts (Barr, 1904). The importance of differentiating and understanding the cause and prognosis of one's mental deficiency continued to inform ongoing research into the treatment of ID for centuries to come (Roberts, 1952; Schalock & Luckasson, 2013).

National Associations

After witnessing firsthand the inadequate services and advocacy for children with disabilities, Edgar Allen made it his life's effort to ensure the other children received proper care (Williams, 1994). In 1919, Mr. Allen founded the Ohio Society for Crippled Children as an organization advocating for the rights of disabled children. The organization began requesting donations to fund children's services and advocating for children's right to live. In 1967, the organization had slowly gained a national presence and officially changed its name to Easter Seals. As the Americans with Disabilities Act (ADA) developed, Easter Seals pioneered the advocacy movement for those with disabilities in Washington, DC. Easter Seals focuses on providing services to families within five categories: live, learn, work, play, and act. Easter Seals served as an example for other advocacy organizations within the United States and worldwide (Williams, 1994).

In 1930s, the National Association of Parents and Friends of Mentally Retarded Children began forming groups to advocate for improving their children's care (Hay, 1952). By 1951, the United States and Canada had over 125 groups with thousands of members. The growing membership resulted from two very important areas: (1) parents and the community's awareness that children were not receiving appropriate treatment and (2) the medical community simultaneously developing new treatments for conditions previously thought to be untreatable. This association, which later became known as the National Association for Retarded Children (ARC), focused on circulating accurate information on mental health and advocating for adequate treatment, education, vocational services, housing, and government policies (Hay, 1952).

Simultaneously, in 1946, the National Mental Health Foundation was founded, which was a civilian-run organization focused on the dissemination of factual information about mental health to legislators, educators, the public, and mental institutions. This foundation advocated for an increased standard of care for mental health treatment, education of the layperson on aiding those with mental health problems, promoting focus on psychiatry programs within already developed universities, and furthering current mental health professionals understanding of the illnesses ("National Mental Health," 1946).

In 1979, the National Alliance on Mental Illness (NAMI) originated as a small grassroots organization. NAMI focuses on educating, advocating, listening, and leading. NAMI develops educational programs to inform families and providers on mental illness and its personal implications. NAMI frequently spearheads public policy ensuring appropriate representation of the rights of individuals with mental illness in legislation. NAMI offers a helpline to assist in connecting families with local providers and supporting individuals with suicidal ideation. NAMI also hosts frequent events to increase the public's awareness of mental illness and work toward destigmatizing the field (NAMI, 2018).

Appropriate Training for Service Providers

President Eisenhower signed the Education of Mentally Retarded Children Act (1958), which allotted funds to provide additional training to universities on educating individuals with mental retardation. When the act, P.L. 85–926, was first signed, it allocated $11 million per year for educators and professionals to gain additional knowledge and understanding of mental retardation. Through this added knowledge, these leaders create programs within already established colleges and within local public school systems aimed at teaching and adapting curriculum for those with mental retardation (Martin, Martin, & Terman, 1996). An addendum was passed in 1963, P.L. 88–164, which expanded on the earlier act to include adaptation for other disabilities (e.g., emotional disability, deaf, crippled, speech impaired, blind, and other health impairments). From the initiation of P.L. 85–926 through the addendums, over 20,000 educators and professionals received training to adapt education to affected individuals. From the initial $one million allotment per year, this amount expanded to $55 million allotted in 1970 ("Programs for the Handicapped," 1969).

Terminology Changes Over Time

The terminology to refer to ID continues to change over time. In the early 1990s, labels for individuals with ID were imbecile, feeble-minded, idiots, and mental deficient in the early 1900s (Barr, 1904). In 1952, the American Psychiatric Association (APA, 1952) published the first *Diagnostic and Statistical Manual* (DSM-I) classifying this disorder as "chronic brain syndrome with mental deficiency" (p. 14) and "mental deficiency" (p. 23). In 1959, the American Association of Mental Deficiency introduced the term "mental retardation" and changed their name to the American Association of Mental Retardation (AAMR) (Fredericks & Williams, 1998). In the 1960s, APA (1968) published their second edition of the DSM-II, which incorporated the new diagnosis of "mental retardation." It was not until the publication of DSM-III in 1980 that APA (1980) addressed that mental retardation does not solely include a deficit in intellectual functioning but also impairment in adaptive skills. From 1980 through the early 2000s, this remained the definition and conceptualization for mental retardation. In 2010, the World Health Organization and the AAMR, now known as the American Association on Intellectual and Developmental Disabilities (AAIDD), formed work groups to prepare for proposed changes in the International Classification of Diseases (ICD-11). In 2010, the ICD-11 implemented the change in terminology to "intellectual disability" following President Obama signing "Rosa's Law" which changed "mental retardation" to "intellectual disability" in federal education laws (Tassé, Luckasson, & Nygren, 2013). Shortly after, DSM-5 was released in 2013 and agreed and incorporated the diagnosis "intellectual disability" (APA, 2013).

Deinstitutionalization

Many individuals with mental health diagnoses lived in state hospitals, which reached its peak census in 1955 with over 550,000 individuals hospitalized (Bachrach & Lamb, 1989). Over the next decade, the deinstitutionalization movement progressed, with the federal government's formalization of deinstitutionalization beginning in 1965 as the civil rights movement gained traction and advocates fought for the least restrictive environment (Chow & Priebe, 2013). This transition did not occur over night, and it took decades to fully transition individuals from state hospitals to outpatient community mental health centers ("Deinstitutionalization Movement," 2007). To successfully deinstitutionalize and rehabilitate, society needs proper funding to create treatment centers and transitional housing. Additionally, for this process to be effective, individuals need to be compliant with treatment recommendations and have the financial and social supports to meet these goals (Bachrach & Lamb, 1989). Unfortunately, due to limited rehabilitation services in America, many affected individuals become homeless.

Federally Funded Programs

In 1965, the federal government passed Title XIX within the Social Security Act (1965), which instated the federal- and state-level Medicaid programs (Klees, Wolfe, & Cutris, 2009). Title XIX identified individuals with low income, children, pregnant women, blind individuals, and permanently disabled individuals. An individual was considered disabled if their physical or mental diagnosis prevents them from being able to work. This was the first legislation of its type to recognize that individuals with disabilities need additional funding for appropriate services. The Medicaid plan covers a variety of treatments, including inpatient-, outpatient-, residential-, and community-based centers (Social Security Act, 1965).

Special Olympics

Through the late 1950s and early 1960s, Eunice Kennedy Shriver became abundantly aware of the injustices faced by individuals with ID; therefore, she made it her personal mission to create an atmosphere conducive to individuals with ID to thrive and enjoy life (Special Olympics, 2018). In 1962, Ms. Shriver held her first summer camp in Washington, DC, which included sporting events and outdoor activities. In 1967, Chicago proposed an idea to replicate the Olympics track meet for those with ID. The following summer of 1968, Ms. Shriver held the first International Special Olympics Summer Games in Chicago, IL, leading to the formal incorporation of Special Olympics as an organization that fall. Throughout the 1970s, the Special Olympics continued to grow within the United States, and by 1977, the winter Olympics developed. At the 1987 International Special Olympics held in Indiana, athletes from 70 countries competed (Special Olympics, 2018). The Special Olympics continues to be a remarkable organization promoting the enjoyment of life for those with disabilities and advocates for individual's rights in the progression of disability legislation.

Disability Legislation and Right to Treatment

The first legislative recognition in favor of increased funding for individuals with ID came in 1970 with the Developmental Disabilities Services and Facilities Construction Amendments (1970). This act provided states with funding for treating, giving services, and creating new treatment facilities for those with ID. The Developmentally Disabled Assistance and Bill of Rights Act (1975) served as an amendment to the earlier policy and included the advocacy of individuals with developmental disabilities, early screening, and the protection of their rights. The "rights of the developmentally disabled" were described as including individuals' right to treatment, services emphasizing the individual's potential, and appropriate funding for this treatment. An additional amendment, the Developmental Disabilities Act of 1984, addressed treatment goal of establishing services to help the individual with gaining independence, assimilation into the community, and supporting individuals to become employed. This Act and its amendments represent the shift within society in understanding the importance of quality of life of individuals with disabilities and advocating for their right to achieve this.

While legislation occurred on a federal level in the 1970s, states were also similarly grappling with legislation to improve care for individuals with ID. For example, in the state of Alabama, quality of patient care and access to safe-staffing models at Bryce State Hospital became the cornerstone of *Wyatt* v. *Stickney* (1971). The state of Alabama increased taxes on cigarettes, which affected Bryce State Hospital's ability to pay their employees. Therefore, they fired around 100 employees, leaving few professionals to care for the residents and patients. The ratios for patient to provider were outrageous: 1 psychiatrist served over 1500 patients, 1 nurse cared for 250 patients, and 1 doctor tended to over 350 patients (Carr, 2004). The focus and ruling of *Wyatt* v. *Stickney* (1971) laid the foundation for future cases recognizing patients', including those in mental health facilities, right to appropriate treatment and safe environments (Perlin, 2011).

O'Connor v. *Donaldson* (1975) was the first case to reach the US Supreme Court on the basis of right to treatment and constitutionality of confinement. After receiving a diagnosis of paranoid schizophrenia in 1957, Kenneth Donaldson's father civilly committed him. Donaldson petitioned for his release, claiming that he was not receiving treatment. Donaldson asserted that it was his constitutional right to discharge himself or receive treatment (Fields, 1976; Wold, 1975). The appellate court ruled on the presumption that Donaldson's constitutional right was to receive treatment, therefore, ruling against his discharge request. In *O'Connor* v. *Donaldson* (1975), the US Supreme Court ruled in support of Donaldson, declaring that he was involuntary committed, which deprived him of his personal liberties. The court stated that the only justification for involuntary commitment is if an individual is receiving treatment or is dangerous; given that neither of these was true for Donaldson, they ruled that a violation of his constitutional rights occurred. They further indicated that an individual's mental illness, considered independently, is not enough to qualify for involuntary commitment (Fields, 1976; Wold, 1975).

In 1980, the Civil Rights of Institutional Persons Act (CRIPA) further established the rights of individuals in institutions (e.g., prisons, hospitals, mental health facilities, nursing homes). The Attorney General claimed that any setting receiving federal aid much respects individual's rights. CRIPA (1980) specifically protects individuals against sexual abuse, inappropriate mental health treatment, inefficient rehabilitation, inadequate education, and abuse or neglect. CRIPA (1980) does not establish new rights for individuals; rather CRIPA creates a system for the Department of Justice (DOJ) to monitor and prosecute violations.

In the early twenty-first century, the Developmental Disabilities Assistance and Bill of Rights Act set the stage for increasing accessibility of treatment within the field of ID. This act supports ongoing research of developmental disabilities and ID to ensure federal policy conforms to updated research. This act also advocates for the individual's rights and protects them from unlawful abuse. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 created numerous programs and legal counsel to represent those with intellectual and developmental disabilities in policy. There are state counsels which represent their rights and ensure that updated policies adhere to disability laws and remove individuals' barriers to treatment and participating within society. Protection and advocacy groups also appeared to advocate and empower individuals to represent themselves. Also created were University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDS) to ensure educational organizations represent their rights and provide appropriate accommodations (Developmental Disabilities Assistance and Bill of Rights Act, 2000).

Educational Rights for the Disabled

A class action lawsuit, *Pennsylvania Association for Retarded Citizens (PARC)* v. *Commonwealth of Pennsylvania* (1972), filed petitions against the board of education and specific school districts. This was the foundational case in establishing students' right to education. *PARC* v. *Pennsylvania* (1972) claimed that students with mental retardation did not receive the same, if any, education as their peers. This case argued that the 14th Amendment of the US Constitution specifies that legislation cannot impede on citizen's rights (e.g., right to education). Therefore, school systems were violating this right by denying students with mental retardation the right to their education. The ruling on this case asserted that law requires school districts to offer public education to all children, regardless of mental abilities. Shortly after this case, a similar class action suit, *Mills* v. *Board of Education* (1972), was brought against Washington, DC. Schools excluded upwards of 18,000 children with mental and physical disabilities from receiving public education. The ruling of *Mills* v. *Board of Education* (1972) emphasized students' right to education and required schools to redistribute their financial allocations to provide adequate funding for students with mental and physical disabilities (Yell, Rogers, & Rogers, 1998).

Both cases laid the foundation for federal legislation, Section 504 of the Rehabilitation Act of 1973. This act asserts that discrimination against individuals based on their disability, including mental health diagnoses, is unlawful. This legislation particularly applies to any organization that receives federal funding, which includes educational institutions (Yell et al., 1998). The Education for all Handicapped Children Act of 1975 (EAHCA) offered states federal funding for special education services. As previously discussed, states must offer free education; therefore, EAHCA serves as an incentive and support for states to provide adequate education. EAHCA (1975) posits that students have the following rights: modified education, free education, least restrictive environment, nondiscrimination, and due process. EAHCA also incorporated

Individualized Education Program (IEP) that tailors a student's education to their particular needs (Yell et al., 1998). In 1990, EAHCA changed its name to the Individuals with Disabilities Education Act (IDEA) that altered the wording to represent person-first language (e.g., individual with a disability). IDEA (1997) amended earlier legislation to include specialized category for autism, emphasis on parental involvement, and serving individuals from infancy through the age of 21.

National and International Legislation

In 1982, the United Nations established the World Programme of Action (WPA) Concerning Disabled Persons. The WPA addresses disability advocacy from a human rights perspective, focusing on country's legislation and policies for the equality of the individual. Given the foundation within the UN, the WPA addresses disability rights and advocacy at an international level and aims to empower individuals to become fully integrated into society as active participants. This initiative tackles countries' lack of resources and this role in the perpetuation of disability among future generations. WPA strives to prevent, rehabilitate, and create equal opportunities for those with disabilities across the world (WPA, 2018).

Established within the Department of Education in 1978, the National Council on Disability (NCD) has been monumental in federal advocacy efforts for those with ID. This council briefs the president, congress, local/state governments, and other agencies on issues affecting individuals with disabilities. NCD collects data to present to their counsel, participates in debates related to monumental issues, and prepares solutions to problems related to disabilities (NCD, 2018). NCD was instrumental in the development of the Americans with Disabilities Act (ADA), which expanded upon previous legislation impacting federally funded programs to include private businesses in being responsible for respecting the rights of those with disabilities (Waterstone, 2015). ADA (1990) protects individuals against discrimination at work, at home, in public locations, on transportation, in recreational settings, institutionalizations, and accessing public services. Prior to the passing of ADA (1990), other legislations protected individuals' civil rights, but it lacked protection based on a disability. In addition to protecting individuals with physical disabilities, ADA (1990) also protects against mental impairment.

Olmstead v. *L. C.* (1999) was instrumental in establishing mental health patients' rights to appropriate treatment without confinement and institutionalization against their will. The case involved two women, Lois Curtis and Elaine Wilson, who were both diagnosed with mild ID and treated at a hospital in Georgia. Both women voluntarily committed themselves. However, after reaching treatment goals, the hospital prohibited their discharge to a community treatment facility. Lois Curtis remained hospitalized for 3 additional years after her psychiatrist considered her fit for discharge. The premise of *Olmstead* v. *L. C.* (1999) sits upon an individual's human rights, and unlawful confinement violates these rights as stated in ADA (1990). This case escalated to the US Supreme Court after numerous appeals by the state of Georgia defending their actions of not releasing these women. The US Supreme Court agreed with the previous courts that Georgia was acting in violation of ADA (1990) and the state holds the responsibility of allocating proper funding to ensure patients have access to necessary care (e.g., state hospital versus community-based setting). This case merges previous cases both on an individual's right to treatment, disability law, and adhering to federal legislation (McCants, 1999).

Applied Behavioral Analysis

The Journal of Applied Behavioral Analysis published their first periodical in Spring 1968 and continues to publish four volumes per year (JABA, 2018). O. Ivar Lovaas, often credited with developing applied behavior analysis (ABA), proved its effectiveness with children with autism spectrum disorder (ASD) and

ID. ABA is an intensive behavioral treatment that utilizes positive reinforcement and interventions to solicit positive behaviors and discourage undesirable behaviors. Lovaas pioneered the treatment for these disorders by emphasizing the importance of early intensive intervention or ABA. Lovaas' earlier research focused on understanding antecedents and consequences and functional behavior analysis (Smith & Eikeseth, 2011). Lovaas, Koegel, Simmons, and Long (1973) published a preliminary study assessing the long-term effects of ABA, which demonstrated that if parents were involved in the treatment and trained in behavioral principles, children had longer-lasting benefits and decreases in behaviors. However, when institutionalized, the initial gains from ABA dissipated, and the child returned to baseline functioning. Lovaas (1987) published a comprehensive article discussing the effectiveness of ABA for children with ASD and ID. This study assesses long-term behavior treatment and concluded that almost half the participants reached normal cognitive functioning and at grade level school performance. Additional findings by Lovaas showed that of those 50% of students placed in special education classes, around 40% of students functioned at a delayed level, with the remaining 10% being profoundly intellectually disabled (Lovaas, 1987). McEachin, Smith, and Lovaas (1993) published a longitudinal study documenting the effectiveness of long-term early intervention behavior therapy, demonstrating that by the age of 7, participants were comparable to typically developing peers. In sum, Lovaas and his colleagues' findings emphasized the importance of beginning ABA early: children who participated in extensive treatment prior to beginning school achieved more optimal outcomes. There is extensive research on ABA and its implications within the field of ID.

Disability Culture

Over the past centuries, individual's, society's, and the international community's beliefs on disability have shifted. Chicago held the first Disability Pride Parade in the United States in 2004 (Schmich, 2017). This parade symbolized the drastic shift in perception of disability within the United States and society's move toward acceptance of differences and individuality. As technology improved, national organizations, blogs, and social media outlets now host open conversations about disability and disseminate accurate information that was previously unavailable to the general public (Brown, 2015). Now, more than ever, individuals embrace their differences and disability, and there are many public figures who openly discuss their disabilities and the challenges they face. Disability culture has boomed over the past few decades as information is readily available online (Brown, 2015).

Summary

This chapter attempts to disseminate the long, complicated history of ID while highlighting key points that were influential in the forward trajectory of the perception of mental health, specifically ID. ID's early history is traced back to ancient Roman, Egyptian, and Greek philosophers. Initially, many philosophers and scientists attempted to understand mental health and individuals who did not conform to what was typically expected. Treatment facilities ranged from asylums to institutions, to inpatient hospitals and residential treatment facilities, to now, more commonly, community mental health centers. As the understanding of mental health and ID began establishing within the United States, individuals began to fear those different than themselves, leading to the eugenics movement. Stemming from eugenics and involuntary institutionalization began the legislative history in the United States, which laid the foundation for modern-day civil rights. National organizations were established, which spearheaded the civil rights movement and fought the battle against the stigma of mental illness and ID. As the understanding of ID advanced, individuals and national organizations fought for the rights of those with ID, specifically their right to quality humane treatment and appropriate education. Numerous laws were passed protecting individuals' rights and abolishing ancient treatment methods. As individuals were educated on ID, additional trainings were created for those treating individuals with ID. Newer treatment modalities were discovered that were evidence based for ID. As the cultural perception of ID shifted, the terminology used to discuss individuals with ID adapted to be more sensitive.

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