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ELIMINATION OF THE INVISIBLE BARRIERS TO SOCIAL INCLUSION: DISSECTING THE ROLE OF TERMINOLOGY IN SERVICES AND SUPPORTS RELATED TO INTELLECTUAL DISABILITY

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Abstract

Studying the definition and implication of intellectual disability through a sociocultural lens, highlights the obscurity and implication of social factors upon the terminology that has been used to label, classify and define intellectual disability and how this terminology has reflected society’s perspectives and understanding of the condition. The conceptualization of the term *intellectual disability* has significantly evolved over the last nineteenth, twentieth and twenty-first centuries due to changing labels, classifications and definitions and the specific terminology chosen to be utilized in general description, clinical settings, research and policy. Theoretical models of intellectual disability have also been proposed in the same notion, to further assist defining intellectual disability (ID) and assisting society in understanding intellectual disability. These models have further served to provide a conceptual foundation for society to use in assistance to adequately meet the needs of those with an intellectual disability, however, these models also provide insight of the pre-conceived attitudes and perspectives that have existed by those forming and/or applying these models. This paper will first examine the evolving perception of disability based upon terminology utilized to name, classify and describe “intellectual disability” in US medicine; dissect the role of terminology and language ideologies of terminology utilized in research and policy in response to cultural perception of intellectual disability in western society; and discuss how the use of terminology and the specific model of disability utilized specifically within western society and the US, continues to contribute to the marginalization and oppression of individuals with intellectual disability.
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Introduction

"It is not whether your words or actions are tough or gentle; it is the spirit behind your actions and words that announces your inner state." - Chin Ning Chu

As noted, words are powerful. Words can describe, depict, reflect, transmit, relate, dismiss, and affect messages being conveyed to a listening audience. The words for which we choose to name, describe and explain a concept reflect our greater understanding and preconceived attitude towards that concept. Similarly, words can be perceived in a particular way based on our prior knowledge, and therefore, can influence the way for which we interpret the name or message being communicated. Language is a highly specialized mode of communication, either spoken, signed and/or written, consisting of the use of words, signs and symbols methodologically structured to reference ideas, objects, processes, and relations in the physical and social world in our surroundings (Marshack, 1992). Language is a predominant factor in exchange of information from one to another. The words for which we choose to utilize to name, classify and describe concepts influence our daily lives as they depict the norms and standards for which we abide our actions to, and the specific terminology we choose can be a great tool for analyzing societal perception and understanding of a specific subject. According to the Sapir-Whorf hypothesis, or now more commonly known as linguistic relativity, language can influence one's thoughts and decision-making, ultimately affecting a speaker's and audience's perception and cognition of a subject (Koerner, 2002). So, in turn, not only can words influence the perception or understanding of the physical and social world, but can also be analyzed in such a way that depicts the cultural history and reflects the values, beliefs, attitudes, interpretations and perceptions of society.
at a given time. The general field of disability studies, and specifically the study of intellectual disability, has been significantly shaped by terminology used to name, classify and describe such conditions.

Intellectual disability is a term coined in the historic succession of phrases applied to people in the US who are identified as having significant limitations in both intellectual functioning and in adaptive behavior (Definition of Intellectual Disability). People identified as having an intellectual disability tend to be marginalized and excluded from within their communities due to their decreased intellectual functioning causing the need for an increased amount of support (Riddell & Watson, 2014). The conceptualization of disability has considerably evolved in recent history in efforts of reducing health and social disparities and inequalities through improved acknowledgement of people’s basic human and civil rights. As the US tends to be a socially dominant culture, it has significantly contributed to the way intellectual disability and the associated disabilities are viewed (Riddell & Watson, 2014). Culture, therefore, has been a leading force in the evolution of the terminology within the naming and conceptualization of intellectual disability and the evolution of these terms has been highlighted in several social and political movements seen throughout history related to the development of various disability models, deinstitutionalization, evolution of terminology, civil rights movements (i.e. Independent Living Movement), and creation and enactment of political acts (i.e. Americans with Disabilities Act). Stigmatizing attitudes and negative beliefs within the wider community may have reduced over time but are a continuing concern and can pose major barriers to social inclusion (Akrami,
Ekehammer, Claesson, & Sonnander, 2006; Brown, Ouellette-Kuntz, Lysaght, & Burge, 2011).

Many have argued that intellectual disability is a socially constructed condition for which the intellectual impairment can be understood in social, political, and cultural terms, as opposed to the sole absence or malfunctioning of a physiological system (Riddell & Watson, 2014). As the paradigm of disability has shifted, new conceptualizations of normalcy and independence have begun to emerge, exemplifying the importance and significance of terminology’s role in adequately depicting comprehensive descriptions of such paradigms. This change in normalcy began with the principle of normalization created by sociologist, Wolf Wolfensberger around the 1970s. Wolfensberger and his colleagues explained normalization as an ideology of human management (Wolfensberger, Nirje, Simon, Perske, & Roos, 1972). They had slightly altered the definition to conform to a Western societal audience from previous foreign ideologies. For example, Bank-Mikkelsen, the head of the Danish Mental Retardation Service, originally phrased normalization in the late 1950s as, "letting the mentally retarded obtain an existence as close to the normal as possible," however, it was not until, 1969 where the principle was systematically stated in British literature in the Journal of Mental Sub normality by Nirje, the director of the Swedish Association for Retarded Children (1972). This explanation of the principle was described as, "...making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society," (Kugel & Wolfensberger, 1969). This description was formally utilized in Scandinavian literature in development of the first major treatise on the topic. It led provisions and services for those with
intellectual disabilities, which ultimately led to the spread of the principle to overseas leading to the altered phrasing of normalization by Wolfensberger in the early 1970s. Wolfensberger et al.'s normalization principle was then rephrased as "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible," (1972). It conceptualized the standard of acceptable norms to which defined “normal” by establishing a set of behaviors and characteristics that are deemed culturally acceptable and appropriate amongst a specific group of people. This idea has continued the molding of the “standard of normal” and has shaped the conceptualization of disability beyond the medical involvement of the condition by acknowledging the additional external factors, including sociocultural influences, that impact one’s experience of disability. As the principle of normalization began to gain popularity, sociocultural influences began to gain recognition in their role in the civil rights and social movements surrounding disability which also impacted the sociocultural perception of integrating people with intellectual disability into mainstream society.

Culture can then be viewed as a lens for which we create, tone and aspire our perceptions, beliefs, values, characteristics, qualities and actions upon, for which coherence is based upon the voices of many, not all exactly the same, yet each one being made significant by the involvement and dependency on others (McDermott & Varenne, 1995). Culture withholds a magnitude of different positions and roles for people to inhabit, all of which have physical, psychological and social requirements that one must possess; in addition to, these roles and positions having to be defined by characteristics that distinctively symbolize their role in relation to others and their community. Now the
requirements and characteristics that one must possess, need to be distinguishable, measurable, and describable for which we can then determine what may be a desirable versus undesirable trait and what may need to be noticed, addressed, altered and remediated, if possible, in efforts to achieve their desired role within their community/society. There are also requirements to become a member of a society as "one must learn or be socialized into its cultural assumptions and rules, including what (or who) is considered "normal" and typical and categorized as "different," (Barnes & Mercer). This is where the standardization of acceptable norms is created, described and dictated by the terminology one chooses to use. For example, the theoretical framework of ability versus disability has been developed based on the notion of a standard set of skills we have deemed as necessary or fundamental for one to possess to complete a task or to engage in a certain activity. That being said, slight variations in the skill/ability may be noted, however, may not necessarily result in being labeled *disabled*. Often, the term *disabled* or being deemed as having a *disability*, is when one has “a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person’s ability to engage in certain tasks or actions or participate in typical daily activities and interactions,” (Merriam Webster, 2018). Simply, this definition of “disability” is created from the difference that an individual may demonstrate deviating from the set of “norms” set forth by social conditions.

Through this definition of disability, this identifies the basic structural framework for which we understand what a *disability* entails, and places the responsibility of ability versus disability, upon the individual and not the society. This definition exemplifies it is the condition for which the individual possess that is the cause of their inability to engage
in a certain task or participate in what US culture has defined as typical activities based upon the norms set forth by the majority, and calls for the need for the individual to conform or lose the opportunity for engagement. In comparison, the sociocultural lens of disability examines the contextual factors surrounding the individual that may not be adequate enough to meet the needs of the individual to complete this task. This definition above eliminates the influence of external contextual factors and removes any responsibility of disengagement away from the task or situation in question. Like previously discussed, through recent history, civil rights, social movements, disability and therapeutic models have begun to recognize the significance external determinants and factors have upon individuals with “disabilities”, however, terminology used in definitions and description still remains to focus on the individual responsibility of ability. The American Association on Intellectual and Developmental presently characterizes intellectual disability based on significant limitations in both intellectual functioning and adaptive behavior, but stresses that additional factors must be considered including community environment typical of individual's peers and culture. Even this definition though, emphasizes the social construction of intellectual disability as it heavily influenced not only on the individual's functional capability, but upon the norms set forth by peers and their culture.

In this paper, I will examine the shifting perception of disability based upon terminology utilized to name, classify and describe intellectual disability, dissect the role of terminology and language ideologies of terminology utilized in research and policy in response to cultural perception, and discuss how the use of terminology utilized specifically within the US culture and related Western medicine disability models
continues to contribute to the marginalization and oppression of individuals with intellectual disability (ID). I will explain these themes by first analyzing the historical evolution of selected terminology and associated events contributing to the change in terminology chosen; then I will evaluate the associated policies that were affected by the change in terminology selected and the effects caused by language written within such policies; and finally will analyze the current terminology utilized to label and describe intellectual disability, how this influences sociocultural perception of people with intellectual disability and in turn, how the sociocultural perception affects the experience of intellectual disability.

**Part I: Evolution of Terminology to Describe Intellectual Disability and its Interdependent Relationship Upon Societal Perception of Intellectual Disability**

Undoubtedly, the sociocultural interpretation and theoretical approach of disability has evolved within the Western sociocultural history and it is reflected within the changes of terminology used to name what is now labeled as *intellectual disability* (ID) in the United States. Many have argued that intellectual disability initiated as a socially constructed condition significantly impacted by societal standards (Ginsburg & Rapp, 2013; Tasse, 2013; Albrecht, Seelman, & Bury, 2001, Manion & Bersani, 1987). These standards were what defined normal behavior and characteristics of individuals within that society; however, these standards varied greatly in definitions dependent on the sociocultural influences including people, the environmental context, and services available. It is also important to recognize, though, that intellectual disability was, and continues to be, a very important health condition often causing many other health related issues to that individual, as well as greatly impacting all nations’ health, education and
economic implications, however it wasn’t it more recently that these specific needs were adequately addressed (Tasse, 2013). The origination of the currently accepted term, *intellectual disability*, has greatly evolved over the years and its previous terms demonstrate the historical prominent features of medical terminology, yet the choice of words that were selected to originally define intellectual disability displays the lack of understanding of what exactly the condition entailed. Commonly, medical terminology incorporated the use of Ancient Greek and Latin terms to help name and distinguish the bodily structures involved and/or affected, and the type, condition or process of disease. Terms chosen were in order to help describe abnormal phenomenon that medical professionals observed when examining a new condition. So, like other medical terminological phrases, the terminology selected to label what others recognize as intellectual disability now, had Ancient Greek and Latin origin influence, using words with “similar” meaning, classifying the behavior observed by professionals from social science and medical disciplines, eventually becoming a part of the newly developing study of disability and psychology. The terms chosen ultimately created the reality and overall general understanding of the beginning conceptualizations of disability and specifically, intellectual disability. For instance, the term “moron”, is derived from the Greek term “moros” meaning foolish, stupid, dull. This was one of the first terms used to describe intellectual disability and shortly evolved into the term “imbecile” which was derived from the Latin word “imbecillus” meaning “without a supporting staff” and French term meaning “physically weak” (Wehmeyer, 2013). Despite the lack of congruency some of these terms and their originated meaning had in relation to intellectual disability, they were still coined as medical labels to describe this condition.
during these previous time periods. However, unlike other popular medical conditions, such as “diabetes mellitus” that have kept the same name labeling the same condition for hundreds of years due to the significant similarity of its ancient terminology origins, terms such as moron, imbecile, and mental defective were adopted and then quickly abandoned as growing stigmatization of terms plagued the intent of such labels due to the inconsistencies in behavior it was meant to be describing.

As labels, classifications, definitions and descriptions are offered to the public, the terminology used to classify and describe these labels continues an interdepending relationship shaping and being shaped by, societal understanding and interpretation of the condition. This trend may be seen through the evolution of the terminology used to label intellectual disability. Many argue that intellectual disability is a socially constructed condition based on the standards of what is deemed as normal versus deviant continually shaped by conditions that exclude full participation within one's community (Ginsburg & Rapp, 2013; Tasse, 2013; Albrecht, Seelman, & Bury, 2001, Manion & Bersani, 1987). With sociocultural norms evolving as time goes on, it has shown difficult to find a term that facilitates both adequate identification and communication of how the condition presents itself and should be categorized (Tasse, 2013; Luckasson & Reeve, 2001). Likewise, policies, support, and services established in relation to intellectual disability are dependent on accurate terminology naming the condition and the ordering of words used to describe the condition to accurately depict the circumstances and experiences of these individuals classified as having ID; however, the experience of intellectual disability greatly varies person to person and is differently understood by different sociocultural groups, professional disciplines and non-professional alliances resulting in
misrepresentation of these individuals and inefficient support, services and policies negatively affecting their daily lives (McClimens, 2007). The identity of intellectual disability depends so heavily on how we speak of ID based on our choice and order of words.

The evolution of the terminology surrounding intellectual disability, reflects the slow-moving progress towards improved communication of the operational and constitutive definitions of ID. During the nineteenth and twentieth centuries, social science and behavioral professionals were solely responsible in the naming such condition in efforts to classify this social class and to determine a plan of action to solve this societal "problem”, yet these professionals did so without any input received by stakeholders such as family members or individuals categorized has having an intellectual disability.(Noll, Smith & Wehmeyer, 2013). Prior to this time, there was very little mention and discussion of intellectual disability, with seldom instances being formally discussed or calling for action, possibly suggesting the exclusion and neglect of these individuals from the prospering communities. The emphasized saliency to find a distinctive label for this phenomenon demonstrated the shifting perception of the sociocultural standards of normal, and what was deemed a desirable versus undesirable trait to be successful in society due to the shift from modernization to industrialization of society resulting in creation of the working class. With the rise of the Industrial Revolution and society's new emphasis on capitalism, membership of the working class became increasingly more desirable emphasizing the inability to be able to complete more complex tasks becoming increasingly apparent for those with an intellectual disability (Wehmeyer, 2013).
The term *idiocy* was originally used as the formal label of intellectual disability as it was derived from the Greek terms *idatas* meaning private person, and *idios* meaning peculiar (2013). Like previously discussed, medical terminology during the early nineteenth century was heavily based upon Ancient Latin and Greek origins. As individuals were naming and describing a condition related to intellectual disability during this time, the term *idiocy* identified those who were peculiar and different in behavior, ultimately set aside from their community. Instances of this condition, though, could be found in very few medical and philosophical texts, specifically discussing mental disorders observed at this time, few legal documents, and only a couple artistic expressions where idiocy was defined by poverty, incompetence and dependence (Wehmeyer, 2013). Psychology became particularly interested in insanity and eventually grew interest in idiocy, especially as at the time, it was comparable as another form of insanity, where a level of thought was present but significantly distorted but was deemed the most hopeless form and often received the least attention. Jean Etienne Esquirol, a French psychiatrist, attempted to differentiate this condition from insanity, describing *idiocy* as “…not a disease but a condition in which the intellectual faculties are never manifested; or have never been developed sufficiently to enable the idiot to acquire such an amount of knowledge as persons his own age reared in similar circumstances are capable of receiving,” (Morel, 1860). Individuals often feared those with intellectual disabilities as the cause of the disability was unknown and often was attributed to divinity of some sorts. Some cultures even believed intellectual disability was a punishment by God, others believed ID was caused by some sort of demonic possession (Wehmeyer, 2013). Since the behavior was deemed unusual and deviant from societal norms, the term
quickly became associated with undesirable stereotypes that society associated with the label of idiocy in the form of negative beliefs and expectations (Scior, Connolly, and Williams, 2015). Problems such as this begin to arise when labels and their associated descriptions are misunderstood and unclear in the relation of context regardless of whether appropriate or inappropriate intention for the correctly intended message to be conveyed often resulting in the future connotation and context being misconstrued (McClimens, 2007). So, as the field of medicine began to slowly advance and incorporate with the growing specialization in disability, changes to terminology were proposed in efforts to more accurately represent the description and classification of the phenomenon and to distance away from the negative attitudes and stigmatizing perceptions. As medicine advanced, the application of science to ID started to shift perception of the causes of ID from divinity and/or shunning to being caused by some sort of physical condition.

Dr. Samuel George Howe published *On the Causes of Idiocy*, which presented and discussed the description of “idiocy”, the prognosis of such condition and the specific classifications of fools versus simpletons to the Legislature of Massachusetts (1993). Within this text, he discussed the premise for which he believed idiocy occurred and regarded the varying degrees of idiocy as a “disease of society” due to a “consequence of some violation of the natural laws”. He examined 574 individuals within 77 towns who were, “condemned to hopeless idiocy, who [were] considered and treated as idiots by their neighbors, and left to their own brutishness. They [were] also idiotic in a legal sense…incapable of entering into contracts, and [were] irresponsible for their actions,” (1993). Dr. Henry H. Goddard proposed a classification system for intellectual disability
as well based upon the concept of mental age originally proposed by Alfred Binet and Theodore Simon. Idiocy was divided into three categories: “idiots” were individuals deemed as having a mental age of less than 3 years, “imbeciles” were individuals with a mental age of 3-7 years and “morons” were deemed of having the mental age of 7 to 10 years. Analyzing the terminology chosen to name and describe this condition, it represents many messages about the perceived value and human relationships between the two broad classes of people, those identified as having the condition versus those classifying who are members of this class (Luckasson & Reeve, 2001; Simeonson, Bjorck-Akersson, & Lollar, 2012). The naming process can be perceived as a manifestation of a metaphorical representation of the sociocultural perception of such phenomenon, with intention to classify and communicate symptoms related to set of particular characteristics (Duchan & Kovarsky, 2005). The terminology and phrases utilized, such as “condemned to hopeless idiocy”, “left to their own brutishness”, “incapable”, “irresponsible”, creates a negative tone surrounding the description of this condition and therefore, undesirable in nature and cultures a negative stigmatization towards those identified as having the condition (Goddard, 1912).

As medicalization continued to further in medicine, psychology and social work dove deeper into the study of intellectual disability, terminology continued to reflect these advances, incorporating more differentiation in how intellectual disability was conceptualized, either by typology or by level of impairment, and more emphasis was placed on distinguishing between sub-concepts of idiocy. Other terms began to emerge as the call for specific classifications of idiocy began to increase in the early 1900s. Attempts to classify conditions systematically by every intricate detail possible, led the
subconcepts of idiocy to develop. This shift in terminology was heavily influenced by the increasing professional specialization caused by the growth of the institutional system. Professionals began to condemn the word idiocy as nonscientific due to lack of a comprehensive definition and the growing stigma surrounding this phrase, so other terms such as “imbecility”, “feebleminded”, “mental deficiency” began to take place (Ireland, 1877). These terms referenced the state of intellectual functioning and were represented again by medical terminology that was coined by other Ancient Greek and Latin terms to further the understanding of the concept construct.

The medicalization, and particularly the psychological specialization, of the field of intellectual disability at the start of the 20th century emphasized the transition from the very vague understanding and un-differentiating sense of peculiarities in the nineteenth century, to the development of medical terms to more accurately describe the experiences, observations and symptoms associated with intellectual disability and attempt to further understand the cause and prognosis. The idea of medicalization encompasses defining human conditions and problems as a medical condition, which then is addressed via medical diagnosis, prevention and treatment. So when intellectual disability began to be addressed in such a way, it created a new power relationship between medical professionals, individuals identified with intellectual disability and their families. Feeble-mindedness became the umbrella term for which imbecility, mental defectiveness, moronism, and idiocy fell under. Martin W. Barr and Earle Francis Maloney wrote the text, Types of Mental Defectives (1920), which categorized mental deficiency into 5 major classifications, further defined by the grade of disability, as well as the type of living and learning conditions recommended for that classification, in
which were first proposed by Isaac Kerlin in Provision for Idiotic and Feeble-Minded Children (1884). The five major classifications included “idiot”, “idio-imbecile”, “imbecile”, “moral-imbecile”, and “backward or mentally feeble”. The four conditions for which the classifications would fall under were “asylum care, long-apprenticeship and colony life under protection, custodial life and perpetual guardianship and trained for a place in the world,” and these signified whether the individual was capable of learning a trade that was deemed useful within the local community, plus the level of care needed for living, and the proper level of supervision deemed appropriate at that time (Barr, 1920). The terms idiot, imbecile, and moral-imbecile were further divided into the subcategories: idiot was divided into apathetic, excitable, profound and superficial, dependent on if “improvable”; imbecile further defined into low, middle and high-grade, dependent if trainable in some sort of occupation with supervision; and moral-imbecile further classified in low, middle and high-grade, dependent if mentally and morally deficient plus trainable in some sort of occupation (1920).

Barr defined each condition by the origin of the word for which it was derived from and then the explanation for the distinction of classification. *Idiot* was described as “incapable of holding communication with another, therefore set apart-alone,” similar to its origin Greek term as a “private person; peculiar” in which the condition sets the individual apart from others in society due to the peculiar behavior exhibited. Imbecile was taken from the Latin terms, “imbecillis”, “bacillum”, and “in vacillo” which translates to “needing a staff, wanting strength of mind, and weak and feeble” (Barr, 1920). Barr described *imbecile* as, “expressive of a certain degree of intelligence, but unstable, incapable, irresponsible,” and further was classified by grade. The two were
differentiated based on “The idiot intelligently sees nothing, feels nothing, hears nothing does nothing, and knows nothing. He simply lives alone-the solitary one. The imbecile, on the other hand, is able to see, to understand, and to discriminate in greater or less degree,” (1920).

Descriptions of the classification were formulated based on the professional interpretation of observations of behavior exhibited by these individuals and assumptions of what professionals believed these individuals may or may not be capable of doing. Barr further utilized the terms idiot and imbecile to formulate the term idio-imbecile to classify the individuals who did not quite meet the specifications of an idiot or imbecile but rather deemed as “improvable in self-help and helpfulness, but trainable in very limited degree to assist others” but still requiring asylum care. The idio-imbecile shared common characteristics of the two as he described, “The idio-imbecile, hardly a step-in advance of the idiot, stands, as his name denotes, midway between idiot and imbecile, sharing the physical characteristics of the former, with something of the limited mental capacity of the lowest grade of the latter,” (1920). Furthermore, was the moral imbecile, defined as “mentally and morally deficient” and classified as well into three grades, low, middle and high. This classification was also known as “defective delinquents” due to their though display of deviant behaviors as “psychic forces are marker, are peculiar and distinctive features, the perversion or complete absence of the moral sense being revealed according to the character of the grade in which it appears. Indeed, this class is so crooked that it is parallel to nothing, and those who belong to it are morally blind just as other children are physically blind,” (1920). Barr described this class of mental defectives as enjoying bringing attention to themselves through mischievous actions and pranks.
Barr warned that, “Sometimes their perversions are marked by a superficial cleverness and good looks, and it may be, in a few cases, great physical beauty; and the stigmata of degeneration may not be apparent-or at least only to those who have carefully studied the subject-though it is always there,” (1920).

As noted, Barr’s definitions included detailed descriptions of exemplary case studies emphasizing the differences of each classification as well as include detailed backgrounds and prognosis for each condition. His definitions led to the emphasis that a mental “defect” associated with feeblemindedness could be classified as either mentally, morally, or both and commonly these defects were associated with degeneration. Like most classifications systems of this era dividing feeblemindedness into three subcategories (i.e. idiot, imbecile, and moron), the developing social services system primarily was concerned with whether the individual with an intellectual impairment was deemed needing supervised care versus people who may be more capable of living within their community. Ironically though, it was the latter that was a greater threat to society due to their weak morality and poor judgement making. Additional illustrations and depictions of these subgroups, commonly denoted individuals with intellectual impairment as severely inferior to others in society, emphasizing the stigmata of their “degeneration” and lower states of functioning.

As the conceptualization of intellectual disability shifted from previously emphasizing one having weak mindedness, the conceptualization now emphasized the underlying issue was due to a defect of the mind leading to the common use of the terms mental deficiency, mentally defective and mental subnormality now labeling intellectual disability. Wehmeyer described this shift, “The nature of the “defect” of the mind (mental
deficiency) was inferior performance (mental sub normality) [in comparison to normalized standards], characterized by mental slowness (mental retardation) (Wehmeyer, 2013). This shift in concept model adopted a functional component relating to adaptive behavior. As the name and classification changed, it continued impacting how society not only identified and described the condition, but now it was significantly affecting how society addressed intellectual disability in forms of treatment. Families affected by this condition at this time solely relied on the advice of professionals specializing in this field. However, professionals explained that family members would be unable to provide adequate care and treatment for their loved ones with an intellectual disability, therefore, justifying practices such as the involuntary sterilization and institutionalization practices performed by these professionals.

To better understand the level for which an individual with an intellectual disability would be capable of living, French psychologist Alfred Binet and his student, Theodore Simon published one of the first intelligence tests, the Binet-Simon test, which identified levels of intelligence for children who demonstrated notably below average levels of intelligence for their age. This test was based upon a baseline of intelligence that was established based on results from testing a wide range of children varying in ages on various measures, and then results were categorized first by age and then by highest levels of achievement. Common levels found in same age groups were then considered to be the normal level for that age. Since this testing method compares one’s ability to the common ability of others at their age, the general practices of this test were easily transferable to testing different populations. This test quickly gained popularity in the psychology community, and eventually led to the development of the Stanford-Binet
Intelligence in 1916, a localized version of the exam for people in the US. This version consisted of revisions made to not only to help identify individuals with intellectual impairments, but as well as identify individuals who possibly had above average levels of intelligence. Approximately five official editions have been created and implemented since the implication of the original version in 1916 and this test continues to be utilized in effectively assessing all levels of ability in people in a broad range of ages.

Practices such as institutionalization and involuntary sterilization, were proposed based on the notion that the growing identification of individuals with intellectual disability were no longer a small burden of their community, but rather becoming a societal problem placing the general progression of society at risk. As terminology began emphasizing the deficiency of a physiological structure, science began focusing more on finding a biological cause and explanation for the occurrence of intellectual disability. One major scientific contribution was the incorporation of conclusions based upon the Mendel experiments of biology and heredity. American eugenicists assumed that complex human characteristics were comparable to the characteristics found in Mendel’s plant experiment, intelligence was inheritable, therefore, isolation, involuntary sterilization and ultimately eugenics would solve this identified societal problem (Noll, Smith, & Wehmeyer, 2013). The application of the genetic theory to the heritability of intellectual disability was the narrated in case studies such as the Kallikak family and the Jukes. These narratives were written in efforts to make significant strides in their agenda to segregate individuals with intellectual disability in large institutions, away from their communities and eventually establish laws to forcibly sterilize people as seen as having ID. Despite the number of mega-institutions continuing to grow in numbers and be
heavily regulated by state agencies, they were grossly underfunded, understaffed and immensely overpopulated. The Great Depression exacerbated these conditions and resulted in dehumanizing conditions, violations of human and civil rights and a diminution of basic human dignity (Noll, Smith, & Wehmeyer, 2013). It was during this time, that the nation overall was greatly struggling, and families were forced to depend on the state for assistance. As more and more individuals were institutionalized, institutional administrations began to recognize that institutions were not equipped to provide one the level and quality of care and two, adequate space for the rapidly increasing intakes.

As primary terminology naming the condition shifted, so did the sub classifications of intellectual disability based on one’s alleged ability for growth and development: educable, trainable, or custodial. Distinctions between the classes were similar to the former, as it was dependent based on the person’s presumed ability to complete or learn a task, but greater emphasis was now placed on adaptive skill deficits. Examples of these skills includes significant limitations in one’s ability to exhibit self-care, home living, social skills, community use, functional academics, and leisure activities. Educable was the classification utilized for individuals, professionals believed could be taught academic skills, such as reading, writing, and mathematics. Trainable was meant for individuals who professionals believed could benefit from learn basic living skills, such as dressing, self-care, and feeding. Finally, custodial was the classification commonly used for individuals who professionals believed would be significantly limited in developmental abilities and often received very few habilitative learning opportunities.

Edgar Doll, an American psychologist, illustrated mental deficiency in terms of limited adaptive behaviors related to life skills, proposing six criteria for mental
deficiency, “1. Social incompetence; 2. Due to mental subnormality; 3. Which has been developmentally arrested; 4. Which obtains at maturity’ 5. Is of constitutional origin; and 6. Is essentially incurable,” (Wehmeyer, 2013). The incorporation of social incompetence as one of the criteria, he operationalized its significance through development of the Vineland Social Maturity Scale, espousing the term social maturity in reference to adaptive behaviors related to life skills such as communication, self-help, locomotion, occupation, self-direction, feeding, and socialization. Utilizing this scale, it measured behavior on a continuum spectrum, indicating specific areas for which an individual demonstrated difficulties versus abilities. This new notion emphasized the functional component of intellectual disability, subtly incorporating the understanding of one’s abilities, ultimately beginning the next shift in naming and classifying the condition.

At the end of World War II, late 1950s and beginning of early 1960s, the term mental deficiency already began to gain significant negative social connotation and was being replaced more commonly with the use of mental retardation. In 1959, the American Association on Mental Deficiency released its fifth manual on terminology and classification consisting of the first official definition of the term mental retardation as “the sub average general intellectual functioning, which originates during the developmental period and is associated with impairment in one or more of the following: (1) maturation, (2) learning, and (3) social adjustment,” (Heber, 1959). The manual specifically identified maturation, learning and social adjustment as components of adaptive behavior and in an updated supplement of the manual released two years after the fifth edition, the issue repeated the definition, however replaced the phrase, “in one or more of the following:” with “in adaptive behavior” (Heber, 1961). Therefore, the new
definition read as “the sub average general intellectual functioning, which originates during the developmental period and is associated with impairment in adaptive behavior: (1) maturation, (2) learning, and (3) social adjustment,” (Heber, 1961). New classifications of the term mental retardation were adopted replacing educable, trainable, and custodial. These terms included mild instead of educable; moderate, instead of trainable; and severe, instead of custodial.

Concurrent with the evolvement of naming, classification and description of intellectual disability, parental perception of appropriate care began to shift as well. Previously, the perception of intellectual disability was solely crafted by professionals in efforts to solidify their role in the diagnosis and treatment of individuals with ID and this was communicated via the terms, idiot, moron, imbecile, and degenerate. The message conveyed was extremely negative which ultimately led to the inhuman practices seen in the early twentieth century, however, parents were forced to believe this was what was not only best available, but the best option for the future for their children. The new perception of intellectual disability began to unfold as iconic figures, such as Roy Rogers and Dale Evans, delivered a very different message. In a text written by Evans, Angel Unaware, she writes through the eyes of their daughter Robin, who was diagnosed with Down Syndrome. Through this text, it described the lived experience of intellectual disability and ultimately that children, like her, should be accepted in their community and loved at home (Wehmeyer & Schalock, 2013). It was texts such as this that promoted the idea that individuals with disabilities are not just a result of parent’s malfunctioning genetics nor failure of the parent’s actions, but rather they belong with their families and to be members of their communities. Advocacy though was slow in
developing for people with intellectual disability. Much of the work done was completed by allies, such as parents, friends, siblings, and others with a strong connection to someone with an intellectual disability, as they fought for awareness and acceptance of individuals with an intellectual disability within their community. The disability rights movement began to develop in the 1960s as a collective of people with different kinds of disabilities coming together to fight for improved equal rights. Allies and stakeholders called for change in practices resulting in discrimination and recognition that people with disabilities are the best experts on their needs, differing from once was thought to come strictly from professionals.

Terminology remained stagnant for quite some time after the implementation of the term mental retardation, however, perception of individuals with intellectual disability and the treatment of those with intellectual disability continued to slowly evolve. The most significant phase was the initiation of the disability movement that marked self-advocacy by individuals with disabilities emerging in the early 1970s and following through the 1990s via civil rights and social movements. This phase included events such as the independent living movement, disability rights movement, process of deinstitutionalization, implication of Americans with Disabilities Act, and development of the normalization principle. Organizations also began to respond to requests of self-advocates to incorporate the inclusion of individuals with intellectual disability in involvement of chapter activities in a meaningful manner, regardless of whether governmental, professional, political, or parent-focused affairs. Self-advocacy movement leaders rapidly formed becoming recognizable representatives of organizations and began changing the way individuals with intellectual disability were socially perceived. As the
importance of self-advocacy of people with intellectual disability grew, the call for obsoleting negatively connoted language began to gain significant importance in the abandonment of previous terminology, such as moron, idiocy, defective, and retardation from political and social language.

As previously discussed, one can see the slow development of the functional model of disability beginning to form in the mid 1900s, it was not, however, until 1992, when the American Association on Mental Retardation’s, now known as the American Association of Intellectual and Developmental Disabilities (AAIDD), Terminology and Classification committee officially adopted the functional model of intellectual disability, or mental retardation at the time. This model proposed that disability manifested as a state of functioning that existed within the person’s abilities and limitations and the context for which a person’s daily activities occurs. What was significant about the adoption of this specific model was it formally recognized the relationship of human functioning and the context for which it occurred, the person-environmental context. In this new publication of the classification of intellectual disability, what was dramatically different in the comparison of the construct of mental retardation and intellectual disability, was that this new construct, "the former (mental retardation) viewed disability as a defect within the person, while the latter (intellectual disability) views the disability as a the fit between a person's capacities (and implied in that is limited capacity as a function of neural impairment) and the context in which the person is to function," (Ferguson, & Wehmeyer, 2013). However, despite the change in model of disability, the committee did not formally change the terminology labeling intellectual disability.
Similarly, the beginning for the call for change in terminology began to take place during this time period. In 1991, The National Association for Retarded Citizens changed its name to The Arc, dropping the associated acronym in response to the growing stigma surrounding the word "retarded". However, it was not until the early 2000s where one starts to see the transition from the term mental retardation to intellectual disability beginning to take place. The term intellectual disability was first initiated into executive order by President George W. Bush when he signed the executive order to rename the President’s Committee on Mental Retardation to the President’s Committee for People with Intellectual Disabilities in 2003 (Ford, Acosta & Sutcliffe, 2013). The transition in terminology was then formally enacted into law by the US Senate and the House of Representatives (S 2781-111th Congress, 2009) and President Barack Obama in October of 2010 via Rosa’s Law and continues to be the most socially and politically acceptable term to date. This law mandated the change in terminology to reflect references of mental retardation to read as “an individual with intellectual disability” in all affecting laws, government agencies, various public and private organizations and related federal, health, education and labor agency regulations. In congruence, the American Association on Mental Retardation is now the American Association on Intellectual and Developmental Disabilities.

In addition, advocacy for continued acknowledgement and use of the term intellectual disability to be implemented within definition and diagnosis of the disorder itself within professional and common language continues within the US. Both the World Health Organization and American Psychiatric Association have drafted their newest editions to the International Classification of Diseases (ICD-11) and the Diagnostic and
Statistical Manual of Mental Disorders (DSM-5) adopting the term intellectual disability in response to the more common use of the term within the medical field as well as the increased percentage of services and supports who receive funding based on the diagnostic criteria found for this disorder. There has also been discussion of the use of the phrase “disorders of intellectual development” steering away from the use of the word disability, recognizing the differences in ability that can range from person to person, regardless of the standard of normalcy.

**Part II: Influence of Terminology Upon Sociocultural Perception and the Impact on Social Services and Political Movements**

Terminology surrounding intellectual disability in naming, defining and describing plus sociocultural perception have had an interdependent association contributing to experience of intellectual disability by all stakeholders, including persons with an intellectual disability, family members, friends, professionals specializing in this field, and the US society. Further explanation of this relationship is demonstrated through significant events including and impacting individuals with an intellectual disability through recent history. Social and cultural factors have had a significant impact on this relationship. Many even argued that intellectual disability is a socially constructed condition based on the standards of what is deemed as normal versus deviant continually shaped by conditions that exclude full participation within one's community (Ginsburg & Rapp, 2013; Tasse, 2013; Albrecht, Seelman, & Bury, 2001, Manion & Bersani, 1987). However, there are also momentous historic events and movements that have erected in response to terminology used to label, classify and describe intellectual disability that demonstrate the latter half of the relationship.
When examining terminology involving intellectual disability, analyzing sociocultural factors during a specific era can give clues to sociocultural perception of the idea of general disability, and the role an individual with intellectual disability may have occupied during this time. The socially constructed theory of intellectual disability in the US has been theorized based on the notion, culture greatly influences societal norms, values and beliefs amongst its people. Likewise, the construct of intellectual disability can also be understood in relation to the social determinants of health, including where one lives, works, learns and participates in leisure can affect a wide range of outcomes related to intellectual disability, both positively and negatively (Social Determinants of Health, 2018). So taking not only the terminology specific to solely defining intellectual disability, but also, terminology describing these conditions for which people with intellectual disability were/are living in during a given time, can indicate the conceptualization of intellectual disability both in clinical definition, sociocultural perception, and personal experience. For instance, a professor of disability studies, Michael Oliver discusses the social model of disability in which the experience of disability is greatly influenced by, “…society’s failure to provide appropriate services and adequately ensure the needs of the disabled people are fully taken into account in its social organization,” (1990). It is in this instance we see the development of the ideologies related to able- versus dis-abledmindedness, and the relation for which the empowerment of the ideology of the *able-body* begins to develop (Riddel & Watson, 2014; Oliver, 1990). These ideologies of normality, able-bodiedness and able-mindedness, he stated, dominant the social culture and then become the standardized norm of ideal characteristics of individuals. Individuals who lack in possessing a
desirable ability, it becomes recognized as personal tragedy, which others have defined as creating the natural attitude defining the order social existence creating those defined as able-bodied superior to those who are labeled as disabled. So dependent on the social conditions for which surround persons with intellectual disability, in addition to what society has classified as normal versus abnormal, the entirety of the conceptualization of intellectual disability is impacted.

Language for which we use to classify and describe intellectual disability has greatly contributed to the discernment of abled versus disabled. Medicalization paved the grounds for which medical professionals and others commonly dictate the standard of norm and it continues to manipulate popular perception of the conceptualization of able-bodiedness and able-mindedness. The language for which professionals specializing in this field from the late nineteenth century to present day have described conditions such as intellectual disability has significantly impacted members for which are labeled as having an intellectual disability. As medicalization has significantly influenced the sociocultural aspect of society in the US, it is seen as the site of power struggles between different social groups, particularly able-bodied versus disable-bodied and who classifies into each category. Some questions begin to arise when determining what constitutes as a disability versus ability: “When does a physical difference count, under what conditions, and in what ways, and for what reasons?” which McDermott and Varenne argue are deeply cultural issues and are dependent on how the impairment is noticed, identified and made consequential (1995). It is for which the lives of those living with difference in intellectual levels comparative to the societal norm are either enabled or disabled by those surrounding them.
The evolution of terminology used to identify, describe and diagnose intellectual disability demonstrates the interrelating influence of sociocultural perception and understanding at a given era of time. Historically, records show that whenever a new name has been proposed and introduced to identify and describe an existing condition, the previous name was being abandoned due to the stigma and negative connotation those names have acquired (Tasse, 2013). Similarly, if terminology used within the definitions and descriptions had a negative connotation or negative meaning, individuals began to formulate a negative understanding and perception of the condition, ultimately resulting in the development of a plaguing stigma surrounding that condition. Notably, during the shift from the nineteenth and twentieth century, and again in the shift from the twentieth and twenty first century, terms used to identify, classify and describe intellectual disability have changed numerous times in response to changes in social importance and recognition. When we see these changes in terminology utilized to identify, classify and describe a condition, we can ask ourselves what were the events leading up to this change, how does this change influence and involve stakeholders, and how do these changes impact our society overall.

In the mid-nineteenth century, we see a dramatic change in socioeconomic structure from what was once a largely agricultural economy to a manufacturing industrialization of US cities. As waves of immigrants began to flood the country, the production of goods and services massively increased drastically urbanizing city settings. Socially, industrialization challenged individuals and families alike to realign priorities to emphasize growth and prosperity. Participation in public education became a norm instead of a luxury for all elementary-aged children and higher education and research
became established to allow for social and economic expansion of community and states. Advancement in production and rapid growth in urban populations, sociocultural standard of norms and political structures were rapidly evolving calling for significant attention from policy makers and social reformers. People who were poor, ill, or disabled, in terms of the newly forming standard of norms, began to be recognized as social problems of disease, immorality and poverty (Wehmeyer, 2013). This initiated the separation of those identified as with or without intellectual disability. Prior to this period, very few instances of intellectual disability, otherwise described as idiocy during this time, were remarkably noted in historical records and often the condition was only described amongst the lower classes and within abstract writings of physicians and philosophers. This absence of descriptions of intellectual disability can be believed to represent society’s neglect and invisibility of the social condition during this that time; however, amidst these drastic socioeconomic and political changes, people who were identified as idiotic during this period of prosperity, were becoming increasingly recognized as members of a growing population identified as being. During this era of societal evolution, the gap between the productive versus debilitating populations began to expand exponentially, resulting in the call for improved identification and conceptualization of idiocy and the prognosis for which this phenomenon may have on an individual, a community and society.

The Industrial Revolution brought new ways of doing and thinking about things. New production methods brought upon new ways businesses went about manufacturing products and resulted in a dramatic change for which the way people lived. The establishment of small towns and cities began to increase exponentially in size resulting
in the increasing number of workers, companies needed to operate their new factories. However, these towns and cities were unplanned and unorganized resulting in extremely poor living conditions: overcrowding, poor sanitation, high crime and exploitation of labor. During this era, efficient production of goods was valued, but human well-being was not, especially amongst the lower class. Although state institutions and other related “services” were developed for individuals with disabilities, most cities and towns were ill-equipped to accommodate or even to recognize the economic, health and social hardships suffered by many people, especially those with disabilities (Brown & Radford, 2015).

Solutions to problems posed by those identified as having a disability and medicine overall, were conceptualized in ways similar to how products were now being produced; the human body could be seen as a structure operating based upon its components inside, and when a disability presents its self, it is due to the failure of functioning in one of its physiological parts and/or systems. Institutionalization was first proposed based on the notion, if individuals with disabilities were unable to thrive in the workplace and living environments within the developing inner cities, asylums and almshouses would provide a place for which they could be rid of those stressors. However, like cities and towns were rapidly growing in population, so were these institutions and quickly were becoming overcrowded and grossly underfunded. The initial notion of an institution, first proposed by Dorothea Dix, was in efforts to separate individuals with mental illnesses and intellectual disabilities from imprisonment residing with individuals who committed crimes. This notion was promoted at first by people with good intention, offering a place of peace of mind to families where loved ones could be
cared for. Asylums and public institutions were an innovative answer to the question posed of how would society care for these individuals. Through a statewide investigation, Dix had founded that the current state of prisons, where individuals with mental illnesses and intellectual disabilities were living alongside criminals, were greatly underfunded and unregulated described as (Dix, 2006),

“…dwelling in circumstances not only adverse to their own physical and moral improvement, but productive of extreme disadvantages to all other persons brought into association with them…The condition of human beings, reduced to the extremest states of degradation and misery, cannot be exhibited in softened language…the present state of Insane Persons confined within this Commonwealth, in cages, closets, cellars, stalls, pens! Chained, naked, beaten with rods and lashed in obedience.”

Dix pleaded with legislature in reform for the conditions for which these individuals were subjected to living in to be replaced with the development of public asylums and state run institutions. Between her investigative work describing the horrid conditions for which these individuals were experiencing, and Dr. Samuel Gridley Howe, another social reformer, they were able to set aside 5 million acres of land for the building of public state institutions. Dr. Samuel Gridley Howe also contributed to the development of sheltered workshops and training schools with the intention for individuals with intellectual disabilities to develop skills necessary to be able to return to their families in their own communities. However, because of the economic troubles faced by all of society after the Civil War, there were very few opportunities for individuals with disabilities to become employed. This resulted in the initial
overpopulation and decrease in funding of state institutions as individuals were not returning to their communities causing them to permanently reside in these conditions, and now even more people were becoming increasingly identified as having an intellectual disability as diagnostic efforts began to improve. It was during this time, the creation and implementation of state institutions for individuals with disabilities and mental illness were on the rise. Some have even defined this time as the institutional era, joining the foundational structure of a state institution, in addition to the state of mind of society reflecting their perception upon people with disabilities (Brown & Radford, 2015). One way some have conceptualized this shift in societal values is through the lens of modernity (Radford, 1994). This involved the criticality of the idea of the market and more so, the general foundational structures based upon progression, creative destruction, surveillance and rational bureaucracy and technique (1994). With these changes to society overall, brought upon even more significant changes to individuals with developmental disabilities: creation of new daily challenges and the communal response to these challenges.

For people with an intellectual disability, this time period was filled with mixed intentions. The development of asylums, almshouses, and state institutions were first constructed in efforts to provide treatment and improved living conditions for these individuals away from the unhealthy conditions experienced in the rapidly urbanizing cities. It was concurrent with the offering of public education, attempting to build self-contained sites offering opportunities for employment, skill development and social support. On the other hand, science was rapidly advancing, medicine and psychology specifically focusing on improving understanding intellectual disability was increasing
and research began to focus on the heredity of intellectual disability, human evolution and variation. With this combination, institutions began to be utilized as the physical site of segregating these individuals from their own communities.

The construct of idiocy was continually evolving creating the movement toward improving identification and conceptualization of this phenomenon gaining the particular interest amongst psychologists, physicians and social workers, eventually leading to the professional specialization and medicalization of intellectual disability. William Ireland, a physician and superintendent of an English asylum, crafted a general definition for idiocy emphasizing it as a developmental condition originating in childhood, “Idiocy is a mental deficiency, or extreme stupidity, depending upon mal-nutrition or disease of the nervous centers, occurring either before birth or before the evolution of the mental faculties in childhood,” (Ferguson & Wehmeyer, 2013; Ireland, 1877). Ireland was known to be most concerned with the origins of idiocy, with emphasis on the pathological influence that paved way for even greater classifications of the condition: 1) genetous idiocy; 2) micro cephalic idiocy; 3) eclampsia idiocy; 4) epileptic idiocy; 5) hydrocephalic idiocy; 6) paralytic idiocy; 7) cretinism; 8) traumatic idiocy; 9) inflammatory idiocy; 10) idiocy by deprivation (Ferguson & Wehmeyer; 2013; Ireland, 1877). Each of these classifications of the origins of idiocy offered a scientific approach; further exemplifying the new-aged medicalization trend of this condition. It furthered common belief that there was direct correlation between a defected or defaulting physiological system within one’s body that was causing such behavior. Similarly, Isaac Kerlin, a first generation asylum superintendents at the Pennsylvania Training School for Feeble-Minded Children and prominent figure in the Association of Medical Officers of
American Institutions for Idiotic and Feeble-Minded Persons (now known as the American Association on Intellectual and Developmental Disabilities), focused on the classifications of levels of functioning, further categorizing the levels of “idiots and imbeciles” and creating two other categories “idio-imbeciles” and “moral imbeciles”. Each of these categories were further defined based on the observable behavior displayed by the individual.

The language used to describe these classifications even further, played a significant role in impacting the perception of the prognosis of the condition. What was once an optimistic outcome dependent on the type of training, treatment and support received based on their classification, slowly shifted toward a pessimistic overview, divorcing prior prospect of cure and remediation regardless of the classification. It was for which the language utilized to describe these conditions, significantly impacted not only the general perception of the condition, but the individuals who were believed and identified as having such. Martin Barr described this perceptual shift in relation to the increasing pressure for need of confinement for not only the individual’s well-being, but for society’s safety as well. It was becoming increasing apparent the need for direct supervision as emphasis was now placed on the idea of defect, yet Barr described this partially due to the miscomprehension of terms used to describe this condition. With further classification of what was once a broad umbrella encompassing such a wide range of characteristics of not only intellectual disability, but immorality, criminality, other mental illnesses and health conditions, the better professionals believed to understand the condition for which they were observing. However, it was common conception, similar to Barr’s, that started to gain popularity of the majority and impact the shift into finding a
solution to what seemed to be an unfixable concern, “The mistaken idea of seeking a cure for mental defect doubtless has its root in a misapprehension of terms and in confounding idiocy with insanity. In the latter, there may be found cure as for any other disease; but idiocy is not a disease, it is defect, and one might as reasonably talk of restoring limbs to one born without them as curing a defective brain,” (Barr, 1904).

Professionals began seeking improvement in all aspects of this condition; improved naming, describing, classification, estimate of prognosis, and proposals for solutions, partially presumed to be caused by the increasing pressures individuals with intellectual disability were causing on society as the changes in production were taking place and states were held responsible to responding to the rapid growth of these communal maladies. The first step was finding clinical terminology specifically naming and defining intellectual disability, and detaching the condition from its previous umbrella term, insanity, via the term “feeble-mindedness”. Feeble-mindedness became the new umbrella term for which imbecility, mental defectiveness, moronism, and idiocy fell under. Emphasis that was once placed on identifying, naming and general describing the condition, was now shifting to how professionals should be specifically classifying and distinguishing between types of intellectual disability and finding a cure/solution to this disorder/societal problem. What was once believed to be a result of an individual's parents' either violating natural laws and/or enactment of sins causing a curse upon their offspring (Howe, 1858), the cause of intellectual disability began to shift as well.

Health professionals, such as physicians, psychologists and social workers, specializing in intellectual disability studies, started to develop a foundation of research related to heredity, evolution and human variation in hopes of improving understanding
of ID overall. The heredity agenda was driven by so-called pedigree studies focused on intellect being an inherited trait. The earliest case study was written Richard Dugdale, a New York social reformer who was a member of the New York Prison Association. He had written The Jukes: A Study in Crime, Pauperism, Disease and Heredity, outlining a study on criminal heredity based on investigative work while interviewing prisoners in an upstate New York jail. Dugdale had founded that many of the inmates were related to each other, which then led him to trace their lineage back to a single family. From here, he estimated the economic cost resulting from the multiple generations of criminals, dependency, and immorality (Murphy, 2011). Due to the complexity and intricate details outlined in this report, Dugdale’s study sparked interest of other social reformers, professionals and politicians convincing them social deviancy indeed was inherited and could result in cumulative degeneracy greatly negatively impacting the general public.

Dugdale’s work initiated similar studies furthering detailing the “correlation” between criminality, poverty, and incompetence in the same instance of the initiation of the eugenics movement in the United States. Medical and scientific research, such as the Jukes and other related studies, offered authoritative justification for contributing to the development of segregated institutions and relating policies eventually leading to eugenic practices, such as sterilization and prohibition of marriage of individuals with intellectual disability. Building upon the general philosophy that intellectual disability was an inheritable condition and that separation and segregation of these individuals identified as having an intellectual disability from their communities could potentially solve this emerging societal problem, one can see the emerging values and ways of thinking that expanded dramatically during the Industrial Revolution.
Transitioning into the twentieth century, the eugenics movement began to transcend as more and more authors began writing about the correlation between feeblemindedness, social deviance, and hereditary. Medicalization of this condition initiated the evolution of construct the condition as, “the cause of defectiveness, dependency, and deviance that was transmitted from parent to child through some combination of biological and environmental factors,” (Murphy, 2011). Through this foundational structural description, the defect, defiance and social deviance was a direct result of a defected physiological system. It began the recognition of genetic involvement, in addition to environmental factors, however, due to the increase in studies such as the Jukes, often time the interplay of environmental factor was minimized. This led to societal connotation of this condition as one that is undesirable and incompatible with the modern changes occurring within communities, and one that could be socially controlled via segregation, sterilization and marriage restriction (Murphy, 2011; Carey, 2003).

The use of institutions was already in place for individuals founded of having mental illnesses, including intellectual disabilities. The eugenics movement, which brought upon the theory that the human population could be improved upon the notion of controlling desirable human qualities based on their associated hereditary traits, began to gain popularity as a solution to this growing societal problem. Professionals maintaining superior control, oversight, and knowledge of intellectual disability, at this time, quickly joined into these efforts. What was once an effort to provide a supportive and learning environment for individuals with intellectual disabilities with intentions to return to their
communities with skills necessary for daily living and work, now institutionalization was now intended for segregation of these individuals away from their communities.

In pseudo-case studies, such as the Juke Family or the Kallikak family, social and scientific theories were offered in attempts to address the issues surrounding intellectual disability in hopes of bringing answers to the public issue. It was within this context where we start to see the perception of ID shift as the fields of medicine, new explanations to what was once a mystery began being offered. In Henry Herbert Goddard's text, The Kallikak Family, a Study in the Heredity of Feeble-Mindedness, he references both the Kallikak Family and the Jukes Family story first published by Richard L. Dugdale (Goddard, 1912). In discussion of the Jukes family, Goddard discusses his correlation between criminality and feeble-mindedness, in which the best reasoning for which criminals are made is due to being feeble-minded (Goddard, 1912). Through this discussion, he analyzes that when individuals with an intellectual disability are children they are placed in schools with their peers but due to their "mental defect" are unable to learn anything of value or that can assist them in making a living when out in the community, which ultimately leaves them dependent upon others. However, due to the hereditary nature that Goddard believes intellectual disability possess, a great majority of these individuals do not have relatives who are neither willing or capable to take care of them, therefore, the responsibility then becomes a "direct burden upon society" (Goddard, 1912). He further classifies this group of individuals into two main subgroups based on temperament,

"Those who are phlegmatic, sluggish, indolent, simply lie down and would starve to death, if someone did not help them. When they come to the attention of our
charitable organizations, they are picked up and sent to the almshouse, if they cannot be made to work. The other type is of the nervous, excitable, irritable kind who try and make a living, and not being able to do it by a fair day's work and honest wages, attempt to succeed through dishonest methods. "Fraud is the force of weak natures." These become the criminal type."

Descriptions such as this had a significant impact upon how society not only viewed individuals with an intellectual disability, but also upon how they treated individuals with an intellectual disability. People believed individuals with an intellectual disability were incapable of learning any sort of skill that may not only assist them personally in making a living, but also contribute to the newly prospering economy and developing working class. Through descriptions such as Goddard's, it demonstrates the diminished value that individuals with an intellectual disability were perceived to have within their community, therefore, very limited accommodations were made for these individuals to even potentially have the chance of learning some sort of skill.

These explanations for such behavior, including criminality that Goddard believed was caused by those with an intellectual disability, were supported by evidence related to genetics and the Kallikak family. The Kallikak family study followed a woman in Goddard’s institute, Deborah Kallikak (pseudo-name for the real Emma Wolver) and her distant great grandfather, Martin Kallikak. Goddard created a detailed pedigree study, utilizing similar principles based on Mendel’s laws, detailing her family’s lineage. Martin Kallikak, her distant great grandfather, was founded to have two separate families with two different women, one being his wife with no previous history of developmental disabilities and another with a woman who was believed to be feeblely minded. The
family for who Martin had with his wife, went on to be prosperous and successful individuals, free of any intellectual impairment; whereas the other woman Martin had a relationship with, they had a son, Martin Kallikak Jr., who grew up and went on to have children who resulted to be considered poor, mentally ill, delinquent and intellectually disabled. He constructed intricate family trees detailing the family lineages displaying the comparisons between each side with incorporation of Mendelian ratios of inheritance of dominant and recessive genes and their associated traits, particularly feeble-mindedness. Goddard was interested in the heritability of feeble-mindedness and often wrote of the invisible threat of recessive genes that marked feeble-mindedness that could be carried by individuals who were perceived to be healthy and intelligent.

During this time, it must be remembered, that Mendel's laws were a significant contribution to scientific advances occurring during this era, and particularly to the field of eugenics in justifying human characteristics, such as intelligence, were inheritable. The starting statement of the discussion of findings and conclusions drawn from the study reads as, “No one interested in the progress of civilization can contemplate the facts presented in previous chapters without having the question asking why isn’t something done about this?” (Goddard, 1912). Within this statement alone, phrases such as “why isn’t something done about this” after discussing the description of feeblemindedness during this time period, creates a negative inference that this is a problem that must be solved. It is for which the conclusions Goddard presumes is identifying "feeble-mindedness [as] largely responsible for these social sores," in which he is referring to the "bad side" of paupers, criminals, prostitutes, drunkards, and examples of all forms of social pest with which society is burdened. Goddard furthered discussed proposed
solutions to effectively addressing this condition, in which he particularly stressed the need to be concerned with the "moron-type" of feeble-mindedness, as Goddard states these individuals would be more likely to bear children.

The method in which Goddard frames this societal issue was perceived by readers, both professional and general public, as a potential threat to the prosperity of growth of society due to the specific terminology used to one, describe the situation and condition of intellectual disability, but also in his proposal of follow-up. Identifying individuals as the “moron-type” and telling readers society is now faced with a “huge problem”, he went on to describe Martin Kallikak Sr.’s bearing of children as a “real sin of peopling the world with a race of defective degenerates,” which he continues to accuse the Kallikak children and grandchildren to continue committing the same sin over and over without any concern. The two issues that Goddard defined society as facing was the difficulty of knowing who was feeble-minded and the difficulty of how to appropriately take care of these individuals once they were identified.

Catalysts such as the Kallikak and Juke families’ case studies, only contributed more to the rapid decreasing in likelihood of individuals returning to their families. In one of the first leading texts discussing intellectual disability in the early twentieth century, Martin Barr published *Mental Defectives* (1904). This text was considered one of the first modern American-written texts on intellectual disability which Barr discussed terminology, classification, etiology, diagnosis and prognosis, treatment, and associated conditions. Barr had also discussed the significance of heredity in understanding the construct and impact of intellectual disability upon communities. The language used in this text is a significant reflection of the general perception of intellectual disability by
professionals which then was reflected to the public of how to generally understand this condition and its sub-classifications.

Within the first chapter, Barr describes and defines various titles of the term mental defect based on other languages’ synonymic phrases such as the Greek term iditas, Latin term Amentia, French term imbecile, and the English terms backward and feebly-gifted (Barr, 1904). As previously discussed, these terms were utilized in formulation of Americanized terminology to label intellectual disability. Barr described each term and their implication on the conceptualization of intellectual disability, and how each term was either accurately descriptive of the condition or if it was misleading and misrepresentative of what he perceived the condition to be. For example, Barr discussed the differences between the terms idiot and imbecile as, “The idiot intelligently sees nothing, feels nothing, hears nothing, does nothing, knows nothing. He simply lives alone- the solitary one. The imbecile, on the other hand, is able to see, to understand, and to discriminate in greater or less degree,” (Barr, 1904). Comparatively, the label “moron” was explained as, “…accepted though it be by some, does not cover the ground; while merely a name to the general public, to others it proves absolutely misleading. Derived from the Greek word meaning “silly”, it does not suggest remedy; whereas “imbecile,” implying weakness, feeble mentality and vacillation, leads directly to the possibility of strengthening and development,” (1904). It was comparisons and explanations such as these that offered the public insight into expectations, or lack thereof, they could place on individuals with intellectual disability. Unfortunately, the lack of expectations became of popular opinion due to statements such as, “The idiot intelligently sees nothing, feels nothing, hears nothing, does nothing, knows nothing,” implying as if the human is empty-
minded. It is important to recognize here, that descriptions as such were based solely on observations from others; personal accounts of those identified as having an intellectual disability were not considered in formulation of such descriptions. Thus, creating the superior versus inferior relationship between able-minded versus disable-minded.

Further into the text, he discusses the various etiologies of intellectual disability that were common amongst professionals during this time, heavily emphasizing the role of heredity and the importance of acknowledging the causation in future prevention of the potential spread of the disability,

“Again, a knowledge of causation and the assurance that many pathways lead to one condition of ill, idiocy-a condition which may be doubled and quadrupled through inheritance-should surely have its influence in inducing the adoption of means of prevention, wiser and more humane than those practiced by older nations to preserve the integrity of society. Not by destroying the life of the weakling but by refusing to allow him to perpetuate a maimed existence; next by a simplification of all life, be it in the pursuit of wealth or learning, of occupation or amusement- a conservation in lieu of dissipation of energy; then, after this elimination of harmful influences such selection in mating, as shall insure only survival of the fittest,” (Barr, 1904).

Shortly after this text was published, the eugenics movement continued to drastically expand in efforts to promote elimination of this population due to the devaluing of people with intellectual disability. The negativity surrounding the perception of what intellectual disability was based upon the terminology used to label and describe the condition, in addition to the offering of evidence-based support of heredity of
intellectual disability, the gap between able-minded versus disable-minded expanded exponentially. Outsiders feared intellectual disability as it was described as a plaguing condition. It was proclaiming statements such as, “in these [families] we have surely found evidence…that the hereditary transmission of imbecility is at once the most insidious and the most aggressive of degenerative forces; attacking alike the physical, mental and moral nature, enfeebling the judgment and will while exaggerating the sexual impulses and the perpetuation of an evil growth, a growth too often parasitic,” that called for stakeholders to take action representing the devalued role of individuals with intellectual disability during this time (Barr, 1904).

This identification and in-depth discussion of what was described as a societal problem stimulated discussion and calling for proposed solutions to prevent spreading of what seemed to be a controllable disorder in efforts to eliminate behavior that was seen as synonymous with intellectual disability such as poverty, sloth, crime and sexual profligacy. Goddard, Dugdale and other similar professionals, all urged for the public to call for changes which eventually led to the popularity and spread of the eugenics movement. The eugenics movement applied principles related to improving the genetic quality of the human population and social order. This concept was put forward as a popular proposed solution to the societal issues surrounding intellectual disability in attempts to eliminate defectives in efforts to overall improve the human race. Methods such as continued segregation, compulsory sterilization and prohibition of marriage began to take place as answers for this calling. Institutionalization rapidly began to increasingly expand as a proposed method of segregation from the general community and nationwide, institutions began to reach maximum capacity. Many states also began to
adopt sterilization laws for individuals that were deemed as unfit for the overall protection and health of the state and local communities, resulting in prohibition of procreation. For example, in the US Supreme Court case Buck v. Bell, 274 U.S. 200, the Court ruled that the Virginia Sterilization Act of 1924 permitting enforced sterilization of the unfit, including individuals with intellectual disability, as it was deemed it did not violate the Due Process clause of the Fourteenth Amendment. This allowed the superintendent of the Virginia State Colony for Epileptics and Feebleminded, Dr. Albert Sidney Priddy, to sterilize an 18-year-old patient identified as being feeble-minded with a mental capacity similar to a 9-year-old according to IQ testing at that time. Dr. Priddy argued that the patient in question possessed a genetic threat to society as members of her family had record of prostitution and immorality and she eventually went on to have an illegitimate child, ultimately leading to her involuntary sterilization.

Actions related to support of the eugenics movement denied basic human and civil rights to those identified as having an intellectual disability. This left this group of individuals to be living in horrendous living conditions due to the rapidly increasing populations within institutions. Despite the upsurge in populations within these institutions, more institutions were not built due to the little funding available and the lack of regard people had towards individuals with an intellectual disability and/or mental illnesses. On a sociocultural scale, members of the able-minded class dominated members classified as having an intellectual disability; all decision-making was based upon judgements made by professionals both related and unrelated to the specialization of disability of what was deemed best for this group of people. In reference to Bourdieu’s theory of habitus, people act in ways that are deeply ingrained within based upon habits,
skills, and beliefs due to their life experiences and individuals will interact with those who share similar symbolic elements (Riddle & Watson, 2014). Social inequalities between these two classes continued on as individuals with intellectual disability were deemed inferior and needed to be cared for, away from the general public, in efforts to limit their influence upon those deemed as able-minded. Bourdieu suggests that as we navigate our social environments based upon our habitus, so for those socially identified as being disable-minded, they would have a difficult time navigating an able-minded’s social environment as these two social classes do not share the same habits, skills and intellectual beliefs. However, if we go back to examining the ideology of disability as a socially constructed concept, it is for which our cultural creation of the standard of norms are creating these separate understandings of habitus and there for oppressing individuals with intellectual disability from accessing similar life experiences as those without an intellectual disability.

In the late 1930s, all Americans were subjected to the financial effects of the Great Depression. As institutions continued to grow in population size in response to professional opinion, the inability for families to now meet the financial needs of their children with disabilities began to exponentially grow causing even more families to choose institutionalization for their children in hopes for receiving special education services and support there. However, as the US entered World War II, many of the attendees at these institutions were also drafted, leaving an increasing shortage of workers to properly staff the growing institutions. As previously discussed, institutions were once intended for training and education in daily living and work skills, but as enrollment increased, this commitment to education was quickly abandoned. However, as
the shortage of staff became quickly apparent and the rising costs to meet the needs of the growing populations were revealed, institutional self-sufficiency was promoted. Individuals that were once hoped to return to their communities with skills necessary to lead semi-independent lives, those were skills were now focused on providing free labor for the institution they were living within. States utilized this free labor as a means of reducing funding and staffing deemed necessary for institutions to continue. So, as the lack of proper care and support continued to increase, conditions quickly worsened at rapid rates.

Intellectual disability during this time was a stigmatizing condition causing oppression and marginalization for those recognition as having such. Individuals with an intellectual disability were essentially dehumanized in nature as their basic human rights went unacknowledged and they were left in the hands of professionals that deemed their condition as devalued and unfit for society. These individuals were rid from everyday life activities within their own communities and placed in institutions in rural areas away from the view of most people. The negative persona sculpted by medical professionals specializing in intellectual disability studies skewed public sociocultural perception of intellectual disability. The language chosen to label and describe this condition is a reflection as such, and the resulting perception led to the surrounding decisions, events, and even policies impacting in their social, emotional, behavioral, and physical treatment.

As World War II ended, the US economy began to improve fostering improved opportunities for families to care for their children with disabilities. Several texts were published by prominent pop figures detailing the hope, possibility and potentials children with disabilities could have (Wehmeyer & Schalock, 2013). The deteriorating conditions
and vastly overpopulation of institutions became the target of social reformers creating national attention upon these pressing issues postwar. Scientific advances also continued to unfold several cures and vaccinations that resulted in debilitating conditions, such as polio and tuberculosis, creating a sense that intellectual disability could too, eventually have a cure. And the largest contributor of them all was the new understanding and awareness of disability as thousands of returning service individuals were returning home with physical and other related disabilities caused by involvement in the war. It was veterans who upheld society's moral obligation to provide support, services and the opportunity for remediation to successfully reintegrate within their communities. Veterans, individuals with disabilities and their related allies began to call for reform in terms of innovation in rehabilitation and treatment.

However, with the increase in scientific advances, brought upon additional unethical practice and research methods taking place during this time as well. Individuals with intellectual disability that were presently institutionalized were subject to participating in scientific research studies without providing consent and often fully unaware of their participation in such study (Wehmeyer & Schalock, 2013; Smith & Mitchell, 2001; D'Antonio, 2004). One of the individuals who had involuntary participated in a study conducted at the Walter E. Fernald State School, testified later describing the feeling of participating in such study without regard towards their well-being, "You really feel like you must have been someone insignificant...how were you any more important than a bug or rat in a laboratory" (Wehmeyer & Schalock, 2013; D'Antonio, 2004). This statement reflected the continued diminished value that professionals still had in regard to individuals with intellectual disability; there was no
acknowledgement of the potential negative effects that could result from their participation.

Upon the American Association on Mental Deficiency (AAMD) releasing the first official definition of the term mental retardation in 1959, it began the recognition of core components of the condition that would remain foundational to today's present definition. Here is where we can explore the shift in not only terminology labeling and classifying the condition, but now a formal definition for the condition is offered providing precise explanation. As Schalock, Luckasson, and Shogren describe, “Defining refers to explaining precisely the term and establishing the term’s meaning and boundaries…Assumptions are an explicit part of the definition because they clarify the context for which the definition arises and indicate how the definition must be applied,” (2007). The formal definition defined mental deficiency as, “the sub average general intellectual functioning, which originates during the developmental period and is associated with impairment in one or more of the following: (1) maturation, (2) learning, and (3) social adjustment,” (Heber, 1959). Within this definition there are formal components of intellectual disability that have evolved minimally; age of onset during the developmental period and maturation, learning and social adjustment that shortly after was folded into a single term, adaptive behavior, and this term is continued to be used today. This definition shown here also demonstrates the shift in perception of construct of general disability, and specifically individuals with intellectual disability.

Previously, persons identified as having an intellectual disability were identified as being feeblely-minded as they failed to adapt socially to their environment and demonstrate socially deviant behaviors (Schalock, Luckasson, and Shogren (2007)
creating the social approach to intellectual disability. Then as the socially constructed condition began to formulate, and as medicine began to intervene with a more scientific approach, we began to see the medical model of intellectual disability form giving rise to the intellectual approach as IQ testing began to gain popularity. This definition from the AAMD demonstrates the shift to the new approach, dual criterion; “the first formal attempt to systematically use both intellectual functioning and adaptive behavior,” to identify those with intellectual disability (2007). The identification of adaptive behavior was a crucial changer to the shift in perception of the definition and the general construct of intellectual disability. It was identified the limitations in adapting to environmental demands, acknowledging the relationship between context and behavior.

As the definition of intellectual disability evolved, historical events were occurring specifically affecting those identified as having an intellectual disability. In 1961 President John F. Kennedy summoned the President’s Panel on Mental Retardation, which developed A Proposed Program for National Action to Combat Mental Retardation. The panel focused on premises including individuals with disabilities and their current state of exclusion from schools, community activities, and areas of public and private life activities, as well as the major issue; large, state-run and grossly underfunded and under-resourced institutional facilities with high rates of neglect, abuse and horrific living situations that began to publicly surface. With efforts to improve programs and services for those identified as having an intellectual disability, several amendments and acts were proposed and enacted, including the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. This act was to provide federal funding for the development of community-based mental health
centers and improved research facilities in the United States, eventually leading to
deinstitutionalization. Concurrently, there was also the introduction of the antipsychotic
medication, chlorpromazine, and then the introduction of Medicaid and Medicare during
this time that greatly influenced deinstitutionalization into being possible. The policies
surrounding deinstitutionalization of persons with intellectual and developmental
disabilities continued to spread state to state based on the Californian policy makers’
initial solution to the overcrowding and overpopulation seen in state institutions and to
replace institutional living conditions, to smaller community-based living.

The development of the community-based mental health centers was meant to
serve as an alternative to state-institutions so individuals with an intellectual disability
would have improved access to their communities and could receive treatment within
their home and work. However, as deinstitutionalization occurred, many individuals were
released back into communities that lacked facilities or expertise to provide the
appropriate support needed. Many individuals with disabilities wound up living in
assisted living centers for older adults, at home with their families or overall homeless
without the assistance they needed. Situations such as this existed for thousands of
individuals; the intention of improved integration of individuals with disabilities back
into their communities lacked the acknowledgement of the contextual component of the
disability, the adaptive behavior to the contextual environment of a task. Supportive
services and adaptive accommodations were very rare during these initial years of
deinstitutionalization causing the movement to go from a more inclusive intention, to
now many smaller settings lacking the supportive care needed for these individuals to
enjoy equal access to their community. This is where it is exemplified the power of
enablement versus disablement of the two social groups. Many communities chose not to utilize the funds to build the proposed centers and the ones who did, none of them were fully funded from the start nor provided with enough funds to operate long-term. Individuals with intellectual disability at this time continued to be segregated from their communities as they still could not equally access opportunities those without were able to. Many still faced stigmatization and ultimately discrimination from those in their communities furthering the oppression of this group of people despite the efforts of deinstitutionalization. It was not until additional laws were passed to specifically denote discrimination solely on the basis of possessing a disability as violation of one’s civil rights.

During this time, was also a time filled with multiple civil rights movements for marginalized individuals, not just those identified as having a disability. Two of the initial movements, the Independent Living Movement and the Disability Rights Movement, encompassed two main ideas: people with disabilities were the best experts of their own needs and oversaw their own advocacy organization; and people with various types of disabilities began to collectively join to organize together for political power. The Independent Living Movement began to gain momentum as community-based groups of people with different types of disabilities began to join in identification of barriers and gaps in service delivery. To address barriers once identified, actions plans were developed to educate the community of these existing barriers and then advocate for political change to address related existing regulations and eventually the calling for barrier-removing legislation. Unfortunately, though, much of this advocacy was based on individuals with a physical disability, not an intellectual disability. The Disability Rights
Movement, though, did better acknowledge the rights of people with intellectual and developmental disabilities. Unlike in the physical disability communities, often led by individuals who identified as having some sort of physical disability, much of the advocacy work for individuals with intellectual disability came from allies, such as, parents, family members, friends, and those with a strong connection to someone with intellectual and developmental disabilities. They advocated for individuals with intellectual disability to have improved acceptance into their communities; equal access to education and employment opportunities; and the freedom from discrimination, abuse and neglect. Movements such as these called for a shift in power from professionalization to individualization of care, demedicalization of disability, deinstitutionalization of living, and improvement of inclusion within their physical and social communities. Individuals a part of this group challenged the socially conceptionalized idea of personhood, expanding the acknowledgement of diversity within the Western US culture.

In general, people understand the idea of their body, health, illness, and ability based upon different approaches of what human beings should be defined by their sociocultural surroundings (Pool & Geissler, 2005). The embodiment of personhood not only defines the society’s influence upon a person, but also in which a person incorporates themselves in one’s society. Individuals with disabilities and related stakeholders called for action to recognize the poor conditions for which society was allowing these individuals to be exposed to within their living institutions as well as the severely limited access to equal opportunities as those without disabilities. Through organized efforts, individuals with disabilities began to shift their role in their society calling upon changes in political efforts. They were calling upon change for which
individuals without disabilities were currently perceiving those with disabilities as being inferior, but now demanding for equality of rights and access. The deinstitutionalization movement symbolically represents this change as it called for individuals with disabilities to move from an excluded physical environment to a more community inclusive environment. This change embodies the characteristic that a culture is polyphonic, encompassing the voice of many, “each one brought to life and made significant by the others, only sometimes by being the same, more often by being different, more dramatically by being contradictory,” (McDermott & Varenne, 1995). They were challenging the assumption that one must present ability in a particular way to be in a sociocultural group of others without the perceived disability by pushing the boundaries of what diversity entails. The categorization of being disabled was a way of locking out these individuals presenting differences in ability from accessing their communities in ways others who were socially defined normal could. As McDermott and Varenne describe, “A disability may be a better display board for the weaknesses of a cultural system than it is an account of real persons,” (1995). The language for which describes a disability and the way for which it denotes disability as its own social class was challenged and the call for change was finally answered.

The Rehabilitation Act of 1973 prohibited discrimination of individuals with intellectual disability in federal programs and services receiving federal funds. Key phrases such as “prohibiting discrimination” and “no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under” emphasizing the shift in perception of disability. This was the first of several civil rights laws guaranteeing lawful and equal opportunity for people with
disabilities. Analyzing the verbiage used in these policies emphasizes the perceptual change stakeholders were calling for within society, however, the ambiguity of the language left for a wide area of subjective interpretation. For example, “no qualified individual”, based on the term qualified, emphasized the need for an individual to possess particular characteristics of meeting a certain description to satisfy job-related requirements. Without the proper accommodations or even understandings of one’s need for accommodations to be successful, many jobs were still left unobtainable. Additional laws, though, continued to be proposed, enacted, and amended in efforts to improve individuals with disabilities involvement within their communities for equal opportunities and access. A few other major ones included. but are not limited to, The Bill of Rights Act of 1975, The Education for Handicapped Children Act of 1975, The Civil Rights of Institutionalized Persons Act of 1980, The Omnibus Budget Reconciliation Act of 1987, The Americans with Disabilities Act of 1990 and The Individuals with Disabilities Education Act of 1990. All of which include language related to improved inclusion of individuals with intellectual disabilities in access to all areas of life that were once restricted or completely inaccessible based upon disability alone.

For instance, specifically examining the amendments made to the Bill of Rights in 1975 one can analyze a specific change in verbiage of how not only the public perceived intellectual disability during this time period, but the value of humanitarianism and autonomy of individuals who were recognized as having an intellectual disability. The amendments made articulated that individuals with intellectual and developmental disabilities have the right to appropriate services, treatment and habilitation in the least restrictive setting that maximizes developmental potential (Administration for
Community Living, 2017; P.L. 94-103, 1975). Also within this amendment included that public funds should not be distributed to any program that may conflict with, nor meets, the minimum standards: nutritious diet, medical and dental services, prohibition of physical restraints, visiting rights for relatives, and compliance with fire and safety (2017; 1975). This exemplified the newly recognition of the safety and general well-being of individuals with intellectual and developmental disabilities while accessing public services to assure their safety and well-being to avoid circumstances that they once were subject to in the under regulated institutional setting. Shortly later, further amendments were made to this law articulating the general goals for public services for individuals with intellectual and developmental disabilities, emphasizing the value in their achievement to reach their maximum potential through increased independence, productivity, and integration into the community (Administration for Community Living, 2017; P.L. 100-146; 1987). Here one can examine the vast improvement of language shifting from the early twentieth century that began with the pessimistic, unhopeful demise for individuals recognized as having an intellectual disability with supported efforts to remove this group from the local community, to now efforts focused on embracing this group back into their communities.

Personal embodiment started to encompass self-empowerment and embracing independence for those with disabilities. As the social construction of intellectual disability continued to be molded by political and social structures of the surrounding culture, stakeholders began to call for a replacement of terminology naming intellectual disability, away from mental retardation and mental deficiency. Individuals with an intellectual disability began to gain involvement in decision making influencing their
daily lives and community living. One of the biggest shifts was the call for the term mental retardation to be replaced with a more acceptable term by all stakeholders, including individuals with the condition and their families. The term mental retardation originally served to replace the historical terms idiot, imbecile, and moron that were previously discussed. And like previous terms, it was chosen with its primary basis originating in Latin as *retardare*, meaning “to make slow, delay, keep back, or hinder”. However, like its precursors, even by the 1960s this term already began taking on a partially derogatory meaning as phrases such as “retard” or “retarded” became a common colloquialism many people used to degrade and insult people with disabilities and additionally, used as a synonym for “dumb” and “stupid” by people without disabilities.

The term mental retardation was eventually increasingly replaced by the term intellectual disability, as seen by organizations such as the American Association on Intellectual and Developmental Disabilities (AAIDD); International Association for the Scientific Study of Intellectual Disabilities; President’s Committee for People with Intellectual Disabilities; professional journal titles, and associated published research (Schalock, Luckasson, and Schogren, 2007). The slow integration of this term eventually led to a nation-wide movement by Special Olympics, Best Buddies and their supporters, “Spread the Word to End the Word” in efforts to end the use of the word retarded in relation to discussion of individuals with intellectual and developmental disabilities. In this campaign, it identifies the term retard(ed) as an exclusive, offensive, and derogatory word towards individuals with intellectual disabilities and by raising awareness within schools, organizations and communities, the campaign is directed towards promoting improved inclusion and acceptance of people with intellectual and developmental
disabilities through calling for change in terminology utilized (R-Word, 2017). The campaign emphasizes the role of terminology and language upon its influence of societal attitudes, and in turn, how those attitudes impact decision-making and overall actions. Similarly, the American Association on Intellectual and Developmental Disabilities (AAIDD) adopted the term intellectual disability in the 11th edition of AAIDD’s Intellectual Disability: Definition, Classification and System of Supports, in which Schalock states the transition was in efforts to abandon the derogatory term, mental retardation, and its associated stigma surrounding this phrase (2007). In 2010, former President Barack Obama officially signed bill S. 2781 into federal law, also known as Rosa’s Law, removing the term mental retardation and mentally retarded from federal health, education and labor policy, replacing the term with intellectual disability. This term facilitates identification and communication in a respectful, dignifying manner as recognized by all stakeholders. Tasse expanded upon this name change as, “meant to better represent breadth of study of its memberships, people with an intellectual disability and people with developmental disabilities and not an indication of a new classification term,” (2013). Rosa’s Law significantly impacted many federal laws and statutes requiring amendments to terminology to replace previous mental retardation for intellectual disability.

Part III: Present Day Terminology & the Impact Upon the Lives of People with Intellectual Disability

As terminology began to formally shift amongst various professional stakeholders, questions began to arise regarding the exact reasoning behind the call for change, specifically, “Why is the term intellectual disability currently preferred to mental
retardation? How might the use of the term intellectual disability impact the current
definition of mental retardation? How might the use of the term intellectual disability
affect persons diagnosed or eligible for a diagnosis of mental retardation?” (Schalock &
Luckasson, 2007). The specific name of the condition itself gives rise to much meaning
to the overall interpretation of the condition, and as we have seen historically, the
terminology previously used was very vague in description and often inaccurate in
encompassing actuality of the condition. The condition itself is dependent on the
understanding of what is perceived as normalized behavior, functioning and performance,
so it is imperative that the description be specific and comprehensive in identifying who
will be classified and labeled as having such condition. However, the new terminology
did not entail the emergence of a new group, but rather it covers the same population that
was once diagnosed with mental retardation. This way every individual that was eligible
for diagnosis of mental retardation, is eligible for diagnosis for intellectual disability,
and still has access to the same supports and services that were offered before for this
population.

In the process of naming, many stakeholders and authors have emphasized the
need for the term to meet certain criteria to confirm the transition of terminology is
appropriate and fitting for the condition being described. The key factors discussed
include, (a.) the term should be specific, refer to a single entity, permit differentiation
from other entities, and enhance communication (b.) it must be used consistently by
different stakeholder groups (e.g. individuals, families, schools, clinicians, lawyers,
physicians, professional organizations, researchers, and policy makers), (c.) the term
must adequately represent current knowledge and be able to incorporate new knowledge
as scientific advances occur, (d.) the term must be robust enough in its operationalization to permit its use within multiple purposes, including defining, diagnosing, classifying and planning supports, (e.) the term should enhance an essential component of naming a group of people, which is to communicate important values, especially toward the group (Schalock & Luckasson, 2013; Luckasson & Reeve 2001; Schalock, 2011). Many have agreed that the current term intellectual disability fulfills these criterion (Schalock & Luckasson, 2013; Schalock & Luckasson, 2005). The ability to attach a specific name or term to a general concept is a significant process, especially when the concept entails describing and labeling a particular group of people and classifying who are members of the group. The process has been recognized as carrying many messages about the general understanding of the group, as well as representing their perceived value and humanistic relationship to their communities and society overall (Luckasson & Schalock 2013).

Historically, like we have previously discussed, the terminology chosen to represent and describe this group of people has held a negative connotation in nature of the description as well as the origin for which the term originated from. The current construct of intellectual disability is like the general construct of disability, in which it emphasizes the interrelationship between person-environmental and the systematic application of individualized supports that can enhance human functioning and performance. Through this definition, it is taking the focus away from deficits of the individual and the expression of individual functioning, and instead, analyzing the impact of the role of environmental and contextual barriers and limitations. Many have even gone as far as recognizing there are two distinct definitions of intellectual disability, operational and constitutive, for which one can be used to classify for who qualifies as a
member of this group based on diagnosis through observation and measurement versus the other defining the construct of the condition and clarifying theoretical underpinnings providing a clarified framework for policies and practices (Luckasson & Reeve, 2013).

The current operational definition of intellectual disability gives rise to the clinical description of diagnosis. The most commonly used definition of intellectual disability has been formulated by the American Association on Intellectual and Developmental Disability as "Intellectual Disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18," (2018). Intellectual functioning generally refers to one's mental capacity, such as their ability to learn, reason, problem solve, and perceive and has commonly been measured based on IQ testing. It is important to recall IQ testing has played a significant role in the history of intellectual disability. The Binet and Simon Test of Intellectual Capacity originated as a key determinant in the eugenics movement based upon one's performance on this IQ test. The main idea of using this test was based upon Goddard's efforts to eliminate "undesirable traits" founded upon the diagnosis of people who did not perform clinically well, thus determining them to be intellectually inferior and subject to institutional isolation or involuntary sterilization to segregate this group of individuals from those deemed as prosperous. Intellectual functioning levels obtained from tests similar to the Binet and Simon Test of Intellectual Capacity are now used conjunctively with assessment of adaptive skill areas to base diagnosis of intellectual disability if
prevalent before the age of 18 and to assist in determining levels of support and care needed.

The constitutive definition of intellectual disability exists upon the notion that it disability is the expression of limitations in individual functioning that represents a substantial disadvantage to the individual within a social context (Schalock & Luckasson, 2013). Through this definition, it identifies the social-ecological relationship intertwined within disability, and through the last few decades, this relationship has gained significant recognition, especially due to changing societal attitudes, roles, and policies and the impact on how one may experience illness and/or disability as well as the intertwining of biological and social causes of ID (2013; Aronowitz, 1998). Through identification of these factors based on the terminology chosen in this definition, focus on a person-centered defect that was once historically seen, now has shifted to a multidimensionality of the disability itself in both personal and socially expected functioning. This shift in focus now brings awareness to the sociocultural and environmental components of the disability, and even broader, acknowledgment of personal empowerment, self-determination, and greater emphasis on basic human and civil rights.

Because of this change in perspective towards what intellectual disability is comprised of, it also identifies the discrimination, marginalization and oppression of persons with intellectual disability that has occurred historically, but also in present day as well. Public policy has driven not only diagnostic and classification processes over the years, but it also drives the underlying principles and sociocultural values reflecting and influencing the perception of the needs, capabilities, and values of people identified as having ID. In turn, public policy and the specific terminology and language used within,
impacts how public policies are carried out both in services and support and then experienced by people with intellectual disability. This relationship between terminology used to label, define, and classify intellectual disability, as well as, the terminology involved in public policies, social-political movements and research, and the outcomes experienced by people with intellectual disability continues to have a significant effect on the latter. For example, in 2008, the Americans with Disabilities Act (ADA) was amended, reaffirming that the two purposes of the ADA were to deliver “a clear and comprehensive mandate for the elimination of discrimination” and “clear, strong, consistent, enforceable standards addressing discrimination,” (The ADA Amendments Act of 2008). Using strong language and phrases such as “elimination of discrimination” and “clear, strong, consistent, enforceable”, is identification of one, the shift of perception of intellectual disability, as previously discussed, and secondly, the acknowledgement of the call for continued change to better improve the experience of intellectual disability as a natural and normal part of human existence. It expands the spectrum of accepted behaviors and intellect functioning, acknowledges the differing of abilities, and recognizes the use of various supports and services to engage in community daily living.

However, despite the improved efforts to adjust terminology to better depict intellectual disability, the social component of disability still interferes with the experience of intellectual disability. Various components, such as the physical characteristics of the human-made environment and remaining stigmatizing attitudes and perceptions still interfere with successfully improving the lives of people with intellectual disability and meaningful integration of people with intellectual disability. Previous
research demonstrates that increased contact between individuals with intellectual disability and developmental disability (IDD) and the mainstream population, can lead to more positive attitudes towards those with IDD (Keith, Bennetto, & Rogge, 2015). As communities create more inclusive environments enabling successful access to not only physical inclusion, but meaningful integration between the environment and social contexts, more opportunities will arise for individuals with IDD and the mainstream population to interact. Fortunately, studies do show that there are an increasing number of individuals with IDD experiencing increased amounts of opportunity for inclusion and integration within their schools and community with the mainstream population, however the quality of interact needs to be better understood (2015).

Various components, such as the physical characteristics of the human-made environment and remaining stigmatizing attitudes and perceptions still exist and continue to interfere with successfully improving the lives of people with intellectual disability. Because opportunities for integration are becoming more available to people with IDD, it is essential to understand the differences of outcomes that can result from positive and negative types of interaction. Research has demonstrated that the nature of contact between the two groups is distinctly related to both sides’ types of attitudes, whether positive or negative, and more specifically, studies have also demonstrated that a better quality of contact and interaction was associated with lower levels of prior prejudice and stigma towards people with IDD (Keith, Bennetto, & Rogge, 2015; Barr & Bracchitta, 2012; McManus, Feyes, & Saucier, 2010; Piercy, Wilton, & Townsend, 2002). As previously discussed, overall changes in policy and services and general societal perception and understanding of intellectual disability have all improved over the
years, demonstrated through numerous historical accomplishments and evolution of the terminology utilized, but stigma and discrimination against people with IDD continues to remain (Werner & Abergel, 2017; Schalock et al, 2010; Siperstein, Parker, Bardon & Widaman, 2007). This experience of stigma and discrimination has been found to negatively impact people with intellectual disability’s in various of life domains such as well-being, self-esteem, autonomy, self-determination, and overall quality of life (2017). When this type of stigma and discrimination is experienced, it leads to a decreased quality of interaction, and eventually limiting the amount of wanting to experience community interactions with those without IDD.

With efforts to continue improving the terminology, not only labeling the condition, but also the language detailing what IDD is comprised of; how it may impact individuals, their families and communities; and how IDD is experienced by people with the condition, it can be seen as a step towards improving the general perception of IDD and eventually eliminating the stigma surrounding the condition. In the US specifically, Rosa’s Law is an example of this as it was enacted to not only replace mental retardation and mentally retarded, with a more appropriate, accurate and less stigmatizing term, but it also eliminated the depreciatory term from all federal law books with the term intellectual disability (Werner & Abergel, 2017; Ford, Acosta, & Sutcliffe, 2013). Similarly, the ideology of people first language has begun to become more commonly used by all stakeholders when describing individuals with disabilities. This linguistic ideology is focused on the concept that people with disabilities are people first, and removing the emphasis on the disability, but rather is one of several aspects of the whole person. For example, previously an individual with intellectual disability would have been described
as a mentally retarded person, but now, in addition to the evolution of the terms, we see a change in the semantic structuring of words as well, shifting this phrase to a person with intellectual disability. Person first language is considered to be an objective way of better acknowledging, communicating and reporting on disabilities in efforts to eliminate the generalizations, stereotypes and devaluing of the person with a disability (What is People First Language, n.d).

It is imperative now, how society structures the discussion related to intellectual disability as it must focus on what specific terminology is being utilized and how it is being interpreted. By no longer endorsing stigmatizing language it will begin to foster more positive cognitions of people with intellectual disability demonstrating overall acceptance of people identified as having intellectual disability in efforts of reducing social distance between those identified with and those identified without. But if terminology used is not specific or detailed enough in fully depicting the needs of people with intellectual disability, health and social disparities will continue to exist for this population. For example, in the early 21st century, the US Surgeon General published “Closing the Gap: A National Blueprint to Improve Health of Persons with Mental Retardation” summarizing a comprehensive plan to improve the health and well-being of people with intellectual disability (USDHHS Closing the Gap, 2002). This was during the same time period as the introduction of the term intellectual disability began to unfold.

This report summarized four main recommendations related to 1.) promote early identification, inclusion and self-determination of people with intellectual disability; 2.) prevent and manage the occurrence and impact of health conditions; 3.) empower caregivers and family members to adequately meet the needs of persons with intellectual
disability in their care; 4.) promote healthy behaviors in people with intellectual disability (2002). With the increased attention to the health and social well-being of people with intellectual disability, research has vastly increased specifically identifying areas that are needing to be addressed to improve health care. Papers have begun to outline the steps needed to reduce social and health disparities, however, it is how the language is being interpreted to carry out such changes that continues to be the barrier.

The term inclusion is one of the most commonly used phrases in policies and research in reference to people with disabilities being included with the mainstream population of people considered without disability. It has been frequently noted, however, that despite people with intellectual disability physically being in their community, there still remains a gap between people being a part of their community and the individual, often resulting in little sense of belonging or membership to the actual social community itself, and few meaningful relationships with nondisabled community members (Amado, Stancliffe, McCarron, and McCallion, 2013). This has emphasized the ambiguity of the term inclusion, calling for action on more detail description of what this truly means.

With improved efforts to define areas causing the existing social and health disparities, one of the key factors contributing to meaningful, or lack there of, social engagement between people with intellectual disability and their communities, relates to supportive services staff and the quality of assistance provided (2013). Numerous of factors have been discussed in relation to the variance of quality of support staff assistance, and new approaches have been made to better train supportive staff in providing assistance to people with intellectual disability. For example, the active support approach was proposed based on the idea of “helping people to be actively, consistently,
and meaningfully engaged in their own lives regardless of their support needs,” (Olson, n.d). Through the use of active support, it thoroughly defines what is required to meet these needs providing a better expectation of what is truly meaningful engagement within one’s community as opposed to sole physical inclusion. As efforts begin to focus more on how we are thoroughly defining and describing such expectations written in formal policy and law, in addition to, adequately detailing the needs of each individual, better outcomes will begin to result as supportive assistance and services can be developed to minimize the gap between expectations and reality.

**Conclusion:**

As terminology continues to play a crucial part in how people with intellectual disability are perceived, understood and treated in their community, it is essential to continue evaluating the terminology chosen and analyze how the community is utilizing this language. Intellectual disability is the most currently preferred term describing the significant limitations in both intellectual functioning and in adaptive behavior originating before the age of 18. The terminology both labeling and describing this condition has significantly evolved in recent centuries with an interrelating relationship between the language used to name and conceptualize this condition, and the sociocultural perception of intellectual disability by individuals within the US western society. The sociocultural perception and language utilized has also greatly impacted many of the policies and movements enacted greatly impacting the lives of individuals with intellectual and developmental disabilities, and continues to be significant contributing factors influencing their developmental potential and overall independence in their daily living.
When naming, defining and assessing the impact on intellectual disability on an individual it is imperative to analyze the external contributing factors, such as the sociocultural and environmental context for which the individual is living in. Professionals have now gone as far as stressing the consideration of linguistic diversity and cultural differences in the way people may communicate, behave, and interact when describing intellectual disability and its unique impact upon an individual and their family in US westernized medicine and their surrounding community. Intellectual disability is now understood in terms of the fit between a person's capacities and the demands of their environment, as opposed to the difficulties caused by a problem within the person as once believed. Individuals with ID are now given more opportunities and resources to learn the skills necessary to complete daily tasks and community living skills in efforts to live more independent and fulfilling lives and also environments are becoming better accommodating to adjust the context for which these behaviors occur in.

The language for which we now choose to construct policies that allow these opportunities to occur, especially in regard to supportive services, it is imperative that it is carefully written with appropriate associated terminology to be accurately understood and then carried out in the manner intended. Supportive services and continuing educative opportunities are crucial for community integration to not only be successful, but meaningful for the individuals to feel as an active part of their community. With improved language and terminology promoting improved community integrative experiences, the perception of people with intellectual disability will continue to improve fostering more positives for both people with and without intellectual disability.
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