

**(De)Humanization in Communication with the Intellectually Disabled**

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## **Abstract**

*A metaphorical journey through how intellectual disability is currently defined, a concise history on how society has treated the intellectually disabled, the philosophical considerations of “being,” including the path to dehumanization when considering a person as less than a whole being, and proposition of a future approach to humanize perspectives and communication with the intellectually disabled. Technical approaches are fundamental but it is only in the unification with lived experience that conceptions can change from the tolerable to the compassionate. Anecdotal stories from the mother of a developmentally delayed child serve to bridge the gap between theory and practice.*

## Introduction

Questions surrounding the conceptualization of what it means to be “human” have long plagued philosophers, sociologists, theologians and society alike (Bickenbach, Felder, & Schmitz, 2014) (Carlson, 2010) (Gross, 2019) (Keith & Keith, 2013) (van Inwagen, 2022). In many instances these questions were contrived to debate specific societal issues such as gender, racial, and religious inequalities. A marginalized group still suffering from being viewed as “less than human” within society, and in need of understanding and representation, are the disabled, specifically the intellectually disabled (ID). Physical, emotional, and behavioral issues contribute to both the marginalization of this group and the vulnerability in comparison to other groups, as communication can be unclear or in some instances completely disregarded. Barriers in communication have contributed to a significant research gap due to “legal limits on research participation by intellectually disabled people, ethical difficulties associated with conducting empirical research with ‘vulnerable’ participants, and practical challenges associated with recruitment and informed consent” (Harding, 2021, p. s29). This lack of research and understanding have led to a lack of community-based services (Bharti & Bhatnagar, 2018) or even appropriate coping strategies made available to the ID and those who love them. Though clearly at a disadvantage from a functional perspective somehow the implication also follows that the ID are inferior: ethically, philosophically, and morally. Like many who are deeply devoted to the care and representation of the ID, I have a close and personal connection with someone labeled as ID, my son, William. For basic information, William is an eight-year-old that attends a public school that caters to special needs children running the gamut from

severe to mild disability, both physically and intellectually. He has recently undergone evaluations from trained professionals that suggest his intellectual level is on par for a three-year-old, as well as suffers from mild cerebral palsy and a dormant seizure disorder. Though he has issues with fine motor movement overall, he is perfectly ambulatory and is emotionally present. The fact that he responds appropriately on an emotional level gives me further cause to root out the genesis of dehumanization and to nullify as much as I possibly can. Instead of accepting social dehumanization of the ID as an unspoken reality, the aims of this ethnographical research paper is to take a metaphorical journey through what intellectual disability *is*, a concise history in the United States on how society has treated the intellectually disabled, the philosophical considerations of “being,” including the path to dehumanization when considering a person as less than a whole being, and proposition of a future approach to humanize societal perspectives and communication with the intellectually disabled. My fervent hope is to change at least one individual's future communication with the ID from indifferent to conscientious and cognizant of the unique being before them.

### ***Defining Intellectual Disability***

There have been several iterations of what it means to be “intellectually disabled,” which range from the purely medical, to the legal, to the deeply personal. In a naturalist sense, J.B. Gould (2022), a staunch disability advocate, professor emeritus with graduate degrees in philosophy and theology and fellow parent of an intellectually disabled son, finds a definition as simple as “a departure from typical human functioning”. (p. 496) Such an account is clearly too broad as this definition would see

any number of psychological issues as significant disability. Besides this, what is “typical human functioning” to begin with (Patti, 2020)? The medical definition is far narrower, though still differs from source to source. The Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-IV) terms intellectual disability as involving “impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains assess an individual’s ability to cope with everyday tasks” (Patel, Greydanus, & Merrick, 2014, p. 203). These specific domains include the practical (such as self care-and everyday activities), the social, and the conceptual (such as found in math and reasoning). These deficiencies can also range from mild, moderate, severe, or profound in one or all categories. An issue surrounding this type of classification is that Intelligent Quotient (IQ) scores are a cornerstone of DSM-IV definition of mental retardation and disability. A deeper look into how these scores are calculated reveals serious deficits as the test began as only “A Failure of Intelligence Test” for children for placement in special education (Keith & Keith, 2013). The American Association on Intellectual and Developmental Disabilities<sup>1</sup> classifies severity in another way as “intensity of needed supports” with intermittent, limited, extensive and pervasive (Gould, 2022). This particular definition goes on to consider functioning only within the context of normal environments and in direct comparison to average performing peers (Carlson, 2010). Throughout each differing definition is the comparison to “species-typical function” (Bickenbach, Felder & Schmitz, 2014) heavily involving communicative aspects. However, do psychosocial disabilities necessitate large scale dehumanization? To continue along these lines is to continue practices that

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<sup>1</sup> <https://www.aaid.org/intellectual-disability/historical-context>

are wholly archaic in a modern world that emphasizes inclusion regardless of race, creed, or gender.

### ***A Brief History***

Implications within humankind's history show that to continue along this trend is to place certain individuals as being less worthy of consideration and far removed from the bulk of society, a core tenet of dehumanization. The medical definition gives birth to the concept of the "personal tragedy model," that having a disability is objectively bad and is a tragedy for all involved and should at all costs be prevented and cured (Carlson, 2010). The danger behind this viewpoint is the actions that can and have stemmed from it in the past. In the nineteenth century, the thought was that the "feeble-minded," idiots, imbeciles and morons (actual classifications of that era) (Carlson, 2010) needed to be housed far away from the good minded rational public, lest the menace of idiocy be passed to others or these unstable individuals cause physical harm to a productive member of society (Parker, Monteith, & South, 2020). Another claim is that of the need to protect such a vulnerable population from being neglected in terrible living conditions, as though the institution would inherently care more so than familial relations. To put overall feelings of the educated running these facilities during this time succinctly, one need look no further than Dr. Samuel Gridley Howe, who directed the Massachusetts School for Idiotic and Feeble-minded Youth. Howe was seen as an expert of his time, having first hand, in depth experience with the intellectually disabled. Dr. Howe, a man appointed on a commission in Massachusetts to investigate the treatment of "idiots," describes a patient in one of his cases as "he is,

in form and outline, like a human being, but in nothing else” (Carlson, 2010, p. 31). In yet another case Howe writes “but alas! . . . [one] (sic) finds, even in our fair commonwealth, breathing masses of flesh, fashioned in the shape of men, but shorn of all other human attributes. . . . Idiots of the lowest class are mere organisms, masses of flesh and bone in human shape” (Carlson, 2010, p. 31). Institutionalization was the only recourse available, for both the intellectually disabled and their families alike, though physical and mental treatment in these facilities was hardly aimed at improving quality of life but instead aimed at experimentation and discussion of these subhuman creatures. These types of viewpoints paved the way for such egregious behavior as involuntary sterilization and euthanasia (Parker, Monteith, & South, 2020) based on the ideology of eugenics. Eugenics by way of intelligence and rationality made its way into the 20th century as the foundation for the mass extermination of people with disabilities in the Nazi T4 program at its worst point (Keith & Keith, 2013). Though instances of euthanasia and sterilization dropped, institutionalization was unchanged and still had a firm grip on the United States. By 1969, it was reported that “zoos spent more per capita for the care of large animals than some American institutions did for the care of people with intellectual disability” (Keith & Keith, 2013, p. 134). It was not until the 1980’s that concerns about quality of life began to improve the situation and care of the ID (Keith & Keith, 2013). The long lasting effects of this history has created within American societal structure the notions that the ID are, in effect, still not entirely whole, something between merely existing as a base level being and being fully human, with all of the attributes that make up the species.



## Ethics of Being

*Cogito ergo sum* (I think, therefore I am) seems a practical enough explanation of “being” within western philosophical thought (Keith & Keith, 2013). However when it is broken down, several questions still remain. If the ID has issues communicating what they are thinking, does this make them less than a whole being? Does consciousness make a being? Is it simply the process of rationality that creates the self and thus a whole being? A simple standard to determine consciousness includes “The ability to discriminate, categorise [sic], and react to environmental stimuli, the integration of information by a cognitive system, the reportability of mental states, the ability of a system to access its own internal states, the focus of attention, the deliberate control of behaviour [sic] and the difference between wakefulness and sleep” (Gross, 2019, p. 57). Of these criteria are certainly issues that the intellectually disabled struggle with communicating, namely reporting mental states and control of behavior which can range from mild to severe depending upon the individual. There is no further explanation on whether each part of the standard needs to be fulfilled in order for consciousness to be recognized and as with many of these philosophical statements the burden of interpretation lies upon the ethics and morality of the reader (or in practice with the physician, psychologist, teacher, etc.). Within *Being: A Study in Ontology*, Peter van Inwagen (2022), an American analytic philosopher and the John Cardinal O'Hara Professor of Philosophy at the University of Notre Dame, uses past philosophical work to examine differences between “being” as a verb and the idea of simply existing without any form of consciousness. Martin Heidegger, who would go on to contribute to Nuremberg racial laws, used the work of Georg Wilhelm Friedrich Hegel, a leading mind

in modern Western philosophy in the most contradictory way. From this work Heidegger claimed three principles: “Being is universal, being is indefinable and being is self-explanatory” (van Inwagen, 2022). Though he would later go on to regret his endorsement of Eugenics and the Nazi party, again the philosophy of being is still one left to the interpretation of the reader. Viewing these principles in an objective manner by pushing aside the unethical use by Heidegger, the contradictory use becomes incredibly apparent. Being is universal as it is extended to everything that is in existence, a plant has just as much stock in being as does a breathing human, which leads to Being as ultimately indefinable as everything in existence can offer no argument for existing and will continue to do so unless specifically interfered with. Finally Being is self-explanatory, meaning that being surpasses all judgements humans may come to and that to understand anything beyond is to understand Being in its most basic form. We cannot discuss the plant mentioned above without at least acknowledging it’s very being in this world. Jean-Paul Sartre does begin to offer the conceptualization of different kinds of being, with specific distinctions between simply existing (such as the inanimate object does) and the being that any creature with agency and consciousness does (van Inwagen, 2022).

Understanding being on these terms then brings up the relationship between being, intelligence, rationality, and the ability to act on one’s own interests, essentially the considerations of agency. The history of ID, especially within the United States, sees the view of those with ID lacking intelligence and rationality and thus being undeserving and incapable of any type of agency. This viewpoint has allowed mass rates of institutionalization to take place, with no consideration of the ID having the ability of

choice in any matter (Carlson, 2010). C.F. Goodey (2011), a prominent author and researcher in Disability Studies, surmises that humans are both objective and subjective beings. An objective classification is one of mere biology in relation to the world. This is the simple distinction between human and other animals.<sup>2</sup> The subjective is that in which we consider what it is to be human, that is sufficiently distinctive from the other animals. Goodey finds that this includes “the capacity to make abstractions and to reason logically; one who cannot reason in this way is intellectually disabled, and in this context intelligence becomes a dominant trait. It follows then, that if reason is a necessary condition of humanity, it is easy to dehumanize the person who lacks the ability to reason” (Keith & Keith, 2013, p. 47). Still intelligence itself is highly subjective, the hunter gatherers viewed intelligence as memory of where the animals can be easily picked off and where the edible growths were located (Menger, 2009). Most of modern history found intelligence to be held only by the white man, with this intelligence varying in description among each specific culture (Elphick, 1983). In effect intelligence becomes a social construct -(Keith & Keith, 2013)- able to be modified among each society and determined by the current “powers that be.” Another determinant of intelligence is practicality, essentially the ability to adapt and survive (Keith & Keith, 2013). This view presents more problems, as with the range of the ID severities, some would be “enough” and others would not, leading into a descent of questions of morality, are those capable of rationalizing themselves as a being worthy of surviving morally worth more than those who cannot? In practice, however, those who have not been

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<sup>2</sup> For the purposes of this paper the subjectivity of animals is not discussed; the author concedes the possibility.

seen as rational have been left out of the definition and privileges of being considered wholly human.

With the ability to rationalize comes a conception beyond being, that of the “rational self.” Personal and moral agency includes a recognition of others and self and interactions of the two in the wider social sphere. George Herbert Mead took the works of Hegel and the like and further fine-tuned it with his contribution of an original theory of the development of the self through communication, using social science research to further examine the human experience (Keith & Keith, 2013). Mead posits the self is developed first with the recognition of the self existing separately from others, then by using communication and interaction in an environment of others followed by self-reflection. This reflection indicates an ability beyond instinctual reaction and surpassing a “conversation of gestures” (Keith & Keith, 2013). The claim then is that the individual can only learn to develop the self by being within a supportive, nurturing social system. Continued isolation (such as found frequently in institutionalization) serves little purpose except to continue to limit and abuse the humanity of the institutionalized. Left alone, the construct of being ID, of being less than, increases the chances of fusion between the construct and the self, ultimately becoming a part of who the individual sees themselves as rather than something out of their control (Williams, 2017). What it means to be and all of the moral implications that come along with it will continue to be a question with no singular or final answer. Instead of relying so heavily on constructs of intelligence and rationality to compose the being, perhaps more stock could be put into another aspect of humanity, that of sociality and inter-being. The ID may lack the ability to consistently communicate with others but still require the same in

terms of social need and are still able to realize another uniquely human trait, the ability to feel. Cartesian philosophy might have changed what it means to be human had the saying been adapted to the more inclusive “*Sentio, ergo sum* (‘I feel, therefore I am)’” (Gross, 2019).

### ***Beyond Descartes***

Does one have to verbally communicate the experience of having feelings or emotions to show their very existence? If this were the case the entire vein of research into non-verbal communication would mean little. In fact an entire world of meaning and symbolism is provided with the “conversation of gestures” (Mead et. al, 2015). William quite frequently operates within this realm; It was not until the past year that he moved beyond what was defined as “mildly verbal.” He cries as most do, when he is hurt physically or emotionally. William often cries in response to emotional triggers, exhibiting his ability to feel. Love is William’s most pervasive emotion, with his exhibitions of it daily and tending to be too rough for most. Our dog, Fritz, is one of William’s favorite friends. Still Fritz has limits to the love he is willing to accept and will move away when he has had enough. William will follow doggedly for fifteen minutes until showing his frustration by crying and telling me that Fritz is in trouble and should be in timeout because he was “not nice.” The entirety of this interaction is fully laden with emotion. It might be irrational to expect a dog to take a lot of borderline abusive love but is it really irrational to love a dog to the extreme?

Again irrational, William is not afraid to show his love to anyone and everyone. Yesterday when picking him up from school, he showed his affection blatantly to

everyone we passed in the hallways and parking lot with hugs and kisses. In a post-COVID world we do have understandable reservations about excessive touching and I do hold him back, but it is for this reason alone. He is not afraid to love everyone regardless of status. I am reminded specifically of a time we went grocery shopping and a homeless man was standing in the entrance asking for money. I wanted to quickly pass by, as I had no extra to give and quite frankly no urge to have a conversation. Instead William got away from me when I was getting a shopping cart and before I knew it, had launched himself at the man, crushing him into a hug. It is in these moments that I become ashamed of myself and am reminded of what it really means to love everyone, unconditionally.

### **Less than Being**

As important as considerations of being is at which point the individual is considered as less than a whole being. Apart from the above claims, many other factors influence whether an individual is considered in any way less than those in the average populace. An important aspect of rationality is that of reasoning. Those who have more issues with reasoning at a fast pace are acknowledged as intellectually disabled (Bickenbach, Felder & Schmitz, 2014). Reasoning takes many forms from the ability to solve problems to overall decision making with beneficial outcomes as a priority. According to Patel, Greydanus and Merrick (2014) a breakdown of the decision-making process includes: the ability to make and clearly communicate a choice, if the individual has understood pertinent information needed when making decisions including thought into weighing costs and benefits, and if the individual is able to appreciate the

consequences of whichever choice is made. Flaws in using this process include consideration for the emotions of the individual as well as the attention of the individual. Delay or inability to complete any one of these criteria results in the labeling of intellectually disabled which begins the slope towards being less than.

Psychological and medical considerations tend to be narrower in focus in regards to specific brain processes however the implications remain the same. Richard Gross (2019) discusses two such specific processes: generative computation and episodic memory that directly affect intellectual ability. Generative computation defines how the brain creates and strings together information, such as linkage of symbols to meaning, mathematical computation and sentence structure and sequence. Any type of struggle with computation directly affects IQ levels as the test itself is focused on overall collection of “rationality” by quick completion of patterning activity. Episodic memory (EM) involves the ability to remember past events in the first person and when viewed in relationship with semantic memory, which is when the individual simply “knows”. The absence of any type of “consciousness” is readily apparent as there lies little room for any type of self-reflection in rote memorization (Gross, 2019). If ability to reflect internally is a marker for humanity, it should be noted that the intellectually disabled may very well be able to carry out this process even if the ID have trouble verbalizing it.

Overall levels of sociality and verbalization play a role in determination of ID. A simple change from the accepted norms of communication lends to the ID not having a place among others and thus the notion of not actually requiring a social place to begin with. Social intelligence can be traced through examination of Theory of Mind (ToM), which concerns actions deep in the social mind that pertain to emotions of others and

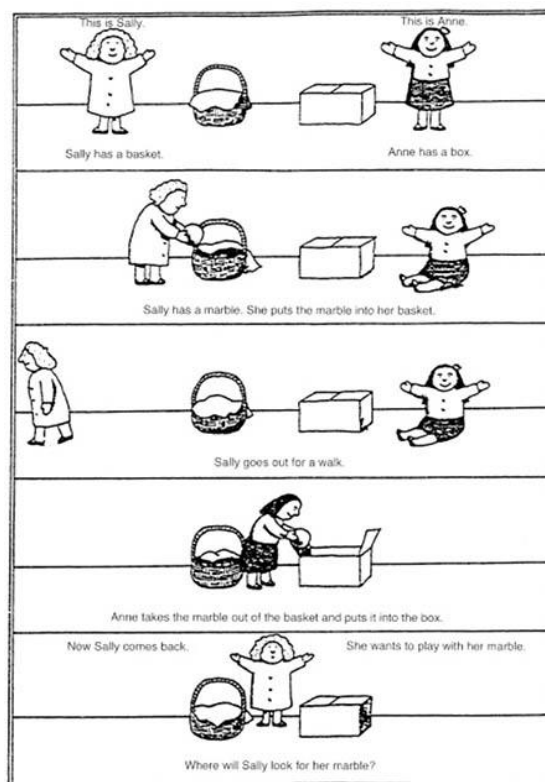
how the individual uses these suppositions (Gross, 2019). The major implication of ToM is the inference that every person has an operating mind and that one can make certain conclusions about others' minds based on non-verbal actions and overall proficiency in social interaction via the abilities to express oneself and empathize with others. ToM facilitates understanding of others, real (such as in the historical context) and imagined (being moved by the plight of fictional characters, as though they were in fact in existence). This capability specifically allows for a “universal human experience” especially in tandem with other parts of the social mind including aspects of culture, language and ultimately cooperation, which allows for evolution in other forms of intelligence that require teamwork as well as different modes of processing, organizing and expressing the world and human life within it.

Machiavellian intelligence is the antithesis of teamwork, in which the individual comes to rely on falsehoods in order to advance themselves. This predilection for deceit is another uniquely human attribute. The Sally-Anne False Belief Test (Gross, 2019), is a psychological test created to measure this ability to deceive. Created in 1985 the test concerns two players, Sally and Anne, and is best described with use of the original cartoon in Figure 1.

## **Figure 1**

*Original Sally–Anne cartoon used in the test by Baron-Cohen, Leslie and Frith (1985)*





Average developing, Autistic, and Down's syndrome children were tested, with results showing most of the average and Down's syndrome children being able to attribute "false belief" to others while the Autistic were largely incapable (Gross, 2019). This test suggests that ultimately some of the ID are in fact capable of deception and so must have ToM. Still the ID are diminished even further by attitudes of not being capable of a high level of well-being, even if the ID person claims a decent quality of life. The "simpliciter claim" contends that the existence of a psychological/physical trait in a person automatically lessens well-being because they are automatically worse off than the average person (Gould, 2022). This idea runs rampant among society without the consideration of what a high quality of life *really* is. Is it possession of material goods? Is it the ability to achieve in work/sports/academia? Is it being socially accepted and

celebrated? Could quality of life simply be the ability to make decisions rationally? The questions are difficult to answer for the average person yet seem to be answered for the ID without their opinion or consent.

### ***Theory of Mind with William***

Within the past year, something seems to have changed within William. He has learned some norms prevalent within American culture and actively attempts to be silly with them. Rules around eating with others seems to be one he likes to shirk, with the aim of making others laugh rather than blatantly disrespecting anyone. A favorite move of his in the past few weeks is eating his food in unusual ways. William has enacted his own agency in its entirety in this regard. He first started by wanting to eat as our dog does, using only his mouth. I would react by laughing at him which has then spurred his creative attempts in eating. He has since moved to balancing his food in precarious situations, such as across the top of a bottle, and then trying to eat it before it falls. He does so with the aim of making me laugh but when I've left the room, he will often search around to find the next impractical object to eat his food off of. On the topic of food, William also operates much like his ID peers, he has a limited diet he refuses to budge from, which consists of mostly fried and potato based foodstuffs. In this he exercises his own agency as well by refusing foods he does not recognize. I have even attempted vegetable based options, such as tater tots made from broccoli. After his close inspection, he finds a difference and will refuse. Though an issue for me as his mother, this serves the purpose of his expressing his desires with refusal. In this expression he also does exhibit some preference that impacts his own definition of

quality of life. I abhor tomatoes and olives and refuse to eat them in any circumstance. As an adult some may scoff but otherwise it is seen as personal preference, yet when William exerts such control it's seen quite differently. Instead of an exertion of personal preference it's seen as an issue needing to be fixed. I have been assured repeatedly by medical professionals that he is quite healthy and so have chosen to respect his preference and simply encourage trying other options.

### ***Social Dehumanization***

When having a conversation with a stranger, a certain amount of respect is expected in American conversation. To break this norm in the modern day has become taboo enough to be regularly videoed and dispersed to the community at large for social humiliation. Surpassing even the worst depictions of humiliation are those of social dehumanization, something which occurs for a particular subset of the population, the ID, during the majority of public encounters. In this case however, when faced with so much personal observation in how someone with ID is treated daily, in a variety of social settings, personal bias makes way for advocacy. In the medical situation, one would expect a certain amount of catering to the ID, at the very least to create a baseline of individual understanding rooted at the source for optimum care. The emphasis instead, in my experience, is on gathering information from the caregiver.

Many times, medical professionals, once realizing what they perceive to be William's communicative limitations, will then veer so far off course of a normal conversation so as to either continue without care for actual interaction from William or ignore him from that point out. This can be understood to a degree, as successful

treatment requires facts sometimes beyond the ID's scope, yet the ethics as per the Hippocratic Oath demands the opposition, "I will use regimens for the benefit of the ill in accordance with my ability and my judgment, but from [what is] to their harm or injustice I will keep [them]" (Miles, 2005, p. xiii). According to this, the injustice of ignoring the emotional comfort of the patient goes against the very ethics of doctoring. The Oath goes further to define the following of the ethics within for the purpose of "being held in good repute among all human beings for time eternal" (Miles, 2005, p. xiv). The history of medical professionals in America has been uniformly dismal as evidenced before and even as medicine has attempted to address and transform itself to be more humane, the inhumane view of the ID has persevered and for the most part remains unchallenged. William, like all individuals with ID, is a human being after all, who may be limited in some communication or expectancy of rationality but cannot in any way be defined as limited in human being. Individuals with ID have much to teach us -including medical professionals, caregivers, and parents- if we can learn to *actually* listen to those who may be unable to speak or speak differently from what is expected.

I cannot speak on the education system as a whole but I can speak on my experience within the local daycare system in North Carolina. These facilities are generally privately run though are expected to uphold certain criteria within statutes created by the Child Care Commission (Child Care Rules, Law, and Public Information, n.d.) Within the general statutes only one specific mention of care of special needs children is found: "Learning activities that promote inclusion of children with special needs" (Chapter 110 of the North Carolina General Statutes, N.C. § 110-91 (2017 & rev. 2019)) As privately owned facilities, and with no incentive to care for special needs

children, the wider percentage within North Carolina do not provide any type of care for any children deemed disabled. Even if one finds a daycare willing/able to provide care, there are no specific guidelines as to the care provided. This means that caregivers unable to afford the highest level of care are then forced into a situation where a child may be placed in a corner, utterly ignored, as they are unable to communicate with children or daycare providers anyways. In which ways is this considered the humane treatment of disabled children (particularly for those without wealthy parents)?

The biggest social situation of all is the wider public setting. This includes all manner of public space: the grocery store, park, zoo, church, etc. In these places instead of kindness, I watch helplessly as William is treated with quiet whispers, stares of disdain. As though he is infectious, something to be utterly avoided, individuals scamper away lest they be roped into a situation of actually confronting the child. The dehumanizing efforts to avoid contact are heartbreaking, admittedly more so to myself than to William, as he operates with kindness and genuine love for all with whom he comes in contact with. Seen as a disability in its own right, the unrequited trust he places in strangers, I instead posit the viewpoint of the willingness to love despite rejection. There have even come instances, particularly in restaurants, where loud objections have been voiced that he “does not belong there” due to his inability to be as quiet as others deem he should be when in reality he has no more or less right to enjoy a public meal than any other does. In fact, William goes further than most labeled as fully functional, in showing respect for a server’s time and humanity.

The wider public operates (consciously or otherwise) under the guise of the ID as being uniquely less human within a society of better-spoken human beings and so find it

easier to push aside notions of humanity that the ID deserve (Bickenbach, Felder & Schmitz, 2014). This pushing aside goes far beyond the terminology of in-group and out-group and strays into the realm of dehumanization. “Dehumanization can be broadly understood as the denial of mind, complex internal life, and overall humanness to an individual or Group” (Parker, Monteith & South, 2020). Though clearly observable, the prejudice that society holds against the ID is one that is not able to be distinctly understood by concept or measurement. Parker, Monteith & South attempt to create a study on the basic grounds of whether this dehumanization can be determined as ambivalent or antipathetic towards the ID, particularly those developmentally disabled. Ambivalent views suggest that the disabled should be cared for and protected until such time that it becomes an inconvenience, after which a more hostile view rears its head, when the individual should then be kept separate from the general population (Parker, Monteith & South, 2020). This study found that though these specific prejudices begin in an ambivalent form they have equal opportunities to turn into those of hostile views and thus the overt dehumanization in social settings, public policy and at worst punitive policies (Parker, Monteith & South, 2020).

Another form of dehumanization recently studied by Belgian psychologist Jacques-Philippe Leyens in 2000, is that of infrahumanization which “occurs when people attribute more secondary emotions (e.g., nostalgia)—perceived as being not shared with other species—to the ingroup than to the outgroup” (Rasset et. al, 2022). In these instances the ID are viewed as less human by way of their not experiencing what most within psychology accept as a full range of human emotion. “*Not All “Intouchables”*”, a study done on how the public views the intellectually and/or physically

disabled, describes some emotions as Uniquely Human (UH), such as human secondary emotions like civility and Human Nature (HN) which includes general emotionality such as helpfulness. Such a breakdown of characteristics can be helpful when seen through the psychological lens in determining emotional development but has somehow exuded into the realm of public thought, perpetuating an idea of who is more or less able to be fully human. The Stereotype Content Model has shown “that social judgments occur based on two fundamental dimensions: warmth and competence” (Rasset et. al, 2022). This model attempts to explain what happens on the macro level of communication in a public setting. The ID has to meet certain expectations of warmth and competence to be deemed acceptable within this sphere, otherwise the process of dehumanization seems to engage. With their study, *“Not All Intouchables”* showed a clear repetition of blatant or subtle dehumanization aimed directly towards the ID in contrast to both the general public as well as the physically disabled based upon the attribution of UH and HN characteristics ascribed to different groups. Does there exist a way of reframing public thought on the ID in a way that allows for humanity to be appreciated even in the most disabled? Perhaps by sharing stories of people with ID and those who love and care for them could further this process of appreciating the full humanity to be found within each individual.

### ***William’s Humanity***

Humanity is hard to define as a singular “thing” and is instead a compendium of factors. I certainly argue that the existence of any is the existence of humanity within the individual in its entirety. A core component of humanity within William is his ability to

love, often without reservation. It is often seen as one of his limitations, as he does not distinguish between situations and would be at risk for exploitation by nefarious persons. This remains a matter of perspective though, as one could easily refuse to leave their own home for fear of a crime taking place. In an ideal utopian world everyone would be expected to act much more like William, with love and acceptance being the only appropriate measure of humanity and those who act with hate and malice being relegated to “less than human.” Many children William’s age love the holidays as they get a break from schooling as well as being inundated with presents and sweets. William, however, looks forward to Halloween above all others. His love for this particular holiday stems not from candy (which he never eats) but instead because of the nature of the holiday. It is the only one in which he can visit people's homes and have his own version of a conversation. He might not understand how adults perceive the flow of a conversation ought to go but absolutely relishes in the ability to be welcomed with smiles and open arms at every doorstep. His unbridled joy at this change of the general societal perspective is genuinely infectious and, I hope, could be the start of changing preconceived notions regarding the ID.

### **Making Room: Modes of Being Together**

The objective of changing societal perspective can seem a daunting one but history has shown, with the upheaval of viewpoints on race and sexuality, that over time and with significant advocacy it is possible. As a species, humanity changes all of the time - and we’re changing more quickly than ever. The best example of this is that only a little over a hundred years ago women won the right to vote via decades of suffrage.



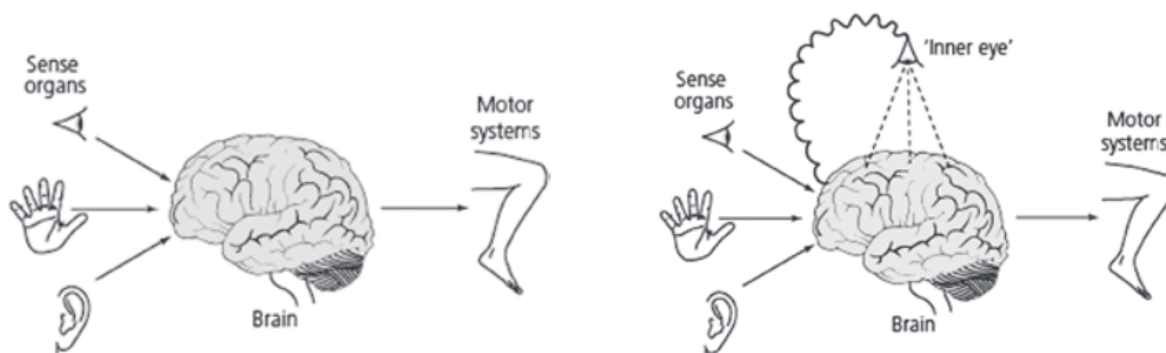
The tearing asunder of long held belief and social policy begins with the objective discussion of what these beliefs are rooted in and the possibility of a fairer, fuller, more nuanced and diverse perspective. Sociality is one of the core tenets of humanity, as inclusion in the social sphere is required for development of cognitive and moral characteristics (Bickenbach, Felder & Schmitz, 2014). As such an important aspect of a human(e) life, this concept - the concept of the social, the together- above all others, should be the foundation of a new social framework for understanding the ID. While traditional rationality may be lacking within the ID, morality is to a much higher degree incredibly subjective, variable, plural and accomplished in groups. To claim a human being is devoid of any type of morality is exceedingly “unjustified speciesism” (Bickenbach, Felder & Schmitz, 2014) as moral claims cannot be proven to belong specifically to humanity above any other. For instance, take the relationship between mother and offspring. Is it truly moral for the mother to always care for the offspring or is it simply survival of the species overall? Are there not equal instances of filicide between humanity and other species? Morality, as well as rationality, are “social constructions” (Carlson, 2010) and vary widely in scale depending on differing cultures and further still within each individual. Since morality and rationality are constructed socially, this brings about serious fundamental questions of what can even be considered as a minimum level of either morality or rationality to be present within the human being to quantify the existence of humanity within.

A differing proposal for the minimum of humanity would then rely on the subject of consciousness: an explanation of the individual’s subjective experience and overall brain activity and processing of information working in tandem, much more so than

mere biological process of reaction to external stimuli, known as primary consciousness (Gross, 2019). Primary consciousness can be found in the vast majority of species capable of primal feelings of hunger, fear, etc. Higher-order consciousness, the ability to act and reflect on these actions in regards to past, present and future (Gross, 2019) begins the distinctions between animal and human consciousness. These differences begin the foray into differences of consciousness and self-consciousness, an all important distinction between human and animal that forms the basis for symbolism and thus language, evolving humanity into a uniquely hyper-social, hyper-mediated creature.

## Figure 2

*Differences between Animal and Human Consciousness re-drawn from Humphrey, 1986 by Richard Gross (Gross, 2019)*



Individuals' subjective experiences and reflections, including feelings and sensations, are fused together to form the notion of “qualia” (Gross, 2019). The subjective nature of qualia does deem it ultimately intransferable between individuals but in no way diminishes the importance of the recognition of the existence of qualia within others, the proverbial “walking a mile in another's shoes.” This recognition forms a strong basis for the existence of humanity within those previously considered

incapable. With this viewpoint of human consciousness intact the issue becomes less of whether the individual should be continually dehumanized but rather the individual's capability to communicate the existence of their qualia effectively -and for others to be able to genuinely listen to and interpret their qualia. What follows from the recognition of qualia in an individual is an implication of the existence of the "self." This self grows firstly out of qualia but is built upon by relationships with others within the confines of the social narrative structure, the continued reflection of identity using the stories told about us and stories that we tell (Keith & Keith, 2013). The continuation of isolation from others is, in this way, the utmost level of dehumanization possible, an act humanity does not even acknowledge as appropriate care for our animal companions' well-being.

Considerations of well-being for the ID are skewed based upon the observer which leads to even more confusion precipitating dehumanization. The able observer views disability through the lens of the "bad difference view," that the ID's lives are intrinsically worse off in comparison to the average individual (Gould, 2022). These conceptions are unfounded when viewed realistically, as the foundation for these beliefs is deeply rooted in an ableist culture and, in reality, every individual's disability impacts well-being differently depending on other circumstances such as the severity of the disability as well as general levels such as family support or financial situation. Without question the individual with ID faces significant barriers in living a "full" life by way of inability to participate in certain activities of everyday life but there is no evidence that this is mutually exclusive to having a high quality of life. The World Health Organization<sup>3</sup> has defined positive mental well-being as the state "which allows individuals to realize their abilities, cope with the normal stresses of life, work productively and fruitfully, and

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<sup>3</sup> <https://www.who.int/activities/promoting-well-being>

make a contribution to their Community” (Bharti & Bhatnagar, 2018). Such a definition is highly problematic as it includes many biases that are not even applicable from culture to culture. One culture may view fruitful work as that which is rewarded with materialistic goods whilst the next may view the same work as individualistic and selfish. The abstraction of well-being and quality of life should at the very least be restructured into one that can apply for the greater part of the population. James Gould (2022) posits a different way in measuring quality of life, one in which subjective and objective theories work in collaboration, wherein the individual’s personal satisfaction plays as much of a role as those extrinsic standards of productivity and contribution. The personal assessment of quality of life has brought up the most significant issues with this proposal in relation to the ID specifically, as most of these individuals lack the ability to communicate conclusively. Proxy reports are less desirable to researchers (Keith & Keith, 2013) but in these instances advocacy becomes paramount and vital in relaying personal experience and information from the ID to the third person.

### ***William’s Teachings on the Meaning of Life***

One of William’s favorite activities is to go to the park near our home. When we go there we end up taking the same path every time. Many who give care and work with the ID can attest to the importance of the routine for these individuals. Our first stop is at the swings, where William finds happiness in the simple act of swinging. He heartily enjoys the feeling of swinging but also being near the hub of activity, laughing as all the children do in play. Once he has had his fill we walk the same worn path with our dog Fritz. At one time I had forgotten a doggy bag to pick up after him in which William quite

loudly admonished me, to my utter dismay. This too is part of our routine and my departure from it meant I had broken a golden rule. At the end of the path lies a small portion of Lake Hickory surrounded by trees, overgrowth and benches. There we sit, sometimes for an hour or more. In the beginning, this used to really bother me as we were not accomplishing anything. There is always another objective, another task at hand. Over time I've seen his wisdom. Instead of the mad dash to the "next thing" we instead enjoy everything as it *is*. The quiet sound of the water flowing, the wind rustling the trees, the people engaging in *life*, the animals doing what they must. The objectives morph instead into the enjoyment of life in its simplest form. For all of the intelligence I am meant to bear as an adult, as a mother, I consistently learn from him what it means to actually take part in existence.

### ***Ethical Advocacy***

The individual's capacity for communication is dependent upon several variables such as the medical, practical and social (Patel, Greydanus, & Merrick, 2014). Each of these situations will be unique and so the impetus of ethical advocacy is placed with the intermediary, the advocate. As William's mom, that's me - the advocate. Stories within *Being a member of a self-advocacy group: experiences of intellectually disabled people* (Gilmartin & Slevin, 2010) focus on the positives of the ID being a key member of the process, both with and without the use of an intermediary, particularly noting the keenest advocates being those of caregivers pushing for marginalized voices to be heard. This key component should become ethically central to advocacy, with ultimate deference to the ID rather than the intermediary. Their concerns and experience *should*

be central, even if they are difficult to access and express. Advocacy is closely tied to legal guardianship, wherein another individual is given authority over decision making related to the ID. Guardianship runs the spectrum from total authority over decisions to one in which decisions are shared. Historically legal guardianship is very rigid in its reliance on the advocate, with the ID becoming nothing more than the sum of their disabilities (Patel, Greydanus, & Merrick, 2014). We have to do better.

An exploration into changing this norm began with The Everyday Decisions Project<sup>4</sup>, which considered how the ID make decisions with and without support, with a primary focus on the operation of the Mental Capacity Act 2005 (MCA) set out in Article 12 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) (Harding, 2021). The MCA concerns the ID in Britain, both in legal matters as well as concerning ethics in research, with a significant barrier in research that provides for the inclusion of the ID, even in instances that could move forward without their inclusion or consent (Harding, 2021). The ID are often facilitated in day to day communications with caregivers with a variety of multisensory approaches such as talking mats/devices and pictures of differing choices available. *Reading Comprehension of Learning Tasks with Pictorial Symbols* (Noll, Roth & Scholz, 2018) found the use of symbols with text provided four functions for those attempting to communicate “Symbols support the general comprehension of the text, Symbols are used to recheck meaning, Symbols help if comprehension problems arise and Symbols help for understanding individual words (student uses one or more examples to illustrate the symbols’ function)”. Working together these functions provide flexibility for the ID depending on their needs and mental capacity. Though not an aid in rationality and

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<sup>4</sup> [https://legalcapacity.org.uk/wp-content/uploads/2017/12/Everyday\\_Decisions\\_Project\\_Report.pdf](https://legalcapacity.org.uk/wp-content/uploads/2017/12/Everyday_Decisions_Project_Report.pdf)

reasoning, the use of these types of aids provides for the implementation of self-advocacy in all of its forms. Self-advocacy provides for personal empowerment, which offers an existence for the ID in which they can exert control and voice an opinion, in effect asserting their own rights and beliefs (Gilmartin & Slevin, 2010). The ID would still be limited in their power to change major issues but this level of new empowerment would at least afford the ID that distinct human attribute of a voice.

### ***Personal Self-Advocacy***

William is not often given the gift of choice as he is deemed incapable of “true” rationalization. I am an adult who supposedly should be able to rationalize nearly everything that comes my way and still I make mistakes, big and small, as often as anyone around me does. Yet I do not have to exert my control loudly and physically, it is given to me inherently whereas William must somehow “prove” to everyone around him that he is worthy of making choices that relate to him specifically. William goes beyond simply advocating for what he intends to eat or not to eat. His voice may not be as clear as others but still exists in what he chooses and how he chooses to do it. William visibly shows his preference for certain individuals over others by landing himself directly in their lap. Many interpret this as another inability to act respectfully in the social setting and the clear denial of his size as an eight-year-old child but I choose to see this as an honor. If the room is full of people and he chooses to sit in my lap, I am quite happy to be the center of his attention, even briefly. At the end of my day I would much rather be seen as valuable by someone who accepts everything about me, flaws and all, than to compete for attention among others whose ulterior purpose is questionable at best.

## Conclusions

Humanity arose from the basis that as human beings we share commonalities with each other and have developed corresponding customs and habits in relation, which reveals the inherent importance of a social life (Bickenbach, Felder & Schmitz, 2014). Bernard Williams proposes an interesting thought experiment relating to what he terms “human prejudice:” Imagine a group of highly intelligent Martians visit this world and come to the conclusion that the eradication of human beings is necessary. Some may believe in the Martian proposition whereas most would defend themselves and humanity as a whole with human life and survival taking precedence. The argument of what it means to be human becomes untenable in this experiment as we are all biologically human, with any notions of dehumanization and prejudice being readily abandoned. This quick abandonment belies the importance of any of these distinctions.

One of these distinctions with the ID is that of functional disadvantage, still its existence does not imply lesser moral or ethical status of humanity. A naturalistic view of disability is ultimately theoretical and only sees disability as a departure from typical human functioning (Gould, 2022) which can significantly impact daily life but holds no real bearing on the other characteristics of humanity that lies within the ID. Another thought experiment is that of the third-person judge as presented by Ron Admunson (Gould, 2022) involving that of the slave. The happy slave can disclose a good quality of life, even if untold injustices occur within slavery. The outsider knowing of these injustices questions this quality of life as even though the slave does not recognize it, the outsider does. Though not in all ways compatible with the ID, the comparison with slavery is made when considering that “The happy slave has an epistemically-privileged



inside position—he can see that he is happy. But non-slaves have an epistemically-privileged outside position—they can see that he is a slave. While we should not ignore or under-emphasize self-reported quality of life—to do so would be epistemically unjust—neither should we absolutize or over-emphasize it” (Gould, 2022). The distinctions between subjective and objective should be held in equal relation rather than continuing the practice of the objective only.

A proposal for the normalization of the subjective within the ID comes from Wolf Wolfensberger’s concept of social role valorization, an idea of upgrading the value of the ID within the roles they do play, as neighbor, friend, child etc. (Keith & Keith, 2013). Such a concept takes away from the importance of rational ability and IQ tests and values instead the socialization at the heart of humanity. Normalization has also been theorized and philosophized by Paul-Michel Foucault (1996), who found that human norms are highly subjective and become internalized en masse as “truths,” pushing individuals to adapt their behavior to get closer to these norms, leaving power and social control with a questionable few rather than with society as a whole. The social constructions of norms takes a basic truth, such as the fact that the ID do exist in the world and bastardize this truth into what became a history of institutionalization, which ultimately helped no one and hindered every regard of the ID as part of society and humanity. Instead the new conclusion should be that of inclusion of the ID, both body and mind, with person centered planning that focuses on the differing criteria of strengths, capacities, preferences and needs (Patel, Greydanus, & Merrick, 2014) instead of the dehumanization of the individual into being only that which they are

incapable of. Though little can change about the disabilities the ID suffer from, much can change on how society perceives, cares for, and humanizes them.

### ***Humanizing Stories***

Criminals who commit the worst atrocities against their fellow human are frequently labeled inhumane for their intentional atrocities yet the ID who have committed no acts of genuine ill will are consistently relegated to the fringes of society simply because the barriers in communication exist. Imagine being trapped within one's own mind, able to feel and able to think, but unable to put into words any expression. Society then turns it back, exiling you into the symbolic "corner of the room." One's only hope becomes mere recognition from any passerby and that just maybe, one day, the offer of a seat at the table of humanity might be offered because if nothing else *can* be changed at the very least a friend would provide comfort.

Advocacy makes the caregiver that friend and the advocate then becomes something far greater when willing to take up the mantle of becoming the mouthpiece for the muted. Focused, lived experience alongside raw, hard data (Adams & Herrmann, 2023) turns the data from conjecture to reality. The reality is that the ID do suffer from communication limitations but it is not realistic to assume the ID do not have a tangible lived experience and even less realistic to continue to treat them as only "breathing masses of flesh" (Carlson, 2010, p. 31) especially when considering what each specific lived experience can teach about nearly every facet of human life. Through every aspect of William's life he has taught me more about quality of life and in life than I could ever hope to glean from any piece of research or writing. I have learned patience

during a tantrum, empathy from looking into his eyes and imagining what he goes through every minute of every day, true joy in forgetting the construct of time, the power of love from parent to child, the faithful perseverance it takes to force an unwilling body to act, the resilience of mind it takes to ignore adversity, how to cope with the grief of almost losing a child, and the lived experience of observing the subtle and overt acts perpetrated by others that results in the dehumanization of a living, feeling, human being. These emotions, when harnessed together, will continue to fuel my ambition to push society into humanizing each unique story from the ID and in turn do what every parent sets out to do, make this world a better place for my child.

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