

Ethics, Public Policy and Care of Individuals with Intellectual Disability

Peter Smith, MD, MA

Editor's Note: There are a number of ethical issues, some hidden, in care for individuals with developmental disabilities that can only be fully understood in light of the history of epidemiology. Dr. Smith describes issues related to human dignity, care equity and disparity in outcomes as well as problems with the financing of medical education that exacerbate the problem. This overview is a version of a talk given by Dr. Smith at CHA's 2018 Theology and Ethics Colloquium in St. Louis.

LANGUAGE AND HUMAN DIGNITY

The terms that describe individuals are important. Any person or organization that seeks to work with individuals with disabilities has to learn to use the language conventions that are considered respectful, and avoid those that are viewed as outdated or disrespectful.

The first and most important rule is to always employ "person-first" language. One would say a child with Down syndrome rather than a "Down's baby". A second rule is to avoid language that focuses on victimization or charity. A person does not "suffer" from autism spectrum disorder and people are not "confined" to a wheelchair. Instead, a person meets criteria for autism spectrum disorder or uses wheelchairs for mobility. Within the

community of individuals with intellectual and developmental disabilities (IDD), there has been a long history of medical-clinical terms that have become stigmatizing and insulting. For example, the terms "moron," "idiot" and "imbecilic" were technical terms meant to categorize individuals with cognitive impairments, but are now seen as inappropriate. The same is true for "mental retardation."

Furthermore, there is an important and ongoing evolution in the terms used to describe the differences experienced by people with disabilities. For example, the term "handicap" is almost never acceptable: The only uses that aren't considered disrespectful are: (1) "People used to use the term 'handicap'; and (2) "He has a low handicap in golf." A term that is much more useful, especially in health care, is "impairment." In this context, impairments are losses or diminutions in the function of body parts or systems. For example, a measurable loss of hearing at certain (or all) frequencies would be a "hearing impairment."

Likewise, an above-the-knee amputation would lead to a mobility impairment. Much of the work of health care is found in the documentation and support of impairments. The term "disability" is not synonymous with "impairment." A disability is the personal diminution in life goals due to an

impairment. It is crucial for health care professionals and organizations to recognize that impairments that would frequently cause disability in the past often do not do so today. Changes in technology and society have led to a quiet revolution for people with disabilities. For example, there is a man living now who does not have feet and is one of the fastest humans in recorded history. Did the doctors tell his family when he was born with malformations of his legs that he would never walk? In another example, due to changes in law that resulted in the development of special education programs, individuals with intellectual disability are increasingly engaged in a typical curriculum with their peers, are increasingly employed, and increasingly more independent. Furthermore, some losses are not perceived as disabilities by the persons who experience them, especially if they are present from birth or early in life. Within the community of individuals with autism spectrum disorder, there are some who see others, termed “neurotypical”, as the ones who are different.

DEFINITIONS OF INTELLECTUAL DISABILITY

Intellectual disability is the term created by the American Association on Intellectual and Developmental Disabilities (AAIDD) that is used to describe individuals in multiple settings (educational, medical, legal) who have impairments in cognition. It is similar to definitions of mental health impairments found in the DSM. Intellectual disability is not a rare condition: Between 5 and 8 million Americans of all ages (1-3% of the general population) experience intellectual disabilities. According to the AAIDD website, (<https://aidd.org/intellectual->

[disability/definition](#)), there are three main parts of the definition:

Intellectual disability: Intellectual disability is characterized by significant limitations in both **intellectual functioning** and in **adaptive behavior**, which cover many everyday social and practical skills.

Intellectual Functioning: Also called intelligence, “intellectual functioning” refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or up to 75 indicates a limitation in intellectual functioning.

Adaptive Behavior: Adaptive behavior is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.

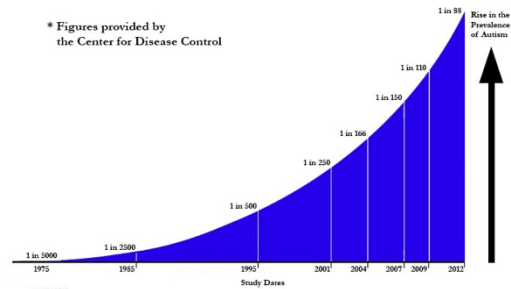
- Conceptual skills—Language and literacy; money, time, and number concepts; and self-direction.
- Social skills—Interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, the ability to follow rules/obey laws and to avoid being victimized.
- Practical skills—Activities of daily living (personal care), occupational skills, health care, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Standardized tests can also determine limitations in adaptive behavior.

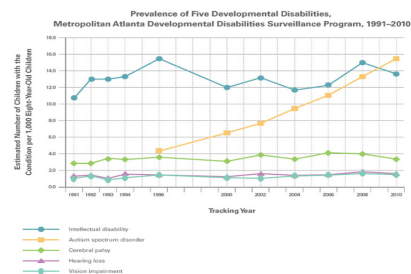
AGE OF ONSET

Intellectual Disability is one of several developmental disabilities. Evidence of the disability appears during the developmental period, which in the U.S, usually appears before the age of 18. In defining and assessing intellectual disability, the AAIDD stresses that additional factors must be taken into account, such as the community environment typical of the individual's peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave. Finally, assessments must assume that limitations in individuals often coexist with strengths, and that a person's level of life functioning will improve if appropriate personalized supports are provided over a sustained period. Only on the basis of such many-sided evaluations can professionals determine whether an individual has intellectual disability and tailor individualized support plans.

Autism Spectrum Disorder is a neurodevelopmental disorder that originates in childhood. It is not fully understood and there are many different subgroups or "ways to have" autism. The formal definition has changed over time and will likely change in the future. There are three main features that lead to the diagnosis of an autism spectrum disorder: (1) language difficulties; (2) social relationship difficulties; and (3) atypical behaviors. It is now generally recognized that autism is not the rare condition it was considered to be when it was first described but is rather a more common condition within human variation.



The Centers for Disease Control and Prevention (CDC) currently estimate autism's prevalence as 1 in 68 children in the United States. This includes 1 in 42 boys and 1 in 189 girls. This is much higher than estimates from prior to 1975. This significant rise in the prevalence of autism is due in large part to changing definitions of autism and a widening of the criteria for diagnosis. In addition, there has been increased awareness in the general public and among medical and public health professionals about effective treatments for autism. Heightened awareness about effective treatments has spurred a massive public health effort to increase surveillance and diagnostic efforts, which have led to improved detection. Due to the effect of these changes, it is difficult to determine if there has been a rise in the actual number of individuals with autism. Regardless of the causes, autism has become one of the most common disabilities tracked by the CDC.



DISPARITY IN HEALTH OUTCOMES

For decades, it has been well known that people with ID and ASD experience substantially poorer health outcomes than their peers who do not have disabilities. They are more likely to die earlier and have poorer health overall. In addition, they are more likely to live with a wide range of complex health conditions, including epilepsy, sensory impairments, respiratory disorders, obesity, diabetes, oral health problems, and mental health problems.

Historically, health disparities for individuals with ID/ASD were attributed to biology. For example, individuals with many known chromosomal abnormalities that “cause” intellectual disability also are at increased risk for various negative health conditions. Previously, doctors and public health officials generalized this understanding across all individuals with ID, presuming that whatever “caused” their ID was also “causing” their worse health outcomes.

However, more recent research has demonstrated health inequity plays a large role in the “cascade of disparities.” This newer research has demonstrated that barriers to access to health care and health promotion programs contribute to their worse health outcomes. For example, diabetes prevention programs are not designed to take into account the specialized language needs of individuals with ID and ASD. In addition, the quality of management of health conditions is worse for these populations due to the lack of training in medical schools and residencies specifically directed towards individuals with ID and ASD. Doctors have very little or no exposure to training related to ID and ASD because there are no curricular mandates for medical schools

or residencies to include them in their training. Further, lifestyle factors (often related to housing options) contribute to worse health for individuals with ID and ASD.

An Example: Women with Intellectual Disability (ID) Data from the Medical Expenditure Panel Survey from 2000 & 2002,¹ showed that women with cognitive limitations were much less likely than nondisabled women to have had a Pap test within the last year. In addition, women with cognitive limitations were also less likely to have received a mammogram in the last year. However, they were approximately 60 percent more likely than nondisabled women to have received a flu shot in the last year, likely due to requirements that are linked to their housing. These individuals are more likely live in group homes to support their daily living, and many of facilities require residents to have annual flu shots. In addition to measurable decreases in health outcomes were troubling attitudinal findings: Women with cognitive impairments were 49 percent less likely to report that their doctors showed them respect, 41 percent less likely to report that their care provider listened to them and were 48 percent less likely to report that their doctor spent sufficient time with them.

An Example: Down Syndrome Down syndrome (DS) is the most common chromosomal cause of ID. It is often the “face” of ID, due to known facial features. DS can lead to multiple potential health conditions, including congenital heart disease, gastrointestinal difficulties, increased risk for developing some specific cancers (especially in childhood), difficulties with growth (including increased likelihood of having thyroid dysfunction) throughout life, and increased risk

for dementia in older adult life (the exact percentage is still unclear).

Down syndrome is named after the English doctor, John Langdon Down, who in the 19th century was the first to categorize the common features of people with the condition. In Paris in 1958, Dr. Jerome Lejeune discovered that DS is a genetic disorder whereby a person has three copies of chromosome 21 (“Trisomy 21”) instead of two. There are also very rare forms of Down syndrome (less than 6 percent) called Translocation Down Syndrome or Mosaic Down Syndrome. In 2011, the CDC estimated the frequency of Down syndrome in the U.S. is 1 in 691 live births (up from 1 in 1,087 in 1990). The current estimate of people in the U.S. with Down syndrome is over 400,000. Some estimates put the worldwide population of people with Down syndrome at more than 6 million. Because of the increase of live births of people with Down syndrome and the recent dramatic increase in their lifespan, over the next 20 years a significant increase in the population of people with Down syndrome in the U.S. is expected.⁴

There has been a continued expansion in prenatal screening protocols to detect DS during pregnancy. However, the expansion in screening has not been matched with expansion in the education of physicians. In one study, 45 percent of obstetricians admitted their training on prenatal genetic testing was “barely adequate” or “nonexistent.”² A study of families of children with Down syndrome regarding how they received the diagnosis found that physicians gave information that was often factually incorrect, including statements like “*this meant that she would never live on her own or hold a job*”.³ The situation has become so bad that states have had to pass laws mandating that

doctors present accurate information about Down syndrome to parents.

In addition, despite being the most common, DS is the least funded major genetic syndrome in the entire NIH budget. In addition, major portions of funding are directed to screening projects, not improving the care of individuals with DS. This means that there is less support for specialists in DS, which is why there is little exposure to DS teaching in medical schools and residencies.

SUBSPECIALTY IN CRISIS: LACK OF TRAINING AND FUNDING

Developmental-Behavioral Pediatrics (DBP) and Neurodevelopmental Disabilities (NDD) are two subspecialties within pediatrics. Specialists in DBP and NDD undergo years of extra training after general pediatrics residency and are the primary clinicians who are dedicated to ID and ASD (and other disabilities).

In 2017, a national survey of the current subspecialists dramatically documented what most already knew: There are not enough DBP and NDD doctors and the months-long waiting time for new patients to see DBP and NDD doctors is the longest in all of medicine. Furthermore, conditions will soon get worse because 33 percent (159) of those surveyed indicated they will retire within 3-5 years and there are only 31 fellowship graduates each year. The survey also documented that DBP and NDD doctors are overwhelmed and burning out, in part due to the dramatically increasing need for their expertise along with the shortage of DBP and NDD specialists.

This situation is due in large part to the fact that medical centers and medical schools are dominated by internal medicine and surgery departments; there are simply more of these types of doctors (adults are sicker than kids). In addition, pediatrics focuses on prevention and is more outpatient-oriented in its care. In the U.S., pediatrics also pays less than other specialties. Even when pediatricians do exactly the same medical “things” as internists (as judged by the codes used to bill public-financed insurers), internists make more money because Medicare pays better than Medicaid and pediatricians only bill Medicaid. Compounding the problem of adult-centered medical centers, there is no equivalent adult subspecialty in DBP or NDD or representation of ID or ASD when curricula are created, budgets are approved, and leadership decisions are made. As a result, very few leaders of medical schools or medical centers ever explicitly think about ID or ASD, unless they have a relative who has ID or ASD. Conceptually, pediatrics is too often seen by these leaders as “shrunk” adult medicine. This is backwards thinking - all adults were once children and it has been clearly established that many “adult” disease processes start in childhood. In the 20th century, pediatricians broke from AMA during the “socialized medicine” debate. Then in the 21st century, health care reform was based on a “medical home” model that developed from work done for decades by pediatricians.⁵

ETHICS AND POLICY

Simply put, the U.S. health care system needs to put more money into the support of clinicians who serve individuals with ID and ASD. There is a need for direct support for DBP & NDD practice, including better salaries. In addition, health care spending needs to be shifted away

from hospitals and surgeries and towards care coordination, behavioral health, and social supports. This is true across all of medicine, but it is especially important for individuals with ID and ASD. Further, there will need to be more support of training programs for subspecialty doctors, nurse practitioners, physician assistants, general pediatricians, and family practitioners.



Peter Smith, MD, MA

Associate Professor of Pediatrics
University of Chicago School of Medicine
Chicago
psmith2@peds.bsd.uchicago.edu

ENDNOTES

¹ This is a telephone survey of approximately 31,000 households in US, which included 15,831 women aged 18 to 64 years. A total of 296 respondents (representing an estimated 1.14 million women) had a cognitive impairment (a proxy for ID). The survey includes 8 measures of health care access and 5 measures of satisfaction with care.

² Adapted from material accessed at Global Down Syndrome Foundation website.

³ Cleary-Goldman et al., *Obstetrics & Gynecology* 107(1), 11–17.2006

⁴ Skotko, *Pediatrics* 2005;115:64-77

⁵ For example, The American Academy of Pediatrics made it official policy that “every child deserves a medical home,” in 1998.