Ethics, Medicine and Public Health (2015) xxx, xxx--xxx



Available online at

**ScienceDirect** 

www.sciencedirect.com

Elsevier Masson France
EM consuite
www.em-consulte.com



DOSSIER "DISABILITY" / Studies

# Intellectual disability is "a condition, not a number": Ethics of IQ cut-offs in psychiatry, human services and law

La déficience intellectuelle « n'est pas un seuil, mais un état » : l'éthique de l'utilisation du seuil de quotient intellectuel (QI) dans la psychiatrie, les services sociaux et le droit

S. Greenspan (PhD, Emeritus Professor)<sup>a,\*</sup>, J.C. Harris (MD, Professor)<sup>b</sup>, G.W. Woods (MD, Adjunct Professor)<sup>c</sup>

Received 16 May 2015; accepted 3 July 2015

#### **KEYWORDS**

Intelligence; Disability; Categorization; Ethics Summary Diagnosis in psychiatry and related fields is complicated by the fact that symptoms overlap across categories, comorbidity of diagnoses is commonplace, and information about a specific physical etiology (critical for diagnosis in medicine) is typically lacking. The field of intellectual disabilities/intellectual developmental disorder (IDD) differs from other psychiatric categories in the historically heavy reliance on IQ cut-offs to create the expectation of a clear demarcation between people who have IDD and those who do not. There is increasing dissatisfaction with this practice, however, as reflected in the move by DSM-5 away from a "disability" and towards a "disorder" emphasis. The May 2014 US Supreme Court majority decision in Hall v Florida which outlawed the use in death penalty cases of a "bright line" (IQ of 70) arbitrary IQ ceiling that ignores the standard error of five points exemplifies this evolving perspective, as reflected in the opinion delivered by Justice Kennedy that "intellectual disability is a condition, not a number". In this paper, we trace the evolving history of our understanding of intelligence (and the increasingly outmoded nature of the entrenched concept of full-scale IQ)

http://dx.doi.org/10.1016/j.jemep.2015.07.004 2352-5525/© 2015 Elsevier Masson SAS. All rights reserved.

<sup>&</sup>lt;sup>a</sup> Department of Educational Psychology, University of Connecticut, Storrs, CT, USA

b Department of Psychiatry, Johns Hopkins University, Baltimore, MD, USA

<sup>&</sup>lt;sup>c</sup> Boalt School of Law, University of California, Berkeley, CA, USA

<sup>\*</sup> Corresponding author. 9424 Erin Lane, Littleton, CO 80127, USA.

E-mail addresses: stephen.greenspan@gmail.com (S. Greenspan), jharrisd@jhmi.edu (J.C. Harris), gwoods@georgewoodsmd.com (G.W. Woods).

and describe the various efforts in three fields—human services, psychiatry, and law—that have been made to go beyond reliance on IQ ceilings and to reestablish a more scientifically accurate as well as clinically appropriate approach to IDD. Three ethical principles—beneficence/non-maleficence, consistency and rationality—are used to indicate why continued reliance on IQ ceilings in diagnosing IDD is a morally questionable practice.

© 2015 Elsevier Masson SAS. All rights reserved.

#### MOTS CLÉS Intelligence; Invalidité; Catégorisation; Éthique

Résumé Le diagnostic des maladies mentales en psychiatrie et dans les domaines associés est complexe du fait du recoupement des symptômes à plusieurs maladies, de la fréquence de la comorbidité des diagnostiques différentes et du manque de renseignements pertinents sur une étiologie physique spécifique (ceux qui sont indispensables pour un diagnostic médical). Le domaine des déficiences intellectuelles (DI)/troubles du développement intellectuel (TDI) diffère des autres catégories du domaine psychiatrique à cause de cette attente de pouvoir définir une démarcation claire du seuil de quotient intellectuel (QI) afin d'identifier les personnes atteintes de TDI ou de celles non affectées. Cette pratique (de fixer un seuil de QI pour le diagnostic des patients) induit une insatisfaction grandissante. Cependant, nous voyons que le DSM-5 est plutôt considéré comme un trouble alors qu'il était considéré antérieurement comme une déficience. La décision de la Cour suprême des États-Unis dans le procès Hall contre Florida en mai 2014 interdit l'utilisation des cas des peines de mort pour la définition des « seuils explicites » arbitraires ; ce point de vue évoluant avec son interdiction de la mise en pratique des « seuils explicites » arbitraires (en dessous d'un QI de 70) ignorant la déviation standard de 5 points, illustrant bien que ce seuil est en évolution constante. Ce point de vue est un exemple donné dans l'opinion émise par le Juge Kennedy : « la déficience intellectuelle n'est pas un seuil mais un état ». Dans cette étude, on trace l'histoire de notre compréhension de l'intelligence (et la nature de la notion indéracinable de QI en général, une notion de plus en plus désuète) et on décrit nos différents efforts dans trois domaines—les services sociaux, la psychiatrie et le droit—où il fallait aller plus loin que le recours à un seuil de QI pour pouvoir aborder DI d'une façon plus juste scientifiquement et cliniquement. L'objectif de ce travail était de considérer trois principes éthiques—la bienfaisance/non-malfaisance, la cohérence, et la rationalité—et, à partir de ces conclusions, de présenter en quoi l'utilisation de seuils de Ol pour le diagnostic des DI est une pratique qui soulève de vraies questions morales. © 2015 Elsevier Masson SAS. Tous droits réservés.

### Introduction

In DSM-5, the fifth edition of the Diagnostic and statistical manual of mental disorders [1], the condition formerly known as mental retardation was renamed "intellectual disability (intellectual developmental disorder)", which we shall refer to in this paper as "IDD". The first part of this name, "intellectual disability", was selected to bring the manual's terminology into line with current, less pejorative, terminology used in most other countries and, increasingly, in North America [2]. The second part of the DSM-5 name--"intellectual developmental disorder"—was placed inside parentheses to indicate a potential name in a future revision, in keeping with ICD-11 (the in-process eleventh edition of the World Health Organization's International classification of diseases) whose proposed new name [3], expected for release in 2017, is "disorders of intellectual development''.

In signaling a likely eventual preference for a term emphasizing "disorder" over one emphasizing "disability",

the authoring committee was distancing itself from what many consider an excessive reliance on an arbitrary ceiling on a psychological measure (IQ score) to define what is essentially a neurodevelopmental category [4], in a medical manual where all other conditions are defined through a disorder (qualitative) rather than through a disability (numeric) method.

This conflict between IDD's dual role—as a disability and as a disorder—reflects the fact that IDD is an outcome status, used by various bureaucracies (schools, courts, adult service agencies, etc.), that can be caused by numerous biological (prenatal, perinatal or postnatal accidents, maternal infection or ingestion of teratogens, inherited conditions) or environmental (malnutrition, severe deprivation) factors, and which as a label is a gateway to necessary support, benefits and services intended to help a person cope and survive in various social settings.

While other mental health diagnostic categories (e.g., schizophrenia)—like IDD—are defined in terms of behavioral manifestations or deficits, they are medical/clinical

constructs, which do not necessarily have a primary bureaucratic purpose, even though they might have some bureaucratic utility. Intellectual Disability, on the other hand, until the effort by the authors of DSM-5 to move to more of a disorder emphasis, is a purely bureaucratic status (although there are literally hundreds of medical and psychiatric conditions that may lead to that status), whose primary purpose is to determine eligibility for various protections, entitlements, programs and (less so, today) persecutions (such as involuntary sterilization or incarceration). Medically, however, the focus is on neurodevelopmental and brain functioning.

Because a bureaucratic disability status is regularly determined by a gatekeeper who may lack clinical qualifications or the time to really get to know deficits of the individual being evaluated, and also because bureaucracies cannot find every applicant eligible, there is a natural preference for reductionistic rules, for determining whether or not an applicant is eligible for the desired status. Hence, the attractiveness of IQ ceilings, and the historic reluctance of bureaucracies to entertain the idea that determining if a person has cognitive deficits significant enough to deserve special protections should involve looking at the whole person and not just a single numeric index. This reductionistic approach has been reinforced by mental health disciplines, which cannot always provide a solid scientific foundation for the decisions that need to be made. However, the story of IDD, especially in the 20th century, was essentially the story of a socially constructed (but nevertheless real) disability category whose proponents sought to create the impression that its upper boundary was defined by science [5].

The retiance on IQ ceilings to diagnose IDD has long been disputed on policy grounds [6], but here we dispute it on ethical grounds. IDD has proved to be a fertile field for the exploration of ethical issues, much of it from a biomedical perspective [7,8]. Some, but hardly all, of the ethical issues relating to people with IDD that have been addressed in journals and books are: informed consent [9], marriage and sexuality [10], moral agency [11], organ harvesting [12], labeling, stigmatization and terminology [13], institutional abuses [14], selective abortion [15], eugenic euthanasia [16], denial of life-saving surgery [17], use of aversives [18], spirituality [19], political rights [20], positive caregiving [21], paternalism [22], medical experimentation [23], normalization and non-restrictiveness of services [24], and development of professional codes [25].

In this paper, we address an issue that has been much analyzed within the IDD field from a policy, practice and epidemiological standpoint, but has not to our knowledge previously been discussed as a problem in ethics. That issue has to do with the centrality of IQ ceiling cut-offs both to define the IDD category in clinical manuals, and to make decisions about admitting or denying access to various programs, benefits or protections for a particular individual. Four principles of professional ethics will be used to make the case that IQ ceiling cut-offs are ethically suspect (the descriptions that follow in parentheses are specifically tailored for classification purposes):

 "consistency" (all categories for classifying different groups of people should be arrived at using similar methods), also known as "justice" (all people with very similar needs profiles should be treated the same);

- "rationality" (science, not scientism, should be the basis for a category presented as evidence-based);
- "beneficence" (categories should provide services for all people who legitimately need and deserve them);
- "non-maleficence" (classification practices should be avoided that are grievously harmful).

Before we elaborate on why these ethical principles apply to the topic of IQ ceilings, some brief background information about intelligence and its role in the definition of ID is provided. Following the ethical analysis, we describe some of the ways in which the distorting effects of IQ ceilings are being alleviated in psychiatry, human services and law.

### Overview of intelligence, intellectual disability and IQ ceilings

IDD has been a part of the human condition since its inception, and references to it-under various names-can be found in ancient documents over the millennia [26]. A major distinction between ancient and more recent literature on IDD is the current greater emphasis on less severe and less visible forms of the disorder. Even in the dozens of genetic and biological syndromes that are known to be strongly associated with the onset of IDD, in many instances IQ scores tend to be found in the range (IQ between 55 and 75) of what is generally (and misleadingly) termed ''mild'' IDD. It is in part because IDD is today a somewhat hidden disability, and is not always immediately obvious to the casual observer, that the field has come to rely so heavily on IQ ceiling scores, which create the comfort of having an objective and clear-cut basis for saying someone is ''IDD'' or ''not IDD". Unfortunately, staying in one's comfort zone does not always make for a valid or appropriate diagnostic decision framework.

On an intuitive level, it makes sense for the category of IDD to be tied closely to the construct of intelligence, as the prototype for IDD is people who are "slow" and have significant problems thinking, showing good judgment, avoiding risks, and performing academic tasks [27]. The problem is that, even to this day, intelligence is a poorly defined construct whose meaning is not universally agreed-upon [28], and there is growing sentiment to the effect that IQ scores are very imperfect measures of "intelligence" [29]. As noted by a leading intelligence scholar [30], "human intelligence has long been on the borderline between a scientific and a quasi-scientific field within the scope of psychological science. This is partially because its study and measurement have been particularly susceptible to socio-political agendas, but also because tests or theories of intelligence have too often ranged from inadequate to nonexistent".

There are four overlapping reasons for dissatisfaction with the assumption that IQ is the best or only measure of intelligence:

- there are important areas of content, such as "social intelligence" that are not tapped at all by IQ tests [31];
- there are other types of tests, such as measures of "executive functioning" that do a better job of assessing what we think of as intelligence [32];
- there is a growing feeling that "full-scale IQ" (the summary index that is the only one typically used for decision

- purposes) is an outmoded concept, and that quantitative and descriptive profiles across tests and batteries are more useful [33];
- there are problems with norm obsolescence [34] and unreliability of scores and test administration [35] that cause errors which make it improper to put so much emphasis on any single score.

These four issues will be revisited somewhat in different sections of this paper.

To understand the content limitations of IQ scores, it is necessary to know something about the history of intelligence testing. Until the advent of the 20th century, efforts to construct measures of intelligence were unsuccessful. Two educational psychologists in France-Albert Binet and Theodore Simon-were asked by the French government around the turn of the last century to construct a test to be used to identify children unable to benefit from newly established universal public education. Although their earlier research was more broadly based, focusing on judgment and reasoning in social and other non-academic spheres, the test they constructed in response to the government's request was essentially made up of items taken from the school curriculum at different grade levels. For this reason, Anastasi [36], one of the deepest thinkers about psychological testing, opined that there is essentially no difference between measures of intelligence (which she termed "aptitude") and measures of academic achievement and potential. Obviously, this fact (which continues in current tests which for the most part are still modeled on the Binet-Simon) is problematic if one accepts that one can be intelligent (or non-intelligent) in ways other than on academic tasks [37]. Furthermore, even within academic contexts, we now understand the multiple skills that are part of brain functioning (such as visuospatial coordination, weighing of complex decisions, and other aspects of neuropsychological ability) that are still only poorly tapped by current intelligence measures.

The popularity of the French test skyrocketed when two American psychologists with strong eugenicist beliefs—Henry Goddard and Lewis Terman—translated it into English, and established it as a basis for their racist and classist social agenda in identifying so-called "morons" (a term coined by Goddard, meaning fools) and having them institutionalized, sterilized and prevented from immigrating into the United States [38]. The shut-off of immigration for decades from Eastern and Southern Europe (among other places) was in fact fueled by poorly (some would say corruptly) conducted studies and polemics aimed at protecting the purity of the "white race".

Initially, intelligence estimates were based on "mental age" (MA), which essentially were raw score averages tied to different levels of chronological age (CA). This contributed to over-estimates of IDD in the population, because of a failure to understand that rate of growth in MA varies across developmental periods, and starts to plateau in adolescence. Political commentator Walter Lippman [39], an outspoken early critic of intelligence testing, made fun of this finding by writing: "A startling bit of news has recently been unearthed and is now being retailed by the credulous to the gullible: 'The average mental age of Americans... is only about fourteen'... This remark is precisely as silly as

if one had written that the average mile was three quarters of a mile long". In fact, the popularity of MA declined with the increasing use of IQ, a term and statistic invented by a German psychologist, Wilhelm Stern [40]. It was initially based on a ratio (MA/CA  $\times$  100) method in which MA played a role, but was later replaced by a more reliable "deviation" method (establishing separate norm tables for different age groupings, where individual scores are converted to IQ scores based on distance from the population mean). As the convention is that the population mean is arbitrarily set at 100, and the standard deviation at 15, a score of 70 thus places someone at two standard deviations below the mean, or (using a normal distribution conversion table) at the 2nd percentile of the population.

Until 1961, IDD was not tied to any specific IQ score, but in that year the American Association on Mental Deficiency (today termed the American Association on Intellectual and Developmental Disability, or AAIDD) published a diagnostic manual (Heber, 1961) in which they established a ceiling for IDD at a score that was one standard deviation (SD) below the population mean (or 85 using instruments with a standard deviation of 15). Using what is termed a "z-score" conversion table, this places one at the 17th percentile of the population, which was obviously too high, given that the consensus among IDD scholars, based on nothing except opinion, was that people with IDD made up about three percent of the population [41].

In establishing the ceiling so high, the idea was that an invented second criterion, termed "adaptive behavior" (adaptive functioning in DSM terminology) would tap into someone's competence in the outside (non-academic) world. Because the adaptive behavior criterion was not used for a long time (and instruments initially lacked population norms), the AAIDD in 1973 lowered the ceiling to minus two standard deviations (full-scale IQ of 70), which placed someone at the second percentile. Just as 85 (17th percentile) was too high, 70 (2nd percentile) was too low, especially as the adaptive behavior criterion began (through rating instruments, primarily) to come into wider use. To prevent excessive numbers of "false negatives" (people who deserve IDD designation but are denied it because their IQ score was over the ceiling), some flexibility has been recommended, with the term "approximately minus two SDs" generally used to indicate the need to take into account the standard error of IQ scores (which would raise the ceiling to 75), correct scores downward to take account of obsolescence of norms of older tests (the so-called "Flynn effect''), and take into account the learning effects accruing from multiple test administrations (the so-called "practice effect").

The diagnostic framework for IDD contains three ''prongs'':

- · intellectual functioning deficits;
- adaptive functioning deficits;
- developmental onset.

The issue of IQ ceilings affects only the first prong, but the second prong enters into the picture in two ways:

 aspects of real-world intellectual incompetence (such as poor academic and social functioning) can be viewed as problems of intellectual functioning (if adaptive behavior were approached in terms of cognitive as opposed

to personality or motivational deficits, thus supporting a merging of the first two prongs);

in practice, adequate adaptive functioning is typically used to correct for "false positives" (when a person has low-enough IQ to fall under the ceiling but "really" should not be considered to have IDD), but inadequate adaptive functioning is typically not used to correct for "false negatives" (when a person's IQ is too high and thus viewed as non-qualifying, when he or she should "really" be considered to have IDD).

The reason for this imbalance reflects both the continued primacy and mystique of the IQ statistic, as well the ''disability'' status of IDD, in which bureaucracies have a need both for clear and rigid "yes" or "no" decision rules that do not take into account the true nature of scientific inquiry, which is always about ambiguity and evolution, rather than certainty and stasis. It also must be viewed in light of the history of IDD definitional efforts, when the early concern (because IQ ceilings at one time were only minus one SD) was mainly on false positives (as, for example, in excessive labeling of poor and minority children), and the evolution was from a time when IDD was approached solely in terms of IQ and moved (because of false positives) to development of prong two as a counter-balance. However, this balancing effort never went so far as to establish a true equality between the two prongs. In such an equality, a determination that someone has IDD would be based on an integrated weighing of both prongs, and neither prong would have primacy. In the current situation, to the contrary, IQ has a veto over the diagnosis, but adaptive functioning does not. This problem of using too high (in relation to a cutoff) IQ score to deny the ID diagnosis to someone seen as "really" deserving it, is at the heart of the ethics problems addressed in this paper, as illustrated by an example that will be discussed in following sections.

### How IQ ceilings are problematic in relation to three ethical principles

Categorical classification in general (not just for IDD), both in DSM and in other manuals, has been subjected to many critiques, with some of the criticisms raising ethical concerns [42]. Among these critiques have been: devastating impact on patients and families [43]; lack of scientific validity support for the categories or taxonomies [44]; falseness of claims of adequate diagnostic reliability [45]; misuse in forensic practice [46]; pathologizing of normal behavior variants such as shyness [47]; reflection of cultural and political biases [48]; role of economic motives and conflicts of interest [49]; and scientific as well as humaneness superiority of a taxonomy based on dimensions rather than categories [50]. In the current paper, we are not participating in an attack, ethical or otherwise, on categorical classification per se, or DSM-5 in particular. Rather, we are focusing only on one category, IDD, and even there we are not criticizing the most recent definition (one of us [JCH] was the lead author of the IDD section in DSM-5), which we believe represents a major move away from reliance on IQ cut-offs. Rather, we are focusing on the use of IQ cut-offs in the definition and diagnosis of IDD, both in clinical manuals but more importantly in the way categories are actually used in practice: in clinics, court rooms, and government benefitdetermining agencies. The meaning of this distinction will hopefully become more apparent in subsequent pages.

In the balance of this section, we analyze ethical issues in the use of IQ ceilings in relation to the following principles: consistency (also known as justice), rationality, beneficence and non-maleficence. These latter two are typically addressed separately, but we combine them, as beneficence and non-maleficence are obviously very closely related. The widely known biomedical ethics framework of Beauchamp and Childress [51] contains three of the above principles, but we have dropped their fourth principle—"autonomy"--and substituted another: "rationality". Autonomy (which emphasizes the client's right to information as well as ultimate decision-making authority) has obvious importance in medicine, but it does not really apply to our focus in this paper, which is bureaucratic decision-making by others, and where desire for services or protections by the client or his/her advocate is, by definition, generally required to start that decision process. The principle of rationality is not part of the Beauchamp and Childress list, as their focus assumes the validity of scientific practices, but it is included here, because invalidity of practice is our main focus.

## How IQ ceilings violate the ethical principles of beneficence and non-maleficience

In terms of the branch of ethics known as consequentialism (also known as utilitarianism), the thing that makes a practice morally good or bad is whether it has positive or negative consequences for the people to whom it is applied. This is in line with the branch of philosophy known as pragmatism, the essence of which can be stated as ''theories and models are to be judged primarily by their fruits and consequences'' [52]. Beneficence (promotion of positive consequences) and non-maleficence (avoidance of negative consequences) can, therefore, be described as reflecting a consequentialist/pragmatic worldview.

For our purpose (human classification), the beneficence principle can be stated as "practitioners and agencies have an obligation to advance the welfare of the people they come in contact with". Thus, beneficence addresses the positive consequences of a practice, i.e., those aspects that make it morally good. The non-maleficence principle is the flip side of beneficence, in that it obliges clinicians and agencies to avoid practices that harm the interests of people they come in contact with. Of the two, non-maleficience is probably more important, as reflected in the Hippocratic oath's primum non nocere ("above all, do no harm!"). This reflects the reality that, while our services, interventions and decisions may not always be capable of helping the people we serve or evaluate, one should always strive to avoid hurting them.

In the past, especially when the IQ ceiling was set more liberally at minus one standard deviation (17th percentile, or IQ of 85), the problem of false positives (people who do not deserve the IDD label being given it) was rampant. It was considered to be problematic (which was why the

ceiling was lowered), because of stigmatization, waste of resources, segregation and diversion from better educational opportunity. Today, as a result of lowering the IQ ceiling so dramatically to minus two standard deviations (2nd percentile, or IQ of 70), the problem is mainly one of false negatives, that is people who deserve IDD services but are denied it because they do not meet an artificial criterion that should not be the main reason for determining degree of need for services. Here the conviction is that the benefits of being appropriately given the IDD label are substantial, and far outweigh any negative consequences, especially for children and adults whose denial of needed services and protections can bring unfortunate consequences.

There are myriad examples of how the rigid reliance on the 70 IQ ceiling has had very significant impacts on the welfare of an individual universally seen as deserving the benefits and/or protections that go with the IDD label. One that is well-known in Western Canada involves Neil Fahlman, a young man in British Columbia of First-Nations ethnicity who was adopted at age five weeks. As a child, he had three diagnoses: fetal alcohol spectrum disorder (FASD), IDD and what today would be termed ASD (autism spectrum disorder). As a child and pre-adolescent, Neil qualified for developmental disability services under the IDD rubric, as his full-scale IQ was below the minus two standard deviation threshold used in BC by Community Living British Columbia (CLBC, a Crown Corporation) to determine eligibility for residential services. He also met the other two criteria for a diagnosis of IDD: onset in the developmental (pre-18) period and significant deficits in adaptive functioning. Starting at age 15, Neil was funded by CLBC for living in foster homes (and eventually in his own small home) due to behavior outbursts, with one-on-one daily supports but with continued involvement by his adoptive parents. The program was costly (\$77,000 per year) but less expensive than institutional alternatives (such as prison), given Neil's very poor judgment and impulse control problems (e.g., lashing out at others). When Neil reached age 19, his eligibility for CLBC services needed to be re-established. However, his newly-obtained IQ score of 79 was now a few points above the approximately minus two standard deviations standard, and that was cited as the basis for denial of services even though his adaptive behavior scores were still in the moderate (minus three standard deviation) range. Neil's family sued CLBC, and a panel of three judges ruled that the use of a specific IQ cut-off to determine continued eligibility (which had never been discussed in the agency's authorizing legislative history) was arbitrary and unfair. The agency was ordered to continue serving him and to devise a more equitable, and less IQ-driven, formula for making eligibility determinations for other applicants.

#### Principle of consistency

Consistency is considered by many to be the most essential of ethical principles; indeed Gensler [53] has termed consistency "the whole of philosophy". This principle refers to the need to avoid contradiction, by applying the same moral principles in dealing with all persons, situations and issues [54]. The Bible's "Golden Rule" ("do unto others as

you would have them do unto you''), for example, can be considered a variant of the consistency principle.

A common form of consistency has been termed the "justice principle". The term justice has many usages, but in ethics [51] it generally refers to fairness, namely the idea that people should be treated on the basis of what they deserve, rather than on the basis of who they know, how much money they have, or where they fall in the power hierarchy [55]. Obviously people differ in terms of abilities and opportunities, but adherence to justice—through a sub-principle termed by Rawls "the difference principle"—would ensure that people with equal talents should have equal opportunities, with any inequality favoring the interests of the least advantaged rather than (as is the case in most social systems) favoring the interests of the most advantaged.

The previous case—involving Neil Fahlman—can be used to illustrate how the rigid use of IQ ceilings to determine IDD eligibility is morally questionable under the consistency principle. Recall that the young Mr. Fahlman was identified in childhood as having IDD, based on a neurodevelopmental disorder (FASD), a qualifying IQ score (in the 60's), and very severe deficits in social, conceptual and practical adaptive functioning. The clear biological basis of his disorder, the severity of the adaptive deficits, his comorbid behavior disorders, including a diagnosis of autism spectrum disorder, caused him to clearly qualify for the IDD label, and the benefits that accrued from the label. In fact, Mr. Fahlman was more impaired than most same-age peers with similar IO but who had adaptive needs that were less serious. Yet he was dropped from eligibility by the British Columbia authorizing agency for one reason, and that was that his full-scale IQ score at age 19 was now a few points over the agency's ceiling. Although the court cited a narrow legal rationale (the absence of discussion of a ceiling in the bill's legislative history), they likely based their decision on the blatant unfairness of the action. The consistency principle (whether articulated or not) underlies most judgments of unfairness, as reflected here in the fact that a severely impaired young man, who had been deemed eligible for IDD services beginning at a young age, should not suddenly be deemed ineligible (while less severely impaired clients continued to be eligible) on such an artificial and arbitrary

#### Principle of rationality

In meta-ethics (the study of ethical concepts and terminology as used by moral philosophers), the term "rationality" refers to the need to base behavior, as well as moral arguments, on reason (conscious use of logic and reality) rather than emotion or preference. In applied ethics (our focus in this paper), the term rationality is sometimes used to refer to the need for professionals or agencies to base their practices on valid science [56]. Thus, it would be considered irrational and unethical for an engineer to propose a building method or formula that has not been proven to be safe, for a physician to prescribe a medicine that has not been shown to be effective, or for a mental health professional to use, or propose, a diagnostic category that is idiosyncratic and lacking in scientific validity.

Ethics of IQ cut-offs

The use of standard deviation units on IQ tests to define the upper limits of the ID category was portrayed by its supporters [57] as based on science but one could argue that it is an exercise in "scientism" rather than science. Scientism, an expression coined by the economist Friedrich Hayek in the 1930s, is a term used generally in a derogatory fashion to express "the view that the methods of study appropriate to physical science can replace those used in other fields such as philosophy and, especially... the social sciences" [58]. Peterson [59] opined that "the best way to understand the charge of scientism is as a kind of logical fallacy involving improper usage of science or scientific claims".

The use of IQ cut-offs to define the IDD category is based on the long-standing belief that the prevalence rate for the disorder is 3% of the population. This number was entirely a made-up guess, which Mercer [41] described as a myth; her epidemiological studies, in fact, found that the prevalence was either higher or lower than 3%, depending on which age one chose to look at (in that study, conducted four decades ago when the main problem was over-use of the IDD label in schools, resulting in many false positives, the rate went down as people entered adulthood; today, where schools are reluctant to assign the IDD label, and the bigger problem is false negatives among young people, the adult prevalence is more likely to be higher than the child prevalence). The translation of the belief about the disorder's prevalence to an IQ ceiling score was based on two related false assumptions:

- that one could meaningfully define the IDD class solely on the basis of a single number;
- that one could pick a number that would reliably and validly differentiate the population of people who deserve to be seen as having IDD from those who do not.

Certainly, no matter where one draws the line (except perhaps close to the population mean) there will be people above the line who are wrongly seen as not deserving the IDD label and below the line who should not be recipients of the label.

In 1961, the AAIDD published what is considered its first diagnostic manual, and the stated rationale was to provide a corrective against the IDD section in DSM-II. Two problems were noted with DSM-II:

- the use of outmoded and now-offensive terms (such as 'fidiot', 'fimbecile' and 'moron') in DSM-II;
- the absence of a scientific (i.e., numeric) basis for the DSM-II classification system, as reflected in the absence of a specified IQ ceiling, or a statistical scheme for subcategories.

The statistical convention selected by the AAIDD classification committee (and later adopted by DSM) was standard deviation (SD) units. As noted earlier, in 1961 the criterion was minus one SD (the 17th percentile which was too inclusive), but in 1973 that was changed to minus two SD's (2nd percentile), which was too exclusive. The expectation had been that practitioners would use prong two (adaptive functioning) to reduce the prevalence to closer to 3%, but that expectation did not pan out. But the larger question never seems to have been asked, namely: "What is there about a standard deviation unit that merits its usage as the basis for defining the IDD category?"

The best answer we can discern is that it provided a seemingly scientific rationale for a decision (where to draw the 10 line) that in fact was largely arbitrary. 10 standard deviation units were also used to specify the subcategories ("mild" falls between minus 2 and minus 3 SDs, "moderate" between minus 3 and minus 4 SD's, etc.). But this numeric sub-categorization scheme was never emphasized much (in 1961 it was found only in a single footnote in a single table) and in recent manuals, has been largely abandoned in favor of severity of support needs in AAIDD [60] or, level of adaptive functioning (DSM-5). While SD units have failed to stick as the basis for sub-categorization, they continue to be the basis for establishing the upper ceiling of IDD, even if efforts have been made to lessen its use in a rigid manner (see next section for a description of those efforts). In terms of our focus in this paper, namely the ethics of IQ ceilings in classifying IDD, the creation of a scientistic (i.e., pseudo-scientific) basis for deciding who should be denied services or protections, be they clinical, medical or forensic, seems to violate the principle of rationality and, thus, to be an unethical practice.

### How three fields have come to address the IQ ceiling problem

The unfairness of using arbitrary and artificial SD-based IQ ceilings to define IDD and, thus, to deny the ID label and its related benefits to deserving applicants or petitioners, has drawn increasing concern in recent years. Part of this concern is attributable to the fact that the mean IQ of many IDD-related disorders (even including Down syndrome) has risen over the years due to early intervention, ending of institutionalization, etc. [61] and many disorders where virtually all individuals once easily qualified for a diagnosis of IDD, some (sometimes, many) individuals with very significant support needs and adaptive patterns identical to, or more severe than, that of persons with lower IQs, are now in danger of losing the IDD label. Various tactics have been employed to address this problem, most of them being efforts to ameliorate the effects of IQ ceilings (by interpreting them more flexibly) rather than more directly addressing the scientifically (and morally) questionable continued use of IQ ceilings and IQ SD's in the first place. In this section, we briefly survey how the IQ ceiling problem has been addressed in three fields: human (residential and vocational) services, the criminal courts, and psychiatry.

### How the human services field is addressing the IQ ceiling problem

Greenspan et al. [62] have coined the term "IDD-equivalence" to refer to accommodations that are made by governmental or quasi-governmental agencies when they provide services, supports or protective arrangements to people who—because of brain impairment—function as if they have IDD but fail to qualify for the IDD label because their IQ scores are above the arbitrary (minus 2 SD) cut-off that typically is relied upon for access to IDD entitlements or benefits. IDD-equivalence accommodations are what those

authors describe as "an attempt to free the human services field from the straight-jacket that has been imposed by over-reliance on full-scale IQ ceiling scores, which functioned as a gatekeeper (and barrier) for developmental services eligibility". These accommodations can take various forms, which are summarized briefly below. A fuller description can be found in the above-referenced paper.

The most common solution has been to create a broader umbrella category, typically named "developmental disability" (DD) and then locate IDD within it, with service eligibility for DD instead of just IDD. This then creates a two-track path to IDD services: traditional (IQ ceiling-based) IDD, or more flexible (less IQ-driven) DD. Within this broader DD framework, two options have been followed: categorical, or dimensional.

A categorical approach involves defining DD as IDD plus one or more other disorders, such as Prader-Willi syndrome (a very common add-on). Thus, in Connecticut, the authorizing statute defines developmental services as available to people with IDD (using relatively rigid IQ ceiling criteria) or individuals with a medical (genetic test-based) diagnosis of Prader-Willi syndrome (PWS), regardless of their IQ score. The rationale is that individuals with PWS straddle the minus 2 SD ceiling, but all have the same chromosomal abnormality and very similar severe adaptive deficit patterns (in actuality, severity of impairment varies widely, as is true in most chromosomal conditions). A problem with using categorical add-ons is that there are never more than a half dozen or so mentioned, but there are many dozens (actually hundreds) of developmental disorders associated or correlated with IDD but where IQ scores can cross over the minus 2 SD

Why limit ID-equivalence status to some but not all such categories? The answer is three-fold: reliability of diagnosis, financial impact, and politics. The Connecticut adding of PWS occurred after an all-out lobbying campaign by parents and professional advocates for individuals with PWS. This disorder has very low prevalence (1/15,000 to 1/30,000), that can now be diagnosed by a very reliable blood test, and where the financial impact on the state treasury (because of the low numbers) would be minimal. Under the circumstances, the state could do the ethically right thing, in line with the consistency principle (i.e., it would be inconsistent to provide services to some but not all people with PWS). But when parents and advocates for people with ASD asked for similar treatment, they were turned down. The reasons cited were that ASD is a much vaguer and less reliable diagnosis for which there is as yet no biological/etiological diagnostic test, and the numbers are very large and growing, and the impact on the state budget would thus be significant.

Thus, while the state cited the consistency principle when (for PWS) the impact was financially negligible, it felt impelled to violate it (for ASD) when it was not. While money considerations have some legitimacy in deciding which disorders are disability-eligible (in a society, unlike say the Netherlands, that does not allow for virtually 100% disability eligibility authorization), it should be obvious that political effectiveness is not a fair or ethically legitimate consideration.

A categorical solution is what the British Columbia government came up with to address the court's concern in the Neil Fahlman case. Because Neil (who at one time was

eligible for the IDD label but then lost it when his IQ went up) had fetal alcohol spectrum disorder (FASD) as well as autism spectrum disorder (ASD), the BC solution was to create two portals for developmental services: the conventional portal (IQ below approximately 70 plus adaptive deficits) and an alternative portal where IQ no longer mattered, as long as an applicant had one of the two brain-based disorders—FASD or ASD—possessed by Nell, along with the extremely severe adaptive functioning deficits that he possessed.

To ensure that applicants were truly disabled, the province set a very difficult adaptive functioning bar: minus 3 SD's on a standardized rating measure, such as the Vineland Adaptive Behavior Scale. While Nell obviously met that standard (which placed him at a fraction of the bottom percentile), only a tiny percentage of people with FASD or ASD can. This creates four ethical problems:

- it forces the Vineland raters (typically parents) as well as the clinicians they hire (typically psychologists, who are paid well on a case basis by the province) to lie, by grossly exaggerating adaptive deficits;
- it limits eligibility only to people with the same exact disorders as the person (Fahlman) who sued for relief, and a specific lawsuit hardly provides a fair (consistent) basis for defining DD, given that it leaves out people with many other brain-based diagnoses (including ASD and FASD) with similar issues:
- it creates another consistency problem, by using a grossly more stringent prong two standard for alternate pathway applicants than for people with garden-variety IDD, thus making a joke out of the notion of IDD-equivalence;
- it violates the rationality principle, in that it still buys into the scientistic fallacy that standard deviation units on a single test (in this case, of adaptive functioning) provide a legitimate basis for defining and diagnosing a clinical disorder

The other common approach to establishing IDDequivalence is to use a functional as opposed to a categorical criterion. An example is in California, which has four categorical portals (IDD, autism, epilepsy and cerebral palsy, all with a requirement of significant adaptive deficits) for DD service eligibility, but then has a so-called "fifth category" which is defined as someone who otherwise would not qualify (because of IQ over the ceiling) for DD services, but who can now qualify if he or she can be shown to have similarly severe deficits and/or similar support needs as someone who has IDD. This makes a lot of sense, but as two of us have found out whenever we have sought fifth category eligibility for someone in California, it is an almost impossibly difficult case to make, and usually requires months of appeals, aided in some cases by legal action (this raises a consistency problem, as appeals are greatly helped by money, connections, perseverance and system knowledge). In fact, legislators in California have been discussing dropping the (non-categorical) fifth category, a move that reflects concern about the financial costs associated with its growing implementation.

The term "developmental disability" was first used in a US statute in 1970, initially as a categorical framework (mental retardation [now IDD], plus cerebral palsy, autism and "other neurological conditions" originating before age 18). In 1975, the categorical list was revised, with the

expression "other neurological conditions" dropped (a big mistake, as it had allowed application beyond the specified few categories) and with two other categories now added: autism and dyslexia. One expression was inserted, to indicate that these add-on categories were "closely related to mental retardation" (the choice of dyslexia was questionable on that ground).

In 1978, the definition switched to a functional framework (see Gettings [63] for a review of the legislative history of DD). In a functional approach, eligibility for services is based on showing deficits in several skill domains. The framework devised in 1978 is still being widely used today in many state and provincial statutes throughout North America. Its most recent (2000) formulation involves "substantial functional limitations" in three of these seven "areas of major life activity": self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, and "reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated". The problem with this list, which has no theoretical or empirical justification, is that it was generated for a facilities and program funding bill, and was never intended to be used as a diagnostic framework. Aside from the fact that the content is inadequate (for example, there is no item reflecting social competence, in spite of its centrality to the adaptive problems of people with IDD), the specification of three areas of deficit is entirely arbitrary. Thus, this framework, part of an effort to reduce IQ ceilings as a barrier to service, can itself be questioned on ethical (in this case, rationality) grounds.

### How the legal field is addressing the IQ ceiling problem

The sub-title of this article—"intellectual disability is a condition, not a number"-is a direct quote from the 2014 majority opinion written by US Supreme Court Justice Anthony Kennedy in Hall v Florida. That was a lawsuit filed by a condemned prisoner in Florida, named Freddie Lee Hall. In 1978, Mr. Hall was sentenced to death for the brutal rape-murder of a 21-year-old woman who was seven months pregnant. His co-defendant in that case, Mack Ruffin, was also sentenced to death, but eventually had the sentence converted to life in prison, a differential treatment justified on the basis that he was younger than Hall and (unlike Hall) lacked any prior conviction for a violent offense. Hall filed several appeals, all of them rejected by the courts. The 1978 trial occurred prior to the US Supreme Court's 2002 Atkins v Virginia ruling (which exempted people with IDD from execution), at a time when IDD could be presented as a mitigating factor (during the penalty phase of a capital trial) but not as an absolute exempting factor. Because Hall's original trial did not adequately examine mitigating factors, a new jury proceeding was held in 1989 to weigh anew aggravating and mitigating factors, and replay the penalty phase of the trial. The new jury again recommended death, and the new trial judge affirmed that finding.

During the new penalty trial, the defense presented several witnesses attesting to Hall's having been given the label mental retardation as a child, and who spoke to his many limitations (including one IQ score of 60). The judge, using his discretion, again imposed a death sentence, finding that the aggravators in this case greatly outweighed the mitigators. Although he did not dispute that Hall had IDD, the judge did not find it sufficient to reduce sufficiently the degree of Hall's criminal culpability. In a 1993 ruling, a majority of the Supreme Court of Florida affirmed this second sentence of death. However, a strong dissent by Justice C. Barkett, with Justice J. Kogan concurring, set the stage for the later overturning of Hall's death sentence by the US Supreme Court. In the dissent, Justice Barkett noted that there was considerable evidence throughout Hall's life that he had IDD, that the trial judge accepted that he had IDD, and that evolving standards of decency and fairness required that having IDD limited Hall's degree of criminal culpability for his acts, however heinous they might have been. Execution must be reserved for the worst crimes and the worst offenders, Justice Barkett asserted, and while the crime certainly fell in the worst category, Hall's status as someone with IDD disqualified him from being placed in the category of worst offenders.

Hall's legal situation changed in the wake of the 2002 Atkins decision, when IDD went from a capital mitigating to a capital exempting factor, and he sought and obtained a hearing to address the question of whether or not he qualified for a diagnosis of IDD within the Florida criminal justice system. The problem he faced is that Florida was one of at least five states (the others being Alabama, Kentucky, Virginia and North Carolina) that had a statutory "bright line" where a full-scale IQ score of 70 or less was needed to have other aspects of one's IQ claim (such as adaptive functioning) even considered. While most other jurisdictions followed the AAIDD and DSM qualifier "approximately two standard deviations below the mean", thus building some flexibility into consideration of prong one, in Florida the test score was considered not as a range but as an absolute number, not subject to any further interpretation. Because Hall had a recent score of 71 (which was well within the margin of error of the test, had it been able to be considered), the Florida high court rejected Hall's Atkins petition, and no consideration of the other two prongs (or even a fuller exploration of prong one) was allowed to occur. Thus, an IQ ceiling score criterion, utilized in the most rigid fashion imaginable (he missed by a single point), was used to cut off any consideration of Hall's impaired functioning, which had caused him to be repeatedly given the IDD label during his school years.

The US Supreme took up the matter in oral arguments in January of 2014. The case was of interest in part because in the original Atkins decision, the court had left it up to the individual states (and federal government) which still had the death penalty to devise its own definitions and procedures for determining IDD. In the April 2014 ruling by Justice Kennedy, however, the majority stated that while states continued to have considerable leeway in *Atkins* proceedings, when considering the use of IQ test scores they could not completely ignore the consensus in the scientific and medical communities about the need to consider sources of error affecting obtained scores. As noted in the court's published

summary, it was stated that "the rejection of a strict 70-point cut-off in the vast majority of States and a consistency in the trend... toward recognizing the SEM (standard error of the mean) provide strong evidence of consensus that society does not regard this strict cut-off as proper or humane". While Hall opened the door to a more holistic approach to considering whether someone has IDD, the metaphorical "King IQ", his crown slightly askew, continued to reign, at least in the legal sphere, as the court called for flexibility and judgment in interpreting IQ ceilings but did not outlaw them outright.

### How the psychiatry field is addressing the IQ ceiling problem

At the outset of this article, we noted that the IDD section in DSM-5—the Diagnostic and statistical manual of mental disorders (5th edition) (American Psychiatric Association, 2013)—represents a departure from DSM-IV (with its 5th edition, DSM switched from Roman to Arabic numbering), as well as the various AAIDD manuals, in signaling a move from a disability to a disorder orientation. IDD is now located within a section of the manual termed "neurodevelopmental disorders'' (previously it was in a section reserved for conditions originating in childhood and adolescence). This change indicates that IDD, along with related diagnoses (such as ASD) is a medical/psychiatric condition marked by early impairments in brain development, and whose diagnosis requires clinical methods relying upon informed professional judgment (and not just psychometric methods that specify a point on a statistical continuum). Central to this assault on the disability (numeric) orientation is a minimizing (albeit not yet a full repudiation) of IQ scores and IQ ceilings. This move away from a fixation on IQ testing can be seen in various DSM-5 passages, as highlighted below.

In the very first paragraph, prong one is described thusly: "deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing". The list of intellectual functions consists mainly of abilities not tapped by IQ tests, and while intelligence tests are mentioned, there is no ceiling specified and equal importance is attached to clinical assessment.

Levels of severity (termed ''specifiers'') are described thusly: 'The various levels of severity are defined on the basis of adaptive functioning, and not IQ scores alone, because it is adaptive functioning that determines the level of support required. Sub-categories ('mild'', 'moderate'', etc.) are no longer tied to IQ deficit ranges.

Elaboration on intellectual functioning goes as follows: critical components include verbal comprehension, working memory, perceptual reasoning, quantitative reasoning, abstract thought, and cognitive efficacy. These skills go beyond (and some are not included in) IQ tests.

However, the above is somewhat inconsistent with "intellectual functioning is typically measured with individually administered and psychometrically valid, comprehensive, culturally appropriate, psychometrically sound tests of intelligence. Individuals with IDD have scores of

approximately two standard deviations or more below the population mean, including a margin for measurement error (generally +5 points)... Clinical training and judgment are required to interpret test results and assess intellectual performance". Thus while IQ ceilings are still mentioned, they are to be interpreted thoughtfully and flexibly, with an evaluator being an interpreter, and not just a reporter, of test scores.

S. Greenspan et al.

There is considerably more mention of sources of error in IQ scores, and need to interpret them carefully. This is seen in the following passage: "Factors that may affect test scores including practice effects, and the 'Flynn effect' (overly high scores due to out of date test norms). Invalid scores may result from the use of brief intelligence screening tests or group tests; highly discrepant individual subtest scores may make an overall IQ score invalid. Instruments must be normed for the individual's sociocultural background and native language. Co-occurring disorders that affect communication, language, motor or sensory function may [also] affect test scores."

In the most direct disparagement of IQ testing, reflecting a recognition of more effective methodologies for determining the brain-based skills that make up intelligence, the manual asserts the following: "Individual cognitive profiles based on neuropsychological testing are more useful for understanding intellectual abilities than a single IQ score. Such testing may identify areas of relative strengths and weaknesses, important for academic and vocational planning."

In a distinct departure from previous manuals, where adaptive functioning came into play mainly when prong one was met, and prong one was essentially equated with IQ score, the manual stated that "IQ test scores are approximations of conceptual functioning but may be insufficient to assess reasoning in real-life situations and mastery of practical tasks... For example, a person with an IQ score above 70 may have such severe adaptive behavior problems in social judgment, social understanding and other areas of adaptive functioning that the person's actual functioning is comparable to those with a lower IQ score. Thus, clinical judgment is needed in interpreting the results of IQ tests". In essence, the manual states that IDD should be considered even when ceilings are exceeded, if adaptive functioning levels are severe enough. Another departure was in placing special emphasis on social incompetence, a functional domain that has traditionally been given short shrift in the IDD field, and among cognition authorities generally.

In line with a growing awareness of the importance of social-cognitive deficits in IDD, the manual states that: "There may be associated difficulties with social judgment, assessment of risk, self-management of behavior, emotions, or interpersonal relationships, or motivation in school or work environments. Lack of communication skills may pre-dispose to disruptive and aggressive behaviors. Gullibility is often a feature, involving naïveté in social situations and a tendency for being easily led by others... Gullibility and lack of awareness of risk may result in exploitation by others and possible victimization, fraud, unintentional criminal involvement, false confessions, and risk for physical and sexual abuse. These associated features can be important in criminal cases, including Atkins-type hearings involving the death penalty."

Ethics of IQ cut-offs 11

In sum, the psychiatry field, as reflected in its diagnostic manual, DSM-5, has taken a major step away from the heavy focus on IQ scores, and IQ ceilings, for defining and diagnosing the disorder. It should, however, be seen as a transitional document, as residues of the former emphasis on IQ ceilings can still be found.

### Conclusion: IQ ceilings as an example of Moore's paradox

Cambridge University's noted philosopher G.E. Moore once gave a lecture in which he asserted that there is no inconsistency between the fact that it is raining out and the fact that someone believes it is not raining out. His even more famous colleague (famous both for genius and eccentricity), Ludwig Wittgenstein, was so intrigued by this assertion—which he dubbed ''Moore's paradox''—that he came to the older man's lodgings tater that evening, roused him out of bed, and begged him to repeat the lecture. In using the rain example, Moore was not making a connection to IQ ceilings in the diagnosis of ID but he could have been, as reflected in the following real-life application.

A few years ago, one of us was at a conference and turned to a colleague (a well-known psychologist who specializes in IDD) and said: "Look outside, it is really raining hard." The colleague looked out the widow and said: "No it isn't." When pressed for an explanation, the colleague explained: "See that man walking by? He is not wearing a hat or holding an umbrella. Also, the forecast did not call for rain." To which the reply was: "Look at the raindrops falling in that puddle. And if you stick your hand out the window you will feel it getting wet." Without ever having heard of Moore's Paradox, the first author [64] used that exchange to illustrate how the IDD field, influenced by psychologists with their fixation on IQ scores and artificial standard score criteria, has been "all wet" in its approach to the definition and diagnosis of IDD.

Moore's Paradox could be reframed as a form of cognitive distortion that occurs when one gives more weight to an indirect indicator (not wearing a hat/having an IQ score above an arbitrary ceiling) than to a direct indicator (rain hitting one's hand/how someone actually functions in the world) to draw a conclusion about a physical (raining or not) or social (having IDD or not) reality. The reality at issue here, namely that someone "really" has ID but is unfairly being prevented from having it acknowledged, is a reality that can we believe be best recognized by knowledgeable professionals relying on clinical/medical integrated judgment and information gathered about how someone actually functions in various settings. This is analogous to a person with a lifetime of experience of getting out of (or staying in) the rain recognizing when it is raining out by calling on his or her own sensory perception and intuitive cognitive judgment. Using indirect correlational and predictive data (no raincoat seen, a dry weather forecast) can cause someone to incorrectly conclude it is not raining, just as indirect correlational and predictive data (an IQ score above an arbitrary ceiling) can cause someone to incorrectly conclude a person does not have IDD when in fact he or she does.

The continuing primacy of full-scale IQ within the definition and diagnosis of IDD is attributable in part to what evolutionary biologist Stephen Jay Gould [65], in his book The mismeasure of man (about what he saw as the regrettable use of full-scale IQ to characterize people with IDD, including his own son), described as two "deep fallacies": the fallacy of "reification" and the fallacy of "ranking". Reification was described by Gould as the "tendency to convert abstract concepts [such as the g factor in IQ] into entities", while ranking was described as the "propensity for ordering complex variation as a gradual ascending scale". Reification is particularly important in understanding the relevance of Moore's paradox to the continued primacy of IQ and IQ cut-offs, as it caused IQ to go from being a correlate of brain health and a predictor of relevant outcomes to being seen as if it was itself the best indicator of brain health and the most concrete and real outcome of

Our position in this paper is that denying the benefits of the IDD label, through excessive reliance on the pseudoscientific invention of an IQ ceiling, is an unethical act. It is analogous to telling someone who just came through a rainstorm that you do not believe their story of getting rained on because they are not wearing a raincoat or carrying an umbrella. The ultimate unethical act, according to Immanuel Kant, is telling a lie. Someone who truly has IDD has a right to have their story believed. The question to be addressed by relevant professional fields is "how do we know if someone truly has IDD?" The answer is not a simple one, but it is unlikely to be obtained by merely looking at an IQ score alone. To paraphrase Justice Anthony Kennedy: human beings cannot be reduced to a number.

#### Disclosure of interest

The authors declare that they have no conflicts of interest concerning this article.

#### References

- [1] American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. DSM-5 Arlington, VA: American Psychiatric Association; 2013.
- [2] Schalock RL, Buntinx WHE, Borthwick-Duffy S, Bradley V, Craig EM, Coulter DL, et al. Intellectual disability: definition, classification, and system of supports. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2010.
- [3] Salvador-Carulla L, Reed GM, Vaez-Azizi LM, Cooper SA, Martinez-Leal R, et al. Intellectual developmental disorders: towards a new name, definition and framework for "mental retardation/intellectual disability". World Psychiatry 2011;10:175-80.
- [4] Greenspan S, Woods GW. Intellectual disability as a disorder of reasoning and judgement: the gradual move away from intelligence quotient-ceilings. Curr Opin Psychiatry 2014;27(2):110—6.
- [5] Noil S, Smith JD, Wehmeyer ML. In search of science: intellectual disability in late modern times (1900 to 1930). In: Wehmeyer ML, editor. The story of intellectual disability: an evolution of meaning, understanding and public perception. Baltimore: Paul H. Brookes; 2013. p. 117–56.

- [6] MacMillan DL, Siperstein GN, Gresham FM. A challenge to the viability of mild mental retardation as a diagnostic category. Except Child 1996;62(4):356-71.
- [7] Dokecki PR. Ethics and mental retardation: steps towards the ethics of community. In: Rowitz L, editor. Mental retardation in the year 2000. New York: Springer-Verlag; 1992. p. 39—51.
- [8] Dokecki PR, Zaner RM, editors. Ethics of dealing with persons with severe handicaps: toward a research agenda. Baltimore: Paul H. Brookes; 1986.
- [9] Carlson L. Research ethics and intellectual/disability: broadening the debates. Yale J Biol Med 2013;86(3):303-41.
- [10] Greenspan S. A sex police for adults with mental retardation? Comment on Spiecker and Steutel. J Moral Educ 2002;31: 171-9.
- [11] Vehmas S. Disability and moral responsibility. Trames 2011;15(2):156-67.
- [12] Kuhse H. Singer P. Should the baby live? The problem of hand-icapped infants. Oxford, UK: Oxford University Press; 1985. p. 90—108.
- [13] Keith H, Keith KD. Intellectual disability: ethics, dehumanization and a new moral community. New York: Wiley; 2013.
- [14] Wolfensberger W. The new genocide of handicapped & afflicted people. 3rd ed Syracuse, NY: Syracuse University Training Institute for Human Service Planning, Leadership & Change Agentry; 2005.
- [15] Louhiala P. Preventing intellectual disability: ethical and clinical issues. Cambridge, UK: Cambridge University Press: 2003.
- [16] Ronen GM, Meaney B, Dan B, Zimprich F, Stögmann W, Neugebauer W. From eugenic euthanasia to habilitation of ''disabled'' children: Andreas Rett's contribution. J Child Neurol 2009;24(1):15—27.
- [17] Savulescu J. Resources, Down syndrome and cardiac surgery. Br Med J 2001;322(7291):875—6.
- [18] Gerhardt P, Holmes DL, Alessandri M, Goodman M, Social policy on the use of aversive interventions: empirical, ethical, and legal considerations. J Autism Dev Disord 1991:21(3): 265-77.
- [19] Swinton J. Critical reflections on Stanley Hauerwas' theology of disability: disabling society, enabling theology. J Relig Disabil Health 2004;8(3/4).
- [20] Redley M. Maina E. Keeling A. Pattni P. The voting rights of adults with intellectual disabilities: reflections on the arguments, and situation in Kenya, England and Wales, J Intellect Disabil Res 2012;56(11):1026—35.
- [21] Sailor W, Dunlap G, Sugai G, Horner R. Handbook of positive behavior supports. New York: Springer; 2009.
- [22] Bannerman DJ, Sheldon JB, Sherman J, Harchik AE. Balancing the right to habilitation with the right to personal liberties: the rights of people with developmental disabilities to eat too many donuts and take a nap. J Appl Behav Anal 1990;23:79—89.
- [23] Krugman S. The Willowbrook hepatitis studies revisited: ethical aspects. Rev Infect Dis 1985;8(1):157-62.
- [24] Rose-Ackerman S. Mental retardation and society: the ethics and politics of normalization; 1982 [Yale Faculty Scholarship Series, paper 585].
- [25] Greenspan S, Love P. Elements for a code of everyday ethics in disability services. In: Karan O. Greenspan S, editors. Community rehabilitation services for persons with disabilities. Newton, MA: Heinemann-Butterworth Publishers; 1995. p. 90–108.
- [26] Harris JC. Developmental neuropsychiatry: vol. II: assessment, diagnosis, and treatment of developmental disorders. New York: Oxford University Press; 1998.
- [27] Dexter LA. On the politics and sociology of stupidity in our society. Soc Probl 1961:9(3):221–8.
- [28] Sternberg RJ, Detterman DK, editors. What is intelligence?: contemporary viewpoints on its nature and definition. Norwood, NJ: Ablex: 1986.

- [29] Collins N. IQ tests do not measure intelligence. The Telegraph 2012 [Internet] http://www.telegraph.co.uk/science/science-news/9755929/IQ-tests-do-not-reflect-intelligence. html
- [30] Sternberg RJ. Successful intelligence: finding a balance. Trends Cogn Sci 1999;3(11) [Internet] http://www.uv.es/genomica/spa/inves/Sternberg.pdf
- [31] Stanovich K. What intelligence tests miss: the psychology of rational thought. New Haven: Yale University Press; 2009.
- [32] Diamond A. Executive functions. Annu Rev Psychol 2013;64: 135—68.
- [33] McGrew KS, Flanagan DP, Keith TZ, Vanderwood M. Beyond g: the impact of Gf-Gc specific cognitive abilities research on the future use and interpretation of intelligence tests in the schools. Sch Psychol Rev 1997;26(2):189—210.
- [34] Flynn JR. Massive IQ gains in 14 nations: what IQ tests really measure. Psychol Bull 1987;101:171-91.
- [35] Suen HK, French J. A history of the development of psychological and educational testing. In: Reynolds CR, Kamphaus R. editors. Handbook of psychological and educational assessment of children. 2nd ed New York: Guilford; 2003. p. 3–23.
- [36] Anastasi A. What do intelligence tests measure? In: Anderson SB, Hemlick JS, editors. On educational testing: intelligence, performance standards, test anxiety, and latent traits. San Francisco: Jossey-Bass; 1983. p. 5—28.
- [37] Gardner H. Frames of mind: the theory of multiple intelligences. New York: Basic Books; 1983.
- [38] Smith JD. Wehmeyer ML. Good blood, bad blood: science, nature and the myth of the Kallikaks. Washington: American Association on Intellectual and Developmental Disability; 2012.
- [39] Lippman W. The mental age of Americans, New Republic 1922;32:412.
- [40] Stern W. Die psychologischen methoden der intelligenzprüfung. Leipzig: JA Barth; 1912.
- [41] Mercer JR. Labeling the mentally retarded. Berkeley: University of California Press; 1973.
- [42] Shackle EM. Psychiatric diagnosis as an ethical problem. J Med Ethics 1985:11(3):132—4.
- [43] Anonymous. How using the DSM causes damage: a client's report. J Humanist Psychol 2001;41(4):36-56.
- [44] Craddock N, Owen J. The Kraepelinian dichotomy—going, going... but still not gone. Br J Psychiatry 2010;196(2):92.
- [45] Kirk SA, Kutchins H. The myth of the reliability of DSM. J Mind Behav 1994:15(1&2).
- [46] Greenberg S, Shuman DW, Meyer RG. Unmasking forensic diagnosis. Int J Law Psychiatry 2004;27(1):1–15.
- [47] Lane C. Shyness: how normal behavior becae a sickness. New Haven: Yale University Press; 2007.
- [48] Bayer B. Homosexuality and American psychiatry: the politics of diagnosis. Princeton, NJ: Princeton University Press; 1981
- [49] Sharfstein SS. Big pharma and American psychiatry: the good, the bad, and the ugly. Psychiatr News 2005;40(16).
- [50] Krueger RF, Watson D, Barlow DH, et al. Introduction to the special section: toward a dimensionally based taxonomy of psychopathology. J Abnorm Psychol 2005;114(4):491–3.
- [51] Beauchamp TL, Childress JF. Principles of biomedical ethics. 6th ed New York: Oxford University Press; 2001.
- [52] McDermid D. Pragmatism. Internet Encyclopedia of Philosophy. http://www.iep.utm.edu/pragmati/; undated [Internet].
- [53] Gensler HJ, Ethical consistency principles. Philos Q 1985;35(139):75-88.
- [54] Velasquez M, Andre C, Shanks T, Meyer MJ. Consistency and ethics. Issues Ethics 1988;1(4):1—12.
- [55] Rawls J. A theory of justice. New York: Oxford University Press; 1971.
- [56] Nozick R. The nature of rationality. Princeton, NJ: Princeton University Press; 1993.

#### Ethics of IQ cut-offs

- [57] Clausen J. Ability structure and subgroups in mental retardation. Washington, DC: Spartan Books; 1966.
- [58] Webster. Scientism. In: New Collegiate Dictionary. 9th ed Springfield, MA: G.C. Merriam: 1983.
- [59] Peterson GR. Demarcation and the scientistic fallacy. Zygon J Relig Sci 2003;38(4):751—61.
- [60] Luckasson R, Coulter DL, Polloway SA, Reiss S, Schalock RL, et al. Mental retardation: definition, classification and systems of support. Washington, DC: American Association on Mental Retardation; 1992.
- [61] Menolscino FJ, Egger ML. Medical dimensions of mental retardation. Lincoln, NE: University of Nebraska Press; 1997
- [62] Greenspan S, Brown NN, Edwards W. FASD and the concept of "intellectual disability equivalence". In: Nelson M, Trussler M, editors. Law and ethics in fetal alcohol spectrum disorder. Amsterdam: Springer; 2015.
- [63] Gettings RM. Forging a federal-state partnership: a history of state and federal developmental disabilities policy. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2011.
- [64] Greenspan S. How do we know if it is raining out? Why existing conceptions of intellectual disability are (mostly) all wet. Psychol Intellect Disabil 2011;37(2):5—6 [fall issue].
- [65] Gould SJ. The mismeasure of man. New York: W.W. Norton; 1981