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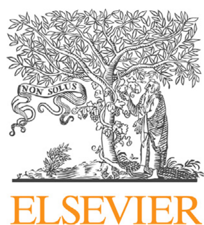

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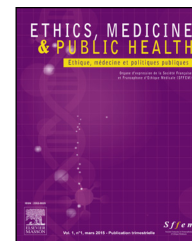

DOSSIER ''DISABILITY'' / *Studies*

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

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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)

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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.
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MOTS CLÉS
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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 QI pour le diagnostic des DI est une pratique qui soulève de vraies questions morales.
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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

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