

# 13-1183-CV

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UNITED STATES COURT OF APPEALS  
FOR THE SECOND CIRCUIT

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ANDREW ADAMS,

*Plaintiff-Appellant,*

v.

FESTIVAL FUN PARK, LLP,

*Defendant-Appellee.*

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On Appeal from the United States District Court  
for the District of Connecticut

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**BRIEF OF AMICI CURIAE NATIONAL EMPLOYMENT LAWYERS  
ASSOCIATION, THE ARC OF THE UNITED STATES, THE NATIONAL  
DISABILITY RIGHTS NETWORK, THE OFFICE OF PROTECTION AND  
ADVOCACY FOR PERSONS WITH DISABILITIES, AND DISABILITY  
RIGHTS VERMONT, SUPPORTING APPELLANT AND URGING  
REVERSAL**

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## **INTEREST OF AMICI**

Amici are organizations dedicated to advocating for the rights of persons with disabilities, and have special expertise with respect to understanding intellectual disabilities such as the one at issue in this case. The specific statement of each amicus organization is in Tab A of the attached Appendix. Amici respectfully submit this brief pursuant to Rule 29 of the Federal Rules of Appellate Procedure.

Amici write to highlight the district court's misunderstanding of intellectual disability and how such conditions should be analyzed under the ADA Amendments Act of 2008 (ADAAA). All parties have consented to the filing of this brief. Fed. R. App. P. 29(a).<sup>1</sup>

### **RULE 26.1 CORPORATE DISCLOSURE STATEMENT**

None of the Amici has any parent corporation or any publicly held corporation that owns 10% or more of its stock.

### **SUMMARY OF ARGUMENT**

There are currently no published opinions by this Court construing the “actual disability” prong of the recently enacted ADAAA, and no Circuit has yet

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<sup>1</sup> Pursuant to Fed. R. App. Proc. 29(c)(5) and Loc. R. 29.1(b), counsel certifies that neither party's counsel authored this brief in whole or in part; neither party nor their counsel contributed money that was intended to fund preparing or submitting the brief; and no one other than amici, their members, or counsel contributed money that was intended to fund preparing or submitting the brief.

applied those standards to intellectual disability.<sup>2</sup> It is critically important that this Court have the fullest understanding of the ADAAA's changes to the disability analysis and, when applying them, of the inherent nature of intellectual disability.

Amici urge this Court to correct the misunderstanding of intellectual disability reflected in the opinion of the district court below. Accordingly, Amici discuss how such conditions should be analyzed in reliance on Congress' amendment of the Americans with Disabilities Act in 2008 in the ADAAA. Amici explain the definition and inherent nature of intellectual disability, reflecting both the consensus of the scientific community and wide acceptance by the courts.

Amici demonstrate how *a person with intellectual disability, by definition, satisfies the standard for an "actual disability"* under the ADAAA's expansive analysis. *All persons with intellectual disability, by definition, have a lifelong condition resulting in "significantly subaverage intellectual functioning," and also have "substantial limitations in present functioning" in two or more "adaptive*

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<sup>2</sup> Amici use the term "intellectual disability" in place of "mental retardation," except when quoting others. Although the latter term is used by the parties, and appears in the record evidence and some relevant case law, it is offensive to many persons and is being replaced by more modern terminology. *Talavera v. Astrue*, 697 F.3d 145, 148 n.2 (2d Cir. 2012); *Hooks v. Workman*, 689 F.3d 1148, 1159 n.1 (10th Cir. 2012). *See also* R. Schalock, R. Luckasson, K. Shogren, *The Renaming of Mental Retardation: Understanding the Change to the Term Intellectual Disability*, 45 *Intellectual & Developmental Disabilities* 116 (Apr. 2007), included at Appendix Tab B (hereafter "*Renaming of Mental Retardation*"). The terms refer to the same condition, however. *Id.* at 116; 29 C.F.R. § 1630.2(h)(2) and (j)(3)(iii) (EEOC's ADAAA regulations noting that intellectual disability was formerly termed "mental retardation"). *See also* "Rosa's Law," Pub. L. No. 111-256, 124 Stat. 2643 (2010) (mandating use of term "intellectual disability" in place of "mental retardation" in federal enactments and regulations).

skills” that are themselves major life activities. Amici point to further support for their argument in the ADAAA’s statutory language, as well as in its enforcing regulations and legislative history.

In addition, the primary case relied on by the Appellee and the district court, *Littleton v. Wal-Mart Stores, Inc.*, 231 Fed. Appx. 874, 877 (11th Cir. 2007), is no longer good law after the enactment of the ADAAA. Finally, Amici describe: how the evidence offered by Appellant in this case is consistent with a diagnosis of intellectual disability; how the ADAAA’s greatly-expanded definition of a “regarded as” disability was ignored by the Appellee and the district court below; and how a reasonable juror could find in Appellant’s favor on these issues.

## **ARGUMENT**

The ADAAA applies to the conduct at issue this case because the harassment and alleged constructive discharge occurred in 2009, JA426–427, after the statute’s effective date.<sup>3</sup> Nonetheless, Appellee’s motion for summary judgment mentioned only that the amendments did not change the prima facie elements of a disability claim, JA119, while making no reference to the ADAAA’s changes to the “actual disability” prong. Additionally, Appellee relied on two “actual disability” cases, JA 401, but both were decided prior to the ADAAA, and

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<sup>3</sup> The ADAAA became effective on January 1, 2009, Pub. L. 110–325, § 8, 122 Stat. 3553 (Sept. 25, 2008), 42 U.S.C. § 12101 (Note).

one, *Littleton*, is a rather notorious example of the pre-ADAAA judicial interpretations of disability that Congress explicitly sought to correct through enactment of the new law. *See* Part II (D) below. Unfortunately, the district court repeated Appellee’s mistakes in its opinion. JA433.

As to the “regarded as” prong, instead of citing the new statutory language, Appellee quoted an Ohio district court case that *misquoted* that language. JA122. As a result, Appellee omitted a key phrase from the statute, and then cited a *pre-ADAAA* case applying the overturned standard. JA122 (citing *Piascyk v. City of New Haven*, 64 F. Supp. 2d 19 (D. Conn. 1999)). Again the district court followed this erroneous path, citing the same wrong case. JA434. The lower court here made the same mistake this Court corrected in *Hilton v. Wright*, 673 F.3d 120, 128–129 (2d Cir. 2012) (reversing summary judgment). Amici seek to assist this Court in making similar corrections in this case.

## **I. THE DEFINITION OF “INTELLECTUAL DISABILITY”**

In defining intellectual disability the Supreme Court relies on the definition published by the American Association on Intellectual and Developmental Disabilities (“AAIDD”),<sup>4</sup> as well as the substantially similar definition in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental*

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<sup>4</sup> At the time of the decision in *Atkins*, this organization was called the American Association on Mental Retardation, but it has since changed its name. *See* <http://aaidd.org/about-aaidd>; *Hooks v. Workman*, 689 F.3d 1148, 1159 n.1 (10th Cir. 2012).

*Disorders* (“DSM”). *Atkins v. Virginia*, 536 U.S. 304, 308 n.3 (2002). *See also Heller v. Doe by Doe*, 509 U.S. 312, 321–322 (1993). These definitions include the following features:

- “substantial limitations in present functioning”;
- manifesting before age 18;
- “significantly subaverage” intellectual functioning;
- limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work; and
- many different causes negatively affecting or affected by the functioning of the central nervous system.

*Atkins, supra*, 536 U.S. at 308 n.3, 318.<sup>5</sup> The Supreme Court has also recognized that individuals with intellectual disability “by definition ... have diminished capacities to understand and process information, to communicate, to abstract from mistakes and learn from experience, to engage in logical reasoning, ... and to understand the reactions of others.” *Atkins, supra*, 536 at 318.

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<sup>5</sup> *See also Renaming of Mental Retardation* at 118 and 123 (Appendix Tab B attached); The Arc, Intellectual Disability, <http://www.thearc.org/page.aspx?pid=2543>. The Court in *Atkins* also noted that the definitions used in most state laws were substantially similar. *Atkins, supra*, 536 at 317 n.22. *See, e.g.*, Conn. Gen. Stat. § 1–1g.

Although slightly modified over the years, the definition remains substantially similar,<sup>6</sup> and continues to be followed by the courts. *See, e.g., In re Hearn*, 418 F.3d 444, 445 (5th Cir. 2005) (“Mental retardation is a disability characterized by three criteria: significant limitation in intellectual functioning, significant limitation in adaptive behavior and functioning, and onset of these limitations before the age of 18. American Association on Mental Retardation (‘AAMR’), *Mental Retardation: Definition, Classification, and Systems of Supports* 1 (10th ed. 2002).”).

Moreover, these substantial limitations are intrinsic to the condition, which is also lifelong<sup>7</sup> and permanent. *Heller v. Doe by Doe*, 509 U.S. 312, 323 (1993) (“Mental retardation is a permanent, relatively static condition ....”). *See also Talavera v. Astrue*, 697 F.3d 145, 152 (2d Cir. 2012) (“... it is reasonable to presume ... that claimants will experience a fairly constant IQ throughout their lives.”) (internal quotes and brackets omitted).

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<sup>6</sup> *See Renaming of Mental Retardation* at 119 and 123–124 (Appendix Tab B attached). *See also* DSM-IV at 39 (1994); DSM-IV-TR at 39 (2000).

<sup>7</sup> Treatment of an Intellectual Disability (The Arc), <http://www.thearc.org/page.aspx?pid=2545>.

## II. “ACTUAL” DISABILITY UNDER THE ADA

### A. By Definition, An “Intellectual Disability” Is An “Actual” Disability.

Even before the ADA, courts recognized that “certain impairments are by their very nature substantially limiting.” *Heiko v. Columbo Savings Bank, F.S.B.*, 434 F.3d 249, 256 (4th Cir. 2006). Such is the case here. By the very definition set out above, people with intellectual disability are substantially limited in multiple major life activities. First, and again *by definition*, intellectual disability must result in “substantial” limitations, Part I above, the exact terminology in the ADA.

Second, intellectual functioning must be “significantly” below average. Part I above. Significantly sub-average means that an individual’s intelligence places them at least two standard deviations below the mean, or in the lowest two-and-a-half to three percent of the population. This definition has been consistent over time, and generally results in an IQ score of approximately 70 to 75 or below. *See, e.g., Renaming of Mental Retardation, supra*, at 124 (Appendix Tab B attached); DSM-IV at 39 (1994); DSM-IV-TR at 39 (2000); DSM-V at 37 (2013).

Once again, by definition the diagnosis of an intellectual disability requires intelligence that is “significantly” below average. That limitation is *beyond* what is required by the ADA, which expressly states that a “substantial” limitation is

something less than “significant.” Pub. L. 110-325, §§ 2(a)(8) and 2(b)(6), 42 U.S.C. § 12101 (Note) (finding that former EEOC “regulations defining the term ‘substantially limits’ as ‘significantly restricted’ are inconsistent with congressional intent, by expressing too high a standard.”).

Also, “substantial limitation” is measured against “most people in the general population.” 29 C.F.R. § 1630.2(j)(1)(ii); H.R. Rep. 110-730, Pt. I, 110th Cong., 2d Sess., at 9 (June 23, 2008), and the comparison “need not be exacting, and usually will not require scientific, medical, or statistical analysis.” 29 C.F.R. Part 1630 App., § 1630.2(j)(1)(v), 76 Fed. Reg. 16978, 17009 (Mar. 25, 2011). Here, however, the scientific community has performed such a statistical analysis for intellectual disability (complete with standard deviations, as described above). The mathematical exactitude available here thus exceeds ADAAA requirements.

In addition, intellectual functioning is part of brain functioning, which is explicitly listed as a major life activity in the ADAAA, 42 U.S.C. § 12102(2)(B). Appellant argued this below, JA227, but the district court did not mention it.

Moreover, intellectual functioning—also called intelligence, and referring to general mental capacity such as learning, reasoning, problem solving, and so on<sup>8</sup>—is itself a major life activity (or a collection of them), as it fits well with the other

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<sup>8</sup> See, e.g., AAIDD, Definition of Intellectual Disability, <http://aaidd.org/intellectual-disability/definition>.

examples in the statutory list. That statutory list is not exclusive, of course. 42 U.S.C. § 12102(2)(A) (“include, but are not limited to”). Doubtless, too, a substantial limitation in intellectual functioning directly affects several other major life activities listed in the statute at § 12102(2)(A), including learning, reading, concentrating, and thinking. It also correlates to cognitive functioning, which was recognized as a major life activity even before the ADAAA. *See Gagliardo v. Connaught Laboratories, Inc.*, 311 F.3d 565, 569 (3d Cir. 2002); *Brown v. Cox*, 286 F.3d 1040, 1045 (8th Cir. 2002) (ability to perform cognitive functions on the level of an average person).

The ADAAA’s list of major life activities also includes the operation of neurological functions. 42 U.S.C. § 12102(2)(B). In passing the ADAAA, Congress recognized that a person with an intellectual disability “would be found to be substantially limited in the operation of a major bodily system because he is materially restricted in neurological function.” H.R. Rep. 110-730, Pt. I, 110th Cong., 2d Sess., at p. 10 (June 23, 2008).<sup>9</sup>

The definition of intellectual disability also requires measurable limitations in various areas of adaptive skills, which themselves reflect many other major life

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<sup>9</sup> The House Reports are fully applicable to Senate version of the ADAAA that ultimately passed. Joint Statement of Reps. Hoyer and Sensenbrenner, 154 Cong. Rec. H8294 (Sept. 17, 2008) (“Hence, the Report of the House Committee on Education and Labor and the Report of the House Committee on the Judiciary, as well as our Joint Statement introduced into the CONGRESSIONAL RECORD on June 25, 2008, continue to accurately convey our intent with regard to the bill we are passing today.”).

activities. For example, the skills recognized in *Atkins* include major life activities explicitly listed in the ADAAA at 42 U.S.C. § 12102(2)(A), as well as close correlatives of listed or recognized major life activities. This is reflected in the following chart:

Adaptive Skills for ID Diagnosis ( <i>Atkins</i> ) <sup>10</sup>	Recognized Major Life Activities
Communication	Communication <sup>11</sup>
Self-care	Caring for oneself <sup>12</sup>
Working	Working <sup>13</sup>
Social skills	Interacting with others; <sup>14</sup> functioning socially in everyday life <sup>15</sup>
Functional academics	Learning <sup>16</sup>
Home living	Keeping house; <sup>17</sup> performing basic household chores; <sup>18</sup> living independently <sup>19</sup>
Community use	Getting around outside <sup>20</sup>
Self-direction	Living independently <sup>21</sup>

<sup>10</sup> *Atkins v. Virginia*, 536 U.S. 304, 308 n.3 (2002).

<sup>11</sup> 42 U.S.C. § 12102(2)(A).

<sup>12</sup> 42 U.S.C. § 12102(2)(A).

<sup>13</sup> 42 U.S.C. § 12102(2)(A).

<sup>14</sup> 42 U.S.C. § 12102(2)(A).

<sup>15</sup> *MX Group, Inc. v. City of Covington*, 293 F.3d 326, 337 (6th Cir. 2002) (ADA Title II claim).

<sup>16</sup> 42 U.S.C. § 12102(2)(A).

<sup>17</sup> *Brown v. Arizona*, 2011 WL 2911054, at \*7 (D. Ariz. July 20, 2011). There is further support for this major life activity in the studies that the Supreme Court relied on in interpreting the definition of disability pre-ADAAA. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 485 (1999).

<sup>18</sup> *Bear v. Exxon Mobil Corp.*, 2004 WL 2603727, at \*4 (E.D. La. Nov. 15, 2004).

<sup>19</sup> There is support for this major life activity in the studies that the Supreme Court relied on in interpreting the definition of disability pre-ADAAA. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 485 (1999).

<sup>20</sup> There is support for this major life activity in the studies that the Supreme Court relied on in interpreting the definition of disability pre-ADAAA. See *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 485 (1999).

In light of the above, evidence of a diagnosis of an intellectual disability is *by definition* sufficient evidence of a disability under the ADAAA. The EEOC has come to the same conclusion. In its ADAAA regulations it states that

the individualized assessment of some types of impairments will, in virtually all cases, result in a determination of coverage...[and that g]iven their inherent nature, these types of impairments will, as a factual matter, virtually always be found to impose a substantial limitation on a major life activity. Therefore, with respect to these types of impairments, the necessary individualized assessment should be particularly simple and straightforward.

29 C.F.R. § 1630.2(j)(3)(ii). It then lists intellectual disability as an example of such a condition. 29 C.F.R. § 1630.2(j)(3)(iii) (“For example ... an intellectual disability (formerly termed mental retardation) substantially limits brain function...”). This is in keeping with the Congressional goal that the ADAAA provide “consistent” standards. Pub. L. 110-325, § 2(b)(1), 42 U.S.C. § 12101 (Note).

One further point needs clarification. Some of the evidence offered in this case states that the Appellant has “mild mental retardation.”<sup>22</sup> Mr. Adams

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<sup>21</sup> There is support for this major life activity in the studies that the Supreme Court relied on in interpreting the definition of disability pre-ADAAA. *See Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 485 (1999).

<sup>22</sup> *See* Part II (E) below.

translates this as “a slight mental retardation”<sup>23</sup> but it is actually a term of art “typically used to describe people with an IQ level of 50–55 to approximately 70.” *Atkins, supra*, 536 U.S. at 308 n.4 (citing the DSM-IV). *See also* DSM-IV-TR at 42 (2000). Many experts find the term misleading because it suggests to non-experts that the effects of the condition are “mild.” M. Snell and R. Luckasson, *Characteristics and Needs of People With Intellectual Disability Who Have Higher IQs*, 47 *Intellectual and Developmental Disabilities* 220, 228 (June 2009), included in Appendix at Tab C (hereafter “Characteristics and Needs”). *See also* AAIDD, *Intellectual Disability: Definition, Classification, and Systems of Support* at 152–153 (11th ed. 2010).<sup>24</sup>

The effects of this condition are decidedly *not mild*. “All people with intellectual disability, including those with higher IQs, belong to a single disability group (people with intellectual disability).” *Characteristics and Needs, supra*, at 221. Every single diagnostic criteria and manifestation of intellectual disability described above is present in these individuals. “By definition all individuals with intellectual disability have significantly impaired intellectual abilities and adaptive

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<sup>23</sup> Plaintiff-Appellant’s Brief at 5 and 14. One common feature of everyday life for individuals with this diagnosis is a tendency to minimize the intellectual disability. AAIDD, *Intellectual Disability: Definition, Classification, and Systems of Support* at 155 (11th ed. 2010).

<sup>24</sup> “Terminology and concepts used within one field or profession (such as ID) are frequently not understood clearly by members of another field or profession. As a result, confusion and misunderstanding can occur within the courtroom and impact legal decisions.” AAIDD, *User’s Guide to Intellectual Disability: Definition, Classification, and Systems of Supports* at 25 (2012).

behavior ... [and the] characteristics emerging from significantly impaired intellectual abilities are shared by the entire group of individuals.” *Id.* at 228. These individuals “struggle in society” and have “limited academic skills,” and the “underlying cognitive challenges of having limited intelligence play havoc with ordinary mental processes...” *Id.* at 220, 222, 226. *See also* AAIDD, *Intellectual Disability: Definition, Classification, and Systems of Support* at 151, 153, 161 (11th ed. 2010).

This Court has correctly described “mild mental retardation” as a “serious mental ailment.” *Abrahams v. MTA Long Island Bus*, 644 F.3d 110, 113 (2d Cir. 2011). In passing the ADAAA, Congress also recognized this fact. H.R. Rep. 110-730, Pt. I, 110th Cong., 2d Sess., at p. 10 (June 23, 2008) (“an individual with mild mental retardation (intellectual disability) would be considered materially restricted in the major life activities of learning and thinking.”).

**B. Intellectual Disability Is An “Actual Disability” When Assessed Under The Broad Construction That The ADAAA Requires.**

It would be hard to overstate the extent of the change the ADAAA made to the definition of disability. Although the ADAAA “retained the basic structure and terms of the original definition of disability ... the Amendments Act altered the interpretation and application of this critical statutory term in fundamental ways.” 29 C.F.R. Part 1630 App., § 1630.2(g). *See also Gibbs v. ADS Alliance Data*

*Systems, Inc.*, 2011 WL 3205779, at \*3 (D. Kan. July 28, 2011); *Norton v. Assisted Living Concepts, Inc.*, 786 F. Supp. 2d 1173, 1185 (E.D. Tex. 2011).

The Amendments Act expands the ADA’s definition of disability in ways that the appellate courts have variously described as “significant,”<sup>25</sup> “substantial,”<sup>26</sup> and “important.”<sup>27</sup> Without question it broadens the scope of the ADA,<sup>28</sup> lowers the bar for establishing disability<sup>29</sup> and expands the class of protected individuals.<sup>30</sup>

Congress passed the ADAAA because it was dissatisfied with judicial and agency interpretation of the ADA, finding that they improperly excluded many people from coverage.<sup>31</sup>

The ADAAA now requires that the definition of disability be construed “in favor of *broad coverage of individuals ... to the maximum extent* permitted by the terms of this Act.” 42 U.S.C. § 12102(4)(A) (emphasis added); 29 C.F.R. § 1630.1(c)(4). *See also* 29 C.F.R. Part 1630 App., §§ 1630.2(g) (“The legislative history of the ADAAA is replete with references emphasizing this principle.”).<sup>32</sup>

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<sup>25</sup> *See, e.g., Serednyj v. Beverly Healthcare, LLC*, 656 F.3d 540, 552 n.2 (7th Cir. 2011); *Rohr v. Salt River Project Agricultural Imp. and Power Dist.*, 555 F.3d 850, 860–861 (9th Cir. 2009).

<sup>26</sup> *Hennagir v. Utah Dept. of Corrections*, 587 F.3d 1255, 1261 n.2 (10th Cir. 2009).

<sup>27</sup> *Miller v. Illinois Dept. of Transp.*, 643 F.3d 190, 195 n.1 (7th Cir. 2011); *Hohider v. United Parcel Service, Inc.*, 574 F.3d 169, 188 n.17 (3d Cir. 2009).

<sup>28</sup> *Godfrey v. New York City Transit Authority*, 2009 WL 3075207, at \*6 n.4 (E.D.N.Y. Sept. 23, 2009).

<sup>29</sup> *Markham v. Boeing Co.*, 2011 WL 6217117, at \*3 (D. Kan. Dec. 14, 2011).

<sup>30</sup> *Lopez v. Kempthorne*, 2010 WL 174889, at \*18 n.32 (S.D. Tex. Jan. 14, 2010).

<sup>31</sup> Pub. L. 110-325, § 2(a)(6), 42 U.S.C. § 12101 (Note); *Rohr v. Salt River Project Agricultural Imp. and Power Dist.*, 555 F.3d 850, 853 (9th Cir. 2009).

<sup>32</sup> In addition to the history cited by the EEOC, see Statement of Sen. Hatch, 154 Cong. Rec.

In other words, “[t]he Act emphasizes that the term ‘substantially limit’ under the actual disability prong shall be interpreted as broadly as possible.” *Norton v. Assisted Living Concepts, Inc.*, 786 F. Supp. 2d 1173, 1185 (E.D. Tex. 2011).<sup>33</sup>

Intellectual disability fits easily under this new, mandatory standard of analysis.

**C. The ADAAA’s Legislative History Explicitly Supports Coverage For Individuals With An Intellectual Disability.**

The ADAAA’s legislative history expressly states that “an individual with *mild mental retardation* (intellectual disability) would be considered materially restricted in the major life activities of learning and thinking.” H.R. Rep. 110-730, Pt. I, 110th Cong., 2d Sess., at p. 10 (June 23, 2008) (emphasis added). The same report also suggests that under the ADAAA, a person with an intellectual disability “would be found to be substantially limited in the operation of a major bodily system because he is materially restricted in neurological function.” *Id.* See also Joint Statement of Reps. Hoyer and Sensenbrenner, 154 Cong. Rec. H8294 (Sept. 17, 2008).

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S8354 (Sept. 11, 2008) (“the bill directs that the definition of disability be construed in favor of broad coverage. This reflects what courts have held about civil rights statutes in general”); Statement of Rep. Miller, 154 Cong. Rec. H8288 (Sept. 17, 2008) (“the scope of protection ... [is] to be generous and inclusive.”); Statement of Rep. Hoyer, 154 Cong. Rec. H8293 (Sept. 17, 2008) (“By voting for final passage of the ADA Amendment Act, we ensure that the definition of disability will henceforth be construed broadly and fairly.”).

<sup>33</sup> See also *Rohr v. Salt River Project Agricultural Improvement and Power District*, 555 F.3d 850, 861 (9th Cir. 2009) (“Beginning in January 2009, ‘disability’ was to be broadly construed and coverage will apply to the ‘maximum extent’ permitted by the ADA and the ADAAA.”).

Congress also explicitly found that while it “expected that the definition of disability under the ADA would be interpreted consistently with how courts had applied the definition of a handicapped individual under the Rehabilitation Act ... that expectation has not been fulfilled...” Pub. L. 110–325, § 2(a)(3), 122 Stat. 3553 (Sept. 25, 2008), 42 U.S.C. § 12101 (Note). The legislative history similarly recognizes that “Congress modeled the ADA definition of disability on the definition of ‘handicapped individual’ contained in the Rehabilitation Act ... which the courts had interpreted broadly to include persons with a wide range of physical and mental impairments such as ... intellectual and developmental disabilities.” H.R. Rep. 110-730, Pt. II, 110th Cong., 2d Sess., at p. 6 (June 23, 2008). *See also id.* at 7–8 (giving as an example of someone with a record of a substantially limiting impairment one “who had, but no longer has, cancer, or a person who was misclassified as being mentally retarded.”); *id.* at 9 (criticizing fact that “individuals with disabilities that had been covered under the Rehabilitation Act and that Congress intended to include under the ADA—people with serious health conditions like ... intellectual and developmental disabilities—have been excluded from protection.”).

The official and bipartisan Statement of Senate Managers is fully consistent, stating in Part II:

Thus, some 18 years later we are faced with a situation in which physical or mental impairments that would previously have been found to constitute disabilities are not considered disabilities under the Supreme Court's narrower standard. These can include individuals with impairments such as ... intellectual disabilities .... The ADA Amendments Act rejects the high burden required in these cases and reiterates that Congress intends that the scope of the Americans with Disabilities Act be broad and inclusive. ... These steps, resulting from extensive bipartisan negotiation and discussion among legislators and stakeholders, are intended to provide for more generous coverage and application of the ADA's prohibition on discrimination through a framework that is more predictable, consistent, and workable for all entities subject to responsibilities under the ADA.

Statement of the Managers to Accompany S. 3406, The Americans with Disabilities Act Amendments Act of 2008, 154 Cong. Rec. S8345 (Sept. 11, 2008).

Numerous individual statements in the Congressional Record are substantially similar:

- “In recent years, the courts have narrowed the definition of who qualifies as an ‘individual with a disability.’ As a consequence, people with conditions that common sense tells us are disabilities are being told by courts that they are not in fact disabled, and are not eligible for the protections of the law. ... Impairments that the Court says are not to be considered disabilities under the law include ... intellectual disabilities  
.....<sup>34</sup>
- “The law has been repeatedly misinterpreted by the courts that have used an extremely narrow definition of disability. This definition is so narrow that many defendants with clear disabilities cannot even get their case heard in a courtroom because they do not qualify as having a disability. People with disabilities excluded from protections under the ADA include those with ... intellectual disabilities.”<sup>35</sup>

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<sup>34</sup> Statement of Sen. Harkin, 154 Cong. Rec. S7956 (July 31, 2008).

<sup>35</sup> Statement of Sen. Dodd, 154 Cong. Rec. S8356 (Sept. 11, 2008).

- “[T]he lower courts have now gone so far as to rule that people with ... even intellectual disabilities are not disabled. ... The ADA Amendments Act finally rights these wrongs.”<sup>36</sup>
- “Under this narrow interpretation, individuals with ... mental retardation ... have been denied their rights under the ADA because they are labeled as ‘too functional’ to be considered ‘disabled.’”<sup>37</sup>
- “[I]n 2002, the [Supreme] Court held that a ‘demanding standard’ should be applied to determining whether a person has a disability. As a result, millions of people Congress intended to protect under the ADA—such as those with ... intellectual disabilities ...—are not protected as intended.”<sup>38</sup>
- “Like H.R. 3195, the lower standard demanded by S. 3406 will provide broad coverage, consistent with how courts had approached cases under the Rehabilitation Act prior to enactment of the ADA, where individuals with a wide range of physical and mental impairments such as ... intellectual and developmental disabilities qualified for protection ....”<sup>39</sup>

The EEOC guidance also notes that Congress intended courts to return to earlier interpretations, which had included intellectual and developmental impairments in the definition of disability. 29 C.F.R. Part 1630 App., § 1630.2(j)(3), 76 Fed. Reg. 16978, 17012 (Mar. 25, 2011).

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<sup>36</sup> Statement of Sen. Reid, 154 Cong. Rec. S9626 (Sept. 26, 2008).

<sup>37</sup> Statement of Rep. Holt, 154 Cong. Rec. H6070 (June 25, 2008).

<sup>38</sup> Statement of Rep. Scott, 154 Cong. Rec. H6070 (June 25, 2008).

<sup>39</sup> Statement of Rep. Nadler, 154 Cong. Rec. H8289 (Sept. 17, 2008).

**D. The District Court’s Reliance On The Pre-ADAAA *Littleton* Case Was Inappropriate.**

The only case involving an intellectual disability relied on by the district court was *Littleton v. Wal-Mart Stores, Inc.*, 231 Fed. Appx. 874, 877 (11th Cir. 2007) (finding that individual with intellectual disability did not have a disability under the pre-amendments ADA). JA433. This is particularly inappropriate because this unreported case is one of the cases expressly and repeatedly criticized by Congress in enacting the ADAAA.

Besides repeatedly stating that an intellectual disability *does* qualify for coverage under the ADAAA, *see* Part II (C) above, the legislative history also expresses the Congressional expectation that *Littleton* (often identified by name) would be decided differently under the ADAAA. H.R. Rep. 110-730, Pt. I, 110th Cong., 2d Sess., at p. 10 (June 23, 2008); Statement of the Managers to Accompany S. 3406, The Americans with Disabilities Act Amendments Act of 2008, 154 Cong. Rec. S8844 at n.17 (Sept. 16, 2008) (“We expect that this illustrative list of major life activities (including major bodily functions), in combination with the rejection of both the ‘demanding standard’ in *Toyota* and the consideration of mitigating measure in the *Sutton* trilogy will make it easier for individuals to show that they are eligible for the ADA’s protections under the first prong of the definition of disability. While it is impossible to predict the type of

cases that will be brought following passage of this bill, we would expect that the bill will make it easier for individuals in cases like the following to qualify for the protections of the ADA—*Littleton v. Wal-Mart Stores, Inc*, 231 Fed. Appx. 874 (11th Cir. 2007) (individual with intellectual disability)...”).

*See also* Joint Statement of Reps. Hoyer and Sensenbrenner, 154 Cong. Rec. H8294 (Sept. 17, 2008) (similar); Statement of Sen. Harkin, 154 Cong. Rec. S7956 (July 31, 2008) (“In recent years, the courts have narrowed the definition of who qualifies as an ‘individual with a disability.’ As a consequence, people with conditions that common sense tells us are disabilities are being told by courts that they are not in fact disabled, and are not eligible for the protections of the law. *In a ruling last year, the 11th Circuit Court even concluded that a person with an intellectual disability was not ‘disabled’ under the ADA.*”) (emphasis added); Statement of Sen. Harkin, 154 Cong. Rec. S8349 (Sept. 11, 2008) (similar); Statement of Sen. Reid, 154 Cong. Rec. S9626 (Sept. 26, 2008) (“Unfortunately, we didn’t expect then that Supreme Court decisions would narrow the law’s scope contrary to congressional intent. As a result, the lower courts have now gone so far as to rule that people with ... even intellectual disabilities are not disabled. ... The ADA Amendments Act finally rights these wrongs.”).

Moreover, *Littleton* has been cited by scholars as an example of a case decided incorrectly under the pre-amendments ADA. *See, e.g.*, Sharona Hoffman,

The Importance of Immutability in Employment Discrimination Law, 52 Wm. & Mary L. Rev. 1483, 1491 (April 2011) (“Courts most often interpreted this definition narrowly, finding that various conditions either do not affect a major life activity or are not sufficiently limiting to constitute disabilities under the ADA. For example, *one notorious case held that an individual with mental retardation was not disabled for purposes of the ADA* [citing *Littleton*].”) (emphasis added; footnotes omitted); Bradley A. Areheart, The Anticlassification Turn in Employment Discrimination Law, 63 Ala. L. Rev. 955, 976–977 (2012) (“The ADA’s impact in the employment context has been widely viewed as meager. . . . Courts have found plaintiffs with serious physical or mental impairments, ranging from mental retardation, to cerebral palsy, to cancer, are not disabled under the ADA. [citing *Littleton*] . . . Congress passed the ADA Amendments Act of 2008 (ADAAA) to strengthen faltering disability protections.”).

According to Westlaw, *Littleton* has not been cited by any other federal court in this Circuit, outside of the Court below. Moreover, Westlaw reveals that it has never been cited *by any court* in a case governed by the ADAAA, except by the Court below. There is good reason for avoiding reliance on the case. In its analysis *Littleton* expressly relied on the *Toyota Motor* holding that disability is a “demanding standard.” *Littleton, supra*, 231 Fed. Appx. at 876 (“We are mindful that the Supreme Court has stated that the term ‘disability’ is to be ‘interpreted

strictly to create a demanding standard for qualifying as disabled.”). Congress expressly rejected that standard in the ADAAA. Pub. L. 110-325, §§ 2(a)(5)–(7) and 2(b)(4)–(5), 122 Stat. 3553 (Sept. 25, 2008), 42 U.S.C. § 12101 (Note). *Littleton* also relied on the EEOC’s “significantly restricted” standard, 231 Fed. Appx. at 877, but again, Congress has rejected it, Pub. L. 110-325, §§ 2(a)(8) and 2(b)(6), 42 U.S.C. § 12101 (Note), and the EEOC has rescinded it. 29 C.F.R. § 1630.2(j)(1)(ii) (“An impairment need not prevent, or significantly or severely restrict, the individual from performing a major life activity in order to be considered substantially limiting.”).

**E. The Evidence in This Case Would Allow A Reasonable Juror To Find That The Appellant Had A Disability Under The ADAAA.**

Amici note that in this case the Appellant testified that he had an intellectual disability, and he described both symptoms<sup>40</sup> and an educational history<sup>41</sup> that are consistent with such a condition. Disability is often established by the individual’s

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<sup>40</sup> Mr. Adams testified that he was a slow learner, was in special-ed in school, had a learning disability, was not like the rest of the guys, took longer than others to do things, and constantly had to go at a slower pace to pick things up, JA 183, JA 201, JA265–JA267, JA303, JA 316; that as a result, JA 183, his co-workers repeatedly called him “stupid,” JA 181, JA269, JA336; that he was told he had “slight mental retardation,” JA 185, JA303, JA304, JA315; that he has problems spelling, can only read at third- or fourth-grade level, can only remember up to five things, and cannot go to college or get a really good job. JA 185, JA 265.

<sup>41</sup> Appellant testified that he was in special ed in school, JA265, JA316, and that he took life-skills classes like how to wash clothes, etc. JA303–304. The educational records he offered were consistent. JA188–196 (referencing planned skills training in (among other things) activities of daily living and money management).

own testimony as to its manifestations,<sup>42</sup> and the fact that such testimony comes from the plaintiff does not make it improperly self-serving.<sup>43</sup>

Appellant also offered documentary evidence in support of his diagnosis, namely, the educational diagnostician's evaluation, JA187, and an IEP (special education) plan. JA188–196. It is typically in school that individuals with this condition are first identified and diagnosed. AAIDD, *Intellectual Disability: Definition, Classification, and Systems of Support* at 152 (11th ed. 2010). Although the district court found these documents to be in inadmissible form (apparently because they were not sworn to or lacked foundation), JA430–432, that is not the proper standard at the summary judgment stage, where substance is more important than form.<sup>44</sup>

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<sup>42</sup> See, e.g., *Head v. Glacier Northwest Inc.*, 413 F.3d 1053, 1058–1059 (9th Cir. 2005) (expert testimony not always required). See also *Lederer v. BP Products North America*, 2006 WL 3486787, at \*4 (S.D.N.Y. Nov. 20, 2006) (expert testimony may be unnecessary if condition's manifestations are well-known and well-established).

<sup>43</sup> *Hill v. Tangherlini*, \_\_\_ F.3d \_\_\_, 2013 WL 3942935, at \*2 and n.1 (7th Cir. Aug. 1, 2013); *Sanchez v. Vilsack*, 695 F.3d 1174, 1180 n.4 (10th Cir. 2012).

<sup>44</sup> Courts “need not decide whether the [document] itself is admissible. It would be sufficient if the contents ... are admissible at trial ....” *Fraser v. Goodale*, 342 F.3d 1032, 1036 (9th Cir. 2003), *cert. denied*, 541 U.S. 937 (2004). See also *Davis-Bell v. Columbia University*, 851 F. Supp. 2d 650, 675–676 (S.D.N.Y. 2012) (“While evidence produced by the party opposing a summary judgment motion need not be in a form that would be admissible at trial, its content must nonetheless be admissible”) (internal quotes and cites omitted); *Bernhardt v. Interbank of New York*, 2009 WL 255992, at \*5 (E.D.N.Y. Feb. 3, 2009) (“Occasional statements in cases that a party opposing summary judgment must present admissible evidence should be understood in this light, as referring to the content or substance, rather than the form, of the submission.”) (internal quotes omitted); *Masters v. F.W. Webb Co.*, 2008 WL 4181724, at \*12 (W.D.N.Y. Sept. 8, 2008); *Daniel v. American Bd. of Emergency Medicine*, 237 F. Supp. 2d 336, 351–352 (W.D.N.Y. 2002) (Kettering first argues that the Mattison Letter is inadmissible as evidence in opposition to summary judgment because it is not a sworn statement. There is, however, no

Although Appellee argued below that Mr. Adams performed at approximately grade level, JA114, it mischaracterized the testimony. Mr. Adams simply testified that he was in the same grade as his age group. This is unsurprising given the legal preference that children with disabilities be “mainstreamed.” *Board of Educ. v. Rowley*, 458 U.S. 176, 181 (1982); *M.W. ex rel. S.W. v. New York City Dept. of Educ.*, \_\_\_ F.3d \_\_\_, 2013 WL 3868594 (2d Cir. July 29, 2013). Unfortunately, the Appellee’s misinterpretation appears to have confused the district court. Mr. Adams did not merely describe his reading ability while in the fifth grade, as the District Court below stated. JA430. Instead Mr. Adams testified that *even now*, he could only read at a third or fourth-grade level, JA184,<sup>45</sup> which is less than half the national average.<sup>46</sup> This is evidence of a substantial limitation in reading, which is itself a major life activity. 42 U.S.C. § 12102(2)(A).

The evidence in this case is consistent with Appellant having an intellectual disability. Amici urge that if the Court finds sufficient evidence to support such a

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requirement that the evidence submitted in opposition to summary judgment be admissible as evidence at trial. Rather, the requirement is that the information be reducible to admissible evidence sufficient to carry Plaintiffs’ burden of proof at trial.”).

<sup>45</sup> According to the DSM, this is typical for an individual with this disability. DSM-IV at 41 (1994) (“By their late teens [individuals with ‘Mild Mental Retardation’] can acquire academic skills up to approximately the sixth-grade level.”); DSM-IV-TR at 43 (2000) (similar).

<sup>46</sup> According to the Harvard School of Public Health, the average reading level for adults in the United States at the relevant time was the equivalent of eighth to ninth grade. *Teaching Patients with Low Literacy Skills* at 3 (2d ed.), <http://www.hsph.harvard.edu/healthliteracy/files/2012/09/doakchap1-4.pdf>.

conclusion, *by definition that is sufficient evidence of an “actual disability” under the ADA.*

### **III. EVEN IF THE APPELLANT DID NOT HAVE AN “ACTUAL” DISABILITY, HE HAD A “REGARDED AS” DISABILITY**

The district court held, in reliance on Appellee’s contention, that in order to prove a “regarded as” disability the Appellant had to prove that his employer “perceived his impairment as substantially limiting.” JA433–434. This standard is patently incorrect, as this Court observed in *Hilton v. Wright*, 673 F.3d 120 (2d Cir. 2012):

Although both parties thought that Hilton needed to demonstrate that the defendants regarded him as being substantially limited in a major life activity, it is clear that he was only required to raise a genuine issue of material fact about whether Dr. Wright and/or DOCS regarded him as having a mental or physical impairment. Hilton was not required to present evidence of how or to what degree they believed the impairment affected him.

*Id.* at 129.

“Regarded as” is now considered to be an “impairment standard;” the concepts of “substantial limitation” and “major life activity” are simply irrelevant to the analysis. The proper question is whether the Appellant was subjected to an adverse action “because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.”

42 U.S.C. § 12102(3)(A).

Appellant testified that when he was hired, he told both the General Manager and his own supervisor that he had a learning disability and was a slow learner, JA201, JA266, JA316; that he could not learn like the rest of the guys, JA266–267; that he had been in “special ed” in school, JA265, JA316; and that he could not remember multiple things, JA 185, JA265. Appellee’s summary judgment motion did not appear to contest any of that testimony. Therefore, Appellant presented sufficient evidence that he disclosed an impairment,<sup>47</sup> namely a recognized, permanent<sup>48</sup> learning disability.<sup>49</sup> Appellee should thus be held liable on Mr. Adams’ “regarded as” claim if the actions of its employees were taken as a result of that real or perceived impairment. The district court erred in failing to apply the appropriate standard.

## CONCLUSION

For these reasons, the Court should reverse the district court’s order granting Appellant’s motion for summary judgment, and remand the case for further proceedings.

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<sup>47</sup> Impairment does not require formal diagnosis or complete understanding of a condition’s cause. *Hutchinson v. Ecolab, Inc.*, 2011 WL 4542957, at \*9 n.10 (D. Conn. Sept. 28, 2011).

<sup>48</sup> Because this impairment lasted more than six months, the Appellee would not be able to raise the “transitory and minor” defense in 42 U.S.C. § 12102(3)(B) and 29 C.F.R. § 1630.15(f), which in any event was not one of the 24 defenses it pled. See JA41–45.

<sup>49</sup> One must have a significant learning disability in order to be eligible for special-education services. See *Hiller by Hiller v. Board of Educ. of Brunswick Cent. School Dist.*, 743 F. Supp. 958, 970–971 (N.D.N.Y. 1990).

Respectfully submitted,



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## CERTIFICATE OF COMPLIANCE

1. This brief complies with the type-volume limitation of Fed. R. App. P. 31(a)(7)(B) because it contains 6,766 words, excluding the parts of the brief exempted by Fed. R. App. P. 32(a)(7)(B)(iii).

2. This brief complies with the typeface requirements of Fed. R. App. P. 32(a)(5) and the type style requirements of Fed. R. App. P. 32(a)(6) because it has been prepared in a proportionally spaced typeface using Microsoft Word in 14 point Times New Roman.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "B. East", is written over a horizontal line.

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## CERTIFICATE OF SERVICE

The undersigned hereby certifies that the foregoing Motion was filed electronically on this 26th day of August, 2013. Notice of this filing will be sent by operation of the ECF system to all counsel of record, who are deemed served upon receipt of the notice of docket activity pursuant to Local Rule 25.1.

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# **APPENDIX**

## **TAB A**

## STATEMENTS OF INTEREST OF AMICI

The **National Employment Lawyers Association** (NELA) is the largest professional membership organization in the country comprised of lawyers who represent workers in labor, employment and civil rights disputes. Founded in 1985, NELA advances employee rights and serves lawyers who advocate for equality and justice in the American workplace. NELA and its 68 circuit, state, and local Affiliates have a membership of over 3,000 attorneys who are committed to working on behalf of those who have been illegally treated in the workplace. NELA's members litigate daily in every circuit, affording NELA a unique perspective on how the principles announced by the courts in employment and benefit cases actually play out on the ground. NELA strives to protect the rights of its members' clients, and regularly supports precedent-setting litigation affecting the rights of individuals in the workplace.

**The Arc of the United States, Inc.** (The Arc) is the largest national community based organization of and for people with intellectual and developmental disabilities. The Arc advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. It provides an array of services and supports for over a million individuals with intellectual and developmental disabilities and families through more than 700 state and local chapters across the nation. The Arc is devoted to ensuring the civil

rights of and promoting and improving supports and services for all people with intellectual and developmental disabilities.

The **National Disability Rights Network** (NDRN) is the non-profit membership association of Protection and Advocacy (“P&A”) agencies that are located in all 50 states, the District of Columbia, Puerto Rico, and the United States Territories. P&A agencies are authorized pursuant to various federal statutes to provide legal representation and related advocacy services, and to investigate abuse and neglect of individuals with disabilities in a variety of settings. The P&A System comprises the nation’s largest provider of legally-based advocacy services for persons with disabilities. NDRN supports its members through the provision of training and technical assistance, legal support, and legislative advocacy, and works to create a society in which people with disabilities are afforded equality of opportunity and are able to fully participate by exercising choice and self-determination, including the opportunity to secure and maintain competitive, integrated employment.

The **Office of Protection and Advocacy for Persons with Disabilities** was established by statute in 1977. Conn. Gen. Stat. § 46a-7. The State of Connecticut recognized that it “has a special responsibility for the care, treatment, education, rehabilitation of and advocacy for its disabled citizens” and the Office of Protection and Advocacy has the authority to “represent, appear, intervene in or

bring an action on behalf of any person with disability...in any proceeding before any court...in this state in which matters related to this chapter are in issue....” Conn. Gen. Stat. §46a-11(7). In the case before this Court, The Office of Protection and Advocacy has a particular interest in assuring that individuals with intellectual disability are fully integrated into the community and given a fair opportunity to maintain competitive employment. It is in furtherance of its statutory obligations that The Office of Protection and Advocacy requests permission to appear as *amicus curiae*.

**Disability Rights Vermont** (DRVT) is the federally authorized and mandated protection and advocacy system for the State of Vermont. DRVT has been providing legal advocacy services to people with disabilities, including people with intellectual disabilities, in Vermont since 1991. DRVT is involved in advocacy and litigation to redress discrimination against individuals with all forms of disability throughout Vermont, including assuring that people with intellectual disabilities receive the protections afforded by the ADA. DRVT believes that preserving and assuring the protections of the ADA for people with intellectual disabilities is crucial to the work DRVT does to fight illegal and counterproductive discrimination at all levels on behalf of Vermonters with disabilities.

# **APPENDIX**

## **TAB B**

# Perspectives

## The Renaming of *Mental Retardation*: Understanding the Change to the Term *Intellectual Disability*

Robert L. Schalock, Ruth A. Luckasson, and Karrie A. Shogren, With Sharon Borthwick-Duffy, Val Bradley, Wil H. E. Buntinx, David L. Coulter, Ellis (Pat) M. Craig, Sharon C. Gomez, Yves Lachapelle, Alya Reeve, Martha E. Snell, Scott Spreat, Marc J. Tassé, James R. Thompson, Miguel A. Verdugo, Michael L. Wehmeyer, and Mark H. Yeager

### Introduction and Overview

There is considerable and intense discussion in the field of intellectual disability/mental retardation about the construct of disability, how intellectual disability fits within the general construct of disability, and the use of the term *intellectual disability* (Glidden, 2006; Greenspan, 2006; MacMillan, Siperstein, & Leffert, 2006; Schalock & Luckasson, 2004; Switzky & Greenspan, 2006b). This discussion is occurring within the context of competing world views of the philosophical and epistemological underpinnings of the conceptions of intellectual disability/mental retardation (Switzky & Greenspan, 2006a).

Increasingly, the term *intellectual disability* is being used instead of *mental retardation*. This transition in terminology is exemplified by organization names (e.g., the American Association on Intellectual and Developmental Disabilities—AAIDD, International Association for the Scientific Study of Intellectual Disabilities, President's Committee for People With Intellectual Disabilities), journal titles, and published research (Parmenter, 2004; Schroeder, Gertz, & Velazquez, 2002). A number of questions have emerged with the increased use of the term *intellectual disability*:

- Why is the term *intellectual disability* currently preferred to *mental retardation*?
- How might the use of the term *intellectual disability* impact the current definition of *mental retardation*?
- How might the use of the term *intellectual disability* affect persons diagnosed or eligible for a diagnosis of mental retardation?

Our purpose in this article is to clarify the shift to the term *intellectual disability*. At the heart of that

shift is the understanding that this term covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.

In addition, in this article we explore why the field is shifting to the term *intellectual disability*. Increased understanding is based on a clear distinction among the *construct* used to describe a phenomenon, the *term* used to name the phenomenon, and the *definition* used to precisely explain the term and establish the term's meaning and boundaries. In this article we represent the first of a planned series of articles by the AAIDD Committee on Terminology and Classification in which we will share our thoughts and ask for input from the field prior to the anticipated publication in 2009/2010 of the 11th edition of the definition, classification, and systems of supports manual (*The Manual*).

Throughout the article we stress that understanding the term *intellectual disability* is enhanced by dialogue and clarity. To that end, the following terms will be used:

- *Construct*: an abstract or general idea that is formed by arranging parts or elements, based on observed phenomena, in the context of a theory. The construct of intellectual disability is contained within the broader construct of disability, aligning and integrating the framework for assessment and intervention of intellectual disability within the broader construct of disability.
- *Name*: the term that is used to refer to a construct (in this case, mental retardation or intellectual

disability). The name/term should refer to a single entity, permit differentiation from other entities, and improve communication. In addition, the name should adequately represent current knowledge and be robust enough in its operationalization to permit its use for multiple purposes (e.g., defining, diagnosing, classifying).

## The Constructs: Disability and Intellectual Disability

### *Construct of Disability*

The current construct of disability is focused on the expression of limitations in individual functioning within a social context and represents a substantial disadvantage to the individual. Disability has its genesis in a health condition that gives rise to impairments in body functions and structures, activity limitations, and participation restrictions within the context of personal and environmental factors.

### *Construct of Intellectual Disability*

The construct of intellectual disability belongs within the general construct of disability. Intellectual disability has evolved to emphasize an ecological perspective that focuses on the person–environment interaction and recognizes that the systematic application of individualized supports can enhance human functioning.

### *Explanation of the Constructs*

The current construct of disability has emerged over the last 2 decades due primarily to an increased understanding of the process of disablement and its amelioration. Major factors in this evolution include (a) the research on the social construction of illness and the extensive impact that societal attitudes, roles, and policies have on the ways that individuals experience health disorders (Aronowitz, 1998); (b) the blurring of the historical distinction between biological and social causes of disability (Institute of Medicine, 1991); and (c) the recognition of the multidimensionality of human functioning (Luckasson et al., 1992, 2002; World Health Organization [WHO], 2001). Because of these factors, the concept of disability has evolved from a person-centered trait or characteristic (often referred to as a “deficit”) to a human phenomenon with its genesis in organic and/or social factors. These organic and social factors give rise to functional limitations that reflect an inability or con-

straint in both personal functioning and performing roles and tasks expected of an individual within a social environment (De Ploy & Gilson, 2004; Hahn & Hegamin, 2001; Nagi, 1991; Oliver, 1996; Rioux, 1997).

This social–ecological conception of disability is reflected well in current publications of both the American Association on Mental Retardation (AAMR), now the AAIDD, and WHO. In the 2002 *Manual* (Luckasson et al., 2002), *disability* was defined as the expression of limitations in individual functioning within a social context and represents a substantial disadvantage to the individual. Similarly, in the World Health Organization’s (2001) *International Classification of Functioning*, *disability* is described as having its genesis in a health condition (disorder or disease) that gives rise to impairments in body functions and structures, activity limitations, and participation restrictions within the context of personal and environmental factors.

The importance of this evolutionary change in the construct of disability is that intellectual disability is no longer considered entirely an absolute, invariable trait of the person (DeKraai, 2002; Devlieger, Rusch, & Pfeiffer, 2003; Greenspan, 1999). Rather, this social–ecological construct of disability, and intellectual disability, (a) exemplifies the interaction between the person and their environment; (b) focuses on the role that individualized supports can play in enhancing individual functioning; and (c) allows for the pursuit and understanding of “disability identity,” whose principles include self-worth, subjective well-being, pride, common cause, policy alternatives, and engagement in political action (Powers, Dinerstein, & Holmes, 2005; Putnam, 2005; Schalock, 2004; Vehmas, 2004).

## The Name/Term: *Intellectual Disability*

The term *intellectual disability* is increasingly being used instead of *mental retardation*. Terminology for what is now referred to as intellectual disability has varied historically. Over the last 200 years, terms have included *idiocy*, *feeble-mindedness*, *mental deficiency*, *mental disability*, *mental handicap*, and *mental subnormality* (Goodey, 2005; Mercer, 1992; Schroeder et al., 2002; Stainton, 2001; Trent, 1994; Wright & Digby, 1996).

Luckasson and Reeve (2001) discussed five important factors that need to be considered when selecting a term. First, the term should be specific, refer to a single entity, permit differentiation from

other entities, and enhance communication. Second, it must be used consistently by different stakeholder groups (e.g., individuals, families, schools, clinicians, lawyers, physicians, professional organizations, researchers, and policy makers). Third, the term must adequately represent current knowledge and be able to incorporate new knowledge as scientific advances occur. Fourth, it should be robust enough in its operationalization to permit its use for multiple purposes, including defining, diagnosing, classifying, and planning supports. Fifth, it should reflect an essential component of naming a group of people, which is to communicate important values, especially towards the group. This aspect of the naming process (i.e., communicating important values) has generated a great deal of discussion, with many individuals asserting that the term *mental retardation* does not communicate dignity or respect and, in fact, frequently results in the devaluation of such persons (Finlay & Lyons, 2005; Hayden & Nelis, 2002; Rapley, 2004; Snell & Voorhees, 2006).

There is an emerging consensus that not only does the term *intellectual disability* meet these five criteria, but that the term is preferable for a number of reasons. Chief among these are that the term *intellectual disability* (a) reflects the changed construct of disability described by the AAIDD and WHO, (b) aligns better with current professional practices that focus on functional behaviors and contextual factors, (c) provides a logical basis for individualized supports provision due to its basis in a social-ecological framework, (d) is less offensive to persons with the disability, and (e) is more consistent with international terminology.

## The Definition

*Defining* refers to explaining precisely the term and establishing the term's meaning and boundaries. The authoritative definition of *intellectual disability/mental retardation* is that of the AAIDD (previously the AAMR). The definition in the 2002 AAMR Manual (Luckasson et al., 2002, p. 1) remains in effect now and for the foreseeable future. This definition is shown here with a minor edit that substitutes the term *intellectual disability* for *mental retardation*:

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

Assumptions are an explicit part of the definition because they clarify the context from which the definition arises and indicate how the definition must be applied. Thus, the definition of *intellectual disability* cannot stand alone. The following five assumptions are essential to the application of the definition of *intellectual disability*.

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve. (Luckasson et al., 2002, p. 1)

Significant consequences can result from the way a term is defined. As discussed by Gross and Hahn (2004), Luckasson and Reeve (2001), and Stowe, Turnbull, and Sublet (2006), a definition can make someone (a) eligible or ineligible for services; (b) subjected to something or not subjected to it (e.g., involuntary commitment); (c) exempted from something or not exempted (e.g., from the death penalty); (d) included or not included (as to protections against discrimination and equal opportunity); and/or (e) entitled or not entitled (e.g., as to Social Security benefits).

## Historical Approaches

Historically, four broad approaches (i.e., social, clinical, intellectual, and dual-criterion) have been used for purposes of definition and classification. Remnants of these four approaches are still evident in current discussions regarding who is (or should be) diagnosed as an individual with an intellectual disability (see, for example, Switzky & Greenspan, 2006a).

*Social approach.* Historically, persons were defined or identified as having mental retardation because they failed to adapt socially to their environment. Because an emphasis on intelligence and the role of "intelligent people" in society was to come later, the oldest historical definitional approach focused on social behavior and the "natural behavioral prototype" (Doll, 1941; Goodey, 2006; Greenspan, 2006).

*Clinical approach.* With the rise of the medical model, the definitional focus shifted to one's symp-

tom complex and clinical syndrome. This approach did not negate the social criterion but gradually shifted towards a more medical model that included an increase in the relative role of organicity, heredity, and pathology and led to a call for segregation (Devlieger et al., 2003).

*Intellectual approach.* With the emergence of intelligence as a viable construct and the rise of the mental testing movement, the approach changed to an emphasis on intellectual functioning as measured by an intelligence test and reflected in an IQ score. This emphasis led to the emergence of IQ-based statistical norms as a way to both define the group and classify individuals within it (Devlieger, 2003).

*Dual-criterion approach.* The first formal attempt to systematically use both intellectual functioning and adaptive behavior to define the class was found in the 1959 American Association on Mental Deficiency (AAMD) *Manual* (Heber, 1959), in which *mental retardation* was defined as referring to subaverage general intellectual functioning that originates during the developmental period and is associated with impairments in maturation, learning, and social adjustment. In the 1961 AAMD *Manual* (Heber, 1961), maturation, learning, and social adjustment were folded into a single, largely undefined new term, *adaptive behavior*, that has been used in all subsequent AAMR manuals. The dual-criterion approach also has included age of onset as an accompanying element.

### Definitional Consistency

Although the term or name has changed over time, an analysis of the definitions used over the last 50+ years shows that the three essential elements of intellectual disability/mental retardation—limitations in intellectual functioning, behavioral limitations in adapting to environmental demands, and early age of onset—have not changed substantially. A summary of this analysis is presented in Appendix A (definition) and Appendix B (age of onset criterion).

Consistency is also reflected in related concepts and definitions not shown in Appendices A and B. For example, Scheerenberger (1983) reported that the major elements (intellectual deficits, problems coping with the demands of everyday life, and onset during the developmental period) common to the current definition were used by professionals in the United States as early as 1900. Similarly, the National Research Council (2002, pp. 1–5) reported that the first formal AAMR/AAIDD definition of

the phenomenon was in 1910. This definition defined such persons as being feeble-minded, with development arrested at an early age or as evidenced by an inability to manage the demands of daily life or keep up with peers. Analogously, the Individuals With Disabilities Education Act of 2004 defines *mental retardation* as significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior, and manifesting during the developmental period that adversely affects a child's educational performance.

### Construct's Boundaries

Appendix C summarizes how the establishment of boundaries has been operationalized in the AAMR/AAIDD manuals since 1959. Two essential points are evident in these operationalizations. First, the cut-off criterion, based on SDs from a population mean, pertained primarily to the IQ element. As of the 2002 AAMR *Manual*, a corresponding cut-off criterion was established for the adaptive behavior element. Second, SDs currently are and primarily have been used to establish the boundary of intellectual disability.

The three appendices show clearly how both the definition and its operationalization have remained consistent over time. The minor changes that have occurred reflect three phenomena: (a) advances in understanding of intellectual functioning and adaptive behavior; (b) advances in measurement theory and strategies that permit the use of statistical procedures to control for measurement error (standard error of measurement), practice effects, and normative changes over time; and (c) the essential role of clinical judgment in the administration, scoring, and interpretation of psychometric instruments (Schalock & Luckasson, 2005; Schalock et al., 2007).

This historical consistency supports the trend in the field and the conclusion of the major organizations that regardless of the term used to name this disability, the same population has been described. This conclusion is the same as that drawn by The President's Committee for People With Intellectual Disabilities (2004), which stated,

The PCPID [President's Committee for People With Intellectual Disabilities] considers the terms *mental retardation* and *intellectual disabilities* to be synonymous, covering the same population in number, kind, level, type and duration of the disability, and the need by individuals for specific services and supports. Thus, The American Association on Mental Retardation's definition for "mental retardation" serves as the definition for "intellectual disabilities." (p. 3)

This conclusion is critical because of the essential role that the term *mental retardation* plays in public policy. For example, in the United States, a diagnosis of mental retardation is commonly used to determine eligibility under state and federal disability programs, such as Individuals With Disabilities Education Act—IDEA (2004), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver. In addition, the term *mental retardation* is also used for citizenship and legal status, civil and criminal justice, early care and education, training and employment, income support, health care, and housing and zoning (Schroeder et al., 2002).

## Conclusion

*Intellectual disability* is the currently preferred term for the disability historically referred to as *mental retardation*, and the authoritative definition and assumptions promulgated by the AAIDD (previously the AAMR) remain the same. The term *intellectual disability* covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability, and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.

The fact that the construct of intellectual disability belongs within the general construct of disability helps one understand why the term *intellectual disability* has emerged as a preferred term to replace *mental retardation*. The term *intellectual disability* (a) reflects the changed construct of disability proposed by AAIDD and WHO; (b) aligns better with current professional practices that are focused on functional behaviors and contextual factors; (c) provides a logical basis for individualized supports provision due to its basis in a social–ecological framework; (d) is less offensive to persons with disabilities; and (e) is more consistent with international terminology.

We anticipate that discussions will continue in an attempt to further refine the construct of intellectual disability, improve the reliability of diagnosis, and better understand these aspects of human functioning: the nature of intelligence, adaptive behavior, and disablement. In addition, the field will continue to examine the relationships between people with intellectual disability and other defined

groups (such as those with learning disability, developmental disability, and traumatic brain injury); the provision of individualized supports to enhance individual functioning; the impact of the consumer and reform movements on the field; the effects of terminology upon peoples' lives; and the impact of an increased understanding of the biomedical, genetic, and behavioral aspects of the condition (Luckasson, 2003; Schalock & Luckasson, 2004; Switzky & Greenspan, 2006a). At this time and for the foreseeable future, the definition and assumptions of intellectual disability/mental retardation remain those promulgated by AAMR in 2002; the term, however, is changed to *intellectual disability*.

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**Appendix A**
**Historical Definitions of *Mental Retardation* as Formulated by the American Association on Mental Retardation (AAMR) and American Psychiatric Association (APA)**
**American Association on Mental Retardation:**

1959 (Heber): Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in one or more of the following: (1) maturation, (2) learning, (3) social adjustment. (p. 3)

1961 (Heber): Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior. (p. 3)

1973 (Grossman): Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period. (p. 1)

1983 (Grossman): Same as 1973. (p. 1)

1992 (Luckasson et al.): Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, *existing concurrently with* related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (p. 1)

2002 (Luckasson et al.): Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. (p. 1)

**American Psychiatric Association (Diagnostic and Statistical Manuals)**

1968 (*DSM-II*): Mental retardation refers to subnormal general intellectual functioning which originates during the developmental period and is associated with impairment of either learning and social adjustment or maturation, or both. (These disorders were classified under "chronic brain syndrome with mental deficiency" and "mental deficiency" in *DSM-I*.) (p. 14)

1980 (*DSM-III*): The essential features are: (1) significantly subaverage general intellectual functioning, (2) resulting in, or associated with, deficits or impairments in adaptive behavior, (3) with onset before the age of 18. (p. 36)

1987 (*DSM-III-R*): The essential features of this disorder are: (1) significantly subaverage general intellectual functioning, accompanied by (2) significant deficits or impairments in adaptive functioning, with (3) onset before age of 18. (p. 28)

1994 (*DSM-IV*): The essential feature of mental retardation is significantly subaverage general intellectual

functioning (Criterion A) that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety (Criterion B). The onset must occur before age 18 years (Criterion C). Mental retardation has many different etiologies and may be seen as a final common pathway of various pathological processes that affect the functioning of the central nervous system. (p. 39)

2000 (*DSM-TR*): Same as 1994. (p. 41)

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## Appendix B

### Age of Onset Criterion

Tredgold (1908): A state of mental defect from birth, or from an early age, due to incomplete cerebral development. (p. 2)

Tredgold (1937): A state of incomplete mental development. (p. 4)

Doll (1941): A state of social incompetence, obtained at maturity, or likely to obtain at maturity, resulting from developmental arrest of constitutional origin. (p. 215)

Heber (1959; 1961): . . . which originates during the developmental period (i.e., birth through approximately 16 years). (p. 3)

Grossman (1973): . . . manifested during the developmental period (upper age limit at 18 years). (p. 11)

Grossman (1983): . . . manifested during the developmental period (period of time between conception and the 18th birthday). (p. 1)

Luckasson et al. (1992): Mental retardation manifests before age 18. (p.1)

Luckasson et al. (2002): This disability originates before age 18. (p. 1)

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## Appendix C

### Cut-Off Criteria Associated With Establishing the Condition's Boundaries

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#### Intellectual Functioning Cut-Off Criteria

1959 (Heber): Less than one standard deviation (*SD*) below the population mean of the age group involved on measures of general intellectual functioning. (p. 3)

1961 (Heber): Greater than one *SD* below the population mean. (p. 3)

1973 (Grossman): Two or more *SDs* below the population mean. (p. 11)

1983 (Grossman): IQ of 70 or below on standardized measures of intelligence; upper limit is intended as a guideline and could be extended to 75 or more. (p. 11)

1992 (Luckasson et al.): IQ standard score of approximately 70 to 75 or below based on assessment that includes one or more individually administered general intelligence tests. (p. 5)

2002 (Luckasson et al.): Approximately two *SDs* below the mean, considering the standard error of measurement for the specific assessment instruments used and the instruments' strengths and limitations. (p. 58)

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#### Adaptive Behavior Cut-Off Criteria

2002 (Luckasson et al.): Performance that is at least two *SDs* below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, or practical, or (b) an overall score on a standardized measure of conceptual, social, and practical skills. (p. 76)

# **APPENDIX**

## **TAB C**

# Perspectives

## Characteristics and Needs of People With Intellectual Disability Who Have Higher IQs

**Martha E. Snell and Ruth Luckasson, With Sharon Borthwick-Duffy, Val Bradley, Wil H. E. Buntinx, David L. Coulter, Ellis (Pat) M. Craig, Sharon C. Gomez, Yves Lachapelle, Alya Reeve, Robert L. Schalock, Karrie A. Shogren, Scott Spreat, Marc J. Tassé, James R. Thompson, Miguel A. Verdugo, Michael L. Wehmeyer, and Mark H. Yeager**

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This is the fourth article in a series of articles from the Terminology and Classification Committee of the American Association on Intellectual and Developmental Disabilities (AAIDD). The intent of these articles is to communicate the organization's thoughts on critical issues associated with terminology, definition, and classification in the field of intellectual disability and to stimulate discussion from the field relevant to the 11th edition of AAIDD's *Diagnosis, Classification, and System of Supports Manual* (working title). In the first article (Schalock et al., 2007), we explained the reasons for shifting from the term *mental retardation* to the preferred term *intellectual disability* and stated that the two terms refer to the same group of people. In the second article (Wehmeyer et al., 2008), we distinguished between operational and constitutive definitions of intellectual disability and discussed their application to understanding the construct underlying the term intellectual disability. Although operational criteria for diagnosis have been generally consistent for the past 35 years, the construct underlying the term intellectual disability (and, thus, the constitutive definition of intellectual disability) has changed significantly due to the impact of the social–ecological model of disability. In this model, intellectual disability is understood as a multidimensional state of human functioning in relation to environmental demands. The third article (Thompson et al., 2009) focused on the supports and support needs of persons with intellectual disability. This article suggested that (a) supports can be conceptualized as a bridge to more meaningful life experiences and personal outcomes, (b) the support needs of individuals

can be considered within models of human functioning, (c) a five-component process for individualized supports planning can guide the work of planning teams, and (d) supports planning can be differentiated from other planning approaches used in the field of intellectual disability.

In this fourth article, we describe the group of individuals with intellectual disability and higher IQs and the challenges that they face in life. Individuals with an intellectual disability who have higher IQs struggle in society. This is true despite the fact that all individuals with intellectual disability typically demonstrate strengths in functioning along with relative limitations. This group of people with intellectual disability who have higher IQs constitute about 80% to 90% of all individuals with intellectual disability. (*Intellectual disability* is used to address the same population of individuals as the term *mental retardation* [Schalock et al., 2007].) Frequently, there are no identifiable causes for the disability. Most of these individuals are physically indistinguishable from the general population because no specific physical features are associated with intellectual disability at higher IQs. Similarly, unlike in the case of certain genetic “behavioral phenotypes,” no definite behavioral features are specifically associated with intellectual disability with higher IQs. Personalities also vary widely, as in the rest of the human population: Some individuals with intellectual disability are passive, placid, and dependent, whereas others are industrious, cooperative, appropriately assertive, or even aggressive and impulsive. There is considerable variation in the lifestyle outcomes achieved by adults with intellectual disability who have higher

IQs. Whereas many of these individuals “living ‘independently’ predictably will need support in relation to specific issues” (e.g., housing, employment, transportation, health services; Stancliffe & Lakin, 2007, p. 443), some individuals in this group “may develop homes and home lives independent of a formal agency support once the time comes for them to live separately from their families” (Felce & Perry, 2006, p. 410). These documented outcomes contrast sharply with the incorrect stereotypes that these individuals cannot have friends, jobs, spouses, or children or be good citizens.

People in this group primarily are identified when they are in school, because school demands place their intellectual and adaptive behavior limitations in clear relief and because schools have funding, bureaucracy and management systems (albeit imperfect), and a legal obligation to identify disabilities in all children. However, beyond school age, when activities may be less “intellectual,” bureaucracies do not routinely identify people having problems because of intellectual limitations (Campbell & Fedeyko, 2000), and needed services and supports are unavailable or rejected. As a result, these people continue to experience significant difficulties achieving success or even a healthy existence in adulthood.

Frequently, the gap between their capabilities and the demands from their environments grows as they leave school, as society becomes more complex, and as the standards for successful adulthood climb. Well-designed individualized supports can help bridge the gap between capabilities and demands, but the reality is that many of these individuals do not have access to needed supports. Thus, life’s demands frequently impose overwhelming challenges to those who live with significantly limited intellectual ability and adaptive behavior.

In this article, we describe the group of individuals with intellectual disability and higher IQs and discuss how individuals in this group are delineated depending on which classification system is used. In addition, we explore how intellectual limitation exists along a continuum, revealing many similarities in human-functioning limitations between individuals on either side of the definitional dividing line. That is, individuals with intellectual disability and higher IQs (slightly below the ceiling of approximately 70–75) share much in common with individuals without a diagnosis of intellectual disability, whose function-

ing is sometimes referred to as *borderline*: Individuals who do not have intellectual disability but who have low IQs, above the ceiling of approximately 70–75. Last, we reiterate the critical importance of creating accessible, individualized supports.

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## Classification Systems and Intellectual Disability

All people with intellectual disability, including those with higher IQs, belong to a single disability group (people with intellectual disability). However, the application of various classification systems to subdivide the group leads to somewhat different ways of understanding these individuals and their needs. Classification systems based on relevant criteria should be selected by clinicians and others for specific professional purposes that in some way benefit the individuals who are classified. For example, service providers may choose classification systems that subdivide the group of people with intellectual disability into smaller groups based on support needs, such as using the Supports Intensity Scale (Thompson et al., 2004) assessment to classify individuals by the intensity of their support needs. Physicians and geneticists may subdivide the group based on their etiology (e.g., genetic classification systems), whereas psychology and education researchers sometimes subdivide the group by IQ or adaptive behavior score bands (e.g., the mild, moderate, severe, profound classification system).

Each of these sortings, however, should cause individuals with intellectual disability with higher IQs to emerge into clearer view, albeit in slightly different ways. The variety of classification systems that are based on different criteria may partially account for why this group historically has had so many different names. Earlier names, most of which now are highly stigmatizing (e.g., feeble-minded, moron, “moral idiots” [Trent, 1994, p. 20]), were followed by new names taken from then-current definitions or classification systems (e.g., educable mental retardation and mild mental retardation) or names reflecting periods challenging particular characterizations of this group or an expansion of this group: for example, the “six-hour retarded child” (PCMR, 1969), students with “general learning disability” (MacMillan, Siperstein, & Gresham, 1996), and the “forgotten generation” (the combined group of people with intellectual

disability with higher IQs and people without intellectual disability but with lower IQs, whose IQs are just beyond the intellectual disability range; Tymchuk, Lakin, & Luckasson, 2001). In general, the names have followed from the classification system or purpose for classifying.

Whatever classification system is used, however, it is critical to point out that the challenges faced by individuals with intellectual disability who have higher IQs are significant, and these challenges are similar in many ways to the challenges faced by the group of people with slightly higher IQs (a) who may not be officially diagnosed as having a disability or meet diagnostic criteria for intellectual disability, but (b) who share many limitations in functioning with individuals with intellectual disability who have higher IQs and do meet these criteria. Edgerton (2001) lamented the societal and professional abandonment of these individuals: “Perhaps the most sobering realization is that the majority of these individuals [former “six-hour retarded children”] are not cited in the research literature nor are they known to the mental retardation/developmental disabilities service delivery system” (p. 3).

In some ways, it may seem counterintuitive to consider the challenges of individuals with intellectual disability with higher IQs as being equal to or sometimes greater than those with intellectual disability at lower IQs. However, several factors aggravate their challenges: Expectations for performance are higher for people with intellectual disability with higher IQs than those with lower IQs, the tasks given to them are more demanding because of the higher expectations, and a failure to meet those expectations is frequently met by others blaming the individual or the individual blaming him- or herself. Moreover, many individuals with intellectual disability with higher IQs attempt to hide their disability or attempt to pass as normal or try to appear intellectually capable and, thus, miss out on or even reject accommodations that might have been available if their disability had been declared or identified. In addition, the impact of intellectual disability may be increased by the lack of access to needed mental health care, medical care, nutrition, and relationship and parenting assistance. Society’s increasing lack of neighborly care for one another may hit people with intellectual disabilities in poorer neighborhoods especially hard. It is clear that only individualized needs assessment will lead to understanding the

unique challenges faced by a person with intellectual disability, whether he or she has a higher or lower IQ.

To further describe the challenges faced by many individuals with intellectual disability with higher IQs, we address (a) areas in which societal threats are especially marked (e.g., education, socioeconomic status, employment, and housing) and (b) the often inadequate response systems of individuals with intellectual limitations that increase their vulnerability in everyday life.

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## Everyday Lives of People With Intellectual Disability With Higher IQs

### *Societal Issues*

The lifelong experience of having reduced intellectual and adaptive abilities creates a vulnerability that is shared among members of this group. As adults, these individuals have limited academic skills, are often poor, are underemployed or unemployed, and tend to not live independently.

*Education.* The trend in national figures, as traced by Polloway, Lubin, Smith, and Patton (in press) over the past 25 years, indicates little overall variability in the percentage of the school-aged population identified as receiving special education services under the category of “mental retardation” (0.9%), but great variability from state to state. Polloway et al. suggested that slightly more than half of the 0.9% of the school-aged population receiving special education (or 0.5%) should be classified as having mild mental retardation, that is, intellectual disability with higher IQs. (In this section we use the term “mental retardation” because the U.S. Department of Education [2007] and most state departments of education still use this term in place of intellectual disability.)

Several important national trends are described by Polloway et al. (in press). First, compared with all other disability groups, children and adolescents with mental retardation spend the most time in separate classrooms, away from their peers in general education: 51.8% of students receiving special education services under the category of mental retardation versus 18.5% of students in any categorical area. During the 1990s, national rates for the inclusion of these students in general education increased from 27.3% to 44.7%, whereas rates for separate setting placement decreased from 72.7% to 55.3% but with great variability among

states (Williamson, McLeaskey, Hoppey, & Rentz, 2006). As of the late 1990s, national placement trends reached a stable plateau, but these trends continue to be highly variable across states (Williamson et al., 2006).

Second, federal data (U.S. Department of Education, 2007) also indicate a 3:1 ratio of being identified with mental retardation for African American students in contrast to Caucasian students. Disproportionality is greater for African American students than for any other ethnic group. In addition, African American students have a higher probability of being categorized by schools with the label of mental retardation than being categorized with any other high-incidence disability. Findings by Skiba, Poloni-Staudinger, Gallini, Simmons, and Feggins-Azziz (2006) and others (Fierros & Conroy, 2002; U.S. Department of Education, 2007) pointed clearly to this disproportionality: 11% of the school population are African Americans, but more than 29% of students served under the category of mental retardation are African American. Many factors have been proposed as contributors to the disproportionate number of African American students in special education; these factors include poverty, racism, special education decision-making processes, test bias, unequal opportunity in general education (educational resources, number of African American teachers, etc.), school discipline, and disconnect between school culture and African American culture (Mercer, 1973; Skiba et al., 2008).

Third, although drop-out rates are generally high for all students with disabilities (recent average of 33.6% across disability groups), Polloway et al. (in press) reported that during the 2002–2003 school year, these rates decreased slightly, with 28.6% of students with mental retardation leaving school early. Last, recent federal data show that only 2% of students with mental retardation are “declassified” from special education, a figure that is lower than for students with learning disabilities (9%) or emotional disturbance (10%). Thus, summarizing these national trends, students served in the category of mental retardation compared with other high-incidence disability categories spend the majority of their school day in separate classrooms, tend to receive special education services and remain categorized longer, and are 25% more likely to be African American and 33% more likely to drop out before finishing school. Even with these educational system problems,

many students and their families thrive while in school, only to suffer insurmountable odds when they leave school and face service discontinuity at best or, more likely, a total lack of needed supports.

*Socioeconomic status.* Fujiura’s (1998, 2003) research revealed a significantly reduced income for families of all types with a member with intellectual disability–developmental disabilities than for families in the general population; within single-parent households, this contrast was even greater (Fujiura, 1998, 2003; Lewis & Johnson, 2005). The proportion of single-parent households among those with intellectual disability–developmental disabilities is twice that of U.S. family households, with the great majority being headed by women; the economic disadvantage in these households was found to be large (Fujiura, 2003). Compared with nondisabled peers or peers with most other disabilities, youths with intellectual disability who were several years out of high school were found to have almost no successful experience with credit cards or charge accounts and only 1 in 10 had a checking account (Wagner, Newman, Cameto, Garza, & Levine, 2005). In contrast to the majority (two thirds) of youths with other disabilities who showed an increase in having drivers’ licenses at this same age, only a minority of youth with intellectual disability with higher IQs had either drivers’ licenses or permits. These limitations, related both to a disadvantaged socioeconomic status and cognitive limitations, can be significant barriers to increased self-sufficiency.

*Employment.* Wagner, Newman, Cameto, Garza, and Levine (2005) found that youths with intellectual disability are less likely than youth with learning disabilities to get a job, but they are far more successful getting jobs than youths with visual or orthopedic disabilities. Young adults with intellectual disability greatly improve in employment 2 years out of high school, although African American youth with any disability are significantly less likely to be employed at this time than Caucasian youth with any disability. Two years out of high school, hours, pay-rate, and the type of jobs held by all youth with disabilities tend to improve, with a significant decline in personal care jobs and an increase in trade jobs like plumbing and carpentry. Other commonly held jobs include maintenance, food service, and retail positions.

Although it is true that people with intellectual disability with higher IQs are more likely to be employed than people with intellectual disability

with lower IQs, their employment rate (27.6%) is far below the national average in the general community (75.1%) and more often consists of part-time work, in entry-level service jobs, with low wages and minimal benefits (Yamaki & Fujiura, 2002). Transportation to get to work and back home continues to be a primary difficulty. Stancliffe and Lakin (2007) reported that the median income for this group “was 20% below the poverty threshold and about one-third of the median total income of the general population” (p. 437). Despite these bleak statistics, there is optimistic evidence that many of these people with intellectual disability with higher IQs can be gainfully employed in the community when given adequate training and on-the-job supports (Mank, 2007) and when they are supported to become more self-determined (Wehmeyer & Palmer, 2003)—that is, when they learn to assume more autonomy and make more personal choices in their lives.

*Housing.* The majority of youth with disabilities (including intellectual disability) still live at home 2-years post-high school (Wagner et al., 2005). Compared with the general U.S. population, the income level of people with intellectual disability living on their own or with roommates is below the poverty level. “These individuals are simply too poor to afford even the most modest rental housing” (O’Hara & Cooper, 2005, as cited in Stancliffe & Lakin, 2007, p. 436). Although flexible housing supports exist for people with intellectual disability (e.g., rental assistance under Section 8 voucher programs from the Department of Housing and Urban Development), waiting lists are excessive and the application process is particularly challenging to these individuals (Galbraith, 2001). Compared with adults with disabilities other than intellectual disability, people with intellectual disability have lower rates of living independently (Blackorby & Wagner, 1996; Luftig & Muthert, 2005). Although more women with intellectual disability with higher IQs live independently than do men in the same category, this finding appears related to a higher marriage rate in these women than in men with intellectual disability (Blackorby & Wagner, 1996; Richardson & Koller, 1996). In other independent living areas, women with intellectual disability have less positive outcomes than do men in the same category (Rouso & Wehmeyer, 2001). For adults with intellectual disability who use disability services,

Gardner and Carran (2005) reported low rates of independent living, a fact that may be related to the greater needs these individuals have and/or to service providers who find a lower risk for supporting individuals in group homes than in semi-independent settings. “People [with intellectual disability] in the formal service system live in more supervised environments than peers with similar abilities who are outside this system” (Stancliffe & Lakin, 2007, p. 434).

*Health.* People with intellectual disability and higher IQs tend to have higher rates of obesity, poorer nutrition, and are hospitalized more often and for longer periods than are adults with no intellectual disability (Stancliffe & Lakin, 2007). Health-related challenges for these individuals include accessing health services, affordability, transportation to services, communicating health problems to medical personnel, identifying their disability and their need for support in following health treatments, and inadequate or nonexistent medical histories (Spitalnik & White-Scott, 2000). Despite these problems, appropriate health supports can make a positive difference in healthy lifestyles (Stancliffe & Lakin, 2007).

*Friendships and social behavior.* Greater loneliness in adults with intellectual disability with higher IQs was reported when individuals lived in larger residences and expressed fear about their living condition, whereas less loneliness was reported when people liked where they lived and reported more social contact (Stancliffe et al., 2007). Boys with intellectual disability with higher IQs have been reported to exhibit antisocial and delinquent behaviors more frequently than their male peers without intellectual disability (Douma, Dekker, Ruiter, Tick, & Koot, 2007). Despite these findings, behavioral interventions for challenging behavior have been demonstrated as being effective with this same group (Didden, Korzilius, van Oorsouw, & Sturmey, 2006).

*Family well being.* Similar to their peers without disabilities, a large majority of youth with intellectual disability (89%) were reported to be single 2 years after leaving high school (Wagner et al., 2005). Annual incomes of those who were married or living with a partner were \$5,000 or less. Few of these people receive the social–sexual teaching that might assist them in their personal lives. Attempts to establish an intimate relationship with another person are often met with restrictions and fear (Walker-Hirsch, 2007).

In a study analyzing where people with intellectual disability live in developed countries (e.g., U.S., Canada, Australia, Wales, England), Braddock and his colleagues found that the vast majority of children and a substantial fraction of adults with intellectual disability lived with their family rather than on their own or with others (Braddock, Emerson, Felce, & Stancliffe, 2001). In a survey of adults with intellectual and developmental disabilities, Brown, Renwick, and Raphael (1999) found that 46% lived with their families. When they do establish families of their own, it is well documented that families in which one or both parents have cognitive disabilities face greater challenges than other families in raising their children; however, positive outcomes can be enhanced if they receive appropriate supports to navigate adult living, maintain their family, and protect, support, and guide their children (Tymchuk, 2006).

*Rights.* The ability to know one's rights and make those rights a reality depend on civic education and access to stable and knowledgeable advocates. The limitations in education described earlier result in many people who never have the opportunity to learn about democracy or rights with their classmates. A tendency by these individuals to deny their intellectual disability and reject services associated with intellectual disability may mean that their rights to supports or to just treatment are not exercised.

Stancliffe and Lakin (2007) identified the additional support needs experienced by a significant subset of this group: guaranteeing justice for those "caught up in the justice system" and educating the police, lawyers, and judges who work with these individuals so that needed accommodations can be made (e.g., fair questioning). Very few legal resources exist for people with disabilities who do not have the finances or wherewithal to hire a private lawyer.

Current research emphasizes the all-encompassing effects of poverty and unemployment on the lives of people with intellectual disability who are living independently (Stancliffe & Lakin, 2005). These research findings emphasize several influential characteristics of everyday living that often have a "tipping effect" on their individual lives and around which supports should be designed: (a) having a reasonable income and ongoing employment, (b) circumventing the restrictive and potentially stigmatizing regulations for acquiring social

services, (c) accessing inexpensive transportation, and (d) obtaining affordable housing.

### *Social Judgment Challenges*

Many researchers have found that individuals with intellectual disability with higher IQs are vulnerable to risks due to their sometimes inadequate response systems, interpersonal competence, social judgment, or decision-making skills (Greenspan, 2006a, 2006b; Khemka & Hickson, 2006; Nettlebeck & Wilson, 2001; Patton & Keyes, 2006; Spitalnik & White-Scott, 2000). These challenges are linked to reduced intellectual and adaptive abilities that make it difficult to problem solve and to be flexible in thinking; both limitations create a susceptibility to dangers that is shared among members of this group (Greenspan, 2006a). Some have argued that some aspects of these characteristics may represent a socialization process and may sometimes be viewed as adaptive responses to stigmatizing and deficient environments (Bogdan & Taylor, 1994; Goffman, 1961). It is likely that both processes are involved (reduced abilities and adaptation to one's life circumstances) in these susceptibilities and vulnerabilities.

For some people in this group, these social judgment challenges may mask their disability temporarily, but ultimately these characteristics can contribute to their vulnerability. Research supports intervention to counter these characteristics, such as teaching appropriate interactions and self-managing conversations with typical peers (Carter & Hughes, 2007). Special educators and parents typically work with these individuals during the school years to teach suitable interpersonal relations, caution with strangers, and social skills while encouraging them to dress, talk, and act like their peers. Still, there is a scarcity of effective interventions regarding social judgment by adolescents with intellectual disability that effectively prevent abuse by acquaintances or strangers (Nettelbeck & Wilson, 2001) or that teach motivation-based decision making at a developmentally appropriate level (Khemka & Hickson, 2006).

Next, we describe four contributors to inadequate social responding and judgment in individuals with intellectual disability who have some verbal and social skills: denial, a desire to please, gullibility, and naiveté or suggestibility.

*Denial or a necessity for passing.* This factor was originally referred to by Edgerton (1967) as putting on the "cloak of competence." Starting in 1960,

Edgerton followed 110 adults who had been deinstitutionalized from Pacific State Hospital in Los Angeles between 1949 and 1958. This longitudinal study found that before being institutionalized, many of these individuals were told, in the terms of the era, that they had deficient intelligence (even though some may not have fit today's definition of intellectual disability); once in the institution, they had opportunities to enhance their damaged self-esteem by differentiating themselves from others with more extensive intellectual disability who also resided there, by forming friendships with individuals like themselves, and by feeling accepted by some employees. Deinstitutionalization presented them with a strong motivation to explain their hospitalization as due to "nerves," surgery, alcoholism, and so forth, and to deny the stigma of the label of intellectual disability. Although "passing for normal" was motivated by an attempt to avoid the prior stigma of being identified as "retarded," after leaving the hospital and returning to the real world, many of these individuals struggled with the presence of their incompetence.

Today's motivation for denial by individuals with intellectual disability can come from attempting to avoid the possibility of being placed in self-contained, special education classrooms that are separated from the other students in the school or from being associated with activities or services that are openly linked to individuals with intellectual disability. Thus, denial of disability can emphasize one's social isolation and restrict learning opportunities, but may appear to many people with intellectual disability and their families as a way to reduce the stigma they experience. This denial of limitations may be accompanied by the tendency to exaggerate one's abilities. Individuals with intellectual disability may go to great lengths to hide their limitations, consuming significant effort to attempt to appear as their often-mistaken image of competent (Perske, 2005).

*Desire to please.* People with intellectual disability tend to do what others want in an effort to be accepted or liked by them. This can lead to agreeing to do something risky or inappropriate to please another person (e.g., exaggerating one's own accomplishments, making false confessions by saying things that the individual thinks police want to hear). In stressful situations or under pressure, an individual may acquiesce, due at times to a desire to please, or because of inexperience,

communication limitations, or fear. Although this trait of overfriendliness can be an asset (it creates a helpful attitude and a pleasant personality with trustworthy individuals), when coupled with gullibility or limited decision making and untrustworthy people, this trait can result in agreeing without understanding and thereby may increase an individual's vulnerability (Greenspan, Loughlin, & Black, 2001; Khemka & Hickson, 2006).

*Gullibility.* This characteristic, often identified as a cardinal feature of intellectual disability, includes occurrences of being successfully fooled, tricked, or lied to by others (Greenspan, 2006b). When individuals with intellectual disability are gullible, it may result in their being taken advantage of, being made fun of without realizing it, or being talked into doing things without understanding the potential consequences (e.g., participating in a practical joke but being left with the blame, confessing to crime they did not commit; Patton & Keyes, 2006).

*Naiveté–suggestibility.* This trait appears to others as being overly trusting of others, immature, innocent, or inexperienced. For example, an individual might believe or agree to what someone says with little or no question, particularly if that person is in a position of power. The person with intellectual disability tends not to see or to understand the fine points, nuance, or subtlety of novel or complex social situations and behavior. When in settings with predictable routines and trusted people, this characteristic is less visible. Individuals exhibiting this trait have a tendency to quickly look to others for guidance due to their difficulty understanding a situation and their frequent history of failure in novel situations. This trait may result in making poor choices. The combination of suggestibility and gullibility may increase one's risk of making poor decisions.

The underlying cognitive challenges of having limited intelligence play havoc with ordinary mental processes and may result in having difficulties making sense of the world through consistent, reliable, socially mature levels of planning, problem solving, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience. However, research has demonstrated that systematic, formal instruction can sometimes improve these abilities in some environments, if provided early and consistently and with appropriate supports that are available as needed (e.g., Browder, 2007; Carter & Hughes, 2007; Snell,

2007). However, as Greenspan discussed (2007, p. 5) “[E]ven in situations where the warning signs are evident and the consequences of a bad decision are potentially serious,” an individual with significant cognitive limitations (intellectual disability with a higher IQ) may be unmindful of risk. The motivation to deny his or her disability or to please others can further distract an individual from being objective or alert to reality, thus contributing to poor decision making.

We believe that these potential features of inadequate social responding are not limited to people with intellectual disability who have higher IQs but are evident in most individuals with intellectual disability with lower IQs who have some verbal abilities as well as in many individuals who do not technically fit the diagnosis of intellectual disability but who have significantly lower IQs. However, these traits appear to be expressed more consistently and overtly in people with intellectual disability (Khemka & Hickson, 2006) because of their limited intellectual abilities. It is crucial not to stereotype this heterogeneous group; certainly not all people in this group are victimized, particularly not those who have sustained, positive family support. However, many people with intellectual disability and higher IQs are not in the service system and, thus, do not have access to professionals who could assist them in learning to avoid victimization and provide help if victimization occurs.

Some researchers have explained these potential traits in part as being less due to a disorder of learning and more due to a disorder of thinking (Greenspan, 2002). For example, many people with significantly limited intellectual ability and adaptive behavior may be competent learners in some supported settings in which learning is strategically and formally designed and appropriate supports are provided, especially in settings with regular routines (e.g., schools in which good special education supports are provided). Actual or relative strengths often coexist in an individual with intellectual disability. With the right supports, functional academic skills can be learned (e.g., purchasing items with the correct amount of money, using a telephone or cell phone, reading a paper to identify what is playing when at theaters) and everyday survival skills can be mastered (e.g., taking the right bus to get to a destination, knowing when to be friendly and with whom). Not all people with intellectual disability demonstrate inadequate social responding all the time; appropriate sustained supports help reduce the

likelihood that problems will result from these tendencies. Coupled with this, these individuals often have some awareness of their own limitations compared with others and are motivated to be socially accepted. Their challenges arise from “developmentally based abnormal brain structure or functioning” (Greenspan, 2006, p. 182), leading to difficulty in flexibly applying what they know, “coming up with solutions to real-world problems” (p. 182), and doing so in new and ambiguous situations. Life’s expectations frequently impose overwhelming challenges for many people with intellectual disability when they confront unpredictable and demanding settings that may be socially confusing or coercive. These same individuals appear more comfortable and successful in predictable and familiar surroundings. For these reasons, individuals with intellectual disability are exceedingly vulnerable (socially, academically, practically) unless they are given formal or informal supports and systematic backup protections. As Greenspan noted, “The essence of MR [intellectual disability], from the standpoint of definition and diagnosis, is thus found not in the relative absence of especially routine skills but in the relative inability, especially under conditions of ambiguity or stress, to figure out when and how to apply those skills” (p. 176).

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### Struggling to Survive Outside a Supports Framework

A “person’s support needs reflect a limitation in human functioning as a result of either personal capacity or the context in which the person is functioning” (Thompson et al., 2009, p. 136). Thompson et al. described the need for supports in individuals with intellectual disability as an enduring rather than a temporary characteristic. Identifying a person’s specific support needs poses a challenge, as these needs are many times not directly observable but must be inferred from indirect assessment and self-report. Individuals with intellectual disability “are people who require the provision of ongoing, extraordinary (when compared to their nondisabled peers) patterns of support” (p. 137). When those supports are made available to individuals with intellectual disability, there are two outcomes: (a) Their functioning in typical life activities in mainstream settings is enabled, but (b) their improvement does not remove the possibility that they will persist in needing ongoing supports.

Individualized supports make it possible for people with intellectual disability to function with some success in everyday life. “Put another way, if supports were removed, people with intellectual disability would not be able to function as successfully in typical activities and settings” (p. 137).

The five-step process that Thompson et al. (2009) described for planning individualized supports starts with person-centered planning to identify what is important to a person, with discussions “not constrained by available services or by perceived barriers such as fiscal restrictions or limitations in a person’s skills” (p. 140). Stancliffe and Lakin (2007) and others also have argued that need-based resource allocation should be applied to all individuals with intellectual disability so that resources and supports are individualized to suit needs. Others have also emphasized the importance of personal choice when identifying supports for social interactions and living and working in the community (Felce & Perry, 2007; Mank, 2007). Needs-based resource allocation depends not only on reliable assessment of needs but a continuous match between an individual’s needs and preferences and the supports provided. Consistent with this process, Breihan (2007) recently reported that U.S. adult service agencies have dramatically improved in their offering of choices of care providers to young adults with intellectual disability, with 7 states offering unlimited individual choice, 34 offering restricted individual choice, and only 9 states still dictating the care provider. Despite these improvements, most service systems suffer from (a) high staff turnover due to low pay, (b) limiting needs-based individual funding to only new recipients with intellectual disability, and (c) providing paid supports through a traditional facility-based service system that determines from averaged service costs for groups of people in specific locations. “Such funding is rarely flexible, individually tailored, or portable, because it is not associated with specific individuals or their needs” (Stancliffe & Lakin, 2007, p. 440).

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### **A Call for a Supports Framework That Spans IQ Limitations**

#### *Rationale for a Continuum of Intellectual Disability*

AAIDD includes all individuals with intellectual disability who meet the diagnostic criteria

under one term—Intellectual Disability. To divide this group into classification subgroups, according to needs for supports, is accomplished with a classification system such as the Supports Intensity Scale (Thompson et al., 2004). We reason that it is not warranted to develop separate *diagnoses* or labels for individuals with intellectual disability with higher IQs or for those with intellectual disability with lower IQs (as stated earlier, however, subdividing according to a specific *classification* system may be warranted). Intellectual ability is a core metric for assessing and describing individuals with intellectual disability. By definition, all individuals with intellectual disability have significantly impaired intellectual abilities and adaptive behavior; whether at higher IQ or lower IQ, all individuals with intellectual disability fall within the definition. The characteristics emerging from significantly impaired intellectual abilities are shared by the entire group of individuals. This universal characteristic of individuals with intellectual disability however does not mean that they all have similar needs, nor does it deny the existence of actual or relative strengths in individuals with the disability.

Once an individual’s IQ is known (which was essential for the diagnosis) nothing further is gained by classification of that IQ score into an IQ band or range. We already recognize the potential error involved in accurately diagnosing intellectual disability, with its grounding in IQ and adaptive behavior assessment and its “cut off” of two standard deviations below the mean, factoring in standard error. To attempt to create different diagnostic criteria for the already small group of individuals with intellectual disability, and to separate and identify them into diagnostic groups (mild intellectual disability and moderate intellectual disability, for example) is not supported and may introduce additional error. This notion of separate diagnoses would take us backwards to the incorrect stereotype that individuals with intellectual disability with higher IQs have “mild” needs, and those with lower IQs have “profound” needs, neither of which provides any specificity for designing individualized supports. Work to improve diagnosis, classification, and systems of supports must continue, however, and it may be useful to have a variety of functional classification systems from which clinicians may choose given that the clinician: (a) has specified a particular purpose for classifying, and (b) has matched the purpose to the

attributes of the classification system. Classification systems should be responsive to explicit purposes for categorizing individuals with intellectual disability into subgroups.

### *Nature of the Intellectual Disability “Cut Off”*

As described earlier in this article, individuals who fall outside the category of intellectual disability, whose functioning is sometimes referred to as *borderline* (people with IQs slightly above the ceiling of approximately 70–75) share much in common with individuals diagnosed with intellectual disability who have higher IQs (slightly below the ceiling of approximately 70–75). They share many of the challenges and vulnerabilities that make life difficult for people with intellectual disability. The President’s Committee on Mental Retardation (PCMR; now the President’s Committee for People with Intellectual Disabilities [PCPID]), in its 1999 *Report to the President*, referred to this combined vulnerable group of people who have “mild mental retardation” and borderline disability as “the forgotten generation” or people with “mild cognitive limitations.” Despite their functional limitations, this group of people may not access services because they do not qualify for a *disability* label or because they may not seek services for the same reason as individuals with intellectual disability with higher IQs (e.g., stigma, difficulty in navigating the social service system, and so forth). The PCMR identified many challenges facing this group that, despite the lack of an intellectual disability diagnosis, are similar to those faced by individuals with intellectual disability with higher IQs. These challenges are listed in the Appendix.

### *Respect for All People Along the Continuum of IQ Limitations*

Many of the problems of individuals with limited intellectual ability are exacerbated by societal contexts in which there is generalized lack of understanding by other people. Along with this lack of understanding, there is often concomitant lack of respect or even presence of fear. Thus, people with intellectual limitations go through life both misunderstood and disrespected. Formation of attitudes begins during the school years, with most youth attaining their understanding of individuals with intellectual disability not through direct contact but through secondary sources (the media and conversations with parents or teachers). With

less than 11% of students with intellectual disability fully included in general education classes across the United States (Smith, 2007), the opportunity for interpersonal interactions to occur between these students and their nondisabled peers are minimal. Findings reported by Siperstein, Parker, Bardon, and Widaman (2007) on the attitudes of a large national sample of middle school students toward inclusion of students with intellectual disability sadly affirmed prior research that ordinary people hold negative perceptions of the competence of people with intellectual disability. Typical middle school children were found to have minimal contact with their peers with intellectual disability; to not desire social interactions with them, especially out of school; to view them as being “moderately impaired” or less competent than their “mild impairments”; and to believe that inclusion should be limited to nonacademic classes because of potentially negative effects.

Merely increasing inclusion under our current education policies would likely not yield any improvements in peer attitudes; current school practices do not systematize shared responsibility to serve the needs of all children with disabilities, from the preparation of general and special education teachers, principals, and superintendents to the ways we organize schools and funding and address student performance accountability (Smith, 2007). However, Siperstein and his colleagues (2007) advised that there is clear evidence that attitudes toward individuals with intellectual disability can be changed in positive directions but not without a lot of effort; the key to attitude change lies in “finding ways for youth to witness the competence of people with intellectual disability” (p. 453).

### *Fit Between Human Capacity and Environment Defines the Need for Supports*

A wide discrepancy emerges when people with intellectual disability who have needed supports are contrasted with similar individuals in the same circumstances who do not have needed supports. Consider a young woman with intellectual disability and with a higher IQ who has earned money and is provided supports for how to spend, save, or budget it. Supports might consist of several years of instruction and supervised practice with shopping and interacting with store employees, as well as ongoing assistance at school and home in budgeting.

With these specific supports, this young woman can learn useful skills that allow choice and control in her life, and she is less likely to be exploited. By contrast, a peer without specific supports continues to be dependent on others for shopping and faces a higher probability of being taken advantage of by others. Individualized supports depend on accurate and ongoing assessment coordinated with family members, schools, and adult agencies who have the capacity to deliver those supports and monitor their outcomes. A history of inadequate supports contributes to an individual's failure to address the everyday demands in his/her life and to a thwarted potential.

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## Summary

In this article, we described the group of individuals with intellectual disability who have higher IQs and the societal and social judgment challenges they face in everyday life. Ordinary life demands frequently impose overwhelming challenges to these people who live with significantly limited intellectual ability and adaptive behavior. Intellectual limitation exists along a continuum, revealing many similarities in human functioning limitations between individuals on either side of the definitional dividing line. Good professional practices require that any diagnosis of intellectual disability in a person be followed by the assessment and provision of needed supports to that person. Merely diagnosing intellectual disability is unlikely to improve the functioning of the individual. Episodic attention to the people whose IQs lie just above the diagnostic cut off must be converted to a deliberate societal commitment to address their needs in a sustained fashion.

We conclude that intellectual disability occurs along a continuum, as does intellectual ability, and must be described and understood in that way. Even with general consensus on the cut-off criteria for diagnosing intellectual disability, it is critical to remember that people slightly above the cut off typically perform similarly to those slightly below the cut off. Regardless of their qualifying diagnostic test scores, all individuals with intellectual disability have significant limitations in intellectual ability and adaptive behavior and require supports that are matched to their individual needs and preferences. This need for supports does not stop at the IQ and adaptive behavior cut-off points in the intellectual disability definition.

In addition, we conclude that individuals with intellectual disability with higher IQs face significant challenges in society across all areas of adult life and that many individuals who may not receive formal diagnoses of intellectual disability or who fall slightly above the upper ceiling for a diagnosis of intellectual disability share this vulnerability. Only through an increased understanding of the ongoing strengths and limitations of each individual with intellectual disability can we achieve better clinical judgment and identify appropriate supports and with the provision of individualized supports accomplish fairness in society. To realize their potential and reduce suffering in this group of people, our society must create nonstigmatizing, accessible, and individualized supports that apply proven interventions and build on the strengths of these individuals, starting in early childhood. Hence, good professional practices require that any diagnosis of intellectual disability in a person be followed by the assessment and provision of needed supports to that person; merely diagnosing intellectual disability is unlikely to improve the person's functioning.

Last, we conclude that the episodic attention to the people whose IQs are borderline or just above the diagnostic cut off must be converted to a deliberate societal commitment to address their needs in a sustained fashion. This will require partnerships by government and relevant advocacy and professional groups. The early work of Edgerton (1967, 2001), the PCPID, and others must be integrated into this critical thrust.

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### Appendix Contemporary Challenges Facing People With Cognitive Limitations

1. An increasingly complex, information-based and technologically demanding society.
2. Less “neighborliness” to help people with social, commercial, and governmental settings.
3. Barriers related to cognitive limitations are less likely to be “accommodated” than barriers related to physical limitations.
4. Changes in public policies that affect low-income, unemployed, and homeless people have a disproportionately negative effect on individuals with cognitive limitations.
5. Any changes to existing support programs cause gaps or exclusion because it takes longer to gain information, understand new options, and attempt to reenter a program.
6. Desire to avoid additional stigma of a “disability” service system but lack of skills necessary to enter a generic service (if one exists).
7. Lack of access to stable and knowledgeable advocates.
8. Vulnerability to secondary disabilities as a result of poor or no access to health or mental health services.
9. Increased stress, loneliness, anxiety, depression, victimization, violence, and maltreatment because of inadequate preparation for independent living, lack of supports, tendencies toward errors of judgment, acquiescence to perceived authority, gullibility, naiveté, and exploitation by others.
10. Restricted employment opportunities related to limited academic skills, segregation and lack of social connections, and higher rates of school dropout.

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