

# 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**

DOI: 10.1352/1934-9556-47.3.220

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.

---

## 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., feebleminded, 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.

---

## 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, Ruiters, 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).

---

### 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).

---

### 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.

---

## 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.

---

## References

- Blackorby, J., & Wagner, M. (1996). Longitudinal postschool outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children, 62*, 399–413.
- Bogdan, R., & Taylor, S. J. (1994). *The social meaning of mental retardation: Two life stories*. New York: Teachers College Press.
- Braddock, D., Emerson, E., Felce, D., & Stancliffe, R. J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia. *MRDD Research Reviews, 7*, 115–121.
- Breihan, A. W. (2007). Who chooses service providers? The spread of consumer choice,

- 1992–2004. *Intellectual and Developmental Disabilities*, 45, 365–372.
- Browder, D. M., Trela, K., Gibbs, S. L., Wakeman, S., & Hallis, A. A. (2007). Academic skills: Reading and mathematics. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 292–309). New York: Guilford Press.
- Brown, I., Raphael, D., & Renwick, R. (1999). *The Quality of Life Project: Results from the follow-up studies*. Toronto, Ontario, Canada: Center for Health Promotion, University of Toronto.
- Campbell, V. A., & Fedeyko, H. J. (2000). The Healthy People 2010 process. In A. J. Tymchuk, K. C. Lakin, & R. Luckasson (Eds.), *The forgotten generation: The status and challenges of adults with mild cognitive limitations* (pp. 221–240). Baltimore: Brookes.
- Carter, E. W., & Hughes, C. (2007). Social interaction interventions: Promoting socially supportive environments and teaching new skills. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 310–329). New York: Guilford Press.
- Didden, R., Korzilius, H., van Oorsouw, W., & Sturmey, P. (2006). Behavioral treatment of challenging behaviors in individuals with mild mental retardation: Meta-analysis of single-subject research. *American Journal on Mental Retardation*, 111, 290–298.
- Douma, J., Dekker, M. C., Ruiter, K. P., Tick, N. T., & Koot, H. M. (2007). Antisocial and delinquent behaviors in youths with mild or borderline disabilities. *American Journal on Mental Retardation*, 112, 207–220.
- Edgerton, R. B. (1967). *The cloak of competence: Stigma in the lives of the mentally retarded*. Berkeley: University of California Press
- Edgerton, R. B. (2001). The hidden majority of individuals with mental retardation and developmental disabilities. In A. Tymchuk, K. C. Lakin, & R. Luckasson (Eds.), *The forgotten generation: The status and challenges of adults with mild cognitive limitations* (pp. 3–19). Baltimore: Brookes.
- Felce, D., & Perry, J. (2007). Living with support in the community. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 410–428). New York: Guilford Press.
- Fierros, E. G., & Conroy, J. W. (2002). Double jeopardy: An exploration of restrictiveness and race in special education. In D. J. Losen & G. Orfield (Eds.), *Racial inequality in special education* (pp. 39–70). Cambridge, MA: Harvard Education Press.
- Fujiura, G. T. (2003). Continuum of intellectual disability: Demographic evidence for the “forgotten generation.” *Mental Retardation*, 41, 420–429.
- Galbraith, S. (2001). A home of one’s own. In A. J. Tymchuk, K. C. Lakin, & R. Luckasson (Eds.), *The forgotten generation: The status and challenges of adults with mild cognitive limitations* (pp. 141–167). Baltimore: Brookes.
- Gardner, J. F., & Carran, D. T. (2005). Attainment of personal outcomes by people with developmental disabilities. *Mental Retardation*, 43, 157–174.
- Goffman, E. (1961). *Asylums*. New York: Anchor Books.
- Greenspan, S. (2006a). Functional concepts in mental retardation: Finding the natural essence of an artificial category. *Exceptionality*, 14, 205–224.
- Greenspan, S. (2006b). Mental retardation in the real world: Why the AAMR definition is not there yet. In H. N. Switzky & S. Greenspan (Eds.), *What is mental retardation? Ideas for an evolving disability in the 21st century* (pp. 167–185). Washington, DC: American Association on Mental Retardation.
- Greenspan, S. (2007). *Steps toward an understanding of foolish behavior*. Littleton, CO: Unpublished manuscript.
- Greenspan, S., Loughlin G., & Black, R. S. (2001). Credulity and gullibility in people with developmental disorders: A framework for future research. *International Review of Research in Mental Retardation*, 24, 101–135.
- Khemka, I., & Hickson, L. (2006). The role of motivation in the decision making of adolescents with mental retardation. *International Review of Research in Mental Retardation*, 31, 73–115.
- Lewis, D. R., & Johnson, D. R. (2005). Costs of family care for individuals with developmental disabilities. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 63–89). Baltimore: Brookes.
- Luftig, R. L., & Muthert, D. (2005). Patterns of employment and independent living of adult graduates with learning disabilities and mental

- retardation of an inclusionary high school vocational program. *Research in Developmental Disabilities*, 26, 317–325.
- MacMillan, D. L., Siperstein, G. N., & Gresham, F. M. (1996). A challenge to the viability of mild mental retardation as a diagnostic category. *Exceptional Children*, 62, 356–371.
- Mank, D. (2007). Employment. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 390–409). New York: Guilford Press.
- Mercer, J. (1973). *Labeling the mentally retarded*. Berkeley: University of California Press.
- Nettelbeck, T., & Wilson, C. (2001). Criminal victimization of persons with mental retardation: The influence of interpersonal competence on risk. *International Review of Research in Mental Retardation*, 24, 137–169.
- Patton, J. R., & Keyes, D. (2006). Death penalty issues following *Atkins*. *Exceptionality*, 14, 237–255.
- Perske, R. (2005). Strange shift in the case of Daryl Atkins. *Mental Retardation*, 43, 454–455.
- Polloway, E. A., Lubin, J., Smith, J. D., & Patton, J. R. (in press). Mild intellectual disabilities: Legacies and trends in concepts and educational practices. *Education and Training in Developmental Disabilities*.
- President's Committee on Mental Retardation. (1969). *The six-hour retarded child*. Washington, DC: U.S. Government Printing Office.
- Richardson, S. A., & Koller, H. (1996). *Twenty-two years: Causes and consequences of mental retardation*. Cambridge, MA: Harvard University Press.
- Rouso, H., & Wehmeyer, M. L. (Eds.). (2001). *Double jeopardy: Addressing gender equity in special education*. Albany: State University of New York Press.
- Schalock, R., Luckasson, R., & Shogren, K., With Borthwick-Duffy, S., Bradley, V., Buntix, W., et al. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, 45, 116–124.
- Siperstein, G. N., Parker, R. C., Bardon, J. N., & Widaman, K. F. (2007). A national study of youth attitudes toward the inclusion of students with intellectual disabilities. *Exceptional Children*, 73, 435–455.
- Skiba, R. J., Poloni-Staudinger, L., Gallini, S., Simmons, A. B., & Feggins-Azziz, R. (2006). Disparate access: The disproportionality of African-American students with disabilities across educational environments. *Exceptional Children*, 72, 411–424.
- Skiba, R. J., Simmons, A. B., Ritter, S., Gibb, A. C., Rausch, M. K., Cuadrado, J., et al. (2008). Achieving equity in special education: History, status, and current challenges. *Exceptional Children*, 74, 264–288.
- Smith, P. (2007). Have we made any progress? Including students with intellectual disabilities in regular education classrooms. *Intellectual and Developmental Disabilities*, 45, 297–309.
- Snell, M. E. (2007). Advances in instruction. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 249–268). New York: Guilford Press.
- Spitalnik, D. M., & White-Scott, S. (2000). Access to health services. In A. J. Tymchuk, K. C. Lakin, & R. Luckasson (Eds.), *The forgotten generation: The status and challenges of adults with mild cognitive limitations* (pp. 203–220). Baltimore: Brookes.
- Stancliffe, R. J., & Lakin, K. C. (2007). Independent living. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 429–448). New York: Guilford Press.
- Stancliffe, R. J., Lakin, K. C., Doljanac, R., Byun, S., Taub, S., & Chiri, G. (2007). Loneliness and living arrangements. *Intellectual and Developmental Disabilities*, 45, 380–390.
- Thompson, J. R., Bradley, R. E., Buntinx, W. H. E., Schalock, Shogren, K. A., Snell, M. E., & Wehmeyer, M. L., With Borthwick-Duffy, S., Coulter, D. L., Craig, E. M., Gomez, S., Lachapelle, Y., Luckasson, R. A., Reeve, A., Spreat, S., Tassé, M. J., Verdugo, M., & Yeager, M. H. (2009). Conceptualizing supports and the support needs of people with intellectual disabilities. *Intellectual and Developmental Disabilities*, 47, 135–146.
- Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., Rotholz, D. A., et al. (2004). *The Supports Intensity Scale (SIS): Users manual*. Washington, DC: American Association on Mental Retardation.
- Trent, Jr., J. W. (1994). *Inventing the feeble mind: A history of mental retardation in the United States*. Berkeley: University of California.

- Tymchuk, A. J. (2006). *The health & wellness program: A parenting curriculum for families at risk*. Baltimore: Brookes.
- Tymchuk, A., Lakin, C., & Luckasson, R. (Eds.). (2001). *The forgotten generation: The status and challenges of adults with mild cognitive limitations*. Baltimore: Brookes.
- U.S. Department of Education. (2007). *27th annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: Author.
- Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). *After high school: A first look at the postschool experiences of youth with disabilities. A report from the National Longitudinal Transition Study-2 (NTLS-2)*. Menlo Park, CA: SRI International.
- Walker-Hirsch, L. (Ed.). (2007). *The facts of life and more: Sexuality and intimacy for people with intellectual disabilities*. Baltimore: Brookes.
- Wehmeyer, M. L., Buntinx, H. E., Lachapelle, Y., Luckasson, R. A., Schalock, R. L., & Verdugo, M. A., With Borthwick-Duffy, S., Bradley, V., Craig, E. M., Coulter, D. L., Gomez, S. C., Reeve, A., Snell, M. E., Spreat, S., Tassé, M. J., Thompson, J. R., & Yeager, M. H. (2008). The intellectual disability construct and its relation to human functioning. *Intellectual and Developmental Disabilities, 46*, 311–318.
- Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities, 38*, 131–144.
- Williamson, P., McLeaskey, J., Hoppey, D., & Rentz, T. (2006). Educating students with mental retardation in general education classrooms. *Exceptional Children, 72*, 347–361.
- Yamaki, K., & Fujiura, G. T. (2002). Employment and income status of adults with developmental disabilities living in the community. *Mental Retardation, 40*, 132–141.

Received 9/25/08, first decision 10/7/08, accepted 10/29/08.

Editor-in-Charge: Steven J. Taylor

---

#### Authors:

**Martha E. Snell, PhD** (E-mail: snell@virginia.edu), Professor, Department of Curriculum, Instruction,

and Special Education, University of Virginia, P.O. Box 400273, 405 Emmet St., Charlottesville, VA 22904. **Ruth Luckasson, JD**, Distinguished Professor, Regents' Professor, and Chair, Department of Educational Specialties, University of New Mexico, College of Education-Hokona Hall 102, MSC05 30401, Albuquerque, NM 87131.

---

### 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.

---

Adapted with permission from: Tymchuk, A., Lakin, C., & Luckasson, R. (Eds.). (2001). *The forgotten generation: The status and challenges of adults with mild cognitive limitations* (pp. xxvi–xxvii). Baltimore: Brookes.