Behavioral Health Services for Persons with Intellectual and Developmental Disabilities

Marc J. Tassé, Elizabeth A. Perkins, Tammy Jorgensen Smith, and Richard Chapman

Overview of Intellectual and Developmental Disabilities

Intellectual and developmental disabilities (IDD) do not possess any protective factor against the onset of behavioral disorders. In fact, research has shown that persons with intellectual disability, autism spectrum disorder, and related developmental disabilities are more susceptible to certain behavioral disorders than persons in the general population. Due to an individual's intellectual disability and/or developmental disability, the correct identification and treatment do not always follow a standard and expected course. We also know that the presence of behavioral health issues increases the challenges of properly supporting these individuals to live successful lives at home, school, and work and in the community. In this chapter we will focus on intellectual and developmental disabilities as well as touch upon autism spectrum disorder.

The American Association on Intellectual and Developmental Disabilities (AAIDD; Schalock et al., 2010), an interdisciplinary professional society founded almost 140 years ago, and the American Psychiatric Association (APA, 2013) define intellectual disability as originating during the developmental period and being characterized by significant impairments in both intellectual functioning and adaptive behavior.

M. J. Tassé (✉)
The Ohio State University, Columbus, OH, USA
e-mail: Marc.tasse@osumc.edu

E. A. Perkins
Department of Child & Family Studies, College of Behavioral and Community Sciences, University of South Florida, Tampa, FL, USA

T. J. Smith
College of Behavioral and Community Sciences, University of South Florida, Tampa, FL, USA

R. Chapman
University of South Florida, Tampa, FL, USA

B. L. Levin, A. Hanson (eds.), *Foundations of Behavioral Health*,
https://doi.org/10.1007/978-3-030-18435-3_12

Significant impairments are defined as functioning that is approximately two standard deviations or more below the population mean, and limitations in adaptive behavior include skill deficits in the performance of conceptual, social, and/or practical skills.

The *Diagnostic and Statistical Manual for Mental Disorders* (DSM-5) (APA, 2013) defines autism spectrum disorder (ASD) as being characterized by impairments in two realms: (1) social use of communication (including interpersonal skills and reciprocity, back-and-forth communication, understanding non-verbal social cues, eye contact, use and recognition of body language, understanding gestures, recognizing different emotions embedded in facial expressions, etc.) and (2) restricted, repetitive, and stereotyped patterns of behavior and interests or activities, including stereotyped motor behaviors, echolalia, idiosyncratic phrases, insistence on sameness, and hypo- or hyper-reactivity to sensory input or other sensory aspects. The presence of social communication deficits and restricted, repetitive behaviors and interests manifest during the developmental period and result in significant impairments across multiple life areas.

Developmental disabilities also are an administrative category of individuals defined under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act; Public Law 106-402) and can include a variety of known conditions. Section 102(8) of the DD Act defines developmental disability as a severe, chronic disability that:

1. "Is attributable to a mental or physical impairment or combination of mental and physical impairments"
2. "Is manifested before the individual attains age 22"
3. "Is likely to continue indefinitely"
4. "Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency"
5. "Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated" (DD Act; Pub. L. 106-402, §102.8, pp. 1683–1684).

In addition, the Act also addresses infants and children to age 9 who have substantial developmental delays or specific congenital or acquired conditions. These children may be considered to have a developmental disability without meeting three or more of the criteria described above in 1 through 5 if the individual, without services and supports, has a high probability of meeting those criteria later in life (DD Act; Pub. L. 106–402, §102.8, p. 1684).

Epidemiology

Some broader definitions of developmental disabilities are inclusive of conditions such as hearing loss, vision impairment, learning disability, and attention deficit/hyperactivity disorder, and, with such definitions, the prevalence rates are as high as

14% of the total population of children between the ages of 3 and 17 years (Boyle et al., 2011). For the purposes of this chapter, however, we will use the definition of developmental disability found in the DD Act of 2000.

According to Larson et al. (2001), developmental disability and intellectual disability are not perfectly overlapping conditions. In their study on the prevalence of DD and ID, 48% of individuals had a developmental disability but no co-occurring intellectual disability, 28% had a developmental disability and an intellectual disability, and the remaining 24% had an intellectual disability but no developmental disability (Larson et al., 2001).

The estimated prevalence of intellectual disability is theoretically between 2 and 3% of the general population. This estimate is based on our knowledge of the normal distribution of abilities in the general population and the expected proportion of individuals who would be approximately two standard deviations below the population mean (Tassé & Grover, 2013). However, because the condition is diagnosed when the individual's functioning in both intellectual functioning and adaptive behavior are significantly subaverage, the actual estimated prevalence falls to approximately 1% of the total population (APA, 2013). Since intellectual disability is a condition that is diagnosed based entirely on the individual's intellectual and adaptive functioning, its etiology can be almost anything and is often multifactorial, including prenatal, perinatal, and postnatal risk factors (see Table 1). It is estimated that 30–40% of all cases of intellectual disability have no known cause(s).

The prevalence of ASD has been on the rise for the past two decades, increasing almost 300% between 1996 and 2010 (Van Naarden Braun et al., 2015). Boys have consistently been at greater risk of having ASD than girls (i.e., 4:1). The Centers for Disease Control and Prevention (CDC) publishes regular estimates of the prevalence of ASD at approximately 2-year intervals. In 2014, the CDC reported the prevalence of ASD to be approximately 1 in 68, up from its previous 2012 published report of 1 in 88 (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2012, 2014).

There is some debate within the field whether the extent to which these increases in prevalence might be a reflection of better case ascertainment and identification, possibly as a result of an increase in awareness and access to services, or whether these changes in prevalence rate are a result of a true increase in incidence. It should be noted that the most recent prevalence statistics published by the CDC in April 2016 indicated, for the first time in many years, no change in the prevalence of ASD, remaining at 1 in 68 (Christensen et al., 2016). Hence, autism spectrum disorder remains an important public health concern in the United States, with lifetime costs

Table 1 Risk factors

Prenatal	Genetic or chromosomal disorders, metabolic disorders, trauma or injury that impacts fetal development, infection/toxins
Perinatal	Anoxia, infection, other trauma
Postnatal	Sensory deprivation, nutritional deficiency, environmental toxins/poisons (e.g., lead, mercury, pesticides, etc.), trauma/infection, or brain injury

associated to ASD estimated at approximately $3.2 million per person. These costs are driven largely by behavioral therapies in childhood, extensive adult care, as well as large indirect societal costs due to lost productivity (Ganz, 2007).

Behavioral Health and IDD

People with IDD are susceptible to presenting all forms of behavioral health problems found in the DSM-5 (APA, 2013). Not only are they susceptible, but they are three to four times more likely than the general population to present with behavioral health problems (Fletcher, Loschen, Stavrakaki, & First, 2007). Among the more common comorbid behavioral health conditions in people with ID, not unlike in the general population, are conditions such as depression and anxiety disorder (Fletcher et al., 2007). Whereas individuals with ASD may also present with high frequencies of comorbidity of anxiety disorder and depressive disorders, children also may present frequently with oppositional defiant/conduct disorder and attention deficit/hyperactivity disorder (Simonoff et al., 2008).

Some evidence has supported the need to adapt the symptoms or signs characteristic of psychiatric disorders in people with intellectual and developmental disabilities. This led to the publication of the *Diagnostic Manuals—Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability* (Fletcher et al., 2007), which adapted the diagnostic criteria of the DSM-IV-TR (APA, 2000) for persons with IDD. An adaptation of the DSM-5 (APA, 2013) was published in 2016 (Fletcher, Barnhill, & Cooper, 2016). In most cases, the diagnostic criteria are relatively the same for people with milder forms of ID, but differences in number count and type of signs and symptoms associated with various DSM diagnoses appear with more significant levels of impairment in cognitive functioning and expressive language.

Problem behavior is also a common concern among clinicians working with individuals with IDD. Siegel et al. (2014) reported the most common reasons for admission to a specialized in-patient unit for children with IDD were problem behaviors, such as aggression, self-injurious behavior, property destruction, and tantrums, which led to placement in this restrictive clinical setting. The presence of problem behavior in individuals with IDD is, in fact, the most often cited reason for exclusion from more inclusive settings or placement into a segregated classroom/school, home, in-patient unit, and/or employment (Bruininks, Hill, & Morreau, 1988; Lakin & Stancliffe, 2005). Children with ASD are also six times more likely to be hospitalized in a psychiatric unit than children without ASD (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). Therefore, effective and coordinated intervention strategies are crucial to preventing and eliminating problem behaviors and increasing adaptive skills and overall quality of life in people with IDD.

Substance Abuse

There was a time when few individuals with IDD had opportunity to access illicit drugs and alcohol. With the movements of normalization, valorization of social role, and self-determination, as well as the reduction of coercive controls and restriction of individual rights and freedoms of persons with IDD, came the greater likelihood of individuals with IDD making bad choices that led to less desirable outcomes. The increased prevalence of substance abuse is one such example. While the prevalence of illicit drug and alcohol use in people with IDD is relatively low, their risk of having a substance-related problem is comparatively high (Carroll Chapman & Wu, 2012). The severity of the problem of substance abuse in people with IDD is exacerbated by the fact that few effective treatments available for people with IDD exist and people with IDD typically avoid or rapidly abandon treatment interventions for substance abuse (Frielink, Schuengel, Kroon, & Embregts, 2015).

Although individuals with IDD face a variety of barriers to achieve meaningful inclusion in the community, opportunities that support inclusion for individuals with IDD include customized employment strategies, the promotion of self-advocacy and self-determination for individuals with IDD, and strategies for successful support at the end-of-life.

Customized Employment

Customized employment (CE) is defined by the Workforce Innovation and Opportunity Act (WIOA, Pub. L. No. 113–128) as: "*competitive integrated employment*, for an individual with a significant disability, that is based on an individualized determination of the *strengths, needs, and interests of the individual* with a significant disability, *designed to meet the specific abilities of the individual* with a significant disability *and the business needs of the employer*, and carried out through flexible strategies" (USC 29 Chapter "Pharmacy Services in Behavioral Health", §705(35)(A), pp. 186–187, *italics by authors*). CE "utilizes an individualized approach to employment planning and job development—one person at a time… one employer at a time" (Office of Disability Employment Policy, ODEP, (2018), para. 1).

The CE process facilitates employment possibilities for job seekers with disabilities who, due to life complexities, have had difficulty obtaining employment through traditional vocational rehabilitation processes. It considers unique aspects of each person such as age, type of disability, functional capacities, disposition, and interaction style. The CE process also recognizes contextual factors including resources, living arrangements, geographical location, and services and supports that the person receives (Smith, Dillahunt-Aspillaga, & Kenney, 2017).

Why Customized Employment?

CE is a positive process that focuses on "real work in the real world" and involves:

- Painting an accurate picture of a job seeker through the discovery process;
- Utilizing a strength-based approach to identify talents, interests, abilities, and conditions in which the job seeker can be successful;
- Welcoming and empowering others, especially those closest to the job seeker, as active participants in the process through development of a person-centered team.
- Developing relationships with potential connectors and mentors in the community.

Negotiating employment opportunities that meet the needs of both the job seeker and the employer presents a number of challenges. To do so, to create "real work in the real world", the CE process consists of the six key elements: (1) the discovery process, (2) the vocational profile, (3) the customized employment planning meeting, (4) the visual resume, (5) customized job development and negotiation, and (6) accommodations and post-employment support.

Discovery

Discovery is a type of naturalistic assessment that uses qualitative methods to gather information useful in building a narrative snapshot of a job seeker to facilitate the identification of ideal working conditions (Callahan & Condon, 2007). Discovery is a vital part of the CE process because it promotes improved employment matching. The discovery process takes place in natural environments, such as the home, neighborhood, and community. It includes interviews, conversations, observations, and records reviews to get to know the job seeker and his or her interests, talents, and conditions for employment (e.g., environmental tolerances, social interaction skills, etc.).

Vocational Profile

The discovery process culminates in the development of a vocational profile that provides a descriptive picture of the job seeker. It is a robust, narrative report that provides a foundation for effectively negotiating personalized potential job opportunities with employers (Condon & Callahan, 2008). The profile is a living document that can be amended as new information is uncovered making it a particularly useful tool for students transitioning from school to the community and workforce. Profiles provide "an alternative format to traditional evaluation reports that compare persons with complexities to general standards and others" (Callahan, Shumpert, & Condon, 2011, p. 5).

Customized Employment Planning

The customized planning meeting includes the job seeker, family, friends, advocates, service providers, vocational rehabilitation (VR) counselors, and other stakeholders chosen by the job seeker. Ideally, it occurs within 2 weeks of the completion of the vocational profile. The purpose of the meeting is to develop a CE blueprint that bridges the gap between discovery and job placement. The information contained in the vocational profile is utilized to develop a specific plan of action for achieving a competitive, integrated employment outcome in a job that matches the individual's interests, talents, requirements, and conditions for employment.

Visual Resume

The visual resume is a sales tool to introduce the job seeker to potential employers. It is different from a typical resume in that it utilizes photos or video clips to demonstrate the job seeker completing tasks/skills essential to the position. This tool is very useful for individuals who may not be able to express their talents and abilities verbally as is traditionally done through the interviewing process. The visual resume may also be utilized to explain the concept of CE to an employer.

Customized Job Development and Negotiation

Customized employment includes negotiating employment opportunities with employers through the identification of unmet business needs that may be fulfilled by the talents of a job seeker. Typically, this process does not begin with a response to an advertisement for employees but rather through meeting with employers and touring businesses to identify mutually beneficial matches. Customized job development strategies include (1) job carving, the process of breaking jobs down into their key components and reassigning those pieces in more efficient or understandable way; (2) job sharing where two or more people share a position based on the strengths of each; and/or (3) job creation where a new job description is developed based on unmet needs of the employer (ODEP, 2018).

Accommodation and Post-Employment Support

Post-employment supports have been proven to be beneficial for people with disabilities who may encounter issues that they are not prepared to handle without assistance (Targett, Wehman, McKinley, & Young, 2004). Prior to vocational rehabilitation case closure, assistance should be provided in the development of natural supports and resources for targeting solutions to challenges prior to the loss of employment. In addition, employees and employers should be aware of the services available through the Job Accommodation Network (askjan.org) to aid in the identification and implementation of accommodations as required by the Americans with Disabilities Act.

An Example of Customized Employment

Individual	Allen has autism with limited speech. Through the discovery process, Allen is identified as having an interest in video games and a talent for organization and data entry
Setting	A local video store that sells new and used games has multiple employees who, when interviewed, state that they all prefer answering questions and selling games to stocking and organizing. While they are helping customers, games that have been ordered or bought for resale are typically set aside until there is time to enter the inventory into the computer and put it on the shelves. The sales floor quickly becomes disorganized due to movement of product by browsers. When a customer requests a particular game, the system does not show that it is in stock because it has not yet been entered into the computer, or the system does show it is in stock but the game cannot be located on the shelf because it is out of place. The employer indicates that, typically, employees are hired to perform all aspects of the job (selling, stocking, etc.)
Result	A customized approach allows the individual with autism to be hired to enter games into the computer, stock, and organize product. This leaves more time for other employees to sell and makes it much easier to access games that are in stock. In addition to an increase in sales, morale is increased because employees spend more time doing work that they enjoy. A win-win!

With the possibility of finding employment tailored to an individual's ability, persons with IDD become more independent and take on more responsibility for their lives, such as making decisions regarding work, housing, transportation, and health. Becoming more independent means they must learn to advocate for themselves.

The Self-Advocacy Movement for Individuals with IDD

The self-advocacy movement for individuals with intellectual and developmental disabilities is, in itself, a civil rights movement. The movement has its own unique values and beliefs that constitute self-advocacy. The related disability rights movement, also known as self-determination, places a strong emphasis on psychological independence and control over one's life (Conyers, 2003). The efforts to establish disability rights also may be seen as a political movement with a unique set of values, which include self-warmth and involvement in the political process (Putnam, 2005).

In the United States, the self-advocacy movement has a very vibrant history that dates back to the 1980s (Traustadóttir, 2006). Self-advocacy organizations were formed to help individuals with disabilities take control over their lives and to help individuals with disabilities have the right to leave institutions to live in the community and live in their communities (Traustadóttir, 2006).

Definition of Self-Advocacy

Self-Advocates Becoming Empowered (SABE), a national self-advocacy organization, defines self-advocacy as follows:

> Self-advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe.(Hayden & Nelis, 2002, as cited in Caldwell, Aaron, & Rizzolo, 2011, p. 1)

Other alliances, such as the Florida Self-Advocacy Alliance (FSAA), have developed similar lists of values. The FSAA focuses on seven values: (1) moving forward, (2) expressing choices, (3) being independent, (4) knowing when to ask for help, (5) not being afraid to ask for help, (6) believing in oneself, and (7) letting go (Chapman & Jenkins, 2011).

The self-advocacy movement was based on the foundation of two models defining disabilities: (1) the medical and (2) the social models (Pledger, 2003). The medical model, also known as the biomedical model of disability, sees individuals with disabilities as having limitations that affect their ability to function and that need to be "fixed." Since the medical model views individuals with disabilities as having medical problems, the medical professional is the expert who can "fix" their problems. The social model of disability views disability as a culture that is affected by social oppression (Magasi, 2008) and has been used successfully for political activism. The "social model" does not view disability as a limitation that needs to be treated by a medical professional but rather promotes the concept of disability pride (Magasi, 2008).

Disability pride is seen as a rejection of the medical model of disability and recognizes disability as a vibrant culture (Magasi, 2008) and part of a unique cultural identity. Over 155 people participated in a study of a group of disability rights activists from the Americans Disabled for Assistance Programs Today (ADAPT) movement. Participants reported having a great sense of pride about being an individual with a disability, and they indicated that they would not want to be "cured" of their disability (Hahn & Beaulaurier, 2001).

Self-Advocacy as a Federal Priority

Self-advocacy is a major priority for the Federal government. Guidelines for federally funded State Councils on Developmental Disabilities are written into 42 US Code §15,025, and these Councils have a primary responsibility of supporting self-advocacy for individuals with DD (Caldwell et al., 2011). The Administration on Intellectual and Developmental Disabilities (AIDD), an agency within the Federal government, has taken a new interest in supporting self-advocates who have IDD. The AIDD sponsored two self-advocacy summits to (1) examine how the Federal government can support self-advocates throughout the country and (2) to note the issues and challenges that self-advocates face (Caldwell et al., 2011). The report features four areas challenging self-advocates around the country. These four areas are (1) barriers to self-advocacy, such as transportation; (2) public perception of individuals with developmental disabilities, mainly the continued use of such outdated language as mentally retarded; (3) support of self-advocates; and (4) the establishment of a technical assistance center to support the self-advocacy movement (Caldwell et al., 2011).

There are a number of national organizations involved in the self-advocacy movement; however, three are of particular note: (1) Self-Advocates Becoming Empowered (SABE), (2) ADAPT, and (3) Autistic Self-Advocacy Network (ASAN).

Self-Advocates Becoming Empowered (SABE) is a self-advocacy organization comprised of individuals with developmental disabilities. Founded in 1993, SABE was the initial self-advocacy organization for individuals with developmental disabilities (Ward & Meyer, 1999). The mission of the organization is to "ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes" (SABE, 2011). A major focus of the organization is advocating for the deinstitutionalization of individuals with developmental disabilities.

ADAPT, considered the radical component of the self-advocacy movement, seeks to promote change on behalf of individuals with disabilities by utilizing civil disobedience. One of the oldest self-advocacy organizations, ADAPT (then American Disabled for Accessible Public Transit) began its national campaign for lifts on buses and access to public transit for people with disabilities in 1983. It played a major role in gaining passage of the Americans with Disabilities Act (ADA), focusing on requirements relating to accessible transit, and the perception of the ADA as civil rights law. Describing itself as "a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom" (ADAPT, 2018), APAPT advocated for the Disability Integration Act (2017). The Act would require changes to policies of public entities and long-term service and supports insurance providers to increase resources and supports for persons with disabilities to live independently within their communities.

The Autistic Self-Advocacy Network (ASAN), a national self-advocacy organization for individuals with ASD, advances the principles of the disability rights movement with regard to ASD. ASAN believes that the goal of autism advocacy should be to facilitate a world in which people with ASD enjoy the same access, rights, and opportunities as all other citizens. ASAN works to empower people with ASD across the globe to take control of their lives and the future of their common communities. The Network seeks to organize the community of persons with ASD to ensure their voices are heard in national conversations. Their slogan is "Nothing About Us, Without Us!" (ASAN: Autistic Self-Advocate Network, 2018).

With the increased emphases on self-advocacy and longer life-spans for persons with IDD, there is growing concern, from social and public policy perspectives, on how persons with IDD can age successfully with appropriate community and residential supports.

Aging with an Intellectual and Developmental Disability

The need to research the diverse processes of aging, whether social, physical, psychological, or biological, led to the discipline of gerontology (i.e., the study of aging) and geriatrics (i.e., medical care of older adults). In general terms, gerontology generally refers to those who are 65+ years of age. As the population aged 65+ rapidly increases, so will the demand rise for practitioners who serve the aging population. In the United States, we are in the midst of the aging of the baby boomer generation (i.e., people born during 1946–1964). Every day over 10,000 Baby Boomers reach age 65, increasing the current percentage of the US population of older adults from 13% to 18% by 2030 (Cohn & Taylor, 2010). This demographic change is well known to those in the fields of geropsychology and geropsychiatry who specialize in the study, prevention, and treatment of mental disorders in old age (see Chapter "Older Adults" in this volume for additional information on older adults and behavioral health).

The majority of individuals with IDD now have a similar life expectancy (LE) to that of the general population. Historically, the gap had been far greater, but in recent decades, the gap has closed quite dramatically. For example, between 1983 and 1997, LE rose an astonishing 24 years for people with Down syndrome, eight times the rate of increase for the general population in that same period (Yang, Rasmussen, & Friedman, 2002). Comparatively speaking, people with IDD are a relatively small segment of the aging population, with 641,860 people aged 60 years in 2000, a figure that is expected to double to 1.2 million by 2030 (Heller, Stafford, Davis, Sedlezky, & Gaylord, 2010).

Nevertheless, there is a significant proportion of aging individuals with IDD who need lifelong supports or will be accessing support services when their family caregivers can no longer provide such care. Unfortunately few professionals are ready to meet the challenges that arise in providing appropriate supports for aging people with IDD, even though their numbers are rapidly rising (Perkins & Moran, 2010). According to the National Association for the Dually Diagnosed (NADD, 2016), 30–35% of people with IDD have behavioral health problems. Therefore, 1/3 of aging people with IDD are likely to have lifelong behavioral health issues (e.g. depression, anxiety) or develop new ones. The remainder of this section will draw attention to three topics that are often overlooked areas of practice that behavioral health practitioners can provide invaluable supports to people aging people with IDD: Alzheimer's disease; coping with loss, grief, and death; and preparation for end-of-life.

Alzheimer's Disease and IDD

Justifiably, Alzheimer's disease is a major public health and behavioral health concern, prompting the passage of the National Alzheimer's Project Act in 2011 (Pub. L. 111-375). This legislation provides for a coordinated national strategy and essential framework to combat what the Alzheimer's Association describes as "one of America's most feared and costly diseases" (Alzheimer's Association, 2016). Currently 5.4 million Americans have Alzheimer's disease, which is projected to almost triple to 13.8 million persons by 2050, if efforts to prevent or cure the disease are not successful (Alzheimer's Association, 2016).

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed to examine and report on the needs of adults with ID and dementia. After the National Alzheimer's Project Act was passed, the NTG advocated for and tracked progress on the implementation of the national plan with specific emphasis on inclusion of people with intellectual disabilities (Bishop et al., 2015). The NTG, a nationwide collaboration of researchers, clinicians, and long-term care providers, has produced a range of practice guidelines, screening tools, education and training curricula (see www.AADMD.org/NTG for further information).

People with Down syndrome are at an increased risk of developing Alzheimer's disease. Onset occurs at a much earlier age, between 40 and 49 years, compared with 72 years in the general population. Duration is 5–8 years compared with 7–20 years in the general population (Head, Powell, Gold, & Schmitt, 2012; Head, Silverman, Patterson, & Lott, 2012). Though not all conditions associated with IDD present with any greater risk of developing Alzheimer's disease than the general population, one unfortunate ramification of increased longevity of all people with IDD is there are many more individuals reaching ages when the prevalence of developing Alzheimer's disease increases. Also, a number of potential risk factors differentially impact people with IDD, including more limited cognitive reserve, greater propensity for significant head injuries, obesity, and poor cardiovascular health (NTG, 2012).

Though Alzheimer's disease has no known cure, pharmacological and environmental treatments can slow the disease's progression and improve quality of life. An early diagnosis is crucial to maximize treatment effects. Unfortunately, this can be very difficult because the onset of the disease can be harder to detect in those with pre-existing intellectual disability. Furthermore, commonly used screening instruments are not normed or appropriate for people with intellectual disability. As such, the NTG-Early Detection Screen for Dementia is highly recommended, as it can help identify people with dementia-like symptoms whose behaviors are from other causes (e.g., medication interactions, depression, thyroid disorders), and the screen can be easily incorporated into an annual wellness check (NTG, 2016). It is crucial to establish a baseline of functioning to discern what may be a new potentially dementia-related symptom or behavior and what is the established idiosyncratic behavior for a particular individual. Compiling a detailed history can be more problematic in people with IDD, especially those who live in residential group homes, due to gaps in caregivers' knowledge.

Diagnostic overshadowing (Reiss & Szyszko, 1983) is a particular challenge, whereby behavioral health professionals attribute signs and symptoms to the intellectual disability and not to the manifestation of a behavioral health condition. Indeed, for some individuals who are non-verbal, new or novel behaviors may be their attempt to communicate the changes and confusion that they are experiencing with their cognitive functioning. Conversely, some can do so very eloquently. "My Thinker's Not Working," an aptly named title of a report from NTG (2012), is actually a quote from an individual with IDD who was describing the effects of Alzheimer's disease.

Careful probing and observation by professionals and caregivers may assist the communication of symptoms of forgetfulness and the differential impact on spatial, short, and long-term memory. All general protocols for Alzheimer's disease management, psychosocial, behavioral, environmental, and pharmaceutical are equally applicable to people with IDD, but for more specific guidance refer to Moran, Rafii, Keller, Singh, and Janicki (2013).

Coping with Loss, Grief, and Death

An inevitable part of life is experiencing loss, and with increasing age, one is more likely to do so. It is a part of the human experience, and as such, people with IDD should be fully supported to express their feelings when losses occur. Aside from all the usual situations that can result in a sense of loss (e.g., changes of job, moving home, death of a loved one, the ending of significant intimate relationships and friendships, development of chronic health issues, etc.), it is important to consider other events and changes that may trigger a sense of loss with people with IDD.

The vast majority of people with IDD will live with their parents and other family caregivers for their entire life. Gains in longevity have resulted in many people with IDD now outliving their parents and potentially siblings, too. The death of family caregivers may also coincide with a move out of the family home into a completely new environment (e.g., to a group home). Such changes can be extremely abrupt and very traumatic.

Another scenario that arises for those who live in group homes and other residential settings is the loss/retirement of a formal support worker with whom the individual with IDD was particularly close and does not understand why someone who was a daily presence in their lives is now only seen occasionally, if at all. Similarly, a noted issue is the high turnover of direct support professionals, leading to instability and constant change in the staff that people with IDD may form close attachments. Professionals should be alert to the variety of potential and perhaps innocuous causes of loss that may trigger a grief reaction and be sensitive to the relative impact it may have upon the individual.

When people with IDD experience grief, they will have the same range of physical, emotional, and behavioral reactions. However, the degree to which the person understands the traumatic loss and the reasons behind the loss, coupled with their ability to express and/or communicate their feelings, can all impact how a loss is processed and grieved. Furthermore, a person may experience a death of a loved one but has never really conceptualized or had the opportunity to learn about the finality of death. Interestingly, Lipe-Goodson and Goebel's work (1983) suggested that the understanding of death is not as dependent on intellectual disability and more so on chronological age, emphasizing the importance of experiential learning. Thus, any type of loss experienced across the lifespan is an opportunity to increase understanding about loss. Such understanding can be further cemented by having discussions of former friends/relatives who have died, or favorite pets. Inclusion of people with IDD at funeral/memorial services is also very important, in saying goodbye and collectively grieving with others.

People with IDD may manifest their grief in different ways, including having an unwarranted sense of guilt or displacement of their sense of anger on others, especially in those with limited understanding to why an event has occurred (Doka, 2010). Another issue is *disenfranchised grief*, when an individual experiences a loss but that loss is not mourned, socially supported, or worse still even acknowledged (Doka, 2002). Unfortunately, people with IDD often experience disenfranchised grief from inappropriate and inadequate response from family or professional caregivers who have had little training or guidance on how to support people with IDD in their grief (Lavin, 2002).

Another issue is that professionals, friends, or family may feel that people with IDD need to be protected and may shield them from open discussion regarding death, disclosure of a particular event, and attendance at funerals (Lavin, 2002). Such overprotectiveness actually denies the right of the individual to learn how to cope with the loss and can lead to an increased sense of isolation, confusion, and anxiety. Generally, it should be remembered that constant reassurance and extra time may be needed to establish a therapeutic relationship when a person with IDD receives grief counseling. When a death is imminent, or occurs, the individual with IDD should have the same opportunities to be physically present and involved with the dying/dead person as any other would (Doka, 2010). Unfortunately, though many people with IDD may need additional support to cope with the death/significant loss, few may actually receive it, as professionals are generally unaware and uneducated about their unique issues. Fortunately, there is a growing interest to address this shortcoming. The Hospice Foundation of America's (2013) self-study course, "Supporting Individuals with IDD through Serious Illness, Grief, and Loss," is one such example.

Preparation for the End-of-Life

Thinking about our own mortality and preparing for our death and beyond is something we universally acknowledge as something we should do, but increasing age does increase the probability that we would formalize such plans. Even so, according to a survey conducted by the AARP Research Group (2000), in those aged 50+, 60% have a will, 23% have a living trust, and 45% have a durable power of attorney, but only 17% have all three! Another study found that in those 18 years and older, 60% want their end-of-life wishes to be respected, yet only a third of them had completed advance directives (Pollack, Morhaim, & Williams, 2010). Against the apparent reluctance for end-of-life planning for people with no intellectual/cognitive difficulties, one can imagine the task can seem even more onerous for people with IDD, their family caregivers, and professionals who support them. However, Kingsbury (2010) advocates that advanced care planning for health/end-of-life wishes can and should be incorporated into regular person-centered-planning practices.

One of the major tenets of person-centered planning is to empower individuals to have control over their own lives and make choices that reflect their own needs. Person-centered planning gives the advantage of having a structured process to identify cultural, spiritual, and family rituals that may not be known and can be updated and modified as circumstances may dictate or with changes in someone's expressed wishes (Kingsbury, 2010). Also it is recommended to start these conversations sooner rather than later, although approaching general decision-making issues first, before the more poignant end-of-life planning is advisable (Kingsbury, 2010). For example, begin with general topics such as potential organ donation, versus personal wishes for interment. For further guidance, resources, such as *People Planning Ahead: Communicating Healthcare and End-of-Life Wishes* (Kingsbury, 2009), provide an invaluable framework for professionals engaged in this area.

Traditionally, many people with IDD have had all major decisions in their life made by legal guardians, but there is a growing movement that advocates for "Supported Decision-Making," whereby people use trusted family/friends and professionals, so they can make decisions without the need for "overly broad and restrictive guardianships" (Blanck & Martinis, 2015). The right to make one's own decisions on critical aspects of one's health, choices for treatment, and ultimately death are some of the most fundamental decisions we make. Friedman and Helm (2010) rightly describe end-of-life choices as being one of the most compelling issues that require clarification and insight. Such importance is not diminished in any way whatsoever by having an intellectual disability; quite the reverse, it is even more critical that such decisions, and wishes, are correctly identified, respected, and implemented.

Implications for Behavioral Health

Working with persons with IDD can be challenging, due to the burden of disease attributed to co-occurring intellectual/developmental disabilities and mental illnesses (Einfeld, Ellis, & Emerson, 2011). However, in the United States, approximately one-third (32.9%) of the total number of individuals with IDD served by state developmental disability agencies have mental illnesses (MI), one-third (32.9%) have some combination of IDD and MI, and 22.7% needed support to manage self-injurious behavior, 38.8% for disruptive behavior, and 25.1% for destructive behavior (Human Services Research Institute & National Association of State Directors of Developmental Disabilities Services, 2013). Clearly, individuals with IDD and co-occurring MI require a flexible array of services to help them effectively reside in their communities. Services and funding models need to be designed to promote the necessary flexibility and services infrastructure persons with IDD and MI need based on the individual.

Behavioral health professionals must be prepared to competently provide treatment to individuals with disabilities. According to the self-advocacy movement, the medical model is not an acceptable treatment framework for individuals with disabilities. Many of those who are involved in the self-advocacy movement believe that having a disability is an extraordinary gift. Behavioral health professionals must be able to recognize this and to help individuals with disabilities become empowered.

Behavioral health professionals also need to recognize individuals with disabilities as a unique culture rather than a population that should be pathologized and treated with special care. It is important for professionals to embrace this vibrant culture and become aware of the disability rights movement and how it affects the counseling relationship. Empowerment is a critical responsibility of behavioral health professionals. Behavioral healthcare professionals need to work with individuals with disabilities and be willing to get involved in the self-advocacy movement.

As we close this chapter, we would like to reiterate the importance of being able to "age in place," in local communities, with person-centered services, developing workforce competencies, receiving integrated and effective services provision, and helping to develop and implement proven models of care and treatment for people with IDD and behavioral health disorders.

References

AARP Research Group. (2000). *Where there is a will... Legal documents among the 50+ population: Findings from an AARP survey*. Washington, DC: AARP. http://assets.aarp.org/rgcenter/econ/will.pdf

ADAPT. (2018). *Welcome to ADAPT* [Web page]. Philadelphia PA: National ADAPT. https://adapt.org/

Alzheimer's Association. (2016). *2016 Alzheimer's disease facts and figures*. Chicago, IL: Author. https://www.alz.org/documents_custom/2016-facts-and-figures.pdf

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR*. Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Arlington, VA: Author.

ASAN: Autistic Self-Advocate Network. (2018). *About* [Web page]. Washington, DC: ASAN. http://autisticadvocacy.org/about-asan/

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators. (2012). Prevalence of autism spectrum disorders – Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *MMWR: Surveillance Summaries, 61*(3), 1–19.

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators. (2014). Prevalence of autism spectrum disorder among children aged 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR: Surveillance Summaries, 63*(2), 1–21.

Bishop, K. M., Hogan, M., Janicki, M. P., Keller, S. M., Lucchino, R., Mughal, D. T., … Wolfson, S. (2015). Guidelines for dementia-related health advocacy for adults with intellectual disability and dementia: National Task Group on Intellectual Disabilities and Dementia Practices. *Intellectual and Developmental Disabilities, 53*(1), 2–29. https://doi.org/10.1352/1934-9556-53.1.2

Blanck, P., & Martinis, J. G. (2015). "The right to make choices": The national resource center for supported decision-making. *Inclusion, 3*(1), 24–33. https://doi.org/10.1352/2326-6988-3.1.24

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., … Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics, 127*(6), 1034–1042. https://doi.org/10.1542/peds.2010-2989

Bruininks, R., Hill, B. K., & Morreau, L. E. (1988). Prevalence and implications of maladaptive behaviors and dual diagnosis in residential and other service programs. In J. A. Stark, F. J. Menolascino, M. H. Albarelli, V. C. Gray, & National Strategies Conference on Mental Illness in the Mentally Retarded (Eds.), *Mental retardation and mental health: Classification, diagnosis, treatment, services* (pp. 1–29). New York, NY: Springer.

Caldwell, J., Aaron, K. K., & Rizzolo, M. K. (2011, September). *Envisioning the future: Allies in self advocacy: Final report*. Washington, DC: The University of Illinois at Chicago, Institute on Disability and Human Development. https://nccdd.org/images/Public_Policy/Public_Policy_Topics/Full_Self-Advocacy_Summit_Report.pdf

Callahan, M., & Condon, E. (2007). Discovery: The foundation of job development. In C. Griffin, D. Hammis, & T. Geary (Eds.), *The job developer's handbook: Practical tactics for customized employment* (pp. 23–35). Baltimore, MD: Paul H. Brookes Publishing.

Callahan, M., Shumpert, N., & Condon, E. (2011). *Profiles: Capturing the information of discovery*. Gautier, MS: Marc Gold & Associates.

Carroll Chapman, S. L., & Wu, L. T. (2012). Substance abuse among individuals with intellectual disabilities. *Research in Developmental Disabilities, 33*(4), 1147–1156. https://doi.org/10.1016/j.ridd.2012.02.009

Chapman, R. A., & Jenkins, A. (2011). *The values of the self advocacy movement*. Tampa, FL: The Florida Self Advocacy Alliance.

Christensen, D. L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., Constantino, J. N., … Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years–autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR: Surveillance Summaries, 65*(3), 1–23. https://doi.org/10.15585/mmwr.ss6503a1

Cohn, D. V., & Taylor, P. (2010, December 20). *Baby boomers approach 65 – glumly*. Washington, DC: Pew Research Center Social & Demographic Trends. http://www.pewsocialtrends.org/2010/12/20/baby-boomers-approach-65-glumly/

Condon, E., & Callahan, M. (2008). Individualized career planning for students with significant support needs utilizing the discovery and vocational profile process, cross-agency collaborative funding and social security work incentives. *Journal of Vocational Rehabilitation, 28*(2), 85–96.

Conyers, L. M. (2003). Disability culture: A cultural model of disability. *Rehabilitation Education, 17*(3), 139–154.

Croen, L. A., Najjar, D. V., Ray, G. T., Lotspeich, L., & Bernal, P. (2006). A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics, 118*(4), e1203–e1211. https://doi.org/10.1542/peds.2006-0127

Developmental Disabilities Assistance and Bill of Rights Act, Pub. L. No. 106–402. (2000). https://www.gpo.gov/fdsys/pkg/PLAW-106publ402/html/PLAW-106publ402.htm

Disability Integration Act, S.910, 115th Congress. (2017). https://www.congress.gov/bill/115th-congress/senate-bill/910

Doka, K. J. (2002). *Disenfranchised grief: New directions, challenges, and strategies for practice*. Champaign, IL: Research Press.

Doka, K. J. (2010). In S. L. Friedman & D. T. Helm (Eds.), *End-of-life care for children and adults with intellectual and developmental disabilities* (pp. 261–271). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability, 36*(2), 137–143. https://doi.org/10.1080/13668250.2011.572548

Fletcher, R. J., Barnhill, J., & Cooper, S.-A. (2016). *DM-ID-2: Diagnostic manual, intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability*. Kingston, NY: NADD Press: National Association for the Dually Diagnosed.

Fletcher, R. J., Loschen, E., Stavrakaki, C., & First, M. (2007). *Diagnostic manual-intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability*. Kingston, NY: NADD Press.

Friedman, S. L., & Helm, D. T. (2010). *End-of-life care for children and adults with intellectual and developmental disabilities*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Frielink, N., Schuengel, C., Kroon, A., & Embregts, P. J. C. M. (2015). Pretreatment for substance-abusing people with intellectual disabilities: Intervening on autonomous motivation for treatment entry. *Journal of Intellectual Disability Research, 59*(12), 1168–1182. https://doi.org/10.1111/jir.12221

Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine, 161*(4), 343–349. https://doi.org/10.1001/archpedi.161.4.343

Hahn, H., & Beaulaurier, R. L. (2001). Attitudes toward disabilities: A research note on activists with disabilities. *Journal of Disability Policy Studies, 12*(1), 40–46. https://doi.org/10.1177/104420730101200105

Hayden, M., & Nelis, T. (2002). Self-advocacy. In P. C. Baker, M. D. Croser, & R. L. Schalock (Eds.), *Embarking on a new century: Mental retardation at the end of the 20th century* (pp. 221–233). Washington, DC: American Association on Mental Retardation (AAMR).

Head, E., Powell, D., Gold, B. T., & Schmitt, F. A. (2012). Alzheimer's disease in down syndrome. *European Journal of Neurodegenerative Disease, 1*(3), 353–364.

Head, E., Silverman, W., Patterson, D., & Lott, I. T. (2012). Aging and down syndrome. *Current Gerontology and Geriatrics Research, 2012*, 412536. https://doi.org/10.1155/2012/412536

Heller, T., Stafford, P., Davis, L. A., Sedlezky, L., & Gaylord, V. (2010). People with intellectual and developmental disabilities growing old: An overview. *Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities, 23*(1), 2–3. https://ici.umn.edu/products/impact/231/231.pdf

Hospice Foundation of America. (2013). *Supporting individuals with IDD through serious illness, grief, and loss* [Web page]. Washington, DC: Author. https://register.hospicefoundation.org/products/supporting-individuals-with-idd-self-study-dvd

Human Services Research Institute, & National Association of State Directors of Developmental Disabilities Services. (2013). *National Core Indicators Adult Consumer Survey 2011–12 final report*. Cambridge, MA: Authors. http://www.nationalcoreindicators.org/upload/core-indicators/CS_2011-12_Final_Report.pdf

Kingsbury, L. A. C. (2009). *People planning ahead: A guide to communicating healthcare and end of life wishes*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Kingsbury, L. A. C. (2010). Use of person-centered planning for end-of-life decision making. In S. L. Friedman & D. T. Helm (Eds.), *End-of-life care for children and adults with intellectual and developmental disabilities* (pp. 275–289). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Lakin, K. C., & Stancliffe, R. (2005). *Costs and outcomes of community services for people with intellectual disabilities*. Baltimore, MD: P.H. Brookes Pub. Co.

Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J. H., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal of Mental Retardation, 106*(3), 231–252.

Lavin, C. (2002). Disenfranchised grief and individuals with developmental disabilities. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 307–322). Champaign, IL: Research Press.

Lipe-Goodson, P. S., & Goebel, B. L. (1983). Perception of age and death in mentally retarded adults. *Mental Retardation, 21*(2), 68–75.

Magasi, S. (2008). Infusing disability studies into the rehabilitation sciences. *Topics in Stroke Rehabilitation, 15*(3), 283–287. https://doi.org/10.1310/tsr1503-283

Moran, J. A., Rafii, M. S., Keller, S. M., Singh, B. K., & Janicki, M. P. (2013). The National Task Group on Intellectual Disabilities and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. *Mayo Clinic Proceedings, 88*(8), 831–840. https://doi.org/10.1016/j.mayocp.2013.04.024

National Association for the Dually Diagnosed. (2016). *Information on dual diagnosis* [Web page]. Kingston, NY: Author. http://thenadd.org/resources/information-on-dual-diagnosis-2/

National Task Group on Intellectual Disabilities and Dementia Practices. (2012). *My thinker's not working: A national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their community and receive quality supports*. Chicago, IL: University of Illinois at Chicago, Department of Disability and Human Development, Rehabilitation Research and Training Center on Aging with Developmental Disabilities-Lifespan Health and Function. http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf

National Task Group on Intellectual Disabilities and Dementia Practices. (2016). *NTG-EDSD screening instrument* [Web page]. Hamden, CT: Author. http://aadmd.org/ntg/screening

Office of Disability Employment Policy. (2018). *What is customized employment?* [Web page]. Washington, DC: U.S. Department of Labor. https://www.dol.gov/odep/categories/workforce/CustomizedEmployment/what/index.htm

Perkins, E. A., & Moran, J. A. (2010). Aging adults with intellectual disabilities. *JAMA, 304*(1), 91–92. https://doi.org/10.1001/jama.2010.906

Pledger, C. (2003). Discourse on disability and rehabilitation issues. Opportunities for psychology. *American Psychologist, 58*(4), 279–284.

Pollack, K. M., Morhaim, D., & Williams, M. A. (2010). The public's perspectives on advance directives: Implications for state legislative and regulatory policy. *Health Policy, 96*(1), 57–63. https://doi.org/10.1016/j.healthpol.2010.01.004

Putnam, M. (2005). Conceptualizing disability: Developing a framework for political disability identity. *Journal of Disability Policy Studies, 16*(3), 188–198. https://doi.org/10.1177/10442073050160030601

Reiss, S., & Szyszko, J. (1983). Diagnostic overshadowing and professional experience with mentally retarded persons. *American Journal of Mental Deficiency, 87*(4), 396–402. http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1983-10672-001&site=ehost-live

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., … Developmental, D. (2010). *Intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Self-Advocates Becoming Empowered. (2011). *Welcome to SABE!* [Web page]. Author [SABE]. http://www.sabeusa.org

Siegel, M., Milligan, B., Chemelski, B., Payne, D., Ellsworth, B., Harmon, J., … Smith, K. A. (2014). Specialized inpatient psychiatry for serious behavioral disturbance in autism and intellectual disability. *Journal of Autism and Developmental Disorders, 44*(12), 3026–3032. https://doi.org/10.1007/s10803-014-2157-z

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 921–929. https://doi.org/10.1097/CHI.0b013e318179964f

Smith, T. J., Dillahunt-Aspillaga, C. J., & Kenney, R. M. (2017). Implementation of customized employment provisions of the workforce innovation and opportunity act within vocational rehabilitation systems. *Journal of Disability Policy Studies, 27*(4), 195–202. https://doi.org/10.1177/1044207316644412

Targett, P. S., Wehman, P. H., McKinley, W. O., & Young, C. L. (2004). Successful work supports for persons with SCI: Focus on job retention. *Journal of Vocational Rehabilitation, 21*(1), 19–26.

Tassé, M. J., & Grover, M. D. (2013). Normal curve. In F. R. Volkmar (Ed.), *Encyclopedia of autism spectrum disorders* (pp. 2059–2060). New York, NY: Springer.

Traustadóttir, R. (2006). Learning about self-advocacy from life history: A case study from the United States. *British Journal of Learning Disabilities, 34*(3), 175–180. https://doi.org/10.1111/j.1468-3156.2006.00414.x

Van Naarden Braun, K., Christensen, D., Doernberg, N., Schieve, L., Rice, C., Wiggins, L., … Yeargin-Allsopp, M. (2015). Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan atlanta, 1991-2010. *PLoS One, 10*(4), e0124120. https://doi.org/10.1371/journal.pone.0124120

Ward, M. J., & Meyer, R. N. (1999). Self-determination for people with developmental disabilities and autism: Two self-advocates' perspectives. *Focus on Autism and Other Developmental Disabilities, 14*(3), 133–139. https://doi.org/10.1177/108835769901400302

Yang, Q., Rasmussen, S. A., & Friedman, J. M. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: A population-based study. *Lancet, 359*(9311), 1019–1025.