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## **Ability Status, Self-Advocacy, and Individuals with Neurodevelopmental Disabilities: Neurodiversity-Informed Training for Professionals and Caregivers**

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Ability Status, Self-Advocacy, and Individuals with Neurodevelopmental Disabilities:  
Neurodiversity-Informed Training for Professionals and Caregivers

BY

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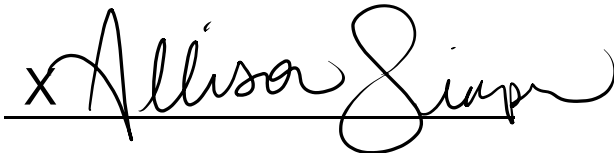
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Date: 1/5/2021

Ability Status, Self-Advocacy, and Individuals with Neurodevelopmental Disabilities:  
Neurodiversity-Informed Training for Professionals and Caregivers  
BY

ALLISON SIMPSON, M.S.

Submitted to the Faculty of the Graduate School of  
Eastern Kentucky University  
in partial fulfillment of the requirements for the degree of

DOCTORATE OF PSYCHOLOGY

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## ABSTRACT

Ability status in U.S. society is a critical social and cultural identity. “Disability” is often viewed through the lens of pathology as an illness. This kind of view affects not only the personal identity of individuals with neurodevelopmental disabilities, but also their treatment by others in the community, employers, caregivers, and others in their system of interaction. Even individuals who are strong self-advocates can be silenced by this kind of lens. A more empowering way to view individuals with neurodevelopmental disabilities is through the lens of neurodiversity in order to see their abilities, needs, wishes, and lives. The current project proposes the development and evaluation of a manualized training program to build awareness, knowledge, and skills in an effort to build allyship for individuals with neurodevelopmental disabilities

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## Section I: Introduction

The American Psychiatric Association (APA; 2013) uses the term “neurodevelopmental disorders” to describe a cluster of conditions that can be diagnosed during the developmental period. Individuals with neurodevelopmental disabilities such as Autism Spectrum Disorder (ASD) and Intellectual Developmental Disorder (IDD) face a higher risk for abuse and violations of personal rights and freedoms than neurotypical peers (Feldman, Owen, Anderews, Hamelin, Barber, & Griffiths, 2012). This disparity is seen across medical and mental health, residential and group home, educational, employment, and domestic settings (Bagatell, 2010; Browder, Bigby, Knox, Beadle-Brown, Clement & Mansell, 2012; Bambara, & Belfiore, 1997; Burkhardt & Obiakor, 2008; Davies, Stock, King, Wehmeyer, & Shogren, 2017; Shogren, Wehmeyer, Reese, and Ohara, 2006; Feldman et al., 2012; Reindl, Waltz, and Schippers, 2016). Since the 1960s, self-advocates with neurodevelopmental disabilities have organized to gain self-determination and bring light to the oppression they face personally and systematically (Bagatell, 2010). However, the community has faced a considerable amount of resistance from neurotypical professionals and care providers due to long-held stereotypes and implicit biases about the legal, social, and economic status of individuals with neurodevelopmental disabilities (Bagatell, 2010; Wehmeyer 2017). Even the strongest self-advocates find their voices silenced and their strengths, needs, desires, and wishes ignored by those who should know better. While many trainings exist to teach individuals with disabilities how to advocate for themselves, and to train professionals and care providers to serve this population, there is little literature

investigating the efficacy of such programs. Furthermore, there are no programs in the treatment research literature that address training through a neurodiversity perspective.

Research suggests that a neurodiversity-informed method to train those who work with individuals who have neurodevelopmental disabilities may be beneficial to both individuals with disabilities and those who provide them with care and services. This program seeks to utilize multicultural theory to build awareness, knowledge, and skills for working with a neurodiverse population. By addressing implicit biases, increasing understanding of the disability community and systemic oppression, and developing skills for more culturally sensitive and responsive care, this program will meet an immense need.

## Section II: Literature Review

### Methods for Literature Review Search

The literature review was conducted utilizing the database APA PsychINFO, in order to gain an understanding of previous research into the concept of ability status, self-advocacy, as well as current professional practices and trainings. In addition to information about neurodevelopmental disabilities this literature review also includes information about physical and acquired disabilities. Due to a paucity of literature in the area of training individuals who work with and care for neurodevelopmental disabilities, some literature from broader the studies of training in cultural awareness is reviewed, as well.

Some key search terms included: self-advocacy, self-advocacy and neurodevelopmental disabilities, self-advocacy and Autism Spectrum Disorder, self-advocacy and Intellectual Developmental Disorder, ability status, disability identity development, professional training and neurodevelopmental disabilities, group home culture, neurodevelopmental disabilities and residential settings, neurodevelopmental disabilities and employment settings, multicultural awareness training, and more. The journals that were utilized included the following: *Ethos*, *Intellectual and Developmental Disabilities*, *Journal of Behavioral Education*, *British Journal of Learning Disabilities*, *Journal of Intellectual Disability Research*, *International Journal of Disability, Development and Education*, *Rehabilitation Psychology*, *Disability and Health Journal*, *Worldviews on Evidence-Based Nursing*, *Training and Education in Professional Psychology*, *American Journal on Intellectual and Developmental Disabilities*, *Journal of Intellectual Disabilities*, *Journal of Intellectual and*

*Developmental Disability*, and the *Journal of Applied Research in Intellectual Disability*. Several books on neurodevelopmental disabilities, self-advocacy, and multicultural psychology were included in the literature review, as well.

### **Neurodevelopmental Disabilities**

#### *Introduction to Neurodevelopmental Disabilities*

As previously noted, the APA (2013) defines neurodevelopmental disorders as conditions that occur in the developmental period. Several conditions are encompassed by the neurodevelopmental disorders umbrella, including Intellectual Developmental Disorder (IDD), Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Language Disorder, and Specific Learning Disorder, among others (APA, 2013). All neurodevelopmental disorders are the result of underlying differences in brain structure and function that can lead to challenges with performing in academic, social, domestic, community and occupational settings. Due to these challenges, individuals with each of these diagnoses likely face discrimination and societal barriers; however, the emphasis of this project is upon individuals with intellectual and developmental disabilities, such as IDD and ASD, who are frequently in the care of others well into adulthood and have the most immense need for responsive caregivers and professionals.

According to Wehmeyer (2017), differences in brain structure and function have existed for as long as human beings have existed; however, these first began to be labeled and categorized as separate entities in the 1800s. Historically, society and its institutions have misused these labels and categories in a way that has resulted in exclusion, othering, and abuse (Wehmeyer, 2017). Various iterations of labels exist,

that have shifted and taken different forms as science and research have provided more information, and the current label used to describe individuals with differences in cognitive, adaptive, and social functioning, is “intellectual and developmental disabilities,” or “neurodevelopmental disabilities.” The label is broad, and unspecific, influenced by personal, public, critical, and definitional meanings that each impact perceptions associated with those with those labels (Wehmeyer, 2017).

Wehmeyer (2017) describes the “definitional meaning” of intellectual and developmental disabilities as that which is utilized to describe disability by professionals and care givers looking to provide appropriate services and care. This meaning is determined by service providing bodies and is likely most in line with the diagnostic criteria provided in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; APA, 2013) or other diagnostic and classification systems. While there is some debate over the use of these terms in medical and mental health, it is largely deemed necessary, especially in managed care settings and places where insurance covers the cost of services provided. The objection to the use of the neurodevelopmental disabilities label, and awareness of the negative impacts associated with the label, are considered to be the “critical meaning,” as coined by the Wehmeyer (2017). The “personal meaning,” captures the unique feelings of an individual with an intellectual or developmental disability, and how it affects them and their family, while the “public meaning” captures the sociocultural, political, and environmental contexts. According to Wehmeyer (2017), it is impossible to separate these meanings in regard to the perceptions and connotations that come to be associated with neurodevelopmental disabilities. Therefore, in order to understand the experience of a person who has IDD,

ASD, or some other disability, it is important to take all of the definitions into consideration and view individuals through a multicultural lens.

### **Multiculturalism and Ability Status**

Multiculturalism is an ever-expanding field that encompasses a wide range of topic, including race, gender identity, sexual orientation, and socioeconomic status, among others (Sue & Sue, 2013). Issues surrounding multiculturalism are a growing interest of public concern that one can observe simply by scrolling through social media; however, there is a disparity between the emphasis on disability identity and other cultural groups that extends into professional literature (Forber-Pratt & Zape, 2017). Nevertheless, Wehemeyer's (2017) emphasis on the fluid definition of disability across time and place that is derived through social and environmental factors is evidence that it is a social construct or cultural identity. The paucity of research into this particular area of identity development serves as evidence that this section of the population is largely underrepresented and underserved.

For the purpose of this project, ability status will be defined simply as whether or not a person has a disability. Forber-Pratt, Mueller, and Andrews (2019) discuss ability status, also frequently referred to as disability status, as a representation of one's disability identity. They emphasize that the disability community is a heterogeneous group, and that it is important to understand the broad range of individuals who belong to that community (Forber-Pratt et al., 2019). Just as any other cultural identity, ability status has a spectrum of privilege and oppression that exists within individuals, communities, and larger institutions. Regardless of the type of disability a person has, they face negative stereotypes, discrimination, and barriers in the environment that

impede their independence and quality of life. They experience oppression because they live in a world that is not designed to be accessible to them, and in many cases, is hostile toward them. Individuals without disabilities, also called “abled” individuals, experience privilege, in that they exist in a world that is designed for them, and do not face the same stereotypes and barriers in society that people with disabilities face.

According to the Center for Disease Control and Prevention (CDC; 2013), over 53 million adults living in the United States have some kind of disability. Paniagua (2014) explains that an entire disability community exists that is based upon acceptance of human variation, orientation toward vulnerability and interdependence as a part of life, and tolerance for difficult and less-than-desired outcomes, among other characteristics that most individuals with disabilities possess. Sue and Sue (2013) mention that these individuals often face negative attitudes from those who do not have disabilities, ranging from ignorance, to being overly sympathetic, and to dismissiveness. It is likely that these attitudes are both rooted in implicit biases about individuals with disabilities, as well as in the way that disabilities are conceptualized.

Forber-Pratt et al.(2019) describe three different types of models that can be used to conceptualize disabilities: medical models, social models, and diversity models. Medical models identify disabilities as diseases that must be cured while social models define disabilities as barriers in the environment that result in an individual’s disablement. Diversity models are similar to social models but establish ability status as a distinct social group (Forber-Pratt et al., 2019). Using a diversity model, one would conclude that individuals with disabilities may consider their disability as an integral



piece of who they are, their identity, rather than a disease or problem that must be fixed or corrected.

Wehmeyer (2017) provides more detail about different perspectives of disability, including the medical and social models, and offers an additional legal perspective. According to the author, the legal model defines intellectual and developmental disabilities as statuses granted by government and legal institutions. While it is largely out of use today, traces of this ideology can still be seen in modern laws, particularly those regarding guardianship, in which the held assumption is that in order to have legal power over one's rights respected, one must meet certain, arbitrary standards of intellectual functioning (Wehmeyer, 2017). Per the author, the medical or "biomedical" model, defines intellectual and developmental disabilities through the lens of pathology, deficits, and impairment in functioning, and it is defined based upon an arbitrary "norm" that can have negative impact on these individuals when it is the only way to define a person with a disability. While the medical model can be useful for informing professionals and care providers about what an individual might need, it can also lead to limiting views of individuals with disabilities (Wehmeyer, 2017). Similar to the social and diversity models discussed in Forber-Pratt et al. (2019), Wehmeyer (2017), defines the social or human rights model as focused upon disability as a sociocultural construct that is impacted by attitudes and environments. He suggests that the social model is imperative for closing gaps between exclusion and inclusion, and that doing so will require self-advocates, advocates for legal change, and healthcare providers working collaboratively to promote person-centered planning, fund programs, offer support, and provide services. Wehmeyer (2017) states that these efforts are

currently limited due to professional adherence to unhelpful models and biases as well as emphasis on segregated and exclusionary approaches.

According to Forber-Pratt and Zape (2017), identity is elusive and difficult to describe, but it undergoes a change process in which one becomes aware of themselves and their memberships to certain cultural groups. Forber-Pratt, Lyew, Mueller, and Samples (2017) conducted a literature review to analyze the identity development in those with disabilities. They defined disability as a unique identity that shapes an individual's worldview, as well as how they perceive themselves. They assert that individual acceptance of one's disability is important to identity development and stated that it is crucial for those who work with disabled populations to be aware of available disability services, informational resources, and communities, as well as their own biases. Additionally, Forber-Pratt and Zape (2017) propose the "Model of Social and Psychosocial Disability Identity Development," which focuses upon the importance of acceptance, relationships, involvement, and community. This identity development model suggests that becoming involved with a disability community, forming a relationship with others with disabilities, and becoming an advocate for oneself and others is an important part of identity development (Forber-Pratt & Zape, 2017).

Much of the disability literature is centered upon individuals with physical disabilities, and more specifically, those that are acquired (Forber-Pratt et. al., 2017; Forber-Pratt et al., 2019; Forber-Pratt & Zape, 2017). Still, this author believes that the discussion of ability status, disability identity, and identity development are applicable to individuals with neurodevelopmental disabilities due to similar experiences of

barriers and oppression within society, which will be evidenced by the discussion of the literature regarding the Self-Advocacy Movement and the concept of neurodiversity.

### **Self-Advocacy and Neurodiversity**

As is the case with many other minority groups, people with disabilities have organized in order to bring awareness to the societal barriers and discrimination they face in hope that changes will be made (Bagatell, 2010; Wehmeyer, 2017). For the neurodevelopmental disability community, this organization has taken the form of self-advocacy. One European study describes self-advocacy as both a movement to assist individuals with neurodevelopmental disabilities in acquiring self-determination skills, as well as a grassroots organization designed to lobby for change within societal institutions (Buchanan & Walmsley, 2006). Both definitions are important for individuals with neurodevelopmental disabilities, as they build awareness and promote action (Miller & Keys, 1996), as well as help to foster inclusion (Browder et al., 1997). Individuals with neurodevelopmental disabilities are considered a vulnerable population, and often experience not only discrimination by professionals and institutions, but also abuse by those who care for and provide services to them (World Health Organization, 2012). Learning how to self-advocate is important for individuals with neurodevelopmental disabilities, as is educating those who work with them about the societal barriers they face.

#### *The Self-Advocacy and Neurodiversity Movements*

The Self-Advocacy Movement is considered a civil rights movement for those with intellectual and developmental disabilities (Friedman, 2017). It began in the 1960s when other civil rights movements formed; however, it did not take hold in the United

States until the 1970s, when the first self-advocacy group formed following the diagnostic broadening of the Autism Spectrum and the resulting increase in prevalence of people diagnosed (Bagatell, 2010). Advocacy and self-advocacy increased as professionals began to recognize the impact and importance of self-determination for individuals with neurodevelopmental disabilities in gaining access to their communities (Browder et al., 1997). Furthermore, the evolution of the internet has assisted individuals with neurodevelopmental disabilities in sharing their experiences and developing communities in which they are accepted and affirmed for the very things that have led toward their discrimination in other settings, including medical, mental health, employment, educational, a domestic environments (Bagatell, 2010).

According to Bagatell (2010), many self-advocates within the movement seek a “differences” and “neurodiversity” model of their conditions, rather than those that conceptualize disability as a “disease” or series of deficits. In fact, in accordance with notion of disability identity, many individuals with ASD consider their diagnosis to be part of who they are and would prefer that it be accepted rather than changed (Bagatell, 2010). It is likely that individuals with other neurodevelopmental disabilities share similar opinions. Bagatell (2010) argues that ASD and other neurodevelopmental disabilities, just like physical disabilities, are a social construct, and that the problem lies not within the disabled person, but with attitudes held by society.

Many self-advocates, particularly those with ASD, take issue with the rhetoric and practices held and conducted by neurotypical policymakers, professionals, and care providers (Bagatell, 2010). In recent years, the growth in rates of ASD diagnosis has been treated as a public health crisis, and it has been framed by some as an epidemic

rather than an increase in identification (Bumiller, 2008). Additionally, “labeling power” has historically been, and still remains, in the hands of medical professionals, who diagnose through observation and differential diagnosis (Bumiller, 2008).

At the heart of the self-advocacy movement is the concept of neurodiversity, which is a movement in philosophy defined by Bumiller (2008) as reframing neurodevelopmental disabilities as inheritable genetic variations that add to the richness and complexity of human nature. This stands in stark contrast to the previous, pathologizing conceptualizations of ASD and other neurodevelopmental disabilities. It also aligns with the views upheld by the social and diversity models of disability. Bumiller (2008) states that self-advocates among the disability community have taken objection to the power held by the medical profession to define their identities, label them as “tragedies,” diminish their abilities, and overpathologize their common characteristics. According to Bumiller (2008), the societal push for normalization, inclusion, and tolerance still relies on neurodiverse populations learning to follow standards of a nondisabled society. She explains that the neurodiversity movement instead seeks to recognize the unique qualities of individuals with neurodevelopmental disabilities and reframe social challenges as social differences (Bumiller, 2008).

Despite the neurodiversity movement’s embrace of inheritable genetic differences, recent discoveries about potential genetic causes of intellectual and developmental disabilities has led to growing concern about the return of eugenics rhetoric and genetic intervention (Wehmeyer, 2017). Self-advocates have spoken out against such notions, as well as voiced concern that their non-disabled allies and advocates would not share the same view and continue to support “a cure” (Wehmeyer,

2017). Wehmeyer (2017) emphasizes the need for professionals in the field of disabilities to work with self-advocates to shape and increase positive values for and about people with neurodevelopmental disabilities. He also asserts that the continued growth of the self-advocacy movement shows that people with disabilities who are asserting their desire to be consulted on issues related to them (i.e., policy and service issues, research agenda), and that the results have been demonstrated in the increased empowerment and numbers of disabled individuals marrying, having children, attending post-secondary school, gaining employment, and attaining personal fulfillment. Arguably, the self-advocacy and neurodiversity movements have had an overwhelmingly positive influence on individuals with neurodevelopmental disabilities and those who work with and care for them. With that being said, self-advocates have still faced a considerable amount of backlash from a largely neurotypical society (Bagatell, 2010; Wehmeyer, 2017).

#### *Resistance to Self-Advocacy and Neurodiversity*

For as long as the self-advocacy and neurodiversity movements have existed, proponents of the movement have faced criticism and objection to the principles they uphold (Bagatell, 2010). As with any civil rights movement in which oppressed or minority groups begin to speak out about discrimination and demand justice, self-advocates with neurodevelopmental disabilities have faced backlash from a majorly neurotypical society. Wehmeyer (2017) states that this pushback began in the 1970s when government and professionals within the mental health field began the process of deinstitutionalizing and normalizing individuals with intellectual and developmental disabilities. He explains that much of the criticism took the form of societal bias and

stereotypes, as well as concern for the safety and well-being of formerly institutionalized individuals; however, proponents of normalization continued to push for community inclusion. Self-advocates testimony and the testimony of advocates and care providers have helped establish legal rights and ensure respect and protection from unfair laws and discrimination, a seemingly insurmountable task considering that they have faced societal, governmental, legal, and other systems that are determined to view them as fundamentally different (Wehmeyer, 2017).

Bagatell (2010) wrote about his experiences observing a self-advocate group for individuals with ASD, and he mentions that group members discussed experiencing objection to their desire to speak for themselves and for objecting to harmful campaigns, language, and treatment practices. Specifically, the author mentioned that group members were disturbed by professionals and care providers seeking to “cure them.” Bagatell (2010) also noted that self-advocates from the group who he interviewed expressed a desire for help, but that the challenges with which they wanted assistance were often dismissed by those who worked with them. According to Wehmeyer (2017), people still question the degree to which people with neurodevelopmental disabilities can be self-advocates, and how those related to intellectual functioning can understand their own rights and handle leadership positions; however, consistently, self-advocates have asserted that the largest barriers they face in society are the punitive attitudes and negative biases against them.

Despite the conflict between opposing models of disability, there is hope that common ground can be found between the medical and social/disability proponents. Kapp, Gillespie-Lynch, Sherman, and Hutman (2013) conducted a study to examine the

perceived opposition between medical and neurodiversity models, and among individuals with varying degrees of relation to ASD (i.e., individuals, friends, relatives, professionals, etc.). They found that self-identification as autistic and neurodiversity awareness were related to positive views of neurodevelopmental disability, and that this overlaps between both medical and neurodiversity models. They also found that recognition of negative aspects and parenting practices that celebrate and relieve, but do not eliminate ASD did not differ between groups. Furthermore, they found that the major differences between those with ASD and those without ASD were that people with ASD were more likely to be aware of neurodiversity, found the diagnosis to be more central to their identity, and were less interested in research about cures and causation than neurotypical participants. Kapp et al. (2013) argued that the overlapping beliefs about neurodiversity awareness and celebration-related parenting practices reflect the recognition and acceptance that autism cannot be cured. They hint at a trend whereby neurotypical loved ones, care providers, and professionals begin to see autism and neurodevelopmental disabilities as an identity out of practicality while neurodiverse individuals choose to adapt to the neurotypical world out due to a practical need to survive in societies that are slow to enact sociocultural and political change (Kapp et al., 2013). Still, these results, taken into consideration with other information about the self-advocacy and neurodiversity movements suggest that neurotypical individuals who work with and care for those with neurodevelopmental disabilities could benefit from learning information about neurodiversity and challenging their biases to become more celebratory of individual differences in human nature.



### *Current Resources For and Practices with Self-Advocates*

Many individuals with neurodevelopmental disabilities, even self-advocates, have teams of individuals with whom they work, and who provide resources and services for them. Most individuals with neurodevelopmental disabilities receive services through federally funded, community-based waiver programs. Friedman (2017) conducted an analysis to examine the self-advocacy services provided within these waiver programs. The author found that there are two general types of self-advocacy services provided: stand-alone services, which are designed to enhance participants' ability to function independently in the community and offer peer support, and embedded services, which are those included within the context of other services. The author also found that despite the existence of these programs, they are widely underutilized, and argued that underutilization is likely the result of "low expectations" for participants in the programs and poor management practices (Friedman, 2017).

Most self-advocacy resources, whether stand alone or embedded services, are designed to teach leadership and self-advocacy skills to individuals with neurodevelopmental disabilities. Feldman et al. (2012) conducted a randomized control trial to test the effectiveness of a program that was created to instruct individuals with intellectual and developmental disabilities. Per the authors, the program was assigned to address the concern of rights violations committed by medical professionals, with the belief that teaching self-advocacy skills to individuals with neurodevelopmental disabilities will help them avoid abuses by professionals. The program proved to be effective for individuals with mild and moderate intellectual disability, and the authors recommend more comprehensive programs. However, this research did not make any

comment on the practices of the professionals who work with clients who have neurodevelopmental disabilities (Feldman et al., 2012).

Cone (2000) interviewed non-disabled advisors of self-advocacy groups to gather information about the operation of the groups as well as the role they played in their operation. According to the author, self-advocacy groups should theoretically grow in independence and require less oversight from advisors as time passes and members learn appropriate leadership skills; however, many advisors reported that they performed the same administrative and operational activities for the groups consistently over time. Cone (2000) argues that these results suggest that either members actually need long-term support or advisors may not believe participants capable of running groups on their own. This is consistent with Friedman's (2017) suggestion of a "low expectation" bias toward clients with disabilities.

Conversely, Caldwell (2010) conducted interviews with self-advocates across the U.S. in order to identify themes of self-advocacy and leadership development in individuals with neurodevelopmental disabilities, and found that individuals who emerged as strong self-advocates believed that participating in the self-advocacy movement, and in self-advocate groups, helped them to develop self-advocacy skills. Caldwell (2010) explains that the opportunity to practice leadership skills and learn from other self-advocates was reported to be a contributing factor to growth, along with having a strong support system and accessible community environments. This apparent difference between the opinions of individuals with neurodevelopmental disabilities and their neurotypical service providers is of particular importance for this project.

This literature suggests that individuals with neurodevelopmental disabilities are able to learn self-advocacy skills and practice self-determination and self-direction when provided with the appropriate resources. Many individuals with learning disabilities want to share the stories of their lives, and these stories have proven to be a valuable way for individuals with disabilities to gain self-determination and teach those who support people how to best be advocates and allies (Traustadóttir, 2006). This, however, does not account for the bias of neurotypical caregivers and service providers to perceive that people with intellectual and developmental disabilities will not be able to advocate for themselves. It also does not account for rights violations and abuses committed against this population due to implicit biases that are the result of cultural differences in ability. Teaching individuals with neurodevelopmental disabilities to self-advocate is important; however, as research suggests, self-advocates often increase their skills the most when interacting in a community with other self-advocates. Furthermore, regardless of individuals' ability to speak up for their own needs and wants, if those around them do not listen or take their statements seriously, people with neurodevelopmental disabilities will likely not receive the full benefit of possessing such skills.

### **Current Treatment of Individuals with Neurodevelopmental Disabilities**

The concerns of self-advocate community regarding the tension and resistance from neurotypical service providers, caregivers, and community members, when considered against the backdrop of privilege, oppression, and ability status, emphasize the presence of an overarching societal dilemma. Biases and stereotypes can influence the way individuals are treated across settings, and thus it is important to examine the

current trends in working with and providing care for people with intellectual and developmental disabilities. Specifically, it will be important to make note of the strengths that exist across various settings and disciplines, as well as to notice weaknesses, and areas where neurodiversity-informed changes could be made. This training program is designed to be applicable across professions, and therefore literature examining practices across medical, mental health, direct support, residential, academic, employment, community, and domestic settings will be included in this review.

Individuals with intellectual and developmental disabilities are at a higher risk for abuse and violations of personal freedoms and rights than neurotypical individuals (Feldman et al., 2012). In many cases individuals with neurodevelopmental disabilities are ignored and dismissed and invalidated. In other cases, professionals fail to obtain appropriate informed consent or assent due to professional beliefs that disabled individuals will not be able to understand information provided to them. They also face exclusion and social isolation, challenges in achieving academically, and barriers to obtaining employment. Furthermore, this population faces higher rates of physical, verbal, and emotional abuse and neglect by family members and/or other care providers. It is important, when looking for solutions to adjust institutional attitudes, to consider the current practices, both good and otherwise.

#### *Medical and Mental Health Settings*

Medical and mental health settings see a high degree of patients and clients with neurodevelopmental disabilities. Everyone needs healthcare, and in the case of people with ASD, IDD, and other developmental disabilities, behavioral and psychological services are often recommended as well. Shogren et al. (2006) found that despite being

at higher risk for certain medical conditions, people with intellectual and developmental disabilities are less likely to receive preventative screenings and care, and that they are less likely to have positive health outcomes as a result. They argue that self-determination and self-direction of healthcare services should be made commonplace in order to address these disparities. While there is often question as to whether individuals with intellectual differences can understand and advocate for themselves in medical settings, the medical self-advocacy training program implemented and tested by Feldman et al. (2012) stands as a good example that such self-direction is possible and encouraged.

With regard to mental health professions, the same biases and attitudes that affect the medical professions still apply. Clinical and counseling psychology often pride themselves on multicultural awareness and understanding of diversity yet continue to conceptualize cases through the lens of neurotypicality. While the primary goals of many individuals with intellectual and developmental disabilities are independence and are independence and community inclusion, and mental health practitioners are particularly equipped to help clients meet those goals, many mental health practitioners underestimate their clients and their potential for a good quality of life (Sue & Sue, 2013). These professionals have also been criticized for over-relying on instructional interventions and teaching skills to help clients adapt to and function in a society that is not always accessible to them (Browder et al., 1997). Such skills trainings can be helpful, but Browder et al. (1997) argue that independence and inclusion are better fostered by advocacy on behalf of clients, promotion of natural supports, and ensuring a positive environmental match. They state that such practices give people opportunities

to practice self-management, putting them in the position to experience life-long growth and learning. Specifically, Browder et al. (1997) emphasize the importance of client-centered approaches that allow individuals to challenge their own stigmatization and focus upon individuals' strengths and naturalistic inclusion as opposed to inclusion that is based upon "readiness" or other criteria.

Sue and Sue (2013), who are considered experts in the field of multicultural psychology, suggest that mental health professionals who work with individuals who have disabilities of any kind should examine their views of clients with disabilities, question their biases, and focus upon supporting clients to gain a sense of control. Forber-Pratt et al. (2019) conducted a literature review to examine practitioners' roles in working with clients who have disabilities. The authors suggested that practitioners should view themselves as allies and collaborators with disabled clients rather than experts whose role is to "fix" them. They argue that it is a practitioner's responsibility to understand intersectionality, respect the choice of terminology (i.e. identity-first vs. person-first language), embrace universal design for removing barriers, act as an ally, recognize oversensationalizing of disabled individuals, inform oneself of current rights issues facing the community, check implicit biases, and embrace cross-cultural solidarity. Forber-Pratt et al. (2019) focused their research and suggestions on individuals with physical disabilities; however, the same concepts apply to developmental disabilities, and it is likely that such practices would promote a more positive experience for these clients.

Other complaints that self-advocates have made about mental health practitioners surround dismissed concerns regarding treatment modalities, specifically

Applied Behavioral Analysis (ABA) (Bagatell, 2010). Despite its status as an empirically supported intervention, ABA stands as one of the more controversial treatment practices in use at present due to its long history of using aversive consequences to modify behavior. Although present day ABA is rooted in learning theory and focuses on operant conditioning and positive reinforcement, its use is still a cause for anxiety among individuals with disabilities who believe it to be “dehumanizing.” It is likely that there is a lack of proper explanation of ABA strategies to individuals with neurodevelopmental disabilities, and that the miscommunication causes concerns to grow. The Autistic Self-Advocacy Network (ASAN), is notable for speaking out against the use of ABA as a primary intervention for ASD, and has encouraged professionals in mental health and other fields to offer other options (ASAN, 2015). Regardless of the efficacy of ABA treatments, mental health professionals should not dismiss the concerns of those neurodiverse clients who raise concerns about ABA or any other treatment modality. Focusing on clients’ personal goals and needs and treating them as the experts on themselves can help to ameliorate some of the anxieties associated with treatment.

### *Residential and Group Home Settings*

In addition to receiving psychological services, many individuals with neurodevelopmental disabilities live in residential or supported community environments. These residential settings can be places where individuals with disabilities can thrive, and they can be settings where individuals face discrimination and abuse. Two studies by Australian researchers explored the “culture” in group homes that produced poor outcomes for residents and in those that produced better

outcomes. Bigby, Knox, Beadle-Brown, Clement, & Mansell (2012) investigated the culture in underperforming group homes in order to determine any theme that might contribute to poor performance. Several overarching characteristics were noted, including misalignment of organization values and staff values, staff-centered practices, and resistance to change and new ideas. Additionally, and most relevant to the current project, underperforming homes were found to have a culture of “otherness” in which direct support staff believed that residents are fundamentally different from them and are therefore too impaired to benefit from disability policy or engagement and inclusion. Underperforming group homes were those in which staff believed that their purpose was to do things for residents rather than helping residents to complete tasks for themselves.

Bigby and Beadle-Brown (2016) examined the culture in group homes with better outcomes than those that underperformed. Their research found that better-performing group homes had cultures that were characterized by staff who believed residents were fundamentally similar to them and had a sense of overall positive regard. They also found that the staff of these group homes held positive regard for residents, were very person-centered and responsive to both verbal and nonverbal cues and believed that their purpose was to support residents in living the lives they wanted to live. The authors suggest that this sort of high quality, responsive support is more likely to result in better quality of life and outcomes for individuals with intellectual and developmental disabilities.



### *Educational Settings*

Education practices have an important role in the lives of people with neurodevelopmental disabilities. Unless parents choose to homeschool, most neurodiverse children attend school where they receive an education that is hopefully adapted in a way that is accessible to them. Self-advocates have emphasized the important role that good, attentive teachers played in their academic success, and suggested that inclusion be a priority (Bagatell, 2010). For over a decade, there has been a push for children with neurodevelopmental disabilities to have as much access to general curriculum as possible, while also being exposed to instruction in self-determination and self-reliance utilizing individual in and out of school experiences, assistive technology, and the involvement of families and community (Burkhardt & Obiakor, 2008). It is believed that exclusion of neurodiverse children and restriction of personal choice are bad for the educational community (Burkhardt & Obiakor, 2008).

Several different strategies have been proposed, researched, and implemented in the school setting to help insure inclusion of children with disabilities. These strategies include utilization of augmented learning strategies such as graphic organizers, chunking techniques, and mnemonic devices and student-directed approaches such as supported goal setting and problems solving (Lee et al., 2006) Additionally, there are other, more indirect and instructional interventions gaining empirical support that utilize peers supports. There are a variety of peer-mediated interventions (PMI) that utilize peers of those with autism, typically in inclusive settings (Watkins et al., 2014). They agree to serve as coaches for social skills training by providing cues, prompts, natural reinforcement for use of appropriate social skills, and even direct instruction through

modeling, roleplaying, and social scripts (Watkins et al., 2014). It is likely that PMIs are helpful for fostering not only academic and social attainment, but also in decreasing the occurrences of bullying faced by students with disabilities. Educating peers about disabilities could be helpful for promoting and ensuring inclusion.

Despite societally held biases of low-expectations, people with neurodevelopmental disabilities can and do attend post-secondary schools. According to Burkardt and Obiakor (2008), neurodiverse individuals are attending colleges at higher rates than ever; however, they often require access to accommodations to be successful and are more likely to prosper in environments where accessibility is embraced. They assert that, while the legislation exists to ensure that individuals with disabilities are supported in a college environment, it is not always appropriately enforced, leading to challenges and adversity for neurodiverse college students.

Shogren et al. (2018) studied the performance of individuals with intellectual and developmental disabilities in post-secondary school as it is related to self-determination status. They found that the biggest factor into positive outcomes were the experiences they had in their primary education, such as access to general curriculum and participation in regular assessments. In this study, accommodation was not found to be related to performance, as so few individuals actually received services for which they were eligible. It is possible that societal misconceptions about neurodiverse individuals and college attendance, as well as personal choice to not self-disclose disability impact the services and accommodations individuals receive in post-secondary school.

As with primary education, peer mentors can be and are utilized for individuals with neurodevelopmental disabilities in college settings. One such practice is called structured social planning, and it has been shown to work in improving social integration and academic success for college students with ASD (Ashbaugh, Koegel, & Koegel, 2017). This type of intervention involves supporting a student with autism to schedule interest-aligned social activities in which to participate, training that individual in organizational skills, and assigning a peer mentor to support the person with ASD throughout the process (Ashbaugh et al, 2017).

As a whole, children and adults with intellectual and developmental disabilities experience barriers in completing some of the activities in a school environment. One such barrier involves the process of testing (Davies et al., 2017). Davies et al. (2017) argue that, while alternative testing procedures exist, they often do not allow for much self-direction. The authors piloted a study to test a cognitively accessible, self-paced testing system, demonstrating its technical merit, feasibility, and utility in helping individuals have greater accuracy on tests. These types of technology-assisted accommodations are helpful in promoting inclusion.

### *Employment Settings*

According to Sue & Sue (2013), 90% of individuals with a psychiatric disability are unemployed, which is the highest rate of any disability group. Despite the challenges in finding employment, there is evidence that maintaining a job can have a positive impact on individuals with neurodevelopmental disabilities and their families (Hedley et al., 2016). Meaningful employment is an important component for individuals, regardless of ability status, to have a good quality of life (Burkhardt &

Obiakor, 2008), and social integration within employment is a key factor related to positive outcomes for adults with intellectual and developmental disabilities (Kirby, 2016).

Unfortunately, the research investigating employment programs and interventions individuals with intellectual and developmental disabilities is limited (Hedley et al., 2016). Dean, Shogren, Hagiwara, and Wehmeyer (2018) conducted a literature review to examine the relationship between positive quality of life and health outcomes and attainment of meaningful employment. While they found that research in the area was limited, they explained that there is a general positive trend in quality of life and health benefits for individuals who have an occupation that they enjoy.

Integrated employment, in which people with disabilities work among non-disabled peers for the same wages and benefits is viewed as optimal for economic and community security (Dean et al., 2018). However, according to Burkhardt and Obiakor (2008), individuals with intellectual and developmental disabilities often need support at their places of work that inhibit the ability to obtain an integrated position. There are several different options for supporting individuals with neurodevelopmental disabilities in the work setting. One option that Burkhardt and Obiakor (2008) mention is “supported employment,” in which an individual is placed at a job designed for a neurotypical person and provided with an “employment specialist” who assists them with work-related problems.

People with neurodevelopmental disabilities have been shown to benefit from natural supports in the process of finding and keeping a job (Wilczynski, Trammell, & Clarke, 2013). These supports often occur in the form of vocational training, education

about available resources, guidance in looking for suitable job environments and filling out applications, as well as in preparing for the interviews (Wilczynski et al., 2013). Furthermore, it is important that natural supports also be in place once an individual is employed using scaffolding for job tasks and involving coworkers in the process of coaching employees with autism (Wilczynski et al., 2013). Some technological interventions have also begun to show promise, particularly methods using video modeling or discrete, in-ear audio prompting for job-related tasks (Wilczynski et al., 2013).

Another empirically supported method for promoting positive employment outcomes in adults neurodevelopmental disabilities is customized employment (CE), which involves an individual finding an employer that is willing to adapt a job position in various ways to cater to that person's strengths and weaknesses (Wehman et al., 2016). According to Wehman and colleagues (2016), CE looks different for each individual and often employs strategies for areas including, but not limited to, managing lunch breaks (i.e. alarms on mobile devices, schedules), completing tasks and transitioning independently (i.e. visual schedules, reminders, decision trees), social interaction (i.e. written or audio scripts, roleplaying), handling frustration and down time (i.e. rehearsal, visual support, self-monitoring plans), and task initiation (i.e. circular web schedules, numbered lists).

Despite the varying supported employment options for individuals with neurodevelopmental disabilities, many remained under employed. This could be in part due to difficulties related to acquiring a job. Vocational training is used frequently for any individual who struggles to find and keep an employment, and it has shown

considerable efficacy in helping individuals with neurodevelopmental disabilities learn job-related skills such as organization, time management, and interacting with customers as well as pre-employment skills of finding, applying, and interviewing for positions (Seaman & Canella-Malone, 2016). Additionally, with recent advances in technology, vocational skills, like many others, can be trained using interactive computer programs. One such intervention shown to be efficacious involves utilizing virtual reality software to help individuals to improve interviewing skills (Smith et al., 2014), which could be a very important step in helping individuals obtain jobs.

Another likely reason that individuals with intellectual and developmental disabilities continue to struggle to find and maintain meaningful employment is that negative attitudes about people with disabilities are difficult to tamp out in work environments. Many employers still hold on to beliefs of low expectations and assumptions about ability that impact their willingness to hire neurodiverse people (Burkhardt & Obiakor, 2008). In some cases, employers may even be ignorant to the laws in place to protect individuals with disabilities and their right to employment (Burkhardt & Obiakor, 2008). Going forward, people with intellectual and developmental disabilities, as well as companies that offer employment to those individuals, would benefit from intervention and training that combats stereotypes about neurodiversity, and provides employers with information that helps them to better support their employees with disabilities.

### *Domestic Settings*

Family members and care providers can also have a significant impact on individuals with developmental disabilities through their own interactions with and

treatment of those individuals. Many self-advocates report that family and care providers can be sources of both support in the community and barriers to inclusion, as individuals with neurodevelopmental disabilities struggle to gain independence from family members and seek inclusion in household decisions (Caldwell, 2010).

According to Kirby (2016), outcomes regarding residential independence among adults with neurodevelopmental disabilities vary from person to person, and it often depends on a plethora of other factors. Specifically, people with autism in particular, who have a greater functional capacity within areas of social integration, daily living skills, and cognitive performance are more likely to live independently (Kirby, 2016).

Furthermore, those who come from secure family backgrounds with parents who expect and encourage independence often have more success at establishing independence as well (Kirby, 2016). While there has been a society wide shift toward community inclusion and against housing in residential facilities, it is important to note that simply living in the community does not ensure that an individual will have access to meaningful social engagement, employment or other experiences that result in more life satisfaction (Wehmeyer, 2017)

Reindl et al., (2016) conducted a study to examine the tension between parental control and care, finding that individuals living in parent-initiated supported living settings lack freedom and personalization. More specifically, they found that parental attitudes and beliefs can impact personalization, impede the development of a positive disability identity, lead to poor self-efficacy, and limit how much an individual is able to choose with whom they live and whether or not they have romantic relationships. Reindl et al. (2016) recommend that interdependence and self-direction should be the

focus of both parents, care providers, and those who work at supported living environments. Furthermore, they state that teaching self-determination and self-advocacy skills is not enough build social inclusion and integration and argue that the onus of ensuring positive experiences for individuals with disabilities is on parents, care providers, community members, and institutions, and the removal of accessibility barriers (Reindl et al., 2016).

Due to the remnants of the legal model of disability, many adults with intellectual and developmental disabilities are under the guardianship of parents, other relatives, or a state-appointed person, and cannot legally make decisions about their own care in many situations. One proposed solution to this problem, and framework for helping people with intellectual and developmental disabilities to exercise autonomy and self-determination over life decisions is supported decision making (SDM; Shogren Wehmeyer, Lassman, & Forber-Pratt, 2017). According to the authors, despite the fact that the framework is still in development, they have hopes that shifting toward provision of decision-making supports that take into consideration the sociocultural context, environment, and support needs related to each individual. Given this information, it appears that parent and/or care providers may benefit from learning ways to be more responsive to the needs of those for whom they care.

### **Professional Development and Training in the Neurodevelopmental Disabilities**

#### **Field**

Anyone in a service profession, particularly medical and mental health fields, as well as in schools and employment settings, has the potential for working with or providing services to individuals with neurodevelopmental disabilities. As with other



diverse populations, providing services and care to individuals with neurodevelopmental disabilities requires some degree of multicultural awareness in order to be sensitive and responsive. In a 2016 research brief report published by the University of Kentucky's Human Development Institute, Melvoli et al. surveyed individuals with neurodevelopmental disabilities across Kentucky to ask them what they need in order to thrive in their communities. While transportation and employment were reported as the most prevalent issues, self-advocacy and the necessity of sensitivity training for providers, nurses and healthcare staff were also noted as important. These results indicate that current training programs either fail to address cultural sensitivity, do not place enough emphasis on cultural sensitivity, or trainees fail to carry the concepts from their training into their service and/or care provision (Melvoli et al., 2016). The following portion of this literature review will discuss current and suggested training practices used for both general and specialized settings, as well as their strengths and weaknesses.

### *Specialized Training Practices*

Employee orientation and training are typical processes for ensuring that new employees are appropriately prepared to perform the tasks a given job requires. This is no different for organizations and institutions that provide services to individuals with neurodevelopmental disabilities. Many such organizations utilize specifically designed training protocols such as Active Support (Mansell & Beadle-Brown, 2012).

Communities, and educational settings also have programs to educate people about intellectual and developmental disabilities, such as psychoeducation and person-centered approaches (Shipton & Lashewicz; Browder et al, 1997) Person-centered

approaches and Active Support are two of the most commonly referenced concepts in neurodiversity-focused training found in the literature, and they are often used in tandem to promote quality care for individuals with disabilities.

Shipton and Lashewicz (2017) conducted a literature review to investigate the factors influencing quality of care received by adults with neurodevelopmental disabilities and other mental health conditions living in group homes. They found that self-determination and social inclusion are central to good quality of care, and that person-centered approaches and Active Support seem to play a role in helping clients to be understood, experience personal security, and have some degree of personal freedom. Person-centered approaches are largely focused upon collaboration and attention to a client's own desires and goals. Research has shown that using a person-centered approach in community-based instruction for people with neurodevelopmental disabilities allows for an increase in community living competence by empowering people to learn from themselves and self-manage (Browder et al., 1997). The premise of these approaches is to allow an individual with an intellectual or developmental disability choices and self-determination, while those around them serve as advocates and offer natural supports (Browder et al., 1997).

Active Support training is designed specifically for use in group home settings with supervisors and direct support professionals to foster opportunities, support individual choice, schedule activities, and provide engagement and support as people with neurodevelopmental disabilities participate in daily life (Mansell & Beadle-Brown, 2012). The principles of Active Support coincide with person-centered approaches and provide a structure to teach person-centeredness to those who support individuals with

neurodevelopmental disabilities. The research surrounding the impact and efficacy of Active Support training is mixed. Some results suggest that Active Support training for staff is not associated with an improvement in engagement for individuals (Qian, Larson, Tichá, Stancliffe, & Pettingnell, 2019), while others suggest that it is an effective strategy for training and empowering staff and care providers (Riches, Harman, Keen, Pennell, Harley, & Walker, 2011). Organizational and exosystem factors, such as issues related to management, turnover rates for staff trained, among others, could play an important role in determining whether or not active support interventions are effective (Qian et al., 2019; Riches et al., 2011). This suggests that some problems with the efficacy of Active Support could be ameliorated through making changes to the way that staff and supervisors are trained.

While much of the literature on training focuses upon group home and residential settings, schools and educational institutions are also ideal environments for neurodiversity-focused training (Rilotta & Nettlebeck, 2007). In one school district, Rilotta and Nettlebeck (2007) examined the impact of social and educational integration combined with an “awareness of disability” training for school students. They found that awareness programs for neurotypical classmates can lead to the development and maintenance of positive attitudes toward people with neurodevelopmental disabilities, and that programs that involved education, guest speakers from the community, and direct contact or interaction resulted in better outcomes. Children who received awareness of disability training in this format developed long lasting, positive attitudes about inclusion in an educational setting (Rilotta & Nettlebeck, 2007). It is possible

that similar trainings would produce more inclusion-mindedness outside of the school as well.

### *Diversity Training*

Beyond the specialized training professionals and care providers receive for working with those who have neurodevelopmental disabilities, training in broad multicultural competency can introduce concepts related to ability status as well. Clinical and counseling psychology graduate programs utilize a standard structure for developing multicultural competency in their students, however, other professions have utilized similar training approaches with some measure of success (Govere & Govere, 2016; Stevenson, Cheunt, & Leung, 1992). Govere & Govere (2016) conducted a systematic literature review examining both the impact of multicultural competency training on healthcare professionals as well as the relationship between multicultural competence and patient satisfaction. Most of the literature reviewed suggested that training had a positive influence on providers' multicultural competence. The authors also found that improved multicultural competence was associated with improvements in the self-reported satisfaction of patients (Govere & Govere, 2016). Similar programs have also been used to effectively enhance the cultural competency of those who work in social services or child protective services (Stevenson et al, 1992).

Jones, Sander, and Booker (2013) outlined the methods used for instructing cultural competency within graduate programs, noting that the most important first step is to ensure safety. According to the authors, competency building occurs through self-awareness, and noticing and challenging of preconceived attitudes and biases, building understanding of other cultures, applying multicultural awareness to work settings, and

subverting the systematic challenges that face the culturally diverse. The authors provide suggestions for activities and components of training, including the involvement of culturally different mentors (Jones et al., 2013). The structure of graduate training appears to be flexible and adaptable for use outside of the classroom setting and would likely translate easy for use in other professions or the community.

#### *Need for a Neurodiversity-Informed Training Program*

All of the interventions and programs discussed in the literature and outlined in the previous sections of this review are important and valiant efforts to increase inclusion and improve the quality of life for individuals with intellectual and developmental disabilities. Despite all of these efforts to promote positive outcomes for neurodiverse individuals, societal attitudes and stereotypes remain one of the most prominent barriers for people with neurodevelopmental disabilities (Bumiller, 2008). Person-centered care, active support, and supported decision-making, as well as supported employment, and accessible education strategies cannot have the full and intended positive impact if those who implement programs and provide accommodations still retain implicit, detrimental attitudes about those who they support. Teaching individuals how to self-advocate and voice their own needs and concerns is vital, but often not enough when facing a resistant, neurotypical society. The best way to address these barriers is to challenge the biases of those who provide care and services to neurodiverse people.

Experts in multiculturalism and disability posit that working with individuals who have disabilities is fundamentally similar to working with other oppressed groups, and that clinicians and professionals must examine their own views of those with

disabilities so that they might identify and question potential biases (Forber-Pratt et al., 2019; Sue & Sue, 2013). As previously noted, individuals with neurodevelopmental disabilities believe that sensitivity training or their providers is necessary (Mevoli et al., 2016). Research provides evidence to support the notion that when self-advocates are listened to appropriately, this allows for dialogue that increases engagement and quality of life ( Ryan & Griffiths, 2015), and it is imperative that professionals be trained on ways to listen and be allies.

Forber-Pratt et al. (2019) conducted a literature review with the purpose of persuading practitioners to reconsider their approach to people with disabilities. They emphasize that allyship is considered a fundamental responsibility for people in positions that directly impact individuals with disabilities, with special consideration to the fact that views about disability can have such a huge impact on individuals. According to the authors, professionals who are allies to the disability community view themselves as collaborators and advocates rather than experts who must “fix” a disabled person. In order to be effective allies, non-disabled individuals must be attentive to needs, engaged with individuals, and open to viewing clients as members of a diverse community, and one such way to establish these qualities is to increase awareness, knowledge and skills related to disability community (Forber-Pratt et al., 2019).

The developing of awareness, knowledge, and skills is the basis for multicultural competency training programs (Sue & Sue, 2013). Multicultural competence training programs are already widely utilized in a number of fields, with special prominence in clinical and counseling psychology professions; however, only one piece of literature could be located for the current project that details a program specifically designed to

build multicultural competence with disabilities in mind (Rillotta & Nettlebeck, 2007), and it was shown to have significant effects on attitudes and inclusion in a primary education setting. Therefore, it seems likely that a similar program with a neurodiversity-informed foundation, that promotes allyship would be an effective method for removing barriers in other settings and among other professions.

### Section III: Program Overview and Development

#### **Basis/Foundation of the Program**

The proposed program is to be called “Neurodiversity-Informed Training for Professionals and Caregivers,” and is developed upon the foundation of multicultural competency-building with an emphasis on promoting allyship and advocacy. The program will utilize the model of multicultural instruction that relies on developing awareness of one’s own attitudes and biases, providing knowledge about diverse populations, and developing skills for working with those populations (Jones et al., 2013), but specifically gear the activities and discussions to work with the disability community.

According to Jones et al. (2013), it is standard practice in multicultural competency-building to have experiential components to training, including the assigning of a culturally different mentor. Experiential components have also been shown to be a valued part of the experience of those who received Active Support training (Riches et al., 2011). In order to include an “experiential piece” as well as to provide culturally diverse mentors, the program will hire a number of willing self-advocate leaders to facilitate activities within the program. Not only does this allow for the development of applicable skills, but it also provides self-advocates with a platform to speak up for themselves and be heard. A recurring theme in the reviewed literature on self-advocacy and the development of positive identity for people with disability is the engagement and participation in leadership activities (Caldwell, 2010; Forber-Pratt & Zape, 2017; Miller & Keys, 1996; Traustadóttir, 2006). It is the hope of the present author that the involvement and collaboration with self-advocates will create an



environment where they can practice and build leadership skills that they can take to their communities, as well as add depth and richness to the training experience of those who participate.

### **Program Format and Organization**

The current program is designed to be completed as a 2-day workshop. On the first day, the emphasis will be on addressing biases and providing information about the disability community. Biases will be addressed using activities similar to those suggested in Jones et al. (2013), and it will involve the discussion of implicit biases, provision of hypothetical scenarios, and group activities. Knowledge will be provided in a PowerPoint lecture format, and will cover topics including, but not limited to neurodevelopmental disabilities, the disability community, self-advocacy, ability status, neurodiversity, and allyship. Time will be provided for questions, simple learning activities, and discussions. The second day of the workshop will be led primarily by the paid self-advocates hired specifically to help with the workshop, and will take the format of a “conference” in which trainees attend small “breakout sessions” with self-advocate presenters who speak on any relevant topic of their choosing. Larger group sessions will be conducted for broad, overarching themes, and the workshop will be concluded with a question and answer session with a panel of self-advocates. It should be noted that self-advocates should not be present on the first day of the workshop. The primary reason is to avoid any unnecessary harm that might result from resistant trainees. Any such problems can be handled on the first day of the workshop so that self-advocates feel safe to present their stories on the second day.

The specific learning objectives for these workshops are the following:

1. Participants will define the following terms: neurodevelopmental disability, neurodiversity, self-advocacy, advocacy, and allyship
2. Participants will explain challenges faced by individuals with neurodevelopmental disabilities.
3. Participants will identify personal biases about people with disabilities.
4. Participants will recognize the key features of disability culture.
5. Participants will state the steps of effective allyship.
6. Participants will develop strategies for incorporating neurodiversity into own work/care provision.

See Appendix A for a sample Neurodiversity-Informed Training Workshop agenda.

### **Training Content**

As previously mentioned, the training content will be derived from activities utilized in multicultural competence and allyship (see list of suggested activities and instructions in Appendix B). The knowledge-based lecture will be organized into a PowerPoint presentation covering many of the topics presented in this literature review. The information presented in the PowerPoint can be found in Appendix C. Finally, with respect to the self-advocate's breakout sessions and large group discussions, the self-advocates will choose their own topics, while the larger group session will be focused upon some central theme such as neurodiversity, inclusion, or some other topic. The large group session should be geared toward the needs of the trainees in attendance. An example would be a session about being neurodiverse in the workplace if the trainees were supervisors or administrators from companies hoping to hire employees with developmental disabilities.

## **Program Evaluation**

### *Short-Term*

In order to evaluate the efficacy of the program in the short-term, trainees will be administered self-assessments that provide information about awareness of biases and attitudes as well as knowledge of the topic before and after the workshop.

### *Long-Term*

To gather more longitudinal data about the efficacy of the program, a 1-year follow-up assessment will be provided to those who participated in the workshop. Additionally, information could be gathered about the outcomes of those with neurodevelopmental disabilities at the site where the training was conducted before the training occurred and a year after the training. More specifically, organizations will be asked to report specific changes made to practices following the training, as well as employee behavior and satisfaction of individuals served.

## **Budget/Cost**

The workshop could be relatively inexpensive to conduct if it is done as a consultation within an organization, with the primary expense being the payment for the self-advocate facilitators' work. The rate of pay for the self-advocates is based upon the average rate of pay per hour for support group facilitators with additions made for the fact that self-advocates will spend time preparing their presentations and materials. The full expense for paying facilitators will vary depending upon the number of facilitators present, though it should not exceed more than five individuals. The only other regular expense would be the cost of printing handouts and other materials. However, the workshop could be more expensive to conduct were it to be conducted at a conference,

or if it were necessary to secure a venue. A sample, high-end budget that was utilized for a grant application to pilot and market this project at a state conference is included in Appendix E. It is important to note that this budget is not reflective of the cost it would take to host a typical neurodiversity-informed training session, but rather to begin the process of determining its empirical basis.

In order to afford the cost for conducting Neurodiversity-Informed Training workshops, there are several options available. One option is to apply for grant-funding through one of the various grant-providers that support efforts for improving the lives of people with disabilities. Another option is to charge a fee for participation. For larger attendances extra proceeds could be stored in a fund and utilized for future workshops. Finally, those who organize the trainings could solicit donations from local businesses or pursue corporate sponsorships. The method for funding the workshops will likely vary between organizers.

## Conclusion

There is a long history across professional and domestic settings of viewing neurodevelopmental disabilities as diseases that must be cured or problems that must be solved; however, many people with disabilities view their disability as an identity and not an illness and ask that those who work with and care for them do the same. There are many strong programs for helping neurodiverse individuals become self-advocates, but no such programs to train professionals and caregivers to be effective allies. In order to reduce the risk of abuse and rights violations and in order to ensure a better quality of life for individuals with neurodevelopmental disabilities, it is important that allyship be fostered, and this program would address that need.

## References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.). Washington, D.C.: Author  
<https://doi.org/10.1176/appi.books.9780890425596>
- Ashbaugh, K., Koegel, R. L., & Koegel, L. K. (2017). Increasing social integration for college students with autism spectrum disorder. *Behavioral Development Bulletin*, 22(1), 183-196. Doi:10.1037/bdb0000057
- Autistic Self Advocacy Network. (2015, July 28). *ASAN praises ED letter urging schools to look beyond ABA*. Retrieved from  
<https://autisticadvocacy.org/2015/07/asan-praises-ed-letter-urging-schools-to-look-beyond-aba/>
- Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos*, 38(1), 33-55. <https://doi.org/10.1111/j.1548-1352.2009.01080.x>
- Bigby, C., & Beadle-Brown, J. (2016). Culture in better group homes for people with intellectual disability at severe levels. *Intellectual and Developmental Disabilities*, 54(5), 316-331. <https://doi.org/10.1352/1934-9556-54.5.316>
- Bigby, C., Knox, M., Beadle-Brown, J., Clement, T., & Mansell, J. (2012). Uncovering dimensions of culture in underperforming group homes for people with severe intellectual disability. *Intellectual and Developmental Disabilities*, 50(6), 452-467. <https://doi.org/10.1352/1934-9556-50.06.452>
- Browder, D. M., Bambara, L.M., & Belfiore, P.J. (1997). Using a person-centered approach in community-based instruction for adults with developmental

- disabilities. *Journal of Behavioral Education*, 7(4), 519-528.  
<https://doi.org/10.1023/A:1022815604235>
- Bumiller, K. (2008). Quirky citizens: Autism, gender, and reimagining disability. *Signs*, 33(4), 967–991. <https://doi.org/10.1086/528848>
- Burkhardt, S. A., Obiakor, F. E. (2008). *Autism and Developmental Disabilities: Current Practices and Issues*. Bingley: Emerald Group Publishing Limited.
- Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*, 54(11), 1004-1014. <https://doi.org/10.1111/j.a326.x>
- Centers for Disease Control and Prevention. (2013). People with disabilities: Who are they and what do we know? (Rep 2015; 64: 777-783). Retrieved from <https://www.cdc.gov/ncbddd/disabilityandhealth/features/key-findings-community-prevalence.html>
- Cone, A. A. (2000). Self-advocacy group advisor activities and their impact/relation to self-advocacy group development. *International Journal of Disability, Development and Education*, 47(2), 137-154. <https://doi.org/10.1080/713671109>
- Cserti, R. (2020, January 30). *45 Ice breaker games [that your team won't find cheesy]*. Retrieved from <https://www.sessionlab.com/blog/icebreaker-games/#ice-breaker-games-to-kick-off-meetings>
- Davies, D. K., Stock, S. E., King, L., Wehmeyer, M. L., & Shogren, K. A. (2017). An accessible testing, learning and assessment system for people with intellectual disability. *International Journal of Developmental Disabilities*, 63(4), 204–210. <https://doi.org/10.1080/20473869.2017.1294313>

- Dean, E. E., Shogren, K. A., Hagiwara, M., & Wehmeyer, M. L. (2018). How does employment influence health outcomes? A systematic review of the intellectual disability literature. *Journal of Vocational Rehabilitation, 49*(1), 1–13.  
<https://doi.org/10.3233/JVR-180950>
- Feldman, M.A., Owen, F., Anderews, A., Hamelin, J., Barber, R., & Griffiths, D., (2012). Health self-advocacy training for persons with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(11), 1110-1121.  
<https://doi.org/10.1111/j.1365-2788.2012.01626.x>
- Forber-Pratt, A. J., Lyew, D. A., Mueller, C., & Samples, L. B. (2017). Disability identity development: A systematic review of the literature. *Rehabilitation Psychology, 62*(2), 198–207. <https://doi.org/10.1037/rep0000134>
- Forber-Pratt, A. J., Mueller, C. O., & Andrews, E. E. (2019). Disability identity and allyship in rehabilitation psychology: Sit, stand, sign, and show up. *Rehabilitation Psychology, 64*(2), 119–129. <https://doi.org/10.1037/rep0000256>
- Forber-Pratt, A.J., & Zape, M. P. (2017). Disability identity development model: Voices from the ADA-generation. *Disability and Health Journal, 10*(2), 350-355.  
Doi:10.1016/j.dhjo.2016.12.0134
- Friedman, C. (2017). Self-advocacy services for people with intellectual and developmental disabilities: A national analysis. *Intellectual And Developmental Disabilities, 55*(6), 370–376. <https://doi.org/10.1352/1934-9556-55.6.370>
- Gorski, P. (n.d.) *Awareness Activities*. Critical Multicultural Pavilion. Retrieved from <http://www.edchange.org/multicultural/activityarch.html>



- Govere, L., & Govere, E. M. (2016). How effective is cultural competence training of healthcare providers on improving patient satisfaction of minority groups? A systematic review of literature. *Worldviews on Evidence-Based Nursing, 13*(6), 402–410. <https://doi.org/10.1111/wvn.12176>
- Hedley, D., Uljarevic, M., Cameron, L., Halder, S., Richdale, A., & Dissanayake, C. (2016). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism, 21*(8), 929–941. Doi:10.1177/1362361316661855
- Jones, J. M., Sander, J. B., & Booker, K. W. (2013). Multicultural competency building: Practical solutions for training and evaluating student progress. *Training and Education in Professional Psychology, 7*(1), 12–22. <https://doi.org/10.1037/a0030880>
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology, 49*(1), 59–71. <https://doi.org/10.1037/a0028353>
- Kirby, A. (2016). Parent expectations mediate outcomes for young adults with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 46*(5), 1643–1655. Doi:10.1007/s10803-015-2691-3
- Lee, S.-H., Amos, B. A., Gragoudas, S., Lee, Y., Shogren, K. A., Theoharis, R., & Wehmeyer, M. L. (2006). Curriculum augmentation and adaptation strategies to promote access to the general curriculum for students with intellectual and developmental disabilities. *Education and Training in Developmental Disabilities, 41*(3), 199–212.

- Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.
- Mevoli, K., Tanner, A., Adams, C., Rhodes, A., Warren, T., Sherif, V., & University of Kentucky, Human Development Institute (2016). Nothing about us without us: Asking Kentuckians with disabilities about what they need to thrive. *Research Brief*. Human Development Institute. Retrieved from <https://files.eric.ed.gov/fulltext/ED574714.pdf>
- Miller, A. B., & Keys, C. B. (1996). Awareness, action, and collaboration: How the self-advocacy movement is empowering for persons with developmental disabilities. *Mental Retardation*, *34*(5), 312–319.
- Palmer, S. B., Wehmeyer, M. L., Gipson, K., & Agran, M. (2004). Promoting access to the general curriculum by teaching self-determination skills. *Exceptional Children*, *70*(4), 427–439. <https://doi.org/10.1177/001440290407000403>
- Paniagua, F. A. (2014). *Assessing and treating culturally diverse clients: A practical guide*. Los Angeles, CA: Sage.
- Qian, X., Larson, S. A., Tichá, R., Stancliffe, R., & Pettingell, S. L. (2019). Active support training, staff assistance, and engagement of individuals with intellectual and developmental disabilities in the United States: Randomized controlled trial. *American Journal on Intellectual and Developmental Disabilities*, *124*(2), 157–173. <https://doi.org/10.1352/1944-7558-124.2.157>
- Reindl, M.-S., Waltz, M., & Schippers, A. (2016). Personalization, self-advocacy and inclusion: An evaluation of parent-initiated supported living schemes for people with intellectual and developmental disabilities in the Netherlands. *Journal of*

*Intellectual Disabilities*, 20(2), 121–136.

<https://doi.org/10.1177/1744629516631449>

Riches, V. C., Harman, A. D., Keen, D., Pennell, D., Harley, J. H., & Walker, M.

(2011). Transforming staff practice through active support. *Journal of*

*Intellectual and Developmental Disability*, 36(3), 156–166.

<https://doi.org/10.3109/13668250.2011.598499>

Rillotta, F., & Nettelbeck, T. (2007). Effects of an awareness program on attitudes of

students without an intellectual disability towards persons with an intellectual

disability. *Journal of Intellectual and Developmental Disability*, 32(1), 19–27.

<https://doi.org/10.1080/13668250701194042t>

Ryan, T. G., & Griffiths, S. (2015). Self-Advocacy and Its Impacts for Adults with

Developmental Disabilities. *Australian Journal of Adult Learning*, 55(1), 31–53.

Seaman, R., & Cannella-Malone, H. (2016). Vocational skills interventions for adults

with autism spectrum disorder: A review of the literature. *Journal of*

*Developmental & Physical Disabilities*, 28(3), 479-494. Doi:10.1007/s10882-

016-9479-z

Shipton, L., & Lashewicz, B. M. (2017). Quality group home care for adults with

developmental disabilities and/or mental health disorders: Yearning for

understanding, security and freedom. *Journal of Applied Research in*

*Intellectual Disabilities*, 30(5), 946–957. <https://doi.org/10.1111/jar.12289>

Shogren, K. A., Wehmeyer, M. L., Lassmann, H., & Forber-Pratt, A. J. (2017).

Supported decision making: A synthesis of the literature across intellectual

- disability, mental health, and aging. *Education and Training in Autism and Developmental Disabilities*, 52(2), 144–157.
- Shogren, K. A., Wehmeyer, M. L., Reese, R. M., & O’Hara, D. (2006). Promoting self-determination in health and medical care: A critical component of addressing health disparities in people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 3(2), 105–113.  
<https://doi.org/10.1111/j.1741-1130.2006.00061.x>
- Shogren, K. A., Wehmeyer, M. L., Shaw, L. A., Grigal, M., Hart, D., Smith, F. A., & Khamsi, S. (2018). Predictors of self-determination in postsecondary education for students with intellectual and developmental disabilities. *Education and Training in Autism and Developmental Disabilities*, 53(2), 146–159.
- Smith, M., Ginger, E., Wright, K., Wright, M., Taylor, J., Humm, L., ... Fleming, M. (2014). Virtual reality job interview training in adults with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*, 44(10), 2450-2463.  
Doi:10.1007/s10803-014-2113-y
- Stevenson, K. M., Cheung, K. M., & Leung, P. (1992). A new approach to training child and protective services workers for ethnically sensitive practice. *Child Welfare: Journal of Policy, Practice, and Program*, 71(4), 291–305.
- Sue, D.W., & Sue, D. (2013). *Counseling the culturally diverse: Theory and practice*. Hoboken, NJ: John Wiley & Sons, Inc.
- 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>

- Watkins, L., O'Reilly, M., Kuhn, M., Gevarter, C., Lancioni, G. E., Sigafoos, J., & Lang, R. (2015). A review of peer-mediated social interaction interventions for students with autism in inclusive settings. *Journal of Autism and Developmental Disorders, 45*(4), 1070-1083. Doi:10.1007/s10803-014-2264-x
- Wehman, P., Brooke, V., Brooke, A. M., Ham, W., Schall, C., McDonough, J., ... Avellone, L. (2016). Employment for adults with autism spectrum disorders: A retrospective review of a customized employment approach. *Research in Developmental Disabilities, 53-54*, 61–72. Doi:10.1016/j.ridd.2016.01.015
- Wehmeyer, M. L. (2017). *A comprehensive guide to intellectual and developmental disabilities*. Baltimore, MD: Brookes Publishing.
- Wilczynski, S. M., Trammell, B., & Clarke, L. S. (2013). Improving employment outcomes among adolescents and adults on the autism spectrum. *Psychology in The Schools, 50*(9), 876-887. Doi:10.1002/pits.21718
- World Health Organization (2012, July 11). Violence against adults and children with disabilities. Retrieved from <https://www.who.int/disabilities/violence/en/>

## APPENDICES

## Appendix A: Sample NITPAC Workshop Agenda

## Appendix A: Sample NITPAC Workshop Agenda

### Sample NITPAC Workshop Agenda

#### Day 1

8:00 – Introduction

8:30 – Establishing Group

Safety/Expectations

9:00 – One Word Exercise

9:30 – Pretest Self-Assessment

10:00 – Vignette Activity + Discussion

11:00 – Presentation

12:00 – Lunch

1:00 – Presentation (Continued)

2:00 – Sharing Stories Activity +

Discussion

3:30 - Debrief

4:00 – Wrap-up

#### Day 2

8:00 – Welcome back

8:15– Breakout Session 1

9:15 – Breakout Session 2

10:15 – Break

10:30 – Breakout Session 3

11:30 – Regroup + Process

12:00 – Lunch

1:00 – Group Session

2:00 – Group Q + A

3:30 – Posttest Self-Assessment

4:00 – Wrap-up



## Appendix B: Day 1 Activities Defined

## **Appendix B: Day 1 Activities Defined**

### **Day 1 Activities Defined**

#### **Establishing Group Safety/Expectations**

At the beginning of the workshop, facilitators lead a discussion in which participants identify rules and expectations that are necessary to ensure a sense of security in the more difficult discussion. Facilitators may suggest ideas and poll the participants as well.

#### **One Word Activity, Adapted from Cserti (2020)**

Participants are presented with one word related to the core purpose of the workshop, in this case “Neurodiversity,” and are asked to write down a word or phrase that comes to their mind in relation to it. Participants then take turn sharing their words phrases. If time allows, this will be repeated for other major concepts, including: (neurodevelopmental) disability, advocacy, self-advocacy, and allyship

#### **Awareness Activities**

##### *Vignette Activity*

Facilitators develop or select a vignette relevant to the topic of working with individuals with neurodevelopmental disabilities. Divided into small groups of no more than six, participants will answer the following questions about the vignette:

- What did the professional/care provider do incorrectly in this vignette?
- What did the professional/care provider do correctly in this vignette?
- Is there anything you would do differently?

*Sharing Stories: Prejudice Activity, Adapted from Gorski (n.d.)*

Facilitators divide participants into groups of no more than six people and are given the opportunity to discuss the four of the following stories generally, and then with a specific focus on neurodevelopmental disabilities.

- A time when they experienced prejudice or discrimination
- A time when they discriminated against someone else
- A time they witnessed discrimination and did nothing about it
- A time they a witnessed discrimination and did something about it

During the activity facilitators should offer to tell a story first to encourage participants to share and remind them that the purpose is to understand why discrimination occurs, not to feel guilty.

## Appendix C: Presentation Content Outline

## **Appendix C: Presentation Content Outline**

- I. Introduction to Neurodevelopmental Disabilities (ND)
  - a. What is a ND?
    - i. Definitional meaning (DSM-5) and its purpose
      - 1. ASD, IDD, etc.
      - 2. Insurance, legal issues
    - ii. Other meanings
      - 1. Critical, personal, public
      - 2. Interwoven, form a cultural identity
- II. Introduction to Multiculturalism and Ability Status
  - a. ND as cultural identity
    - i. Operates on system of privilege oppression
    - ii. Called “ability status”
  - b. Disability community
    - i. Membership
    - ii. Features
  - c. Illness Vs. Identity
- III. Self-Advocacy and Neurodiversity
  - a. The Self-Advocacy Movement
    - i. Self-determination
    - ii. Civil rights
  - b. Neurodiversity
    - i. What is it?

- ii. What it means for the disability community
  - c. Resistance
    - 1. Current state of self-advocacy
- IV. Current Treatment of Individuals with NDs
  - a. Higher rates of abuse and violations of personal freedoms across settings
    - i. Medical/Mental Health
    - ii. Residential/Group Homes
    - iii. Educational
    - iv. Employment
    - v. Domestic
- V. Allyship (Forber-Pratt et al., 2019) – Putting It All Together
  - a. Intersectionality
    - i. Definition
    - ii. Importance
  - b. Terminology
    - i. Person-first vs. identity-first
    - ii. Platinum rule
  - c. Universal design
    - i. Accessibility not an afterthought
  - d. Action as an ally
    - i. What steps are you taking?
  - e. Avoid sensationalism
    - i. “Inspiration porn”

- ii. Video example and discussion
  - f. Awareness of disability rights issues
  - g. Check internal biases
    - i. Active
    - ii. Ongoing process (journey not destination)
  - h. Embrace cross-cultural solidarity
    - i. Honoring lived experiences of disabled people and their identities
- VI. Summary
- VII. Questions?

## Appendix D: Self-Assessment Form



## Appendix D: Self-Assessment Form

### Self-Assessment Form

**Participant Name/ID Number:**

**Date of Training:**

**Organization:**

**Relationship to Person With ND:** Self Parent/Care Provider Professional  
Employer Other

**Section I:** Use this scale to rate the following items.

**0= N/A 1= Strongly Disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly Agree**

Item	Response
1. I can define neurodevelopmental disability.	
2. I can define neurodiversity	
3. I can define self-advocacy	
4. I can define advocacy	
5. I can define allyship	
6. I have personal biases about people with neurodevelopmental disabilities.	
7. People with NDs face discrimination.	
8. People with NDs are more likely to be abused.	
9. People with NDs cannot make their own decisions.	
10. People with NDs should have a say in their own care provision.	
11. People with NDs are all the same.	
12. People with NDs are all unique	
13. I can identify the key features of disability culture.	
14. I can state the steps of effective allyship.	
15. Universal design benefits everyone.	

## Self- Assessment Form

**Section II (Posttest Only):** Please respond to the following questions in the space provided.

1. List at least one bias you have about people with NDs of which you became aware during this workshop?
2. List three steps you will take to incorporate the information from this workshop into your care provision/professional practice.
3. What did you like about the workshop?
4. Is there anything that you did not like?
5. Are there any topics not discussed that you wish were covered?

## Appendix E: Sample Budget for Project Pilot

**Appendix E: Sample Budget for Project Pilot**

<b>Payment, travel, and lodging costs for five self-advocate facilitators</b>	<b>\$2000.00</b>
<b>Payment for training development consultation for one self-advocate</b>	<b>\$500.00</b>
<b>ARC of Kentucky 2021 Conference registration for 50 participants</b>	<b>\$5500.00</b>
<b>Principal Investigator ECU graduate student stipend</b>	<b>\$2000.00</b>
<b>Principal Investigator travel and lodging to ARC conference</b>	<b>\$2000.00</b>
<b>ECU faculty sponsor funding for effort on project</b>	<b>\$3450.00</b>
<b>ECU faculty sponsor travel to ARC conference</b>	<b>\$400.00</b>
<b>ECU faculty statistical consultation and publication support</b>	<b>\$3450.00</b>
<b>Graphic design consultation</b>	<b>\$1500.00</b>
<b>Printing costs</b>	<b>\$2000.00</b>
<b>Copyright registration for materials</b>	<b>\$55.00</b>