# Reflecting on the Education Position Statement of AAIDD and The Arc

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#### Abstract

This article expands on 10 critical actions within the American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc's 2018 joint position statement on the right of students with intellectual and/or developmental disabilities (IDD) to have a free and appropriate public education (FAPE): (a) zero reject; (b) nondiscriminatory and comprehensive eligibility evaluations and appropriate assessments; (c) high expectations and FAPE; (d) autonomy, self- determination, and decision-making supports; (e) inclusion and least restrictive environments (LRE); (f) safe and supportive education environments; (g) school choice; (h) family and student participation; (i) lifelong education, transition, and postsecondary education; and (j) system capacity development, funding, oversight, and accountability. Research findings documenting positive outcomes associated with implementing each area of action are described and relevant legal mandates and case law are discussed. Recommendations are made for changes to educational systems and practices that create barriers to the access of FAPE for students with IDD.

*Keywords:* special education, inclusion, least restrictive environment, equity, assessment, free appropriate public education

#### **Reflecting on the Education Position Statement of AAIDD and The Arc**

In 2018, The Arc of the United States in conjunction with the American Association on Intellectual and Developmental Disabilities (AAIDD) developed a joint position statement on the critical importance of a free and appropriate public education (FAPE) for people with intellectual and/or developmental disabilities (IDD) to achieve "the nation's four policy goals of equality of opportunity, full participation, independent living, and economic self-sufficiency" (2018, para.1). Research has also consistently revealed that without inclusive contexts, students with IDD do not have the same opportunities to learn as their peers without disabilities (Taub, McCord, & Ryndak, 2017), and students who are in more inclusive contexts tend to have better quality postschool outcomes than those who are in segregated settings (Jackson, Ryndak & Wehmeyer, 2008; Ryndak, Jackson, & White, 2013; Ryndak, Morrison & Sommerstein, 1999). Despite this evidence of the importance of inclusive educational opportunities, current data show fewer than 17% of students with IDD being educated in an inclusive setting for 80% of the day or more, with less chance of inclusion for this population (Kurth, Morningstar & Kozleski, 2014). The purpose of this article is to provide evidence, through an overview of established research, to support the following elements of a highly effective system of supports and services for people with IDD: (a) zero reject; (b) non-discriminatory and comprehensive eligibility evaluations and appropriate assessments; (c) high expectations and FAPE; (d) autonomy, self-determination, and decision-making supports; (e) inclusion and least restrictive environments (LRE); (f) safe and supportive education environments; (g) school choice; (h) family and student

participation; (i) lifelong education, transition, and postsecondary education; and (j) system capacity development, funding, oversight, and accountability.

# All Means All: Zero Reject

All means all is both the baseline and non-negotiable platform from where people with IDD begin to gain both access and equity. We cannot stress this point enough. It is imperative that when discussing Zero Reject, professionals understand that the antithesis of inclusion is exclusion and thus the pathway toward systemic segregation. As argued in Brown v. Board of Education, separate but equal is inherently unequal and "...by reason of the segregation complained of, deprived of the equal protection of the laws guaranteed by the Fourteenth Amendment" (Brown v. Board, 1958). We must include students with IDD within general education settings as a given without quid pro quo negotiations or restrictions. A fully inclusive and robust program should include a rigorous, unbiased, and relevant Individualized Education Program (IEP) process that provides supports, strategies, and opportunities for dynamic assessment and determines the setting from which students will learn. The opportunity costs alone give credence to an efficient and timely flow from evaluation to identification to the implementation of services. Segregation has been found, on its own, to negatively impact a person's education and motivation to learn (Brown v. Board, 1958).

The use of specialized supports for people with IDD can reduce barriers to inclusion and level the playing field. Technology, especially ubiquitous mobile technologies, are one way to provide supports that facilitate students' full participation in general education settings. Since Braddock et al. (2004) called for seamless integration of technology across communities of practice, assistive technology is now more efficient, portable, and can be discreetly used in the general education classroom and the broader community. Using Moore's law (1965), it is reasonable to contend that these technologies will become even more portable and personalized in the future, further removing barriers and allowing for increased participation.

Many people with IDD also struggle with social isolation, have few friends, and do not participate in many activities outside of school (Chung, Carter, & Cisco, 2012). Underscoring the importance of this finding, Carter et al. (2010) discussed how vital extracurricular activities are to the creation of friendships and experiences, making them the most memorable and enjoyable experiences in school. Research shows a lack of transportation, opportunity, and involvement are the most significant barriers to full inclusion in afterschool, extracurricular activities (Agran et al., 2017). The field must remove these barriers, create high leverage programs, communicate effectively to spur parental involvement and use existing structures to provide safe transportation to these events as many communities are beginning to do.

Segregation can also come in the form of how schools structure discipline programs and safety initiatives, especially in how and whom they choose to suspend and why. Zero tolerance, deficit-oriented, school safety policies create a punitive environment that is not only harmful to learning but has not shown to make schools any safer, and in some cases, less so (American Psychological Association [APA], 2008; Carter, Fine, & Russell, 2014). Further, these programs disproportionately suspend certain groups more than others over "minor rule-breaking" incidents (Losan, Hewitt, & Toldson, 2014, p.1), with people of color and those with IDD among those most suspended (Krezmien, 2017). The combination of demonstrating a practice for suspension of certain groups over others and the fact that these policies are linked to lower student achievement (APA, 2008) leads to a higher probability of students dropping out. States must endeavor to reduce barriers related to harsh disciplinary policies by ending deficit-oriented, punitive behavior management plans that, knowingly or not, establish a school-to-prison pipeline for people with IDD (National Council on Disability, 2015). Schools must track disciplinary action for state-mandated reporting. However, this data must also instruct schools that suspend at high rates to rethink and restructure; as the unintended negative consequences of applying *Broken Windows theory* (Kelling & Coles, 1996) in zero tolerance, "no excuses" (Green, 2015) schools have outweighed its potential for school reform and order. Further, the negative impacts of these programs warrant a discussion that *all* also means students with IDD, those living in poverty, and students with marginalized racial backgrounds. Educators and policymakers must be mindful of the impact these identified risk factors pose on segregation and lack of access.

#### **Appropriate Eligibility Evaluations and Assessments**

Assessments are an essential part of diagnosing and ascertaining a student's academic, developmental, and functional levels--and identifying and understanding an individual's strengths, abilities, and needs. IDEA (2004) *rejects* the "use of any single measure or assessment" for evaluating and determining appropriate educational programs (e.g., IEP, transition plans). This mandate is consistent with researchers' arguments that using a range of assessment strategies (e.g., formal, informal, alternative, and performance-based assessments) to determine and predict the proper supports for students is imperative (Ruppar, Roberts, Olson, 2018; Thoma, Bartholomew, & Scott, 2009; Thoma & Tamura, 2013).

Since the Larry P. v. Riles (1979) ruling that intelligence tests (IQ) likely had a cultural bias, AAIDD has led the way in moving away from diagnostic processes that focus solely on an IQ score. The 1992 AAIDD definition and classification manual (Luckasson et al., 1992) presented a model of intellectual disability that understood multidimensional human functioning concerning environmental demands (Thompson et al., 2009). This model and the more recent classification manual (Schalock et al., 2010) have focused on systems of support rather than individuals' states or traits (Thompson et al., 2009). Tasse, Luckasson, and Schalock (2016) have documented the importance of ensuring that IQ is only one of several measures used to determine the cognitive, emotional, functional, and developmental needs of an individual. These authors have recommended adaptive behavior assessment that considers conceptual, social, and practical skills in typical settings and across time. Adaptive behavior measures represent typical, daily performance and provide a reference point for providing person-centered education and predicting and providing personalized supports (Tasse et al., 2016). Utilizing adaptive behavior measures in conjunction with other measures, provides a more robust profile of the individual's level of functioning that takes into account more than cognitive/intellectual and academic functioning.

It is essential that all assessments and their subsequent support plans are developed using *clinical judgment*, a "key component of professional responsibility" (Schalock and Luckasson, 2014, p. 240). *Clinical Judgment* mandates respect for the individual, research-based practices, training for professionals, and data-based decision making (Luckasson and Schalock, 2015). Designing a clear purpose for and high expectations of learning when developing and using all formative and summative assessments in the classroom and community are critical (Chappuis, 2009; Chappuis et al., 2012). Research and best practice suggest a truly dynamic assessment process for people with IDD, where adjustments, robust specialized supports, and individualized education is a reality.

The IEP is based upon evaluation and assessment, and the parent has a vital role in the IEP process. Before a child is evaluated for special education services, the parent must give permission for the evaluation. Reasons parents may not provide consent include a belief that the evaluation will be harmful to the child, distress regarding the stigma of the disability label, concerns about the credentials or qualifications of the evaluator, an intent to refuse special education services, and apprehension about predetermined placement (Etscheidt, Clopton, & Haselhuhn, 2012). With each subsequent evaluation, the parent must be provided notice of the evaluation procedures (IDEA, 2004). After the evaluation shows the child has a disability and the child is determined to have an educational need, assessments are used to determine needed special education aids and services in the IEP. At any time during this process, parents have the right to refuse or revoke special education services for their child (Etscheidt et al., 2012).

#### High Expectations and Free Appropriate Public Education (FAPE)

What comprises a free appropriate public education (FAPE) is difficult to define. However, case law and federal guidance indicate the need to include high expectations and access to grade-level general education curriculum and instruction (Endrew F., 2017; Yudin & Musgrove, 2015). High familial expectations lead to better post-school outcomes in employment, interdependent living, and quality of life (Carter, Austin, & Trainor, 2012; Doren, Gau, & Lindstrom, 2012). High educator expectations are related to increased academic gains and meaningful inclusion (Cate, Markova, Krischler & Krolak-Schwerdt, 2018). Due to segregation, many students with IDD have historically had access to a limited portion of the general education curriculum and the supplemental learning that occurs in general education classrooms (Browder, Spooner, Ahlgrim-Delzell, Harris, & Wakemanxya, 2008; Kurth et al., 2014; Taub et al., 2019). Low expectations have been a generally accepted practice. For instance, the primary method for teaching reading to students with IDD was to focus on teaching sight words through direct instruction using flashcards (Ruppar, Fisher, Olson, & Orlando, 2018), yet, flashcards are often drilled in isolation from context and opportunities for literacy instruction beyond word identification. In mathematics, these individuals are routinely excluded from access to higher-level mathematics such as Algebra (Rodriguez, 2016), instead of experiencing a full commitment to access, equity, and support for success (NCTM, 2014/2018). The IEP supports student access to the full range of the general education curriculum, which means grade-level general education academic curriculum, extracurricular, and other school-based activities. Teaching in school goes beyond academics; it is the setting and the opportunity for all students to interact and grow that matters. These crucial settings are general education classrooms, the hallways, the cafeteria, among others. The same high expectations are rarely found in segregated and isolated room (Caustin-Theoharis, Theoharis, Orsati, & Cosier, 2011).

High expectations, provided by professionally qualified educators and related service providers who have the support and on-going training, are needed for this effort to be effective (AAIDD, 2018). The use of evidence-based, peer-reviewed practices is essential, and the field must continue to examine what high expectations and evidencebased practices look like for students with IDD. Before the passage of the No Child Left Behind Act of 2001, there was a limited set of topics addressed in each content area (math, science, and English/language arts). Within those topics, a systematic evaluation of educational strategies rarely occurred for teaching students with IDD (Browder et al., 2008).

IEPs are required to provide students with disabilities a FAPE that includes access to and progress in the general education curriculum as detailed in the Individuals with Disabilities Education Improvement Act of 2004 (IDEA). The 2017 court case, *Endrew F. v. Douglas County School District*, reset the expectation for FAPE, arguing a student offered an educational program providing "merely more than de minimis" progress from year to year can hardly be said to have been offered an education at all. For children with disabilities, receiving instruction that aims so low would be tantamount to "sitting idly . . . awaiting the time when they were old enough to 'drop out.'" Rowley, 458 U. S., at 179 (some internal quotation marks omitted).

Thus, IEP goals need to be ambitious and individualized with challenging objectives, built upon a student's strengths, to meet the student's learning, employment, and independent living needs. IEP goals must provide the supports and services that most likely ensure the student makes progress toward achieving the nation's four policy goals of equality of opportunity, full participation, independent living, and economic selfsufficiency (AAIDD, 2018). Additionally, if a parent believes their child's IEP is not ensuring FAPE, the parent may initiate dispute resolution proceedings (Yell, Katsiyannis, & Losinski, 2015; Zirkel & Hetrick, 2017).

# Self-Determination, Autonomy, and Decision-Making Supports

Self-determination and autonomy should be incorporated and supported throughout the educational experiences of students with IDD, and there should be school policy and semi-annual training on these topics, in addition to decision-making supports (AAIDD, 2018).

**Self-determination.** Self-determination is one of the most researched aspects of special education, which holds a strong evidence base as identified through the National Technical Assistance Center on Transition (NTACT, 2019). Although specific researchers and organizations have slightly varying definitions of self-determination, a standard definition is

"a combination of skills, knowledge, and beliefs that enable a person to engage in goaldirected, self-regulated, autonomous behavior. An understanding of one's strengths and limitations, together with a belief in oneself as capable and effective, are essential to selfdetermination. When acting based on these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society" (Field, Martin, Miller, Ward, & Wehmeyer, 1998, p. 2). Wehmeyer (1992) has defined self-determination as being the primary causal agent in your own life, which gave rise to Causal Agency Theory (Shogren et al., 2015). Causal Agency Theory expands the model of self-determination while calling individuals into agentic action through the explicit teaching of self-determination.

There are many component skills beneath the self-determination umbrella; those include such concepts as choice-making, goal setting, and attainment, problem-solving, risk-taking, self- awareness, and self-knowledge (Wehmeyer, Agran, & Hughes, 1998).

Additional literature has added to this list of elements of self-advocacy and understanding of disability. Regardless of which components one may choose, there is substantial agreement that self-determination should be a core focus of teaching individuals with disabilities (Agran, Snow, & Swaner, 1999; Grigal, Neubert, Moon, & Graham, 2003; Thoma, Baker, & Saddler, 2002; Wehmeyer et al., 2012).

Research consistently demonstrates individuals with high levels of selfdetermination achieve more significant postsecondary outcomes (Dattillo & Rusch, 2012; Mazzotti et al., 2013; Wehmeyer & Palmer, 2033; Wehmeyer & Schwartz, 1997). Targeting instruction in educational settings and affording individuals the opportunity to practice self-determination is the primary way to develop such skills (Martin & Williams-Diehm, 2013). Although numerous curricula, lessons, and materials have been created to promote self-determination, many are either not designed for individuals with IDD or not utilized for research purposes. Two of the most promising research-based tools include the Self-Determined Learning Model of Instruction (SDLMI; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000) and Whose Future is it Anyway? (Wehmeyer et al., 2004). NTACT has identified the SDLMI as an evidence-based practice for individuals with IDD. Divided into three sections, the SDLMI is designed for individuals to both articulate goals and work to achieve them through constant iteration. The versatility of this tool allows individuals to work on goals across both academic and transition domains, including employment and independent living (Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Shogren, Plotner, Palmer, Wehmeyer, & Paek, 2014). Whose *Future is it Anyway?* is a complete lesson package geared towards helping students become more active in their educational planning meetings, including both the IEP and

transition planning, and is an evidence-based practice for individuals with IDD as identified by NTACT. Critical components of *Whose Future is it Anyway?* include (a) having self-awareness and disability awareness; (b) decision-making about transitionrelated outcomes; (c) identifying and securing community resources to support transition services; (d) writing and evaluating goals and objectives; (e) communicating effectiveness in small groups; and (f) developing skills to become an active team member, leader, or self-advocate (NTACT, 2017). Programs with high leverage Selfdetermination programs include The Ohio Center for Autism and Low Incidence (OCALI) and Self-Determination.org.

Autonomy. Although conceptually similar to self-determination, autonomy is not an element of self-determination. Although related, autonomy takes on a different concept from self-determination or even supporting independence (Joussemet, Landry, & Koestner, 2008). While self-determination is addressed heavily in the educational arena, autonomy is discussed in the adult service arena (Sierens, Vansteenkiste, Goossens, Soenens, & Dochy, 2009). Research has demonstrated that the more autonomous individuals are, the happier they are with their lives (Deci & Ryan, 2000). The concept of autonomy most aligns with showing responsibility and initiative for oneself, and that independent decision-making is believed to be a universal need for all individuals (Deci & Ryan 2000). Because autonomy intertwines with the notion of capacity for decisionmaking, individuals with an IDD are often perceived as being unable to function autonomously (Carlson, 2010; Davy, 2015). However, this is not accurate; individuals with IDD just may need additional support to reach levels of autonomy (Deci, 2004).

One of the most important factors to remember when discussing autonomy for

individuals with IDD is to ensure inclusivity is maintained (Davy, 2015). In reality, this holds for everyone but is often overlooked for students with IDD. Individuals with IDD may be hindered in their autonomy and forced to act a certain way or accept a predetermined decision if inclusive, person-centered planning is not used (Barber, 1996). Davy (2015) clarified that autonomy is grounded in (a) support, (b) advocacy, and (c) enablement. Davy goes on to clarify that support is most natural in the form of family and friends. Advocacy involves the concept of making space for individuals with IDD to communicate for themselves or provide input to the maximum degree possible. The final step within enablement is ensuring full participation and control is provided to the individual, allowing each individual the means to accomplish their own desires.

**Decision-making support.** It is common for students to reach the age of majority before graduating or exiting public school. Because the IEP is a legal document, once an individual reaches the age of majority, that individual is legally able to make decisions about their educational program. Individuals with IDD, especially those who require extensive or pervasive supports, have often been denied this right as family members who are concerned about an individual's ability to make sound decisions may seek guardianship. However, because guardianship is costly and typically an arrangement difficult to reverse (Andreasian et al., 2014), educators must be knowledgeable about alternatives to guardianship, such as supported decision-making.

Guardianship limits or removes one's autonomy and self- determination (Salzman, 2010). In contrast, supported decision-making gives individuals the power to make decisions about their lives with the support of those they trust and choose to help them (Zhang, Walker, Leal, Landmark, & Katsiyannis, 2019). Supported decision-making

allows the individual to maintain control over life decisions with the appropriate level of support needed from their self-chosen supporters (Jameson et al., 2015). Educators need to have an understanding of supported decision-making so they can educate students and parents about this alternative to guardianship (Zhang et al., 2019). Although there is limited research on supported decision-making practices and outcomes (Kohn, Blumenthal, & Campbell, 2013), supported decision-making does have a theoretical basis and is upheld in court rulings (Zhang et al., 2019).

#### **Inclusion and the Least Restrictive Environment (LRE)**

IDEA (2004) mandates instruction for students with disabilities must take place in the least restrictive environment (LRE) possible and that students not be moved into a separate setting unless, even with the provision of supplementary aids and services, their individual learning needs cannot be met in general education settings. Despite this legal provision, students with IDD are routinely placed in separate, segregated classroom settings (Morningstar, Kurth, & Johnson, 2017) for multiple reasons. One of the many factors influencing student placement decisions are low expectations for the learning capacity of students with IDD. Throughout the history of schooling, educators' low expectations of the learning potential of children and youth with IDD have presented significant barriers to learning opportunities. Too often, educators of students with IDD have provided instruction not linked to the academic curriculum taught to typically developing students (e.g., teaching self-care skills or focusing on tasks deemed functional versus academic) out of a mistaken belief that students could not learn academic skills or that doing so was not practical and thus not need these skills in their daily lives.

Instruction arising from these beliefs was most often provided in separate,

segregated schools or classrooms, resulting in social isolation in addition to limited opportunities to acquire academic skills (Copeland & Griffin, in press). More recently, researchers have compiled a strong empirical base documenting that students with IDD can acquire academic knowledge and skills when given access to the general curriculum and to appropriate, sustained instruction (Lee, Soukup, Little & Wehmeyer, 2009). Furthermore, doing so is associated with more positive adult outcomes. Researchers have documented, for example, students with IDD can acquire higher levels of math (e.g., Browder et al., 2008; Spooner, Root, Saunders, & Browder, 2018) and literacy skills (e.g., Allor, Mathes, Roberts, Jones, & Champlin, 2010) than was once thought possible.

There is increasing awareness, and a growing research base documenting *where* instruction takes place is as important as *what* makes up the content of that instruction. Indeed, it is crucial to remember that special education is a *service* and is not tied to a physical place. Misunderstanding this fundamental principle has too often resulted in students with IDD being placed in separate schools and classrooms in the mistaken belief that individualized instruction and support could only take place in *special* settings (Schwarz, 2007; Wehmeyer, 2013). Researchers have documented repeatedly that students with IDD who are included in general education classrooms have better academic and social outcomes than those who receive educational services in separate classrooms. They are, for example, more likely to receive academic instruction within general education settings (Kurth & Mastergeorge, 2012); to have access to the general curriculum and be working towards grade-level standards (Wehmeyer, Lattin, Lapp-Rincker, & Agran, 2003); and more likely to make progress in academic knowledge and skill attainment when included in general education classes and given appropriate support

to access general education curricular content (Kleinert et al., 2015). Equally as important to consider are the potential negative consequences of receiving education within separate, segregated settings. Ruppar, Fisher, Olson, and Orlando (2018) found that students with IDD in general education settings were ten times more likely to be exposed to academic literacy than students in self-contained classrooms. Causton-Theoharis, Theoharis, Orsati, and Coseir (2011) found students in self-contained classrooms had less access to academic instruction and fewer opportunities to engage in cooperative learning activities with peers as a means of establishing peer relationships.

Developing satisfying peer relationships is also a crucial skill area for all students. Having strong social skills is associated with both successful school experiences and more positive adult outcomes (Agran, Hughes, Thoma, & Scott, 2016). Students with IDD may struggle with social competence (Chung et al., 2012) and often benefit from social skills interventions such as peer support programs and interventions (Carter, 2017). Placing students with IDD in general education settings increases the opportunities to engage in social interactions with peers (Chung & Carter, 2013). Proximity to peers alone, however, is not sufficient to ensure students will acquire social competence or establish meaningful relationships (Carter, 2017). Students also benefit from direct instruction and support (Biggs & Carter, 2017).

The positive academic and social outcomes for students with IDD associated with being included in general education classrooms and receiving instruction alongside their typically developing peers are too important to ignore. School settings are complex, with many factors affecting the quality of education provided to students with IDD. Additionally, there is a long history of denying equitable access to FAPE in the LRE for students with IDD. Nonetheless, legally and ethically, students must be provided with FAPE in the LRE. Given the strong research and practice base to support this effort, the time to act is now.

#### Safe and Supportive Education Environments

As school safety challenges facing individuals with IDD rapidly shift, schoolbased educational professionals (e.g., teachers, principals) need to work collaboratively with specialized instructional support personnel (e.g., school counselors, school nurses, school social workers, school resource officers, therapists, psychologists) to ensure school environments deliberately include academic, environmental, and social/emotional protections. For this to materialize, school professionals and systems must acquire competencies to provide effective mental health supports, abuse- and bullying-prevention interventions, culturally and linguistically diverse communication systems, behavioral supports that prohibit cruel policies and practices, and instruction in the form of universal models and frameworks to create access to the general curriculum (AAIDD, 2018).

Academic safety. Providing safety and protection for individuals with IDD requires schools to bear greater responsibility to ensure the creation of content-learning opportunities that safeguard full participation and inclusion in general education environments. Using frameworks such as Universal Design for Learning (UDL) with individuals with IDD is a pathway to support ways in which instruction, curricula, and assessments create a more accessible and safe learning environment where diversity and differing abilities are honored (Rao, Smith, & Lowrey, 2017; Smith & Lowrey, 2017). For example, parents of a Black child with IDD may experience less fear about their child being excluded from the educational setting when proactive designs and measures to curricula have already been embedded into the school or classroom.

Safe school environments. Creating safe school environments means ensuring policies and procedures, including the use of school-wide intervention and positive behavioral supports, are in place to prevent the exclusion, restraint, and seclusion of individuals with IDD who are often over-disciplined (Vogell, 2014). Schools using School-Wide Positive Behavior Interventions and Supports (SWPBIS) with fidelity have demonstrated significant decreases in suspensions and disciplinary exclusions (Gage, Lee, Grasley-Boy & Peshak, 2018) and have reported a more positive school climate (Bradshaw, Koth, Thornton & Leaf, 2009). SWPBIS programs focus on creating safe schools, including all common school areas, and have even provided a framework for creating safe environments on school buses (Collins & Ryan, 2016; Goldin & McDaniel, 2018).

Social/emotional protections. Because individuals with IDD are more prone to bullying and victimization (Blake, Lund, Zhou, & Benz, 2012) that could have adverse emotional and social health effects (Griffin, Fisher, Lane, & Morin, 2019), safety interventions and measures across professionals and support personnel need to be implemented. Rose and Monda-Amaya (2012) discussed a framework for recognizing, intervening, and decreasing bullying and victimization experiences dealing with students with disabilities. Griffin et al. (2019) specifically addressed bullying and victimization of individuals with IDD and recommended more resources and time to train educational and mental health professionals as well as teaching students with IDD more selfdetermination skills to promote resistance. Still, others have used a School-wide Positive Behavioral Interventions and Supports (SWPBIS) framework in bullying prevention programs (Bradshaw, 2013; Ross & Horner, 2009).

**Safety from abuse or maltreatment.** Behavioral Skills Training (BST) has been used to teach how to avoid potentially abusive situations. A *No-Go-Tell* (Say *No*, leave the situation, and report to a trusted individual) approach has been taught successfully to adults with IDD (Egemo- Helm et al., 2007; Miltenberger et al., 1999). *Keeping Safe* group instruction and support has been effective in teaching adults with IDD how to be safe in the community in terms of where one goes, with whom, and following specific procedures if someone does find themselves in a dangerous situation (Long & Holmes, 2001). Finally, the Circles<sup>®</sup> Program (Walker-Hirsh & Champagne, 1991) has been widely used to teach people with IDD about appropriate and safe interactions with various people, including community helpers (police, firefighters, postal carriers, bus driver), school personnel and support staff, and friends and family.

# **School Choice**

The data on the benefits and drawbacks of charter schools remains mixed in terms of student outcomes, segregation by disability, and funding effects on districts (Frankenberg, Siegel-Hawley, & Wang, 2010; Gleason, Clark, Tuttle, & Dwoyer, 2010). There is a need to further evaluate the responsibilities and effects of charter schools in the outcomes, opportunities, and funding impacts for the education of students with IDD to the same federal accountability levels as other public schools. Any charter or private school that accepts federal funds, including federal vouchers, should be held accountable to the principles, rights, and responsibilities of IDEA, ADAAA, and Section 504. Namely, "they must provide zero reject and free appropriate public education in the least restrictive environment, including nondiscriminatory evaluation, individualized appropriate education plan, access to the general curriculum (academic, extracurricular, and other school activities), procedural safeguards, and parent participation." (AAIDD, 2018, para. 15).

Although public charter schools and schools that accept federal vouchers are legally obligated to accept all students without discrimination based on disability, there is evidence of students with disabilities being counseled out of charter or voucher schools (McLaughlin & Rhim, 2007). Further, while schools may accept some students with disabilities, even those charter schools held up as models of inclusion are not including students with IDD to the same degree as other public schools (Anderson, 2017; National Center for Special Education in Charter Schools, 2017), calling into question what choice is realistically available for students with IDD. Private schools are not currently required to uphold the rights and responsibilities outlined in IDEA. Additionally, private schools accepting vouchers are held to different federal definitions of what discrimination means than public schools, resulting in using federal dollars to support schools that can discriminate against students with disabilities and thus opening the door to federally sanctioned discrimination.

When a student attends a private school with a voucher, money is removed from the public-school system without the process and evaluations that are in place when it is determined that a public school cannot meet the needs of a student with IDD. If funding for public schools is insufficient and current trends of low to no enrollment of students with IDD in non-segregated charter schools continue, these students will be robbed of several less restrictive environments and, arguably, opportunities to learn (Taub et al., 2017).

# Legal Rights Regarding Family and Student Participation

Educators have a responsibility to ensure parents have the information and support needed to exercise their rights under the IDEA (2004) and Every Student Succeeds Act (ESSA, 2015). When providing parents with a copy of the procedural safeguards for the IDEA, schools need to make sure the document is accessible to parents (e.g., in the family's language, large-print version, etc.). Additionally, time needs to be taken to explain the procedural safeguards in easy to understand terminology. Parents need to understand the accountability aspects of ESSA and how that impacts their child with a disability.

Parents also need to be provided information about Section 504 of the Rehabilitation Act, the Americans with Disabilities Act Amendments Act (ADAAA; 2008), and the Family Educational Rights and Privacy Act (FERPA; 1974) and how these laws impact public school and postsecondary education. For example, parents may be confused about the differences in protections and services between high school and college. The IDEA does not cover students with disabilities in college, so students with disabilities in college will not have an IEP. Also, in postsecondary settings, the definition of disability is determined by the ADAAA and Section 504, so it is possible students who did not receive special education services in high school may be eligible for accommodations in college because of the differences in the determination of disability. Further, parents do not have a legal right to their child's educational records once the child is in college. Finally, when students reach the age of majority they assume many of the rights previously held by their parents; thus, it is important for the family to know this will happen and for the student to become familiar with personal legal rights prior to reaching the age of majority or enrolling in postsecondary education.

The most useful IEPs are developed and implemented based upon appropriate assessment and meaningful participation from the family and student. Indeed, parent participation in developing the IEP is one of the founding principles of IDEA (originally known as the Education for All Handicapped Children Act of 1975). However, in order for the family and student to participate as full, contributing members of the IEP team, educators need to reach out to parents for their input in the IEP, help parents and students understand their rights, and provide training to the parents. In the spirit of IDEA, parents are to be equal partners in their children's education; yet, that usually cannot occur unless schools subscribe to that intent.

#### **Individualized Education Program**

The parental role in the evaluation and IEP development and implementation is essential; therefore, it is incumbent upon schools to ensure meaningful participation of parents. Before the actual IEP meeting, parents can be involved in the evaluation, transition assessment, and development of draft goals. If the parents cannot attend the IEP meeting in person, they can participate by phone or video-conference. At a minimum, IDEA requires schools give parents adequate notice of the upcoming IEP meeting, schedule IEP meeting and who will be in attendance, and inform parents they may bring others to the IEP meeting (Yell et al., 2015). Schools need to make good-faith efforts to obtain parental participation during the IEP process and should document how the parents contributed to the development of the IEP (Yell, Katsiyannis, Ennis, & Losinski, 2013). Unfortunately, parents are often passive recipients of information rather than equal partners during the IEP process (Childre & Chambers, 2005; Martin et al., 2006). Parents have identified barriers to their full participation in the IEP process, such as feeling pressure from the IEP team to agree with predetermined decisions and feeling like the IEP team does not value their contributions (Childre & Chambers, 2005). Schools must be careful not to predetermine any component of the IEP, i.e., coming to the meeting with decisions already made about the child's programming and placement (Yell et al., 2015). Another concern is when educators use jargon in meetings that alienates the family or use language that denotes low expectations and deficits regarding their child resulting in lowered participation from parents in the IEP process (Childre & Chambers, 2005). Schools need to be proactive in inviting genuine parent participation in the IEP process and this requires more than just the minimum activities required by IDEA.

Indeed, parents have noted they are more likely to have positive feelings about IEP meetings and their participation when there is a greater level of connectedness between the school and the family; the meeting is focused on specific issues, rather than general conversation; and joint problem-solving between the educators and the family occurs (Childre & Chambers, 2005; Slade, Eisenhower, Carter, & Blacher, 2018). Parent participation provides valuable information for the development of IEP goals, and particularly transition goals as they know the child or youth over time, and in settings other than schools (Thoma & Wehman, 2010).

**Parents who are culturally and/or linguistically diverse.** In particular, parents with special considerations such as those with disabilities or who are culturally and/or linguistically diverse may need additional assistance from schools to be able to

participate fully. Parents who have had negative experiences in school as a child may be reluctant to be involved in their child's education at the school; however, these parents may be very involved with their child's education at home. Schools need to work on making the school environment welcoming and appreciative of the parents. For culturally and/or linguistically diverse parents, the philosophy of special education may conflict with their cultural views, in particular when it comes time for transition planning (Jung, 2011). Care must be taken to understand and honor a family's desires while also meeting the letter of the special education law, IDEA.

Culturally and linguistically diverse parents have reported many barriers to their participation in IEP meetings. One of the most commonly reported challenges to parent participation during the IEP process is when the parent does not speak English at a native-level (e.g., Cheatham & Lim-Mullins, 2018; Lo, 2008; Wolfe & Durán, 2013). When this occurs, not only do the parents feel reluctant to speak, but parents also feel educators do not give them the time to speak and do not value their contributions when they do speak (Cheatham & Lim-Mullins, 2018). Interpreters need training in the jargon of special education; pulling a staff member into an IEP meeting without any instruction on the specialized language and underlying implications can result in poor understanding for the parent (Lo, 2008). Ideally, someone from the community who can advocate for the family and facilitate culturally appropriate communication between the family and school and even interpreting during meetings should attend (Rossetti, Sauer, Bui, & Ou, 2017).

Cheatham and Lim-Mullins (2018) provide suggestions for promoting IEP participation of bilingual, immigrant parents. Educators should reflect on their own

beliefs and potential biases and work to identify and replace any negative beliefs or biases with positive assumptions about the parents and their culture and language abilities. Additionally, educators can use supportive dialogue techniques, such as they would use with students who are learning English, helping parents understand and contribute to the IEP process. Some examples include activating prior knowledge by talking with parents about their child's educational experiences; previewing and defining educational jargon; repeating and emphasizing key words; prompting parents for information such as solutions to problems; using cognates and borrowed words between English and the parents' strongest language; and checking for understanding during and after meetings.

**Student-led IEPs.** Involving students in their IEP meetings has been a strategy used to provide an opportunity for students to communicate their preferences and interests, particularly as they relate to goals for their adult lives (Thoma & Wehman, 2010). While the majority of efforts to involve students in their IEP meetings centers on high school students who are planning for the transition to adult lives, there are examples of how to involve students of all ages in IEP development and implementation processes. For example, Danneker and Bottge (2009) provided six 20-minute lessons on the IEP meetings to four elementary students with disabilities. Data from observations of the IEP meetings, document analysis, and interviews with all the IEP team participants indicated the IEP meetings were student-centered, fostered student self-determination, and resulted in collaborative problem-solving.

Additionally, all of the parents wanted their children to participate more actively in their future IEP meetings after this experience. Thoma and Wehman (2010) described a continuum of student-direction of IEPs, and researchers are beginning to find there are a range of benefits achieved through implementing these approaches. Policy requirements that support the use of student-directed IEP procedures, a description of the studentdirected IEP continuum, as well as the outline of research findings are described below.

**Parent training.** Many parents, especially culturally and linguistically diverse parents, have indicated they feel unprepared for IEP meetings (e.g., Wilson, 2015; Wolfe & Durán, 2013; Zhang & Bennett, 2003). This is an area in which parents need training. Goldman and Burke (2017) conducted a meta-analysis of four studies that used a group experimental design to gauge the effects of parent training and increase parent involvement in special education. The components of the trainings provided in the meta-analysis studies included videos, handouts followed by a phone call, and one-to-one meetings with a training packet. The topics included special education law, parental rights, IEP team member roles, and how to participate in IEP meetings. The duration ranged from 20-60 minutes. Based upon the findings from this meta-analysis, it seems parent trainings need to be more comprehensive, for a longer duration, and not only directed toward increasing the knowledge of parents, but also toward the staff who have such an impact on parent involvement.

Parent training does not have to be formal training provided by the school district. In addition to providing brochures, informational documents, and formal training to parents, schools can provide families with a list of other resources, including websites for governmental resources and contact information for local or regional organizations such as Centers for Independent Living. Parents can be excellent sources of information for each other. Therefore, schools can provide contact information of parent support groups and provide space for meetings.

#### Lifelong Education, Transition, and Postsecondary Education

The education of individuals with IDD should begin as early as possible at home during infancy and continue into early adulthood via postsecondary settings. The ninth essential component of this position statement highlights the lifelong process of education, the importance of systematic coordination among key stakeholders, and how records of educational attainment impact postsecondary outcomes.

**Early intervention.** Shifts in federal policy to include children birth through age three demonstrate the overall focus on preventative approaches to special education services for students with IDD (Farran, 2000). Specifically, Part C of IDEA (2004) mandates that children under the age of three be eligible to receive special education services through early intervention programs if diagnosed with a developmental delay. For young children with IDD, this ensures the implementation of preventive measures and intervention services. Research demonstrates the positive and lasting impact early intervention has for children with IDD (Guralnick, 2005; Smith, Groen, & Wynn, 2000). Results have shown increases in overall cognitive abilities (i.e., IQ scores) in young children diagnosed with autism (Lovaas, 1987) and pervasive developmental disorder not otherwise specified (PDD-NOS; Smith et al., 2000).

Furthermore, high-intensity intervention services are linked to the increased placement of children with IDD amongst typically developing peers (Fenske, Zalenski, Krantz, & McClannahan, 1985). Within school-based services, research continues to emphasize the positive outcomes of early intervention for students with IDD. Phillips and Meloy (2012) found that students with and without disabilities in a school-based pre-K program showed comparable gains in school readiness markers, effectively helping to level the playing field for historically disadvantaged students.

Families of children with IDD face stressors in several categories. Potential stressors may stem from family characteristics, child characteristics, or patterns of interaction (Guralnick, 2005). Guralnick (2005) underscored the dynamic interplay of stressors of families with a child with IDD, all of which can significantly impact child-specific outcomes. Effective and successful programs identify stressors and then design and implement a collaborative, coordinated intervention program to alleviate the stressors (Guralnick, 2005). For young children, birth to school-age, critical to the success of early intervention programs is wrap-around support for families coupled with collaborative efforts by intervention providers.

**Transition services.** The importance of transition planning is embedded throughout this position statement. Critical to success for transition planning and services is shifting the focus of all planning to the individual student (Cobb & Alwell, 2009). Postsecondary goals in education/training, employment, and independent living should be directly informed by student preference and interest (Leonard et al., 2016). Navigating the transition from public school settings and support to postsecondary settings can be fraught with anxiety for students and their families. Special educators, transition personnel, and vocational counselors working in coordination with one another *and* the student set the stage for the achievement of goals and more positive outcomes across postsecondary domains (Cobb & Alwell, 2009).

Further, to ensure student interests and preferences are taken into account, postsecondary goals in education/training, employment, and independent living should be

based on valid and reliable transition assessments with first-hand student input. A plethora of assessments exist across a spectrum of informal to formal assessments. Research suggests that in order to bolster transition plans, at least one transition assessment be formal and part of a multi-assessment approach to goal development (Prince, Plotner, & Yell, 2014; Thoma & Tamura, 2013; Thoma, Bartholomew, & Scott, 2009). While students with IDD may require more assistance and guidance to complete transition assessments, educators should continue to solicit active student involvement in the transition process. Increasing active student involvement in the IEP and transition process has been linked to improved postsecondary outcomes (Mason, McGahee-Kovac, & Johnson, 2004).

The passage of the Workforce Innovation and Opportunity Act (WIOA, 2014; PL. 113–128) has strengthened the involvement of the adult vocational rehabilitation system in the process of supporting the transition to adult life for youth with disabilities, requiring a greater degree of collaboration between the K-12 school systems and the vocational rehabilitation (VR) system. WIOA (2014) requires the provision of "pre-employment transition services" (Pre-ETS) designed to improve competitive, integrated employment outcomes for youth with disabilities. Pre-ETS services include the following required activities/supports (section 113(b) of the Act and §361.48(a)(2)) a) job exploration counseling; b) work-based learning activities; c) counseling on opportunities for enrollment in comprehensive transition programs or postsecondary education programs at IHEs; d) workplace readiness skills including social skills training; and e) instruction in self-advocacy including peer mentoring (Rehabilitation Services Administration, 2014). Until the passage of WIOA (2014), schools were required to

invite VR counselors and representatives of other adult service agencies that were likely to be providing transition services; WIOA instead requires VR counselors provide services to all youth with disabilities as a collaborative approach between the two agencies, designed to improve post-school outcomes for youth with disabilities.

**Individualization of postsecondary planning.** Echoing the sentiment of active student involvement in the transition planning process, individualization based on student interest and preference is essential to design a supportive and effective post-school plan that helps students achieve their goals for a preferred lifestyle. This covers a range of outcomes that can include employment, postsecondary education, community living, community participation, and recreation and leisure activities (Thoma, Bartholomew & Scott, 2009). Once the goals are identified, the transition team determines the transition education and/or services needed to help the student achieve those goals. For example, an identified best practice in the area of employment is to provide students an opportunity for both paid and unpaid work experiences across a variety of domains (Landmark, Ju, & Zhang, 2010). Critical to this process is educators forging collaborative relationships with adult agency providers to offer students opportunities through internships, job shadowing, and volunteer positions. Teachers have traditionally been the connective piece between students and their families to quality service providers, empowering students with greater control and choice as they navigate the postsecondary world (Grigal & Neubert, 2004). As the Pre-ETS requirements of WIOA (2014) are implemented and research is conducted to determine their effectiveness, a more collaborative team may share those responsibilities (Thoma, Taylor, Whittenburg, Gokita, & Scott, in press).

Completion certificates vs. diplomas. There is much debate in the field over

how students with disabilities are exiting high school programs. Across the nation, as many as 15 different types of exit documents existed for students with disabilities (Gaumer Erickson, Kleinhammer-Trammil, & Thurlow, 2007). This number varies from state-to-state and year-to-year regarding available options for either traditional or nontraditional exit from high school. Nontraditional exit options include (a) special education diploma, (b) certificates of attendance,(c) certificates of achievement, (d) transition certificates, and (e) occupational diplomas, among others.

Students with IDD, nationwide, received the highest number of nontraditional exit certificates (Gaumer Erickson et al., 2007). Frequently, the alternative diploma or certificate was seen as substandard outside the field of education (Johnson, Stout, & Thurlow, 2009). The ramifications of this distinction are significant. Not being able to earn a legitimate diploma leaves students with IDD at risk for increased adverse outcomes, such as lower rates of employment and independence (McLaughlin, 2010). Moreover, employers reported being unwilling or unsure about hiring an individual without a traditional diploma (Hartwig & Sitlington, 2008).

The decision of what diploma *track* a student will follow through high school is also placing students with IDD at significant risk of diminished access to general education peers, instruction, and opportunities. Students on a nontraditional exit track are more often placed in segregated special education settings where expectations are lower, and standards of achievement are not equitable to peers on a traditional diploma track (Johnson et al., 2009). Providing access for students with IDD the exit option most beneficial for postsecondary life is critical to promote more positive outcomes.

# System Capacity Development, Funding, Oversight, and Accountability

Several suggestions outlined in the policy brief mirror the interrelated needs and suggestions for improving all public schools. At the state, district, school, and institutes of higher education levels it is vital to recruit, train, and retain a qualified cadre of administrators, educators, and staff who have the expertise and flexibility to meet the needs of students with IDD in inclusive classrooms. There is also a need to ensure legal and lay advocates to support families as they exercise their rights. At the federal, state, and local levels, there is a call to increase active monitoring and enforcement to ensure IDEA, ADA, Section 504, and state special education laws and mandates are met.

Consequently, the federal government must fully fund IDEA, an idea that has long had bipartisan support and needs to be enacted (National Council on Disabilities, 2018). Finally, all students, including those with the most significant cognitive disabilities, must be included in statewide accountability systems. Furthermore, no more than 1% of the state's students should be allowed to be exempt from general accountability data.

### Conclusion

This paper presents research on the existence and significant impact of current barriers and areas of concern around educating students with IDD and presents AAIDD's call for policies and practices that will remove or reduce these barriers. The authors contend that inclusive contexts matter and must be the first non-negotiable for this population in order to increase the likelihood of high-quality post-school outcomes. This paper is of value to educators, parents, guardians, researchers, and other stakeholders as they develop high-quality systems of supports and services. These areas of critical civil rights and educational laws need to be fully implemented in order to provide people with IDD equality of opportunity, full participation, independent living, and economic selfsufficiency in their life spans; "To ensure students with IDD receive the education to which they are legally entitled, all those involved in the education of these students must work to fully implement our nation's civil rights and education laws and accomplish the [above] actions" (AAIDD, 2018).

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