

Viewpoint

Autism and Neurodiversity: Addressing Concerns and Offering Implications for the School-Based Speech-Language Pathologist

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Purpose: The purpose of this article is to address some common concerns associated with the neurodiversity paradigm and to offer related implications for service provision to school-age autistic students. In particular, we highlight the need to (a) view first-person autistic perspectives as an integral component of evidence-based practice, (b) use the individualized education plan as a means to actively address environmental contributions to communicative competence, and (c) center intervention around respect for autistic sociality and self-expression. We support these points with cross-disciplinary scholarship and writings from autistic individuals.

Conclusions: We recognize that school-based speech-language pathologists are bound by institutional constraints, such as eligibility determination and Individualized Education Program processes that are not inherently consistent with the neurodiversity paradigm. Consequently, we offer examples for implementing the neurodiversity paradigm while working within these existing structures. In sum, this article addresses key points of tension related to the neurodiversity paradigm in a way that we hope will directly translate into improved service provision for autistic students.

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Client perspectives are a key component of the American Speech-Language-Hearing Association's (ASHA) mandate to provide evidence-based practice (ASHA, 2005), and yet, the voices of autistic individuals are often not explicitly reflected within our professional literature. As one example, many adults on the autism spectrum have expressed a preference for identity-first language, such as "autistic person" (Hillary, 2015; Kapp et al., 2013; Kenny et al., 2016; Sinclair, 2013), and yet many professionals, organizations, and institutions within the field of speech-language pathology maintain a blanket policy of person-first language (e.g., "person with autism"). What may seem like a relatively trivial language difference reflects underlying differences in how autism is perceived.

In short, person-first language is associated with a medical model that views autism through a framework of disease—a pathology or infliction of the person that requires remediation or cure. In contrast, identity-first language is associated with the neurodiversity paradigm, which views autism as a form of neurobiological diversity that cannot be separated from the person and does not inherently need to be fixed. As summarized succinctly by autistic writer Cassandra Crossman (2019), "Being autistic, similar to being deaf or blind, is intrinsic to one's identity and culture, and cannot and should not be separated from people. We don't carry our autism around with us like a handbag and we are not 'people with autism.' We don't 'live with autism,' or 'suffer from autism.' We are autistic."

The term *neurodiversity* itself is credited to Judy Singer (1999), who coined it as a way to reflect the substantial diversity in human neurology, of which autism is one complex variety. The neurodiversity paradigm is tied to a grassroots civil rights movement that emerged in the 1990s (Bagatell, 2010; Silberman, 2015) as a response to a history of systematic abuses and exclusions of autistic people

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across medical (e.g., institutionalization, harmful treatments, poor diagnostics), social (e.g., stigma/stereotypes, infantilizing, silencing), and civil (e.g., school, career) domains. As summarized by Neumeier (2018, para. 16), “Neurodiversity isn’t a list of words or slogans for people to use or avoid. It’s a social justice movement, with the ultimate goal of vindicating everyone’s inherent worth—and thus their right to enjoy inclusion, freedom, and the supports that allow for both.” Like many other forms of human difference that experience societal stigmatization, autism under the umbrella of neurodiversity has solidified into a social-cultural identity, complete with distinct values, positive identity, community organization and events, artifacts, shared vocabulary and cultural references, distinct communication style, and expressions in the arts (Strauss, 2013).

From its origins, the Neurodiversity Movement has been decentralized, which has contributed to differential or incomplete interpretations of the associated paradigm (see Neumeier’s [2018] reference to “neurodiversity lite” and Jaarsma and Welin’s [2012] distinction between “narrow versus broad” interpretations). Different interpretations often center around weighty issues, such as who gets to represent the autistic community and how to best access critical support services. The account of neurodiversity provided here is generalized to provide the broadest possible coverage of informing features (cf. Angulo-Jiménez & DeThorne, 2019; Armstrong, 2010). A central, and controversial, feature of the neurodiversity paradigm is its rejection of the idea that autism and other forms of neurodiversity are “intrinsically harmful disorders” and advancement of these neurodivergent types as “valuable, natural and/or normal parts of human neurocognitive variation” (Hughes, 2020). Although resistant to autism as *disorder*, the neurodiversity paradigm aligns with the social model of *disability*, which views autistic individuals’ challenges to be caused in significant part by majority society’s biased expectations and lack of support. Specific examples include the enforcement of social norms that require insincere flattery and small talk and built environments that use harsh fluorescent lighting or bolted seats that are fixed close together.

Despite the 30-year history of neurodiversity as a civil rights movement, references to neurodiversity within speech-language pathology have been slow to emerge. A quick search for “neurodiversity” on ASHA Wire as of July 12, 2020, revealed a total of 12 hits, with the first being a 2016 book review (Law, 2016). Donaldson et al. (2017) provided the first substantial ASHA paper devoted to neurodiversity. Their article introduced the concept and emphasized clinical implications: a strength-based approach, identity-first language, and presumed competence. Despite the emergence of scholarship on neurodiversity, misconceptions remain commonplace (cf. den Houting, 2019), and translations to clinical practice remain sparse. A clinician recently remarked to the first author (L. D.) after a presentation on neurodiversity, “I associate neurodiversity with adults on the spectrum; I never really thought about how it applied to children.” Accordingly, the intent of this article is to address three common concerns associated with the neurodiversity

paradigm, particularly as it pertains to school-based speech-language pathology, and to provide associated clinical implications.

Concern #1: Insights from “high functioning” autistic adults are not relevant for children with higher support needs.

Response: Self-advocacy and evidence-based practice are best served when autistic lived experience is integrated with input from familiar caregivers and professional expertise.

One of the primary concerns we hear about the neurodiversity paradigm is that it does not represent or apply to autistic students who are “lower functioning” or have higher support needs (see Jaarsma & Welin, 2012; Lutz, 2013; Opar, 2019). Most agree that self-advocacy is the ideal. However, self-advocacy becomes complicated with younger children or students with highly restricted verbal repertoires, especially given differences in social skill development among autistic students (Shore, n.d.). The challenges autistic students face in self-advocacy are further increased within therapeutic and educational domains that often include inflexible power structures with histories of discriminating against many marginalized groups (Abrahams et al., 2019; St. Pierre & St. Pierre, 2018). Consequently, adult advocacy is often critical.

Adult advocacy for children is informed by an understanding of one’s own childhood experiences. However, because autistic students are often born to nonautistic parents and served by nonautistic professionals, the intentional integration of autistic perspectives can be transformational. A nonautistic adult’s sense of what is beneficial, desirable, or even “normal” may not accurately reflect autistic experiences. As a flashpoint example, many autism self-advocates and their allies have criticized Autism Speaks, founded by the grandparents of an autistic boy, for its early public service announcements that characterized autism in children as a demonic disease that possessed and destroyed caregivers and families and led one mother to consider (in front of her child) committing murder-suicide by driving off the George Washington Bridge (for one parent-ally’s well-known response, see Jess, 2013). In addition to the propagation of harmful rhetoric, critiques against Autism Speaks by the autistic community have centered on its failure to include autistic representation or to invest in local support services that benefit quality of life for autistic individuals (Autistic Self Advocacy Network, 2014).

Based on this history of harmful rhetoric and limited representation, members of the autistic/neurodiversity community have felt the need to be very vocal against communication and intervention practices they believe are harmful. Prominent concerns about harm have been associated with interventions that focus primarily on compliance (e.g., Jones, 2015) and include speech-language therapy that emphasizes conforming to neurotypical social behaviors (e.g., Sibley, 2015). Pressure to conform to neurotypical behavior leads to attempts to hide one’s “true self” from others in order to fit in and avoid negative social responses, a common phenomenon in the autistic community that is referred to as

“masking” or “camouflaging.” Most nonautistic individuals are not likely to have experienced the pressure to mask in the same way and to the same degree as autistic individuals, and therefore are less likely to relate to or predict the negative mental health consequences associated with it (cf. Cage et al., 2018; Cage & Troxell-Whitman, 2019).

Another example of divergent perspectives that tends to emerge between autistic individuals and nonautistic authority figures relates to the perceived value of screen time. Whereas nonautistic parental perspectives and professional authorities often advocate for strict restrictions on screen time (see, e.g., the American Academy of Child and Adolescent Psychiatry’s, [2020] recommendations to parents), autistic adults often point out that virtual time spent exploring interests, experiencing virtual environments, and interacting socially online can be beneficial to autistic development and mental health (cf. Ask Autistic Adults – Resource for Parents of Autistics, n.d.). In fact, work by autistic scholar Kris Harrison (2019) has called for the reconceptualization of media devices as “care structures” that can help address important sensory regulation needs. She highlights that conflict over screen time between parents and autistic children may be due in part to their different sensory preferences and needs (Harrison et al., 2018).

In sum, a basic premise of the neurodiversity paradigm is that autistic individuals best understand their own embodied and lived experiences, leading self-advocates to claim that including autistics in any conversations or actions concerning their welfare is ethically necessary (Autistic Self Advocacy Network, 2016). Discounting input from autistic adults based on the ill-defined and arbitrary nature of functioning labels (Alvarez et al., 2019; den Houting, 2019; Williams, 2019) seems misguided. Self-advocacy and evidence-based practice are best served when autistic lived experience is integrated with input from familiar caregivers and professional expertise.

Implication #1: Elicit and listen directly to the student being served (no matter their age or abilities), and also familiarize yourself with views from the “actually autistic” community.

Self-advocacy is a complex social skill, which is acquired developmentally and requires support. As autistic individuals are acquiring the ability to advocate for themselves, integrating autistic perspectives together with caregiver input is essential for evidence-based practice. First and foremost, practitioners need to listen directly to the students being served (no matter their age or abilities) and familiarize themselves with views from within the “actually autistic” community. There is no shortage now of accessible blogs, videos, books, and essays created by autistic individuals that touch on key topics such as eye contact, social skills, echolalia, stimming, self-harm, communication choice, and so forth (see a sampling of resources from autistic perspectives provided in Supplemental Material S1). For speech-language pathologists, such materials can be useful for self-education, prompts for discussion with autistic clients, and tools for increasing awareness among family members, peers, and colleagues.

Concern #2: The neurodiversity paradigm denies disability.

Response: The neurodiversity paradigm encourages us to recognize environmental contributions to disability.

A second common concern associated with the neurodiversity paradigm is the perception that it refuses to recognize autism as a disability (den Houting, 2019; Jaarsma & Welin, 2012). The neurodiversity paradigm does question the notion that autism is inherently disabling and offers two relevant points. First is the importance of distinguishing autism from associated impairments (e.g., seizures, anxiety disorder, gastro-intestinal difficulties) that may commonly co-occur with autism but do not intrinsically define it. Our use of the term *impairment* here is consistent with the definition provided by the World Health Organization (2002, p. 10) as “problems in body function or structure such as a significant deviation or loss.” This distinction between autism and frequently associated impairments enables us to view the differences connected with autism, such as divergent thinking and intense interest, more neutrally or even positively.

As a second related point, the neurodiversity paradigm highlights that whether autistic traits are disabling can depend largely on *environmental* factors, an idea that is consistent with the social model of disability (cf. Angulo-Jiménez & DeThorne, 2019; Strauss, 2013). For example, the social difficulties experienced by autistic individuals can be mediated in part by acknowledging and questioning the necessity of neurotypical practices, especially those that may feel uncomfortable for autistic students such as direct eye contact and requisite small talk (Bagatell, 2010; Ochs & Solomon, 2010). Similarly, environmental factors such as access to augmentative and alternative communication (AAC), support for flexible multimodal communication practices, and reduction of painful sensory stimuli can go a long way toward ameliorating communication-related disability for autistic individuals, as can efforts to reduce stigma, exclusion, and segregation. Baron-Cohen (2019, para. 5) sums up this view with a direct quotation from an autistic individual: “We are freshwater fish in salt water. Put us in fresh water and we function just fine. Put us in salt water and we struggle to survive.”

Speech-language pathologists are often trained to improve outcomes for autistic students by identifying individual rather than environmental deficits for intervention, despite the fact that the social climate and the behavior of nonautistic peers plays a major role in the exclusion of autistic students. Empirical support comes from an experimental study by Kasari et al. (2012), which compared the effects of two social interventions using a sample of 60 autistic students, aged 6–11 years old: One condition focused directly on the skills of the autistic students, and one focused solely on the awareness and behavior of the nonautistic peers. The latter condition, focused on nonautistic peers, led to better social outcomes for autistic students. Such results call to question: Who is it that really needs to change and why? As the neurodiversity paradigm has empowered autistic voices, we have learned more about the explicit need for everyday supports focused on social

acceptance, communication access, vocational support, and mental health (Pellicano et al., 2014; Robertson, 2010).

Implication #2: Use the Individualized Education Program (IEP) as a means to actively address environmental contributions to communicative competence.

Unfortunately, the current special education eligibility procedures and associated IEP process are largely designed around the concept of disability as an *individualized* disorder that puts the locus of change onto the autistic student (cf. Vidal, Robertson, et al., 2018). This approach tends to minimize the support needs of students who perform well on skills-based assessments and to underestimate the potential of those students who perform poorly. However, there are ways to work within the current system to center the needs of autistic students and to recognize the critical contributions of their environments to success (or failure). As previously mentioned, we need to work toward centering the student's voice and perspective in the assessment and IEP process. In addition, we should include interview and observational data that help capture the complexity and context of a student's everyday school experiences—in other words, not just noting the student's behavior but also identifying environmental factors, both positive and negative, that may be supporting or impeding a student's success. Examples include teacher attitudes, peers' ability to recognize an autistic student's social initiations, access to AAC, and the sensory landscape of the classroom (e.g., bells, alarms, microphone use, type of seating). IEP goals can be written with careful consideration of environmental factors by specifying what supports will be provided. In the following example, note that three key environmental factors (i.e., activity, AAC access, and communicative partner) are specified: *During game play and with access to her speech-generating device, Rosie and a familiar peer will engage in at least three interactive turns.*

Finally, we should fully utilize other aspects of the IEP that acknowledge and specify the importance of environmental factors—not as an afterthought but as a fundamental aspect of the intervention process—specifically those aspects of the IEP designated for supplementary aids, accommodations, modifications, and support for school personnel. These supports can range from individualized accommodations such as access to AAC, extended time, simplified text, and “movement breaks” to more distributed forms of support, such as staff training and peer education. In sum, the neurodiversity paradigm does not deny disability per se, but makes an important distinction between autism and frequently co-occurring impairments, and highlights the role of environmental factors in constructing disability.

Concern #3: The neurodiversity paradigm is not consistent with intervention.

Reframing: The neurodiversity paradigm requires us to adjust our approach to intervention.

Related to how one understands disability is the concern that the neurodiversity paradigm is inconsistent with the provision of intervention (Jaarsma & Welin, 2012). In truth, the word “intervention” does carry a medicalized

connotation of needing to cure a pathology, which can be off-putting to some in the autistic community; the term *supports* may be preferred. Regardless of what term is used, the neurodiversity paradigm does not deny the support needs commonly associated with autism. In fact, a study by Kapp et al. (2013) found that autistic participants, who were in general more aware than nonautistic participants of the neurodiversity paradigm, did not differ from nonautistic participants in their perceptions of the importance of supports to help autistic people gain adaptive skills. Instead of denying the importance of intervention, the neurodiversity paradigm requires us to reconceptualize intervention in a way that centers the needs and strengths of autistic students, and explicitly acknowledges environmental contributions to outcomes (cf. Angulo-Jiménez & DeThorne, 2019; Armstrong, 2010; den Houting, 2019; Donaldson et al., 2017).

Autistic self-advocates and their allies are particularly concerned with interventions aimed at pressuring autistics to adhere to societal standards in ways that change their fundamental nature or self-expression—this is especially the case with the “extroverted ideal” in American education with its pedagogical emphasis on group work and other social learning experiences (Cain, 2012). Autism care professional and advocate Ayana Bailin (2019, para. 7) explains how the distinction matters in clinical assessment for intervention:

When we talk about “not pathologizing autism,” we don't mean “pretending autistic people don't have impairments.” But we also don't assume that neurological and behavioral differences are always problems. For example, there's nothing inherently wrong with disliking social activities. Not wanting to socialize is different from wanting to participate and being unable to. Both are possibilities for autistic people. One requires acceptance, the other requires assistance. Sadly, I have yet to meet a therapist who doesn't treat the two as equivalent and in equal need of correction.

The Neurodiversity Movement has been particularly critical of compliance-based interventions that use powerful behaviorist learning principles aimed at “shaping” autistic behavior to match neurotypical norms through such goals as discouraging self-soothing behaviors (stimming), encouraging direct eye contact, and prioritizing verbalized communication (Silberman, 2015). In contrast, neurodiversity proponents endorse interventions that enable the autistic person to be more successful in how they choose to navigate the world and emphasize the need for the autistic client's participation in selecting the therapy and for their positive assent to all aspects of its delivery—regardless of age or ability.

Implication #3: Center intervention around respect for autistic forms of sociality and self-expression.

One of the first steps in respecting autistic sociality is reflecting on how we talk and write about autistic students. When possible, avoid use of a pathologizing frame and the assumptions that follow. For example, a recent school-based evaluation report of an autistic second grade student included statements such as, “He totally ignored classmates when they spoke to him.” Such a statement

could be rewritten from a more thoughtful and distributed perspective, such as, “When his classmates spoke to him, he did not appear to respond in a way they recognized.” Autistic authors, Bulluss and Sesterka (2020a, para. 11), offer illuminating examples of how we might shift away from a pathologizing frame when we write about autistic behavior: using alternatives such “creative language” rather than “non-functional language,” “preference for sameness and consistency” rather than “rigidity of routine,” and “very passionate about their areas of interest” rather than “narrow, obsessive interests.” In a useful companion piece, Bulluss and Sesterka (2020b) acknowledge that clinicians may be required to use deficit-based language to comply with diagnostic requirements, but highlight that such language does not need to set the tone for the entire diagnostic assessment and subsequent reports.

In aligning with the neurodiversity paradigm, speech-language pathologists might see their role as less about changing autistic behavior and more about facilitating interaction through respect for autistic forms of sociality and self-expression (cf. Donaldson et al., 2017). This is likely to involve building interactions around shared interests, supporting flexible multimodality, respecting sensory needs, understanding the importance of stimming, and fostering acceptance by peers (Bagatell, 2010; Kapp et al., 2019; Ochs & Solomon, 2010; Park, 2010; Vidal, Robertson et al., 2018). From this foundation of respect, speech-language pathologists can introduce the concept of nonautistic behavior as an option for code-switching if deemed useful by the student. From this perspective, neurotypical expectations and skills need not be presented as the standard of worth but rather as a repertoire of knowledge and skills that can be learned and deployed as one chooses (cf. Angulo-Jiménez & DeThorne, 2019). At the same time, the demands and consequences of masking should always be considered, and when possible, discussed, with autistic students. Masking increases cognitive demands, which cause stress, and has been associated with autistic burnout, anxiety, and depression (Beck et al., 2020; Cage et al., 2018; Cage & Troxell-Whitman, 2019; Lai et al., 2017; Raymaker et al., 2020; Russo, 2018). Speech-language pathologists can help reduce some of the burden and pressure associated with masking by emphasizing communication and empathy as two-way streets that require accommodation and understanding from autistic and nonautistic partners alike (DeThorne, 2020; Vidal, Ernat, et al., 2018; Wolfberg et al., 2008). Readers are referred to a post by speech-language pathologist Julie Roberts (2020), who offered examples of pragmatic language goals aimed to avoid masking and align more directly with the neurodiversity paradigm.

In closing, the Neurodiversity Movement implicitly asks clinicians to accept that there is no physical or behavioral ideal to which all people should or do conform, either in their constitutions or their capacities. Physical and cognitive human variations and the diverse perspectives that arise from them are inevitable and valuable, whatever their cause. We validate the whole person when we acknowledge that individual or collective differences from mainstream

standards and norms may be neutral or positive, rather than assuming they should be changed to better conform to pre-conceived expectations. We provide better service and ensure better outcomes for our students and their families when we incorporate first-person perspectives into our evidence-based practice—a move that honors the collaboration domain of service delivery—and when we help to discover and are led by students’ goals for improving their whole lives—a move that touches upon the assessment, counseling, and wellness domains within our scope of practice (ASHA, 2016). Specifically, speech-language pathologists are called by the advocacy domain of professional practice to “promote and facilitate access to communication, including the reduction of societal, cultural, and linguistic barriers” (ASHA, 2016). Speech-language professionals can advocate for autistic students both through adjusting current practices, such as by using the IEP process to specify environmental supports, and through going beyond a focus on individual treatment, such as by recommending changes to policy that optimize autistic students’ learning environments and conditions.

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