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"It Is Awful for Your Morale": A Need for Person-Centered Approaches to Speech-Language Services for Autistic Young Adults

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Introduction

Although limited, existing evidence suggests that person-centered principles have not been adequately translated into appropriate speech-language assessment and service delivery for autistic young adults (Forsgren et al., 2022; Savard et al., 2024), particularly those who are the least likely to be represented in the evidence base (e.g., culturally and linguistically diverse communities, autistic people who are non-speaking). For example, U.S.-based autistic young adults report that services over-rely on approaches for young children (e.g., infant-directed speech), decontextualized activities that do not support navigating real-world settings (e.g., watching movies to identify emotions), and clinician-directed priorities (e.g., targeting social communication vs. self-identified priorities of stuttering and family supports; Santhanam & Hewitt, 2021). In this editorial, we argue that speech-language services for autistic young adults must integrate three person-centered principles: (a) developmentally appropriate assessment and services that align with real-world needs; (b) shared decision-making or co-creation of goals with autistic young adults that align with personal priorities rather than prescribed expectations (Gaddy & Crow, 2023); and (c) holistic services that are responsive to contextual influences at the levels of interpersonal, community, and systems (Gregory & Atkinson, 2024).

Identifying the Need

The period of transition from youth to young adulthood has been identified as critical for autistic people (Roux et al., 2024) in both, establishing access to services to support long-term quality-of-life outcomes and gaining increased autonomy to support activities that are meaningful and aligned with personal goals (Schendel et al., 2022). During this developmental stage, the option to access effective, appropriate speech-language services is important for continued growth and communication support. In this editorial, we highlight the need for novel approaches for providing speech-language services to autistic young adults, drawing on a collective understanding of person-centered planning.

Although there is growing attention to the constellation of outcomes of autistic people in adulthood (Eigsti, 2024), communication access remains a critical component of overall quality of life and is a factor that impacts access to preferred activities and environments. Communication modalities, styles, and complexity levels vary considerably across autistic youth (Schaeffer et al., 2023); however, speech-language services are typically mandated within school- and child-based programs. As autistic young people "age out" of secondary education and pediatric services, many face challenges accessing adult care systems, including speech-language supports (Malik-Soni et al., 2022). Disability service systems may provide services to autistic adults with intellectual disability, while those without intellectual disability may lack services (Bradshaw et al., 2020; Šiška et al., 2024). Such challenges have a cascading impact, from building relationships to navigating education, health care, and community settings (de Marchena et al., 2025).

These challenges arise from complex multilevel influences, from systemic influences to provider interactions, including assessment and intervention (Bronfenbrenner, 1977; National Institute on Minority Health and Health Disparities [NIMHD], 2025). At the systems level, most

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autism research has over-focused on individual clinical deficits and childhood versus the lifespan, overlooking heterogeneity in language and communication skills across the autism spectrum (Howlin & Taylor, 2015; Pellicano & den Houting, 2022; Schaeffer et al., 2023). Therefore, existing language measures for young adults are inadequate overall, with varying approaches to assessment and no clear pathway to service eligibility (e.g., Fidler et al., 2011; Johnson et al., 1999). A second challenge is related to implementation of services, including those for speech-language, in routine care settings (Tabak et al., 2017). Autistic adults report unmet communication needs (Cummins et al., 2020), which differ from the needs and priorities of autistic children (e.g., occupation, recreation, and independent living; Billstedt et al., 2011). Thus, to be effective, services for autistic young adults must be person-centered (Shogren et al., 2021).

Person-Centered Approaches

A person-centered approach to care means supporting an autistic person as a unique individual rather than proscribing care based on diagnosis or clinical standards alone. The person's preferences, strengths, goals, communication methods, sensory experiences, culture, relationships, and support needs should guide care planning and decision-making (Nicolaidis et al., 2015; Shaw et al., 2024). Person-centered care is based on the principle that support should be provided with, rather than to, the person. Autistic people should be involved as fully as possible in decisions concerning their health, daily life, and future. This is critical for autistic young adults as they navigate increasing independence and responsibility. Person-centered approaches have been used in special education services, especially during the transition planning process. The emphasis is on self-determination and active student participation, with educational, employment, independent-living, and community goals shaped by the young person's strengths, preferences, interests, and priorities rather than determined primarily by professionals (Scott et al., 2021; Shogren et al., 2021). Family/guardians are involved in decision-making; however, the autistic young adult and their priorities remain the focus.

In clinical practice, shared decision-making may require professionals to adapt how choices and information are presented, such as providing additional processing time, written explanations, or clearly structured options (Levy et al., 2016). Autistic adults' accounts of mental health services suggest that effective care should be tailored to, practical for, accommodating of, and affirming of their individual autistic identity. Research has found that autistic adults want professionals to understand the diversity of autism, provide individualized accommodations, and avoid focusing only on changing or eliminating autistic characteristics (Andoni et al., 2026). These recommendations are wholly relevant for speech-language services.

Understanding Individual and Community Experiences

Our understanding of person-centered speech-language services has developed over time through partnerships with autistic people, families, providers, and community organizations. Community partners identified priorities for speech-language services and voiced concerns about inadequate sensitivity to the background of each autistic person (Girolamo et al., 2024; Seung et al., 2026), which is consistent with broader evidence on overall services during the transition to adulthood (Scott et al., 2021; Taylor et al., 2024). Following the clinical measurement theory (McClimans et al., 2017), we recognized their insight as expert opinions, an integral part of the evidence base for understanding person-centered speech-language services and developing person-centered measures.

One example involves speech-language services and self-determination during the transition to adulthood. Our team was approached by community organizations serving autistic people and families, including one founded by autistic young adults and another founded by a neurodivergent parent of autistic children. While the organizations served autistic people of all ages, initial conversations revolved around service delivery during the transition to adulthood. An autistic young adult from one of these organizations shared how most of their school-based speech-language service experiences were belittling, did not support their autonomy or participation in decision-making, and were not sensitive to their cultural background. Clinicians used "baby talk" and targeted areas in service delivery that were not meaningful, such as social skills, when the young adult's priorities were auditory processing and memory. Services also did not acknowledge the realities of their environments, such as challenges in making friends due to bullying, which reflects problems with peers, and not themselves. Thus, clinical documentation describing individualized planning did not reflect that decisions about assessment, intervention, and service delivery were clinician-directed and largely excluded the autistic young adult and their family, who were central to decision-making per their cultural norms. As the autistic young adult noted, "It was awful for your morale." In this way, lived experience can inform how we understand, measure, and strive for person-centered speech-language services.

These discussions led the community organizations and our team to decide to engage in joint programming and community-based participatory research together. One project was about the experiences of autistic young people with speech-language services during their transition to adulthood within the United States (Girolamo et al., 2024). As community partners emphasized the

importance of recognizing both individual heterogeneity and inclusion in the evidence base, we co-designed a participatory study of speech-language services among autistic adolescents and young adults (ages 13–30), starting from when transition planning begins in some states and approximately 10 years after aging out of federal special education services within the United States (Individuals with Disabilities Education Improvement Act [IDEIA], 2018). Rather than assuming shared experiences based on demographics or clinical traits (Plaut, 2010), we recruited participants underrepresented in research and used person-reported service measures to assess the services received, unmet service needs, and the barriers to services using items from the National Longitudinal Transition Study-2 (NLTS2; Newman et al., 2011) and as adapted in Taylor and Henninger (2015). The NLTS2 was a 10-year U.S.-based federal study that tracked a nationally representative sample of 11,000 high school students in special education (ages 13–16) during the transition to adulthood (Newman et al., 2011). Approximately one third of participants reported receiving speech-language services, one third reported them as an unmet need, and one third did not report them as an unmet need (Girolamo et al., 2024). Participants also reported multiple barriers to services, such as unavailability and ineligibility. To better understand these patterns, we looked to community partner expertise. Reflecting on their experiences, community partners emphasized that person-centered care required considering the "big picture" of communication: environments in which age-appropriate, and culturally and linguistically sensitive communication, shared decision-making, and prioritization of client goals were the norm. These discussions led us to examine how contextual influences shape person-centered speech-language services.

Follow-up work suggested that service experiences varied by relationship to autism (Asare et al., 2026) and led to further examination of how context shapes communication (Girolamo et al., 2026, in press). Autistic young adults, caregivers, clinicians, and organizational leaders all described barriers to services but emphasized different barriers (Asare et al., 2026). Clinicians and organizational leaders focused on structural challenges, such as a need for resources and training to provide culturally and linguistically sensitive assessment-informing service delivery. In contrast, caregivers emphasized low-quality provider interactions, inadequate cultural and linguistic sensitivity, and overwhelming advocacy demands, whereas autistic young adults described a mismatch between their priorities and the available services. In interpreting findings, community partners stated that these differences must be considered within the broader social and policy contexts surrounding autistic young adults. They described how autistic young adults varying in cultural and linguistic backgrounds and their support networks navigate societal norms and policies that shape educational opportunities, health care access, neighborhood resources, and community participation. Hence, priorities for communication, services, and supports often reflect adaptive responses to environments rather than individual or family-level characteristics alone. Partners also highlighted that families continually interpret these realities when making decisions about services, advocacy, and future planning. Because of these discussions, our subsequent and ongoing work examined contextual influences on communication and self-determination (Girolamo et al., 2026). Collectively, this research points to a need to develop person-centered speech-language services by systematically identifying individual, interpersonal, community, and systems influences on service utilization and communication development. Measuring these aspects of the communicative environment is essential for developing assessments, services, and supports that reflect the priorities of autistic young adults.

Considerations in Person-Centered Speech-Language Services

Informed by these examples, the identified needs lead to several considerations for the relevant parties involved in service delivery for autistic young adults. First, the transition to adulthood is a critical developmental period with speech-language and communication priorities that change over time (Cherewick, 2024). We must move beyond prior assessment approaches, such as using measures designed for other populations (e.g., aphasia; Lewis et al., 2008), measures that were normed decades ago (Johnson et al., 1999), or measures that under-identify language impairment (e.g., vocabulary; Calder et al., 2023). While this requires developing measures that align with the reality of clinical practice and service eligibility considerations (DeThorne & Searsmith, 2021), we want to point out existing resources: the Autism Understanding Tool for Introspection and Evaluation for speech-language pathologists to self-reflect on their knowledge about autism (DeThorne et al., 2024) and the Canadian Occupational Performance Measure, which supports personalized identification, prioritization, and tracking of goal-oriented change (Law et al., 2014). Person-centered services must recognize that young adulthood is a unique period requiring appropriate methods for ongoing evaluation. Moreover, this aligns with the movement toward more person-centered approaches for autistic young adults across disciplines (e.g., occupational therapy; Benevides et al., 2023; Patten et al., 2024).

A second consideration involves expanding conceptualizations about speech-language services and delivery methods for young adults. At a systems level, speech-language pathology must prepare clinicians in person-centered approaches. For example, clinicians should not target

social skills based solely upon assumptions (vs. comprehensive assessment) about autistic people lacking the ability to interact with others. Rather, goals and intervention targets should address self-identified needs, such as strategies to support language comprehension, so that an autistic young adult can navigate health care or work toward an employment goal. Service delivery methods are equally important. Clinicians must presume competence, communicate respectfully, and engage autistic young adults as active partners in service delivery. Respect also means recognizing that many speech-language services have been oriented toward children and adolescents. Service delivery must communicate that services were designed for autistic young adults, and not some other population (Lewis & Oyserman, 2016). Our team's experiences showed that infantilized and clinician-directed speech-language service undermined trust and participation. Conversely, service delivery methods that championed collaboration, a neurodiversity-affirming approach, and autonomy facilitated engagement and created opportunities to pursue personal goals that aligned with broader outcomes (e.g., postsecondary education and employment). Thus, person-centered speech-language services must span both, targets in service delivery and how clinicians partner with autistic young adults and their support networks throughout service delivery.

A third consideration involves the broader contexts in which autistic young adults live. Clinicians should create opportunities for individuals to discover and share how their identities, communities, and lived experiences shape priorities for speech-language, communication, and autonomy. Conversely, clinicians should avoid making assumptions about priorities based on diagnosis or demographic characteristics. Consistent with the broader literature (e.g., Taylor et al., 2024), community partners have emphasized that autistic young adults from culturally and linguistically diverse backgrounds and their families may face low-quality provider interactions childhood onward. These experiences may influence priorities for supports, self-determination, and decisions about independence, reflecting adaptive responses to environmental demands versus individual characteristics alone. Building this understanding requires developing trust, rapport, and effective health care communication skills that support open dialog and shared decision-making. To be person-centered, clinicians must continually refine their understanding of individual priorities as new information emerges through interactions. This shift requires broader changes within the professions, including both greater representation in the speech-language workforce and evidence base, culturally sensitive training, and the development of assessment approaches that recognize cultural and linguistic variation as the norm. Yet, clinician–client concordance in broad demographic labels alone does not automatically yield improved provider interactions or quality of care (e.g., Meghani et al., 2009; Sweeney et al., 2016). Instead, person-centered speech-language services must consider the lived expertise of autistic young adults because their priorities are part of the collective knowledge central to evidence-based practice, as has recently been modeled in other disciplines (e.g., Jonkman et al., 2026).

Summary and Recommendations for the Field

Based on these considerations, we offer three concrete recommendations for autism research, speech-language pathology, and others involved in speech-language assessment or intervention for autistic young adults.

1. First, acknowledge that young adulthood is a distinct developmental period with speech-language and communication priorities that change over time.
2. Second, develop goals and targets for interventions that address self-identified needs and are aligned with priorities and context.
3. Third, create opportunities for individuals to discover and share how their identities, communities, and lived experiences shape priorities, including those who may be non-speaking and may not yet have access to a reliable means of communication.

Although the theoretical aspects of person-centered planning and service delivery are not new, the field of speech-language pathology and research, more broadly, would benefit from the consideration of these recommendations. The implementation of these systems and service delivery changes has the potential to improve service engagement and impact the outcomes for autistic young adults. Moreover, this aligns with the movement toward more person-centered approaches for autistic young adults across disciplines (e.g., occupational therapy; Benevides et al., 2023; Patten et al., 2024).

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