Editorial: “Innovation informs best practices in autism intervention across the lifespan”

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Autism spectrum disorder (ASD) is a condition characterized by the core symptoms of limited social communication, restricted interests, and repetitive behaviors (1) and is diagnosed in 1 out of every 44 children (2). ASD is pervasive in nature, thus at different developmental milestones, core symptoms affect varying functional life domains, such as physical and mental health, independent living, education, work and relationships (3–6). Autism is a “spectrum” condition because of its variation in severity, types, and comorbidities that affect each individual differently. The social nature of humanity makes social communicative deficits more adverse among those impacted by ASD. ASD occurs across all ethnic, racial, and socioeconomic groups. Due to the complexity of the condition with many individual and environmental factors, effective intervention is challenging.

Evidence-based practices must address “what intervention works for whom under which conditions” to facilitate a person’s positive treatment outcomes (7). Understanding how different attributes influence treatment can inform why some individuals may have differential outcomes in response to the same interventions. Historically, interventions for autistic individuals were designed and implemented in research or clinical settings, followed by efficacy trials that eventually culminated in effectiveness studies in the community (8, 9). However, without stakeholders’ involvement and input at the onset of intervention development and implementation effective and sustainable outcomes are attenuated [e.g., (10)]. This research to practice gap occurs in part because efficacy studies often do not consider the social contexts, perceived needs, values, or beliefs of key stakeholders such as families or individuals with disabilities, which impact treatment acceptability (11, 12). Thus, the field of implementation science calls for the involvement of stakeholders throughout the development process to yield high-quality interventions for autistic individuals that are acceptable and feasible in real-life contexts (8, 13).
Implementation science, design-based implementation research, and community-based participatory research are crucial to understand the pertinent factors and mechanisms necessary for increasing feasibility and acceptability in clinical and community settings, thereby improving implementation fidelity and treatment outcomes.

In this Research Topic Innovation Informs Best Practices in Autism Intervention Across the Lifespan, articles addressed three unique intervention or service domains for individuals with ASD (behavior, secondary transition, and language). More importantly, these articles employed innovative methods (i.e., Linguistic Inquiry and Word Count analysis, collaborative autoethnography, and Expressive Language Sampling Narrative procedure) in investigating pertinent factors to advance these intervention or service domains to improve acceptance, feasibility, delivery, and fidelity.

The first study, Applied Behavior Analysis as Treatment for Autism Spectrum Disorders: Topic Modeling and Linguistic Analysis of Reddit Posts was conducted by Bellon-Harn et al. Despite positive empirical support of Applied Behavioral Analysis (ABA) in early intervention in autism [e.g., (14)] and for short-term cognitive and adaptive behavioral outcomes [e.g., (15)], little is known about the perceptions of ABA in the public sphere. It is critical to understand factors that influence intervention effectiveness and acceptability. The authors investigated the perspectives of ABA from professionals, parents, and autistic individuals using the Linguistic Inquiry and Word Count (LIWC) tool. Results showed that perceptions were mostly geared toward personal experiences and opinions, and little was mentioned about clinical and research information. The authors link themes related to families and autistic individuals’ opinions and experiences with ABA-based interventions to help practitioners support families during this decision process.

The second article entitled Parent-researcher Perspectives on Role Intersectionality Related to Autism Research by Hall et al. Family caregivers often provide lifelong care and support for individuals with ASD, thus, caregivers often become a central part of the life of autistic individuals (16, 17). Hall et al. capitalized on the participants’ roles as both parents and researchers to serve as a resource for others, by understanding the benefits and barriers of having parents who are professionals and are involved as a researcher in conducting research in autism. Using collaborative autoethnography in-depth qualitative interview, results shed light on parent-researchers’ unique perspective in ASD research, highlighting bias toward parents and having parents as assets in autism focused research.

The final article entitled Using Telehealth-delivered Procedures to Collect a Parent-implemented Expressive Language Sampling Narrative Task in Monolingual and Bilingual Families with Autism Spectrum Disorder: A Pilot Study by del Hoyo Soriano et al. examined the feasibility of teaching English-speaking and Spanish-speaking parents to administer the Expressive Language Sampling Narrative (ELS-N) procedures to their children at home through telehealth methods. This innovative method overcomes the limitations of norm-referenced standardized tests to assess autistic individuals with varying degrees of language abilities and performance across different domains (18, 19) by using pictorial methods of assessment that are age and developmentally appropriate (20). The study provides additional evidence to support the validity of the measure and has important implications for families as a collaborative partner in the monitoring of treatment progress.

This special topic addresses autism intervention in diverse topical areas, including applied behavior analysis, language, and parents as agents of research. While ABA has long been established as an evidenced-based practice, recent discussions have raised controversies due to misalignment between the values and philosophies of ABA and the perceived needs of the autism community, which may affect buy-in and sustainability. The use of parents as an implementer and researcher is an innovation to practice, as parents and family caregivers often hold unique knowledge that is valuable in contributing to the planning and care of the individual with autism. These articles serve as a springboard for future research to bridge the research-practice gap in clinical and community settings.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. American Psychiatric Association (2013).
2. Maenner MJ, Shaw KA, Bakken AV, Bilder DA, Durkin MS, Esler A, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 Sites, United States, 2018. MMWR Surveill Summ. (2021) 70:1–16. doi: 10.15585/mmwr.ss7011a1
3. Biggs EE, Carter EW. Quality of life for transition-age youth with autism or intellectual disability. *J Autism Develop Disord*. (2016) 46:190–204. doi: 10.1007/s10803-015-2563-x
4. Havercamp SM, Scott HM. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disabil Health J*. (2005) 8:165–72. doi: 10.1016/j.dhjo.2014.11.002
5. Roux AM, Shattuck PT, Rast JE, Rava JA, Edwards AD, Wei X, et al. Characteristics of two-year college students on the autism spectrum and their support services experiences. *Autism Res Treat*. (2015) 391693. doi: 10.1155/2015/391693
6. Shivers CM, Sonnier-Netto L, Lee GK. Needs and experiences of family caregivers of individuals with autism spectrum disorders across the lifespan. *J Policy Pract Intellect Disabil*. (2019) 16:21–9. doi: 10.1111/jppi.12272
7. Means B, Penuel WR. Research to support scaling up technology-based innovations. In: Dede C, Honan J, Peters L, editors. *Scaling Up Success: Lessons From Technology-Based Educational Improvement*. New York, NY: Jossey-Bass. (2005). p. 176–97.
8. Dingfelder H, Mandell D. Bridging the research-to-practice gap in autism intervention: An application of diffusion of innovation theory. *J Autism Develop Disord*. (2011) 41:597–609. doi: 10.1007/s10803-010-0981-8
9. Smith T. Evolution of research on interventions for individuals with autism spectrum disorder: Implications for behavior analysts. *Behav Analyst* (2012) 35:101–13. doi: 10.1007/BF03392269
10. Suhreinrich J, Stahmer AC, Reed S, Schreibman L, Resinger E, Mandell D. Implementation challenges in translating pivotal response training into community settings. *J Autism Develop Disord*. (2013) 43:2970–76. doi: 10.1007/s10803-013-1826-7
11. Aarons GA, Hurlburt M, Horwitz SM. Advancing a conceptual model of evidence-based practice implementation in public service sectors. *Admin Policy Ment Health Serv Res*. (2011) 38:4–23. doi: 10.1007/s10488-010-0327-7
12. Fixsen DL, Naoom SE, Blase KA, Friedman RM, Wallace F. *Implementation Research: A Synthesis of the Literature*. Tampa, FL: University of South Florida, Louis de la Parte Florida Mental Health Institute. The National Implementation Research Network (2005).
13. Boyd BA, Stahmer AC, Odom SL, Wallach A, Mathis M. It’s time to close the research to practice gap in autism: The need for implementation science. *Autism Int J Res Pract*. (2021) 26:569–74. doi: 10.1177/13623613211064422
14. Peters-Scheffer N, Didden R, Korzilius H, Sturmey P. A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with autism spectrum disorders. *Res Autism Spect Disord*. (2011) 5:66–9. doi: 10.1016/j.rasd.2010.03.011
15. Rodgers M, Simmons M, Marshall D, Hodgson R, Stewart LA, Rai D, et al. Intensive behavioural interventions based on applied behaviour analysis for young children with autism. An international collaborative individual participant data meta-analysis. *Autism Int J Res Pract*. (2021) 25:1137–53. doi: 10.1177/1362361320985680
16. Rispoli KM, Lee GK, Nathanson EW, Malcolm AL. The parent role in school-based teams for adolescents with autism spectrum disorder. *School Psychol Q*. (2019). 34:458–67. doi: 10.1037/spq0000289
17. Smith LE, Anderson KA. The roles and needs of families of adolescents with ASD. *Remed Spec Educ*. (2014) 35:114–22. doi: 10.1177/074193251351354616
18. Kjellmer L, Fernell E, Gillberg C, Norrelgren F. Speech and language profiles in 4- to 6-year-old children with early diagnosis of autism spectrum disorder without intellectual disability. *Neuropsych Disord Treat*. (2018) 14:2415–27. doi: 10.2147/NPT.S171971
19. Kwook EYL, Brown HM, Smyth RE, Cardy JO. Meta-analysis of receptive and expressive language skills in autism spectrum disorder. *Res Autism Spect Disord*. (2015) 9:202–22. doi: 10.1016/j.rasd.2014.10.008
20. Abbeduto L, Kover ST, McDuffie A. “Studying the language development of children with intellectual disabilities”. In: Hoff E, editors. *Research Methods in Child Language: A Practical Guide*. Blackwell Publishing. (2012). p. 330–6.