

Autism Services and Supports: The Need is Global

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Executive Summary

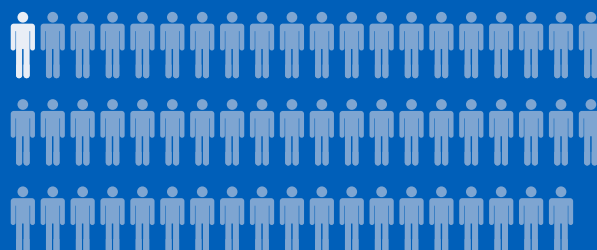
There has been a marked increase in the number of people being identified as having an Autism Spectrum Disorder (ASD) across the world. There are several interventions that foster optimal outcomes for people with ASD and promote the best opportunity for leading a high quality life. Unfortunately, there are not enough providers to match the growing need for ASD evaluations and interventions.

Technology has been an essential tool in disseminating professional knowledge and expert content to areas that need it most; with growing use of technology, the goals outlined in the World Health Organization's call to action become more attainable.

Autism Spectrum Disorder Effective Intervention

The prevalence of autism spectrum disorder (ASD) is increasing globally.¹ The current world prevalence rate is estimated to be 1:160 children.² In countries where prevalence is being monitored, there has been a marked increase. In the United States, prevalence over the last decade has moved from 1:150 in 2000 to the current rate of 1:59—close to a three-fold increase.³ The UK has reported a five-fold increase since the 1990s.⁴

1 in 59 diagnosed with Autism



3X increase since 2000

Awareness of the disorder has vastly improved; however, the delivery of appropriate services and supports has not kept pace with the growing need.⁵ Noting this significant need for support for people living with ASD, the World Health Organization developed a Resolution on Autism Spectrum Disorders in 2014, highlighting the significant unmet needs throughout the world and the specific actions that should be taken by the governments through their health and education ministries.⁶ The Resolution calls for increased and coordinated access to services for individuals and families, strengthening of infrastructure for comprehensive management of care, and other call to action items that must be instituted in order to improve the lives of people living with ASD. Access to effective intervention is a human right and all individuals living with ASD deserve access to effective intervention and the opportunity to achieve their optimal life outcomes.

Due to the lack of universal access to effective intervention, outcomes for children and adults living with ASD has significant room for improvement. Adults with ASD have less than optimal outcomes in the areas of employment, social relationships, physical and mental health, and quality of life.⁷ In one small study, twenty-five percent of adults with ASD were in the clinical range for depression and 20% reported recent suicidal ideation.⁸ In the United States,

approximately one-half (53.4%) of young adults with an ASD have ever worked for pay outside the home since leaving high school- the lowest rate among disability groups.⁹ Children with ASD are more likely to be educated in segregated settings with limited access to their typically developing peers.¹⁰ Youth with ASD are less likely to be employed and living independently than their peers with disabilities other than ASD.¹¹ Families also experience significant stress and hardship due to the lack of services and support. Parents report that it is difficult to obtain services for their child and that services are often uncoordinated and with significant variance between providers.¹² In low resource countries, services are virtually non-existent.¹³ Improving life outcomes for children and adults with ASD will require coordinated efforts to establish a comprehensive system of supports and ensure access to effective intervention for all citizens with ASD. There are interventions that produce quality, life altering outcomes for many individuals. Health and education communities must provide improved professional learning to educators and health care providers, and ensure that children have access to a meaningful educational experience and adults receive the support necessary to become contributing members of society. People with ASD can and do lead meaningful lives when appropriate education and support is provided.¹⁴

Effective Intervention

There are dozens of evidence-based practices that, when delivered with fidelity, support the learning of children with ASD.¹⁵ Their interventions can promote language development,¹⁶ reduce challenging behavior,¹⁷ increase intellectual ability,¹⁸ promote academic skill development,¹⁹ improve social skills,²⁰ and more. Children who do not access intervention early are not likely to achieve these positive outcomes.²¹

These evidence-based practices are not implemented systematically within the educational system.²² There are many identified barriers to this lack of implementation including: lack of professional learning, lack of “fit” between the intervention and the applied learning environment and limited collaboration between research and the applied setting.²³ This lack of application of evidence-based practices is prevalent even in countries with significant economic resources and sophisticated social service networks.²⁴ The scientific community has developed effective interventions, but because the system of support has not taken action and implemented these supports, access to quality intervention continues to be inaccessible to most individuals living with ASD.

Interventions can promote:



language development



reduce challenging behavior



increase intellectual ability



promote academic skills



improve social skills

Evidence-based programs have moved past the research setting and into the applied learning environment in a limited scope, demonstrating that it is possible to provide these interventions in the real-world. The provision of professional learning and a commitment to implementation fidelity results in schools implementing effective approaches including Applied Behavior Analysis²⁵ and interventions to promote social communication skills.²⁶ However, these are still just pockets of excellence where children are accessing the support of quality intervention; the majority of children do not have access to evidence-based interventions when attending school.

Need for Qualified Professionals

Delivery of effective intervention requires qualified professionals. Educators and health care providers must receive specialized training and ongoing professional learning. There are not enough trained health and education providers to support the growing population of people with autism. Applied Behavior Analysis is one of the most effective intervention strategies for people living with ASD; however, there are only 28,000 Board Certified Behavior Analysts in the world. Low resource countries experience a dearth of trained interventionists and significant challenges in finding qualified providers.²⁷ Basic understanding of ASD has been researched and was limited in countries including: Oman;²⁸ China;²⁹ and Pakistan (2017). This research is most likely demonstrative of the needs across the world. Even well-resourced countries like the UK and Canada, lack resources and children with autism do not receive appropriate intervention due to the lack of qualified professionals able to deliver these services and supports.³⁰

Parent mediated interventions are being utilized to provide access to intervention due to the lack of qualified providers and the lack of a social service network of support.³¹ Parents are pivotal members of promoting positive outcomes for children with ASD, but training parents is not a substitute for trained professionals engaging in ongoing intervention. Indeed, parental responsibility may increase the already high stress levels experienced by parents and care-providers.³² Parent engagement should be a component of any child intervention; indeed, the greater community must band together to ensure people living with ASD and their families are supported.

“There are not enough trained health and education providers to support the growing population of people with autism. Applied Behavior Analysis is one of the most effective intervention strategies for people living with ASD; however, there are only 28,000 Board Certified Behavior Analysts in the world.”

Leveraging Technology to Disseminate Evidence-Based Practices

Technology has an increasing role in the professional learning of education and health professionals. Asynchronous access to content allows on-demand access at the convenience of the end-user.³³ Synchronous connection allows access for collaboration and consultative engagement without regard to geography. Utilizing technology allows interconnectedness around the world and disperses the knowledge of the limited number of highly trained professionals.

Technology has allowed increased access to services and supports and increased the access of knowledge of evidence-based practices. Diagnostics can accurately be delivered via telehealth, decreasing the barrier of distance to trained professionals to receive a diagnosis.³⁴ A parent or family member concerned about their child can utilize simple video technology available on a smartphone to upload for a diagnostician to review, and through these simple steps, an accurate diagnosis can be provided³⁵

Beyond diagnostics, technology paired with mentorship has brought best practice and ongoing medical care to children and youth with autism.³⁶ Low resource areas that may not have developmental and behavioral pediatricians or even pediatricians in general, can engage in consultative interaction with a highly trained peer to better guide their practice and treatment of individuals with ASD.³⁷ Parent training for those living in rural environments successfully utilized online learning modules paired with remote coaching, which produced increased use of evidence-based practices in their interactions with their children and meaningful outcomes for their child.³⁸ Self-directed internet training has been utilized by educators to increase their skills in the delivery of evidence-based practices.³⁹ Given the increasing prevalence of ASD, technology must be considered a viable option to disseminate content and provide consultation.

Conclusion

The prevalence increase in ASD demands that health and education develop effective and efficient methods to provide assessment and intervention. There are currently not enough providers to meet these needs. There are many effective interventions for people with ASD that lead to a higher quality of life and promote optimal outcomes for those living with ASD. One strategy to more effectively disseminate knowledge and ability of effective treatment is technology. Technology decreases geographic barriers and improves efficiencies in delivering expert content to areas in need. The World Health Organization has called for action; it is time for the communities of health and education to engage and provide meaningful intervention for every individual with ASD.



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