

Provider Education on Health Care for Adults with Autism Spectrum Disorder

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Background Information

One in 59 children has been identified with Autism Spectrum Disorder (ASD) and the prevalence continues to rise.¹ With this increased prevalence there have been efforts to increase the services available to this population, but certain individuals still struggle to receive the help they need. There has been an improvement over the last twenty years to identify autism in young children. However, the children that were identified over this period are now approaching adulthood, and the infrastructure (specialty care/services, education for providers, evidence regarding best practices) for the care of this population is not as robust as what exists for children with ASD.²

Nearly all (97%) of individuals with ASD received at least one of the 12 commonly used services during high school (including speech-language therapy, occupational therapy, social work, and case management); however, only 63% continue the usage in their 20s.³ This decrease in service utilization is due to a variety of factors, including a cut in funding after age 18, fewer programs providing transitional care, and difficulty locating adult providers who are trained and available to care for the population.⁴ In addition, adults with ASD may experience false assumptions from providers about the ability to understand health care issues, communicate, and navigate the healthcare system. This can lead to lack of appropriate referrals to services such as specialty care (e.g. nutrition, gastrointestinal, speech, occupational therapy).² As a result, adults with ASD report high rates of comorbid health conditions, high healthcare utilization rates, and higher total healthcare expenditures compared to adults without ASD.⁵

Problem Statement

Provider disparities between pediatric and adult populations with ASD lie in the health provider education system. The lack of training on the unique healthcare needs of people with autism has resulted in providers feeling a lack of confidence about their ability to provide treatment to this vulnerable population. While developing an inclusive curriculum would assist providers with treating this population, minimum requirements in accreditation standards do not support the comprehensive development of curriculum to address the educational needs for the future healthcare providers serving adults with ASD. Therefore, specific language must be incorporated into the accreditation standards that mandate training on how to provide diagnostic and treatment services to adults with special healthcare needs, including ASD.

Current legislation/Advocacy

Several professional organizations work on developing training programs for health professionals on the unique healthcare needs for adults with autism, including the following:

- The American Academy of Developmental Medicine and Dentistry has developed a National Curriculum Initiative in Developmental Medicine that is directed towards providing medical students education in the field of developmental medicine. Information on this project can be found here: http://aadmd.org/sites/default/files/NCIDM_Application_Cohort_2_Final.pdf
- In compliance with the recommendations by the National Council on Disability (NCD), the Council on Dental Accreditation (CODA) now requires all US dental schools to modify curriculum and implement training of the graduates to assess and treat patients with intellectual and/or developmental disabilities by 2020. Information on this project can be seen here: <https://ncd.gov/newsroom/2019/dental-schools-IDDD>
- The Autism CARE Act 2019 (P/L 116-60) provides recommendations that seek to improve health outcomes for adults with ASD across their lifespan by addressing things such as medical practitioner training. Information on this project can be found here: <https://www.autism-society.org/wp-content/uploads/2019/10/Detailed-Summary-of-the-Autism-CARES-Act-of-2019.pdf>

Recommendation

We recommend that healthcare professional schools provide their students with adequate education on the healthcare needs of adults with ASD. Curriculum models should include training on how all healthcare providers should interact with adult autistic patients. It should also focus on discipline-specific diagnostic and treatment services that are unique to adults with ASD.

Pros:

- All healthcare providers will be better equipped to interact with and treat adults with autism in their practice.
- There will be an improved transition from pediatric to adult medical care and increased service utilization within the adult population.
- Research has shown that medical students' perception of individuals with disabilities improves after exposure to and training on how to treat this population.⁶

Cons:

- Healthcare providers who have already graduated from graduate school programs will need to seek outside training. The quality of education outside of accredited graduate school programs may not be subject to the same regulations as the accreditation process.
- Individuals seeking healthcare may encounter different services depending on the provider's knowledge and training.

Implementation considerations:

Implementation of curriculum changes will require funding and leadership support from educational institutions to address additional personnel (such as qualified educators and standardized patients), as well as the investment in the time for faculty training. Adding additional training experience in the existing health education may also result in an over-crowded curriculum. As the quality of care improves and more people with ASD receive care, further research regarding best practices and clinical outcomes is needed.

References

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