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Inclusive Healthcare Services for a Neurodiverse Adult Population:

Advocating for Improved Healthcare Services for Autistic Adults

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Autistic perspectives have frequently been excluded from critical conversations that impact their healthcare and daily lives. Research has primarily focused on caregiver accounts or causal factors rather than the lived experience of autistic individuals regarding their healthcare. Despite the recent demand for more participatory research, including autistic individuals in autism research remains rare (den Houting et al., 2021). As a result, the conventional medical model likely presents a biased account of autistic individuals. The medical model often has a singular focus on deficits and their correction, to the point that achievements are paradoxically viewed as a consequence of those deficits. This view undermines individuals' strengths and creates negative preconceptions regarding autistic individuals and their abilities, despite autistic individuals often outperforming neurotypical peers on certain tasks (Pellicano & den Houting, 2021).

Research has historically focused on autistic children, with only 1-2% of all Autism research funding devoted to understanding autistic adult issues (Shattuck, 2019). There is a need

for more research to consider the effects of being autistic across lifespan. One large population-based study in Sweden found that the average life span of autistic individuals is 39.5-58.4 years compared to 70.2 years among non-autistic individuals (Hirvikoski et al., 2016). This is often the result of co-occurring conditions that are treatable and even preventable with the appropriate healthcare. Autistic individuals are disproportionately affected by many co-occurring conditions across all organ systems, including gastrointestinal, neurological, endocrine, visual, ear/nose/throat, skin, liver and kidney, and hematological conditions (Ward et al., 2023). Autistic adults report lower quality healthcare experiences than non-autistic adults on 50/51 items on an anonymized, cross-sectional, self-report questionnaire, including poorer access to healthcare and poorer communication, and increased anxiety, sensory sensitivity, system-level problems, shutdowns, and meltdowns (Weir et al., 2022).

A retrospective data analysis by Vohra et al. (2016) revealed significantly higher healthcare utilization and expenditure among autistic adults compared to non-autistic adults enrolled in Medicaid, including annual outpatient office visits, prescription drug use claims, emergency room, and total healthcare expenditures. These disparities in health among autistic adults are important to recognize, and practitioners must be aware of their impact on overall health-related quality of life. Mental health clinician participants in the study by Maddox et al. (2019) also reported that limited knowledge about Autism was a major barrier to treating autistic adults; 43 of the 44 clinicians interviewed could not recall learning anything about autistic adults in their educational program. Treating autistic patients is not exclusive to pediatricians. All healthcare practitioners need to be educated on the needs of this population and how best to offer inclusive services. Healthcare providers must support autistic individuals to participate in health management, an essential occupation for all adults. A systematic review has shown that Autism-

specific training programs can be effective at improving physicians' knowledge and self-efficacy in caring for autistic patients (Clarke & Fung, 2022).

Specific training programs for autistic adults have been suggested, and many of the challenges are easily remedied. For example, the Psychiatric Management of Adults with Autism (Royal College of Psychiatrists, 2020) suggested allowing additional time for processing and speech formation, using straightforward language, diagrams, and visual text, encouraging a support person to accompany the individual, and keeping the appointment as predictable as possible. A pre-appointment questionnaire and outline of what to expect at the appointment can be useful. The sensory and social demands of a medical appointment should also be considered.

As occupational therapy practitioners, it is within our scope of practice to assist individuals with the management of personal health. This includes advocating for individuals to receive care in a way that is meaningful and impactful in creating better health outcomes. Due to increased co-occurring conditions in autistic individuals and reported lower quality of care, occupational therapy practitioners must strive to make healthcare more accessible for this population. To examine the capacity of an online advocacy resource to improve health outcomes for autistic adults, an advocacy toolkit was developed using a participatory approach with autistic adults to address changes needed in healthcare education and delivery.

The toolkit was created using Canva (2026), which is available online for others interested in promoting neurodiversity and increasing the accessibility of healthcare services for autistic adults can be viewed here. See Appendix A: Advocacy Toolkit Table of Contents (<https://canva.link/lwg2ft5mjbwg0uq>). The toolkit was distributed to occupational therapy practitioners, autistic adults, parents and caregivers of autistic children and adults, and other healthcare professionals, and the quality of the resource was evaluated by analyzing responses to

questions in a REDCap survey completed by 85 participants. During this process, we advocated for continuing education on neurodiversity for healthcare professionals applying for re-licensure and the incorporation of autistic adult needs within healthcare education curricula.

Quantitative feedback data was collected through an online RedCap Survey linked on the resources' final page, which was available in English. Survey questions are listed under Appendix B: Toolkit Survey Development. Informed consent was implied by participation in the anonymous online survey. REDCap (Research Electronic Data Capture) (Harris et al., 2009) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture, (2) audit trails for tracking data manipulation and export procedures, (3) automated export procedures for seamless data downloads to common statistical packages and (4) procedures for data integration and interoperability with external sources. This project was not reviewed by the IRB and was labeled as a quality improvement initiative.

Survey data was evaluated from the 85 participants who viewed the toolkit, including occupational therapy practitioners, autistic adults, parents and caregivers of autistic children and adults, and other healthcare professionals. The data can be found in a graph in Appendix C: Results for Advocacy Toolkit Evaluation. All survey participants reported that the toolkit was well organized, and eighty percent of survey respondents reported that the toolkit is helpful for their needs. Ninety-seven percent of those who viewed the toolkit report that it helps promote advocacy for neurodivergent individuals. The results of this project indicate that an advocacy toolkit may be useful in promoting advocacy for improved clinician education on meeting the healthcare needs of autistic adults. This is important for healthcare professionals, organizations,

and systems because current practices can be disabling and present barriers to access for autistic adults that can lead to poorer health outcomes.

Future research is needed to consider the healthcare needs of autistic adults. As autistic recognition and diagnosis expand, additional research should consider the impacts of intersectionality, including gender diversity and racial diversity, on autistic adults' access to equitable health care. With an estimated 1 million autistic teens entering adulthood over the next decade (Anderson et al., 2020) it is imperative to improve transitional care processes from pediatric providers to adult medicine providers.

This toolkit serves as a mechanism for occupational therapy practitioners to use and provide to other healthcare providers who are less familiar with engaging with autistic individuals. Further studies should also include autistic stakeholders throughout the process to develop accessible and relevant measurement tools and resources. Autistic individuals can help address patient-provider communication challenges, the physical and sensory environment of healthcare facilities, and systemic barriers to accessing services. Autistic individuals should also be included in the development and improvement of Autism-related content within education for healthcare providers. Education on the needs of autistic adults for healthcare providers should be improved, and further research is needed to evaluate the effectiveness of such provider training. This resource plays a valuable role in assisting occupational therapy practitioners in advocating for the needs of a neurodiverse population.

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Appendix B: Toolkit Development Survey

Questions for toolkit feedback

Survey Questions: 5-point Likert scale

1. This toolkit is well organized.
2. This toolkit is helpful for my needs.
3. This toolkit is helpful for promoting advocacy for neurodivergent individuals.
4. I could see myself using this toolkit in the future.

Appendix C: Results for Advocacy Toolkit Evaluation

Results section: visual

