

First Thoughts: The Vulnerability Experienced by Adults with Severe Autism

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Abstract: *For many reasons, adults with severe Autism Spectrum Disorder (ASD), are some of our most vulnerable citizens. To understand what we mean by this, in this essay we look closer at what makes this group unique. In particular, we discuss what we mean by severe Autism, and what we know (and what seems to be missing) from research about adults with severe ASD. Unfortunately, since most academic research in this area has focused on children, and children who would not likely be considered to have severe Autism, there is still much that academic research does not tell us. But other sources can fill in some of these gaps. This essay ends with some thoughts about why this lack of academic research is not harmless, as it prevents the needs of adults with severe Autism from being represented where decisions are made. However, the answer is not simply to “do more research”; the way that research is done must also change.*

Introduction

For many reasons, adults with severe Autism Spectrum Disorder (ASD) are some of our most vulnerable citizens. This is not a new claim, of course, as one of the first studies of adults with Autism in Ontario, the result of an extensive review of the literature and survey published in 1991, was titled *Our Most Vulnerable Citizens*.ⁱ In this series of three short essays we focus on this vulnerability, knowing that there are many ways of being vulnerable, and that raising awareness of the particular aspects of vulnerability experienced by adults with severe Autism is crucial to make needed social changes. This first essay sets the stage by discussing how part of understanding the nature of this vulnerability is to recognize the uniqueness of the group: what we mean by *severe* Autism, and what we know (and perhaps don't know) from academic research about *adults* with severe ASD.

What do we mean by *severe* Autism Spectrum Disorder?

To define *severe*, we draw from the definition found in the current version of the Diagnostic and Statistical Manual of Mental Disorders, now in its fifth edition (DSM-5).ⁱⁱ This criterion does not

cover the entire experience of Autism, as it is an authoritative definition and not attempting to capture an exhaustive account. We will use this definition here, as it helps us be clear about our starting place. An individual is diagnosed with Autism Spectrum Disorder according to the DSM-5 if they demonstrate persistent deficits in social communication and social interaction across multiple contexts, and restricted, repetitive patterns of behaviour, interests, or activities, and finally that these symptoms are present from early childhood, and limit or impair everyday functioning. In addition to this, the DSM-5 asks the clinician to determine whether an individual's ASD is accompanied by other aspects, such as with or without intellectual impairment, and with or without language impairment. These accompanying factors greatly impact the severity of an individual's Autism.

Clinicians use a variety of assessment tools, such as questionnaires and structured observation, to go into depth about a person's life to determine whether and to what extent an individual meets the DSM-5 definition, and gather information to determine the level of severity of the impairments.ⁱⁱⁱ The distinction of *severe* is attributed when an individual's experience of Autism meets the DSM-5 criteria of severity of the individual's deficits in the two categories of (1) social communication, and (2) restricted, repetitive behaviours, from Levels 1-3. These levels indicate degrees of support an individual needs for each of the two diagnostic categories. Level 1 is the least severe, indicating that the individual "Requir[es] support," Level 2 means the individual "Requir[es] substantial support," and finally Level 3 means the individual "Requir[es] very substantial support." If an individual's experience, for example, of social communication is that "Without supports in place, deficits in social communication cause noticeable impairments," this is considered to be Level 1 ("Requiring support"). If an individual has "Marked deficits in verbal and nonverbal social communications skills [...] apparent even with supports in place," this is Level 2 ("Requiring substantial support"). Whereas for an individual's experience to be considered Level 3, it would mean that "Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning," and so the individual "Requir[es] very substantial support." This is where we draw the definition of *severe* ASD, that an individual would require very substantial support (Level 3) in either or both areas due to deficits in social communication, and restricted, repetitive behaviours.

In addition to this clinical definition, other sources offer helpful expansions of what severe ASD involves. For instance, the UK charity St. Elizabeth's states that, "Severe autism [...] means that an individual needs a great deal of support – it is not unusual for a person with severe autism to require 24/7 support and supervision."^{iv} And of course, we need to keep in mind what the authors of research articles call the "heterogeneity" or "variability" of people with Autism – meaning there is great diversity found in how the same diagnosis presents in each individual's life. Although adults with severe ASD will share important similarities that would result in *severe* ASD according to what the DSM-5 outlines, each person's experience of those aspects, and so the specific nature of their needs for support, will be unique.^v

Why adults?

It is likewise important to take a closer look at why it is the case that *adults* with severe Autism are uniquely vulnerable. Unfortunately, there is a lack of research specifically on adults with ASD altogether, without even narrowing to adults with *severe* ASD in particular. Researchers in

this area often acknowledge the gap, while also recognizing that there is an important difference between adults with ASD, and children or adolescents. For example, one author wrote that ASD in adulthood is a complex condition that should be distinguished from ASD in childhood and adolescence, especially for high levels of co-occurring psychiatric conditions and specific needs.^{vi}

So why is there this gap when it comes to research articles specifically about adults? Autism isn't new, but the clinical use of the term began in the 1940s and became more common in the 1960s. This means that the first cohort of adults who were diagnosed with Autism as children began to enter old age in roughly 2012.^{vii} And so one reason for the lack of research specifically about adults with ASD could be due to less time to perform this work. Another reason is that there is a lack of measurement tools, such as psychiatric tests, that are proven reliable for this population in order to do the research. This is especially true for individuals who would qualify as having severe ASD, with severe deficits in social communication, and/or severe levels of restricted and repetitive behaviours. Of the research articles found for this current project that did focus on adults, the majority seemed to select their participants based on those who were most likely to best fit the testing instruments. That is, individuals with less severe ASD symptoms, with more spoken language, and without accompanying intellectual disability. As one author stated, "there are few tools designed to capture the complex clinical presentation of ASD in adulthood."^{viii} This presents a dilemma, since the tools are needed for research, but research is needed to develop these tools for the full range of people's experience with Autism. And importantly, tools that can include individuals with severe Autism, and those who are nonspeaking or communicate in other ways.

What can we learn from longitudinal studies about adults with Autism?

Another source to learn about adults with Autism are longitudinal studies that follow individuals with an Autism diagnosis over long periods of time, such as from childhood to adulthood. These studies identify a specific aspect of individuals' experiences or assessment results to track and compare, and while these kinds of studies are rare they are growing, and we will note some examples here. One longitudinal study followed the behavioural outcomes of participants over time, performing assessments once as children and once as adults. Authors stated that there were large variations both between the participants at each point in time, and when comparing the outcomes at the two different time points. This means that participants were very different from each other in both instances, and very different in their own outcomes between the two time points. The authors interpreted this as reflecting the large individual variability that is characteristic of individuals with ASD. One notable finding of this longitudinal study is that there was some improvement in adaptive functioning in the group over time, particularly in daily living skills, but less improvement in socialization skills.^{ix} This combination of variability and positive report was also found in a teacher's account of following a small group of their students with Autism and similar diagnoses as they grew up, from school age to when they were 30-40 years old. The teacher recorded that each of the ten individuals made great progress, but with varied outcomes.^x

One area that researchers have identified as having much to benefit from longitudinal studies is the impact of aging on older adults with Autism. Even within the DSM-5, the section titled “Development and Course” within the overview of ASD states, “Scarcely anything is known about old age in autism spectrum disorder.”^{xi} This is especially significant since the results of recent studies challenge assumptions that adults with Autism are at a higher risk for accelerated cognitive aging. Some results even suggest that individuals with Autism may be *less* susceptible to typical cognitive aging affects.^{xii} Longitudinal studies are needed, among other things, to understand a full picture of the aging process for people with ASD.

Many authors are also quick to remind readers of the limits of these longitudinal studies because of the way they have been done so far. As we mentioned above, these studies face the lack of fitting assessment tools for adults with ASD, but they are also limited by their distinct pattern of who most often are in these studies, and those who are not. In particular, participants of longitudinal studies are often described as a result of “convenience sampling,” meaning, they are people with whom researchers already have an ongoing connection with through a treatment program or clinical facility. This makes them convenient to include. And so, participants of longitudinal studies have most often been recipients of expert and dedicated support through treatment centres, which is not everyone’s experience. Looking closer still, there are patterns of who are most likely to have access to these kinds of centres: people who are most often white, from families that are English speaking, and with high socioeconomic status. Researchers note this as something that limits the findings of study results, as well as indicates important changes for future research.

What is still unknown?

Although this is not an exhaustive account, we can draw together some lessons of what we know and don’t know about adults with severe ASD in academic research. And what we are left with is much that remains unknown. The majority of research articles found focus on children, and those rare studies that do focus on adults, study adults who most likely would not be considered to have *severe* ASD in the sense we mean here. This imbalance in the research does not go unnoticed in the field. As one author wrote: “the vast majority of studies have focused on either young toddlers and preschoolers or older higher functioning, verbal children primarily because they are easier to evaluate using standard assessment tools, and they are more compliant...”^{xiii} Simply put, one reason that certain groups of individuals with Autism are more studied is because they are easier to study.^{xiv} And unfortunately, assumptions often take the place of research results until those studies are performed.

What does this lack of research cost?

When considering the little that research offers us specifically about adults with severe ASD, it’s important to recognize how this increases their vulnerability. Academic research directly contributes to what interventions, treatments, and services are designed and sustained on a larger scale. When government bodies are looking to make evidence-based decisions on policy making, or where to allocate resources, for example, the evidence to support specific answers is lacking. It is difficult to advocate for solutions to meet the needs of adults with severe Autism when there is little research on the needs themselves.

This consequence has been documented in the literature. For example, one group of researchers identified this as part of the challenge when considering how to evaluate whether older adults with ASD had their needs met within residential care in the UK. The authors stated that,

“Very little is known about the support needs of older autistic adults in general, or their specific needs within residential care services. As such, it is impossible to determine whether existing residential services are meeting the needs of older autistic adults.”^{xv}

Another example of this comes from psychiatry. Several authors have acknowledged that there is a lack of evidence-based conclusions for which treatments psychiatrists should use with patients who have Autism and depression, leaving psychiatrists without best practices to ensure they provide the best care.^{xvi} Where there is little research, the needs and experiences of adults with severe ASD remain unrepresented in places where decisions that impact them are made.

The solution here is not simply to do more research to provide the evidential backing for the support adults with severe Autism need, rather, more *and different* research is needed. What we need is research that does not simply engage those who easily fit with existing study designs and who are convenient to the researchers; research that prioritizes capturing first-person experiences; researchers that engage with the work in a way that is sensitive to the people and families it includes. And of course, research that contributes to relevant improvement in tangible ways for people with Autism.

A way forward?

One source of guidance for these changes is the autobiographies of individuals with Autism and their families. Although autobiographers are not speaking for all people with Autism, one author argues that “Autism narratives [...] are creating the language in which to describe the experience of autism” and by doing so are “helping to forge the concepts” we use to think about Autism.^{xvii} These works can also reveal common ways people who don’t have Autism are mistaken in their assumptions about people who do. For example, works by Temple Grandin have been credited with “depicting an inner autistic world” which people were surprised to learn existed.^{xviii} That readers were surprised by this is likely just one of many examples of mistaken assumptions we are sure to find elsewhere, including within research. If researchers were to draw from the many forms of autobiographical work of adults with Autism in order to contribute to their concepts and ways of thinking about Autism, this could positively impact how studies are designed and results are interpreted. And ultimately, this could be one part of how we address the lack of research about adults with severe ASD in a way that can more accurately represent the needs of this vulnerable group in places where decisions are made.

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- ⁱ Autism Society Ontario and Adult Task Force. 1991. *Our Most Vulnerable Citizens: A Report of the Adult Task Force*, Autism Society Ontario. Guelph, Ont. <https://www.oaarsn.ca/wp-content/uploads/2021/09/vulnerable.pdf>.
- ⁱⁱ American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition*. Arlington, VA, Washington, pgs. 50-59. The DSM-5 further specifies that these symptoms are present in the early developmental period of the individual's life, that they cause clinically significant impairment in social, occupational, or other important areas of current functioning, and that they are not better explained by an intellectual disability or global developmental delay.
- ⁱⁱⁱ For example, the *Autism Diagnostic Interview* (ADI-R), an interview assessment answered by parents of the individual, and the *Autism Diagnostic Observation Schedule* (ADOS-2), from which clinicians use suitable modules to qualitatively assess the individual, are considered "gold standard" assessment tools that clinicians use to determine whether someone meets the criteria as outlined in the DSM-5. For more, see: Singer, E. 2013. "Gold Standards." *Spectrum | Autism Research News* (blog). February 12, 2013. <https://www.spectrumnews.org/opinion/gold-standards/>.
- ^{iv} "Facts and Figures: Epilepsy, Autism and Complex Needs." n.d. St Elizabeth's Centre. Accessed February 10, 2021. <https://www.stelizabeths.org.uk/services-for-adults/health-and-therapy/facts-and-figures-epilepsy-autism-and-complex-needs/>.
- ^v The DSM-5 is not the only authoritative definition of Autism, of course. For instance, the International Classification of Diseases (ICD) developed and updated by the World Health Organization (WHO), also includes definitional criteria for ASD. The ICD, with its most recent version ICD-11 published in 2019, is a global document developed by a much wider range of contributors than the DSM, which is developed by the American Psychiatric Association. Interestingly, in the most recent version, the ICD-11 mirrors the changes in how ASD is defined in the DSM-5. For this present discussion, it is relevant to note that the DSM-5 includes severity levels, whereas the ICD-11 the severity is indicated through sub-diagnoses. The ICD-11 can be found here: <https://icd.who.int/en>.
- ^{vi} Keller, R., S. Chierigato, S. Bari, R. Castaldo, F. Rutto, A. Chiocchetti, and U. Dianzani. 2020. "Autism in Adulthood: Clinical and Demographic Characteristics of a Cohort of Five Hundred Persons with Autism Analyzed by a Novel Multistep Network Model." *Brain Sciences* 10 (7): 416. <https://doi.org/10.3390/brainsci10070416>, pg. 7.
- ^{vii} Happé, F., and R. Charlton. 2012. "Aging in Autism Spectrum Disorders: A Mini-Review." *Gerontology* 58 (1): 70–78. <https://doi.org/10.1159/000329720>, pg. 70.
- ^{viii} Sandercock, R., E. Lamarche, M. Klinger, and L. Klinger. 2020. "Assessing the Convergence of Self-Report and Informant Measures for Adults with Autism Spectrum Disorder." *Autism* 24 (8): 2256–68. <https://doi.org/10.1177/1362361320942981>, pg. 2257.
- ^{ix} Magiati, I., X. Tay, and P. Howlin. 2014. "Cognitive, Language, Social and Behavioural Outcomes in Adults with Autism Spectrum Disorders: A Systematic Review of Longitudinal Follow-up Studies in Adulthood." *Clinical Psychology Review* 34 (1): 73–86. <https://doi.org/10.1016/j.cpr.2013.11.002>, pg. 84.
- ^x Sperry, V. 2001, *Fragile Success: Ten Autistic Children, Childhood to Adulthood*. Paul H. Brookes Publishing Co., Baltimore. Information taken from review found here: <https://www.oaarsn.ca/fragile-success-ten-autistic-children-childhood-to-adulthood-by-virginia-walker-sperry/>.
- ^{xi} American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition*, pg. 56.
- ^{xii} Groenman, A., H. Geurts, J. van Rentergem, T. Radhoe, C. Torenvliet, and W. Van der Putten. 2021. "Ageing and Heterogeneity Regarding Autism Spectrum Conditions: A Protocol Paper of an Accelerated Longitudinal Study." *BMJ Open* 11 (3). <https://doi.org/10.1136/bmjopen-2020-040943>, pg. 2.
- ^{xiii} Tager-Flusberg, H., and C. Kasari. 2013. "Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum." *Autism Research* 6 (6): 468–78. <https://doi.org/10.1002/aur.1329>, pg. 468.
- ^{xiv} It is not just studies focused on adults that have problematic patterns of course. For example, some studies that focus on children are also being called into question for their reliability. A recent unpublished report found that studies on the effectiveness of early interventions have "multiple types of bias and an overreliance on caregivers to report outcomes." For more see: Hess, P. 2021. "Methodological Issues Plague Studies of Early Autism Interventions." 2021. *Spectrum Autism Research News* (blog). May 6, 2021. <https://www.spectrumnews.org/news/methodological-issues-plague-studies-of-early-autism-interventions/>.
- ^{xv} Crompton, C., C. Michael, M. Dawson, and S. Fletcher-Watson. 2020. "Residential Care for Older Autistic Adults: Insights from Three Multiexpert Summits." *Autism in Adulthood* 2 (2): 121–27. <https://doi.org/10.1089/aut.2019.0080>, pg. 121.

^{xvi} Brugha, T. 2019. “Autism in Adulthood: Widespread, Invisible, Neglected, Misunderstood-Not Our Problem?” *Psychiatric Times*. Accessed February 27, 2021. <https://www.psychiatrictimes.com/view/autism-adulthood-widespread-invisible-neglected-misunderstoodnot-our-problem>, pg. 24.

^{xvii} Hacking, I. 2009. “Autistic Autobiography.” *Philosophical Transactions of the Royal Society B: Biological Sciences*. <https://doi.org/10.1098/rstb.2008.0329>, pg. 1467.

^{xviii} Hacking, 2009. “Autistic Autobiography,” pg. 1469.