

Changing Minds: The Harm of False Assumptions

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Abstract: *It is not simply the high and complex needs of adults with severe ASD that make them vulnerable, it is how those needs have been understood – and misunderstood – by those in positions of authority and society more generally. Beginning with a brief history to provide context, this essay will then discuss research articles that are raising questions of possible misunderstandings and false assumptions about people with Autism. And furthermore, we look at how these false assumptions negatively impact attitudes toward, and the treatment of, people with Autism in a way that increases their vulnerability. This essay ends with a short discussion of ways we can change our minds about how we think about Autism that has the potential to make positive change.*

Introduction

Adults with severe Autism are some of our most vulnerable citizens. In the previous essay of this series, we discussed the way individuals experience vulnerability due to their conditions. But it is not just the conditions that contribute to their vulnerability, it is how those conditions – what have been called “core symptoms” of severe Autism – have been interpreted and responded to over time. While the definition of Autism has continued to evolve over the years, in this essay we will look at some historical false assumptions and potential present-day misunderstandings of Autism raised by researchers and how they leave adults with severe Autism and their families vulnerable to poor treatment based on those assumptions.

A History of Misunderstanding

The history of Autism, and the evolution of Autism as a diagnosis are well documented,¹ but a brief overview is helpful here. The words “autism” and “autistic” were first used in a clinical setting in 1910 to describe specific symptoms observed in individuals with schizophrenia when they became withdrawn.² This introduced Autism as a psychiatric condition, and a condition that clinicians thought to be mostly of psychogenic origins, that is, it was caused by emotional or psychological factors rather than biological or physical ones. Researchers at the time determined that the emotional and psychological causes were distant and uncaring parents, especially mothers. By the 1950s, the theory referred to as “refrigerator mothers” was popularized, blaming

mothers for causing Autism in their children by their “lack of maternal warmth.” During the 1960s, however, research and clinical opinion shifted to view Autism as having biological causes, rather than psychogenic ones. Over time Autism has been viewed as connected developmental disorders, before most recently being identified as a spectrum disorder (i.e., Autism Spectrum Disorder in the DSM-5³), with varying degrees of severity.

For our current focus, the lesson we want to draw from history is how the perception people have of Autism – and in particular, people who make decisions about causes and treatment – connects to how people with Autism and their families are treated. When Autism was thought to be the result of cold parenting, the range of approaches to therapy were created to suit that belief, including removing children from their parents to live in institutions. Parents, mothers especially, were vilified, and children were the victims. When beliefs about the cause of Autism shifted away from psychogenic causes and toward biological ones, new treatments that focused on interventions were developed, viewing children with Autism as medical patients to be treated. Without having input into the conclusions of what Autism is and what people with Autism need to live full lives, people with Autism and their families were vulnerable to the consequences of these conclusions. This connection between wrong conclusions and vulnerability remains today.

Although these perceptions directly impacted people with Autism, their families were also greatly impacted. The term “linked lives” is a helpful way to describe this shared impact both in historical cases and those in the present day. Linked lives refers to the concept that if one member of a family experiences an event, such as being removed from their home to live in an institution, this has implications for the lives of other family members. Often the individual with Autism and members of their family, especially those in a caregiving role, work through these processes together and share life trajectories.⁴ This is important to keep in mind throughout the following sections of this essay.

That was then, what about now?

In many ways, when an individual receives a diagnosis of Autism, especially when they are young, it is a label that is seen first by those around them and sticks with them for the rest of their lives. The label of ‘Autism’ is interpreted by others with assumptions that inform how that person is treated, and often does not leave room for the diversity of expression and uneven abilities that are part of one’s unique experience of Autism, especially in the case of adults with severe Autism. Considering the history of misunderstanding of Autism, and the ways it has translated into unproductive and even harmful treatment of people with Autism and their families, it challenges us to investigate where similar wrong assumptions may be causing negative impact today. In what follows, we will discuss a few examples of possible misunderstandings that researchers have identified.

The first example we consider is how movement and sensory differences of people with Autism are perceived and responded to in ways that may be misguided and harmful. For example, the authors of one article explored the connection between how researchers, clinicians, and those in helping professions *interpret* movement challenges in people with Autism and how people with Autism are *treated*, including the therapies and treatments developed to respond to

those conditions. For example, the authors argued that professionals are trained to see the repetitive behaviours that people with Autism perform as “autistic behaviours” which have led them to interpret these kinds of movements as “volitional and meaningless”, as means of communicating avoidance, and “evidence of diminished cognitive capacity.”⁵ In contrast, however, the authors begin with a belief that many movement differences are a part of human diversity, and draw from first-hand accounts of self-advocates to argue that some behaviours exhibited by people with Autism may not be intentional but are evidence of a person having difficulties in regulating sensation or movement, signs of desire for relationships, and sometimes expressions of meaning. The authors conclude by saying that it is more accurate to interpret movement differences in people with Autism as being neurological, which tend to lead to individuals being appropriately supported rather than simply wanting those behaviours to cease, such as when people with Tourette’s or Parkinson’s show movement differences. Meanwhile, the movement differences of adults with severe Autism are interpreted in negative ways, leaving them vulnerable to lack of support, or support based on the misunderstanding of their meaning.

Relatedly, authors of a recent article argue against what they called “social motivation accounts” of Autism, which hold the “fundamental assumption” that some of the unusual behaviours people with exhibit Autism necessarily reflect diminished social motivation or interest.⁶ Although it is not part of all theories of Autism, social motivation perspectives are an influential approach to studying and designing interventions for people with Autism, especially in early childhood. Authors of this article argue against that fundamental assumption because it is contradicted by people with Autism, it ignores other possible explanations of behaviours unrelated to social motivation, and it views social motivation as residing within a single person rather than a dynamic interaction shared with others. The authors do reference testimony from people with Autism who have said that they are less socially motivated, however, allowing for a range of social motivation within people with and without Autism, they caution making that assumption about each person with Autism someone meets. This is because if we don’t think someone is interested in interacting with us it changes how or whether we interact with them, and “assuming that someone is not socially motivated when in fact they are, can have devastating consequences.”⁷ Not only does this assumption impact how people who do not have Autism interact with those who do, it has consequences for how some findings in Autism research are interpreted, and how intervention targets are determined. The diversity of people’s experience of severe Autism includes varying social motivation and making incorrect assumptions can lead to their harm.

Another example of how wrong assumptions result in further vulnerability for people with Autism is found in education, where the intelligence of children with Autism who do not speak with their voice is consistently underestimated. This underestimation is due to the use of unsuitable cognitive tests, and since these children are without the means to inform their teachers otherwise, they are vulnerable to the consequences of that assumption. For example, one article states that school age children with Autism who have little or no spoken language and are “untestable” through standard assessments of cognitive abilities, have conventionally been judged to be “low-functioning.”⁸ The standard assessments most often being Wechsler-based tests, which research has shown to be unsuited to capture the intelligence of people with Autism, as mentioned in the previous essay. Furthermore, research has also shown that when using a different format of test, in particular one called the “Raven’s Coloured Progressive Matrices” or

Raven's-based tests, a group of participants made up of children with little or no spoken language scored a range of outcomes including some that met or exceeded scores of the general population.

Wechsler-based tests continue to be used in school settings, and when they are, children with Autism and little or no spoken language receive labels of having little cognitive potential. In addition to this label, their age makes them ineligible for many interventions to improve outcomes, hence, they are often wrongly “regarded and treated as though very low-functioning.”⁹ When someone's cognitive abilities are underestimated at a young age it closes off avenues of support and opportunities to them, negatively impacting the trajectory of their lives into adulthood. And as adults, being nonspeaking and assumed rightly or wrongly to have limited cognitive ability, they are often overlooked and are vulnerable to mistreatment and choices others make for them.

There are some cases where people with Autism are treated in ways that the negative impact of false assumptions are obvious. For example, clinicians at the Judge Rotenberg Center in Canton, Massachusetts, attempt to control the behaviours of people with Autism by using electric shock. The centre is a residential institution for people with disabilities and incorporates electric shocks as part of what they call “aversive therapy.” The use of electric shock has been condemned by many disability rights groups and even the United Nations.¹⁰ The way people with Autism and their conditions are perceived can make the difference between something like electronic shock “not considered [to be] torture, but treatment.”¹¹ Furthermore, considering that research has shown individuals with ASD and intellectual disability are at a higher likelihood of suffering from PTSD,¹² the harm of misconceptions of what is a permissible form of treatment can be compounded, having lifelong negative impact.

The previous examples give us reasons to pause and rethink where our interpretations of the behaviours and abilities of people with Autism have been mistaken, and it challenges us to consider how these false assumptions may impact interventions for people with Autism, and adults with severe Autism in particular. The possibility of the above-mentioned researchers being correct in their challenge of accepted views raises questions about how decisions are made to support people with severe Autism. It raises questions about structures of support for people with Autism that view people together based on similar diagnosis that don't allow for the variability of ASD, that assume movement differences are evidence of low cognitive capacity, and that if someone has Autism they automatically have low social interest. The diverse group of adults with severe Autism are then vulnerable to the decisions made based on those assumptions. This is especially concerning for those who are nonspeaking, as they are unable to communicate disagreement or alert others of their mistreatment.

Unfortunately, in addition to the concern of how interventions and support for people with Autism may be based on mistaken conclusions, there is also the concern that very little supports for adults with Autism exist at all. Many know all too well that after the age of 21 most government supports for people with disabilities and/or mental illness drastically decline, with very few options for interventions and therapy specialised for adults with severe Autism. We face difficulty when considering what interventions *ought* to exist as well. A systematic review of psychosocial interventions for adults with ASD found that “relatively little work has

investigated the best and most effective ways to treat adults with ASD in the community.”¹³ This lack of research is noted again in a systematic review looking at outcomes for intervention trials for adults with ASD, with the authors stating that, “although there is considerable research focusing on the identification, assessment and treatment of children with ASD, adult research lags a long way behind” and that intervention research about adults is “limited both in quantity and quality.”¹⁴ Without the needed data, we lack the evidence base for clinical effectiveness, informing effective interventions and support therapies for adults with severe ASD. Recognizing this lack, it is all the more crucial that interventions and targeted support for adults with severe Autism are developed, and that these interventions are supported by strong evidence while being cautious to avoid possible wrong assumptions about Autism.

Looking at Society in General

So far in this essay we have focused on the challenge some researchers have brought to accepted views of Autism among clinicians, other researchers, and those involved in the design and implementation of supports and interventions. However, misunderstanding of people with Autism is much more widespread, and so too are the negative outcomes of those wrong assumptions. Shifting now, we focus on how Autism is perceived by members of society in general, and how those perceptions leave members of this group vulnerable to isolation and harm.

While it is difficult to conclusively say the general sense of what society thinks on any issue, researchers who analyze how topics are presented in news media can offer a helpful perspective of how the general public may think about a topic. For example, a recent longitudinal study of how the topic of Autism was reported over 16 years in American newspapers looked at the use of what the authors identified as “stigma cues.” The authors defined stigma as the “social phenomenon in which members from a subgroup are treated with disgrace or discredit and are disqualified from full social acceptance.”¹⁵ Further, “stigma cues” were identified as subtle ways that news reports attributed this stigma to people with Autism. These cues show up in how reports frame pieces of news to select and focus on certain aspects of an issue, thereby offering an emphasis and recognizability of those particular aspects in the audience through repetition. Although very subtle, this is important because news media representations of Autism have been a major source of information that has shaped how the lay public understand Autism. In this study, the researchers found that there was actually a decrease of stigma cues, but stated that news media has created a “mixed and unhealthy space” for Autism by at times attributing inaccurate blame and focusing on the negative and medical portrayal of Autism, thus adding to the existing social stigma.

Closer to home, an analysis of Canadian newspapers found that stories of Autism were negative, written from predominantly medical perspectives, and disregarded social problems surrounding the issue. It comes as no surprise then, when research suggests that lay public commonly have misconceptions about Autism, and that people with Autism continue to experience stigma and are disqualified from full social acceptance.¹⁶

To connect this back to our focus on adults with severe Autism, it is important to note that the stigma this group experiences is likely two-fold, related both to age and disability.¹⁷ This lack of social acceptance has measurable negative consequences. For example, research has shown that adults with Autism experience high levels of loneliness and isolation, which is associated with poor cognitive functioning in older adults in the general population.¹⁸ Furthermore, research found that three quarters of individuals with Autism are victims of bullying.¹⁹ The impact of false assumptions of adults with Autism held by members of the public, of their own communities, leave them vulnerable to harms of mistreatment and isolation.

Ways to be part of the shift?

There is some good news, however. Many attempts are underway to reframe how we understand Autism and its symptoms, as evidenced by the articles challenging accepted views that were mentioned above. These attempts have the potential to change how Autism is perceived by those in clinical and research roles, as well as members of society more broadly. We can learn from news media researchers and recognize that the information we have about Autism, if only absorbed through news media, is largely negative and includes harmful cues attributing stigma. This, however, can be improved by recognizing the expertise of adults with Autism on the topic,²⁰ and taking advantage of the many available works to learn from people about their lived experiences. These are steps that we can take no matter our professional roles.

Reframing how we understand Autism, and how we perceive the symptoms of ASD, can significantly impact the lives of people with Autism and their families, reducing this aspect of their vulnerability. One additional step recommended by researchers that is worth noting here, is to shift our understanding of the social aspects of Autism from being an impairment that resides in an individual with an ASD diagnosis, to begin to view it as a mutual difficulty in relating, what researchers call the “double empathy problem.”²¹ Just as people with Autism experience difficulty in understanding the minds of people without Autism, so too do those without Autism experience difficulty in understanding the minds of people with ASD; it is a “failure of empathy in both directions.”²² Moving forward with an acknowledgement that the difficulty is mutual, and that those without Autism have much to learn from people who do, the continued shift of perception of Autism and its conditions will create positive change in the experience of people with Autism and their families as it is expressed in research, interventions, and social attitudes alike.

¹ For example: Zeldovich, L. 2018 “The Evolution of ‘Autism’ as a Diagnosis, Explained.” *Spectrum / Autism Research News* (blog). May 9, 2018. <https://www.spectrumnews.org/news/evolution-autism-diagnosis-explained/>; Cook, K. and A. Willmerdinger. 2015. “The History of Autism”. Narrative Documents. Book 1. <http://scholarexchange.furman.edu/schopler-about/1>.

² Historical details in this paragraph are drawn from: Kreis, I., R. Biegler, H. Tjelmeland, M. Mittner, S. Reitan, and G. Pfuhl. 2021. “Overestimation of Volatility in Schizophrenia and Autism? A Comparative Study Using a Probabilistic Reasoning Task.” *PLoS ONE* 16 (1). <https://doi.org/10.1371/journal.pone.0244975>.

³ American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition*. Arlington, VA, Washington, pg. 50-59.

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- ⁴ Joseph-Kent, K. 2016. “Autism Spectrum Disorders and the Healthcare Experiences of Aging Adults.” Dissertation, Miami University. https://etd.ohiolink.edu/apexprod/rws_etd/send_file/send?accession=miami1479940363184625&disposition=inline, pg. 6, 9.
- ⁵ Donnellan, A., D. Hill, and M. Leary. 2012. “Rethinking Autism: Implications of Sensory and Movement Differences for Understanding and Support.” *Frontiers in Integrative Neuroscience* 6. <https://doi.org/10.3389/fnint.2012.00124>, pg. 1.
- ⁶ Jaswal, V., and N. Akhtar. 2019. “Being versus Appearing Socially Uninterested: Challenging Assumptions about Social Motivation in Autism.” *Behavioral and Brain Sciences* 42. <https://doi.org/10.1017/S0140525X18001826>. (Not final copy), pg. 5-9.
- ⁷ Jaswal, V., and N. Akhtar. 2019. “Being versus Appearing Socially Uninterested,” pg. 5.
- ⁸ Courchesne, V., A. Meilleur, M. Poulin-Lord, M. Dawson, and I. Soulières. 2015. “Autistic Children at Risk of Being Underestimated: School-Based Pilot Study of a Strength-Informed Assessment.” *Molecular Autism* 6. <https://doi.org/10.1186/s13229-015-0006-3>, pg. 1.
- ⁹ Courchesne, V., et al., “Autistic Children at Risk of Being Underestimated,” pg. 1.
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- ¹² Kildahl, A., S. Helverschou, T. Bakken, and H. Oddli. 2020. “‘If We Do Not Look for It, We Do Not See It’: Clinicians’ Experiences and Understanding of Identifying Post-Traumatic Stress Disorder in Adults with Autism and Intellectual Disability.” *Journal of Applied Research in Intellectual Disabilities* 33 (5): 1119–32. <https://doi.org/10.1111/jar.12734>.
- ¹³ Bishop-Fitzpatrick, L., N. Minshew, and S. Eack. 2013. “A Systematic Review of Psychosocial Interventions for Adults with Autism Spectrum Disorders.” *Journal of Autism and Developmental Disorders* 43 (3): 687–94. <https://doi.org/10.1007/s10803-012-1615-8>, (Author manuscript) pg. 1-3.
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- ¹⁷ Joseph-Kent, K. “Autism Spectrum Disorders and the Healthcare Experiences of Aging Adults,” pg. 61.
- ¹⁸ 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. 123-124.
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