

Experiencing the Cascade: A Closer Look at Adults with Severe Autism

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Abstract: *Adults with severe Autism are particularly vulnerable because of their conditions, which create needs for support that can be described as high and complex. In this essay, we focus on aspects of severe ASD that often accompany what are considered “core ASD symptoms,” such as externalizing or coping behaviours, Autistic burnout, and sleep problems. We will also take a closer look at mental and physical conditions that many people with ASD experience, research that challenges assumptions about the level and nature of intelligence of people with Autism, and briefly discuss some of the complexity regarding language impairments. Taking these considerations together, this essay ends with a discussion on how these conditions translate into support needs for this group.*

Introduction

In the previous essay, we narrowed down our focus to adults with severe ASD, defining what we mean by *severe* by referring to the DSM-5. For consistency we will continue to draw from the DSM-5 to frame the current essay which seeks to explain why adults with severe Autism ought to be recognized as being some of our most vulnerable citizens, in part because of their conditions. Beginning with a brief description of what are often called the “core symptoms” of Autism, we will then focus on the conditions that research shows are associated with Autism.

What do we mean by “core symptoms” of severe Autism?

The DSM-5, as an authoritative definition, offers a framework for a shared understanding of the symptoms of severe ASD. The definition uses levels to differentiate when an individual’s ASD is considered *severe*, that being when an individual is considered a “Level 3” in one or both main categories that make up the diagnostic criteria. Specifically, an individual would be considered at a Level 3, or severe with respect to social communication, if “severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others.” Someone with severe ASD may, in addition to or instead of, be a Level 3 regarding restricted, repetitive behaviours, meaning that they demonstrate an “inflexibility of behaviours, extreme difficulty with change, or other restricted/repetitive behaviours markedly interfere with functioning in all spheres[, and experience g]reat distress/difficulty changing focus or action.”¹ In addition to these levels, a clinician considers 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.²

Much detail is left out of this authoritative definition, as it is not intended to be an exhaustive account. One aspect it does not attempt to capture is the great diversity of how individuals experience severe Autism, and the various ways it presents in their lives. Further, the definition does not go beyond what can be observed to what lies behind the symptoms. Even the most used "gold standard" assessment tools³ clinicians rely on to diagnose Autism, those that go into depth about an individual's life, are still most often based on observations.

We can add to our understanding by drawing from other sources. One article, for example, offers another perspective of how to understand Autism based on how self-advocates explain their experiences of sensory and movement differences. The authors summarize what they heard from self-advocates about their experiences with Autism in a way that seems to describe the interplay that lay behind the factors included in the DSM-5 definition. For example, the article summarizes that some self-advocates describe "disturbances of sensation and movement [...] frequently constraining [their] ability to communicate, relate to others and participate in life," and that "extreme emotions can cause the individual to become stuck, unable to cease repetition of a movement." And further, that they often experience a "lack sensation or feedback from their bodies and may feel physically unaware of their facial expressions, position in space and movements." The authors also mention that some self-advocates reported that they "experience the sights and sounds of their world as painfully intense."⁴ It seems that experiencing the painfully intense sights and sounds, disturbances of sensation, and becoming "stuck" with extreme emotions, are likely to result in observable behaviours that get identified as symptoms of Autism.

Given the great diversity of how people experience their ASD, we will not attempt to provide an exhaustive account of what severe Autism entails. However, we seek to offer a description that begins to explain why adults with severe Autism are some of our most vulnerable citizens. This explanation does not stop with so-called "core symptoms." The vulnerability these adults experience is also due to the conditions associated with an ASD diagnosis. Research specifically about adults with severe Autism is lacking, but we can draw general understanding from research about conditions that are associated with Autism over someone's lifetime. It is important to keep in mind that these are conditions which someone may experience in addition to, and interacting with, their experience of severe Autism.

Factors in Physical and Mental Health

The following section makes note of conditions often associated with Autism, called "co-morbidities" in the literature, meaning that two or more diseases or conditions occur together at rates that "exceed chance levels."⁵ We will start by looking at physical health, mental health, and what are often called externalizing or coping behaviours. To reiterate, this is not an exclusive list, and not every adult with severe Autism will experience each one of the conditions mentioned, however, they can offer a general picture of possible factors in someone's life.

Physical Health

There are certain physical conditions that research has shown to be prevalent in people with Autism. Studies concentrating on the physical health of adults with Autism have found elevated rates of epilepsy, bowel disorder, constipation, hyperlipidemia, diabetes, immune conditions, stroke, and of Parkinson's Disease in adults with Autism when compared to a comparison group of adults who did not have an Autism diagnosis.⁶ Adults with severe Autism are also likely to experience barriers to accessing preventable healthcare and receiving timely and appropriate treatment. Difficulties reporting pain to doctors due to communication and social impairments, and tactile sensitivities related to medical exams are among the barriers that can lead to missed or delayed diagnosis, preventing the early treatment of conditions, and thus further compounding health issues.⁷

Mental Health Factors

There are higher rates of certain mental illnesses found in people with Autism when compared to the general population. One study compared a group of adults with ASD to a similar group of adults who did not and found that the adults with Autism in the study had higher rates of psychiatric disorders, particularly anxiety and depression, catatonia, bipolar disorder, attention deficit disorder, obsessive compulsive disorder, and schizophrenia.⁸ All of which would present in unique ways in someone's life and interact with their severe ASD.

A recent study introduced an important factor of mental health for adults with Autism, a phenomenon called "Autistic burnout." According to the authors, this is a term often used by adults with Autism to describe a state of "incapacitation, exhaustion, and distress in every area of life."⁹ Researchers gathered input from adults with an Autism diagnosis to learn about their experiences of Autistic burnout. Participants described it as a long-lasting pervasive state of exhaustion, loss of function, and reduced tolerance to stimulus. As for what causes Autistic burnout, participants identified chronic stress and a mismatch of expectations and abilities without adequate supports, and that this state of exhaustion causes loss of health, quality of life, and at times leads to suicidal behaviours.¹⁰ Although the authors of the study note that due to convenience sampling of participants the results do not "represent the full diversity of the autistic adult population," it is the first empirical study to examine this phenomenon, and so indicates an important area of future research regarding the mental health of people with ASD.¹¹

Research has shown that people with Autism and intellectual disability have a higher prevalence of Post-Traumatic Stress Disorder (PTSD) when compared to the general population. A recent study in Norway found that individuals with ASD and intellectual disability are more frequently exposed to potentially traumatic events and are more likely to have symptoms of PTSD overlooked in clinical settings. Authors identified potentially traumatic events that people with ASD and intellectual disability are exposed to, which include bullying, social difficulties, dependency on others, constantly changing intimate support staff, lack of accommodation, inappropriate management of challenging behaviours, negligence or incompetence of caregivers, and the lack of communication means to report abuse.¹² Furthermore, individuals with Autism and intellectual disability may experience a lack of understanding of events and experience those

events differently in ways that are traumatizing. In addition to being more frequently exposed to potentially traumatic events, clinicians easily overlook signs of PTSD when someone also has ASD and intellectual disability, and assume the symptoms are related to the individual's Autism, and not an additional area for treatment.¹³ The researchers stated that their findings indicate that “trauma may be a significant factor” for individuals with Autism and intellectual disability, and can lead to “severe, lasting distress and loss of functioning.”¹⁴

Although the study just mentioned concentrates on adults with both Autism and an intellectual disability diagnosis, it seems that lessons may be drawn about adults with severe ASD with or without intellectual disability. For instance, since adults with severe Autism require very substantial support in their daily lives, and experience higher rates of certain forms of physical and mental illness, they are also likely to result in being frequently exposed to the potentially traumatic events listed above. Additionally, the experience of “diagnostic overshadowing” which is a term used to describe when symptoms of a psychiatric disorder are misinterpreted and attributed to the ASD diagnosis, is a common occurrence and not limited to only those with ASD and intellectual disability.

Various studies have also found higher rates of suicidality in adults with Autism. For instance, one study found a 5-fold higher rate of diagnosed suicide attempts among people with Autism compared to a control group.¹⁵ While the higher rates of suicidality are known and acknowledged in the literature, little research has explored *why* this is the case and more research is needed to offer specific factors. One way researchers are investigating this is by looking at the role of factors known to increase or decrease risk of suicidality in the general population and see the role these factors play in the lives of people with ASD. These factors include employment, depression, anxiety, and satisfaction with living arrangements.¹⁶ Findings of a recent study, however, suggest that an ASD diagnosis is an independent risk marker for suicidality. This means that an ASD diagnosis and Autistic traits explain the difference of rates of suicidality beyond the known risk factors.¹⁷ As we wait for future research to cast more light on factors specific to people with Autism, we must consider this higher rate of suicidality as part of what makes this group of citizens especially vulnerable.

Behaviour

Research identifies that people with Autism may demonstrate what are called “externalizing behaviours,” these are behaviours considered separate from core symptoms of ASD, those being deficits in social communication, and restricted, repetitive behaviours, such as movement differences. Externalizing behaviours are often associated with someone having lower adapting and coping skills, and so some researchers argue that they are more accurately understood as coping behaviours.¹⁸ The literature lists behaviours that include self-injury, aggression toward others, non-compliance, and temper tantrums.¹⁹ Researchers describe these behaviours as difficult to resolve, make daily living challenging, and often lead a family to seek psychological or psychiatric services for support. More research is needed to understand a greater diversity of coping behaviours that negatively impact the individual expressing them, including those that are less obvious, such as social withdrawal. As well, research is needed to further explain the ‘why’ of these behaviours, given that they can be understood as evidence of an individual attempting to cope.

There are other factors that disrupt daily living that research has found with higher frequency in the lives of people with Autism than those without. For instance, individuals with ASD often experience problems sleeping. Research focused on children indicates that the severity of someone's ASD is the single most powerful predictor of sleep problems.²⁰ This lack of sleep would have many negative consequences, but one particular outcome of poor sleeping is the increase of certain behaviours and negative experiences. For example, findings of one study identified that sleep problems in children increase the severity of the presence of oppositional behaviour, aggression, explosiveness, attention deficit, impulsivity, hyperactivity, anxiety, depression, and mood variability.²¹ Another area of difficulty identified in the research is that many individuals with Autism experience fears associated with toileting, and toileting problems.²² These kinds of problems introduce many restrictions to an individual's life, as toileting skills are essential for independent living, and incontinence is identified as a significant barrier to quality of life for people with Autism.²³

This brief overview of conditions that are associated with an Autism diagnosis are a glimpse into what may be involved in someone's experience. To list them in separate categories and apart from the ways they may interact with someone's severe Autism can be misleading, since their presence in someone's life is a complex interplay, with symptoms of one condition initiating a cascade of other symptoms in an individual's physical and mental health, and perhaps being expressed through coping behaviours with further negative outcomes.

A Note About Measurement of Intelligence

When considering the conditions which are associated with having an Autism diagnosis, research articles often identify a particular group within the larger group of people with Autism as the focus of their study: those with an accompanying diagnosis of intellectual disability.²⁴ There is, however, a great deal of disagreement on this topic. One main area of disagreement is the prevalence of intellectual disability among people with Autism. How common is it? Research on the prevalence of intellectual disability in people with Autism at one point estimated there was a co-occurrence as high as 70%, that 70% of people with Autism also had an intellectual disability. But more recent studies suggest the co-occurrence to be much less. One study that focused on children suggested that intellectual disability was present in as few as 30% of children with ASD.²⁵ The explanation these researchers offered for this discrepancy was that Autism can cause cognitive test scores to be artificially low due to an individual's limited social responsiveness and repetitive behaviours that interfere with the testing.²⁶

Researchers acknowledge the lack of fit of cognitive tests for people with Autism, and they recognize the need to use different tests. But this gives rise to disagreement about which tests ought to be used instead. As one researcher stated, "It is well-established that intelligence estimates in people with autism vary with the instrument used for assessment, but opinions conflict concerning which measurement tool is most accurate."²⁷ Although there is yet to be a consensus in the literature of which tests ought to be used, there are developments that are worth noting.

One such development comes from a series of studies that include children and adults with Autism, in which researchers compared the participants' performances on different cognitive tests. These studies indicate that the Wechsler-based intelligence tests, the most commonly used test, not only underestimate the level of intelligence of people with Autism, but show that assumptions made about the *kind* of intelligence that people with Autism have are also likely mistaken. One study of this series in particular found that people with ASD perform higher when taking an alternative test called Raven's Progressive Matrices, and this higher performance challenges the "assumption that Autistic intelligence is only simple, low-level, perceptual expertise, which allows people with ASD to solve only tasks based on rote memory."²⁸ This is because Raven's Progressive Matrices is a test widely accepted to be a reliable measure of high-level analytical reasoning and viewed as a pragmatic measure of fluid intelligence. However, people with ASD are assumed to lack the cognitive processes that researchers understand fluid intelligence to require, such as coordinated executive function, attention control, and working memory. For someone with Autism to perform well on a test that measures fluid reasoning directly challenges assumptions that researchers have held about the nature of intelligence people with Autism have.²⁹

Intellectual disability may be a factor in a person's life with severe Autism, and one that contributes to their vulnerability. However, considering the lack of consensus regarding how intellectual disability is determined for someone with ASD, caution is needed when making any general assumptions.

What about language and communication?

As part of the defining features of Autism, an individual with an ASD diagnosis will have impairments in social communication skills.³⁰ Deficits in language skills, however, are not universal in Autism but roughly 25% of people with Autism speak few or no words.³¹ This difference is represented in a separate but accompanying diagnosis of language impairment alongside ASD, and the DSM-5 instructs clinicians to consider expressive and receptive language abilities separately.³² A generation ago, the number of people speaking few to no words was estimated closer to 50% and researchers agree that the decline to 25% is due to a combination of early intervention programs to help more children develop language, as well as the expansion of the definition of Autism.³³

To help us understand this in more detail, it is worth noting that some researchers propose communication development as having three dimensions: the structural language which is defined by grammar and vocabulary, speech-sound production, and the pragmatics or social communication aspect.³⁴ As one researcher states, these dimensions are not completely independent from each other, and the dimensions have a non-linear and interactive effect on each other.³⁵ And while these three elements are not connected to distinct developmental mechanisms, it does point to the many different factors at play if someone's ASD diagnosis is accompanied by a diagnosis of a language impairment. For example, some individuals have apraxia or an oral-motor impairment,³⁶ difficulties with sensory processing and integration,³⁷ memory issues, and a lack of response to social stimuli as children can lead to someone missing out on important opportunities for developing language.³⁸ Although language skills can be independent of IQ in people with Autism, an individual's comprehension of the language can also be a factor.³⁹ But as

with other aspects of Autism, it is difficult to test a person's language, as these tests include many other factors, such as understanding the demands of the task, the instructions, as well as a person's ability to tolerate the sensory stimulus involved.⁴⁰

Most studies regarding language focus on children, and it is not surprising that researchers favour children with some level of language skills for their studies to fit the instruments used. Unfortunately, few studies have focused on children with very little language, or those who are considered “nonverbal” or “minimally verbal” and so there is little understanding of the nature of their language problems.⁴¹ Even the definition of these terms is still outstanding, a signal of how little research attention this group has received. As one author explained, a clear definition of what it means to be minimally verbal is still needed, as most children (and likely adults) are not “truly nonverbal” which would mean that they have no words or no sounds.⁴² And further, clarity is needed to distinguish “minimally verbal” from “preverbal” which would be a better way to describe a child with delayed language, when this may change over time and with intervention.

For adults with severe Autism and a language impairment, this lack of research further contributes to their vulnerability regarding evidence-based decision making, as discussed in the previous essay. This is in addition to the vulnerability that being minimally verbal or nonspeaking introduces when someone is not able to speak up to share their needs and wants, if they are experiencing poor treatment, contribute to decisions about their lives, and so forth. This lack of language can also lead to a great deal of underestimation of their abilities. An assumption that will lead to many negative outcomes over the course of their lives. For example, one researcher explained that “If they can't speak, then we maybe undershoot them when we assess them and assume that they are much more [intellectually] impaired than they actually are.”⁴³ This is a topic we return to in the next essay.

What does it mean for needs to be high and complex?

Adults with severe Autism are especially vulnerable, in part, because of their conditions and the needs that those conditions generate. A helpful way to describe an individual's needs when they have severe Autism and a range of accompanying conditions is to identify them as having needs that are high and complex. This is a term used to acknowledge, as articulated well by the *Complex Care Group* in New Zealand, that “there is a very small segment of the disabled population that needs to be recognized as different from the rest,” a distinct group of people with intensive needs.⁴⁴ According to the *Complex Care Group*, these needs may be the result of multiple disabilities, behaviours, and serious and ongoing medical conditions. Adults with severe Autism fit this description well. In terms of how these needs are met, due to their intensity and complexity, the general disability support services available will be inadequate to meet those needs or are absent altogether. It is also often the case that someone in this group will communicate their needs in such a way that only those closest to them will understand. This compounds the vulnerability of members of this group, as they are unable to directly advocate for the support they need, whether that is from a doctor, service provider, or within larger forums where decisions that impact them are made.

Support Needs

When considering the unique combination of conditions someone experiences, how those conditions interact, and an individual's unique experience of severe ASD, it becomes clear why the resulting needs are described as high and complex and are a significant reason why such adults are among our most vulnerable citizens. To get an idea of how these different conditions could result in a unique configuration of needs, and the support required to meet those needs, we can imagine a possible scenario of an adult with severe Autism. First, they require very substantial support due to their deficits in social communication and restrictive and repetitive behaviours, they are also thought to have an intellectual disability and language impairment. As part of the individual's diagnostic assessment for Autism, the parents of the individual completed a questionnaire identifying the individual's needs for support regarding adaptive behaviours in areas such as functional academics, home living, health and safety, and self-care. The results indicated that their adaptive behaviours are highly uneven, and extremely low in some areas.⁴⁵

But imagine also that they have been diagnosed with epilepsy, anxiety, and demonstrate coping behaviours such as aggression and self-injury. They often have trouble sleeping. In the past they have experienced traumatic events connected to caregivers who did not know how to handle their behaviours and they have recently been diagnosed with PTSD. Those close to this individual have raised concerns about possible suicidal tendencies. The support this person requires in their daily life is intense and constant, and varies from support for safety and security, toileting and other personal care, dietary support, as well as medical and healthcare support. This is in addition to the support this person needs in their daily life with a broader sense of their wellbeing in mind, such as support for social connection, pursuing interests, and engaging with their community. Generic supports for someone with Autism, for example, or generic supports for someone with anxiety, will not be adequate to meet their needs. This leaves them vulnerable to rely on support from others, trusting those closest to them to understand and meet their needs that are high and complex, as well as to support them to build a life that is meaningful to them.

Although this is a hypothetical example, this fits the picture offered by a recent regional study in Ontario which focused on identifying housing requirements for adults with developmental disabilities and high, complex needs.⁴⁶ The study asked caregivers and individuals who self-identified as having a developmental disability and high, complex needs to describe the adult's, or their own, daily needs. Participants were asked to indicate the different support categories that applied to the person they support or themselves. The two groups answered much the same, with support for safety and security chosen with the most frequency, followed by healthcare, and finally dietary supports.⁴⁷ Support for personal care (including all "Activities of Daily Living," or ADLs⁴⁸), social interactions, environmental needs (controlling stimuli), and support for the person to communicate, were also often mentioned by caregivers as daily needs. These kinds of needs, unique to each individual, require support that is constant and intense. Some caregivers also noted that the way the needs present in the individual's life limited the sources from which to receive support, that aspects of their situation were a barrier to receiving support from friends and family, thus contributing to a reliance on paid services.

Among many factors, where an individual lives has bearing upon how their needs are met. Whether it is living independently with support coming in, living in a shared home, or in

residential care. Beyond ensuring that an individual's specific needs are met, we can also draw some general ideas of how to better design living arrangements to support adults with Autism from recent research. One study sought to learn what adults with Autism would want if they were to live in residential care and asked for their recommendations. The study analyzed contributions of a focus group of adults with Autism (although not those with severe Autism), and found the following themes: the need for managing transitions into residential care, Autism specific training for the staff who work there, recognition and respect for Autistic differences and understanding of Autistic wellbeing, support for physical health, and consideration given to the sensory environment and sensory processes.⁴⁹ The focus groups also recommended that researchers work toward identifying design principles for spaces where people with ASD live, similar to how spaces are designed for people with dementia.⁵⁰ These lessons, and a possible set of design principles, are not limited to a residential care setting. These findings can be taken into consideration no matter where an individual happens to live, further investing in support that meets the needs of members of this vulnerable group.

Who is meeting these needs?

Given that the needs of adults with severe Autism are often high and complex, we must consider how these needs are being met. Research has indicated that the need for services has been found to increase with age for people with Autism, and yet service *usage* actually tends to decrease after the transition to adulthood.⁵¹ Studies that focused on healthcare in Canada and the United States found the number of services used by people with Autism decreases from childhood to adulthood, and continues to decrease until late adulthood, however the use of medications and in-patient services increases.⁵² There are stories behind these trends that are worth more research to discover.

Since the needs of adults with severe Autism will be diverse, the configuration of services used to meet these needs will be likewise diverse. The support someone receives must be individualized to their unique needs in order to properly accommodate their uneven abilities, and the way the severity of their ASD can fluctuate and vary by context. Although parents and family members of adults with Autism are likely to play a large role in providing support, there is a financial cost to ensuring a person's needs are met. A study looking at the United Kingdom and the United States sought to estimate the lifetime economic cost of care for an individual with ASD. Care in this context included medical and non-medical services (e.g., day programs, respite), accommodation, and parental productivity loss.⁵³ The cost was estimated upwards of 1.4 million, and 2.4 million USD from someone with ASD and intellectual disability, with the majority of these costs associated with adulthood.⁵⁴ To address the vulnerability of members of this group we must include attention to their financial needs.

Summing Up

This is not an exhaustive account of an adult's experience of living with severe ASD and accompanying conditions. Autism is a full body experience, unique to each individual. For an adult with severe Autism and a combination of accompanying conditions, this experience

includes needs that are high and complex. The support an individual requires to meet their needs must consider how their conditions interact with their experience of severe Autism, and how symptoms of one condition can trigger the symptoms of others, at times becoming a cascade. Meeting these needs will not be accomplished by generic supports, which further adds to their vulnerability.

For those without severe Autism, there may be discomfort when reading about such conditions (or writing about them), but this is nothing compared to the lived experience. Of course, there is so much more to an individual's life than their experience of these conditions, but we highlight this aspect to raise awareness, to increase sensitivity, and to inform advocacy. An important step toward making positive change in the lives of adults with severe Autism is to recognize and understand the unique vulnerability of this group.

¹ American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition*. Arlington, VA, Washington, pg. 50-59.

² Ibid. 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.

³ 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/>.

⁴ 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. 2.

⁵ Tomblin, B. 2011. "Co-Morbidity of Autism and SLI: Kinds, Kin and Complexity: Co-Morbidity of Autism and SLI: Kinds, Kin and Complexity." *International Journal of Language & Communication Disorders* 46 (2): 127-37. <https://doi.org/10.1111/j.1460-6984.2011.00017.x>, pg.130.

⁶ Croen, L., O. Zerbo, Y. Qian, M. Massolo, S. Rich, S. Sidney, and C. Kripke. 2015. "The Health Status of Adults on the Autism Spectrum." *Autism: The International Journal of Research and Practice* 19 (7): 814-23. Submitted version: <https://escholarship.org/content/qt3v42r5rs/qt3v42r5rs.pdf?t=np9tu4>, pg. 14.

⁷ Croen et al., "The Health Status of Adult on the Autism Spectrum," pg. 15.

⁸ Ibid., pg. 13, 14.

⁹ Raymaker, D., A. Teo, N. Steckler, B. Lentz, M. Scharer, A. Delos Santos, S. Kapp, M. Hunter, A. Joyce, and C. Nicolaidis. 2020. "'Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew': Defining Autistic Burnout." *Autism in Adulthood* 2 (2): 132-43. <https://doi.org/10.1089/aut.2019.0079>, pg. 134.

¹⁰ Raymaker, D., et al., "'Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew,'" pg. 141.

¹¹ Ibid., pg. 141-142.

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>, pg. 1129.

¹³ Kildhal, et al., "'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," pg. 1124.

¹⁴ Ibid., pg. 1129.

¹⁵ Croen et al., "The Health Status of Adult on the Autism Spectrum," pg. 13, 14.

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- ¹⁷ Cassidy et al., "Risk Markers for Suicidality in Autistic Adults," pg. 21.
- ¹⁸ Williams, D., M. Siegel, and C. Mazefsky. 2018. "Problem Behaviors in Autism Spectrum Disorder: Association with Verbal Ability and Adapting/Coping Skills." *Journal of Autism and Developmental Disorders* 48 (11): 3668–77. <https://doi.org/10.1007/s10803-017-3179-0>, pg. 3.
- ¹⁹ Williams et al., 2018. "Problem Behaviors in Autism Spectrum Disorder," pg. 2.
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- ²¹ Mannion and Leader, "Comorbidity in Autism Spectrum Disorder," pg. 1608.
- ²² *Ibid.*, pg. 1611.
- ²³ *Ibid.*
- ²⁴ Intellectual disability would be an accompanying diagnosis on the DSM-5, whereas it would be part of the ASD diagnosis (ASD with or without intellectual disability) on the ICD-11. On their website, the American Psychiatric Association defines intellectual disability as something that "involves problems with general mental abilities that affect functioning" in the areas of "intellectual function (such as learning, problem solving, judgement)" and "adaptive functioning (activities of daily life such as communication and independent living" (<https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>). For some people, the term "intellectual disability" is ill-fitting and condescending, and to use "cognitive disability" in this context is favourable. For this project "intellectual disability" is used simply because it is the term used in the literature that informed this work and carries the definition from the APA. This is not due to approval of the term, however a more fulsome discussion about terms and their meanings is beyond the scope of this project.
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