

# **The Experiences of Individuals With Autism and How to Support Them**

Jessica Low

City University of Seattle in Canada

Department of Arts and Science

Mike Sornberger

CPC 695: Counselling Psychology Research Project

September 26, 2022

### **Abstract**

This literature review focuses on individuals with autism spectrum disorder (ASD). The goal of this paper is to explore the experiences of individuals with ASD and effective ways for counsellors to help them. Using the Adaptive Behaviour Assessment System (ABAS-3) as a framework to explore the experiences of individuals with ASD, I examined three domains of skill: conceptual, social, and practical (Harrison & Oakland, 2015). I concluded that there is a need for more evidence-based research. There is a significant gap between the literature and practice in counselling sessions. Recommendations for counsellors are to continue to engage in the therapeutic alliance with clients and their families, allowing individualized treatments and goals to provide a better quality of life, and also to create community-based programs that will be more workable and effective.

## **The Experiences of Individuals With Autism and How to Support Them**

Autism spectrum disorder (ASD) is a neurodevelopmental disorder involving persistent deficits in social interactions across multiple contexts (Crane et al., 2021; Freund et al., 2019; Kerns et al., 2017; King et al., 2020). Symptoms of ASD can include deficits in communication, as well as restricted and repetitive behaviours and interests. An estimated 1 in 66 Canadian children from the ages of 5 to 17 have been diagnosed with ASD, with a higher rate of diagnosis in males (American Psychiatric Association, 2013; Centres for Disease Control and Prevention, 2022). An increase in awareness among professionals and the public has contributed to an increase in its diagnosed prevalence worldwide (Akhter et al., 2018; Ivanović, 2021). Symptoms can be detected in early childhood but can be masked depending on the individual's environment, characteristics, and support systems (Andersson et al., 2017). For example, the individual's intelligence quotient (IQ) can significantly impact the likelihood of diagnosis because individuals with a higher IQ may not need as much support compared to their lower IQ counterparts. Those who are capable of verbalizing their desires may receive less extensive support from professionals and family members (de Verdier et al., 2020). As ASD is considered a spectrum, there are individuals with ASD who need more support than others because they tend to exhibit more challenging behaviours and emotional disturbances, which in turn results in more stress within the family dynamic.

ASD is a complex condition that does not have a single cause; researchers currently believe that its development is complex and multifactorial (Baghdadli et al., 2019). Each person is different, displaying a unique profile of strengths and challenges. ASD is considered a childhood diagnosis, yet it is still prevalent among adults as a long-term condition (Baghdadli et al., 2019). Working with individuals with ASD characteristics can be complex because of the

high potential for comorbidities with other psychiatric disorders as well as the broad range of severity in an ASD diagnosis (Ivanović, 2021). Research is limited on the impacts of these characteristics across the lifespan after childhood. There is a need to advocate for more research in adult populations in all subperiods of early, mid, and late adulthood to better support individuals with ASD long-term.

The research community has attempted to explain ASD through genetic factors (Billeci et al., 2016; Bishop et al., 2006; Gesundheit & Rosenzweig, 2017; Rad et al., 2020). Some researchers use the broader type phenotype (BTP) to describe the personality characteristics of individuals with ASD to link a genetic component (Mohammadi & Zarafshan, 2014). The BTP refers to the clinical ASD related traits that are inherent within the family (Kanner, 1943). BTP can describe the genetic traits of ASD within the family dynamic and reveal the common link when siblings of children with ASD also have inherent autistic characteristics. Multiple researchers have examined the increased risk factors for siblings to experience behavioural and intellectual challenges (e.g., Billeci et al., 2016; Mohammadi & Zarafshan, 2014; Roemer, 2021). The BTP factor suggests that there is a genetic component to ASD that may give a higher risk for siblings of individuals with ASD to have autistic tendencies. Baghdadli et al. (2019) suggested in their longitudinal research that BTP may be a significant factor in the ability to predict ASD in early childhood. There is a need for more research to link potential genetic factors and the lived experiences of individuals with ASD and the skills needed to do daily tasks.

### **Transition to Adulthood**

There is significantly more research on childhood experiences of ASD compared to adolescent or adulthood experiences. Researchers still struggle to fully understand the experiences of individuals with ASD across their lifespans. There are limited longitudinal studies

exploring the transition from childhood to adulthood among individuals with ASD (Andersson et al., 2017; Baghdadli et al., 2019). Additionally, as the criteria for definition and diagnosis have changed since accepting ASD as a mental disorder, many individuals may have been misdiagnosed or did not meet the previous standard of diagnosis (Parchomiuk, 2021). The changes to the diagnostic criteria for ASD have impacted researchers' abilities to conduct longitudinal studies on the life-long functioning of individuals with ASD. Those who would have been diagnosed from previous Diagnostic Statistical Manuals of Mental Disorders may not be considered with the more recent manual (Weitlauf et al., 2014).

Information gained from child studies can be used as the foundation for long-term research, as it can help determine what the individual, the family, and the community need to do in order to assist in providing a better quality of life (e.g., emotional regulation and independence; Dudley et al., 2019; Parchomiuk, 2021). Longitudinal studies allow researchers to study and understand the natural history that can identify risk and prognostic factors affecting health and development (Baghdadli et al., 2019). Examining patterns or abnormalities and exploring developmental trajectories may explain variables associated with ASD. Single point studies explore specific factors that contribute to the overall experience of ASD, providing interventions that can help reduce maladaptive behaviour or burnout for parents (e.g., coping strategies, support groups, and counselling). Longitudinal studies are needed to discover the experience and transitions that the entire family goes through.

Many mental health services are no longer available as soon as the individual with ASD is considered an adult. There are multiple reasons for losing important resources, the more common examples are loss of funding or the limited awareness of services for the population. Previous integrated and school-based programs are lost and cannot be retained because of limited

space to accommodate the adult population. Once out of high school, many individuals with ASD lose services regardless of whether they are privately insured (Dudley et al., 2019; Wilson et al., 2021). A possible reason for the loss of services is the reduction of funding and awareness the public has towards the diagnosis. Other reasons can include the limited awareness of the healthcare needs of aging adults, shortage of or limited services, and communication difficulties with professionals. The transition is difficult for the individual, and for the parents who support and advocate for them (Ardic, 2020; Malik-Soni et al., 2022; Marsack & Perry, 2018; Wong et al., 2020). Parents often have to continue to support their children throughout adulthood when the individual with ASD is not independent. More services are needed to support adults with ASD because many of these individuals cannot receive or access the services they need.

## **Operationalizing ASD Features**

### ***Comorbidity***

It is common for individuals with ASD to also have intellectual language impairments, motor deficits, and disruptive or challenging behaviours. About 70% of individuals with ASD will have one comorbid mental disorder, and about 40% will have two or more (Rodas et al., 2017; Stadnick et al., 2017). Children with ASD have a higher burden of psychiatric comorbidities than children with intellectual disabilities (American Psychiatric Association, 2013). Common comorbid disorders include anxiety, depression, conduct disorder, disruptive mood dysregulation disorder, and attention deficit hyperactivity disorder (ADHD; Ivanović, 2021; Morie et al., 2019; White & Dicrisio, 2015). With various prevalent disorders co-occurring with ASD, it is difficult to distinguish symptoms for specific diagnoses. For example, anxiety and depression are common comorbid disorders with ASD in all ages, and psychiatric disorders such as ADHD have symptoms assumed to have genetic predispositions that overlap

with common ASD symptoms and comorbidities (Adib et al., 2019; Duarte et al., 2005).

Ivanović (2021) suggests that pharmacological treatments can reduce comorbid disorders such as anxiety and depression to improve the overall quality of life for individuals with ASD.

In terms of research on comorbidities, most of the focus has been on anxiety that impacts the psychological, physical, and social wellbeing of the individual (Catalano et al., 2018; Celal et al., 2020; Hollocks et al., 2019; Ivanović, 2021; White et al., 2018). Anxiety is the most prominent comorbid disorder researchers investigate alongside ASD. There is inconsistent evidence that levels of anxiety are related to intellectual functioning among individuals with ASD (Mingins et al., 2021). Measurements for anxiety have relied on parent reports and the child's ability to express their needs (Mingins et al., 2021). Individuals with lower IQ can have a more difficult time expressing their needs compared to those with higher IQ scores. This makes the diagnosis of anxiety more difficult in less verbal individuals, but not impossible as anxiety can be observed through behaviours in children with ASD (Mingins et al., 2021). Behaviours such as social avoidance or more repetitive or restrictive behaviours are observed more during times of anxiety. Higher IQ individuals may express their needs more effectively than their lower IQ counterparts, which allows them to meet the criteria for comorbid disorders such as anxiety. Therefore, while an anxiety diagnosis may be reached differently in verbal versus non- or less verbal individuals, it is not currently clear whether the existence of an anxiety comorbidity has any correlation to intellectual functioning.

Many individuals with ASD have difficulties with emotion regulation (Samson, Hardan, et al., 2015; Samson, Wells, et al., 2015; Ting & Weiss, 2017). Social and communication deficits can prevent individuals from understanding and regulating the emotions they express. ASD and mood disorders are relatively commonly comorbid (Morie et al., 2019). An

individual's immediate surroundings can evoke strong emotions, which can be challenging to regulate if they are not taught how. First, a person must select a reaction to the emotion, then implement strategies to regulate the response. For individuals with difficulty regulating emotion, this may be taking place in the context of overwhelming distress (Samson, Hardan, et al., 2015). An individual with ASD may find it challenging to control their feelings or process their emotions because they may not have the emotional capacity to recognize the feeling (Morie et al., 2019; Samson, Wells, et al., 2015). It is not uncommon for individuals with ASD to experience alexithymia, or the inability to recognize and express emotions. Although not every individual with ASD meets the criteria for alexithymia, it can explain how some people with ASD struggle with regulating emotions and communicating their needs (Mingins et al., 2021; Morie et al., 2019; Samson, Wells, et al., 2015). A deficit in emotional intelligence can create unhealthy patterns of emotional regulation and increased levels of anxiety or depression. With reduced capacity for regulation, individuals with ASD may express themselves externally through maladaptive behaviours as a way to communicate to others that something is wrong. The severity of the ASD diagnosis may contribute to the deprivation of emotional regulation and understanding of internal or external emotional stimuli.

### ***Diagnosis Severity***

The American Psychiatric Association (2013) introduced three levels of severity to accommodate the range of difficulties in the symptom clusters of social/communication interaction and the restricted, repetitive patterns of behaviour, interest, or activities. The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013) classification splits into level one (requiring support), level two (requiring substantial support), and level three (requiring very substantial support). The three severity



classifications provide criteria related to social communication and restrictive and repetitive behaviour. It is unclear how effective these labels are for diagnosis and whether the impairments are cognitive impairments or adaptive behaviours (Oberman & Kaufmann, 2020; Weitlauf et al., 2014). Each level rates the amount of support and behaviour on a subjective level from the perspective of parents and practitioners, and the severity of the diagnosis fluctuates over time (White & Dicrischio, 2015). There is ongoing research on the relationship between the severity of ASD and psychiatric comorbidity.

There are mixed results on sex and ASD symptom severity. Researchers commonly find that females show a higher degree of severity in social problems while males show a higher degree in repetitive and restricted behaviours (Rodgers et al., 2019). Although the results are minimal, the characteristics that an individual expresses can impact the type of interventions professionals implement. Further research is needed to understand the relationship between the severity of the diagnosis and the experiences different sexes have in daily living.

There are also mixed findings on the impact of diagnostic severity on parents' mental health. The majority of the literature suggests that the severity of the diagnosis is an essential factor because of the severity of symptoms associated with ASD (Morie et al., 2019; Rattaz et al., 2017; Weitlauf et al., 2014). A more severe diagnosis indicates that caregivers need to put more energy into providing care for individuals with ASD. The difficulties lie within daily living tasks, emotional regulation, and behaviours that decrease the wellbeing of parents (Salomone et al., 2018). These challenges can drain the parents' resources and ability to care for themselves. However, caregivers with solid support systems find ways to cope with the severity of the diagnosis using both formal, such as government and professional help, and informal support, for example friends and family. There are reports of poor parental outcomes when caring for

individuals with level three (requiring very substantial support) and those in level one (requiring minimal support; Salomone et al., 2018). Multiple studies show a consistent association between emotional and behavioural dysregulation in individuals with ASD and poor parental wellbeing (Charitaki et al., 2021; Samson, Wells, et al., 2015). A parent of a child with a level three severity will not experience the same impact as a parent whose child is at level one. There is a powerful relationship between parents' mental health and severity of the diagnosis of their child. Symptoms like levels of challenging behaviour, comorbidity factors such as intellectual disability, and level of diagnosis impact the parents and their distress levels. In addition, finding resources for individuals with ASD can increase chronic stress for parents, prevent appropriate coping strategies, and reduce parenting interventions in daily routines.

### **Skills of Daily Living**

Skills necessary for individuals to effectively and independently care for themselves are considered adaptive behaviours or functional skills. Measuring adaptive skills or deficits can help practitioners identify limitations and determine the direction of interventions for individuals with ASD. These skills are needed in everyday domains such as home, school, work, and the community (Jordan et al., 2019; Saulnier & Klaiman, 2018).

The Adaptive Behaviour Assessment System (ABAS-3) explores adaptive skills within the conceptual, social, and practical domains using rating scale reports of teachers, parents, and the individual themselves (Harrison & Oakland, 2015). ABAS-3 describes the daily functions and related skills of individuals with ASD from 0 to 89 years of age. The assessment should be sensitive to the cultural context, sociocultural differences, age differences, and standards for developing adaptive behaviour. The ABAS-3 has shown reliability within the research, offering a standardized tool to assess the adaptability of individuals with ASD needed to be effectively

independent (Prokopiak & Kirenko, 2020). It will be used as an organizational feature to explore the three domains of adaptive skills: conceptual, social, and practical.

### **Key Terms in the Literature**

The terminology used in the literature has recently changed to focus on support needed for individuals with ASD, rather than on level of functioning. In the past, the term used was “high or low functioning,” which depends on the individual’s cognitive and intellectual ability (Bal et al., 2017; Oberman & Kaufmann, 2020). Newer terminology uses specifiers of the impairment, which depend on the individual's independence and the support they already have and will need (Bal et al., 2017). The new terminology creates a better understanding of the specific support that the individual with ASD needs, whether at home, in a school/work environment, or in their community.

### **Research Question**

Individuals with ASD have a wide range of characteristics, including strengths and challenges. Researchers continue to study the characteristics of the symptoms of ASD to conceptualize and understand the nature and severity of the diagnosis. The research asks: what are the experiences of individuals with ASD and how can counsellors assist them? The current literature review outlines essential information that counsellors should have about ASD, as well as best practices for supporting adults with ASD. New and updated research will help counsellors better understand and adapt to the needs of individuals with ASD during their transition into adulthood. The paper will explore the experiences of individuals with ASD in childhood and adulthood.

### **Self-Positioning Statement**

I chose to study ASD because I work with adults with ASD and their families. In the past 4 years, I have had the privilege to personally know some parents and learn how they have worked through caring for their child with ASD. I would like to continue to help families and individuals with disabilities because they have displayed resiliency and continued strength in providing for all the needs of their children. Regardless of ethnicity, cultural values, or economic status, parents and caregivers have shown a continuous fight to give what is needed. These conditions can impact how individuals with ASD get support and resources, which will be explained throughout the paper.

From day one of working with this population, I knew that I wanted to continue to work with them and their families the best way I could. As a community support worker and by providing respite, I could help create conditions for growth for the individual and give the parents space to not be constantly worrying about their child. I believe that as a counsellor, I can provide more to these families as an advocate. With my knowledge and experience working with this population, I can provide the training and programs that many individuals with ASD need to thrive. Actively engaging with parents can help determine the specific needs of the individual with ASD and the family. This paper will link the current research to help develop a better understanding for professionals of the experiences of individuals with ASD and how to support them through points of their life effectively.

When beginning the research, I believed I did not have a bias that would impact the research process. However, I had previously searched for papers that would explain the ideas I had and was cherry-picking articles to confirm my bias. Since then, I have made active efforts to ensure that the research directed my narrative in responding to the research question. I am aware

that as a beginner researcher, I must take the time to reflect and find what is truly meaningful to me. I can limit my self-reflexivity and be aware of my position through self-reflection journals and discussing my position with supervisors and peers. It is critical not to become blindsided in the research to ensure that I do honest, ethical, and truthful research.

### **Literature Review**

Using the ABAS-3 as an organizational structure, the paper will go through conceptual, social, and practical domains that address the developmental stages to better understand behaviours associated with ASD. This paper will review relevant literature on each domain to explain in-depth the participation of individuals with ASD. Given the changes made to the diagnostic criteria with the release of the *DSM-5*, emphasis will be placed on research published within the last 10 years. The ultimate goal of this review is to help counsellors understand best practices for supporting adults with ASD.

### **Conceptual**

The conceptual domain is the forming of thoughts, perceptions, and impressions. The conceptual domain skills in the ABAS-3 consist of assessing communication, functional academics, and self-direction. Communication explores internal and external factors contributing to the deficits individuals with ASD may experience and helps explain reasons for certain behaviours. Functional academics refers to daily activities that individuals engage in during school age, as well as the foundational parts of treatments that will effectively assist long term. Lastly, self-direction includes skills for independence and self-control, such as evaluating task completion, following directions, and choice making.

### **Communication**

Difficulties with communication can lead to academic and interpersonal challenges as the

child enters into complex communication with their peers (Roemer, 2021). In a meta-analysis, Roemer (2021) found that toddlers with ASD scored significantly lower in the receptive and expressive language domains compared to their neurotypical counterparts. It is strongly believed that the BTP has a significant role in the deficits and symptoms of ASD (Roemer, 2021). By assessing relatives of individuals with ASD to determine if language impairments have a shared mechanism to ASD, researchers found a possible genetic overlap that is complex and not fully understood (Pisula & Ziegart-Sadowska, 2015; Roemer, 2021).

Family members inherit similar characteristics. Biological siblings of individuals with ASD are often included in ASD research because of similar genetic components and environmental factors that impact their development. Genetic mechanisms can help understand the development of ASD-specific functional traits and developmental trajectories.

In addition to genetic mechanisms, communication difficulties can also be influenced by environment; for example, the absence of language practice within the home may limit development. It is also challenging to measure the pragmatic language used (e.g., social language skills) because some of the ways individuals with ASD communicate cannot be measured by standard language tests (Roemer, 2021). Individuals with ASD and language difficulties may continue to struggle to perform the skills needed to communicate in the real world compared to in controlled environments. For example, sign language or devices to communicate are not accepted by standard language tests, such as the Children's Communication Checklist 2 (Bishop et al., 2006). Parent reports have been used to measure the abilities of individuals with ASD but these efforts have yielded mixed results because personal factors, such as comparing their child in a different lens, influence parents' reports. There are multiple reasons for deficiency and increased ability, such as social factors, privation of communication within the family home,

progress with time, or genetic factors.

External factors can also impact communication and language deficits for children with ASD. Environmental factors, such as socioeconomic status, can contribute to verbal abilities in children and can predict the language ability outcome in adulthood (Magiati et al., 2014). The understanding of language development for individuals with ASD is still unfamiliar within the research. Maltman et al. (2021) agree that if language difficulties remain by the age of 5, considerable interventions will be needed to help development. Still, individuals with ASD can improve their verbal skills well into adolescence and adulthood with consistent practice and the proper funding to support them. However, individuals with ASD and their families face barriers to getting the necessary services to move in a positive direction; these barriers appear to have an impact on prognosis. Individuals with ASD who come from families that are well educated, employed full time, and are from White backgrounds tend to improve their verbal skills (Maltman et al., 2021). It is likely that higher socioeconomic status correlates with fewer barriers and more access to resources, in turn facilitating development. For struggling families, there is a higher risk of elevated prevalence of ASD. Researchers have speculated reasons such as being in vulnerable conditions and higher levels of deprivation increase the risk of prevalence of ASD (Delobel-Ayoub et al., 2015). Factors such as low education level, family structure, and low family income are also associated with high prevalence with the family dynamic. There is still research needed as much of Maltman and colleagues' study did not go past the age of 5. Especially needed is research that demonstrates the experience of adults with communication and language deficits.

Maladaptive behaviours, such as self-harm, can also be a way for individuals with ASD to communicate their internal distresses. These behaviours can be the result of these individuals'

inability to regulate their emotions effectively. Individuals struggling with psychiatric disorders such as anxiety and depression have increased negative emotions and maladaptive behaviours, such as self-harm (Samson, Hardan, et al., 2015). Parents can effectively support their children when the child's needs are expressed externally rather than internally in order to plan appropriate adaptive strategies. Unfortunately, data on the underlying causes of maladaptive behaviours in individuals with ASD remain inconclusive because of the difficulty of obtaining reports directly from individuals with lower cognitive ability. Parent reports are only snapshots of the child's experience and are sometimes biased towards the parent's experience of dealing with the behaviours. Self-reports are not always reliable, especially if the individual cannot communicate effectively.

### ***Functional Academics***

The ABAS-3 assesses the child's ability to engage during school and learn the fundamentals of daily living. During these years, individuals with ASD can learn basic language, social, and mathematic skills that can benefit them in later years. These years are also crucial for effective treatments such as speech therapy that can impact the child's independence.

Children with ASD in mainstream schooling can experience isolation, alienation, and bullying when socializing with peers, leaving these individuals feeling excluded in the school environment. Having a child experience negativity can sabotage the learning of the fundamentals and result in ineffective treatments. A child's IQ has been considered a factor in their ability to be socially aware and cognitively understand their difficulties within the mainstream classroom (Pisula & Ziegart-Sadowska, 2015; Zainal & Magiati, 2019). There is a high comorbid rate among a child's IQ and their autistic characteristics, making it difficult to disassociate the two. There are still positive aspects for children with ASD to attend mainstream schooling; those that



attend report positive experiences with making friends and learn to embrace their ASD (Hasson et al., 2022). Unfortunately, many teachers feel they do not have the sufficient training and confidence in providing effective support for individuals with ASD in mainstream schools (Bond et al., 2017). By creating more awareness within the school community, it can create a friendlier environment, flexible support, and peer education. Providing more organisational structure and clear expectations within classrooms is essential for students with ASD to succeed both academically and socioemotionally in an inclusive setting (Holcombe & Plunkett, 2016; Soto-Chodiman et al., 2012).

Children in specialized schools feel more supported and are accommodated based on their needs (Zainal & Magiati, 2019). Not only because specialized schools' aims are different from mainstream schools, but their ratios of teacher to students are different, allowing specialized schools to focus on individual students for more extended periods. The goal for specialized schools is to allow students not suitable for the mainstream educational system to still get the education while also learning other daily life skills.

With the support of early interventions, individuals with ASD may be more likely to achieve higher education (Hu & Chandrasekhar, 2021; Nguyen et al., 2020; Zeedyk et al., 2016). There is an increase in independence by going to postsecondary school, moving out, and the student finding their own residence. Postsecondary school has provided a different way of processing information and offers benefits to skills and talents that can help the student excel. The benefits of attending postsecondary school are gaining analytic skills, sincerity, willingness to listen to others, and impartiality (Van Hees et al., 2015). In addition, universities have adapted to accepting individuals with learning disabilities, helping them excel through reasonable accommodations (Van Hees et al., 2015). This in turn helps individuals with ASD to become

more independent and self-directed in ways like their neurotypical peers. However, there is a risk for these individuals to experience academic and personal challenges because of new stressors and demands of postsecondary education (Van Hees et al., 2015; Walsh et al., 2021). These individuals can struggle with their social skills, organization, and time management; they may also feel isolated if they do not socialize with others (Van Hees et al., 2015). These new environments and demands can also lead to a sense of sensory overload when dealing with school, work, and other personal problems. Postsecondary schooling can be a challenging course for an individual with ASD, yet if the individual continues to get the support they need, they can succeed and transition towards employment.

### ***Self-Direction***

The emotions that an individual with ASD expresses can involve greater levels of emotional distress than in neurotypical individuals (Samson, Hardan, et al., 2015; Yorke et al., 2018). This can appear as aggression and meltdowns due to difficulties expressing their needs to an outside observer. Individuals with ASD experience more negative and less positive emotions due to social and cognitive deficits (Samson et al., 2012; Samson, Wells, et al., 2015). Individuals with ASD may experience more negative emotions due to becoming more frustrated with people misunderstanding what they are trying to communicate. The severity of the diagnosis can impact how the individual regulates their emotions because they may not understand how to explain or identify the emotions, let alone use adaptive strategies to overcome challenging emotions effectively. Parents can often coregulate their child's emotions, to both internal and external problems (Ting & Weiss, 2017). Coregulation occurs when parents support the child's emotional development through modeling and encouragement. Although this is

typically observed in younger adolescents developing their skills, it can also be used with adult individuals with ASD because of their deficit in cognition.

Vygotsky's (1934/1962) work is used to understand the emergence of self-regulating behaviour and self-directed speech through the use of mirroring actions learnt from another. Due to the core symptoms of ASD, some individuals with ASD can lack the capacity to create self-directed speech and, therefore, the understanding of self-regulation (Mulvihill et al., 2020). The importance of quality parent-child interactions supports regulatory private speech because of the use of modeling to increase the child's speech and performance. Some individuals with ASD may not use inner speech to regulate their thinking, which may be task-specific (Mulvihill et al., 2020). Therefore, it has become important to acknowledge the impact of early intervention and coach parents in using techniques to improve quality of life for themselves and their children.

Adults with ASD can find it difficult to regulate their emotions independently because of the deprivation of regulated parents. Similarly, children of parents with depressive symptoms have an increased risk of developing behavioural issues and health complications (Marquis et al., 2019; Zablotzky et al., 2013). Therefore, it is essential to acknowledge the needs of the ASD individual and the parent during these times. As individuals transition out of childhood, they would typically meet their own needs and demands rather than relying on their parents. However, for those individuals who cannot gain the ability to support themselves, their parents continue to regulate them, which continues to deplete the parents' abilities.

## **Social**

The social domain assesses leisure and social interaction skills of individuals with ASD. By reviewing the interactions of individuals with ASD and others, deficits within their development can be observed directly. Individuals with ASD can engage with friends in

activities both in-person and online, each having different benefits. The social connection with peers can help reduce challenges such as verbal communication.

Diagnosed symptoms for individuals with ASD include difficulties in social interactions and related stigma and social isolation. There is still a wide social prejudice against people with disabilities (Marsack & Perry, 2018; O'Connor et al., 2020). Individuals with ASD may experience social exclusion from peers or coworkers because of misperceptions of their abilities and skills. Public outings can feel like being on display and judged because of insufficient public awareness. Individuals with ASD may not display any physical markers of a disability, making it difficult for others to understand their nonnormative needs.

Activities such as video games or board games can help individuals with ASD to be social and gain leisure time with friends and family (Finke et al., 2018; Wenzel et al., 2020). They enable individuals with ASD to be challenged in a manageable and enjoyable way compared to other forms of social interaction. Video games can be a gateway to interacting and communicating with peers, serving as a significant protective factor against depression or bullying (Finke et al., 2018). Family leisure time that involves such activities may help the family member with ASD to practice these skills (Wenzel et al., 2020). Through repetitive actions of the family, individuals with ASD can become accustomed to certain activities and incorporate them into their daily routine.

It can be challenging for some individuals with ASD to interact socially with coworkers or supervisors because of insufficient training within the workplace. Individuals with ASD may be reluctant to disclose their diagnosis to others because of stigmatization and response, limiting the risks of discrimination but also limiting their employment opportunities (O'Connor et al., 2020). Without extra support, coworkers are at risk of allowing stigma or attitudes to guide

judgement that can negatively influence employment outcomes for individuals with ASD (Dreaver et al., 2020). Professional development and training programs can help to accommodate individuals with disabilities to get the proper support from employers and employees.

### **Practical**

The practical domain assesses the individual's skill in navigating the community, home, school, and work environments while also demonstrating the skills to care for their health and safety. The skills that are being assessed are necessary to care for themselves independently. It is essential to note the impact parents have within the practical domain for individuals with ASD as parents continue to be significant participants in their lives.

### ***Community Use***

Community use includes the ability to travel, use services, to stay safe in the community, and to use appropriate behaviour. It can be difficult to manage these tasks when dealing with maladaptive behaviours that put the public or the individual with ASD at harm. Maladaptive behaviour can include self-harm, aggression towards people or property, inappropriate behaviour in public, and persistent noncompliance with everyday demands (O'Nions et al., 2018). These actions are responses to internal or environmental triggers to which the individual with ASD is sensitive. Such actions can create vicarious trauma for parents and community members where they may fear for their well-being (Gérain & Zech, 2018). Individuals with comorbid disorders can add stressors and impact the family dynamic. In addition, the time and resources needed to care for the individual with comorbidity can influence the individual with ASD's ability to cope with specific situations.

Adams and colleagues (2020) suggest that IQ may be a preventative measure as it impacts how the individual interprets the experience. These specific behaviours can make

individuals with ASD the target of teasing, bullying, and peer victimization. Behaviours such as meltdowns, rigid rules, and self-injury are reported to cause negative experiences in the school environment compared to verbal tics and repetitive behaviours (Adams et al., 2020). There is a need for more research on these specific adaptive skills and their impact on individuals with ASD.

The chances of sensory overload for individuals with ASD are common and can discourage family members from leaving the house. Overwhelming sensory stimuli such as loud noises can trigger maladaptive behaviours like self-harming, as the individual with ASD can be confused and anxious. Tourism is slowly shifting to become more inclusive, to allow travel and leisure without barriers for those with disabilities. From airports to hotels to attractions sites, there is more attention on providing accessibility and accommodations. Travelling can be overwhelming as it is a change in routine, overstimulating, and an anxiety-provoking activity (Afif et al., 2022; Freund et al., 2019). Individuals with mental disabilities are still finding constraints because of interactional barriers from social interactions. Family members may be engaging in emotional labour during these times to educate others about the diagnosis and the needs of the individual. The research is limited but providing more opportunities for individuals with ASD to experience travel can encourage a positive perception.

### ***Home Living & Self-Care***

Insufficiency and inequality within the healthcare system make it difficult to care for individuals with ASD and their families (Andersson et al., 2017). Where the healthcare system has been successful is primarily due to geographic area and professionals. Support is unequal and uncoordinated, and depends on professional expertise (Andersson et al., 2017). Parents often question the competence of relief staff, and therefore feel like they are the only ones that would

provide the best care for their children (Deb et al., 2020). There is a loss of continuity among staff because of the extensive training needed to understand behaviours and knowledge of the disability. Formal supports such as respite care significantly depend on what parents can provide for their children. The absence of constant formal and informal resources creates a burden for parents and challenges in getting the proper support from the community (Andersson et al., 2017; Volkmar & Wiesner, 2017). It can increase mental health concerns and challenging behaviours for individuals with ASD when parents and caregivers do not have the training to support themselves or their children.

In high acuity circumstances, families may place their child in residential placements to provide additional support that cannot be managed at home. Residential services try to create a living arrangement that accommodates the skills and abilities of the individual and aim to improve quality of life (Carminati et al., 2017). In addition, residential homes are supposed to make the individual feel engaged and supported with personalized organized services. However, some families may disagree with the idea of residential living as the organization must provide free will which some families argue can lead to disengagement and isolation. If the individual does not want to engage with the services, staff cannot force the individual to participate and they can be left alone to their own devices so long as it is safe. In addition, there is not much scientific research on residential living for individuals with ASD. Researchers should focus on some form of self-reports by individuals with ASD rather than only from staff or parents to compare the development of individuals living in residential living to those who live at home.

Regardless of their living situations, adults with ASD have reported not being able to receive or gain access to necessary services. Most adults with ASD continue to live with family members, mainly their parents. About 50%–80% of adults with ASD continue to co-reside with

their parents, 30%–35% live in residential placements, with few living independently but still needing the support of their families (Dudley et al., 2019; Mabel et al., 2020; Marsack & Perry, 2018; Marsack-Topolewski et al., 2021). Independence has become a new form of measurement to qualify for services from the government and funded agencies, making it difficult for more independent individuals with ASD to receive assistance (Dudley et al., 2019). There is a noticeable gap within the literature about ASD after childhood, as long-term outcomes are only beginning to be investigated by researchers. As more individuals transition out of childhood, there is a need for services and other support in all stages of life.

### ***Health & Safety***

Cognitive deficits can exacerbate the effect of ASD on mental health in various ways. Comorbidity with psychiatric disorders such as anxiety and depression may be masked by the ASD diagnosis and the symptoms (Hollocks et al., 2019). There is significant concern about attachment-related anxiety in this population. Some parents may transfer their feelings to their children because of caring duties. This can affect the child's ability to learn to be independent and responsive. As the child is dependent on the parent, the relationship between caregiver and child is more vulnerable to psychological distress during this period. A securely attached parent demonstrates caregiver synchrony, emotional availability, and responsiveness (Keenan et al., 2016). Parents of children with ASD may be at increased risk to struggle to provide these experiences, increasing the risk for experiencing adverse childhood experiences (Keenan et al., 2016; Kerns et al., 2017). This is consistent with evidence suggesting that individuals with ASD are at higher risk than neurotypical individuals of developing mental health concerns (Koudys et al., 2021).



Roughly 30%–42% of youth with ASD also meet the criteria for anxiety disorders (Jenkinson et al., 2020; O’Nions et al., 2018). Social anxiety disorder and generalized anxiety disorder are particularly prevalent in individuals with ASD (Koudys et al., 2021). These internalized disorders can complicate diagnosis and early intervention. Even individuals who normally would be cognitively capable of expressing their needs may not have the language or understanding of their underlying symptoms to accurately voice their issues. Jenkinson et al. (2020) suggest that there may be an additional underlying reason for individuals with ASD to trigger symptoms such as anxiety. The link between anxiety and intolerance of uncertainty seems strong; individuals with ASD are more likely to be social when they know what to expect beforehand (Jenkinson et al., 2020). Disruption in routine for an individual with ASD can result in uncertainty, which in turn may lead to anxiety. Interestingly, research suggests that as the child’s cognitive abilities and IQ increase over time, anxiety and tolerance of uncertainty also increase (Jenkinson et al., 2020). Therefore, anxiety and the tolerance of uncertainty correlate with life's social and other environmental demands.

As the prevalence of ASD rises, there is a need for more research, services, and understanding of the obstacles for those entering adulthood and into their later years. The limited studies suggest a need for an increase of services for those transitioning into adulthood and services long-term to help those aging (Dudley et al., 2019). As they age, individuals with ASD continue to go through difficulties mentally and physically. Environmental factors such as a loss of a loved one, change in life situation, or social isolation may increase the risk of depression (Parchomiuk, 2021). There is a significant need for research in every subperiod of adulthood to determine the trajectory of these issues over time.

## ***Work***

While school is considered a universal right, employment is not. Adults with ASD often struggle to find jobs or employers willing to hire them. Roughly 25%–50% of individuals with ASD are employed, and only those who can vocally communicate are over-qualified (Diener et al., 2020; Goldfarb et al., 2019; Richardson et al., 2019). These individuals face the challenge that employers place more value on communication and social interactions than skillset and experience. Employers who tend to hire individuals with ASD typically have prior knowledge and understanding of the diagnosis, making the transition more beneficial than challenging (Richardson et al., 2019). Unfortunately, many who hire individuals with ASD still struggle with supporting them within the work environment and the labour demands (Goldfarb et al., 2019). Individuals with ASD prefer a structural work environment that is consistent, predictable, and rule-based (Goldfarb et al., 2019). The ideal way is to match the individual with a job that uses the skills and abilities that the individual already possesses and will excel in.

Many individuals with ASD are absolutely capable of meeting the demands of the workforce; the challenge is leveraging individuals' skills to match the employment situation. By using their unique strengths and interests, individuals with ASD are more likely to engage in meaningful work. However, many individuals stress over the demands of the labour market and the work expectations. Individuals with ASD benefit from building their vocational skills to become employable or maintain their employment (Diener et al., 2020; Dreaver et al., 2020; Richardson et al., 2019).

It can be challenging to find the perfect match for a job for individuals with ASD. The current practice is to advocate for matching individuals with ASD to job opportunities related to their particular interests (Goldfarb et al., 2019). The idea is to create self-motivation and

meaning towards a job they would enjoy and find satisfaction in. Unfortunately, there is a paradoxical effect when using the individuals' interest as their job. The special interest is the individuals' "safe haven," where the individual can complete tasks without feeling the pressure of it being a daily chore. By turning the interest into a paying job, it can negatively impact their emotional well-being and disengage the calming qualities of the activity (Goldfarb et al., 2019). Therefore, individuals with ASD and their supporters can benefit from gathering precise information and developing realistic expectations regarding employment.

### **Link to Counselling**

Given the many ways in which individuals with ASD can face challenges in the transition to adulthood, counsellors must be well equipped to provide evidence-based support. By producing researched studies in counselling sessions, professionals can present effective techniques. Fortunately, research across these domains can be integrated to provide a set of best practices. Public education and advocacy can increase awareness and understanding of the diagnosis and what they can do to help. Educating relatives on the diagnosis and strategies to help the immediate family through difficult stages can help decrease social exclusion and increase awareness. By publicly advocating for public health service supports, the recognition can support the individual's well-being and ultimately help the family and community (Marsack & Perry, 2018).

Even after the transition into adulthood, individuals' needs can change. Studies indicate that as the individual with ASD matures through childhood into adolescence and adulthood, a successful transition has the parents' perception in mind (Holmes et al., 2018; Wong et al., 2020). As much of the work is delegated towards the parents on preparation and execution, perceived stress levels can be elevated. The risk of mental health problems for parents are

greater, and counsellors should be actively engaged to support parents when dealing with the added stress. Regardless of the individual's age, behavioural challenges are associated with parent's mental health difficulties.

Accessing resources from the community and government can help individuals with ASD to get the support to provide a better quality of life for themselves and their prominent supporters. The satisfaction of formal or informal support decreases burnout levels for parents as their health care needs are being met (Marquis et al., 2019). Unfortunately, it can also increase stress levels as parents transport and become the liaison for their child to professional appointments, resulting in disruptions to work.

### **Critical Knowledge for Counsellors**

Counsellors need to advocate for individuals with ASD and their parents in finding paramedical resources and support to prevent gaps in services. Providing accurate information to parents creates a sense of confidence and calm to deal with behaviours that may be present for an individual with ASD—providing parents access to support groups that include activities and resources prevents burnout (Catalano et al., 2018). Practitioners should allow parents to ask questions during sessions with their children, to better help the individual outside of sessions. Also, encouraging parents to educate friends and family about the diagnosis can help support the family unit in a more specific approach. Finally, practitioners need to be aware of any cultural significance for the individual and the family by implementing their beliefs, values, and traditions into the experience of preventing burnout.

Relative to the demand, there are limited resources and experts in the field, which prevents many families from getting adequate support compared to other mental health disorders (Catalano et al., 2018; Da Paz & Wallander, 2017; Herrema et al., 2017). Parents tend to go to

general practitioners who may not have a full understanding of the diagnosis, which may result in having a bad experience (de Verdier et al., 2020). Families often report that they do not get taken seriously by medical staff, who assume the child will grow in or out of problematic situations (Churruca et al., 2019). The best way to avoid this would be for all medical and mental health professionals to have basic general knowledge and connection to experts for referral purposes. It can be complicated for families to begin the assessment process and access the resources to diagnose individuals with comorbid disorders. In this case, the families will get help and education sooner rather than later. In most cases, parents have no information or contact information when their children are diagnosed with ASD; therefore, if more professionals are aware of the symptoms, they can assist parents and caregivers in guiding them to the proper resources to help.

### **Implications for Counselling Psychology**

The domains of conceptual, social, and practical adaptive functioning can be used to conceptualize the experiences of individuals with ASD, guiding both research and practice. When integrating this information to further support clients with ASD, each of these domains must be considered to improve both research and practice. Professionals and family members may struggle when dealing with the symptoms of ASD. Barriers include the shortage of congruence between research and practice, which will be addressed in more depth in the fundamental next steps section. Disagreements between professionals and family members can lead to poor use of treatments or misunderstanding from different parties involved which can significantly impact the conceptual, social, and practical domains of the individual with ASD (Jordan et al., 2019; Prokopiak & Kirenko, 2020).

It is difficult to generalize findings within the current research on adults with ASD because of the highly individual nature of each case and the tendency of research to focus on children. Research can help investigate general trends in behaviours, actions, and interactions with others. However, the external behaviours do not provide a complete understanding of the thoughts underlying the actions. Researchers have focused on obtaining data from parental reports or from individuals with higher cognitive functioning and verbal skills to self-report. These limited reports are used as measurements for a broader spectrum of ASD individuals. By doing qualitative studies, it can be difficult to transition the findings into practice and implement certain treatments.

Treatment for individuals with ASD tends to focus on comorbid disorders, such as anxiety, or reducing maladaptive behaviours in the hopes of improving quality of life for the individual and their families (Herrema et al., 2017; Park et al., 2019). There have been considerable strides in therapeutic and intervention research effectiveness for individuals with ASD. Most of this work has focused on the application of CBT to anxiety (Celal et al., 2020; Kilburn et al., 2019; Solish et al., 2020; van Steensel et al., 2017; White et al., 2018). More recently, mindfulness-based therapy approaches have gained traction to effectively treat psychiatric disorders such as anxiety and depression among individuals with ASD (Conner & White, 2018; Da Paz & Wallander, 2017; Hartley et al., 2019; Ridderinkhof et al., 2020; Stockall & Blackwell, 2022; White et al., 2018). Regardless of the interventions used for individuals with ASD, treatment response dictates the direction of therapy because of the uniqueness of each individual's needs (Adams et al., 2020; Celal et al., 2020; Solish et al., 2020). The individual with ASD influences the effectiveness of treatment through their cognitive functioning, core symptoms, and language abilities.

There are multiple factors that can challenge counsellors when working with individuals with ASD, including misunderstandings between family and professionals such as commitment levels towards treatment. Counsellors must be critical when interpreting information gained through reports from informants because they might not be fully truthful or accurate.

Wolstencroft and colleagues (2018) have laid out a number of reasons that parents and other informants may provide inaccurate reports: internalized stigma, stress, parents' own mental health challenges, and difficulty acknowledging their 'children's challenges compared to neurotypical children. Similar to other assessments, teacher reports assessing children's skills can only be used towards specific variables and therefore provide only narrow observations. Teachers with special education, those with higher levels of education and experience working with the ASD population on a regular basis, may better understand and know the child's skills than mainstream teachers (Levinson et al., 2021). Regardless of obtaining evidence from teachers or supporting staff, studies are impacted by expectancy bias (Wolstencroft et al., 2018). Informants masking or exaggerating details about the individual with ASD to professionals can limit the effectiveness of treatment.

Currently, families report inadequate support by agencies and their staff even when getting their services. Specifically, when dealing with comorbid diagnoses, parents perceive agencies and staff as limited in experience dealing with those with more mental health challenges (Wilson et al., 2021). Awareness of limited funding for these adults is slowly coming to light. (Ardic, 2020; Catalano et al., 2018; Zablotzky et al., 2013). With more awareness of the diagnosis, more research on the experiences of adults with ASD is conducted and published, which in turn improves awareness.

Age is a significant predictor of support from policymakers, and inadequate training from agencies reduces consistency when administering resources (Doehring & Volkmar, 2016; Dudley et al., 2019). As individuals with ASD transition into different stages of life, the resources and competency of care becomes scarce. Families begin to find difficulties in proper care because of insufficient research past childhood. This inadequacy in training and support also extends to dealing with accessibility and transparency for families. Parents perceive that support is limited geographically and in information (Wilson et al., 2021). This perception can result in families receiving data through the internet or available information only to receive uncertainty and misinformation.

Culture and religion can be a benefit or a hindrance when getting the support needed for individuals with ASD and their families. Parents are the most important factor in cultural or religious socialization as they transmit their beliefs and values to their children. Parents of children with ASD find cultural or religious socialization difficult because of communication difficulties or difficulties controlling their child's behaviour (Sullivan & Aramini, 2019). This leaves much of the child's socialization within the family because of the feeling of stigmatization or absence of inclusion from religious members. The negative experience from other members can lead to a crisis of faith for parents. Interestingly, religion is considered to have a positive impact on the development of youth because of the increased social support and a positive impact on the sense of self (Sullivan & Aramini, 2019). Individuals with ASD find a sense of belonging and friendship with their spirituality and religion. A significant factor is having supportive and educated leaders that provide a positive experience.

Cultural factors are intertwined with the family's behaviours and values, which determine the development of an individual. Minority populations have the most difficulty when it comes



to being diagnosed. There is a disproportionate underrepresentation of diagnoses, early interventions, and early childhood special education in children with a minority status (Casillas et al., 2017). Counsellors should be aware of racial differences when detecting and diagnosing ASD in children, fixing the system to prevent children from going undiagnosed. White children, on average, get diagnosed and start treatment earlier than their other ethnic counterparts, with African American and Latino children getting diagnosed later in life (Casillas et al., 2017). The cultural and ethnic differences may affect how parents perceive signs and symptoms. White parents are more likely to notice language delays sooner and will act upon the discrepancy (Casillas et al., 2017), making it difficult for minority parents as they are the first line of defence against increasing risk of prevalence.

It can be difficult to provide effective therapy for collectivist families using Western individualized treatment. Since much of therapy is based on an individualistic view, treatments may clash with the family's beliefs and values. It can also be difficult to effectively translate treatments and programs that would provide similar goals in different cultures. There is a need for more research on the experiences of individuals with ASD in non-Western societies and how their society advocates for inclusion and equality. Studies pertaining to advances towards interventions have been widely conducted in Western societies such as the United Kingdom, Canada, and the United States compared to their non-Western counterparts (Ballantyne et al., 2021; Dada et al., 2020; Safi et al., 2022). Contributions from non-Western societies are largely unresearched. The influence of ethnicity, religion, and cultural history can play a significant role in the experiences and development of individuals with ASD and their families. The knowledge and experience working with or alongside individuals with ASD differ between countries and

cultures as well. The deficit of resources can be because of the limited knowledge about the diagnosis to make it more inclusive.

### **Conceptual**

It has become crucial to detect ASD earlier in life to allow individuals and their families to get the proper support and interventions that will impact later development. Understanding the behavioural characteristics of an infant with ASD can help facilitate the progress of accessing interventions and programs to help with the conceptual aspects of child development (Akhter et al., 2018). Unfortunately, the average age to diagnose ASD remains between the ages of 3 to 5 (Stenberg et al., 2021). The missed years of early childhood are pivotal to learning language, communication, and social skills from parents that could have been more effective with early detection. Earlier and more intensive intervention is associated with better communication, academics, and behavioural outcomes (Feige et al., 2021). Westerveld et al. (2021) investigated a coach modelling approach through an 8-week program to promote oral language skills in toddlers with ASD that was designed to change the parents' and toddlers' behaviours. The coach modelling approach included a speech pathologist that provided individualized support for parents to encourage shared reading with their toddlers. The goal of the study was to determine if implementing a reading intervention within a naturalistic setting would encourage early language skills in children with ASD. The researchers found that the toddlers increased verbal participation by creating a more comprehensive vocabulary understanding and verbal participation on a daily basis. While a practical approach to learning verbal behaviour, this approach is solely based on parent-implementation abilities that is feasible if set within the family routine.

Communication devices are increasingly influential in providing treatment for individuals with ASD. Not only allowing individuals to learn social and communication skills, technology is also incorporated within therapy. In addition, using augmented reality (AR) or games can be cost-effective for both treatment and caregiver (Almurashi et al., 2022). Using communication devices has allowed supporters to communicate effectively with individuals who lack verbal capabilities. Individuals with ASD and their families may become more motivated to use these devices because of the simplicity of training to use the programs.

Assistance within the classroom for individuals with ASD can be complex at a young age because of parent and teacher disagreements regarding behaviours. Children with ASD who are cognitively able to join the mainstream system can be missed for extra support if they struggle with internal and external behavioural problems (Levinson et al., 2021). Class size and teacher experience are significant factors that can help individuals with ASD and their families communicate more effectively about issues seen in the classroom and the home environment.

## **Social**

When engaged in structured activities about a preferred interest, children and adolescents can appropriately socialize with their neurotypical counterparts (Koegel et al., 2013). In addition, the higher levels of motivation towards their preferred interests can account for increasing engagement with others whom they may have found difficult with undesirable topics.

Social competence is associated with being able to communicate with others. Yavuz et al. (2019) suggest that as long as individuals with ASD can communicate verbally or nonverbally, they can express their needs and desires to others. Humans have a desire to communicate regardless of communication abilities, and social interventions can improve communication and social skills among individuals with ASD. It is vital that service providers and support members

work on verbal and nonverbal communication skills with individuals with ASD because of the effects on language and social functioning abilities.

As the individual with ASD transitions into adulthood, it can be difficult to maintain social engagement and social competence with others. Individuals with ASD report becoming lonely and expressing the desire to have more meaningful relationships (Koegel et al., 2013). Individuals with ASD that are able to continue with service programs throughout their lifespan may receive a safe environment to engage in socialization with peers. The environment can help reduce the risk of developing mental health problems such as anxiety or depression. A meta-ethnographic study by Nguyen et al. (2020) shares the impact of peer mentorship on adults transitioning into postsecondary education. The programmes offer the opportunity to build skills and interact with peers through the help of mentor coaching, counselling, and encouragement.

Many programs focus on increasing social skills through psychosocial treatments, group therapy, and parent-assisted teaching (Koegel et al., 2013; Wolstencroft et al., 2018). These programs include communication skills and engaging with others, while also providing social support. Although this style of program can be effective for some, it may not work for everyone. It is crucial for parents and medical teams to understand the needs and wants of the individual to provide the proper program; a proper program will fit with previous knowledge and the responsiveness of the individual in order to provide an impactful treatment. A meta-analysis done by Hutchins et al. (2020) identified that two-thirds of individuals with ASD or emotional behaviour disorders show social skill improvements after interventions. Therefore, social interventions effectively improve social cognition, interaction, and communication deficits in individuals with ASD. Yet there is also the inquiry of generalization and maintenance of the skills, which many current studies suggest for future studies (Hutchins et al., 2020; Koegel et al.,

2013; Stenberg et al., 2021; van Steensel et al., 2017; Yavuz et al., 2019). There is a need for more research to capture the multi-dimensional impact of treatment by not only using reports from the individual, parents, and teachers.

Social skills interventions aim to enhance independence, social skills, and assertiveness (Spain et al., 2015). Using techniques such as role-play and rehearsal, individuals with ASD can practice necessary daily skills that are socially acceptable. The skills learnt can reduce a perceived sense of loneliness while enhancing social functioning and knowledge. Intense behavioural interventions can start at an early age for individuals with ASD to establish the repetitive motions and make it easier to engage the child.

### **Practical**

There are specific interventions that counsellors can use to bolster practical skills to be successful and independent. Using strategies such as role-play/rehearsal, modelling, and explicit instructions teaches skills related to independence for community or home use (Marcotte et al., 2020; Thomeer et al., 2019). These techniques need to be adjusted and modified during implementation for more effective outcomes. The practical aspect for individuals with ASD boils down to the informal support built by the parents. Individuals with ASD can benefit from formal and informal support systems that can mediate financial, family, and mental health stressors.

The family unit continues to be the primary support pillar for individuals with ASD throughout their lifespan. The family can provide a sense of acceptance and religious practices to help their child cope with disabilities (Adib et al., 2019). The goal for these individuals is to attain some form of self-sufficiency, regardless of living style. A multigenerational household and a supportive neighbourhood can help provide resilience and growth within the home and the

community (Dada et al., 2020; Marquis et al., 2019). These informal support systems substantially influence family members' mental and physical health based on connectedness.

Paid support such as professionals, respite care, and specialized programs for individuals with ASD allow the parents to pass off responsibility and other obligations from themselves. In addition, agencies and organizations can apply for federal funding to help support individuals with ASD in overcoming barriers to joining the workforce while also supporting employers hiring these individuals. Government support provides a range of services and programs, including job search support, pre-employability services, wage subsidies, and awareness of disability (Government of Canada, 2022). However, these support systems can change once the individual transitions into adulthood because of funding eligibility and accessibility. In addition, the support services can decline or no longer be available because of long waitlists (Marsack-Topolewski et al., 2021; Wilson et al., 2021). The reduction in services after transitioning into adulthood impacts the mental health of individuals with ASD and their families. For families that may not be able to afford or receive specialized programs or specific treatments, the needs, and challenges of individuals with ASD fall onto the primary caregivers, mainly the parents.

### **Parent Involvement**

Parents are positioned to be the leading advocates for their children with ASD to receive long-term care, and it is therefore essential to explore parents' experiences while assisting their children. While seeking resources and providing for their children, parents can experience significant burdens and fatigue. Parents often continue to advocate for their children even into adulthood because of the limited resources available (Wilson et al., 2021; Wong et al., 2020). It is essential to acknowledge the needs of both the adult child with ASD and the parent during these times. The goal of training parents is to provide education to help parents cope with the

struggles of raising a child with ASD. Programs provide skills and allow parents to practice strategies to manage behavioural problems at home and in the community (Gerow et al., 2018; Iadarola et al., 2018).

Parent training is a fundamental step for effective treatments. Parents have become important characters in delivering interventions to their children that are suggested by professionals. When there is flexibility in learning interventions and maintenance for both the counsellor and parents, the interventions can be more effective (Gerow et al., 2018; Scahill & Butter, 2019). Parent programs have become primarily focused on intervening in disruptive behaviour in children with ASD by addressing the experience of parents implementing programs or skills to reduce behaviours long-term. As parents continue to advocate for their child, some are less likely to perform specific interventions because of social obstacles regardless of the advice of professionals (Gerow et al., 2018). Factors such as feasibility and resources are significant aspects that limit parents in accessing these interventions that could effectively reduce challenges and be maintained over time. As individuals with ASD transition from adulthood to old age, research is needed to explore what is effectively needed to provide the care they need. During this time, individuals with ASD may no longer have their parents to care for them.

The improvement of parents' mental health directly impacts the child's quality of life as they are dependent on their parents to help regulate their emotions and thoughts. It can be simple to say that the family dynamic changes when parents caring for individuals with ASD are affected by burnout and compassion fatigue (Ardic, 2020). When parents exert more energy and do not regain their resources, they can find themselves often burnt out or fatigued from caring for another person. Those in the caregiving role can experience caregiver burnout or caregiver burden, which is the exhaustion from attending to the ongoing demands of a dependent

individual (Catalano et al., 2018). A consequence of this fatigue is that the parents' attitude may change from one of positive compassion to a more negative process.

Coping strategies are often proposed to help minimize parents' levels of distress. Emotion-focused coping methods that are forms of avoidance or escape behaviours can lead to higher stress levels (Zablotsky et al., 2013). The best way to help avoid this fatigue is to provide practical techniques to address stressors. Techniques geared to reducing stress for both the parent and the ASD individual result in reduced depression symptoms and better psychological wellbeing. Social groups are deemed an important defence mechanism to reduce stress and improve the well-being of parents. Many therapeutic techniques can be practiced and utilized at home to help reduce burnout.

### **Group Therapy**

Group therapy is highly important for parents caring for others. It provides support and social networking to share thoughts and feelings within a community. Small group interventions are appreciated and well accepted by parents with clinical burnout (Catalano et al., 2018). They have reported not feeling alone in their struggles of caring for an ASD individual. The support groups are a place for parents to normalize and validate their experiences. Parents also report an increase in confidence in coping with daily challenges and being more accepting of their child's behaviours (Anclair et al., 2018; Lindström et al., 2016). In comparison, group therapy for individuals with ASD may not work because of the social aspect, unless the group is designed to target social skill techniques (Paxton & Estay, 2007). Individualized counselling may be more beneficial for ASD individuals when addressing specific deficits.



## **Psychosocial Approaches**

### ***Cognitive-Behavioural Therapy***

Interventions such as cognitive behavioural therapy (CBT) train the individual to identify feelings with the problem and focus on solutions for the problem (Da Paz & Wallander, 2017). Cognitive restructuring and goal setting can help manage the situation and give control back to the individual. At the same time, approaches such as positive psychology aim to reappraise negative experiences and focus on positive attributes to achieve overall wellbeing (Carmassi et al., 2020). Parents learn to identify strengths through exercises involving optimism, forgiveness, and gratitude. These approaches aim to help parents shift their perspective to understand the thought process of their child with ASD before reacting negatively.

The major reviews on CBT for individuals with ASD suggest that it may be challenging to use but efficient (Celal et al., 2020; Solish et al., 2020; van Steensel et al., 2017; White et al., 2018). Investigation of CBT effectiveness in individual and group settings is still in progress. Researchers struggle with individualization in cognitive restructuring, where the individual can misread the social context and lead to cognitive distortions (Celal et al., 2020; Paxton & Estay, 2007). An adaptive version of CBT has been widely used for depression and anxiety and can be effective (Kilburn et al., 2019; Solish et al., 2020). Modifications such as extending the program, more visual aids, and structural worksheets allow different learning styles and accommodate individuals with ASD (Celal et al., 2020). Awareness of personal symptoms is also important in order to be effective; the individual needs to be capable of reporting signs and symptoms and start using the adaptive coping strategies learnt. Therefore, a sense of cognitive functioning is needed to address the symptoms of anxiety or depression. Family participation and length of treatment show significant impacts on the efficacy CBT has for individuals with ASD (Celal et

al., 2020; van Steensel et al., 2017). The repetition of modelling techniques from parents over a long period may be the determining factor in the effectiveness of the intervention, but it is still inconclusive.

### ***Community-Based Therapy***

Outside of hospitals or controlled environment studies, implementing therapy programs within the public can assist in the effectiveness of the programs. Having programs within the community increases feasibility and accessibility, which may result in better results compared to in-care services (Solish et al., 2020; Thomeer et al., 2019). Community-based programs can yield significant positive results when facilitated by mental health professionals. When community-based programs become successful and widely endorsed, they tend to generate long waitlists. More research on the impact community-based programs have outside of therapy, such as long waitlists and effects within the community, would help to better understand these challenges. For example, Solish et al. (2020) completed a study with over 100 youth with ASD to compare a hospital setting to a community-based setting to determine the effectiveness of CBT on anxiety. The researchers found that they could provide programs with similar effectiveness in both the hospital setting as well as within the community. The study's success came with the help of professionals facilitating programs in the community. Outside of the study format, these results may be less repeatable because of the demand that a community-based program places on the required mental health profession. Randomized clinical trials are needed to improve the effectiveness and feasibility of community-based therapy (Thomeer et al., 2019). A common limitation in continuing these programs is the lack of trained staff willing to deliver the treatment and parents' willingness to be involved.

## **Non-Psychosocial Approaches**

### ***Mindfulness-Based Therapy***

Biofeedback and mindfulness therapy can help an individual gain self-acceptance and problem-solving skills, positively affecting the individual's mental health and psychological wellbeing (Carmassi et al., 2020; Da Paz & Wallander, 2017). The process of self-regulation promotes positive outcomes such as forgiveness and compassion. The aim is to improve emotional awareness and regulate behavioural responses. Being present promotes nonjudgement and awareness of choice, which can help create space for individuals with ASD to learn and grow. The mindfulness practice hopes to relieve the compulsion for the parent to solve the problem and encourage the parent to objectively observe and acknowledge the difficulties without the need to change them. The use of relaxation techniques provides parents with training to contract and release muscle tension to distinguish between tension and relaxation in the body (Da Paz & Wallander, 2017). This technique also aims for the person to become aware of the body signs in the moment that signal to use techniques to reduce the pressure.

The use of mindfulness-based therapy (MBT) has been successful in reducing aggressive and noncompliant behaviour, managing psychological distress, improving social communication, and assisting in emotional regulation over time (Conner & White, 2018; Hartley et al., 2019; Ridderinkhof et al., 2020; Spain et al., 2015). Hartley et al.'s (2019) literature review of mindfulness-based interventions identified the benefits of long-term subjective well-being gains in youth and adults with ASD and their caregivers. Unfortunately, there is limited evidence on the effectiveness of this approach in enhancing the well-being of individuals with ASD and their families because of the limited amount of controlled trials to determine efficacy. MBT studies have concentrated on implementing strategies to reduce symptoms such as anxiety to assist in

daily living. The approach presents a promising strategy to reduce psychological distress and emotional clarity for all parties.

Unlike CBT, MBT is used with other deficits other than anxiety and depression. Because self-regulation is a significant component of mindfulness, Ridderinkhof et al. (2020) focused on using MBT to improve attention functioning. Although it may not have improved the speed of resolving the conflict, there were noticeable improvements in the individual's ability to switch attention and disengage from the distressful thought or stimuli. Unlike CBT, which analyzes an individual's feelings, MBT focuses on the attention and acceptance of those feelings (Stockall & Blackwell, 2022). Impaired cognitive function and self-regulation are core symptoms of ASD; the application of MBT can allow a counsellor to focus on strengthening a significant deficit which can impact other factors such as behavioural functioning in individuals with ASD.

### **Fundamental Next Steps for Research**

There is still much work that needs to be done in order to better understand individuals with ASD, especially with regard to the counselling roles and support systems that are most effective. The fundamental steps of basic needs, services, and support must be met prior to continuing with therapeutic treatment, regardless of age. The limitations within the research prevent professionals from sufficiently transitioning treatment ideas into the real world. By acknowledging the limitations of our current knowledge, researchers and professionals can hopefully work towards better supporting individuals with ASD.

### **Limitations of Research**

Although there are still many limitations within the research, there has been immense progress in researching practical approaches to improve the quality of life for individuals with ASD and their families (e.g., parent involvement, modeling, therapy; Marcotte et al., 2020;

Marsack-Topolewski et al., 2021; Thomeer et al., 2019; Wilson et al., 2021). Some of the ongoing difficulties that researchers face are publication bias, small sample size, and limited reliability and validity (Deb et al., 2020; Maltman et al., 2021). For example, studies that do not achieve statistically significant results may not be published, limiting the already narrow pool of studies about individuals with ASD and their experiences. In addition, sample sizes with this specific population are often limited due to personal reasons such as time commitment or inability to meet the study's inclusion criteria. Another reason these studies cannot generalize their findings is because of the deprivation of age and gender distribution among their sample populations.

A significant limitation is a shortage of self-reporting from individuals with ASD who have lower cognitive abilities or are nonverbal. Reports and results have become based on parents' reports, which are somewhat reliable, but are biased towards the effectiveness of treatment towards the parent's mental health and their perceived burden and stress (Gérain & Zech, 2018; Marsack-Topolewski et al., 2021; Salomone et al., 2018; Samson, Wells, et al., 2015; Schieve et al., 2007). This bias may contribute to the extraordinary amount of research on parent training and interventions. Reviewing parents' elements may impact the effectiveness of interventions for their children. Parental bias may be especially significant when dealing with nonverbal individuals with ASD, as it can be difficult to discern nonverbal requests. The goal for future research is to achieve intervention both directly and indirectly with the help of parents (Yu et al., 2019). However, practitioners and researchers must be wary of the impact on parents of caring for individuals with ASD because of the extensive levels of stress that are inherent in the caregiving role.

## **Direction for Future Research**

In order to best serve individuals with ASD, researchers must build a better bridge into practice. A compelling direction for counsellors is to apply successful clinical research into the naturalistic settings of therapy (Luiselli, 2014; Paynter et al., 2017; Scahill & Butter, 2019). Interventions and treatment focusing on the practical domain are needed to benefit individuals with ASD and their experiences in their daily lives. Barriers include limited training and interest from professionals wanting to work with the population. Implementing randomized controlled trials is essential to test the efficacy of interventions and treatment (Conner & White, 2018; Hartley et al., 2019; van Steensel et al., 2017). However, individuals seeking treatment in community settings may present different clinical characteristics than those in academic centres (Scahill & Butter, 2019). This discrepancy can create difficulties for researchers when they attempt to transfer evidence-based interventions and compare the results with past literature. Researchers cannot share treatment effects from different environments and generalize the outcome. The need to replicate studies is vital for moving forward in the literature but can be difficult because of the individualized responses from individuals with ASD.

Training shortages can impact care for an individual with ASD, as the assistance the family does receive is less helpful than it could be and instead of supporting the family it has a negative effect. Poorly trained support personnel can affect families negatively because they may provide inaccurate information or ineffective treatments and services, determining developmental trajectory and outcome (Doehring & Volkmar, 2016). Therefore, there is a need for strong theoretically trained practitioners as well as competent practice professionals. The future direction of research should investigate efficient interventions that professionals can use within the community to improve the quality of life for individuals with ASD and their families.

Training parents and caregivers has become more cost-effective than training professionals to administer interventions to individuals with ASD (Scahill & Butter, 2019). In addition, it has allowed coached parents to maintain and generalize skills long-term. Therefore, it is vital to continue future research in community settings to uncover natural problems and realistic solutions.

Another research limitation is the absence of comparison between cultural differences in the experiences of individuals with ASD and the effects on the interventions. Many of the participants in the studies are White, middle to upper-middle class, and well-educated. Ethnically diverse or under-resourced parents and families are generally not represented and may not be experiencing the same struggles. It is also important to acknowledge that the research is widely Westernized, with very few studies from non-Western countries. Compared to study participants in Canada or the United States, individuals with ASD and their families from non-Western countries or backgrounds may experience different phenomena and quality of life when the same techniques are applied. Translating from the English language without consideration of cultural differences can significantly impact the effects of treatment (Almurashi et al., 2022). It is essential to acknowledge a more diverse population when researching the population's experiences to understand better how to move forward in the research.

Another direction for future research is the unity between the experiences of individuals with ASD and their parents. There is already a lot of discussion about the burden, compassion fatigue, and isolation parents experience when caring for their children with ASD. Correlations between parent characteristics, coping strategies, and parents' self-efficacy can help determine the effects of intervention for the parents and their child (Yu et al., 2019). By exploring each factor and the impacts they have on the experiences of individuals with ASD, the knowledge can

help arrange improvements on quality of life. For example, parents' mental health significantly correlates with their child's mental health risks and their overall experiences (Adib et al., 2019; Catalano et al., 2018; Da Paz & Wallander, 2017; G rain & Zech, 2018; Lindstr m et al., 2016; Marquis et al., 2020; O'Nions et al., 2018; Salomone et al., 2018; Schieve et al., 2007; Ting & Weiss, 2017; Yorke et al., 2018; Zablotzky et al., 2013). Such research into parental health and its correlation with treatment efficacy indicates the importance of assisting parents in caring for their children with ASD through their experience.

### **Recommendations for Practice**

An important reminder for practitioners is to work with the clients and their families to maintain the therapeutic alliance. Therapists should provide direct services to individuals with ASD to improve their functional independence (Marsack-Topolewski et al., 2021). The family's needs can be crucial when discussing the child's needs because the entire family is involved in successful outcomes. It is important to increase therapeutic alliance with individuals with ASD and their families rather than focusing on one or the other. The direct services should include all geographic locations. Currently, rural areas do not get the same care as urban areas, resulting in families having to relocate to get the services they need. In addition, direct services will decrease constraints for parents that parents would usually use to help their child with ASD, allowing parents to have the energy to commit to caring for their child without worrying about needing to teach them skills (Helkkula et al., 2020; Herrema et al., 2017; Wilson et al., 2021).

There is a need to stop mental health professionals from using the "watch and wait approach," especially when parents are asking for their young children to be assessed for ASD. The approach has been used widely by general professionals that have limited experience with ASD and are in small towns in the hopes that the child will grow out of the problem (Andersson



et al., 2017; Churruca et al., 2019). Unfortunately, this approach impacts the time of diagnosis and prevents the initiation of interventions that could help long-term. It is strongly recommended that these professionals refer families to specialists to prevent late diagnosis and treatment. By referring a family sooner rather than later, the family's overall stress can be reduced.

A recommendation for practice is to provide long-term community-based programs. These programs can benefit and empower individuals with ASD and their families through skill training and psychoeducation. In addition, community-based programs tend to be family-centered, user-friendly, cost-effective, and not dependent on professionals long-term (Marsack-Topolewski et al., 2021). The goal should be to promote independence for the individual and their family while also advocating for their needs. Behavioural interventions should not be the only treatment when working with individuals with ASD and their families. It has become a priority for families to reduce maladaptive behaviours to continue daily activities without struggling with tantrums or the fear of onlookers' judgment.

Rather than using treatment manuals as rigid structures that have to be followed, it is more effective to use them as guidelines and suggestions to foster knowledge (Scahill & Butter, 2019). When clinicians use manuals without flexibility, the therapeutic alliance can get lost within the material (Kilburn et al., 2019; Paxton & Estay, 2007). The goal of these programs is to promote self-efficacy in individuals with ASD and their families. The clinician's job is to empower these individuals through evidence-based practice to draw out experiences and deliver the training to help them through difficult times.

### **Reflective Self-Statement**

I found the journey of writing my capstone challenging and motivating. There were times when I had gone down rabbit holes, confident in my direction to then wake up the next day and

find myself in an entirely new rabbit hole. It was challenging to begin writing as I had no focus or end goal. Meetings with the supervisor were fantastic opportunities to get new ideas and receive reassurances about the progress of my work. I have enjoyed collaborating on concepts to improve the structure and the process of the project. I initially wanted to discuss the experiences of individuals with ASD whose caretaker had compassion fatigue and/or caregiver burden. This initial concept became a strong foundation for where I ended up because, to understand the parent's experience, it is essential to understand the individual's experience. I know that if I were to pursue future research, I would be able to use the knowledge gained from this capstone experience to further explore the impacts of caring for individuals with ASD on their caregivers. In addition, it will allow me to provide recommendations on the direction counsellors can pursue when caring for parents. The capstone project has only continued to fill my passion for working with the cognitive disabilities' population.

I am lucky to have found significant personal biases at the beginning of my journey. These biases impacted the perimeters set for research and the direction I was going early on. To have become aware of these biases led to becoming hyperaware and casting the perimeters of my research question too broadly; at times that would impact the primary and secondary sources collected. The meetings with my supervisor helped reduce my anxiety and acknowledged that I cannot find every article. The knowledge I gained from completing my capstone project will project me forward in my career. I hope to work with this population more in a therapeutic setting to create better outcomes. I hope to continue to gather more information with the hopes of remaining objective when working with families. I have already started using the knowledge gained from the capstone project within my work by applying individualistic goals and discussing the developments with the family.

In completing my capstone project, I have become more aware of the scarcity of research to support the validity of interventions used in practice. Also, the shortage of research about daily living for individuals with ASD once transitioning out of secondary school. The capstone project has solidified my dislike of research but sparked my interest in wanting to learn more about how to use the published data and apply it to practice. It has shown me that I have the ability to make a meaningful impact by practicing counselling rather than completing the research. My future goal is to close the gap between research and practice to improve the outcomes for individuals with cognitive disabilities.

### **Conclusion**

The daily life experiences of individuals with ASD are individualized and unique, making it difficult to generalize their experiences in treatment and interventions. The capstone used the ABAS-3 assessment system as an organizational tool to examine the experiences of individuals with ASD in three domains: conceptual, social, and practical.

The literature on the experiences of individuals with ASD concentrates on young individuals from infancy to late adolescence. Understandably, early intervention is the key to beneficial outcomes in later years. Unfortunately, research on ASD in later life is more limited, which negatively impacts the support offered to individuals with ASD once they are out of the school system. Within the existing research, many studies focus on higher cognitive functioning individuals with ASD to provide self-reports on treatment effects (e.g., Wolstencroft et al., 2018; Zeedyk et al., 2016). While important, a significant population is missing within the research as there is not yet a way to gather data from lower cognitive functioning individuals with ASD.

Practitioners have used various types of therapeutic treatments with individuals with ASD, focusing on anxiety and depression reduction. Treatments have included psychosocial

approaches such as CBT, and non-psychosocial approaches such as MBT. In addition, current interventions focus on parent involvement and the indirect effects that influence the well-being of their child with ASD (Hartley et al., 2019). The importance of involving the parents indicates the effect indirect interventions have towards the overall quality of life of individuals with ASD.

To effectively assist individuals with ASD within the counselling realm, practitioners need to maintain a therapeutic alliance with their families to empower the family as a whole. As a profession, counsellors need to continue to ensure that the individual with ASD is the priority and has the flexibility to adapt plans to suit their needs. Practitioners can be more effective by providing more community-based programs that are feasible and practical. There is more power within the community as members can advocate and become self-sufficient throughout the lifespan of the individuals with ASD that the community supports.

The changes that need to be made are linked together. Only changing one link will not be sufficient to help those that need it effectively. The research question asks about the experiences of individuals with ASD and how counsellors can assist them. More research needs to be done before answering the question. There continue to be gaps within the literature on the experiences these individuals with ASD face daily and the effectiveness of interventions.

## References

- Adams, R. E., Lounds, T. J., & Bishop, S. L. (2020). Brief report: ASD-related behavior problems and negative peer experiences among adolescents with ASD in general education settings. *Journal of Autism and Developmental Disorders*, 50(12), 4548–4552. <http://doi.org/10.1007/s10803-020-04508-1>
- Adib, N. A. N., Ibrahim, M. I., Rahman, A. A., Bakar, R. S., Yahaya, N. A., Hussin, S., & Mansor, W. N. A. W. (2019). Perceived stress among caregivers of children with autism spectrum disorder: A state-wide study. *International Journal of Environmental Research and Public Health*, 16(8), Article 1468. <http://doi.org/10.3390/ijerph16081468>
- Afif, I. Y., Manik, A. R., Munthe, K., Maula, M. I., Ammarullah, M. I., Jamari, J., & Winarni, T. I. (2022). Physiological effect of deep pressure in reducing anxiety of children with ASD during traveling: A public transportation setting. *Bioengineering*, 9(4), 157. <https://doi.org/10.3390/bioengineering9040157>
- Akhter, S., Hussain, A. H. M. E., Shefa, J., Kundu, G. K., Rahman, F., & Biswas, A. (2018). Prevalence of autism spectrum disorder (ASD) among the children aged 18-36 months in a rural community of Bangladesh: A cross sectional study. *F1000Research*, 7, 424. <https://doi.org/10.12688/f1000research.13563.1>
- Almurashi, H., Bouaziz, R., Alharthi, W., Al-Sarem, M., Hadwan, M., & Kammoun, S. (2022). Augmented reality, serious games and picture exchange communication system for people with ASD: Systematic literature review and future directions. *Sensors*, 22(3), Article 1250. <http://doi.org/10.3390/s22031250>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://dio.org/10.1176/appi.books.9780890425596>

- Anclair, M., Lappalainen, R., Muotka, J., & Hiltunen, A. J. (2018). Cognitive behavioural therapy and mindfulness for stress and burnout: A waiting list controlled pilot study comparing treatments for parents of children with chronic conditions. *Scandinavian Journal of Caring Sciences*, 32(1), 389–396. <https://doi.org/10.1111/scs.12473>
- Andersson, G. W., Miniscalco, C., & Gillberg, N. (2017). A 6-year follow-up of children assessed for suspected autism spectrum disorder: Parents' experiences of society's support. *Neuropsychiatric Disease and Treatment*, 13, 1783–1796. <http://doi.org/10.2147/NDT.S134165>
- Ardic, A. (2020). Relationship between parental burnout level and perceived social support levels of parents of children with autism spectrum disorder. *International Journal of Educational Methodology*, 6(3), 533–543. <https://doi.org/10.12973/ijem.6.3.533>
- Baghdadli, A., Miot, S., Rattaz, C., Akbaraly, T., Geoffray, M.-M., Michelon, C., Loubersac, J., Traver, S., Mortamais, M., Sonié, S., Pottelette, J., Robel, L., Speranza, M., Vesperini, S., Maffre, T., Falissard, B., & Picot, M.-C. (2019). Investigating the natural history and prognostic factors of ASD in children: The multicentric longitudinal study of children with ASD - the ELENA study protocol. *BMJ Open*, 9(6). <http://doi.org/10.1136/bmjopen-2018-026286>
- Bal, V. H., Farmer, C., & Thurm, A. (2017). Describing function in ASD: Using the DSM-5 and other methods to improve precision. *Journal of Autism and Developmental Disorders*, 47(9), 2938–2941. <https://doi.org/10.1007/s10803-017-3204-3>
- Ballantyne, C., Gillespie-Smith, K., & Wilson, C. (2021). A comparison of knowledge and experience of autism spectrum disorder among teachers in the United Kingdom and

- China. *International Journal of Disability, Development & Education*, 68(2), 160–171.  
<https://doi.org/10.1080/1034912X.2019.1674254>
- Billeci, L., Calderoni, S., Conti, E., Gesi, C., Carmassi, C., Dell’Osso, L., Cioni, G., Muratori, F., & Guzzetta, A. (2016). The broad autism (endo)phenotype: Neurostructural and neurofunctional correlates in parents of individuals with autism spectrum disorders. *Frontiers in Neuroscience*, 10, Article 346. <https://doi.org/10.3389/fnins.2016.00346>
- Bishop, D. V. M., Maybery, M., Wong, D., Maley, A., & Hallmayer, J. (2006). Characteristics of the broader phenotype in autism: A study of siblings using the children’s communication checklist-2. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, 141B(2), 117–122. <https://doi.org/10.1002/ajmg.b.30267>
- Bond, C., Hebron, J., & Oldfield, J. (2017). Professional learning among specialist staff in resourced mainstream schools for pupils with ASD and SLI. *Educational Psychology in Practice*, 33(4), 341–355. <https://doi.org/10.1080/02667363.2017.1324406>
- Carmassi, C., Foghi, C., Dell’Oste, V., Bertelloni, C. A., Fiorillo, A., & Dell’Osso, L. (2020). Risk and protective factors for PTSD in caregivers of adult patients with severe medical illnesses: A systematic review. *International Journal of Environmental Research and Public Health*, 17(16), 5888. <https://doi.org/10.3390/ijerph17165888>
- Carminati, G. G., Carminati, F., Lehotkay, R., Lorincz, E. N., Subirade-Jacopit, V., Rondini, E., & Bertelli, M. O. (2017). Residential placement and quality of life for adults with severe autism spectrum disorders and severe-to-profound intellectual disabilities. *Advances in Autism*, 3(4), 187–205. <http://doi.org/10.1108/AIA-01-2017-0001>

- Casillas, N., Vigil, D. C., & Wang, H.-T. (2017). Latino and non-Latino white parents' experiences raising their child with ASD: An exploratory study. *The Qualitative Report*, 22(8), 2173–2195. <https://doi.org/10.46743/2160-3715/2017.3261>
- Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental health interventions for parent carers of children with autistic spectrum disorder: Practice guidelines from a critical interpretive synthesis (CIS) systematic review. *International Journal of Environmental Research and Public Health*, 15(2), 341. <https://doi.org/10.3390/ijerph15020341>
- Celal, P., Burke, M., Bowman-Perrott, L., Ali, B., Gallup, J., Thompson, J., & Sallese, M. (2020). Effects of cognitive behavioral therapy for reducing anxiety in children with high functioning ASD: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 50(6), 1958–1972. <http://doi.org/10.1007/s10803-019-03949-7>
- Centres for Disease Control and Prevention. (2022, March 31). *What is autism spectrum disorder?* <https://www.cdc.gov/ncbddd/autism/facts.html>
- Charitaki, G., Soulis, S.-G., & Tyropoli, R. (2021). Academic self-regulation in autism spectrum disorder: A principal components analysis. *International Journal of Disability, Development and Education*, 68(1), 26–45. <https://doi.org/10.1080/1034912X.2019.1640353>
- Churrua, K., Ellis, L. A., Long, J. C., Pomare, C., Wiles, L. K., Arnold, G., Ting, H. P., Woolfenden, S., Sarkozy, V., de Wet, C., Hibbert, P., & Braithwaite, J. (2019). The quality of care for Australian children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 49(12), 4919–4928. <http://doi.org/10.1007/s10803-019-04195-7>



- Conner, C. M., & White, S. W. (2018). Brief report: Feasibility and preliminary efficacy of individual mindfulness therapy for adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(1), 290–300. <http://doi.org/10.1007/s10803-017-3312-0>
- Crane, L., Lui, L. M., Davies, J., & Pellicano, E. (2021). Autistic parents' views and experiences of talking about autism with their autistic children. *Autism*, 25(4), 1161–1167. <https://doi.org/10.1177/1362361320981317>
- Da Paz, N. S., & Wallander, J. L. (2017). Interventions that target improvements in mental health for parents of children with autism spectrum disorders: A narrative review. *Clinical Psychology Review*, 51, 1–14. <https://doi.org/10.1016/j.cpr.2016.10.006>
- Dada, S., Bastable, K., & Halder, S. (2020). The role of social support in participation perspectives of caregivers of children with intellectual disabilities in India and South Africa. *International Journal of Environmental Research and Public Health*, 17(18), Article 6644. <http://doi.org/10.3390/ijerph17186644>
- de Verdier, K., Fernell, E., & Ek, U. (2020). Blindness and autism: Parents' perspectives on diagnostic challenges, support needs and support provision. *Journal of Autism and Developmental Disorders*, 50(6), 1921–1930. <http://doi.org/10.1007/s10803-019-03944-y>
- Deb, S. (Shoumi), Retzer, A., Roy, M., Acharya, R., Limbu, B., & Roy, A. (2020). The effectiveness of parent training for children with autism spectrum disorder: A systematic review and meta-analyses. *BMC Psychiatry*, 20, 1–24. <http://doi.org/10.1186/s12888-020-02973-7>
- Delobel-Ayoub, M., Ehlinger, V., Klapouszczak, D., Maffre, T., Raynaud, J.-P., Delpierre, C., & Arnaud, C. (2015). Socioeconomic disparities and prevalence of autism spectrum

- disorders and intellectual disability. *PLoS ONE*, 10(11), e0141964.  
<https://doi.org/10.1371/journal.pone.0141964>
- Diener, M. L., Wright, C. A., Taylor, C., D'Astous, V., & Lasrich, L. (2020). Dual perspectives in autism spectrum disorders and employment: Toward a better fit in the workplace. *Work*, 67(1), 223–237. <https://doi.org/10.3233/wor-203268>
- Doehring, P., & Volkmar, F. R. (2016). Knowledge gaps in ASD research: Short and long term implications for policy. *Journal of Autism and Developmental Disorders*, 46(3), 733–736.  
<http://doi.org/10.1007/s10803-015-2683-3>
- Dreaver, J., Thompson, C., Girdler, S., Adolfsson, M., Black, M. H., & Falkmer, M. (2020). Success factors enabling employment for adults on the autism spectrum from employers' perspective. *Journal of Autism and Developmental Disorders*, 50(5), 1657–1667.  
<http://doi.org/10.1007/s10803-019-03923-3>
- Duarte, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, 9(4), 416–427.  
<https://doi.org/10.1177/1362361305056081>
- Dudley, K. M., Klinger, M. R., Meyer, A., Powell, P., & Klinger, L. G. (2019). Understanding service usage and needs for adults with ASD: The importance of living situation. *Journal of Autism and Developmental Disorders*, 49(2), 556–568. <http://doi.org/10.1007/s10803-018-3729-0>
- Feige, E., Mattingly, R., Pitts, T., & Smith, A. F. (2021). Autism spectrum disorder: Investigating predictive adaptive behavior skill deficits in young children. *Autism Research and Treatment*, 2021, Article 8870461. <https://doi.org/10.1155/2021/8870461>

- Finke, E. H., Hickerson, B. D., & Kremkow, J. M. D. (2018). “To be quite honest, if it wasn’t for videogames I wouldn’t have a social life at all”: Motivations of young adults with autism spectrum disorder for playing videogames as leisure. *American Journal of Speech - Language Pathology (Online)*, 27(2), 672–689. [http://doi.org/10.1044/2017\\_AJSLP-17-0073](http://doi.org/10.1044/2017_AJSLP-17-0073)
- Freund, D., Cerdan Chiscano, M., Hernandez-Maskivker, G., Guix, M., Iñesta, A., & Castelló, M. (2019). Enhancing the hospitality customer experience of families with children on the autism spectrum disorder. *International Journal of Tourism Research*, 21(5), 606–614. <https://doi.org/10.1002/jtr.2284>
- Gérain, P., & Zech, E. (2018). Does informal caregiving lead to parental burnout? Comparing parents having (or not) children with mental and physical issues. *Frontiers in Psychology*, 9, Article 884. <https://doi.org/10.3389/fpsyg.2018.00884>
- Gerow, S., Hagan-Burke, S., Rispoli, M., Gregori, E., Mason, R., & Ninci, J. (2018). A systematic review of parent-implemented functional communication training for children with ASD. *Behavior Modification*, 42(3), 335–363. <https://doi.org/10.1177/0145445517740872>
- Gesundheit, B., & Rosenzweig, J. P. (2017). Editorial: Autism spectrum disorders (ASD)-searching for the biological basis for behavioral symptoms and new therapeutic targets. *Frontiers in Neuroscience*, 10, Article 607. <https://doi.org/10.3389/fnins.2016.00607>
- Goldfarb, Y., Gal, E., & Golan, O. (2019). A conflict of interests: A motivational perspective on special interests and employment success of adults with ASD. *Journal of Autism and Developmental Disorders*, 49(9), 3915–3923. <http://doi.org/10.1007/s10803-019-04098-7>

- Government of Canada. (n.d). *Autism: Supports*. Retrieved April 11, 2022, from <https://www.canada.ca/en/public-health/services/diseases/autism-spectrum-disorder-asd/support-autism-spectrum-disorder-asd.html>
- Hasson, L., Keville, S., Gallagher, J., Onagbesan, D., & Ludlow, A. K. (2022). Inclusivity in education for autism spectrum disorders: Experiences of support from the perspective of parent/carers, school teaching staff and young people on the autism spectrum. *International Journal of Developmental Disabilities*, 1–12.  
<https://doi.org/10.1080/20473869.2022.2070418>
- Harrison, P. L., & Oakland, T. (2015). *Adaptive Behavior Assessment System Third Edition (ABAS-3)*. Western Psychological Services.
- Hartley, M., Dorstyn, D., & Due, C. (2019). Mindfulness for children and adults with autism spectrum disorder and their caregivers: A meta-analysis. *Journal of Autism and Developmental Disorders*, 49(10), 4306–4319. <http://doi.org/10.1007/s10803-019-04145-3>
- Helkkula, A., Buoye, A. J., Choi, H., Lee, M. K., Liu, S. Q., & Keiningham, T. L. (2020). Parents’ burdens of service for children with ASD – implications for service providers. *Journal of Service Management*, 31(5), 1015–1039. <http://doi.org/10.1108/JOSM-01-2020-0011>
- Herrema, R., Garland, D., Osborne, M., Freeston, M., Honey, E., & Rodgers, J. (2017). Mental wellbeing of family members of autistic adults. *Journal of Autism and Developmental Disorders*, 47(11), 3589–3599. <https://doi.org/10.1007/s10803-017-3269-z>

- Holcombe, W., & Plunkett, M. (2016). The bridges and barriers model of support for high-functioning students with ASD in mainstream schools. *Australian Journal of Teacher Education*, 41(9), 27–47. <https://doi.org/10.14221/ajte.2016v41n9.2>
- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine*, 49(4), 559–572. <http://doi.org/10.1017/S0033291718002283>
- Holmes, L. G., Kirby, A. V., Strassberg, D. S., & Himle, M. B. (2018). Parent expectations and preparatory activities as adolescents with ASD transition to adulthood. *Journal of Autism and Developmental Disorders*, 48(9), 2925–2937. <http://doi.org/10.1007/s10803-018-3545-6>
- Hu, Q., & Chandrasekhar, T. (2021). Meeting the mental health needs of college students with ASD: A survey of university and college counseling center directors. *Journal of Autism and Developmental Disorders*, 51(1), 341–345. <http://doi.org/10.1007/s10803-020-04530-3>
- Hutchins, N. S., Burke, M. D., Bowman-Perrott, L., Tarlow, K. R., & Hatton, H. (2020). The effects of social skills interventions for students with EBD and ASD: A single-case meta-analysis. *Behavior Modification*, 44(5), 773–794. <https://doi.org/10.1177/0145445519846817>
- Iadarola, S., Levato, L., Harrison, B., Smith, T., Lecavalier, L., Johnson, C., Swiezy, N., Bearss, K., & Scahill, L. (2018). Teaching parents behavioral strategies for autism spectrum disorder (ASD): Effects on stress, strain, and competence. *Journal of Autism and Developmental Disorders*, 48(4), 1031–1040. <http://doi.org/10.1007/s10803-017-3339-2>

- Ivanović, I. (2021). Psychiatric comorbidities in children with ASD: Autism centre experience. *Frontiers in Psychiatry, 12*, Article 673169. <https://doi.org/10.3389/fpsy.2021.673169>
- Jenkinson, R., Milne, E., & Thompson, A. (2020). The relationship between intolerance of uncertainty and anxiety in autism: A systematic literature review and meta-analysis. *Autism, 24*(8), 1933–1944. <https://doi.org/10.1177/1362361320932437>
- Jones, J., Rodger, S., Walpole, A., & Bobir, N. (2019). Holding the cards: Empowering families through an ASD family goal setting tool. *Topics in Early Childhood Special Education, 39*(2), 117–130. <https://doi.org/10.1177/0271121418766240>
- Jordan, A. K., Thomeer, M. L., Lopata, C., Donnelly, J. P., Rodgers, J. D., & McDonald, C. A. (2019). Informant discrepancies in the assessment of adaptive behavior of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 49*(5), 2024–2034. <https://doi.org/10.1007/s10803-018-03876-z>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*(3), 217–250.
- Keenan, B. M., Newman, L. K., Gray, K. M., & Rinehart, N. J. (2016). Parents of children with ASD experience more psychological distress, parenting stress, and attachment-related anxiety. *Journal of Autism and Developmental Disorders, 46*(9), 2979–2991. <http://doi.org/10.1007/s10803-016-2836-z>
- Kerns, C. M., Newschaffer, C. J., Berkowitz, S., & Lee, B. K. (2017). Brief report: Examining the association of autism and adverse childhood experiences in the national survey of children's health: The important role of income and co-occurring mental health conditions. *Journal of Autism and Developmental Disorders, 47*(7), 2275–2281. <http://doi.org/10.1007/s10803-017-3111-7>

- Kilburn, T. R., Juul Sørensen, M., Thastum, M., Rapee, R. M., Rask, C. U., Bech Arendt, K., & Thomsen, P. H. (2019). Group-based cognitive behavioural therapy for anxiety disorder in children with autism spectrum disorder: A feasibility study. *Nordic Journal of Psychiatry*, 73(4/5), 273–280. <https://doi.org/10.1080/08039488.2019.1622153>
- King, C., Merrick, H., & Le Couteur, A. (2020). How should we support young people with ASD and mental health problems as they navigate the transition to adult life including access to adult healthcare services. *Epidemiology and Psychiatric Sciences*, 29, e90. <https://doi.org/10.1017/S2045796019000830>
- Koegel, R., Kim, S., Koegel, L., & Schwartzman, B. (2013). Improving socialization for high school students with ASD by using their preferred interests. *Journal of Autism and Developmental Disorders*, 43(9), 2121–2134. <http://doi.org/10.1007/s10803-013-1765-3>
- Koudys, J., Perry, A., Ho, H. S. W., & Charles, M. (2021). Mental health status of youth diagnosed with ASD who received early intensive behavioral intervention as young children. *Child & Family Behavior Therapy*, 43(2), 103–113. <https://doi.org/10.1080/07317107.2021.1895415>
- Levinson, S., Neuspiel, J., Eisenhower, A., & Blacher, J. (2021). Parent–teacher disagreement on ratings of behavior problems in children with ASD: Associations with parental school involvement over time. *Journal of Autism & Developmental Disorders*, 51(6), 1966–1982. <https://doi.org/10.1007/s10803-020-04675-1>
- Lindström, C., Åman, J., Anderzén-Carlsson, A., & Lindahl Norberg, A. (2016). Group intervention for burnout in parents of chronically ill children—A small-scale study. *Scandinavian Journal of Caring Sciences*, 30(4), 678–686. <https://doi.org/10.1111/scs.12287>

- Luiselli, J. K. (Ed.). (2014). *Children and youth with autism spectrum disorder (ASD): Recent advances and innovations in assessment, education, and intervention*. Oxford University Press.
- Mabel, O.-B., Oppong, A. K., & Malm, E. K. (2020). The experiences of ageing parents of young adults with autism spectrum disorders (ASD). *Journal of Adult Development*, 27(1), 58–69. <http://doi.org/10.1007/s10804-018-09325-6>
- Magiati, I., Tay, X. W., & Howlin, P. (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>
- Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., Fuentes, J., & Frazier, T. W. (2022). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatric Research*, 91(5), 1028–1035. <https://doi.org/10.1038/s41390-021-01465-y>
- Maltman, N., DaWalt, L. S., Hong, J., & Mailick, M. (2021). Brief report: Socioeconomic factors associated with minimally verbal status in individuals with ASD. *Journal of Autism & Developmental Disorders*, 51(6), 2139–2145. <https://doi.org/10.1007/s10803-020-04646-6>
- Marcotte, J., Grandisson, M., Piquemal, C., Boucher, A., Rheault, M.-È., & Milot, É. (2020). Supporting independence at home of people with autism spectrum disorder: Literature review. *Canadian Journal of Occupational Therapy*, 87(2), 100–116. <https://doi.org/10.1177/0008417419890179>



- Marquis, M., McGrail, K., & Hayes, M. (2020). Mental health of parents of children with a developmental disability in British Columbia, Canada. *Journal of Epidemiology and Community Health*, 74(2), 173–178. <https://doi.org/10.1136/jech-2018-211698>
- Marquis, S., Hayes, M. V., & McGrail, K. (2019). Factors affecting the health of caregivers of children who have an intellectual/developmental disability. *Journal of Policy & Practice in Intellectual Disabilities*, 16(3), 201–216. <https://doi.org/10.1111/jppi.12283>
- Marsack, C. N., & Perry, T. E. (2018). Aging in place in every community: Social exclusion experiences of parents of adult children with autism spectrum disorder. *Research on Aging*, 40(6), 535–557. <https://doi.org/10.1177/0164027517717044>
- Marsack-Topolewski, C. N., Samuel, P. S., & Tarraf, W. (2021). Empirical evaluation of the association between daily living skills of adults with autism and parental caregiver burden. *PLOS ONE*, 16(1), e0244844. <https://doi.org/10.1371/journal.pone.0244844>
- Mingins, J. E., Tarver, J., Waite, J., Jones, C., & Surtees, A. D. (2021). Anxiety and intellectual functioning in autistic children: A systematic review and meta-analysis. *Autism*, 25(1), 18–32. <https://doi.org/10.1177/1362361320953253>
- Mohammadi, M., & Zarafshan, H. (2014). Family function, parenting style and broader autism phenotype as predicting factors of psychological adjustment in typically developing siblings of children with autism spectrum disorders. *Iranian Journal of Psychiatry*, 9(2), 55–63.
- Morie, K. P., Jackson, S., Zhai, Z. W., Potenza, M. N., & Dritschel, B. (2019). Mood disorders in high-functioning autism: The importance of alexithymia and emotional regulation. *Journal of Autism and Developmental Disorders*, 49(7), 2935–2945. <http://doi.org/10.1007/s10803-019-04020-1>

- Mulvihill, A., Carroll, A., Dux, P. E., & Matthews, N. (2020). Self-directed speech and self-regulation in childhood neurodevelopmental disorders: Current findings and future directions. *Development and Psychopathology*, 32(1), 205–217.  
<http://doi.org/10.1017/S0954579418001670>
- Nguyen, L., Jack, S., Ketelaar, M., Di Rezze, B., Soper, A. K., & Gorter, J. W. (2020). Understanding the essential components and experiences of youth with autism spectrum disorders in peer mentorship programmes during the transition to adulthood: A qualitative meta-ethnography. *Child: Care, Health & Development*, 46(6), 667–681.  
<https://doi.org/10.1111/cch.12804>
- O'Connor, C., Burke, J., & Rooney, B. (2020). Diagnostic disclosure and social marginalisation of adults with ASD: Is there a relationship and what mediates it? *Journal of Autism and Developmental Disorders*, 50(9), 3367–3379. <http://doi.org/10.1007/s10803-019-04239-y>
- O'Nions, E., Happé, F., Evers, K., Boonen, H., & Noens, I. (2018). How do parents manage irritability, challenging behaviour, non-compliance and anxiety in children with autism spectrum disorders? A meta-synthesis. *Journal of Autism and Developmental Disorders*, 48(4), 1272–1286. <http://doi.org/10.1007/s10803-017-3361-4>
- Oberman, L. M., & Kaufmann, W. E. (2020). Autism spectrum disorder versus autism spectrum disorders: Terminology, concepts, and clinical practice. *Frontiers in Psychiatry*, 11, Article 484. <https://doi.org/10.3389/fpsyt.2020.00484>
- Parchomiuk, M. (2021). Old age in adults with ASD: Psychosocial aspects—A systematic review. *Review Journal of Autism and Developmental Disorders*, 8(4), 498–512.  
<https://doi.org/10.1007/s40489-020-00229-4>

- Park, S. H., Song, Y. J. C., Demetriou, E. A., Pepper, K. L., Norton, A., Thomas, E. E., Hickie, I. B., Hermens, D. F., Glozier, N., & Guastella, A. J. (2019). Disability, functioning, and quality of life among treatment-seeking young autistic adults and its relation to depression, anxiety, and stress. *Autism*, 23(7), 1675–1686.  
<https://doi.org/10.1177/1362361318823925>
- Paxton, K., & Estay, I. (2007). *Counselling people on the autism spectrum: A practical manual*. Jessica Kingsley Publishers. [https://us.jkp.com/products/counselling-people-on-the-autism-spectrum?\\_pos=1&\\_sid=f2679c62b&\\_ss=r](https://us.jkp.com/products/counselling-people-on-the-autism-spectrum?_pos=1&_sid=f2679c62b&_ss=r)
- Paynter, J. M., Ferguson, S., Fordyce, K., Joosten, A., Paku, S., Stephens, M., Trembath, D., & Keen, D. (2017). Utilisation of evidence-based practices by ASD early intervention service providers. *Autism*, 21(2), 167–180. <https://doi.org/10.1177/1362361316633032>
- Pisula, E., & Ziegart-Sadowska, K. (2015). Broader autism phenotype in siblings of children with ASD—A review. *International Journal of Molecular Sciences*, 16(6), 13217–13258.  
<https://doi.org/10.3390/ijms160613217>
- Prokopiak, A., & Kirenko, J. (2020). ABAS-3 – An instrument for assessing adaptive skills in people with an intellectual disability. *Hrvatska Revija Za Rehabilitacijska Istrazivanja*, 56(2), 154–168. <http://doi.org/10.31299/hrri.56.2.9>
- Rad, F., Mihailescu, I., Buică, A., Stancu, M., Andrei, E., Ionescu, M., & Dobrescu, I. (2020). Is the progress of children with ASD in a behavioural therapy programme influenced by parents' hyper-systemizing? *Journal of Evidence-Based Psychotherapies*, 20(2), 67–78.  
<https://doi.org/10.24193/jebp.2020.2.12>

- Rattaz, C., Michelon, C., Roeyers, H., & Baghdadli, A. (2017). Quality of life in parents of young adults with ASD: EpiTED cohort. *Journal of Autism and Developmental Disorders*, 47(9), 2826–2837. <https://doi.org/10.1007/s10803-017-3197-y>
- Richardson, L., McCoy, A., & McNaughton, D. (2019). “He’s worth the extra work”: The employment experiences of adults with ASD who use augmentative and alternative communication (AAC) as reported by adults with ASD, family members, and employers. *Work*, 62(2), 205–219. <https://doi.org/10.3233/WOR-192856>
- Ridderinkhof, A., de Bruin, E. I., van den Driesschen, S., & Bögels, S. M. (2020). Attention in children with autism spectrum disorder and the effects of a mindfulness-based program. *Journal of Attention Disorders*, 24(5), 681–692. <https://doi.org/10.1177/1087054718797428>
- Rodas, N. V., Eisenhower, A., & Blacher, J. (2017). Structural and pragmatic language in children with ASD: Longitudinal impact on anxiety and externalizing behaviors. *Journal of Autism and Developmental Disorders*, 47(11), 3479–3488. <https://doi.org/10.1007/s10803-017-3265-3>
- Rodgers, J. D., Lodi-Smith, J., Donnelly, J. P., Lopata, C., McDonald, C. A., Thomeer, M. L., Lipinski, A. M., Nasca, B. C., & Booth, A. J. (2019). Brief report: Examination of sex-based differences in ASD symptom severity among high-functioning children with ASD using the SRS-2. *Journal of Autism and Developmental Disorders*, 49(2), 781–787. <http://doi.org/10.1007/s10803-018-3733-4>
- Roemer, E. J. (2021). Beyond the toddler years: A meta-analysis of communicative abilities in siblings of children with autism spectrum disorder. *Psychological Bulletin*, 147(5), 437–454. <http://doi.org/10.1037/bul0000326>

- Safi, M., Opoku, M. P., Alshamsi, M., & Abu-shariha, A. H. (2022). Comparative study of the perspectives on the impact of a culturally responsive picture exchange communication system for children with autism spectrum disorder in the United Arab Emirates. *Frontiers in Pediatrics*, 10, Article 841064. <https://doi.org/10.3389/fped.2022.841064>
- Salomone, E., Leadbitter, K., Aldred, C., Barrett, B., Byford, S., Charman, T., Howlin, P., Green, J., Couteur, A. L., McConachie, H., Parr, J. R., Pickles, A., Slonims, V., Cole-Fletcher, R., Gammer, I., Maxwell, J., Tobin, H., & Vamvakas, G. (2018). The association between child and family characteristics and the mental health and wellbeing of caregivers of children with autism in mid-childhood. *Journal of Autism and Developmental Disorders*, 48(4), 1189–1198. <http://doi.org/10.1007/s10803-017-3392-x>
- Samson, A. C., Hardan, A. Y., Lee, I. A., Phillips, J. M., & Gross, J. J. (2015). Maladaptive behavior in autism spectrum disorder: The role of emotion experience and emotion regulation. *Journal of Autism and Developmental Disorders*, 45(11), 3424–3432. <http://doi.org/10.1007/s10803-015-2388-7>
- Samson, A. C., Huber, O., & Gross, J. J. (2012). Emotion regulation in Asperger's syndrome and high-functioning autism. *Emotion*, 12(4), 659–665. <http://doi.org/10.1037/a0027975>
- Samson, A. C., Wells, W. M., Phillips, J. M., Hardan, A. Y., & Gross, J. J. (2015). Emotion regulation in autism spectrum disorder: Evidence from parent interviews and children's daily diaries. *Journal of Child Psychology & Psychiatry*, 56(8), 903–913. <https://doi.org/10.1111/jcpp.12370>
- Saulnier, C. A., & Klaiman, C. (2018). *Essentials of adaptive behavior assessment of neurodevelopmental disorders*. John Wiley & Sons, Incorporated. <https://www.wiley.com/en->

us/Essentials+of+Adaptive+Behavior+Assessment+of+Neurodevelopmental+Disorders-  
p-9781119075455

Scahill, L., & Butter, E. M. (2019). Conclusions and future directions. In C. R. Johnson (Ed.), *Parent training for autism spectrum disorder: Improving the quality of life for children and their families* (pp. 261–266). American Psychological Association.

<http://doi.org/10.1037/0000111-011>

Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, *119*(Suppl. 1), 114–121.

<https://doi.org/10.1542/peds.2006-2089Q>

Sharif, L., Basri, S., Alsahafi, F., Altaylouni, M., Albugumi, S., Banakhar, M., Mahsoon, A., Alasmee, N., & Wright, R. J. (2020). An exploration of family caregiver experiences of burden and coping while caring for people with mental disorders in Saudi Arabia—A qualitative study. *International Journal of Environmental Research and Public Health*, *17*(17), 6405. <https://doi.org/10.3390/ijerph17176405>

Solish, A., Klemencic, N., Ritzema, A., Nolan, V., Pilkington, M., Anagnostou, E., & Brian, J. (2020). Effectiveness of a modified group cognitive behavioral therapy program for anxiety in children with ASD delivered in a community context. *Molecular Autism*, *11*, 34. <https://doi.org/10.1186/s13229-020-00341-6>

Soto-Chodiman, R., Pooley, J. A., Cohen, L., & Taylor, M. F. (2012). Students with ASD in mainstream primary education settings: Teachers' experiences in western Australian classrooms. *The Australasian Journal of Special Education*, *36*(2), 97–111.

<https://doi.org/10.1017/jse.2012.10>

- Spain, D., Harwood, L., & O'Neill, L. (2015). Psychological interventions for adults with autism spectrum disorders: A review. *Advances in Autism*, 1(2), 79–86.  
<http://doi.org/10.1108/AIA-05-2015-0007>
- Stadnick, N., Chlebowski, C., Baker-Ericzén, M., Dyson, M., Garland, A., & Brookman-Frazee, L. (2017). Psychiatric comorbidity in autism spectrum disorder: Correspondence between mental health clinician report and structured parent interview. *Autism*, 21(7), 841–851.  
<https://doi.org/10.1177/1362361316654083>
- Stenberg, N., Schjolberg, S., Schic, F., Volkmar, F., Øyen, A.-S., Bresnahan, M., Svendsen, B. K., Stephen, von Tetzchner, S., Thronæs, N. T., Macari, S., Cicchetti, D. V., Chawarska, K., Suren, P., & Øien, R. A. (2021). Functional outcomes of children identified early in the developmental period as at risk for ASD utilizing the Norwegian mother, father and child cohort study (MoBa). *Journal of Autism and Developmental Disorders*, 51(3), 922–932. <https://doi.org/10.1007/s10803-020-04539-8>
- Stockall, N., & Blackwell, W. (2022). Mindfulness training: Reducing anxiety in students with autism spectrum disorder. *Early Childhood Education Journal*, 50(1), 1–9.  
<https://doi.org/10.1007/s10643-020-01116-7>
- Sullivan, S. C., & Aramini, V. (2019). Religion and positive youth development: Challenges for children and youth with autism spectrum disorder. *Religions*, 10, Article 540.  
<https://doi.org/10.3390/rel10100540>
- Thomeer, M. L., Lopata, C., Donnelly, J. P., Booth, A., Shanahan, A., Federiconi, V., McDonald, C. A., & Rodgers, J. D. (2019). Community effectiveness RCT of a comprehensive psychosocial treatment for high-functioning children with ASD. *Journal*

*of Clinical Child & Adolescent Psychology*, 48, S119–S130.

<https://doi.org/10.1080/15374416.2016.1247359>

- Ting, V., & Weiss, J. A. (2017). Emotion regulation and parent co-regulation in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(3), 680–689. <http://doi.org/10.1007/s10803-016-3009-9>
- Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45(6), 1673–1688. <http://doi.org/10.1007/s10803-014-2324-2>
- van Steensel, F. J., Zegers, V. M., & Bögels, S. M. (2017). Predictors of treatment effectiveness for youth with ASD and comorbid anxiety disorders: It all depends on the family? *Journal of Autism and Developmental Disorders*, 47(3), 636–645. <http://doi.org/10.1007/s10803-016-2956-5>
- Volkmar, F. R., & Wiesner, L. A. (2017). *Essential clinical guide to understanding and treating autism*. John Wiley & Sons, Incorporated. <https://www.wiley.com/en-us/Essential+Clinical+Guide+to+Understanding+and+Treating+Autism-p-9781118586624>
- Vygotsky, L. (1962). *Thought and language*. MIT Press. (Original work published 1934)
- Weitlauf, A. S., Gotham, K. O., Vehorn, A. C., & Warren, Z. E. (2014). Brief report: DSM-5 “levels of support:” A comment on discrepant conceptualizations of severity in ASD. *Journal of Autism and Developmental Disorders*, 44(2), 471–476. <https://doi.org/10.1007/s10803-013-1882-z>
- Wenzel, K., Townsend, J., Hawkins, B. L., & Russell, B. (2020). Changes in family leisure functioning following a family camp for children with autism spectrum disorder (ASD).



*Therapeutic Recreation Journal*, 54(1), 17–31. <http://doi.org/10.18666/TRJ-2020-V54-I1-9418>

Westerveld, M. F., Wicks, R., & Paynter, J. (2021). Investigating the effectiveness of parent-implemented shared book reading intervention for preschoolers with ASD. *Child Language Teaching and Therapy*, 37(2), 149–162.  
<https://doi.org/10.1177/0265659021995522>

White, S. W., & Dicrisio, A. S. (2015). Introduction to special issue ASD in adulthood: Comorbidity and intervention. *Journal of Autism and Developmental Disorders*, 45(12), 3905–3907. <http://doi.org/10.1007/s10803-015-2635-y>

White, S. W., Simmons, G. L., Gotham, K. O., Conner, C. M., Smith, I. C., Beck, K. B., & Mazefsky, C. A. (2018). Psychosocial treatments targeting anxiety and depression in adolescents and adults on the autism spectrum: Review of the latest research and recommended future directions. *Current Psychiatry Reports*, 20(10).  
<http://doi.org/10.1007/s11920-018-0949-0>

Wilson, K. P., Kaminski-Mainardi, A., Tenbus, J., & Marsack-Topolewski, C. N. (2021). Social communication supports and services for adults with ASD: Parents' perceptions of barriers and needs. *Journal of Family Social Work*, 24(2), 98–117.  
<https://doi.org/10.1080/10522158.2021.1887037>

Wolstencroft, J., Robinson, L., Srinivasan, R., Kerry, E., Mandy, W., & Skuse, D. (2018). A systematic review of group social skills interventions, and meta-analysis of outcomes, for children with high functioning ASD. *Journal of Autism and Developmental Disorders*, 48(7), 2293–2307. <http://doi.org/10.1007/s10803-018-3485-1>

- Wong, V., McGrew, J., & Ruble, L. (2020). Predicting the outcomes of parents of transition-age youth or young adults with ASD. *Journal of Autism and Developmental Disorders*, 50(8), 2723–2739. <http://doi.org/10.1007/s10803-020-04362-1>
- Yavuz, H. M., Selçuk, B., & Korkmaz, B. (2019). Social competence in children with autism. *International Journal of Developmental Disabilities*, 65(1), 10–19. <https://doi.org/10.1080/20473869.2017.1346224>
- Yorke, I., White, P., Weston, A., Rafla, M., Charman, T., & Simonoff, E. (2018). The association between emotional and behavioral problems in children with autism spectrum disorder and psychological distress in their parents: A systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 48(10), 3393–3415. <https://doi.org/10.1007/s10803-018-3605-y>
- Yu, Y., McGrew, J. H., & Bloor, J. (2019). Effects of caregiver-focused programs on psychosocial outcomes in caregivers of individuals with ASD: A meta-analysis. *Journal of Autism and Developmental Disorders*, 49(12), 4761–4779. <http://doi.org/10.1007/s10803-019-04181-z>
- Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(6), 1380–1393. <http://doi.org/10.1007/s10803-012-1693-7>
- Zainal, H., & Magiati, I. (2019). A comparison between caregiver-reported anxiety and other emotional and behavioral difficulties in children and adolescents with autism spectrum disorders attending specialist or mainstream schools. *Journal of Autism and Developmental Disorders*, 49(7), 2653–2663. <http://doi.org/10.1007/s10803-016-2792-7>

Zeedyk, S. M., Tipton, L. A., & Blacher, J. (2016). Educational supports for high functioning youth with ASD: The postsecondary pathway to college. *Focus on Autism and Other Developmental Disabilities*, 31(1), 37–48. <https://doi.org/10.1177/1088357614525435>