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Association Between Therapeutic Interventions and Quality of Life in People with Autism

Taline Movsessian
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Walden University

College of Health Sciences and Public Policy

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Taline Movsessian

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Walden University

2022

Abstract

Association Between Therapeutic Interventions and Quality of Life in People with

Autism

by

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MBA, Western University, 2011

MS, University of Toronto, 2004

Honors BS, University of Toronto, 2000

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

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Abstract

Research exploring the impact of autism interventions on the quality of life (QoL) of adults with autism is scarce. This correlational, cross-sectional survey study was conducted to determine the association between seven interventions—behavioral, social, mental health, daily living skills, vocational, mindfulness, and medications—and the QoL and mental health of adults 18 years and older with autism with no intellectual disability living in Canada. A national sample of 182 autistic adults completed the survey that used the WHOQOL-BREF and Depression, Anxiety, and Stress Scale to measure subjective QoL and mental health, respectively. Behavioral, mental health, and medications were the mostly used interventions (67%, 71.4%, and 82.4%). QoL was lower across all domains of the WHOQOL-BREF compared to the general population and moderate levels of anxiety and depression were reported. Hierarchical multiple regression analysis showed that characteristics, such as autism severity, being female, and older age negatively predicted QoL across all domains except for the physical domain, whereas being in a relationship positively predicted social QoL explaining 35.2% of the variance. Of the seven interventions used, behavioral therapies and receiving mental health support consistently predicted a better QoL across all domains, except for the environment domain where only mental health support was a significant predictor. Autism severity negatively predicted anxiety and depression while none of the interventions reached statistical significance. These findings suggest prioritizing provision of behavioral and mental health interventions to adults with autism and inform future research to evaluate their effectiveness in QoL outcomes as an end goal.

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Dedication

This dissertation is dedicated to my son who has autism and has been the inspiration and motivation for my research in this field. He is a wonderful human being whom I love very much and will always support and encourage to reach his full potential. It is also dedicated to the wonderful teachers, autism professionals, therapists, and counselors for their resilience and the invaluable work they do each and every day to support the needs of the autism community and their families.

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Chapter 1: Introduction to the Study

Autism spectrum disorders (ASD) are a group of neurodevelopmental conditions characterized by deficits in social communication, interaction, and sensory disturbances accompanied by repetitive and restrictive behaviors and interests which limit the person's ability to properly function in society (American Psychiatric Association [APA], 2013). The current prevalence of ASD is estimated at 1-2%, although there is a trend toward increasing numbers being diagnosed (Xu et al., 2018), with current estimated rates of 1 in 54 children having the disorder compared to 1 in 89 in 2015 (Baio et al., 2018). ASD occurs among all racial, ethnic, and socioeconomic groups with a higher prevalence in males versus females with a 3:1 ratio (Baio et al., 2018).

People with ASD are more likely to have a variety of associated comorbidities including attention deficit hyperactivity disorder (ADHD), anxiety, depression, epilepsy, and other neurological, autoimmune, endocrine, and sleep disorders (Fortuna et al., 2016). Though social, behavioral, and communication deficits tend to improve over time, they nevertheless continue to persist into adulthood making long-term outcomes related to employment, education, and independent living highly challenging. Consequently, most adults with ASD remain highly dependent on family members and caregivers, and at least half continue to live with their parents (Hatfield, Ciccarelli, et al., 2018; Marsack-Topolewski et al., 2021). This can have a significant negative impact on the quality of life (QoL) of people with ASD compared to the general population, especially concerning their physical and psychological well-being as well as social integration, communication, and daily living skills (van Heijst & Geurts, 2015). High rates of physical health issues

(40%-60%) including obesity, neurological conditions, gastrointestinal disorders, and sleep disorders have been reported (Croen et al., 2015; Jones et al., 2016). Similarly, higher levels of anxiety, depression, loneliness, and psychiatric disorders have been reported in adults with ASD compared to controls amounting to lifetime prevalence rates of 37% for depression and 42% for anxiety disorders (Hollocks et al., 2019). Finally, significant impairments in factors related to environmental QoL including transport, participation and involvement in daytime activities, and living arrangements have also been reported in adolescents and adults with autism (Knüppel et al., 2018; Lubin & Feeley, 2016). Taken together, these highlight the wide range of factors contributing to a poor QoL in these individuals.

Although a variety of interventions are provided to autistic individuals, especially during childhood, such as behavioral, mental health, and socially-based approaches, most do not consider the impact on QoL later in life (Pfeiffer et al., 2017). Importantly, they are applied for short periods as part of early intervention strategies and their effectiveness, sustainability, and transferability into adulthood is unknown. In addition, the perspectives of key stakeholders, such as autistic individuals and their caregivers regarding the benefits and effectiveness of such programs are not well understood. Finally, there is little evidence around the use of various interventions among the adult autistic population (van Heijst et al., 2015). The current study filled this gap by evaluating the association of therapeutic interventions including socially skills, mental health, behavioral therapies, adaptive/daily living skills (DLS), mindfulness, vocational, and prescribed medications with the QoL and mental health of Canadian adults with

autism. Given the current challenges facing optimal resource allocation and funding across a wide range of autism services, such evidence will, in part, inform prioritization of those interventions that are most relevant to the autism community in achieving a more fulfilling life. This can be used by policymakers and government stakeholders.

A comprehensive overview of the research study is provided in this chapter, divided into several sections. The first section supports the background and relevance of the study, followed by a discussion of the purpose of the study. This chapter also includes a discussion of the theoretical foundation and nature of the study as well as the assumptions, delimitations, and limitations. The final section highlights the significance of the study and summarizes the key elements of this chapter.

Background

ASD is a lifelong, chronic neurodevelopmental condition characterized by deficits in communication, social skills, repetitive behaviors, and restricted interests (National Institute of Mental Health, 2018). In most cases, signs of autism and ensuing diagnosis occur in the first 2 to 3 years of life although the broad range of severity and symptomology is highly variable making ASD a spectrum disorder. The core deficits of autism alongside other comorbid conditions, such as ADHD, ID, and psychiatric disorders persist into adulthood and further limit social participation and the ability of these individuals to become integrated into society (Mason et al., 2018). Together, the ongoing impairments in cognitive, functional, and social ability significantly impact the QoL of people with autism preventing their ability to achieve satisfaction and better outcomes in life.

QoL

The World Health Organization (WHO, 1995) defined QoL as “the individual’s perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standard and concerns” as they relate to the individual’s physical and psychological health, personal beliefs, social relationships, level of independence, and salient features of the environment (p. 1405). Numerous studies including comprehensive reviews and meta-analyses have investigated the QoL of children, youth, and adults with autism and found significant impairments compared to the general population, and even those with other disabilities (Ayres et al., 2018; Khanna et al., 2014; Knüppel et al., 2018; Lawson et al., 2020; van Heijst & Geurts, 2015). Van Heijst and Geurts (2015) found that people with autism had a much lower QoL compared to those without autism across the lifespan, regardless of age. Another study investigating QoL in 370 autistic adults in the UK found a diminished QoL in all domains of the World Health Organization QoL-BREF (WHOQOL-BREF) questionnaire compared to the general population with younger participants reporting a higher QoL compared to older ones in the psychological and environment domains (Mason et al., 2018). Factors such as psychiatric disorders, ID, autism symptomology, and sleeping difficulty have been associated with poor QoL in this population (Knüppel et al., 2018), whereas perceived adequacy of social support from family and friends and ability to cope have been positive predictors of QoL (Khanna et al., 2014). Of note, challenges in social participation, communication, and daily living skills have been shown to negatively affect QoL.

Given the current research and awareness related to the predictors of QoL in people with autism, targeted interventions should focus on approaches that help improve QoL outcomes in this population. However, the outcomes of various interventions offered to children and adults with ASD rarely relate to QoL, nor are they always coherent with the end goals and needs of people with ASD and their caregivers (Pfeiffer et al., 2017). As such, there is a gap in better understanding the outcomes of interventions that are meaningful and important to the autistic population. This study can better inform interventionists, funding bodies, and policymakers in making evidence-based client-centric decisions to help improve QoL.

Interventions

Several therapeutic interventions are offered to individuals with ASD across the lifespan. These include, but are not limited to, socially-based interventions, psychological or mental health interventions, behavioral therapies, adaptive/DLS interventions, prescribed medications, vocational training, and mindfulness interventions (Benevides et al., 2020; Blainey et al., 2017; Keefer et al., 2018; Laugeson et al., 2015; Oswald et al., 2018). Studies evaluating the effectiveness of various interventions have been conducted using experimental, quasi-experimental, single-group pre-post designs, case reports, and case series designs. Most use small sample sizes and implement the intervention for short periods ranging from several days to weeks in a research setting (Benevides et al., 2020).

The outcomes of such studies are rarely linked to improvements in QoL, well-being, or mental health, and instead focus on enhancing the specific deficit or need being targeted. For example, Leung et al. (2019) assessed the effectiveness of a social

competence group intervention using cognitive behavioral therapy (CBT) in 36 adults with autism throughout 15 weeks. The authors noted significant improvements in overall social competence and negative mood as well as the confidence to apply knowledge after each training session. In another interventional study, the efficacy of the Program for the Education and Enrichment of Relational Skills (PEERS) in 22 young adults with ASD (12 treatment and 10 control arms) was assessed (Laugeson et al., 2015). The authors found that overall social skills, frequency of social engagement, and social skills knowledge significantly improved in the treatment group compared to controls and that these were maintained 16-weeks post program implementation. Finally, Benevides et al. (2020) evaluated the impact of various interventions on the health outcomes of people with ASD without ID and found that only two intervention approaches, namely CBT and complementary/integrative mindfulness interventions, had supported improvements in depression, anxiety, and obsessive-compulsive behaviors. These findings underscore the need for further research to measure improvements in QoL outcomes when assessing the effectiveness of autism interventions.

Problem Statement

There is little evidence supporting the effectiveness or outcomes of autism interventions across the lifespan in the published literature, although such evidence may reside in unpublished program evaluation reports. Though a broad range of interventions are introduced early in life upon ASD diagnoses as part of early intervention strategies, assessment of their effectiveness and benefits is often short-lived, in a controlled clinical setting, and based on observer evaluation (Benevides et al., 2020; Pfeiffer et al., 2018).

Moreover, effectiveness studies often use small sample sizes and lack a longitudinal perspective. As such, the true impact of therapeutic interventions in improving QoL is often not a key objective nor an end goal for such programs. Findings from a recent systematic review showed that only two interventions were considered as emerging evidence-based approaches that assessed health outcomes of the autistic population (Benevides et al., 2020). But few studies have evaluated the long-term outcomes of interventions and their impact on health-related outcomes, such as QoL and mental health. Therefore, there was a need to further explore the real-world effectiveness of autism interventions in improving QoL as an end goal. This will ensure a long-term view toward achieving meaningful outcomes across the lifespan rather than focusing on immediate gains, which may not persist in the long run.

Purpose of the Study

The purpose of this quantitative, cross-sectional survey study was to evaluate the association of currently used therapeutic interventions in autism with the QoL and mental health of adults with autism without ID aged 18 years and older living in Canada. Seven therapeutic interventions including social, mental health, behavioral therapies, adaptive/DLS, mindfulness, prescribed medications, and vocational interventions were evaluated as predictors of QoL and depression-anxiety in the sampled population. QoL was measured using mean scores of the four domains of the WHOQOL-BREF instrument (McConachie et al., 2018; WHOQOL-BREF, 1996) including physical, psychological, social relationship, and environment. In addition, the relationship between the seven interventions and depression and anxiety was evaluated using the composite score of the

Depression and Anxiety scales of the DASS-21 questionnaire (Park et al., 2020). Both questionnaires have been validated in the autistic population (McConachie et al., 2018; Park et al., 2020). Additionally, several demographic variables with potential impact on QoL were also tested. These included the participants' age, gender, autism severity, employment status, living status, education level, support status, relationship status, and health and mental health status. These variables were used as covariates in the statistical analysis to control for their effect on the outcome variables.

Research Questions and Hypotheses

This research study comprised two main research questions with associated null and alternative hypotheses. Both questions were quantitative and sought to determine the relationship between a set of predictor and outcome variables.

Research Question 1: What is the association between therapeutic interventions including social skills, mental health, behavioral therapies, adaptive/DLS, vocational, mindfulness, and prescribed medications, and the self- or proxy-reported QoL of autistic individuals aged 18 years and older without intellectual disability (ID) as measured by the WHOQOL-BREF?

H_01 : There is no significant association between therapeutic interventions and the self- or proxy-reported QoL of autistic individuals aged 18 years and older without ID.

H_a1 : There is a significant association between therapeutic interventions and the self- or proxy-reported QoL of autistic individuals aged 18 years and older without ID.

Research Question 2: What is the association between therapeutic interventions including social skills, mental health, behavioral therapies, adaptive/DLS, vocational,

mindfulness, and prescribed medications, and the self- or proxy-reported mental health of autistic individuals aged 18 years and older without ID as measured by the DASS-21?

H₀2: There is no significant association between therapeutic interventions and the self- or proxy-reported mental health of autistic individuals aged 18 years and older without ID.

H_a2: There is a significant association between therapeutic interventions and the self- or proxy-reported mental health of autistic individuals aged 18 years and older without ID.

Theoretical Foundation

The theoretical basis for this research was the precede-proceed model (PPM) for program health planning and evaluation (Green & Kreuter, 1991). The model is used to guide the development and evaluation of evidence-based interventions that meet the needs of the target population, and the model has been used in autism research (Hatfield, Falkmer, et al., 2016). The precede framework is based on predisposing, reinforcing, and enabling factors in educational and environmental diagnosis and evaluation, whereas proceed comprises the policy, regulatory, and organizational constructs in educational and environmental development. Importantly, the model focuses on starting with the end goal in mind, which is depicted in the proceed framework where constant evaluation and updating of targeted interventions in terms of process, impact, and outcomes is conducted to ensure program goals are met.

The proceed component is closely linked to the current research problem and its purpose since it comprises an evaluation of the effectiveness of autism interventions with

the end goal in mind—to improve QoL (Porter, 2016). Further, the model is participatory and involves community members who are most impacted by the health condition. This relates to the nature of this study by using a survey to capture the perspectives of the autism community. The outcome evaluation phase of proceed allows for confirmation of whether the targeted interventions ultimately result in the end goal they were set out to achieve—a better QoL. Though the primary focus of autism programs is to attain behavioral or psychosocial improvements in the short-term, their long-term impact ultimately determines whether a better QoL is achieved by these individuals. A more detailed explanation of the propositions the PPM is provided in Chapter 2.

Nature of the Study

This was a quantitative study using a cross-sectional survey design (Frankfort-Nachmias & Leon-Guerrero, 2018) to ascertain the association of various autism interventions with the QoL and anxiety/depression levels of adults with autism without ID aged 18 years and older. To elucidate whether such associations exist, subjective self- or proxy-reported ratings of QoL were evaluated using the WHOQOL-BREF, and levels of depression and anxiety were assessed using the DASS-21. Subjects were recruited from various sources and completed the questionnaires online using Survey Monkey. The WHOQOL-BREF is a general QoL instrument that has been validated in the adult autistic population (McConachie et al., 2018). It consists of 26 items with two global questions and four QoL domains: physical (seven items), social (three items), psychological (six items), and environment (eight items). Hence, the dependent variables were each of the four QoL domains. The instrument has been used in many studies evaluating the QoL of

autistics (Kamio et al., 2013; Mason et al., 2018). The DASS-21 questionnaire has also been validated in people with ASD without ID and consists of three domains (seven items each) including depression, anxiety, and stress. A composite score of the scales was computed and used as the dependent variable in this study.

The use of the seven autism therapeutic interventions were captured as part of the demographic questionnaire. Therapeutic interventions were coded as dichotomous categorical variables (yes/no) capturing whether the respondent has ever (in the past or present) used the said intervention. Descriptive statistics were used to report on frequencies and means, while a hierarchical multiple regression (HMR) model was employed to investigate the association between the predictor and outcome variables (Hidalgo & Goodman, 2013). This methodology was appropriate here given the nature of the categorical predictor and continuous outcome variables as well as the potential covariates to predict the significance of the interventions on QoL and mental health. An HMR model allowed to determine whether the addition of the interventions of interest significantly improved the model's fit and ability to predict the QoL and mental health outcomes. Demographic variables, such as age, gender, and autism severity were added as Block 1; relationship status, support status, employment status, education level, and having a mental health condition diagnosis were included in Block 2; and the therapeutic interventions (mental health, social, vocational, behavioral, adaptive/DLS, prescribed medications, and mindfulness) were added as Block 3. SPSS 28.0 statistical software was used to analyze the data.

Definitions

Autism severity: The Diagnostic and Statistical Manual defines three levels of autism severity based on the degree of associated deficits related to social communication impairment and restricted, repetitive behaviors (American Psychiatric Association, 2013). Level 1 or “requiring support” is the mildest in severity, Level 2 or “requiring substantial support” is considered as moderate, and Level 3 or “requiring very substantial support” is the most severe level of the condition. Traditionally, the term *high functioning* has been coined to describe Level 1 autistics although this is now outdated. In this study, autism severity was captured as part of participant demographics and included as a potential covariate.

Autism spectrum disorders (ASD): According to the American Psychiatric Association’s (2013) Diagnostic and Statistical Manual, autism is a clinical diagnosis based on five distinct criteria: (a) persistent deficits in social communication and interaction as manifested by a range of deficits in social-emotional reciprocity, nonverbal communicative behaviors used in social interaction, and developing, maintaining, and understanding relationships; (b) restricted, repetitive patterns of behavior and interests; (c) appearance of symptomology in early childhood; (d) significant impairments in social and occupational functioning; and (e) symptomology which is not better explained by intellectual disability (ID) or developmental delay, although both ASD and ID are comorbid conditions. For the purposes of this study, autism diagnosis was based on self- or proxy-reports and not clinician confirmed formal diagnosis.

Intellectual disability (ID): The American Psychiatric Association (2013)

characterized ID as a condition with challenges in both intellectual functioning, such as learning and problem solving, and adaptive functioning, such as activities associated with daily living. Standardized testing is used as part of diagnosing ID with IQ scores of 70 to 75 indicative of significant impairments in intellectual functioning. Adaptive functioning, on the other hand, is assessed using standardized tools with the individuals and interviews with close members. Severity is categorized as mild, moderate, and severe where about 85% of people fall in the mild category. For this study, autistic people with comorbid ID, defined as an IQ score of less than 70, were excluded, although this was based on participant or proxy reports versus a confirmed clinician diagnosis.

Autism Interventions

In general, interventions in this study were defined as those targeting the autistic individual versus interventions aimed at addressing system or organizational interventions, such as policies or programs which impact many individuals. In addition, the impact of interventions aimed at caregivers of autistic adults was excluded.

Adaptive/daily living skills (DLS) interventions: DLS interventions are targeted toward helping people with autism develop a range of skills to become more independent in managing their daily living needs (Autism Speaks, 2021). These include skills such as self-care, preparing meals, shopping, managing finances, and transportation.

Behavioral interventions: Grounded in learning theory, behavioral interventions are based on the premise that behavior is learned through interactions between the individual and their environment (Centers for Disease Control and Prevention [CDC],

2019). Behavioral interventions encourage the use of positive behaviors and aim to reduce harmful behaviors which interfere with learning or functioning. Applied behavior analysis (ABA), discrete trial training (DTT), and intensive behavioral intervention (IBI) are commonly applied behavioral intervention programs.

Mental health services: The World Health Organization (WHO, 2021) defined mental health as a state of well-being in which a person can cope with the normal stresses of life, reach their potential, and contribute to society. The absence of mental health may manifest as experiencing depression, anxiety, and/or mood disorders in individuals including those with ASD. In this study, mental health services included interventions that may have been used to address or alleviate psychiatric disorders by people with ASD. These included psychological or psychiatric counseling, cognitive behavioral therapy (CBT) approaches, group counseling, and social worker support.

Mindfulness interventions: These interventions are used in addition to or instead of traditional medicine and approaches. Mindfulness interventions focus on modifying an individual's thoughts and emotions to achieve a better state of self-awareness and emotional regulation (Conner & White, 2017). They may include approaches such as mind-body medicine, yoga, and meditation among others (CDC, 2019).

Prescribed medications: Medication or pharmacological interventions are highly used in autistic individuals to manage hyperactivity, attention deficit disorders, depression and anxiety, self-injury, or seizures (CDC, 2019).

Socially based interventions: Social skills are a set of abilities that enable an individual to appropriately and competently interact in a given social context (American

Psychological Association, n.d.). These include skills such as communication, building friendships, coping, interpersonal problem solving, and emotional and cognitive regulation. Social skills interventions include participation in social skills groups or workshops, peer to peer mentorship programs, evidence-based social skills programs, such as the Program for the Education and Enrichment of Relational Skills (PEERS; Laugeson & Frankel, 2010).

Vocational interventions: Vocational or employment interventions are aimed toward developing or improving skills and competencies which will help autistic people better manage and succeed in the work setting (Gal et al., 2015). These may be simulated, volunteer, or paid, and include skills such as interviewing, emotional regulation, or skills related to performing job tasks.

Outcome Variables

Quality of life (QoL): The WHO (2022) defined QoL as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. In this study, QoL was measured using the WHOQOL-BREF questionnaire, which consists of two global questions and four QoL domains including physical, social, psychological, and environmental.

Depression and anxiety: According to the WHO (2017), depression is characterized by feelings of sadness, loss of interest, tiredness, low self-worth, sleep disturbances, and loss of appetite, which can range from mild to severe. Anxiety, on the other hand, is a group of disorders characterized by feelings of anxiety and fear which

may take the form of phobias, obsessive-compulsive disorder, panic disorder, and social anxiety disorder. Like depression, symptoms may range from mild to severe with significant impairment of the individual's ability to function and carry on with daily living. In this study, the DASS-21 questionnaire was used to evaluate the levels of depression and anxiety in participants.

Assumptions

Philosophical orientations or paradigms represent ways and approaches in which individuals view the world, their particular place and role, and their interactions within that space and its parts (Burkholder et al., 2016). The positivist view stipulates that knowledge is solely generated through senses and that what is not observable cannot be validated. This tends to align most with quantitative research approaches that are primarily based on the four assumptions of ontology (nature of reality), epistemology (knowledge and reason), axiology (values), and methodological (research strategies). The ontological assumption stipulates that there is only one truth and one single reality that can be studied, experienced, and understood and that this is independent of human experience (Barker & Pistrang, 2015). The epistemological assumption of quantitative research concerns the study of knowledge and that knowledge is objective and quantifiable. The aspects of scope, validity, and methods comprise this assumption. The assumption of axiology emphasizes the objectivity of the researcher and the importance of being value-free, and that bias and subjectivity lead to error (Barker & Pistrang, 2015; Burkholder et al., 2016).

This research is based on these three assumptions. The methodological assumption in this research was based on the positivist paradigm that posits the use of quantitative methods, such as experiments, quasi-experiments, correlational, or other analytical methods that require objective measurements and analysis to generate knowledge (Turner et al., 2013). In this study, the methodological assumptions related to the design, research participants, use of quantitative variables and instruments, and the statistical analysis plan. A cross-sectional, correlational research design was assumed to be appropriate for the conduct of this study and that all criteria for such a design were met (Frankfort-Nachmias & Leon-Guerrero, 2018). Furthermore, a good alignment between the theoretical framework, research questions, hypotheses, and methodology were assumed, which were relevant and applicable to the variables of interest and QoL as an outcome measure grounded by the PPM. Notably, the model assumes that a given intervention was delivered as intended after which outcomes can be measured and attributed to that intervention. However, since this study did not include the process evaluation step of the model, it is assumed that the interventions of interest were in fact administered and delivered as intended. Next, it was assumed that the WHOQOL-BREF and DASS-21 are valid and reliable instruments to measure the expected study outcomes of QoL and mental health, respectively, given their prior use and validation in the autistic population (McConachie et al., 2018; Park et al., 2020).

Assumptions related to the study population pertained to the representativeness of the sample of adult autistics who were 18 years and older who correctly and reliably self-reported their autism and ID status. A critical assumption was that these individuals are

capable of reading and completing the two study questionnaires reliably and accurately. However, the previous use and validation of both instruments in the autistic population provided further reassurance of these assumptions. I also assumed that survey responses provided by parental proxy reports (i.e., how the parent thinks the child would respond to questions) would closely represent those of the individuals. However, there is evidence that supports the validity of this assumption based on high correlations observed between autistic adolescent and adult self-reports and parental proxy-reports around QoL outcomes (Hong et al., 2016; Sheldrick et al., 2012). In addition, study procedures, such as informed consent, confidentiality, and deidentification of respondents were assumed to increase the likelihood of survey completion and accuracy.

Finally, assumptions around data and statistical analyses were based on the fulfillment of the HMR criteria including normal distribution, linearity, homoscedasticity, and absence of multicollinearity between the predictors and covariates, and that potential violations of these assumptions were accurately tested and addressed (Frankfort-Nachmias & Leon-Guerrero, 2018). It was also assumed that the selected covariates were relevant to the research topic and that their inclusion in the model would further strengthen the validity and significance of the research findings.

Scope and Delimitations

This study attempted to delineate autism interventions that are significantly associated with and relevant to impacting the QoL and mental health of people with autism. It included individuals with autism living in Canada who were 18 years of age and older and who did not have ID. Furthermore, it allowed for proxy completion of

study surveys by parents or direct caregivers of the autistic individuals in cases where obtaining their responses was not possible. The study excluded people with ASD under the age of 18 and those with ID. The latter was a deliberate decision to maximize the likelihood of study enrollment, survey completion, and accuracy of survey responses by the autistic individuals given the higher cognitive and functional ability of the selected sample.

Limitations

This study had several limitations that may have affected the internal and external validity of the findings. The cross-sectional, correlational nature of the study limits interpretation of causal relationships between the predictor and outcomes variables, hence, limiting internal validity (Wang & Cheng, 2020). The absence of random selection of study participants may introduce bias and further reduce the internal validity of the study. For example, self-selection bias is a potential threat to validity due to the voluntary nature of participation. It could be conceived that autistic individuals who choose to participate in a survey study may have different characteristics than those who choose not to (Khazaal et al., 2014). Therefore, the external validity and generalizability of the findings may have been compromised if study participants did not represent the target population.

Another bias pertained to social desirability, which is a concern for most quantitative studies utilizing self-reported surveys (Althubaiti, 2016). Social desirability bias may be present as survey participants may tend to provide more favorable responses to obtain the approval of the researchers resulting in an overestimation of the reported

associations than what they truly are. Finally, recall bias may also reduce the internal validity of findings as participants may struggle to remember the types of interventions they had accessed and used in the past. This may have biased the results toward overreporting of interventions which were more recently or currently used.

Another limitation related to the potential involvement of proxy parental reports for individuals who were unable to complete the survey by themselves. This may impact the internal validity of the findings since proxy reports may not accurately reflect first-person ratings, although research has reported high correlations between autistic adolescent and adult self-reports and parental proxy reports around QoL outcomes (Hong et al., 2016; Sheldrick et al., 2012). Given the potential functional and cognitive challenges of the target population, partial survey completion by participants may have been a limitation, although this did not appear to be a significant issue in this study since the survey had a 95% completion rate.

Finally, the exclusion of individuals with ID, a common comorbidity in people with autism, may have overestimated QoL and mental health outcomes since this subgroup of autistic individuals may have a lower QoL and mental health status compared to those without ID. This limitation may have impacted the external validity and generalizability of the findings to the broader autistic population.

Significance

Findings from this research study have significance both from an empirical and practical standpoint. Extensive literature has documented the poor QoL of people with autism across the lifespan even when compared to subgroups with other disabilities and

special needs (Ayres et al., 2013; Hong et al., 2016; Kamio et al., 2013; Lawson et al., 2020; van Heist & Geurts, 2015). Moreover, researchers have evaluated the effectiveness of numerous interventions ranging from early strategies to those applied in adolescence and adulthood to address the unmet needs and deficits of this population (Blainy et al., 2017; Laugeson et al., 2015; Leung et al., 2019; Oswald et al., 2018). Most of these studies, however, have assessed outcome measures directly related to expected improvements of the targeted behavior without a long-term view towards how these interventions may translate into real-life gains. Only a few have considered the perspectives of the autism community as partners and key stakeholders in the process to ascertain the meaningfulness and value of these approaches (Benevides et al., 2020). Therefore, this research study addressed this gap by contributing to the body of empirical evidence to pinpoint which interventions were most relevant to achieving improvements in QoL of people with ASD.

From a practical standpoint, findings from this study may help identify the most useful strategies and interventions which should be prioritized from a health care service delivery perspective. Furthermore, results can also guide decision making among policymakers and agencies regarding the allocation and prioritization of scarce resources and funding to optimize long-term outcomes for this population and better integration into the community. Importantly, findings from this study will raise awareness among multiple stakeholders involved in the management and care of people with autism to support advocacy and client-centered approaches to achieve better outcomes and overall satisfaction.

Summary

This study assessed the association of autism interventions with the QoL and mental health of people with autism 18 years and older without ID. A set of commonly utilized autism interventions including social, mental health, behavioral therapies, adaptive/DLS, mindfulness, prescribed medications, and vocational interventions were evaluated to determine their association with the QoL and mental health of people with ASD. The association between several demographic variables known to impact QoL were also assessed to control for their possible effects on QoL and mental health. The use of an HMR model helped delineate the nature of the relationships between the predictor and outcome variables to help address the research questions posed by this study.

The first introductory chapter of this dissertation provided a comprehensive overview of the various sections, including (a) the background literature, (b) the problem statement, (c) the purpose of the study, (d) the research questions, related hypotheses, and methodology, (e) the theoretical basis of the study, (f) important definitions, (g) the assumptions, scope, delimitations, and limitations underlying the study, and (h) the significance of the study. The following chapter will provide a comprehensive review of the theoretical foundation and existing literature related to the research topic.

Chapter 2: Literature Review

Research has shown a lower quality of life (QoL) for people with autism compared to their neurotypical counterparts (Ayres et al., 2018; Khanna et al., 2014; Knüppel et al., 2018; Lawson et al., 2020; van Heijst & Geurts, 2015). This is true across all age groups and QoL domains, although social QoL appears to be most impacted (Jennes-Coussens et al., 2006; Kamio et al., 2013; Kamp-Becker et al., 2010; Lin, 2014). Though a range of therapeutic interventions are offered to people with ASD to target specific gaps in functioning, behaviors, and communication, their impact on improving QoL and mental health is not well understood. In fact, there is a gap in understanding what a “good” QoL means from the autistic person’s perspective and which interventions are deemed most effective in achieving this goal (Ayres et al., 2018). Most studies focus on evaluating outcomes related to the specific intervention strategy being tested and the deficits it is meant to address. Several studies have assessed the association between a given intervention and health related outcome measures in people with ASD (Ekman & Hiltunen, 2015; Gal et al., 2015; McVey et al., 2016; Siew et al., 2017; Sizoo & Kuiper, 2017; Spek et al., 2013). Intervention types have included CBT, social skills, medical, peer mentoring, vocational, and complementary/integrative interventions, but many of the interventions did not have sufficient evidence supporting their use in autistic adults and were not perceived as important by the autistic community (Benevides et al., 2020).

Given these gaps in existing research, this study aimed to identify the most used interventions by people with ASD residing in Canada, and more importantly, to ascertain whether a relationship exists between these interventions and their QoL and mental

health. Specifically, this cross-sectional, correlational survey research captured the use of autism interventions including social skills, mental health, medical, vocational, behavioral therapies, mindfulness, and vocational and their association with the QoL and mental health of individuals with autism 18 years and older without ID. This research highlights a few important points: (a) the need to integrate measures of QoL in interventional studies, (b) the lack of data regarding which therapeutic interventions matter most to the autistic community, and (c) the voice of the autistic community as an integral part of the intervention process to ensure a client-centered approach.

The second chapter of this dissertation will include the literature search strategy employed. This is followed by a comprehensive review of the theoretical foundation upon which the study is based. Then, the chapter will discuss the existing literature that supports the rationale and importance of this research.

Literature Search Strategy

A comprehensive literature search was undertaken to extract relevant publications pertinent to the research topic. The structure of the literature review was organized around the following topics (a) QoL of people with autism, (b) mental health (depression and anxiety) of people with ASD, (c) commonly used autism interventions and their effectiveness, and (d) association between autism interventions and health outcome measures. In addition, articles describing the theoretical model, precede-proceed, were also procured, as were studies that utilized this theory. Of note, program evaluation reports were not included as part of the search strategy, albeit such reports are usually not published.

Articles searched were all peer-reviewed and mostly published no earlier than 2015 to limit papers published in the past 5 years and to keep abreast of current research findings. Several papers preceded this date as they were seminal to the theoretical model (1991 onwards) or were deemed important evidence related to the topic discussed. In addition, given the lack of high-quality research in certain autism interventions, earlier studies were used. The Walden University search engine was used to search health sciences and psychology databases including Medline, ProQuest, CINAHL, Embase, SAGE Journals, ERIC, and APA PsycInfo. Keywords included combinations of *autism spectrum disorders, quality of life, wellbeing, health-related quality of life, outcomes, mental health, depression, anxiety, effectiveness, efficacy, intervention, program, cognitive behavior therapy, social and communication interventions, psychological/psychosocial interventions, mindfulness/complementary interventions, vocational interventions, adaptive/DLS interventions, and medical interventions*. Google Scholar was also used as a search engine. The search words *Precede-Proceed Model* were used to obtain articles on the theoretical framework, and *WHOQOL-BREF and DASS-21* were used to obtain publications on the two instruments used in the study. Additional sources included reference lists/citations provided in relevant articles and credible websites such as WHO, APA, CDC, and Autism Speaks. These websites were used to obtain information on specific definitions, diagnostic criteria, prevalence rates and statistics, theoretical models, and study methodology and designs.

Theoretical Foundation

Precede-proceed is one of the most used and widely applied models in health promotion practice. The model was first developed by Lawrence Green in 1974 as an evaluation framework, then as precede by Green (Green et al., 1980), and finally as the full framework in 1991 by Green and Kreuter (1991). The model from 1974 was progressively developed into four editions of a book between 1980 and 2005 to explain the precede-proceed approach. The authors described the model's underpinnings as its (a) flexibility and scalability, (b) evidence-based process and evaluability, (c) its commitment to the principle of participation, and (d) its provision of a process for appropriate adaptation of evidence-based best practices (Green & Kreuter, 2005). Precede-proceed is a socioecological model that focuses on the population, rather than the individual, which urges the practitioner to consider the interaction between groups of people and their environments rather than the one-on-one aspect of acute health care (Green & Kreuter, 2005). This is in contrast with intrapersonal theories of health behavior, such as the transtheoretical model or the health belief model, which focus on modifying individual health behaviors to achieve a desired outcome.

Green and Kreuter posited five pillars that ground the precede-proceed model (Porter, 2016):

- a socioecological approach that emphasizes the physical, social, and political ecosystem impacting population health
- a population-centered focus highlighting a public health framework based on upstream determinants of health

- its participatory nature that is community-based and involves key stakeholders, such as professionals, policy makers, community leaders/officials, and members of the target population in the identification, planning, and evaluation of community health and QoL issues
- its quality-of-life focus as the end goal rather than changing behavior, and
- it being strongly grounded based on real-world experience with ongoing evaluations and revisions of targeted interventions and programs.

The participatory and quality of life approaches of the model are most relevant to this dissertation. The participatory aspect emphasizes the importance of involving the target population, in this case, the autistic population, in every phase of the assessment, prioritization, planning, implementation, and evaluation stages; the QoL aspect focuses on beginning with the end goal in mind, which is the objective of this research—to ascertain whether the range of autism therapeutic interventions ultimately improves quality of life as defined by the autism community (Crosby & Noar, 2011).

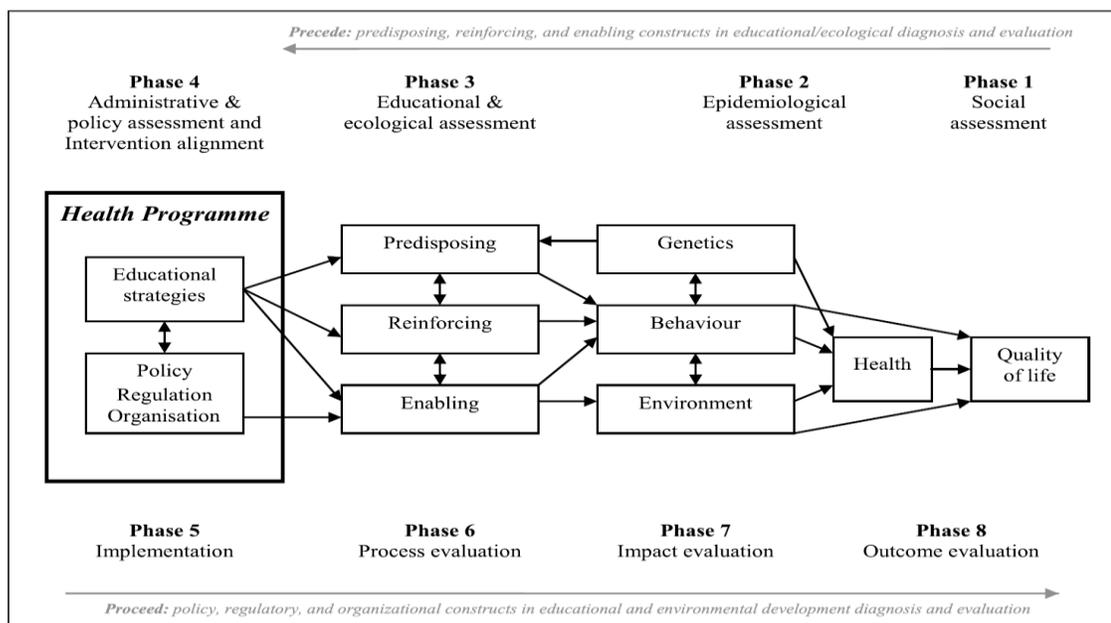
PPM

The PPM is a logic and participatory model structured around two main constructs that are broken down into eight phases. Precede stands for predisposing, reinforcing, and enabling constructs in educational/environmental diagnosis and evaluation; proceed represents policy, regulatory, and organizational constructs in educational and environmental development (Figure 1; Green & Kreuter, 2005). As such, precede is the diagnostic portion of the model and guides the process of conceiving, mapping, and planning an intervention which is aimed toward attaining the end goal. On

the other hand, proceed outlines the steps needed to move forward with the implementation of the intervention and guides its socioecological evaluation. As depicted in Figure 1, the model is a circular process and starts at the upper right and moves counterclockwise, whereas the arrows move from left to right. This is the key premise of PPM, which necessitates planning “backwards” by starting with the end goal in mind and then developing objectives, which, if met, will collectively contribute to the achievement of the desired goal.

Figure 1

Precede-Proceed Model for Health Program Planning and Evaluation



Precede

Precede comprises four phases that guide the selection of the health problem of concern, determining potential causes of the issue, and planning an intervention (Green & Kreuter, 2005). Phase 1, social assessment, is the situational analysis and identifies the

ultimate goal by engaging community members to better understand the multiple issues that impinge on QoL (Green & Kreuter, 2005). This diagnosis uses both objective and subjective information from different sources to prioritize the population's needs to improve their QoL. Phase 2, epidemiological assessment, identifies and prioritizes relevant health issues and sets measurable health-related objectives. This includes identifying the behavior, lifestyle, and environmental factors that affect those issues.

Phase 3, the educational and ecological assessment, focuses on the broader causal factors that may contribute to the health issues identified in Phases 1 and 2. These causal factors may be assessed from the standpoint of several intrapersonal health promotion theories, such as the health belief model, social cognitive theory, and theory of reasoned action (Porter, 2016). Consequently, Green and Kreuter (2005) posited three groups of causal factors including predisposing factors, enabling factors, and reinforcing factors. Predisposing factors relate to knowledge, attitudes, and beliefs which make people more or less likely to adopt healthy lifestyles, behaviors, or accept environmental conditions. Enabling factors are the internal and external resources and skills required to achieve desired behavioral or environmental changes. For example, the availability, accessibility, and affordability of resources and services may enable or inhibit people from achieving the desired change. As such, the latter may require broader community and social action strategies to impact structural change. Finally, reinforcing factors are those that either support or hinder the adoption of the desired behavior (Green & Kreuter, 2005).

Phase 4 focuses on identifying the policy, regulatory, and administrative factors that may influence the implementation of the intervention. Therefore, it considers the

feasibility of the intervention in the context of the internal and external issues to ensure the success of the objectives set out in the earlier phases.

Proceed

Proceed comprises the next four phases (5 to 8) of the model that focus on the implementation and evaluation of the program or intervention (Green & Kreuter, 2005). Phase 5, implementation, is the execution of the planned intervention, whereas Phases 6 to 8 revolve around the process, impact, and outcome evaluations of the intervention. Process evaluation assesses the actual conduct and roll-out of the intervention, impact evaluation considers whether the intervention is having the desired impact on the targeted behavioral or desired environmental changes, and outcome evaluation assesses whether the intervention is achieving the desired outcome that was envisioned in Phase 1.

Application of the PPM in Research

A large body of research has utilized the PPM in the planning and evaluation of various health interventions, programs, and strategies (Cereda et al., 2020; Hatfield, Falmer, et al., 2016; Moshki et al., 2017; Saulle et al., 2020). These span topics including, but not limited to, psychosocial interventions, dietary nutritional programs, physical activity, diabetes programs, educational settings, pain management, cancer screening and prevention, and workplace interventions. For example, Moshki et al. (2017) evaluated the effectiveness of a group-based educational training program on the preventative behaviors of type 2 diabetes mellitus in high-risk individuals using the PPM. Participants in the intervention group showed significant improvements in predisposing, reinforcing, and enabling factors 1 month post-intervention compared to the control group. This

improvement was seen in the nutritional habits of the intervention group, suggesting that the PPM is an effective model in promoting preventative behaviors in patients with high-risk diabetes. In another study, Cereda et al. (2020) identified the need for high participation and performance of breast cancer screening programs in Italy and sought to define and test a planning software application to improve breast cancer screening using the PPM. Local cancer screening program coordinators were involved in the design of the application highlighting the participatory nature of the intervention outlined by PPM. All phases of the PPM were used in the screening program. An audit cycle was also incorporated to collect and evaluate the effectiveness of the programs. Results showed that the software application generated more standardized screening programs that had clearer indicators for monitoring and evaluation compared to the previous year. Therefore, the use of the PPM in this context helped standardize criteria to improve breast cancer screening programs and enables implementation of the audit cycle.

To further demonstrate the breadth of application of the PPM, Saulle et al. (2020) conducted a systematic review to assess its use in educational programs and health screening contexts. Twenty-seven studies were retrieved, of which 13 applied PPM in various cancer screening programs including mammography (five), cervical cancer (five), menopause-inducing cancer treatments, oral cancer prevention, and cancer screening in general. The remaining studies applied PPM in various conditions, particularly in chronic and degenerative disease areas. This systematic review demonstrated the effectiveness of PPM in providing an excellent framework for health prevention programs, especially in the context of screening.

In the area of ASDs, one study used the PPM in the planning and evaluation of autism interventions (Hatfield, Ciccarelli, et al., 2018; Hatfield, Falkmer, et al., 2016, 2017). Hatfield et al. (2016) sought to evaluate the effectiveness of an online interactive transition planning program for adolescents with ASD called the Better Outcomes & Successful Transitions for Autism (BOOST-A) to support their transition to further study, training, or employment. The PPM was used to guide the development of the transition program. The precede component was used to conduct a comprehensive needs assessment to identify factors relevant to the target population (Hatfield, Ciccarelli, et al., 2018) based on predisposing, reinforcing, and enabling factors which then guided the development of the intervention, BOOST-A. Then, the proceed component was used to direct the evaluation of the intervention (Hatfield, Falkmer, et al., 2017). As such, the use of the PPM provided a robust framework for the development of the intervention in accordance with the needs of key stakeholders, adolescents with autism and their parents, as well as evaluating the effectiveness of the online transition program (the intervention) following implementation.

It should be noted that as illustrated above, the PPM is most often used to evaluate the effectiveness of one intervention/program and how it impacts an outcome of interest. However, this dissertation study will contribute uniquely to the body of literature through the application of the PPM to multiple interventions and outcome measures which is different than its typical use.

Application of the PPM in this Study

The theoretical foundation of this research is based on the PPM which seeks to determine the association of several commonly used autism interventions with QoL and mental health. While the overall conceptual framework of the research uses the underpinnings of the PPM for diagnosis of unmet needs and the planning and implementation of effective interventions, it should be noted that it is the *Proceed* framework which is most relevant to the conduct of this study. Of note, the study builds upon the last two phases of the PPM, namely impact evaluation (phase 7) and outcome evaluation (phase 8) of interventions, to ascertain whether they address the issue identified in the earlier phases of the model (phases 1-4 of *Precede*) with a meaningful impact on QoL of people with ASD (Porter, 2016).

Importantly, the involvement of the autistic community in the evaluation process by way of a quantifiable survey fulfills the participatory premise of the PPM which requires the involvement of key stakeholders and the target community in the identification, planning, and evaluation of the health program or intervention (Crosby & Noar, 2011). It is assumed that a participatory approach was undertaken by program administrators and professionals during the phases of *Precede* when behavioral or environmental issues were identified and diagnosed before implementation of a given intervention, although the latter is out of scope for this project. Ultimately, the impact and outcome evaluation from this research should help either reinforce the application of the targeted interventions which meet the end goal or prompt a reassessment and revision to current intervention approaches to ensure meaningful QoL outcomes are achieved.

Literature Review

This study explored the use of commonly used interventions in people with ASD and determined their potential association with QoL and mental health from the perspectives of the autistic individuals or caregiver proxy reports. The functional, behavioral, and psychosocial manifestations of ASD have a significant impact on QoL which significantly challenge the ability of autistic individuals to participate in community and live a fulfilling life (van Heijst & Geurts, 2015).

The literature review section of this proposal will provide a comprehensive examination of published studies and current research which are pertinent to the understanding of relevant topics and justify the importance of undertaking this study. The review will be broken down into several sections including quality of life (QoL), mental health (depression and anxiety), and the use of autism interventions and their effectiveness. Specifically, seven autism therapeutic interventions will be reviewed: 1) socially based interventions, 2) mental health interventions, 3) behavioral therapies, 4) adaptive/DLS interventions, 5) mindfulness interventions, 6) medications, and 7) vocational interventions.

QoL in Autistic Adults and its Predictors

The World Health Organization (WHO, The WHOQOL Group, 1995, p 1405) defines QoL as ‘the individual’s perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standard and concerns’ as they relate to the individual’s physical and psychological health, personal beliefs, social relationships, level of independence, and salient features

of the environment. As such, QoL is a multidimensional construct that is influenced by both personal characteristics, behaviors as well as environmental settings. Related to this is the concept of *health* defined as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (WHO, 1946, p 1315).

In keeping with these definitions, various instruments have been developed and used to ascertain the subjective QoL of individuals with ASD compared to their neurotypical counterparts (Ayres et al., 2018). Given the multidimensional conceptualization of QoL, the WHOQOL-BREF questionnaire has been commonly used in the autistic population to measure various domains of QoL including physical, social, psychological, and environment to better understand the extent to which they are impacted by ASD symptomology, its deficits, and the environment (Ayres et al., 2017; WHOQOL BREF, 1996). Given the importance of QoL as an end goal for many autism interventions and services, it is critical to evaluate the QoL of people with ASD and identify factors which are associated with more favorable outcomes.

Numerous studies evaluating the QoL of adolescents and adults with autism have reported lower QoL across all domains compared to normative samples as well as people with other disabilities (Bishop-Fitzpatrick et al., 2018; Hong et al., 2016; Ikeda et al., 2014; Kamio et al., 2013; Katz et al., 2015; Khanna et al., 2014; Knüppel et al., 2018; Lawson et al., 2020; Mason et al., 2018; van Heijst & Geurts, 2015). A meta-analysis conducted by van Heijst and Geurts (2015) evaluated the QoL of people with ASD across the lifespan. A total of 10 studies with a combined sample size of 486 people with ASD and 17,776 controls were included. Results showed a significantly lower QoL in people

with autism compared to controls with a quite large mean effect size (Cohen's $d = -0.96$). Of note, the lower QoL finding persisted even in the elderly subgroup with autism (age range 53-83) which is often an underrepresented group in autism studies. Furthermore, age, IQ, and ASD severity were not significant predictors of QoL in this study. The large differences in QoL between people with autism and controls underscore that much work needs to be done through targeted interventions to achieve a higher QoL for this population. Additionally, the persistence of poor QoL across the lifespan suggests that interventions need to be tailored to the needs of the autism community on an ongoing basis to ensure better outcomes.

In line with these findings, the largest QoL study to date (Mason et al., 2018) which included 370 autistic adults from the Adult Autism Spectrum Cohort-UK (ASC-UK) reported a lower QoL for people with ASD across all domains of the WHOQOL-BREF compared to the general population. Of note, similar to the study by van Heijst and Greuts (2015), large effect sizes were reported across all QoL domains including physical, psychological, social, and environmental (Cohen's d ranging from 0.74 to 1.63). In this study, younger participants reported an overall higher QoL compared to older adults, while males reported higher QoL in the physical domain and females a better QoL in the social domain. In this study, positive predictors of QoL included being employed, being in a relationship, and receiving support, while having a mental health diagnosis, being female, and autism severity were negative predictors. The lower QoL in autistic adults in the study by van Heijst and Greuts (2015) study and Skevington & Kratochwill (2012) is an important finding as it may reflect inadequate access and provision of appropriate

services to older autistics compared to children and adolescents as well as the inability of those services to meet their unmet needs. Further, the lower social QoL in autistic adults may be related to social isolation as well as a loss of perceived informal support (Happé & Carlton, 2012). The concept of social support is important in the autism population given its association with lower QoL (Bishop-Fitzpatrick et al., 2018). Lower levels of QoL and its association with social support have been reported in adults with ASD compared to matched typical community volunteers suggesting the need to cultivate supportive social relationships through targeted interventions to improve QoL.

While it may be assumed that people with 'high functioning' autism (HFA) fair better than their lower functioning counterparts in terms of their intellectual, functional, and language development capacity, lower QoL outcomes persist in this subgroup as well (Kamio et al., 2013; Kamp-Becker et al., 2010). For example, in a nationwide cross-sectional study of adults with HFASD (Kamio et al., 2013), psychosocial QoL was lower than that of the general Japanese population and factors associated with better QoL included mother's support and early diagnosis. Similarly, an earlier study by Kamp-Becker et al. (2010) evaluating QoL in HFASD adolescents and young adults with no intellectual disability found lower QoL scores in three out of four domains of the WHOQOL-BREF including physical, social, and psychological. Of note, a significant association between 'daily living skills' and QoL was reported in this study highlighting the importance of integrating therapeutic interventions which enable autonomy and independence in everyday life for people with HFASD to improve well-being.

Physical QoL

In addition to the neurodevelopmental challenges, people with ASD are also burdened by a number of physical health issues. Recent evidence has shown high rates of physical problems (about 40%-60%) in autistic adults including obesity, gastrointestinal disorders, allergy, cardiovascular disease, and sleep disorders (Croen et al., 2015; Jones et al., 2016). In a large, diverse study of 1507 adults with autism from Kaiser Permanent Northern California, rates of immune conditions, gastrointestinal and sleep disorders, obesity, hypertension, and diabetes were significantly higher compared to age and sex-matched controls (Croen et al., 2015). Of note, frequent sleeping difficulties, thus poor sleep quality have been associated with poor mental health (Baker et al., 2019) which further exacerbates the issue. Indeed, a study by Khanna and colleagues (2014) assessing the physical health related QoL (HRQOL) of young adults aged 18 to 34 with ASD reported lower levels compared to their peers in the general U.S. population. One-third of participants in this study reported having a physical illness. Autism severity and perceived adequacy of social support were positively correlated with physical HRQOL, while maladaptive coping had a significant negative correlation. Lower physical health and its association with low QoL has been reported elsewhere in young adults with Asperger's syndrome and autism (Knuppel et al., 2018; Lawson et al., 2020) signifying the need for appropriate physical and medical therapies to address these problems.

Another study by Mason and colleagues (2018) assessing the QoL of 370 autistic adults in the UK found that 70% of participants had a physical health condition, such as sleep problems and hypertension. In this cohort, being employed was a positive predictor

of physical QoL. This is an important consideration since over half of autistic adults are unemployed or underemployed (Hirvikoski & Blomqvist, 2015). The 2017 Canadian Survey on Disability (CSD) showed that only 33% of people with ASD aged 20 to 64 years were employed compared to 79% without a disability. Poor employment has been associated with low independence, higher rates of physical and mental problems, and poor community engagement all of which negatively impact QoL (van Rijn et al., 2016). As such, lower QoL scores around the physical domain should not come as a surprise since questions revolve around the persons capacity to work, physical pain, mobility, and energy levels (WHOQOL-BREF).

Psychological QoL

Poor psychological QoL has been reported consistently across various studies in the autistic population. This domain includes items related to the presence or absence of mental health conditions, happiness, being satisfied with oneself, and having a meaningful life (WHOQOL-BREF, 1996). While these variables are highly correlated, mental health conditions are quite prevalent in people with ASD with rates ranging from 70% to 79% (Lever & Greuts, 2016; Mason et al., 2018), although some studies have reported lower rates (Gotham et al., 2015). It could be conceived that those who suffer from psychological disorders also have lower levels of self-satisfaction, self-esteem, self-efficacy, concentration, and have difficulty living a meaningful life. Lawson and colleagues (2020) evaluated the cross-sectional and longitudinal predictors of QoL in a cohort of 244 people aged 15-80 years with autism compared to 165 non-autistic individuals. Cross-sectional predictors of the psychological domain of QoL included

autism traits, mental health, and psychological well-being in the autistic population. In addition, depression symptomology was a unique contributor to all QoL domains of the WHOQOL-BREF in the autistic population, while psychological well-being was a unique predictor of Psychological and Social QoL in both groups. The authors highlight two important findings from this study related to mental health which include the major influence of depressive symptomology on QoL as well as the contribution of psychological well-being to all QoL domains except for Physical QoL.

Lower psychological health among people with ASD is significant and persists across all age and gender categories (Khanna et al., 2014). Additionally, the presence of comorbid mental illness appears to exacerbate the issue in the autistic population as those with comorbid mental illness have lower mental HRQOL scores compare to adults with autism without comorbid mental health (Khanna et al., 2014). As such, therapeutic interventions and treatments aimed at improving the core symptoms of autism should consider the overall psychological profile of the individual.

In addition to the aforementioned predictors of psychological QoL, a range of other predictors have been identified by various researchers. These include being extraverted and not having been bullied (Hong et al., 2016); coping skills and social support (Khanna et al., 2014); and being employed and living independently (Moss et al., 2017). These are important factors to consider when planning and implementing interventions to ensure better QoL outcomes where mental health is concerned.

Social Relationship QoL

Deficits in social skills are a core characteristic of people with ASD which impact several facets of life including forming peer relationships, engaging in social interactions, communication, obtaining employment, and the ability to participate and integrate into the community (Knuppel et al., 2018; van Heijst & Greuts, 2015). Impaired social skills and low social cognition, in general, have been associated with poor QoL outcomes as they often result in social isolation, anxiety, and depression (Lieb & Bohnert, 2017). The social skills challenges facing individuals with ASD are largely rooted in some of the deficits seen in other core elements of autism including the inability to process non-verbal cues, delays in the acquisition of verbal communication skills, repetitive behaviors, and sensory issues. The culmination of these problems has deleterious effects on the ability of autistics to engage in basic social interaction and communication which in turn result in a lack of desire and avoidance of people and social situations.

Of the four QoL domains, (physical health, psychological, social relationships, and environment), social QoL is the most affected and lowest in adults with autism (Jennes-Coussens et al., 2006; Kamio et al., 2013; Kamp-Becker et al., 2010; Lin, 2014). A study by Mason et al. (2018) found that of the 370 adult participants with ASD, 98% reported 'social impairment' as measured by the Social Responsiveness Scale Adult (SRS-A). Of note, gender had a main effect with females reporting a higher social QoL compared to males, although the effect size was small. This finding is consistent with the study by Lawson et al. (2020) who also reported a lower social QoL in males compared to females, although it contrasts with the findings from Kamio et al. (2013) who found a

higher social QoL in males with autism compared to females. The social QoL differences in gender may reflect the tendency of females to be more socially motivated and their ability to maintain friendships compared to males who may find social situations more challenging (Bargiela et al., 2016). Also, this concept has been reported in the autism literature, particularly with respect to females (Hull et al., 2017). Not surprisingly, positive predictors of social QoL included being in a relationship and receiving support, while being older, having a mental health condition, and higher SRS scores were associated with negative social QoL (Mason et al., 2018).

Interestingly, a study by Hong and colleagues (2016) evaluating the concordance between autistic adult self-reports, maternal proxy-reports, and maternal report regarding the subjective QoL of the adults with autism found that the only domain where the adult self-reports and maternal proxy reports differed significantly was the social QoL domain with maternal ratings being lower. This suggests that while mothers may report the subjective QoL of their autistic adult child quite accurately, they may perceive their social relationships as poorer than their adult child's self-perception.

In assessing the longitudinal predictors of QoL in adults with autism, Lawson and colleagues (2020) found that among the sample of 244 participants, baseline autism traits, well-being, mental health, and social QoL were significant predictors of social QoL at 2-years follow-up, although the unique predictor was baseline Social QoL. These results underscore the importance of social skills and the dire impact of their deficit on the QoL of people with autism.

Environment QoL

In contrast to social QoL which is commonly the lowest in the autistic population compared to controls, environment QoL is most often reported the closest to normative levels (Hong et al., 2016; Lin, 2014; Moss et al., 2017). The Environment QoL domain pertains to items such as transport, participation and involvement in daytime activities, safety, access to health services, and living arrangements (Harper, 1998). According to the National Longitudinal Transition Study-2 (Roux et al., 2015), 87% of young adults with autism live with a parent after leaving high school compared to 21% of young adults living in the US. Of note, only 19% of young adults with autism ever lived independently without parental supervision which is in stark contrast to young adults with learning disabilities and emotional disturbance who achieve rates of independent living at 77% and 66%, respectively. Some of the factors contributing to the inability of autistic adults to live independently relate to their cognitive, functional, communication, and daily living skills deficits which make them heavily reliant on their caregivers for support.

In addition to the challenges concerning independent living, transportation issues present yet another challenge to autistic adults. A study conducted by Lubin and Feeley (2016) used focus groups and key stakeholder interviews with people with autism and their caregivers to determine the issues associated with transportation. Findings highlighted the importance of transportation in the lives of people with ASD as a means to achieve greater independence and employment success. Of note, barriers to transportation included lack of familiarity with public transportation modes, an absence of transport options, and cost factors. Parental concerns revolved around the safety of

their adult children using public transportation and the burden of being the primary providers of transport for their adult children. On the other hand, the adult participants with ASD expressed the challenges of relying on their caregivers for transportation as well as their desire to be able to travel independently using public transport or driving (Lubin & Feeley, 2016).

Regarding the impact of these transportation, independent living, safety, and access challenges on the environment QoL of people with autism, Mason and colleagues (2018) found that receiving support significantly predicted environment QoL. Such supports included help at work, daily living tasks, managing money, and organization or planning of daily activities. Not surprisingly, the younger group of participants (17-25 years of age) reported higher QoL in this domain compared to those in the older age groups reflecting the expected provision of more support to younger adults with ASD compared to those who are older. Similarly, even in a high functioning group of adults with autism, environmental factors including mother's support and early diagnosis were also associated with a better QoL (Kamio et al., 2013).

Regarding accessing healthcare, an extensive list of barriers has been identified that prevent or impair the ability of autistic people to obtain the care their need (Dern & Sappok, 2016; Nicolaidis et al., 2015; Raymaker et al., 2017; Vogan et al., 2017). These include patient-level factors, such as verbal communication skills, slow processing of information, sensory issues; provider-level factors including incorrect knowledge, lack of knowledge about autism, lack of flexibility regarding the patient's communication style; and systemic-level issues, such as complexities of accessing healthcare services,

availability of formal or informal supports, and stigma about autism (Nicolaidis et al., 2015). Dern and Sappok (2016) identified a set of barriers to access which comprised of making appointments, discomfort of medical examinations, communication difficulties, hospital changes, and sensory difficulties. Research has suggested that over 75% of people with ASD have experienced three or more barriers to healthcare access, while about three quarters could not access much needed healthcare (Vogan et al., 2017).

Taken together, the noted healthcare access, transportation, and independent living challenges facing people with autism have a significant detrimental impact on their QoL suggesting opportunities for environmental and systemic modifications and interventions which may in part help improve their well-being.

Concordance Between Self-Proxy and Parental QoL Reports

Research studies which assess Quality of life (QoL) often utilize three strategies: 1) self-reports (the participant is asked to complete the survey), 2) parent proxy reports (the parent is asked to report as they believe their child would answer), and 3) parent report (asking the parent to report on their own opinion). While self-reports are increasingly seen as the gold standard providing the most accurate depiction of the person's state of mind and health status, parental reports are often necessary in special populations, such as those with ASD given the significant communication and/or cognitive functioning impairments experienced by this group (Clark et al., 2015; Hong et al., 2016; Ikeda et al., 2014). As such, many studies have focused on examining the reliability and validity of QoL self-report scores by people with ASD and their level of agreement with parental proxy reports and parental reports (Clark et al., 2015; Hong et

al., 2016; Ikeda et al., 2014; Knuppel et al., 2018; Sheldrick et al., 2012; Shipman et al., 2011). Studies in the pediatric, adolescent, and adult populations have generated mixed results with regard to the level of correlation between parental proxy reports, parental reports, and self-reports. This should not come as a surprise since there is an absence of validated and specific instruments which are designed to measure QoL/health related QoL in children and adolescents with ASD.

An earlier study by Sheldrick and colleagues (2012) assessed the concordance between QoL reports among adolescents with ASD and proxy- and parental reports using the Pediatric QoL Inventory (PedsQL). Thirty-nine participants aged 12-18 years with ASD, but no ID were enrolled in the study and asked to complete the PedsQL questionnaire which includes four domains including physical, social, emotional, and school functioning. Similarly, their parents were asked to complete the questionnaire twice, once from the perspective of their child, and then from their perspective. Results showed a higher correlation between adolescent self-reports and parent proxy reports compared to parent reports and adolescent reports. These findings suggest that parents are better able to reflect on the point of view of their adolescent children when asked to answer based on the assumption of their child's perspective (proxy report) than their point of view (parent report). Findings from this study are consistent with those of Hong et al. (2016) who compared the subjective QoL of 60 adults with ASD aged 25 to 44 with their maternal proxy reports and maternal reports using the WHOQOL-BREF. First, findings showed that adults with ASD rated their own QoL reliably (internal consistency) as their maternal ratings. Further, QoL scores from self-reports of adults with ASD were

most closely correlated with those of maternal proxy reports compared to maternal self-reports.

In contrast to these findings, Ikeda et al. (2014) conducted a critical review of QoL measures used in various studies in children and adolescents aged 5 to 20 with ASD and found large discrepancies in QoL scores between self-reports and proxy reports. Importantly, self-reported QoL was reported more favorably or higher in most domains compared to parental proxy reports. Another important finding from this study was that almost all QoL measures lacked psychometric properties for children and adolescents with ASD, although only the PedsQL tool appeared to meet reliability and validity criteria in this population. These results are similar to those reported by Shipman et al. (2011) who also showed lower QoL through parental proxy-reports of adolescents with ASD compared to self-reports. In line with the mixed findings, another study by Clark et al. (2015) which assessed the self- and proxy-reported QoL of 22 adolescents aged 13 to 18 with ASD using KIDSCREEN-52 found low intra-class correlation (ICC) coefficients between adolescent self-reports and parental proxy-reports. Specifically, discrepancies were seen in the scales of self-perception, autonomy, and parent relations. Finally, a more recent large nationwide Danish QoL study of 1738 adolescents and adults with ASD (Knuppel et al., 2018) evaluated the concordance between self- and parental-proxy reports and found that scores were moderately correlated between the two groups, and that individual self-reports of QoL were significantly, but only slightly higher than parental-proxy reports in a few QoL domains. The authors concluded that proxy-reports QoL cannot accurately replace self-reports given the moderate correlations seen between

the two groups and that individuals with ASD report their own QoL differently compared to what their parents may perceive.

Taken together, the totality of the evidence suggests differences in QoL viewpoints between self-reports of the autistic individuals and their parent proxy reports and standard parent-reports, although parental proxy reports appear to more closely reflect self-reports compared to parent reports. As such, where possible, adult self-reports should be the preferred choice in studies and clinical settings where QoL is being evaluated in individuals with autism. However, if adults cannot self-report, then parental proxy-report is the better method compared to parental report.

Mental Health: Depression and Anxiety

People with ASD have an increased vulnerability and risk for comorbid mental health conditions, with depression and anxiety being the most common (Croen et al., 2015; Joshi et al., 2013). Estimated rates of these disorders vary considerably across studies with some reporting rates as high as 70% for depression or anxiety (Lever & Greuts, 2016; Mason et al., 2018) and others reporting rates as low as less than 1% for depression (Buck et al., 2014) and 5% for anxiety (Tsakanikos et al., 2011). The high variability in prevalence rates of mental disorders in the literature reflects a high degree of heterogeneity in methodology, diagnostic tools, and clinical samples used which underscore the importance of well-defined study samples, representation by non-clinical samples, and the use of validated diagnostic tools to reduce bias and heterogeneity (Hollocks et al., 2019; Wigham et al., 2017). A recent systematic review and meta-analysis (Hollocks et al., 2019) using a large sample of studies and participants ($n =$

26,070 for anxiety and $n = 26,117$ for depression) found current and lifetime prevalence of 27% and 42% for any anxiety disorder and 23% and 37% for depressive disorder.

Another systematic review evaluating rates of depression in high functioning (HF) children and adults with ASD reported rates ranging from 1% to 47.1% (Wigham et al., 2017). The prevalence of depressive disorders was higher in the HFASD population compared to the general population which ranged from 2.5% to 10.7% (Center for Behavioral Health Statistics and Quality, 2016; Spiers et al., 2012). The authors recommend caution in the interpretation of these results citing gaps in the methodological aspects of such studies including the inclusion of clinical groups, small sample sizes, and limited options for psychometrically validated measures for people with ASD (Wigham et al., 2017).

A recent study by Park and colleagues (2019) evaluated QoL, disability, distress, functioning, and mental health symptoms in treatment seeking young adults aged 16 to 30 years with autism without ID. These reports were compared to other young adults in the general population presenting with primary mental health disorders including depression, bipolar, psychosis, and anxiety. Results showed that young adults with ASD had significant levels of disability, distress, and impaired QoL compared to controls, and in some cases, these levels were more severe than those presenting with formal mental disorder diagnoses. Of note, severe depression, anxiety, and stress as measured by DASS-21 were reported by the young autistic group which was similar to young adults presenting with primary depression and anxiety disorders. Regarding predictors of distress and QoL, depression predicted QoL and days of lost work, while depression,

stress, and anxiety were all significantly associated with distress. These results underscore the significant mental health burden experienced by young autistic adults which are similar to those with a primary psychopathology and suggest the need for specialized intervention and services to address this high unmet need to improve QoL, distress, and overall functioning in this young population (Park et al., 2019).

When considering the occurrence of mental disorders in youth and young adults with ASD, a Canadian study evaluated the prevalence of mental health issues, service use, and barriers to service use in post-secondary students from the Autism Mentorship Program (AMO) at York University (Ames et al., 2016). Results revealed that over half of participants (56%) had at least one mental health condition, while 52% had at least two diagnoses. As reported in previous studies, anxiety disorders were the most common co-occurring condition followed by mood disorders, such as depression at 24%. Of note, 56% of students reported accessing at least one mental health service and barriers to service use included long wait times, too many steps, and difficulties in describing their problems to health care providers regarding their needs. Taking a lifespan approach, Lever and Geurts (2016) examined the occurrence of psychiatric symptoms and diagnoses in young, middle-aged, and older adults aged 19 to 79 with and without ASD. They found that adults with ASD had a higher prevalence of psychological symptoms and distress compared to the control group and these elevations persisted across the lifespan in all age groups. Seventy-nine percent of the ASD group experienced any psychiatric disorder once in their lives compared to 49% of the comparison group. Here again, depression and anxiety were the most common disorders, although lower rates

were observed in the older versus younger groups suggesting a reduction in psychiatric disorders in late adulthood, also seen in neurotypical aging adults (van Heijst et al., 2020).

Contrary to this finding, a study by Roy and colleagues (2015) reported higher rates of psychopathology in older versus younger adults with ASD, although the 'older' age group in this study comprised of middle-aged adults who were 40 to 62 years old. Indeed, higher rates of depression have been reported in mid-adulthood compared to younger or older individuals (van Heijst et al., 2020). In the study by Lever and Geurts (2016), female gender, lower age, and ASD severity were associated with the presence of any anxiety disorder.

Other studies assessing predictors of mental health disorders in the ASD population have revealed a number of risk factors. Common predictors of depression and anxiety in the autistic population have included alexithymia, autistic traits, executive functioning impairments, female gender, and social camouflaging (Albantakis et al., 2020; Fietz et al., 2018; Hull et al., 2021; Lawson et al., 2015; Morie et al., 2019; Wallace et al., 2016). For example, in examining whether alexithymic and/or autistic traits are risk factors for depression and social phobia in three groups of adults including ASD, those with social interaction challenges without autism, and neurotypicals, Albantakis and colleagues (2020) found that alexithymia was predictive of depressive symptoms, while autistic traits were associated with social phobia. Interestingly, both traits were risk factors for depressive and social phobia symptoms in the neurotypical group and only social phobia symptoms in the socially challenged non-ASD group. These

findings are in line with those of Morie et al. (2019) who also found a strong relationship between alexithymia and emotional regulation which mediated the association between autism traits and anxiety and depression in a group of 64 young adults with high functioning autism. Taken together, these results suggest the important role of alexithymia in depressive and anxiety disorders in people with ASD and the potential benefits of diagnosing and targeting this trait to in part reduce psychiatric symptomology in this population.

In investigating other risk factors for depressive and anxiety disorders in the autistic population, the role of executive functioning (EF) impairments has been implicated (Lawson et al., 2015; Wallace et al., 2016). In a study of 35 adults with ASD and no ID, real-world EF was assessed by parental reports to identify deficits in flexibility and metacognition. Results showed that flexibility issues were associated with anxiety symptoms while metacognition difficulties predicted depressive disorders (Wallace et al., 2016). These findings corroborate with those of Lawson et al. (2015) who also found that real-world executive functioning impairments as measured by lack of flexibility were predictive of greater anxiety and depressive symptoms among a pooled sample of 125 children with ASD and ADHD. As such, interventions targeting flexibility and other EF difficulties, such as behavioral inhibition could ameliorate comorbid psychopathology as a byproduct of autistic symptomology.

Finally, a study by Uljarevic et al. (2020) evaluated self-reported anxiety and depressive symptoms in a sample of 255 individuals with ASD across various age groups including adolescents, young-, middle-aged, and older adults. Results showed an

increasing trend of depression and anxiety levels from adolescence to middle-age followed by a slight decline in older adults. Of note, consistent with other reports, predictors of depression and anxiety included female gender and higher autism severity. Since the latter two are non-modifiable risk factors, these findings emphasize the need to accurately assess and diagnose comorbid mental health issues in this population which are highly prevalent across the lifespan to provide timely support and interventions, particularly in females who appear to be more vulnerable and impacted by these mental disorders.

Autism Interventions

Autism is a lifelong neurodevelopmental condition and the need for supports and services to people with ASD and their families is a continuous and ongoing process (van Heist & Geurts, 2015). Provision of early intervention strategies is widely available and well-established during childhood to support the numerous deficits of this population, although there is a marked decrease known as the ‘service cliff’ in the availability of essential resources and services during and after transitioning into adulthood (Anderson et al., 2018). Nevertheless, even during adolescence and adulthood, there is a broad range of interventions applied to support the needs of this population, each varying in terms of scope, focus, methodology, intensity, and duration. These are always aimed to address the complex challenges and deficits experienced by people with ASD with the goal of improving social interaction and communication, challenging behaviors, mental health (e.g. depression and anxiety), independence and life skills, community engagement, employment opportunities, and ultimately QoL (Benevides et al., 2020). As such, the use

of a combination of interventions tailored to the different needs of individuals with ASD is not uncommon.

When used properly and in the right context, effective interventions can result in positive outcomes by improving functioning, behaviors, adopting new skills, altering the individual's environment and how they interact with their environment (Odom et al., 2010). ASD interventions cannot be a one-size-fits all approach, but rather require a multi-disciplinary team within multiple service delivery systems. For instance, collaboration between healthcare, educational, and other professionals and service providers is commonly seen, although the involvement of parents and caregivers in the implementation and coordinating of interventions is also crucial to optimize outcomes.

Evidence-Based Practice

While there are a broad range of interventions available to meet the needs of people with autism, the selection of the right intervention(s) is of utmost importance to ensure the best fit and the likelihood of producing desired results. Evidence-based Practice (EBP) provides a framework to identify and implement interventions that have the highest likelihood of being effective for a specific individual with autism (The National Professional Development Centre on Autism Spectrum Disorders, [NPDC], n.d.). According to the NPDC (n.d.), 'An evidence-based practice is an instructional/intervention procedure or set of procedures for which researchers have provided an acceptable level of research that shows the practice produces positive outcomes for children, youth, and/or adults with ASD'. As such, EBP provides the highest level of research evidence when integrated with the expertise and opinion of

professionals and individual characteristics (Hume et al., 2021). The historical roots of EBP trace back to Cochrane (1972) who posited that the efficacy and effectiveness of medicine and health practice should be based on empirical, scientific evidence. This was further reinforced by Sackett's and colleagues (1996) who advocated for evidence-based medicine and its medicine movement which was considered as just a 'first step'. Therefore, in this multi-step process, the selection and application of scientifically evidence-based interventions would also depend on the skills and expertise of a seasoned professional who have the ability to implement the appropriate intervention tailored to the autistic individual's specific needs.

Smith (2013) identified two broad classes of interventions that appear in the research literature: focused intervention practices and comprehensive program models (CPM). Focused intervention practices target the individual and are designed to address a single goal or skill of a person with autism (Odom et al., 2010). Some examples include prompting, video modeling, and discrete trial teaching. CPMs, on the other hand, are organized around a conceptual framework and aim to achieve a broad set of outcomes which target the learning and developmental core deficits of ASD. As such, they are applied over a longer period across one or more years (Odom et al., 2014). Some examples of CPM include the early intensive behavior intervention (IBI) program based on the UCLA Young Autism Project (Smith et al., 2000) and the Early Start Denver Model (Rogers et al., 2012).

To date, only three rounds of comprehensive systematic reviews focusing on intervention practices have been conducted by the NPDC and the National Standards

Project (NSP) for children and youth with autism. These reviews have included both randomized controlled trials (RCTs) as well as single case experimental design (SCD) studies which are often excluded from such reviews. While SCDs are traditionally excluded from such systematic reviews due to their limited evidence on efficacy, their exclusion from systematic reviews ignores a substantial body of scientific evidence which has been replicated across multiple studies (What Works Clearinghouse, 2020). Thus, these systematic reviews have included SCDs, except for the first review (Odom et al., 2010) as part of their research methodology.

The first of these reviews were conducted by the NPDC investigators (Odom et al., 2010) which included articles published from 1997 to 2007 over a 10-year period. The second review comprised a more comprehensive review and extended the literature coverage to 22 years (1990-2011) as well as included SCDs along with RCTs as part of the review. Finally, the most recent review by Hume et al., (2021) further expanded the autism intervention literature to include evidence from 2012 to 2017 and addressed questions such as ‘What focused intervention practices are evidence-based? What outcomes areas did evidence-based focused intervention practices address? What are the characteristics of the research designs, participants, and intervention implementation?’ (Hume et al., 2021, p.4). Of note, when comparing the second (1990-2011) and third review periods (2012-2017), more studies were conducted in the 12-14 years old age group (17% to 27%, respectively) and 15-18 years old age group (10% to 17%, respectively). Together, the two systematic reviews included 972 articles from which 28

focused intervention practices were identified and met the criteria set out for evidence-based practice (EBP).

EBP interventions emerging from the reviews included cognitive behavioral/instructional strategies, social skills training, video modeling, visual supports, and sensory integration, among others. In children and youth with autism, commonly evaluated outcomes included communication, social skills, challenging behaviors, as well as mental health, academic, and vocational outcomes which were newly added to the most recent review (Hume et al., 2021). The authors highlight the importance of such systematic reviews which identify EBPs that may be translated into useable and practical information for practitioners. These could then be matched to the learning needs of children and youth with autism to achieve better outcomes.

Interventions in Adults with Autism

In contrast to the availability of evidence-based interventions in children and youth with ASD, the literature is quite scarce in autistic adults (Lewis & van Schalkwyk, 2020). This is likely the result of a high prevalence of early intervention approaches delivered in early childhood to optimize outcomes. While it is recognized that autism is a lifelong neurodevelopmental condition, there exists a sharp decline in the availability and provision of essential services known as the ‘service-cliff’ during and after transitioning into adulthood (Anderson et al., 2018). This, in part is due to the termination of government funding for autism services as well as the scarcity of adult-focused resources which were once available during the earlier years in life (Hatfield et al., 2017). Similarly, the conduct of high-quality research evaluating the efficacy of interventions in

the adult population seems to decrease as well (Howlin & Taylor, 2015). This presents a concerning gap in research and the ability to provide necessary supports and services to adults with autism despite the new challenges they encounter upon transitioning into adulthood. These include loss of critical supports from structured institutions and service providers, the pursuit of independence, increased awareness of their cognitive and social limitations, and challenges with community integration and vocational opportunities. Indeed, several systematic reviews have elucidated the poor quality of research in the autistic adult population, particularly with regard to interventions (Benevides et al., 2020; Lewis & van Schalkwyk, 2020; Taylor et al., 2012).

Although almost a decade old, a seminal systematic review was conducted by the Vanderbilt Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ) to assess the comparative effectiveness of interventions for adolescents and young adults with ASD (Taylor et al., 2012). The AHRQ mandates the generation of Evidence Reports/Technology Assessments through several EPCs to ascertain comparative effectiveness reviews (CERs) of devices, medications, and other relevant interventions to improve the quality of health care. The systematic review focused on research literature on autism interventions for adolescents and young adults aged 13 to 30 as well as interventions aimed at family members (Taylor et al., 2012). Interventions in the following categories were included: behavioral, adaptive/life skills, vocational, educational, medical, and allied health approaches which were compared to no treatment, placebo, or other comparative interventions. Both intermediate and long-term outcomes were assessed including changes in core ASD

symptoms, mental health comorbidities, transition process, and functional behavior (intermediate); and changes in academic and occupational attainment, adaptive independence, mental health, and psychosocial adaptation (long-term). Study quality assessment methodology from previous AHRQ reviews was used to categorize study quality into three levels of *poor, fair, and good*. In addition, strength of evidence defined as ‘the adequacy of the current research, in quantity and quality, and the degree to which the entire body of current research provides a consistent and precise estimate of effect’ was used as *insufficient, low, moderate, or high*. Findings from the systematic review revealed significant gaps and a lack of scientific rigor in research aimed at understanding the impact of interventions for adolescents and young adults with ASD. Of the 32 studies which met the inclusion criteria, most were of poor quality (n=27), five were fair quality, and none were good quality. In addition, of the 10 randomized controlled trials (RCTs) in the review, only five were fair quality, while the remainder were comprised of case series, short-term studies, cross-over, and cohort studies with small sample sizes. Importantly, across all interventions and outcomes the strength of the evidence was insufficient as studies lacked replication, used small sample sizes, were short-term, had poor quality, and addressed disparate interventions and outcomes. Moreover, study populations across all interventions were highly variable ranging from those with ASD and ID to high functioning ASD (Taylor et al., 2012).

Based on these findings, the authors underscore a significant gap in autism research and the urgent need for the conduct of more rigorous and evidence-based studies to ascertain the effectiveness of autism interventions (Taylor et al., 2012). Until the

availability of higher quality research, the large-scale implementation of autism interventions is unlikely. Notably, the lack of RCTs across all intervention categories is troubling, particularly in the category of medical interventions where this design is critically important to capture the occurrence of adverse events. Furthermore, the focus on short-term, highly specific intermediate outcomes and lack of longitudinal studies to better assess the long-term impact of autism interventions is concerning as it limits an understanding of their lasting benefits across the lifespan. The authors note, 'No studies provide adequate information on longer term outcomes, and particularly on outcomes related to achieving goals for independence and quality of life' (Taylor et al., 2012). The latter may reflect the lack of consensus and understanding of the most appropriate and valid outcome measures for the autism population specifically, as well as the lack of empirical evidence which identifies the more relevant and valued outcomes by individuals with ASD and their families. Taken together, findings from this pivotal systematic review highlight the dramatic lack of evidence-based approaches to therapeutic interventions for adolescents and young adults with ASD. Further, they suggest a call to action for researchers to adopt and integrate more robust and standardized approaches to autism intervention study designs, characterization of study participants, description of the intervention and measures of fidelity and adherence.

In line with the recommendations of the review by Taylor et al. (2012), a recent systematic review by Benevides et al. (2020) sought to identify interventions used by autistic adults which addressed their health and health outcomes (physical, mental health, and wellbeing), as well as the quality of the evidence generated for these interventions.

From the 778 studies reviewed, 19 met the inclusion criteria which comprised of using an intervention, measuring a health outcome, and having a sample of at least 50% autistic adults. The studies employed a mix of different designs including case reports or case series (37%), single-subject design (16%), pre-test–post-test single group design (16%), pre-test–post-test quasi-experimental (10%), and randomized controlled design (21%), to examine the effects of an intervention in adults with autism.

Of all the interventions examined, only two were considered as *emerging evidence-based approaches* – cognitive behavioral interventions and mindfulness approaches (Benevides et al., 2020). Cognitive behavioral interventions were used to improve mood and anxiety symptoms in autistic adults, while mindfulness approaches were used to address self-reported depression and anxiety as health outcomes among adults with ASD without ID. Of note, the remainder of the interventions assessed in the study did not have sufficient evidence to support their use in autistic adults. Additional key findings from this systematic review included the need to involve the autism community when evaluating evidence-based interventions, the importance of measuring QoL outcomes regardless of the intervention, since it is an essential indicator of health, and the investigation of other interventions currently used by the autistic population to address their health and well-being (Benevides et al., 2020). Results from this study highlight several key points: 1) despite the large number of studies assessing the effectiveness of interventions in adults with autism, only two approaches met the criteria of *evidence-based approaches*, 2) further research is needed to define and measure QoL outcomes and wellbeing as a result of these interventions, and 3) community-stakeholder

partnerships are needed to better evaluate the relevance, use, and benefits of autism interventions. Table 1 provides a list of studies which have evaluated the association between single interventions with health and health-related outcomes (physical, mental health, and wellbeing).

Table 1

Studies Evaluating the Association of Single Interventions with Health-Related Outcomes

Study	Intervention type	Evidence-based	Health outcome
Ekman and Hiltunen (2015)	CBT	Yes	Self-reported anxiety
Gal et al. (2015)	Vocational	No	Self-reported QoL, subjective well-being
Hesselmark et al. (2014)	CBT	Yes	Self-reported QoL, self-esteem, psychiatric symptoms
McGillivray and Evert (2014)	CBT	Yes	Self-reported anxiety, depression, and stress
McVey et al. (2016)	Social skills	Yes	Parent and self-reported social phobia, social anxiety, loneliness
Roser et al. (2009)	Medical	No	'Distress with psychotic features'
Russell et al. (2013)	CBT	Yes	Obsessive-compulsive behavior
Siew et al. (2017)	Peer mentoring	No	Self-reported well-being, social anxiety, communication anxiety
Sizoo and Kuiper (2017)	CBT Mindfulness	Yes	Self-reported anxiety and depression, mood, rumination
Spek et al. (2013)	Mindfulness	Yes	Self-reported depression, anxiety, rumination
Weiss and Lunsky (2010)	CBT	Yes	Self-reported depression and anxiety

Finally, another recent systematic review highlights the disparities in intervention research in autism. The review by Lewis and van Schalkwyk (2020) sought to quantify how intervention research is applied across age groups and modalities in individuals with autism. A total of 218 studies and 11,213 participants with ASD were included. Results showed that the majority of studies (84%) enrolled people under 18 years of age and that these individuals were more likely to participate in behavioral studies (OR = 1.34, CI: 1.17–1.54) and less likely to be enrolled in pharmacological studies (OR = 0.60, CI: 0.52–0.69) compared to people over 18 years old. The authors raise awareness of the need to increase interventional studies in the adult autistic population and note the multiple barriers contributing to the issue which include prioritization of child and youth recruitment in early intervention research and the decline in parental motivation to engage their adult children in such research with age (Burke et al., 2018). Of note, funding for autism research continues to revolve around genetics, brain mechanisms, risk factors and causes of ASD, and interventions that primarily focus on children (Interagency Autism Coordinating Committee (IACC), 2016). Further, a mere 2% of the national funding from public and private sectors is spent on research in autistic adults (IACC, 2016). As such, there is a gap in the availability of high-quality research which supports the use of effective interventions to improve health outcomes in adults with ASD.

The following section of the literature review will provide a more comprehensive overview of interventions used in adults with autism-related to their use, effectiveness, and limitations. The list of interventions includes social-skills, mental health, behavioral,

adaptive/life skills interventions, mindfulness, medical, and vocational interventions. The selection of these particular therapeutic interventions is based on the available evidence supporting their effectiveness, their relevance to addressing the core deficits and unmet needs of the autistic population, their common use, and their potential association with wellbeing and quality of life as noted in the previous sections of this proposal.

Social Skills Interventions

Deficits in social skills and communication are a core feature of ASD and often present significant challenges to building relationships (APA, 2013). These difficulties extend into adulthood and often appear more pronounced as social demands exceed social skills (Gates et al., 2017). Individuals with ASD experience difficulties in initiating interaction, sustaining social and emotional reciprocity and relationships, and reading and using nonverbal cues. Moreover, most also have difficulties in understanding others mental states, known as the theory of mind (ToM) which has been associated with a lack of acceptance by peers (Slaughter et al., 2015). Such impairments extend beyond the social realm and can interfere with community integration, academic achievements, and vocational opportunities all of which may contribute to isolation, depression, and overall poor quality of life (Spain & Blainey, 2015). Indeed, poor social skills and social cognition have been correlated with poorer QoL outcomes. An earlier study by Howlin et al. (2000) found that about half of young adults with HFASD had no friends, while another national U.S. study of young adults with ASD aged 17-21 found that 55% had not seen a friend and 64% had not talked to a friend in the past year (Liptak et al., 2011). Similarly, deficits in social skills also limit the ability of young adults with ASD to form

romantic relationships. Although this desire is often expressed by those with ASD, the development of such relationships and ultimately marriage is quite rare (Barnhill, 2007; Cederlund et al., 2008).

Given the significant negative consequences of social skills impairments in people with ASD and their impact on QoL, the development, implementation, and evaluation of social skills interventions have been an important area of research. In fact, the National Institute for Health and Care Excellence guidelines (NICE, 2021) recommends the use of group-based and individual-based social skills programs as first-line therapy to improve social skills and relationships in adults with ASD without learning disability or with mild to moderate learning disability. According to NICE (2021), such social interventions should include modelling, peer or individual feedback, strategies to handle difficult situations, explicit rules, and discussion and decision-making.

Studies assessing the effectiveness of group social-skills interventions (SSI) have been primarily conducted in children and adolescents (Cappadocia & Weiss, 2011; Miller et al., 2014; Reichow et al., 2013) and have in general found improvements in social skills. However, several methodological limitations have been identified affecting the internal and external validity of these studies including small sample size, heterogeneity of participants in terms of comorbidities, intellectual functioning, and symptom severity, and differences in outcome measures. Conversely, relatively little research has been done in assessing the effectiveness of group SSIs in adults with autism although most have demonstrated a positive impact of social interventions in improving outcomes in this population.

Several social skills interventions using different protocols to address the social needs of individuals with HFASD and ASD with and without ID have been developed. These employ a range of designs and methodologies including randomized controlled trials (RCTs), quasi-experimental, single-arm intervention, and non-randomized design with program durations ranging from eight to 18 weeks. For this literature review, only the most researched evidence-based SSIs will be covered. These include the University of California LA (UCLA) *Programme for the Education and Enrichment of Relational Skills for Young Adults (PEERS-YA)* (Gantman et al., 2012; Laugeson & Frankel, 2010; Laugeson et al., 2015; McVey et al., 2016; White et al., 2015), *Aspirations Programme* (Hillier et al., 2007, 2011), *Social Skills Group* (Ashman et al., 2017), *Social Cognition and Interaction Training for Adults (SCIT-A)* (Turner-Brown et al. 2008), and *Social Skills Programme* (Howlin & Yates, 1999). These adult SSIs have utilized similar approaches as those in child interventions, such as initiating and maintaining conversations, developing friendships, non-verbal communication, interpersonal skills, and handling bullying. In addition, more adult-specific topics have also been targeted including problem-solving skills at work, employment and job interview skills, social and adaptive skills, romantic dating skills. These SSIs have employed a group format using a variety of therapeutic methods including facilitated group discussion, role play, shared problem-solving, video modelling, behavior modelling, and structured games and activities. Overall, these evidence-based SSIs have shown good efficacy in improving social skills and engagement in adults with ASD.

PEERS-YA. The PEERS program is a manualized evidence-based social skills program originally developed by Laugeson and Frankel (2010) for adolescents with HFASD. The program focuses on making and keeping friends, managing peer conflict, and maintaining romantic relationships. It is a 16-week group intervention delivered to small groups for 90-min sessions, with a parallel carers group and employs directing teaching, roleplay, and feedback techniques. The UCLA PEERS for Young Adults (PEERS-YA) is an adaption of the PEERS program and is the only evidence-based intervention that uses the support of caregivers as an adjunct group to provide social coaching to further reinforce learned concepts and skills acquisition by young adults with ASD. The effectiveness of PEERS-YA has been evaluated in four key studies (Gantman et al., 2012; Laugeson et al., 2015; McVey et al., 2016; White et al., 2015) which have also been the subject of several systematic reviews assessing the effectiveness of SSIs in adults with HFASD and ASD with or without ID (Atkinson-Jones & Hewitt, 2018; Oswald et al., 2018; Spain & Blainy, 2015).

The studies by Gantman et al. (2012) and Laugeson et al. (2015) were conducted at ULCA, while those by White et al. (2015) and McVey et al. (2016) were conducted independently reducing bias. Three studies employed an RCT design (Gantman et al., 2012; Laugeson et al., 2015; McVey et al., 2016) with a delayed control group, while the study by White et al. (2015) used a quasi-experimental pre-post design without a control group, as such changes in outcome could not be attributed to the treatment alone. Overall, the sample size across studies was small ranging from five to 56 participants, although only the study by McVey et al. (2016) was powered to detect between-group differences,

hence increasing the chance of type II error in the other three studies. Moreover, participants were a self-selecting sample which limits the generalizability of the ASD population. Findings from the studies by Gantman (2012), Laugeson (2015), and McVey (2016) were consistent and provided strong evidence that the PEERS-YA intervention improves social skills, social skills knowledge, engagement, and empathy as measured by social responsiveness. Further, the benefits were maintained during the 16-week follow-up period (Laugeson et al., 2015). The only difference noted between studies related to social loneliness ratings which did not improve in the study by McVay et al. (2016) compared to Gantman et al. (2012). The latter may be attributed to the variability in the baseline characteristics of loneliness levels in the two studies.

Similar to these findings, results from White et al. (2015) also suggest the effectiveness of the PEERS-YA program in improving social skills and engagement in individuals with ASD although results should be interpreted with caution given the very small sample size of five participants in the study. Taken together, findings from these studies support the effectiveness of the PEERS-YA intervention in improving social skills deficits in autistic adults. The use of RCT designs in the three studies reduces the potential effect of confounders and is considered the gold standard for evaluating interventions.

Aspirations Programme. The effectiveness of the Aspirations Programme has been evaluated in two studies by Hillier and colleagues (2007, 2011). Aspirations is an eight-week program administered weekly in hour-long sessions to a small group of participants, and focuses on building friendships, social interaction, vocational skills, and

interpersonal problem-solving and communication. It uses a counselling support group model with participant-led discussions. A total of 62 participants aged 18 to 30 were enrolled in the two studies which used a quasi-experimental pre-post design with no control group. The lack of a control group and randomization limit the attribution of positive outcomes to the intervention alone. Further, the possibility of investigator bias cannot be excluded since both studies were conducted by the same researchers in the United States (Atkinson-Jones & Hewitt, 2019).

Findings from these studies showed a mixture of significant and nonsignificant outcomes. For example, there were no significant differences between pre-post intervention attitudes and feelings towards peers based on participant self-reports, although significant improvements in measures of empathy (Hillier et al., 2007) and depression and anxiety (Hillier et al., 2011) were noted post-intervention. Moreover, none of the studies included any follow-up or caregiver reports to ascertain whether positive effects were maintained over time (Spain & Blainey, 2015). Like the PEERS-YA studies, both studies used a self-selecting sample who paid for participation in the study which may limit the generalizability of the findings to the broader ASD population. Of note, while effect sizes were reported by Hillier et al. (2011), the clinical significance of improvements in outcome measures were not described in the study limiting interpretation of results.

Social Skills Programme. The Social Skills Programme is an 18 session monthly social skills intervention administered for two and a half hours each time to support adults with ASD in expressing emotions, improving conversational skills, assertiveness,

employment skills, and coping with stressful situations (Howlin and Yates, 1999).

Strategies such as role-play, structured games and activities, and video feedback are used to implement the program. The effectiveness of this SSI was evaluated by Howlin and Yates (1999) in the U.K. using a quasi-experimental pre-post single-arm design with no control group which enrolled 10 male participants aged 19-44 with autism. Post-intervention changes were captured using a non-standardized checklist completed by participants and their families. Findings showed improvements in communication skills, ability to relate to others, and interpreting others' emotions based on 90% of self-reports and all family reports. Conversational ability which was assessed using video recordings of social activities also improved post-intervention. However, the small self-selecting sample, lack of control group and standardized outcome measures, reduce the study's validity; hence results should be interpreted with caution (Atkinson-Jones & Hewitt, 2019).

Social Skills Group. The Social-skills Group is comprised of 16 weekly one hour sessions aimed at helping adults with ASD improve their conversational skills, expressing emotions, friendships, family, and dating relationships, employment, assertiveness, and coping (Ashman et al., 2017). The intervention uses strategies including discussion groups, multimedia, role play, and paper exercises. Ashman et al. (2017) conducted an RCT with an active control arm to ascertain the effectiveness of the Social-skills Group in improving the social abilities and engagement levels of 19 adults aged 19 to 55 with ASD without ID, although the diagnoses were not confirmed through standardized tools. Of note, 32% of participants in the study were female which is the largest proportion seen

in this area. The active control group, denoted as social interaction group (SIG), also included similar activities to those of the treatment group, although with no training component. Participation in the program was somewhat poor with 70% attendance in the treatment group and 61% in the SIG. Different assessment tools were used through self- and carer reports to measure changes in social cognition, functioning, and ability. Results demonstrated significant improvements across all social domains for both groups, although no differences were seen between the treatment and active control arms. That said, the Social-skills Group experienced more positive trends toward social functioning and ToM skills compared to the SIG. These findings contrast those of the PEERS-YA intervention studies (Gantman et al., 2012; Laugeson et al., 2015) which reported greater improvements in the experimental versus control groups post-intervention (Atkinson-Jones & Hewitt, 2019).

Social Cognition and Interaction Training for Adults. The Social Cognition and Interaction Training for Adults (SCIT-A) intervention for adults with autism is an 18-week 50min per session program which aims to improve social skills, understanding of social situations, and recognizing emotions and expressions through the use of video examples, role play, and discussion (Turner-Brown et al., 2008). In evaluating the effectiveness of SCIT-A, Turner-Brown et al. (2008) used a quasi-experimental non-randomized control study (treatment as usual for the control group) by enrolling 11 participants aged 25 to 55 with autism without ID. Participants were not truly randomized and continued to receive other treatments including medications and individual therapy, although data for four out of six participants in the SCIT-A group was missing which

reduced internal validity. Various self-reported outcomes were measured including emotion perception, ToM, and social communication skills, however, these are not validated in the ASD population. The use of an observational measure, the Social Skills Performance Assessment (SSPA; Patterson et al., 2001), assessed by two independent observers who were blinded to the intervention status, increased the validity of the results.

Study results showed significant improvements in ToM skills, but not emotional perception skills in the treatment group compared to controls. Also, no improvements were observed for social communication (Turner-Brown et al., 2008). The high (92%) attendance rate to the group program as well as the high satisfaction rates by 80% of participants who rated the intervention as ‘very useful’ or ‘useful’ suggest that the program was positively perceived by study participants. Overall, SCIT-A showed beneficial effects in improving ToM in study participants, although the small sample size and lack of validated measures used may explain the lack of efficacy in communication skills seen in the PEERS-YA studies.

Taken together, results from the various social-skills intervention studies (PEERS-YA, Aspirations Programme, Social-skills Group, Social-skills Programme, and SCIT-A) support the effectiveness of these group interventions in improving social communication, knowledge and cognition, and social functioning, particularly reducing loneliness, in adults with ASD without ID. These results are consistent with other systematic reviews conducted in adolescents and adults with autism (Cappadocia & Weiss, 2011; Hotton & Coles, 2016; Reichow et al., 2012). In particular, the largest

systematic review and meta-analysis of 19 RCTs (Gates et al., 2017) which sought to determine the effectiveness of group SSIs and differences between reporting sources, found moderate overall improvements in social competence in youth with ASD reflected by a medium effect size ($g = 0.51$) which corroborated with that of Reichow et al. (2012). Moderate improvements were noted by youth, parents, observers, and tasks, but not teachers highlighting differences based on reporting sources. The most consistent and robust evidence is presented by the PEERS-YA intervention across three RCTs which showed improvements across various social skills domains.

Despite these positive findings, overall inconsistencies among group SSIs exist and may be explained by the small sample sizes, variations in study characteristics, methodological shortcomings, and the use of inconsistent outcome measures some of which lack validity in the ASD population. Furthermore, the lack of follow-up data in all studies undermines the durability of the longer-term effects and real-world impact of these interventions which is of utmost importance. Future research should focus on addressing these shortcomings, targeting a more diverse ASD population such as those with ID and other ethnicities, identify ASD profiles which would benefit most from a specific SSI, and determine the comparative efficacy of these interventions.

Mental Health Interventions

Psychiatric comorbidities have been well documented in individuals with ASD. Comorbid conditions including anxiety and depression are highly prevalent in this population further exacerbating ASD symptoms and resulting in a poor quality of life which interferes with well-being and living a satisfactory life (Kerns et al., 2015;

Santomauro et al., 2016). Both adolescents and adults with ASD experience higher rates of anxiety and depression compared to their normal counterparts (Joshi et al., 2013). Anxiety disorders have been noted in about 40-50% of youth and adults with ASD, while 10-53% meet the diagnosis for mood disorders (Hollocks et al., 2019; Wigham et al., 2017). Given the significant burden these comorbidities impose on people with ASD, psychological interventions have been extensively used to ameliorate the impact of these conditions on well-being and mental health. Like other interventions, research evaluating the use and effectiveness of mental health interventions is more expansive in children and adolescents with ASD as opposed to adults (Ho et al., 2015; Spain & Blainey, 2015; Ung et al., 2015), although several systematic reviews have assessed effectiveness in the adult autistic adult population (Blainey et al., 2017; Murphy et al., 2017; Spain et al., 2015; Weston et al., 2016).

Since rates of anxiety and depression are also highly prevalent in the general population, the NICE guidelines (2011) recommend psychological therapy, in particular cognitive behavioral therapy (CBT), as first line treatment in mild to moderate presentations. NICE also makes similar recommendations for the adult autistic population to address their comorbid psychological disorders, although not to treat the core features of ASD (NICE, 2016). Of note, based on the inherent communication, emotional, and cognitive deficits of autistics, important adaptations of behavioral and cognitive interventions are recommended to meet their needs (Gaus, 2011; NICE 2016). Such adaptations include, 1) a more structured approach with greater use of written and visual tools, 2) greater emphasis on changing behavior rather than cognition, 3) use of concrete

versus metaphorical/ambiguous language and situations, 4) setting clear rules, 5) involvement of a caregiver or family member to implement the intervention, and 6) offering frequent breaks and incorporating topics of interest during the intervention.

Of the various psychological interventions used, CBT is the most studied and evidence-based approach both in the general and autistic population in treating mental health disorders. Other, less studied interventions include behavioral therapy, third-wave approaches, and models targeting transdiagnostic constructs (Keefer et al., 2018). Studies have utilized various methodologies and designs including RCTs, quasi-experimental, case series, and single case designs. Limitations include small sample size, opportunistic samples, heterogeneity of participant characteristics, diagnostic inconsistencies, lack of reporting of treatment fidelity, and lack of treatment details and adaptations made for the ASD population (Blainey et al., 2016; Murphy et al., 2017; Spain et al., 2015; Weston et al., 2016). Further, the psychometric properties of outcome measures remain to be validated in this population. In this section, literature reviews and research evaluating the use and effectiveness of CBT as a common psychological intervention in individuals with ASD will be covered as well as the key limitations of these studies.

Cognitive Behavioral Therapy

Cognitive behavioral therapy (CBT), originally developed for the treatment of depression (Beck et al., 1979) is effective in a range of mental disorders including anxiety disorders, sleep disorders, and psychosis (NICE, 2011; Vitiello et al, 2013). Deemed as the “current gold standard of psychotherapy” in the general adult population (David et al. 2018, p. 1), CBT is a discrete, time-bound, and structured approach which aims to help

individuals to 1) identify thoughts, emotions, and behaviors which impact current symptoms, and 2) develop skills to identify, cope, and counteract anxiety-provoking and distressing thoughts (Beck, 2011). The goal is for individuals to work towards attaining symptom reduction of distressing thought patterns and behaviors. As for the general adult population, CBT is also the most studied and evidence-based approach for the treatment of anxiety and depression in adults with ASD (Weiss & Lunskey, 2010; White et al., 2018). However, researchers have suggested the need for adaptations of standard CBT structure, process, and content for people with ASD for several reasons including deficits in communication, neuropsychological impairments (ToM and cognitive inflexibility), and alexithymia which are commonly associated with ASD (NICE, 2011; Gaus, 2011). As such, several modifications, such as the use of visual methods, tailored outcome measures, emphasis on behavioral vs. cognitive changes, and involvement of caregivers are recommended to optimize CBT intervention outcomes.

In children and adolescents with ASD, several RCTs have shown an overall moderate effect size for the effectiveness of CBT in helping reduce anxiety and mood disorders compared to waitlist control or treatment as usual (Storch et al., 2013; Ung et al. 2015; White et al., 2013; Wood et al., 2015). Of note, these studies have been conducted in children and adolescents who are high functioning and able to engage in CBT, hence limiting their generalizability. Also, the adaptations made to conventional CBT protocols have been highly variable and not consistently reported. Similarly, studies assessing the effectiveness of CBT in improving mental disorders in the adult autistic population have been scant with quality issues due to methodological and conceptual

limitations such as small sample size, heterogeneity in participants characteristics, and variability in outcomes measures, among others (Binnie & Spain, 2013; Kose et al., 2018; Spain et al., 2015).

An earlier literature review by Binnie and Blainey (2013) which sought to determine the effectiveness of individual or group CBT in reducing comorbid psychiatric symptoms in HF adults with ASD found a ‘suggestive’ benefit in this population. The seven studies included in the review (five case reports and two quasi-experimental) highlighted the dearth of high-quality evidence in this area and limitations to making more definitive conclusions. Since then, some RCTs and additional systematic reviews have been conducted to evaluate CBT effectiveness in adults with ASD (Blainey et al., 2017; Murphy et al., 2017; Spain et al., 2015; Weston et al., 2016; Wise et al., 2019). For example, a study by Blainey et al. (2017) evaluated the effectiveness of CBT-based psychological therapy in routine clinical practice in a group of 122 adults with ASD. Results showed reductions in general psychological distress as measured by the Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM) self-report questionnaire. Over 75% improved with 37% showing reliable changes. The authors noted the need for longer durations of CBT in adults with ASD when their distress levels are higher. Limitations of this study included the lack of a comparison control group, lack of specific evidence-based protocol for adults with ASD, lack of generalizability since the study was conducted in a specialist psychological clinical practice setting, lack of adherence to a specific protocol, and no follow up to assess whether the therapeutic gains were long-lasting and maintained (Blainey et al., 2017).

These findings are in line with those of Weston et al. (2016) and Spain et al. (2015) who also found that CBT approaches were effective in reducing psychological impairments in people with ASD. The systematic review by Spain and colleagues (2015) included two RCTs (Russell et al., 2013; Spek, et al., 2013), one quasi-experimental study (Russell et al., 2009); one case series (Weiss & Lunsky, 2010); and two case studies (Cardaciotto & Herbert, 2004; Hare, 1997). CBT approaches included cognitive, behavioral, and mindfulness-based techniques. Overall, findings suggested that applied interventions were moderately effective in reducing comorbid depression and anxiety symptoms. Similar limitations as other studies were noted including small sample size, heterogeneity of participant characteristics, and lack of validation of outcome measures in the ASD population. While the quality of the case reports and quasi-experimental designs could not be comprehensively assessed due to poor designs and methods, the two RCTs with more robust methodology showed improvements in comorbid mental health symptoms, functioning, and positive affect (Russell et al., 2013; Spek, et al., 2013).

Finally, a large systematic review and meta-analysis evaluated the effectiveness of CBT in improving both affective disorders or symptoms of ASD across the lifespan for individuals with ASD (Weston et al., 2016). A total of 48 studies were included in the analysis of which 50% aimed to examine the effectiveness of CBT in affective disorders including anxiety, depression, or emotional regulation. Only four of the 24 studies included adults only, while three had a mixed population of adolescents and adults (McGillivray & Evert, 2014; Pahnke et al., 2014; Russell et al., 2013). Both group- (15) and individual-based (8) CBT were studied. Overall, results showed a small to medium

effect size in the effectiveness of CBT in the treatment of affective disorders dependent upon the type of informant. Self-report measures were associated with a small non-significant effect size ($g = 0.24$), informant-report measures with a significant medium effect size ($g = 0.66$), and clinician-report measures with a significant medium effect size ($g = 0.73$) (Weston et al., 2016). Similar to the other reviews, the authors highlighted several issues with current research concerning CBT interventions in the ASD population – small sample size which limits the ability to draw meaningful conclusions, lack of blinding and independent data management, insufficient reporting of participant adherence and fidelity, absence of a primary outcome measure in RCTs, lack of thorough reporting of CBT adaptations which limit replicability, and adherence to the CONSORT recommendations for reporting of RCTs to increase the quality of the evidence.

Behavioral Interventions

Behavioral interventions are based on learning theory and the principles of operant conditioning first introduced by B.F. Skinner (1953). These approaches rely on the premise that in a given environmental context, reinforcement of behaviors that result in favorable outcomes will persist, while those with negative consequences will reduce or become extinct over time. Applied behavior analysis (ABA) is a widely accepted and well-established approach in the area of autism used to treat a broad range of skills and deficits in individuals with ASD including communication, physical, social, mental, among others (Yu et al., 2020). ABA utilizes strategies such as reinforcement, chaining, prompting, modelling, and extinction aimed at reducing problematic behaviors (Doehring et al., 2014). While there is significant overlap between CBT and ABA, behavioral

interventions do not utilize cognitive strategies, nor higher order cognitive skills, such as ToM. As such, they are readily applied to treat people with ID and the core symptoms of ASD, adaptive skills deficits, and problematic behaviors (Matson et al., 2012; Matson & Jang, 2014; Smith & Iadarola, 2015).

A range of ABA types, some more targeted and others broader, have been used in the treatment of children with ASD. For example, Discrete Trial Training (DTT) teaches skills in a repeated and brief fashion while focusing on specific and ‘discrete’ instructions (Welch & Polatajko, 2016). Stemming from this approach is early and intensive behavioral intervention (EIBI) introduced by Lovaas (1987), which is applied in young children aged two to three years as a comprehensive treatment model (Rosales et al., 2019). It is intensive since it is delivered in a one-to-one format for up to 40 hours per week, several hours per day focused on eliminating atypical behaviors and establishing learning skills. While the superior effectiveness of the EIBI approach in children with ASD has been well established, a review by Matson and colleagues (2013) highlights the lack of evidence to support the long-term gains upon discontinuation of therapy. Indeed, of the 19 EIBI studies included in the review, only three had longer-term follow-up ranging from one to nine years, although the latter was a retrospective analysis (Akshoomoff et al., 2010; Kovshoff et al., 2011; Richards et al., 2009). The authors call upon researchers to incorporate long-term follow-up a priori in EIBI studies to ascertain their true effectiveness in addressing core deficits of ASD. Other behavioral approaches in children with ASD include the Early Start Denver Model (ESDM) (Smith et al., 2000) which targets a broad range of developmental skills, such as communication, social, play,

and cognitive skills, and Pivotal Response Therapy (PRT) which are based on increasing motivation for engagement and interaction generating wider generalized change on behaviors (Mohammadzaheri et al., 2014).

Regarding research supporting the effectiveness of ABA procedures, there is strong evidence to support its use for improving autistic skills and behaviors, although there is high variation depending on how one reviews the data. For example, strong evidence in favor of ABA approaches comes largely from within-subject experimental designs rather than randomized controlled trials (RCTs) (Roth et al., 2014). As such, there is a paucity of evidence to support the efficacy of ABA techniques using random allocation and controlled study designs which would generate higher quality data in this regard. Moreover, as with other autism interventions, the extant ABA literature focuses on assessing effectiveness in children with autism rather than adults, which again points to a significant gap in research where adult autistics are concerned.

A meta-analysis of single-case research studies by Roth et al. (2014) evaluated the effectiveness of behavioral interventions in adolescents and adults with autism. A total of 43 articles with 110 participants were included in the analysis and results showed an overall medium effect size. Behavioral interventions in the areas of academic skills, phobic avoidance, and vocational skills showed strong effect sizes, while problem behaviors, adaptive skills, and social skills interventions had medium effects. Of note, for 81% of studies reviewed, the authors had medium to high confidence in the findings. No differences in effect size were noted across different age groups and cognitive functioning ability indicating consistency in intervention effectiveness. However, a

concerning 77% of the reviewed studies lacked treatment integrity. This is problematic since without treatment integrity data, conclusions regarding the degree to which the independent variable was implemented as detailed in the study or whether the independent variable was associated with changes in the dependent variable cannot be confidently reached. As such, the inclusion of treatment integrity is of high importance to ascertain the effectiveness of behavioral interventions in the ASD population (Roth et al., 2014).

In addition to the targeted behaviors and skills in the review by Roth et al. (2014), the effectiveness of behavioral interventions has also been evaluated in the treatment of mental disorders in autistics, albeit only in anxiety disorders using non-controlled studies (Rosen et al., 2016). This is of concern given the prevalence of these disorders in people with ASD and ID (34-42%) and their impact on QoL (Bakken et al., 2010; Rosen et al., 2016). Various behavioral strategies have been used in this regard including prompting, modelling, and reinforcing, and exposure to the feared stimulus and anti-anxiety stimuli (relaxation techniques) to reduce anxiety (Hagopian & Jennett, 2008; Rosen et al., 2016). One controlled study has explored the effectiveness of a behavioral intervention for anxiety in young people with ASD with unknown cognitive functioning levels (Alli & Priya, 2017). The study used exposure to the target anxiety approach for 3-4 weeks and found significant reductions in anxiety and sensory over-responsivity. These results suggest that the use of behavioral therapy in the treatment of anxiety in individuals with ASD and ID appears promising.

Daily living and independence at home are also an area of challenge for people with ASD. While activities such as dressing, preparing food and meals, self-care, time management, travelling in the community, housekeeping, shopping, and managing money may appear second nature to neurotypicals, they often present significant challenges for most autistic people at varying levels of intensity (Marcotte et al., 2020). As such, interventions aimed at improving independence at home are an important focus area to enable individuals with ASD to exercise some degree of independence. In light of this issue, a recent literature review by Marcotte et al. (2020) evaluated which types of interventions are effective in helping people with ASD over the age of 14 with or without ID develop independence at home. A total of 20 articles and 121 participants were included in the review of which the majority (n=17) were pre-post case series or single-case quasi-experimental designs without a control group. Results showed that behavioral interventions which comprised the majority (40%) of the articles reviewed were among the seven effective interventions identified. These interventions were implemented by a variety of stakeholders including researchers, parents, or practitioners from the field and were related to activities such as food and meals, shopping, and travelling in the community. Notably, there was an improvement in the percentage of steps performed correctly from 24% to 100%, and 90% of the steps were performed correctly within four sessions or fewer post-intervention. Some limitations of this review (Marcotte et al., 2020) included the small sample sizes of the studies; lack of consideration for participants' level of autism severity, hence limited generalizability; lack of RCTs (except for one study) which limits attribution of observed changes to the intervention

alone; and heterogeneity of outcome measures evaluated in the different studies.

Nevertheless, the study provided evidence that the use of behavioral interventions, among others included in the review, may be effective in fostering the development of skills related to living independently at home for people with ASD.

Adaptive/DLS Interventions

The acquisition and maintenance of adaptive skills or behaviors are of high importance in the aging autistic population. Adaptive behaviors include aspects of independence and responsibility which enable one to engage in activities of self-care and interaction with others (Baker et al., 2021). While socialization and communication are critical domains, daily living skills (DLS) is of utmost importance in the autistic population given its association with more favorable life outcomes and better quality of life (Burger-Caplan et al., 2016). DLS includes skills such as personal hygiene, dressing, meal preparation, ability to shop, time management, and financial responsibility (Duncan et al., 2015). Research has shown heterogeneity in adaptive behaviors across the lifespan in individuals with ASD. Individual factors such as cognitive ability, ASD severity, and symptomology may contribute to the variations seen in adaptive skills, although cognitive abilities do not buffer against challenges in DLS even in individuals with average to high IQs (Charman et al., 2011; Kenworthy et al., 2010). For example, despite expectations that high-functioning individuals with ASD would acquire better DLS due to their intact cognitive ability and less severe autism symptomology, these individuals fare worse than their lower IQ counterparts (Roux et al., 2015). This may in part be due to the lack of life skills supports and services provided to those with HFASD compared to those with ASD

and comorbid ID (Chiang et al., 2017). As such, DLS training or interventions remain a critical area of unmet need given their association with better outcomes in various areas including employment, independent living, and forming relationships (Klinger et al., 2021). Indeed, in a large sample of adults with ASD, Klinger et al. (2021) found DLS as a significant predictor of employment outcomes as compared to factors such as cognitive ability and autism symptomology.

Adolescents with HFASD have been shown to lag unexpectedly in DLS despite their higher cognitive abilities and chronological age (Duncan & Bishop, 2015). Over 50% of adolescents with HFASD have shown deficits in DLS falling well below their IQ score which translated to DLS equivalent to five to six years below their chronological age (Duncan & Bishop, 2015). A recent study by Baker et al. (2021) corroborated these findings by demonstrating that adaptive behaviors, specifically DLS, in adolescents with ASD and ID fell well below age-expected values compared to an age-matched typically developing group. Of note, externalizing behaviors, accounted for a significant proportion of the variance in DLS suggesting these factors may exacerbate overall adaptive and social difficulties, hence impact daily functioning (Shea et al., 2018). The authors recommend incorporating adaptive training skills and behavioral management as part of current interventions to better prepare and support adolescents in their development of independence and daily functioning.

Various evidence-based approaches, such as behavioral strategies, video modeling, and technology have been used as interventions for the development of adaptive behavior skills, including DLS, in adolescents and young adults with ASD

(Cullen et al., 2017; Duncan et al., 2018; Kellems et al., 2018; Palmen et al., 2012; Perez-Fuster et al., 2019). While these interventions have shown effectiveness, many are case studies or single-subject design, and quasi-experimental which lack randomization and a control group to confidently attribute skills improvements to the said intervention.

Moreover, most are conducted in individuals with ASD and ID and focus on very specific DLS which limits the generalizability of these skills in real-world settings (Bennett and Dukes, 2014; Wong et al., 2015). Of note, evidence-based group interventions for HF adolescents with ASD are lacking to better prepare them for independence in adulthood.

An early, but important systematic review of the literature (Palmen et al., 2012) evaluated the effectiveness of behavioral interventions in improving the adaptive skills of young adults with HFASD. Of the 20 studies included in the review, 19 showed improvements in adaptive skills and 63% met the conclusive or preponderant criteria for level of certainty of the evidence, while the remainder were deemed suggestive or insufficient due to limitations of study design or lack of treatment fidelity measures. Importantly, the use of technology-assisted procedures, such as video modeling, visual cues, self-prompting as well as reinforcement contingencies and corrective feedback using prompts appeared to be the most promising interventions to improve adaptive skills. The authors conclude that there is a scarcity of research on this topic, and while a decent amount of evidence exists to support the use of behavioral interventions, future studies need to use larger sample sizes and true experimental designs with methodological transparency.

The results of this systematic review are aligned with those of Bennet and Dukes (2014) who expanded the research to include those with autism and comorbid ID. Moreover, several DLS were examined including eating, safety and health skills, domestic skills, cooking, and independent routines. Of the 13 studies included in the review, 12 demonstrated positive results of the interventions used which were based on applied behavior analysis (ABA), such as chaining, video-based instruction, prompting and fading, and differential reinforcement, among others. Only one study showed mixed results, and none reported negative results. Here, again, the authors (Bennet & Dukes, 2014) underscore the lack of high-quality studies in this area of research and the need for multiple replications of single-subject design studies to increase the external validity of interventions.

To address the gap in the lack of group-based interventions targeting daily living skills, Duncan and colleagues (2018) conducted a pilot study to test the effectiveness of a DLS intervention for adolescents with HFASD. Seven adolescents participated in a 12-week manualized group intervention targeting DLS such as cooking, morning routine, laundry, and money management. Striving and Thriving in the Real World (STRW) is a group intervention consisting of 12-weekly 90-minute parent and adolescent sessions using empirically based strategies for skill acquisition, mastery, and generalization. Results showed significant improvements in DLS as measured by the Vineland Adaptive Behavior Scales and four DLS goal attainment scale (GAS) scores at post-treatment and 6-month follow-up. The authors concur the effectiveness of STRW as an intervention to target DLS in adolescents with HFASD, although citing several limitations of the study.

These include the small sample size, lack of randomization and control group, unblinded investigators who were aware of the study objectives, and parental reports of study outcomes which may have biased the results as they may have been motivated to report positive effects of the intervention on DLS of their autistic children (Duncan et al., 2018).

Finally, several recent studies have explored the effectiveness of digital-technology mediated interventions, specifically video-prompting (VP), in improving DLS in autistic individuals (Cullen et al., 2017; Kellems et al., 2018; Monaco & Wolfe, 2018; Perez-Fuster et al., 2019). Video prompting (VP) teaches behaviors and skills by breaking down the video into steps viewed in small clips. The individual watches the clip then imitates a particular step at a time. This is different than video modeling which uses models such as peers, educators, or caregivers who perform the entire skill, then the learning individual watches and replicated the entire skill (Kellems et al., 2015). The study by Kellems et al. (2018) evaluated the use of an iPad as a prompting device to teach three young adults with disabilities (ASD and fragile X syndrome all with ID) DLS including cooking specific meals, cleaning certain areas, and mailing a letter. Findings showed that VP delivered through an iPad was effective in the acquisition of skills in all three young adults and that these were maintained from 12 to 70 days after the last intervention session confirming durability of the response.

In another small study of four male adults aged 25 to 37 with ASD and ID, the effectiveness of a Digital Technology (DT) mediated intervention compared to treatment-as-usual (TAU) was used to improve DLS including washing dishes and doing laundry (Perez-Fuster et al., 2019). A reversal single-subject experimental design was used to

conduct the study. The DT-mediated intervention was delivered using a tablet connected to a lighting system using audio and picture prompts, while the TAU intervention used paper-based pictures and task strips. Findings from the study demonstrated that compared to TAU, the DT-mediated intervention was effective in reducing the number of prompts received from the educator in three out of four subjects, and for decreasing the number of off-task behaviors in all participants during the performance of the activities. The latter is an important finding since off-task behaviors such as self-stimulation or stereotypy may interfere with the success and completion of targeted tasks and activities. Similar to other studies in this area, the small sample size, issues with treatment fidelity, and the lack of maintenance and generalization of the skills were limitations.

As evident, interventions using digital technology, in particular, hand-held devices which deliver video-prompting or modeling have proven effective in improving daily-living skills in young people with ASD and ID. The literature on HF individuals is scarce, although important given the deficits of DLS in these individuals despite misperceptions of their high-functioning cognitive status. Future research should focus on the conduct of higher quality studies which use more rigorous experimental designs and larger samples to ascertain treatment effectiveness highly validity and confidence.

Vocational Interventions

Few individuals with ASD achieve gainful employment during their lifetime, even those with high functioning autism (Nicholas et al., 2015). Indeed, over half of autistic adults are unemployed or underemployed (Hirvikoski & Blomqvist, 2015), and those who find jobs have difficulty maintaining employment with frequent dismissals due

to the complexities that accompany autism. Vocational challenges primarily arise from the social deficits associated with autism limiting the ability to communicate, interact, and socialize in the work environment (Hirvikoski & Blomqvist, 2015). Moreover, issues with emotional regulation, repetitive behaviors, and cognitive functioning further exacerbate the situation, while complexities of the work setting, such as accommodations of the social, physical, and sensory environments are often missing (Kreiger et al., 2012; Richards, 2012). These problems impede adolescents and adults with autism from gaining meaningful employment which in turn result in low productivity, inability to live independently, and achieve a fulfilling life. A large population-based study (Shattuck et al., 2012) found that youth with ASD had the lowest rates of paid employment at 55% compared to adults with other disabilities. Compared to young adults with emotional disturbance, learning disability, speech/language impairment and mental retardation, young adults with ASD earned the lowest average hourly wage (\$8.10 per hour) and had the lowest rates of participation in both paid and unpaid employment.

Despite this significant unmet need and an increase in the number of studies in recent years (Bennet & Dukes, 2014), vocational interventions for autism are particularly understudied and not informed by robust evidence to support their effectiveness (Nicholas et al., 2015). Several systematic reviews (Anderson et al., 2017; Bennet & Dukes, 2014; Nicholas et al., 2015; Taylor et al., 2012) have found weak evidence and poor methodological quality within existing studies. An earlier review by Taylor et al. (2012) which evaluated five vocational interventions for youth and adults with ASD focusing on the transition to adulthood concluded that ‘no study used random assignment,

making it difficult to draw conclusions about the effectiveness of the programs (p. 536). In another systematic review of the extant literature on vocational interventions, Walsh and colleagues (2014) included 17 studies related to vocational interventions. The majority of studies (n=15) used a single case design (SCD) with one correlational and another AB design. Several strategies were identified in these studies including behavioral approaches, video modeling, prompting and feedback via audio coaching, graduated guidance, and a combination of these approaches. While most of these interventions resulted in improvements in the targeted behaviors related to employment outcomes, and benefits were maintained one to three months post-intervention, the review did not report effect sizes and the quality of the studies. As such, the strength of the evidence and the differential effectiveness of these interventions were not assessed.

In line with developing work-related social skills or ‘soft skills’ necessary to support people with autism in securing and maintaining employment, a recent study (Sung et al., 2019) assessed the development, feasibility, and preliminary efficacy of a work-related social skills intervention called ASSET (Assistive Soft Skills and Employment Training) for young adults with HFASD. ASSET is an eight-week group-based program delivered through 90min weekly sessions followed by an optional social hour to practice the generalization of skills. It focuses on peer interaction guided by facilitator feedback and direction. Autism-specific adaptations include video modeling, visual aids, and relevant images and videos to facilitate training. A mixed-methods design was used to evaluate pre-post intervention outcomes, user acceptability, practicality, and efficacy in the 17 enrolled participants. Results supported the use of ASSET as a group-

based social skills intervention targeting work-related outcomes to achieve better engagement, social functioning, self-confidence, and adherence to training in people with HFASD. The authors note several limitations of the study including its quasi-experimental design with a small, non-random, convenience sample and self-reported measures which threaten internal and external validity; use of measures not directly related to work behaviors and administered by employers, thus limiting generalizability to the workplace; self-selection bias; and inability to evaluate long-term effects of the intervention. Nevertheless, findings from this study are consistent with those of Conner et al. (2017) who also reported positive gains with ASSET not only around skill development, but also participant perceptions of being user-friendly, practical, and accepted by the ASD community. The authors recommend the need to evaluate the effectiveness of group-based programs such as ASSET using longitudinal, rigorous research designs with random allocation, control, and larger sample sizes to confirm beneficial outcomes.

A more recent review of vocational skills interventions in adults with ASD (Seaman & Cannella-Malone, 2016), identified 21 interventions studies of which 15 were SCD studies and six were between group comparisons. Of the 15 SCDs (71%) subjected to a quality assessment according to the What Works Clearinghouse Case Design evidence standards (Kratochwill et al., 2010), six met the evidence standards without reservations and three with reservations. Studies were categorized based on three skill types as pre-employment, job task, and job retention. Results showed that over half of the interventions focused on job tasks, while only a small fraction was related to pre-

employment and job retention skills. This is an important finding as the ability to acquire and maintain employment is crucial to successful employment. The studies employed various intervention types including video modeling, covert audio coaching, behavior skills training, and interviewing skills among others. While the authors did not indicate which of the specific practices and interventions may be considered as evidence-based, they nevertheless highlighted the stronger evidence associated with technology-based (video and audio) approaches in improving vocational skills. The authors note several limitations in the reviewed vocational intervention studies including lack of rigorous study designs to ascertain evidence-based approaches vocational skills, lack of tracking and reporting of vocational outcomes, hence social validity, to determine whether the interventions do in fact result in obtaining gainful employment, and limitations related to generalization and maintenance.

To address these limitations, a randomized controlled trial (RCT) by Wehman et al. (2017), evaluated the effects of an employer-based intervention called Project SEARCH plus Autism Spectrum Disorder Supports (PS-ASD) modified from the Project SEARCH model by incorporating applied behavior analysis (ABA). PS is an intensive 9-month job training program for high school students with developmental disabilities to help them acquire job skills and employment. Forty-nine participants aged 18 to 21 were randomized to the intervention- or control groups. Findings showed that at 3 months follow-up, 90% of students in the treatment arm achieved competitive employment compared to only 6% in the control arm. Moreover, 87% of individuals in the treatment group maintained employment at one year post-graduation and displayed increasing

independence compared to 12% in the control group. The authors highlight the excellent employment outcomes associated with the PS-ASD program and the maintenance of the positive outcomes during the follow-up period. It should however be noted that the intervention required an intense level of detailing using ABA implemented by highly skilled specialists supporting employment practices, as well as close collaboration among educational staff, business personnel, and community rehabilitation services which may not be overtly available in a practical real-world setting.

Finally, another systematic review by Anderson and colleagues (2017) assessed the effectiveness of interventions for adults with ASD to promote employment. Eighteen single-case design (SCD) studies were included in the review and interventions were categorized as Behavioral Skills Training (BST), video-based instructions, and self-management protocols. Here, again, the WWC standards were used to assess the quality of the studies and whether they qualified as evidence-based interventions. Nine studies used BST which involved instruction, modeling, prompting, rehearsal or practice, and provision of reinforcement or corrective feedback, four used video-based instruction, and four self-management procedures. Results showed that only BST was considered effective and an evidence-based intervention for improving employment skills in adults with ASD, while video-based instruction and self-management procedures were considered as emerging evidence-based interventions, albeit with variable effects and few completed studies. Of note, seven studies arising from BST interventions reported on generalization effects indicative of robust findings, while social validity was underreported with only half of the studies addressing this concept. Outside of BST, the

authors note the limited and insufficient research in scope and quality aiming to identify effective interventions to address the vocational needs of adults with ASD (Anderson et al., 2017). These findings are in line with the previous systematic reviews noted in this section.

Mindfulness Interventions

In recent decades, mindfulness-based therapies (MBT) have been used to treat various physical and psychological ailments. Mindfulness is described as a state of conscious awareness and attention to the present and experiencing what is in the moment with no judgment (Kabat-Zinn, 1994). It is about being in touch with one's environment and thoughts as a way to better control avoidance of emotion-triggering situations and to increase effective coping mechanisms. Such practices, also called the 'Third wave of cognitive and behavioral therapies' (Hayes, 2004) focus on the concept of acceptance which in turn helps people increase emotional clarity, reduce ruminative thoughts and subsequent depressive moods and anxiety (Cooper et al., 2018). Mindfulness interventions, such as Mindfulness Based Stress Reductions (MBSR) and Mindfulness Based Cognitive Therapy (MBCT) have shown effectiveness in reducing psychological distress and improve wellbeing in the general population (Potes et al., 2018, Wang et al., 2018). MBCT combines cognitive therapy with mindfulness meditation, while MBSR focuses less on cognitive elements and more on experiential learning, hence has been deemed as more suitable to adults with ASD (Spek et al., 2013). Mindfulness approaches are often incorporated into daily living activities, such as running, walking, yoga, listening to music, or even focusing on one's breathing. Autistic adults tend to use

mindfulness practices due to their ease of use and availability through apps and online tools. Furthermore, they help reduce anxiety and stress levels and ruminate thoughts which are often comorbid conditions in autistic individuals.

Indeed, mindfulness interventions have shown promise in children and adolescents with HFASD (Singh et al., 2011, 2014) in reducing non-compliant and aggressive behavior, as well as improving communication. Positive outcomes regarding the effectiveness of MBT have also been shown in adults with HFASD in the management of psychological distress (Sizoo a& Kipur. 2017; Spek et al., 2013) and emotional regulation (Conner & White, 2018; Kiep et al., 2015). In a recent systematic review (Benevides et al., 2020) of various autism interventions which target health outcomes among autistic adults, mindfulness interventions were considered emerging evidence-based approaches alongside cognitive behavior therapy. Moreover, a recent meta-analysis (Hartley et al., 2019) evaluated the effectiveness of mindfulness interventions in enhancing the subjective wellbeing (SWB) across different subgroups including children, adolescents, and adults with ASD and their caregivers. Also, the short- and long-term (post-intervention follow-up) effects of the MBTs were assessed. A total of 10 studies were included in the analysis, and of the 454 participants, 139 were adults, 74 children, and 241 caregivers. Four of the included studies focused on the adult autistic population of which three were quasi-experiments (Conner & White, 2018; Kiep et al., 2015; Sizoo & Kuiper, 2017) and one was an RCT (Spek et al., 2013). As such, only the RCT received an adequate research quality rating, while the others received a weak quality score. Overall, results of the meta-analysis showed positive small to

medium effects of the MBT manuals in improving SWB, with slightly larger gains at follow-up. Of note, there was between-study variability concerning the reported effect sizes with Kiep et al. (2015) reporting very large and positive effect sizes although with differences between individual participants, and Sizoo and Kuiper (2017) and Conner and White (2018) reporting effect sizes small to medium in magnitude.

The study by Spek et al. (2013) was the first controlled trial in adults with ASD and used a 9-week modified MBCT randomizing participants to the treatment arm or waitlist control. The intervention comprised of daily 40-60min meditation aiming to increase awareness and acceptance of bodily sensations, cognitions, and emotions in the context of stressful situations. Modifications to the intervention included shortening the length of the sessions and removing cognitive elements. Results showed that those in the intervention group experienced a significant reduction in depression, anxiety, and rumination, as well as gains in positive affect compared to the control group (Spek et al., 2013). Some limitations of this study included the inclusion of a sample with high verbal abilities which limits generalization to the broader autism community and a small sample size resulting in low power to detect effects.

These results were aligned with those of another quasi-experimental study led by the same researchers (Kiep et al., 2015) which investigated the effectiveness of MBCT in alleviating a variety of psychosomatic symptoms in 50 adults aged 20 to 65 with ASD. Results showed significant reductions in anxiety, depression, somatization, sleeping problems, and rumination. Moreover, increases in positive affect and overall wellbeing were noted. Importantly, these positive outcomes were sustained at nine-week post

intervention suggesting that MBCT was an effective method to improve a variety of psychological and physical symptoms in adults with ASD.

In assessing the comparative effectiveness of mindfulness-based interventions (MBSR) to cognitive behavior therapy (CBT), Sizoo and Kuiper (2017) conducted a quasi-experimental study that evaluated the reduction in depressive and/or anxiety symptoms in adults with HFASD. Fifty-nine adults were included with 32 following the MBSR protocol and 27 the CBT procedure. The MBSR protocol was comprised of 13 weekly sessions and was based on similar strategies as those in the MBCT approach used by Spek et al. (2013) to increase awareness and reduce stress, while the CBT intervention focused on cognitive coping strategies, stress management, and methods to deal with frustration and rumination. Of note, outcome measures, such as depression and anxiety, autism symptoms, rumination, and global mood were captured at baseline, end of the study, and at three months follow-up. Findings demonstrated similar effectiveness of both the CBT and MBSR interventions in reducing self-reported anxiety and depressive symptoms, rumination, global mood, and autism symptoms, and a sustained effect of the gains at the three-month follow-up. However, without a control arm, the positive effects cannot be solely attributed to the applied interventions. It should be noted that some participants preferred MBSR for the treatment of their anxiety symptoms over CBT (Sizoo & Kuiper, 2017). Some limitations included the modest sample size, the lack of a control arm, lack of blinding since sequential randomization was used, and the lack of a comprehensive measure of treatment fidelity.

Finally, in a small quasi-experimental study, Conner and White (2018) evaluated the feasibility and initial efficacy of a modified, individually delivered MBCT in improving emotional regulation difficulties in adults with ASD. Results showed an acceptable treatment fidelity and participant satisfaction confirming the feasibility of the intervention. Furthermore, improvements in impulse control, emotional acceptance, and accessing ER strategies were noted. The study adds to the growing body of evidence in support of the use of MBT in people with ASD (Cachia et al., 2016), specifically targeting a transdiagnostic construct, namely ER. As with other studies in the field, limitations included the small sample size, lack of meeting a specific cut-off for ER difficulties which may have produced a floor effect, a self-selecting sample with HF autism, low inter-rater reliability of treatment fidelity ratings, and a heterogeneous pattern of observed change across participants making it impossible to draw conclusions about effects.

Despite these limitations, current evidence for the use of mindfulness-based interventions suggests that they are effective in addressing various psychosomatic symptoms in individuals with ASD, especially symptoms of depression, anxiety, rumination, and increasing positive affect (Cachia et al., 2016). Future studies should focus on randomized controlled designs with the inclusion of control groups, larger sample sizes, a diverse demographic of the ASD population, and measuring the long-term sustained effects of these interventions.

Medical Interventions

The heterogeneity of behavioral and clinical features in individuals with ASD complexify the understanding of its pathophysiology, hence the development of effective pharmacological treatments to ameliorate core symptoms and associated conditions (Eissa et al., 2018). Despite therapeutic advances in medicine in various disease areas and disorders, there are currently no effective pharmacological medicines targeting the core symptoms of ASD, although some medications have proven effective in reducing co-occurring conditions such as aggression, irritability, hyperactivity, inattention, sleep disturbances, repetitive behaviors, anxiety, and mood disorders (LeClerc et al., 2015). Interestingly, the prevalence of pharmacotherapy in individuals with ASD is quite high, especially in the adult population. A recent systematic review (Jobski et al., 2017) which included a total of 47 studies encompassing a population of over 300,000 people with ASD, showed a prevalence of psychopharmacotherapy ranging between 2.7% and 80% with a median of 61.5% for adults and 41.9% in children. Moreover, psychotropic polypharmacy occurred in 5.4-54% of individuals. Antipsychotics were the most frequently used medications (7.3% to 57.4%; median: 18.1%), followed by attention-deficit and hyperactivity (6.6% to 52.4%; median: 16.6%) disorder (ADHD), and antidepressants (1.1% to 43%; median: 17.2%). Older age and the presence of a psychiatric comorbidity were predictors of a higher prevalence of psychopharmacotherapy and psychotropic polypharmacy. Given the limited evidence supporting the effectiveness of some pharmacological treatments in ASD, such as antidepressants, clinicians should be mindful to only prescribe some drug classes in select

cases based on patient characteristics and the presence of comorbid conditions.

Importantly, medical treatments should be used in combination with behavioral to optimize outcomes (Jobski et al., 2017).

Irritability and Impulsive Aggression. Currently, there are only two atypical antipsychotic medications, risperidone, and aripiprazole, approved by the European Medicines Agency (EMA)/Food and Drug Administration (FDA) for the treatment of ASD-related irritability in children five years and older (Jobski et al., 2017). Large RCTs have shown their efficacy in the treatment of irritability in children and adolescents aged 5 to 17 with ASD (McCracken et al., 2002; Owen et al., 2009). The study by McCracken et al. (2002) showed significant improvements in the number of tantrums, aggressive episodes, and self-injurious behaviors in children randomized to the treatment arm compared to those given placebo. Moreover, a Cochrane systematic review (Ching & Pringsheim, 2012) showed decreases in irritability as measured by the Aberrant Behavior Checklist (ABC) with risperidone (8.09 vs. placebo) and aripiprazole (6.17 vs. placebo). Adverse effects of antipsychotic medications include weight gain, metabolic syndrome, sedation, and gastrointestinal problems, among others.

In contrast to the robust evidence in children with ASD, treatment of irritability has been less studied in adults with autism. In a few small studies, reductions in irritability and aggression were observed after 12 weeks of treatment with risperidone (McDougle et al., 1997) and fluvozamine (McDougle et al., 1996), although irritability and aggression were not the primary outcomes in these studies. Overall, there is limited evidence to support the treatment of irritability in adults with ASD using antipsychotics

and selective serotonin reuptake inhibitors (SSRI), hence benefits should be carefully weighed against the risks prior to their use in adults with ASD.

Hyperactivity and Inattention. While indicated for the treatment of ADHD, methylphenidate has shown efficacy in the treatment of hyperactivity and inattention in children with ASD. A meta-analysis of four RCTs showed a large effect size of 0.67 in children with pervasive developmental disorders (PDD) treated with methylphenidate for a duration of 1-4 weeks (Handen et al., 2000; Posey et al., 2006; Reichow et al., 2013). Notably, response rates to methylphenidate in children with ASD and ADHD appear to be lower compared to those with ADHD alone as shown in a study that reported a response rate of 50% in children with ASD compared to 70-80% with ADHD (Jensen, 1999). Moreover, the severity of side effects is also greater in those with ASD and ADHD compared to individuals with ADHD alone supported by discontinuation rates due to side effects of 18% versus 1.4%, respectively. In further support of these findings, a recent Cochrane review (Sturman et al., 2017) suggested the efficacy of methylphenidate in youth with ASD in reducing hyperactivity although methodologic concerns were noted in the low quality of the studies reviewed. Methylphenidate is associated with significant side effects including decreased appetite, irritability, weight loss, and insomnia.

In addition to methylphenidate, atomoxetine, a non-stimulant drug for ADHD, has also shown efficacy in the treatment of ADHD in children with ASD. One medium and one small-sized RCT demonstrated improvements in symptoms of hyperactivity, but not inattention (effect size of 0.90) (Arnold et al., 2006; Harfterkamp et al., 2012). Common

adverse effects of atomoxetine include insomnia, nausea, and gastrointestinal effects. However, no RCTs, quasi-experimental, observational, or case series studies have evaluated the efficacy of stimulant or non-stimulant medications in treating ADHD in adults with ASD. As such, rules of extrapolation from children's studies are often used to make clinical decisions.

Depression. Evidence supporting the use of pharmacological treatments for depression in adults with ASD is very limited. Despite the high prevalence of mood disorders in the autistic population, there is a paucity of data to show the efficacy of various therapeutic agents. A recent systematic review (Menezes et al., 2020) evaluated the availability and efficacy of psychosocial and pharmacological interventions in the treatment of depression in children and young adults with autism. From the 25 articles included in the review, only 5 investigated the efficacy of medical treatments of which two were single case studies (Bird, 2015; Wink et al., 2014) and three were open-label designs (Golubchik et al., 2013, 2017; Rausch et al., 2005) with small sample sizes (n=11 to 13). Pharmacological treatments included Anti-Epileptic drugs (AEDs), norepinephrine reuptake inhibitors (NRI), stimulants, atypical antipsychotics, and N-methyl-d-aspartate (NMDA) receptor antagonists. While most of the studies showed a marked improvement in depressive symptoms pre- and post-treatment, the strength of the evidence and overall quality for all five studies was low due to lack of consistency, precision, and medium to high limitations of the studies. As such, recommendations regarding the use of pharmacological treatment for depression in autistics suggest practicing caution given the lack of robust evidence as well as the side effects

(gastrointestinal complaints, sedation, weight gain, increased appetite, fatigue, dystonia, and depression) associated with such medications, especially when benefits do not always outweigh risks.

Anxiety and Repetitive Behaviors. Evidence for treating anxiety in adults with ASD is also limited. SSRIs have been used to treat anxiety and repetitive behaviors in ASD, although evidence supporting their efficacy is limited (Jobski et al., 2017). Moreover, the use of SSRIs in individuals with ASD has been associated with an increased risk of adverse reactions, particularly behavioral activation characterized by restlessness, impulsivity, and/or insomnia (Vasa et al. 2014). A Cochrane review published in 2013 found no evidence of the effectiveness of SSRIs in young adults with autism (Williams et al., 2013). For example, the effectiveness of fluoxetine in adults with ASD was studied in two small studies with one reporting significant improvement in obsessions (Buchsbaum et al., 2001) and the other significant reduction in compulsions (Hollander et al., 2012). Similarly, studies have shown the effectiveness of fluoxetine in reducing repetitive behaviors (Hollander et al., 2012), although a larger study of youth with autism did not find any improvements in repetitive behaviors with its use (Herscu, 2020).

The effectiveness of other SSRIs, such as fluvoxamine and risperidone has also been investigated in other studies for the treatment of anxiety, obsessions, and compulsions (McDougle et al., 1996, 1998) with results showing reductions in relevant symptoms as measured by self-reported and clinician-rated outcomes. As such, while benefits with the use of SSRIs for treating anxiety in adults with ASD have been reported

in small studies, effects are modest and evidence is limited, thus their use should be determined on a case-by-case basis per physician discretion.

Finally, a recent meta-analysis conducted by Yale researchers (Zhou et al., 2021) investigated the efficacy of pharmacological treatments for restricted and repetitive behaviors (RRB) in individuals with ASD. Sixty-four randomized, placebo-controlled trials including 3,499 participants with ASD were included. Results showed significant improvements in RRB with the use of antipsychotics, such as fluvoxamine, guanfacine, and buspirone, compared to placebo, although with a small effect size (standardized mean difference [SMD] = 0.28, 95% CIs = 0.08-0.49), $z = 2.77$, $p = .01$). On the other hand, treatments with other frequently used pharmacological treatments including oxytocin, SSRIs, omega-3 fatty acids, and methylphenidate did not show significant improvements in RRB compared to placebo. The authors conclude that current evidence for the treatment of RRB with pharmacological agents is modest with antipsychotic medications showing some benefits. Therefore, future RCTs using standardized study designs and consistent assessment tools are required to better ascertain which treatments may be effective in improving these behaviors in individuals with ASD.

Sleep Disorders. Sleep disturbances are a common occurrence in children with ASD. This may be due to abnormal levels of melatonin secretion as well as abnormalities in circadian rhythm in autistic children compared to their normally developing counterparts (Blackmer & Feinstein, 2016; Tordjman et al., 2005). Treatment with melatonin has proven effective in improving sleep patterns in children with ASD (Souders et al., 2017). A randomized placebo-controlled trial of 160 children aged four to

10 with ASD evaluating the efficacy of 3mg per day melatonin (combined with CBT) for 12 weeks found a significant improvement in insomnia compared to placebo as measured by the Children's Sleep Habits Questionnaire (Cortesi et al., 2012). In addition, 85% of children in the melatonin-treated arm achieved sleep-onset latency of less than 30 minutes.

In a systematic review and meta-analysis of five small studies evaluating the effectiveness of melatonin for sleep disorders in ASD, significant improvements in sleep duration were noted for participants using melatonin with a mean increase of 73min versus baseline and 44 min compared to placebo (Rossignol & Frye, 2011). Conversely, sleep onset latency decreased by 66 min compared to baseline and 39 min compared to placebo, although no changes in night-time awakenings were observed. In these studies, the length of melatonin use ranged from 14 days to over four years with minimal to no adverse effects associated with use.

A larger, prospective, open-label study investigating the efficacy and safety of prolonged-release melatonin in 95 subjects aged 2 to 17.5 years with ASD who completed a double-blind 13-week trial found that after 52 weeks of continuous treatment subjects experienced longer sleep by 62 min, fell asleep 48.6 min faster, had longer (89.1 min) uninterrupted sleep episodes, and less nightly awakenings (Maras et al., 2018). Evidence supporting the use of melatonin in combination with CBT has also shown superiority in reducing symptoms of insomnia compared to melatonin alone, CBT alone, and placebo. In addition, a greater proportion of participants in the combination group

showed clinically significant improvements and fewer dropouts after 12 weeks of treatment (Cortesi et al., 2012).

Despite evidence for the effectiveness of melatonin in children with ASD, there are currently no published studies evaluating its effectiveness for the treatment of sleep disorders in adults with ASD. Only one small retrospective study of six adults with ASD showed that melatonin was effective in reducing nocturnal awakenings and sleep onset latency and improving total sleep time with no reported side effects (Galli-Carminati et al., 2009). Moreover, these benefits were sustained over six months with therapy. Other pharmacologic treatments including mirtazapine, gabapentin, and clonazepam have also been used on a case-by-case basis in individuals with autism whose sleep disturbances are refractory to melatonin, although their prolonged use is not recommended, and the benefits should be carefully weighed against associated risks before initiation of therapy and during use (Blackmer & Feinstein, 2016).

Summary

This chapter has provided a comprehensive review of the literature concerning the QoL and mental health of individuals with autism as well as evidence-based interventions used to alleviate the various deficits and symptoms of ASD. As evident, autism is a complex disorder with multiple challenges which limit the communication, social, cognitive, and behavioral skills of individuals impacted by the condition. These limitations extend into other interrelated manifestations associated with independent living, gaining employment, and ultimately the ability to live a fulfilling life. Of the researched interventions, social skills, mental health, and behavioral approaches appear to

have the most robust evidence to support their effectiveness in improving the various deficits in autism. Specifically, group-social skills interventions, CBT for psychological disorders, mindfulness approaches, and ABA used in various contexts have shown medium to strong effects and are most promising.

On the other hand, the evidence for adaptive/daily living skills, vocational interventions, and pharmacological therapies is not as strong largely due to the lack of rigorous study designs and methodologies used. Importantly, the literature shows a concerning gap in evidence-based interventions in the adult population with ASD as most studies focus on early interventions targeting children with the disorder. Notably, the studies lack rigor in terms of randomized, placebo-controlled designs, robust methodology, heterogeneity of subject characteristics and outcome measures, sampling methods, and capturing treatment fidelity. The highly small sample sizes limit the generalizability of results and power.

Finally, the review has highlighted several important gaps in the literature which are the subject of this dissertation. These include, 1) the lack of longitudinal studies and follow-up to ascertain the lasting effects of autism interventions, 2) the short-term application of interventions with immediate evaluation of outcomes assessed by investigators, and 3) a lack of assessment of whether any of the applied therapeutic interventions translate into meaningful outcomes as they relate to improvements in quality of life and mental health in adults with autism. Therefore, it is presumed that findings from this research project will in part help address these gaps, albeit indirectly,

by delineating interventions which support adults with autism to achieve a better QoL and mental health.

Chapter 3 will focus on the methodological aspects of this research including research design and rationale, population, sampling, and sampling procedures, procedures for recruitment, participation, and data collection, instrumentation and operationalization of constructs, threats to validity, and ethical procedures.

Chapter 3: Research Method

Individuals with autism spectrum disorders (ASD) experience a significantly poorer quality of life (QoL) and burden of mental health disorders compared to the general population and even those with other disabilities (Ayres et al., 2018; Kamio et al., 2013). Several factors including communication and social deficits, cognitive functioning, atypical behaviors, and sensory disturbances limit the ability of these individuals to participate in community and live independent fulfilling lives. Numerous interventions, such as social skills, behavioral, and psychological are implemented in early childhood to help ameliorate specific areas of deficit in individuals with ASD (Benevides et al., 2020). Though evidence-based research partly supports the effectiveness of such interventions in improving skills in an identified psychosocial or behavioral area, the longitudinal impact and maintenance of acquired benefits is largely unknown. This dissertation study aimed to address the identified gap in the research by examining the association between a set of seven broadly categorized autism interventions and QoL and mental health in individuals with ASD. The seven therapeutic interventions included social skills, mental health (depression/anxiety), behavioral, adaptive/daily life skills, mindfulness, vocational, and medication interventions. The association between these interventions and QoL as measured by the WHOQOL-BREF and mental health as measured by DASS-21 was evaluated to ascertain intervention strategies which are most effective in helping autistic individuals achieve a better QoL and mental health status.

This chapter will review the methodology for this research. The following sections will be covered: (a) research design and rationale, (b) study methodology including study population, sample, and sampling procedure; procedures for recruitment and data collection; instrumentation and operationalization of study constructs; and data analysis plan, (c) threats to validity, and (d) ethical procedures. The chapter will close with a summary of key points and concepts.

Research Design and Rationale

This study employed a quantitative method and a cross-sectional correlational research design. The quantitative method is rooted in the positivist paradigm, which posits that knowledge is objective and quantifiable and that there is one single reality that can be studied and experienced independent of human bias (Barker & Pistrang, 2015). Quantitative research involves the collection of numerical data to find relationships or associations between independent and dependent variables through defining null and alternative hypotheses. Statistical analyses are then conducted on collected data to ascertain the presence or absence of significant associations between variables resulting in either acceptance or rejection of the null hypothesis (Barker & Pistrang, 2015). This study utilized a quantitative method where two research questions and associated null and alternate hypotheses with independent and dependent variables were defined and operationalized to set the methodological framework.

In this study, a correlational research design was used to investigate the relationship between independent and dependent variables. A correlational study design is a non-experimental design where a causal relationship between variables cannot be

established since there is no random allocation to groups and the researcher does not manipulate the independent variable(s). In correlational designs, independent variables are denoted as predictor variables, whereas dependent variables are represented as criterion variables (Asamoha, 2014; Frankfort-Namchias & Namchias, 2008). Moreover, correlational designs are used to determine whether a significant linear relationship exists between the predictor and criterion variables as well as the strength and direction of the relationship. I evaluated whether there is a significant association between a set of seven autism therapeutic interventions, namely social skills, mental health (depression/anxiety), behavioral, adaptive/daily living, mindfulness, vocational, and medication interventions (the predictor variables) and QoL and mental health (the criterion variables). In addition, several covariates that may influence QoL and mental health status in the autistic population were assessed to ascertain significant associations. As such, the predictor and criterion variables were operationalized and measured using instruments, namely the WHOQOL-BREF and DASS-21. Both are valid and reliable instruments to measure QoL and mental health outcomes, respectively, and have been previously used and validated in the autistic population (McConachie et al., 2018; Park et al., 2020). Descriptive and inferential statistics were used to determine the significance of the sought-after associations which will result in either rejecting or accepting the null hypotheses. Further, hierarchical multiple regression (HMR) models were used in this study to conduct the analysis (Asamoah, 2014).

Finally, the use of a cross-sectional survey design was appropriate here. A cross-sectional study is a type of observational study where the researcher takes a snapshot of

the population being studied at a single point in time (Salazar et al., 2015). There is no manipulation of the variables studied, and predictors and outcomes are measured at the same time. The strengths of cross-sectional studies are that they are relatively inexpensive and quick to conduct, multiple exposures and outcomes can be studied at the same time, they present no major ethical issues, and they lead to the generation of additional hypotheses (Wang & Cheng, 2020). Conversely, limitations of this study design include the inability to draw causal inferences, susceptibility to biases such as recall and nonresponse bias, and lack of a longitudinal follow-up. Based on the objectives of this study and the lack of national registries or databases in Canada that collect the variables of interest in this study, a cross-sectional survey design was used.

Methodology

Population

The sample population for this study comprised individuals with autism without an intellectual disability (ID) aged 18 years and over residing in Canada. The severity and ID status was based on self- or proxy reports rather than a clinician's formal diagnosis. The current global prevalence of ASD is estimated at 1%, although there has been a significant increase in diagnosed individuals in the last decade, supporting the claim of an autism epidemic (Fombonne, 2001, 2020; Xu et al., 2018). This increase is signified by current estimated rates of one in 54 children having the disorder compared to one in 89 in 2015 (Baio et al., 2018). According to the Public Health Agency of Canada (PHAC), 1 in every 66 children and youth in Canada aged 5 to 17 years old has ASD (National Autism Spectrum Disorder Surveillance System, [NASS], 2018). This amounts to approximately

575,837 of the total population in Canada. The NASS report is based on seven participating provinces and territories (Newfoundland and Labrador, Nova Scotia, Prince Edward Island, New Brunswick, Quebec, British Columbia, and the Yukon Territory) in Canada which represent about 40% of children and youth in the country. Of note, the prevalence is about four to five times higher in males than females with 1 in 42 males and 1 in 165 females diagnosed with ASD. These rates are consistent with those reported in the United States with 1 in 54 children and adolescents being diagnosed with ASD with higher prevalence rates in boys (1 in 34) than girls (1 in 144; Centers for Disease Control and Prevention, [CDC], 2020).

Sampling and Sampling Procedures

For this study, a nonprobability convenience sampling method was used to recruit participants. Though in probability sampling random selection allows for every participant to have an equal chance of being selected from the population, nonprobability samples are based on subjective methods to decide which elements are included in the sample (Etikan et al., 2016). As such, the nonprobability sampling process does not provide all participants in the population an equal chance to be included in the study, hence limiting the representation of the entire population. The latter introduces a source of bias in the study. However, nonprobability sampling is especially useful when randomization is impossible and when the researcher does not have a lot of time, money, or resources to conduct research. Moreover, nonprobability sampling is appropriate when the researcher does not aim to generate results that need to be generalized to the entire population.

Convenience sampling, also known as haphazard or accidental sampling, is a type of nonprobability sampling technique where subjects are recruited based on certain practical criteria, such as geographical proximity, easy accessibility, availability, or willingness to participate (Dörnyei, 2007). As such, the researcher may select subjects that are more readily accessible, limiting equal opportunity for all qualified individuals in the target population to be included. This introduces bias and renders study results that may not necessarily be generalizable to the entire population of interest. Despite these limitations, convenience samples are easy to recruit, affordable, and readily available which makes it a commonly used technique for subject selection (Etiken et al., 2016). In this study, a nonprobability convenience sampling technique was used since participants were included based on their accessibility, availability, or willingness to participate. Specifically, adults with ASD and no ID aged 18 years and older associated with targeted autism service centers, provincial ASD organizations, and social media groups were sought after to take part in the study. Those less than 18 years of age and comorbid ID were excluded from the study.

The sample size for multiple linear regression (MLR) was calculated using G*Power (Faul et al., 2007). Power was set to .80, and a .05 alpha level and large effect size, $f^2 = 0.35$ were used. The estimation of a large effect size was derived from a review of the literature where McConachie et al (2018) undertook psychometric validation of the WHOQOL-BREF in a sample of 306 autistics. They reported large effect sizes when calculating Cohen's d between the autistic sample and normative data for each domain indicating a significantly lower QoL in autistic people. In addition, the QoL of autistic

people was more than one SD below relevant norms in over half of the autistic sample in the study (except for the Environment domain). As such, a large effect size was used for the sample size calculations. The total number of tested predictors was set to 15. These included seven autism interventions as predictors (social, mental health, behavioral, adaptive/DLS, vocational, mindfulness, and medications [all coded into one dummy variable each]) and eight potential covariates (age [continuous], gender [coded into one dummy variable], autism severity [coded into one dummy variable], employment status [coded into one dummy variable], relationship status [coded into one dummy variable], having a diagnosed mental health condition [coded into one dummy variable], highest education level [coded into one dummy variable], and receiving support [coded into one dummy variable]). This yielded a sample size of 68.

Since it was recognized that a sample size of 68 may be small in the context of 15 predictors, all attempts were made to recruit as many participants as possible during the three-month recruitment period. This ensured that the study was appropriately powered to accurately demonstrate significant associations should they exist. As such, a target sample size of up to 150 was considered based on an estimate of obtaining 10 observations per predictor (i.e., 10 x 15 predictors). But it should be noted that due to the study design, each observation/participant contributed to more than one predictor/intervention in this study, offsetting the potential smaller sample size. Although achieving a sufficient sample size was not an issue in the study, the following strategies would have been used to mitigate the issue: contacting additional partnering sites to support recruitment, considering additional social media resources, expansion of study

inclusion criteria to U.S. participants, and removal of interventions with no/minimal use to reduce number of variables evaluated in the study.

Procedures for Recruitment, Participation, and Data Collection

I employed a mixed-mode survey method by combining different recruitment and data collection strategies (de Leeuw & Berzelak, 2016). By using different methodologies for various phases of a survey, such as screening, recruitment, and data collection, or different ways of administering the questionnaire, such as online, telephone, interactive voice response, or mail, the researcher maximizes the likelihood of participation in the study. This is achieved through expanding coverage of the target population which may be hard to reach while increasing response rates and reducing bias. Two phases of the mixed-mode survey methodology were utilized including the contact/recruitment phase and the response/data collection phase (de Leeuw, 2005).

Recruitment Procedures

The recruitment phase strategies included an electronic study flyer outlining details of the study and advertising through provincial autism websites and social media groups. The flyer included information such as the purpose of the study, the investigator's profile and contact information, the role of the participant in completing the survey, the amount of compensation (\$10) provided following completion of the survey, participant consent requirements, Walden's Ethics Review Board contacts, and the associated Survey Monkey link to access the survey questionnaire.

Various channels or modes were used to maximize participant recruitment. These included posting of the study flyer on relevant autism social media sites, such as private

Facebook groups, and gaining permission to post on national and provincial ASD organization websites including Autism Canada, Autism Ontario, Autism Saskatoon, Autism Prince Edward Island, Autism Calgary, and Autism British Columbia. In addition, key stakeholders at several autism institutions and service centers were contacted and agreed to disseminate the study flyer to appropriate clients. Finally, referral networks were used through engaging with ASD professionals who work with autistic individuals and their families to promote the study to those who met study criteria.

Data Collection Procedures

Interested participants accessed the study survey by clicking on the link provided on the study flyer or copy and pasted the link into a search engine. Upon accessing the survey link on the Survey Monkey platform, participants were first presented with the subject consent form. In line with the Walden IRB requirements, the informed consent included: (a) an overview of the objectives and purpose of the study, (b) the role of the participant in completing the survey and its length (no longer than 20 minutes), (c) study inclusion criteria, (d) the role of the researcher, (e) the voluntary nature of the survey and the right to refuse to answer questions without consequence, (f) any potential benefits or risks, (g) small compensation provided for participation in the study, (h) the confidentiality and anonymity of participants, (i) the investigator's and REB board's contact information, and (j) the option to print out and retain a copy of the informed consent form. Participants who met study criteria and provided consent to participate in the study were asked to proceed to the next pages of the survey. The study survey

comprised of a demographic questionnaire including the seven types of interventions used, and two validated questionnaires (the WHOQOL-BREF and DASS-21).

Data Security Procedures

The Survey Monkey platform has several data security and privacy protocols. The survey websites are both password protected and SSL-encrypted. I created and accessed the study survey using a username and password, and participant anonymity was ensured through selecting the *Anonymous Response* option and by deselecting the *Save IP Address* option available on the platform. In addition, the *Single Sign-On* option provided by Survey Monkey was used to ensure that participants completed the survey only once. Participant responses to the study survey were collected and downloaded upon completion of the study followed by deletion of the study link. Survey data were stored on my password-protected laptop and OneDrive Cloud and will be destroyed after 5 years. Similarly, the frame of the survey will be removed from the SurveyMonkey platform after 13 months per the site's regulations (Survey Monkey, 2018).

Instrumentation and Operationalization of Constructs

The study survey included three sections: participant demographics including intervention use, the WHOQOL-BREF to measure quality of life, and the DASS-21 to measure anxiety and depression levels as a composite score.

Demographic Variables

This section of the survey captured variables including participants' age, gender, autism severity, relationship status, living status, education level, employment status, support status, and physical and mental health status. All variables were included in the

descriptive statistics of the analysis and were tested as potential covariates in the statistical model. Age was captured in years as a continuous variable. Gender was collected as a dichotomous variable coded as *female* = 0 and *male* = 1. Autism severity was captured as a dichotomous categorical variable as *Level 1 (High-functioning)* = 1 or *Other* = 0. Relationship status was measured categorically as a dichotomous variable *Single or In a relationship* (coded as 0 or 1, respectively) where participants were asked, 'What is your current relationship status?'. Living status was also measured as a dichotomous variable based on the question 'What is your current living status?' with possible responses as *Live on my own or Live with my family/caregivers* (coded as 0 or 1, respectively). Level of education was measured as a categorical, dichotomous variable by asking participants 'What is your highest level of education?' *High school or less* = 0, or *Post-secondary school/College/University* = 1). Employment status was defined as paid employment (full-time or part-time) measured as a dichotomous variable addressing the question, 'What is your current employment status?' (*Unemployed or student* = 0, *Employed full time or part-time* = 1). For support status, the survey question asked participants to indicate 'What is your current level of support received?' with responses defined categorically and dummy coded as, *I do not receive any support from family/friends/social groups* = 0 or *I receive support from family/friends/social groups* = 1. Finally, participants indicated their current physical and mental health status by responding to the questions, 'Are you currently ill or in poor health?' and 'Do you currently have a mental health condition diagnosis?' with two categories of response *Yes/No* coded as 1/0.

Predictor Variables: Autism Interventions

Seven autism interventions were included on the survey questionnaire following the above section. These included social, mental health, behavioral, adaptive/daily living skills (DLS), vocational/employment, mindfulness, and medications. The following question was asked, '*Please indicate which of the following autism interventions you have ever used (in the **past or present**) to help manage your needs (Please choose all that apply)*'. The use of each intervention was captured as a dichotomous categorical variable *Yes/No*. For each intervention, additional descriptions/examples were provided to help participants better understand the nature of the intervention. For example, mental health support (from psychologist, therapist, social worker, or counsellor, or cognitive behavior therapy (CBT)); vocational/employment support (interview skills, job skills, keeping a job); or mindfulness (yoga, meditation, breathing exercises, physical exercise)). Please see Appendix B for further details on the Demographic and Interventions questionnaire.

Criterion Variable: WHOQoL-BREF

To assess the QoL of individuals with autism in this study, the World Health Organization Quality of Life (WHOQOL-BREF) instrument was used (Harper, 1998). The WHOQOL-BREF assessment is an abbreviated version of the WHOQOL-100 tool developed by the WHOQOL Group in 15 international field centres across different cultures (WHOQOL Group, 1994). Although the WHOQOL-100 is a comprehensive assessment of QoL based on 24 facets and four general questions addressing overall QoL and general health, it may be too lengthy for use in large epidemiological studies where QoL is only one variable of interest. As such, the WHOQOL Group embarked on

developing a more brief, accurate, and convenient version of WHOQOL-100, the WHOQOL-BREF (Harper, 1998). The WHOQOL-BREF was developed by collecting data from 20 field centres within 18 countries (Skevington et al., 2004). At least one question from each of the 24 facets of the WHOQOL-100 was selected based on specified criteria which were then categorized into four domains including *physical health, psychological, social relationships, and environment*. In addition, two items from the overall QoL and general health questions were included resulting in a total of 26 questions. The instrument was published by Harper in 1998 on behalf of the WHOQOL Group.

An international field trial assessing the psychometric properties of the WHOQOL-BREF collected cross-sectional data from 23 countries surveying a total of 11,830 adults with various characteristics including sick and healthy from the general population, but also from primary care, hospital, and rehabilitation settings, serving patients with mental and physical disorders (Skevington et al., 2004). Moreover, the instrument has been used specifically to assess QoL in various ill populations and conditions including, but not limited to autism, cancer, mental disorders, respiratory illness, and diabetes, among others (Abbasi-Ghahramanloo et al., 2020; Lin et al., 2019; Lucas-Carrasco et al., 2011). Finally, the WHOQOL-BREF has been shown to adequately assess QoL in many cultures worldwide and is available in 19 different languages.

Comparisons between the WHOQOL-100 and WHOQOL-BREF domain scores have shown high correlations ranging from 0.89 (domain 3) to 0.95 (domain 1). The

WHOQOL-BREF has been shown to display good internal consistency (Cronbach alpha values ranging between 0.66 and 0.84), discriminant validity (excellent ability in discriminating between ill and well respondents), content validity, and test-retest reliability (Interclass Correlation Coefficient (ICC) = 0.66 for physical health, 0.72 for psychological, 0.76 for social, and 0.87 for environment) (Skevington et al., 2004).

WHOQOL-BREF Scales

All four domains of the WHOQOL-BREF were used in this study to measure a different aspect of QoL. These include physical health (seven items, e.g., activities of daily living, work capacity, sleep), psychological (six items, e.g., self-esteem, positive feelings, memory), social (three items, e.g., relationships, social support), and environment (eight items, e.g., safety, transport). Respondents are asked to rate each question on a five-point Likert scale as *'very poor'*, *'poor'*, *'neither'*, *'good'*, and *'very good'* while thinking about their life in *the past two weeks*. The four domain scores (physical, social, psychological, and environment) denote an individual's perception of QoL in each specific domain, while the two overall questions ask about the person's overall perception of their QoL and about their overall perception of their health. Higher scores signify a higher QoL (WHOQOL-BREF Manual, 1996). Each total domain score is calculated by taking the mean score of all items within each domain, then raw scores are transformed by multiplying by four to make them comparable with the scores used in the WHOQOL-100. As such, the converted scores range between 4-20. Finally, the second transformation converts the domain scores into standardized scores ranging between 0 to 100. All domain scores are quantitative and were measured on a continuous

scale. Permission to use the WHOQOL-BREF was obtained and granted from the WHO National field center prior to its use.

Criterion Variable: DASS-21

The Depression, Anxiety, and Stress Scale (DASS) is a self-reported or clinician administered questionnaire which measures three negative emotional states of depression, anxiety, and stress (Lovibond & Lovibond, 1995). The instrument is unique in its ability to distinguish between the two constructs of depression and anxiety which have been demonstrated to have a high degree of overlap or intercorrelation in symptoms and features. Specifically, the theorists Clark and Watson (1991) posited a tripartite structure of anxiety and depression with shared and unique features related to each construct including negative affect shared by both, an absence of positive affect specific to depression, and physiological hyperarousal specific to anxiety. However, it was the research program of Lovibond & Lovibond spanning from 1979 to 1990 which separately evaluated the psychometric properties of a questionnaire, the DASS, to assess the full range of symptoms of anxiety and depression while providing maximum discrimination between the two constructs (Lovibond & Lovibond, 1995). This led to the discovery of the third construct, stress, which was added to the instrument. Although the DASS was developed prior to Clark and Watson's model of anxiety and depression, parallels between the DASS and tripartite model have been drawn. Each of the resulting three scales consists of 14 items divided into 2-5 item subscales. The depression scale measures dysphoria, hopelessness, lack of interest, and devaluation of life (absence of positive affect); the anxiety scale assesses autonomic arousal, situational anxiety, and

skeletal muscle effects (physiological hyperarousal); and the stress scale is characterized by persistent tension, becoming easily upset or frustrated, and irritability (negative affect) (Lovibond & Lovibond, 1995). Each item is rated by respondents on a 4-point severity/frequency scale over the course of *the past week* denoted as *0 = Did not apply to me at all; 1 = Applied to me to some degree, or some of the time; 2 = Applied to me to a considerable degree or a good part of time; and 3 = Applied to me very much or most of the time*. The three domain scores are calculated by adding the scores for all items in the relevant scale.

The DASS-21 is a short version of the DASS which is more commonly used in research studies. Rather than the basic 42-item questionnaire, DASS-21 consists of 7 items per scale for a total of 21 items (Antony et al. 1998). As such, scores obtained for each scale are multiplied by two to make them comparable to the corresponding full DASS score and norms. Of note, DASS-21 is a *dimensional* rather than a *categorical* conception of psychological disorders. This stems from the assumption and research data which suggest that differences in the three constructs of depression, anxiety, and stress between normative and clinical populations are differences of degree rather than discrete diagnostic categorization of patients into conventional classification systems such as the DSM (Brown et al., 1998). Based on this, cut-off scores for each of the DASS-21 constructs (depression, anxiety, and stress) have been established using conventional severity labels. These include *normal, mild, moderate, severe, and extremely severe*. Of note, a composite score of the two negative emotional symptoms (depression and anxiety) was used in this study.

The psychometric properties of DASS and DASS-21 have been evaluated in both non-clinical and clinical large samples with a lower age limit of 17 years in the development samples ($n = 717$ and 437 , respectively) (Antony et al., 1998; Brown et al., 1998; Lovibond & Lovibond, 1995). The scales have shown high internal consistency and temporal stability (Cronbach's alphas of 0.94 for Depression, 0.87 for Anxiety, and 0.91 for Stress). Moreover, the instruments have shown discriminant and convergent validity with other depression and anxiety instruments including the Beck Anxiety Inventory (BAI) with a high correlation of 0.81 and the Beck Depression Inventory (BDI) showing a correlation of 0.74 (Lovibond & Lovibond, 1995). Factor structure has been substantiated by both exploratory and confirmatory factor analysis. Of note, DASS-21 has shown several advantages over DASS including cleaner factor structure, fewer items, and smaller inter factor correlations. Importantly, the instruments have shown capacity to differentiate between the three constructs of depression, anxiety, and stress (Antony et al., 1998).

The DASS-21 is available in 54 languages and has been used in a variety of nonclinical and clinical populations including cancer patients, drug users, sleep apnea, epilepsy, persistent pain, as well as ASD (Cage et al., 2018; de Haan et al., 2015; Kok et al., 2015; McMullen et al., 2018; Wood et al., 2010). Several studies have reported the adequate internal consistency of the DASS-21 in adults with ASD (Cronbach's alpha for depression = 0.88-0.92; for anxiety = 0.79-0.83, and stress = 0.84-0.86, and total = 0.93) (Cage et al., 2018; Maddox & White, 2015; Nah et al., 2018), although a recent comprehensive validation of the instrument was conducted by Park et al. (2020). In this

study, the psychometric properties of the DASS-21 were evaluated in 123 individuals with ASD and no ID specifically around internal consistency, item-total correlations, convergent validity, and factorial validity. Results showed a Cronbach's alpha value of 0.94 with all items showing satisfactory item-scale correlations ($r = 0.32 - 0.82$) and item-total correlations ($r = 0.40 - 0.77$). In addition, convergent validity was adequate between the DASS-21 and instruments with similar constructs. Finally, factor analysis confirmed the model supporting the use of three factors consisting of depression, anxiety, and stress. Overall, findings from the validation study support the use of the DASS-21 as a screening measure for depression, anxiety, and stress in the autistic population with no ID, albeit the 'dryness of mouth' item from the anxiety scale showed weak performance in the ASD cohort questioning its utility, hence potential removal from the instrument (Park et al., 2020). Of note, for this study, the stress scale and associated seven items were removed and only the depression and anxiety composite score was used. In accordance with the DASS-21 manual (Lovibond & Lovibond, 1995), removal of this scale from the questionnaire is acceptable and does not jeopardize survey results. Per the DASS website, no permission was required to use the instrument (see <http://www2.psy.unsw.edu.au/dass/DASSFAQ.htm>).

Data Analysis Plan

Upon study completion, survey data collected in the SurveyMonkey® platform were downloaded into the SPSS 28.0 statistical software for analysis. As stated in Chapter 1 of this dissertation, this study addressed two quantitative research questions with associated null and alternate hypotheses as below:

RQ1: What is the association between therapeutic interventions including social skills, mental health, behavioral therapies, adaptive/DLS, vocational, mindfulness, and prescribed medications, and the self- or proxy-reported quality of life (QoL) of autistic individuals aged 18 years and older without intellectual disability (ID) as measured by the WHOQOL-BREF?

H₀1: There is no significant association between therapeutic interventions and the self- or proxy-reported quality of life (QoL) of autistic individuals aged 18 years and older without intellectual disability (ID).

H_A1: There is a significant association between therapeutic interventions and the self- or proxy-reported quality of life (QoL) of autistic individuals aged 18 years and older without intellectual disability (ID).

RQ2: What is the association between therapeutic interventions including social skills, mental health, behavioral therapies, adaptive/DLS, vocational, mindfulness, and prescribed medications, and the self- or proxy-reported mental health of autistic individuals aged 18 years and older without ID as measured by the Depression, Anxiety, Stress Scale-21 items (DASS-21)?

H₀2: There is no significant association between therapeutic interventions and the self- or proxy-reported mental health of autistic individuals aged 18 years and older without intellectual disability (ID).

H_A2: There is a significant association between therapeutic interventions and the self- or proxy-reported mental health of autistic individuals aged 18 years and older without intellectual disability (ID).

HMR Model: Hypothesis Testing Research Questions 1 and 2

Multiple regression analysis is used to determine associations or the effects of various predictor variables on an outcome variable. It can also indicate the relative contribution or effect of each predictor variable in terms of magnitude and direction to the total variance or overall fit of the model (Frankfort-Nachmias & Leon-Guerrero, 2018). Hierarchical multiple regression (HMR) is a special form of multiple linear regression which provides a framework for model comparison by building several models through the addition of new variables at each step or 'block'. This allows the researcher to statistically 'control' for certain variables and to determine whether the addition of new variables significantly improves a model's ability to predict the proportion of variance explained in the dependent or criterion variable (R^2).

This research study used five HMR models; four to predict each of the WHOQOL-BREF domains and one to predict the mental health status (DASS-21) of individuals 18 years and older with ASD and no ID. In each instance, a set of potential covariates were entered as blocks into the model to investigate their association with the criterion variable. Model 1/Block 1 comprised of the demographic variables age, gender, and autism severity; Model 2/Block 2 included additional covariates including employment status, relationship status, education level, support status, and having a mental health diagnosis. These covariates were chosen based on a review of the literature which revealed statistically significant associations between these factors and the WHOQOL-BREF or other measures which either positively or negatively predicted QoL across the four domains (Khanna et al., 2014; Mason et al., 2018). Model 3/Block 3

included all seven predictors or therapeutic interventions, the essence of this research study, to determine whether any significant associations exist with the criterion variables.

The reported statistics included the F -value and the adjusted coefficient of determination (R^2) with associated p -values for each of the WHOQOL-BREF domains. The R^2 served as an indicator of the effect size denoting the proportion of the variance in the criterion variables explained by the predictor variables. Moreover, the change in R^2 (ΔR^2) and associated p -value between the three models were reported to show the magnitude and significance of the additional variance explained by each additional model. Standardized β coefficients and associated p -values were reported for each predictor variable to compare the strength, direction (positive or negative), and significance of each in relation to the outcome variable. Higher absolute values indicated stronger effects and p -values $< .05$ indicated significance. The same HMR procedure was repeated for the DASS-21 criterion using a composite score of the depression and anxiety scales calculated by taking the average of both scales.

Point-Biserial Correlations: Correlation Diagnostics Between Variables

Prior to conducting the HMR analysis, point-biserial correlations were used for *diagnostic* purposes to ascertain correlations between the predictor/covariate and outcome variables. Point-biserial correlation is used to measure the strength and direction of the association between a continuous and dichotomous variable (Laerd Statistics, n.d.). It is a special case of the Pearson's product moment correlation which is used when one variable is measured on a dichotomous scale. Like the Pearson coefficient, the point-biserial correlation can range between -1 to +1 with positive values indicating a positive

association and negative coefficients signifying a negative relationship between variables. Of note, point-biserial correlation assumes that the continuous variable is normally distributed and is homoscedastic (Laerd Statistics, n.d.).

A correlation matrix was created to evaluate correlations between each covariate (age, gender, autism severity, relationship status, employment, mental health status, social support status, and education level) and each WHOQOL-BREF domain and the DASS-21 composite score. Furthermore, bivariate analyses were repeated to determine correlations between each of the seven autism interventions and respective outcome variables. Correlation coefficients ranging from 0.1 to 0.39, 0.4 to 0.69, and 0.7 and above were considered small, moderate, and high, respectively (Hinkle et al., 2003). Strongly correlated variables ($r \geq 0.7$) were noted and later assessed in the regression analysis to determine their level of influence and behavior in the multivariable model. It should be noted that these correlation diagnostics were not used to determine the inclusion/exclusion of criterion/predictor variables in the HMR models since such an approach would have prematurely assumed the non-significance of these variables in the overall multivariable model.

Data Screening and Cleaning Procedures

A series of data screening and cleaning procedures were conducted to handle missing data and outliers, where applicable. In accordance with the WHOQOL-BREF Manual (1998), the following data screening and cleaning procedures were used. First, all 26 items of the questionnaire were checked to ensure they had a range of 1-5. Second, three of the negatively framed questions (Q3, Q4, and Q26) were transformed to

positively framed questions. Third, domain scores were multiplied by four and transformed to range between 4-20 comparable to the WHOQOL-100 scales. Descriptive statistics (mean, standard deviation, minimum, maximum) were computed to ensure all domain scores were within the range of 4 to 20. Finally, all domains will be converted to a scale of 0-100 through a second transformation using the formula $\text{TRANSFORMED SCORE} = (\text{SCORE} - 4) \times (100/16)$. The latter procedures were performed using an SPSS syntax file provided by the WHOQOL-BREF organization. Several outliers were detected using boxplots and scatter plots, although kept in the overall analysis since their removal did not have a substantial effect on the overall results. Next, to handle missingness, domains with more than 20% of the data missing were discarded from the assessment (WHOQOL-BREF Manual, 1998). In this dataset, one individual did not complete the full WHOQOL-BREF questionnaire and was therefore excluded from the analysis.

For the DASS-21 questionnaire (Lovibond & Lovibond, 1995), all 14 items of the questionnaire were checked to ensure they had a range of 0 to 3 and no outliers. Descriptive statistics (mean, standard deviation, minimum, maximum) were computed to ensure all scale scores were within the range of 0 to 3. In the case of one missing item, the average score for the remaining items for the scale in question were used. On the other hand, if a substantial number of scores from a scale were missing (more than one missing item per 7-item scale), then the participant was removed (Lovibond & Lovibond, 1995). In this dataset, two individuals did not complete the entire DASS-21 questionnaire and therefore were removed from the analysis. Next, scores obtained for each scale were

transformed by multiplying by two for comparability to the full DASS scores. Finally, a composite score was calculated by taking the average of the two DASS scales.

Descriptive Statistics

In preparation for data analysis, all categorical variables were dummy coded to convert participant responses to numeric variables. Descriptive statistics were computed and reported for all demographic variables, covariates, predictor variables, and criterion variables. For continuous variables including participants' age, the four WHOQOL-BREF domains (physical, social, psychological, and environment), and the two DASS-21 scales (anxiety and depression), mean and standard deviation (SD) were reported. For all categorical covariates including gender, employment, living status, relationship status, health status, having a mental health condition diagnosis, educational level, and support status, and the seven therapeutic interventions (social, behavioral, mental health, vocational, adaptive/DLS, mindfulness, and medication) frequencies and percentages were reported.

Testing of HMR Model Assumptions. Prior to conducting the statistical analysis, key assumptions of the HMR model were tested to ensure they were met. These included a) normality of residuals, b) multicollinearity, c) independence of residuals, d) undue influence, e) linearity, and f) homoscedasticity (Warner, 2013).

Normality of Residuals. The normality assumption was tested using graphical methods including a normal P-P plot of regression standardized residuals to ascertain whether the four WHOQOL-BREF domains and the DASS-21 composite score were normally distributed (Frankfort-Nachmias & Leon-Guerrero, 2018). Violations of the

normality assumption were addressed by using the bootstrapping technique.

Bootstrapping is a statistical procedure which mitigates some of the pitfalls of conventional methods specifically related to the assumptions of normality (Kulesa et al., 2015). While conventional methods assume a normal distribution, bootstrapping does not assume any underlying distribution of the data and derives the estimates of standard errors and confidence intervals. This is achieved through resampling of the original dataset to create many simulated samples which allow derivation of the sampling distribution for the population of interest. As such, bootstrapping is a very useful technique when conventional statistics may result in invalid conclusions since the assumptions of the sampling distribution are not met.

Multicollinearity. Multicollinearity is the occurrence of high correlations between two or more predictor variables in a regression model (Kim, 2019). This is problematic since it may lead to skewed results rendering interpretation of the statistical model less reliable. Potential issues include wider confidence intervals, an increased standard error, and/or R-squared all of which may result in the incorrect rejection or acceptance of the null hypothesis as well as impact the goodness of fit of the model. Since this research study used several covariates and predictors, multicollinearity between variables was assessed by using a set of collinearity statistics and diagnostics.

The variance inflation factor (VIF) was used for the predictor-covariate and covariate-covariate relationships (Hair et al., 2013). VIF values greater than 10 would indicate violation of the multicollinearity assumption. In addition, tolerance which measures the influence of one independent variable on all other independent variables

was tested and values less than 0.1 would indicate the presence of multicollinearity (Kim, 2019). While the VIF indicates the presence of multicollinearity, it cannot detect which predictor variables are causing the multicollinearity, as such in cases of two or more predictors with a VIF value greater than 10, collinearity diagnostics were performed. This entailed evaluation of a matrix composed of the standardized predictor variables and associated *eigenvalues* (λ) and *Condition Indices, and Variance Decomposition Proportions*. Eigen values close to 0 and condition indices more than 10 to 30 for each predictor variable would indicate the presence of strong multicollinearity, especially those with values above 30. To determine which specific predictors were involved in multicollinearity, *Variance Decomposition Proportions* corresponding to each condition index were evaluated (Kim, 2019). In cases where two or more condition indices exceeding 15 to 30 corresponded to variance decomposition proportions above 0.80 to 0.90, those predictor variables would be deemed as being highly collinear. Multicollinearity was not detected between any of the covariate/covariate and covariate/predictor variables in this dataset. The section below describes procedures which would have been performed in the case of multicollinearity.

First, source data would be checked to ensure there is no erroneous recording or coding of data, for example unintentional inclusion of the same variable in the regression model twice will result in multicollinearity (Kim, 2019). Next, in the case of collinearity between covariates, only one variable would be retained for inclusion in the HMR model, while collinearity between covariate and predictor variables would be handled by discarding the covariate and keeping the predictor in the model. Following these steps,

collinearity diagnostics would be rerun and R^2 values in the regression analysis compared to ascertain the impact of removing the redundant variables.

Independence of Residuals. The independence of residuals was tested using the Durbin-Watson statistic to ensure the absence of autocorrelation in the data (Frankfort-Nachmias & Leon-Guerrero, 2018). While test values range between 0 and 4, values between 1.5 to 2.5 indicated no autocorrelation between residuals.

Undue Influence. To test the assumption of undue influence, Cook's distance was used and values below 1.0 indicated that this assumption was also met.

Linearity. Linear regression assumes a linear relationship between the predictor and criterion variables (Frankfort-Nachmias & Leon-Guerrero, 2018). This assumption was checked using a normal P-P plot of the regression standardized residuals to assess the fit of the estimates. Meeting the linearity criteria was reflected by linear distribution of the all the datapoints along the regression line. Violations of the linearity assumption could have biased results of the statistical analysis by increasing the chance of a Type I error or rejecting the null hypothesis when it was in fact true (Jeong & Jung, 2016).

Homoscedasticity. The assumption of homoscedasticity which measures whether the residuals are equally distributed across the regression line was tested using a scatter plot (Jeong & Jung, 2016). A scatter plot of standardized predicted values versus residuals was used to evaluate whether this assumption was met. Equal dispersion of values above and below the horizontal zero line indicated no violation of this assumption.

Threats to Validity

The constructs of internal, external, and statistical conclusion validity play a critical role in determining the scientific merit and conclusions of quantitative studies. Internal validity refers to the ability of the study to meet the sought-after objectives of the study and to generate valid results (Woodman, 2014). These are based on a) accurate participant recruitment and data collection procedures, b) using psychometrically valid instruments, and c) proper data analysis. External validity pertains to the extent to which the results and conclusions derived from the study are generalizable to the broader population of interest as well as to different settings. Finally, statistical conclusion validity relates to the methodology and statistical procedures used to ascertain the relationship between independent and dependent variables and the degree to which they may be violated due to statistical issues (Garcia-Perez, 2012).

Threats to Internal Validity

Several threats to internal validity are applicable in this study due to the correlational, cross-sectional survey design. These include *self-selection bias*, *social desirability bias*, *recall bias*, and *causal ambiguity* (Khazaaal et al., 2014). In the absence of random selection, self-selection bias may have been present due to differences in study participation rates related to specific participant attributes or characteristics. It is conceivable that autistic individuals who chose to participate in this study may have been more involved in online platforms, attend and seek autism interventions and services, and been more adept and comfortable to complete surveys. These factors may have impacted the internal validity of the study as the characteristics of participants and their survey

responses may not have been representative of a randomly selected population (Althubaiti, 2016). It is, however, hoped that the use of a mixed modes method for participant recruitment as well as the conditions outlined in the informed consent form may have helped reduce this bias. These included language around the voluntary nature of participation, maintaining confidentiality of responses, anonymized nature of the survey, answering questions truthfully and honestly, reporting of aggregate versus individual level results, and the benefits and risks associated with participating in the study.

The issue of *social desirability bias* may have also been present in this study. This bias may arise due to participant's tendency to provide more favorable and socially acceptable responses to survey questions, especially those deemed sensitive, which in turn may overestimate positive behaviors or attitudes and underreport negative ones (Althubaiti, 2016; Holtgraves, 2017). Social desirability is one of the commonly reported biases in both correlational and experimental studies utilizing surveys and is usually instigated by the sensitivity of survey questions and/or the researcher's presence during the data collection process. In this study, ways of reducing this bias included the online nature of the survey, the informed consent process, and the use of standardized and validated instruments which minimized the risk of asking questions inappropriately.

Recall bias may have been another threat to internal validity since participants may have not readily recalled historical events such as the types of interventions accessed and used in the past, while overreporting of currently or more recently used interventions may have occurred. The provision of a list of interventions should have in part addressed

this bias by prompting recall versus an open-ended, unaided approach. *Causal ambiguity* was another potential threat to the internal validity of this study. This stems from the use of a cross-sectional design where both predictor and outcome variables are collected at the same timepoint making it impossible to determine their temporal sequence (Warner, 2013). The inability to ascertain whether the predictor variable precedes the criterion variable limits conclusions regarding causal relationships, hence limits internal validity. In this study, it would have been impossible to determine whether the use of interventions resulted in a higher QoL or mental health, or that those with a better QoL may have had a higher tendency to use autism interventions compared to those with a lower QoL. While this threat could not have been avoided or minimized in this study, the focus here was to investigate whether an association between the use of interventions and QoL and mental health existed rather than establishing a directional or causal pathway of this relationship.

Another threat to internal validity pertained to the design of a key question on the study survey which asked participants to indicate their use of autism interventions, '*Please indicate which of the following autism interventions you have ever used (in the **past or present**) to help manage your needs (Please choose all that apply)*'. The use of an intervention in the '*past or present*' may have been conducted in several forms: used and completed, used but not completed, and was being currently used or was ongoing. Since the study did not capture nor assess these differences in participant responses, it is possible that there was heterogeneity among participants who responded '*Yes*' to this question. This may have impacted the reliability of the findings due to the potential underestimation of the association of the intervention with the outcome variables.

Two additional issues may have threatened the internal validity of this study. One pertained to the allowance of proxy parental reports to complete the survey instead of the autistic individuals independently. This may have posed a threat to internal validity since proxy-reports may not accurately reflect first person ratings, although research has shown high correlations between autistic adolescent and adult self-reports and parental proxy-reports around QoL outcomes as described in Chapter 2 of this dissertation (Hong et al., 2016; Sheldrick et al., 2012). The second additional threat to internal validity was related to the potential functional and cognitive challenges of the target population which may have resulted in partial completion of the survey. This would have reduced the number of datapoints available for inclusion in the analyses, hence reducing sample size and power of the study. The use of parental proxy reports in part mitigated this issue in addition to the use of language in the instructions of the survey encouraging participants to fully complete the survey to the best of their ability.

Threats to External Validity

Threats to external validity are related to the *selection of the sample population* for the conduct of a research study, its *environment or ecology*, and the *specificity of the variables* used (Krupnikov & Levine, 2014). *Sample selection* and inclusion/exclusion criteria may limit the generalizability of study findings to those outside of the target study population. Indeed, the narrower the selection criteria for the sample population, the higher likelihood of threat to external validity. In this study, the inclusion of people with ASD without ID aged 18 years and older excluded those with comorbid ID and potentially overestimated QoL and mental health outcomes. It is possible that individuals

with ASD, but without ID may inherently have a higher QoL, mental health status, and higher educational attainment compared to those with ID regardless of the type of intervention used. As such, exclusion of this subgroup may have impacted the external validity and generalizability of the findings to the broader autistic population. That said, targeting a subgroup of autistics without ID is a deliberate decision to maximize the likelihood of survey completion and the accuracy of responses given the higher cognitive and functional ability of this group.

The *threat of ecological validity* is another consideration since one cannot generalize findings from this study to studies which have used different settings or environments (Krupnikov & Levine, 2014). For example, the survey questionnaire for this study was administered and completed online by study participants which may have significantly differed from responses provided in an in-person setting and/or paper format. Finally, the *threat of variable specificity* may have been present in this study limiting the generalizability of findings to other contexts and outcomes. This study used specific instruments to measure the constructs of QoL and mental health in the autistic population, and it is conceivable that studies using different instruments and operationalized variables may obtain different results than those of the current study.

Threats to Statistical Conclusion Validity

Statistical conclusion validity (SCV) refers to the robustness of the conclusions of a research study based on the use of adequate statistical methods to address whether inferences about relationships between variables are reasonable (APA, 2013; García-Pérez, 2012). Threats to SCV pertain to *violations of statistical assumptions*, *low*

statistical power, and reliability of instruments used. Inferential statistical tests assume that a set of specific assumptions are met to ensure suitability of testing the hypotheses. *Violations of statistical assumptions* may result in incorrect inferences about the relationships between variables and increase the likelihood of type I or II errors. In this study, violations of the assumptions of HMR were tested and addressed, as appropriate.

Low statistical power relates to the probability of committing a type II error, hence incorrectly accepting the null hypothesis when there actually is an effect. Low power generally occurs when the sample size is too small to detect a difference or relationship between variables (García-Pérez, 2012). This study conducted a power analysis to calculate the required sample size to reduce the probability of committing a type II error.

Another threat to SCV, *unreliability of measures*, occurs when the predictor and outcome variables in a study are not measured reliably resulting in incorrect conclusions being drawn. This is closely related to the concept of construct validity which refers to the degree to which a test measures the hypothesis it claims to be measuring (Straus & Smith, 2009). For example, given the unique profile of individuals with autism and ASD being a spectrum condition, it is possible that several factors may influence the QoL and mental health of individuals with ASD. As such, it is conceivable that the QoL and mental health instruments used in this study as well as the predictors and covariates included in the statistical model may not have accurately measured QoL and mental health in individuals with ASD due to the diverse set of factors contributing to these constructs. In order to reduce the likelihood of this threat to validity, this study employed

reliable and validated instruments specifically in the autistic population, namely the WHOQOL-BREF and DASS-21, to collect the outcome variables of interest. Moreover, based on a review of the literature, several covariates with evidence suggesting their impact on QoL were included in the statistical model to control for their potential effects. In addition, data were collected in a standardized fashion prompting participants to choose from a list of interventions which they had used. Of note, the list of seven interventions provided were broad categories or types (i.e., medications or mindfulness) rather than specific procedures or approaches (i.e., methylphenidate/risperidone or yoga/mediation, respectively), and as such were not detailed enough to capture the specific type of intervention used by survey respondents. Nevertheless, this broader approach met the objectives of this study which was to delineate the types of interventions which were associated with QoL and mental health, rather than the specific approach or method used.

Ethical Procedures

This study employed several ethical procedures pertaining to IRB approvals, the recruitment and participation of human subjects including vulnerable populations, and data collection, confidentiality, and storage to ensure standards for ethical compliance were met. As guiding principles, the Canadian Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, Second Edition (TCSP2, 2018), the American Psychology Association Ethical Principles of Psychologists and Code of Conduct (APA, 2016), and Walden University procedures were followed.

Prior to conducting the study, applications to the Walden IRB were submitted for review and approval. The application included sections such as informed consent process, participant recruitment procedures, data collection, confidentiality, analysis, and storage, and the questionnaires used in the study with acquired permissions. Since the study involved vulnerable populations, Form D of Walden's IRB application was completed and submitted for approval to ensure all criteria for at risk populations were fully met.

Following IRB approval from the Walden ethics committee, participant recruitment commenced based on initial consent to enroll into the study. The Walden University informed consent form (ICF) template was used and the following information was included to ensure full disclosure of study procedures and expectations: the nature and purpose of the study, researcher's name and role, inclusion criteria, study procedures (what participants are being asked to do and the length of time required), voluntary nature of the study, potential risks and benefits to participants, privacy protocols to ensure anonymity and data security, limitations to use of the dataset by the researcher, and the length of data retention. The IRB approval numbers as well as the contact information of the researcher and ethics review boards were provided in case of additional questions and inquires by participants. The provision of a small gift card in the amount of \$10 was disclosed to participants on the ICF.

To ensure full consent was obtained from participants prior to enrollment into the study, the online survey was made available to those participants who first acknowledged reading, understanding, and agreeing to participate in the study *and* who to the best of their knowledge met the study inclusion criteria (had a diagnosis of ASD with no ID and

were 18 years of age and older). The informed consent procedure ensured that all participants were well aware of the study procedures, privacy and anonymity safeguards, data protection protocols, the potential benefits and risks associated with participation into the study, and its voluntary nature.

Data Collection, Confidentiality, and Storage Procedures

This study used the Survey Monkey platform to capture and store data. The website was encrypted and password protected allowing only the researcher to access the data. Upon completion of the data collection phase, the full dataset was downloaded from the Survey Monkey website into a SPSS 28.0 data file. The data were saved and stored both on the researcher's password protected laptop and OneDrive cloud storage as backup. Survey data were deleted from the Survey Monkey site immediately upon data download, and from the researcher's laptop and OneDrive after five years per Walden's requirements.

Summary

This chapter has addressed several components related to the methodology of the study. Topics such as study population, sampling, recruitment, data collection, instrumentation and operationalization of constructs, hypothesis testing, threats to validity, and ethical procedures were covered. The two research questions which comprised of ascertaining therapeutic interventions which were most effective or significantly associated with improving the QoL and mental health of individuals with ASD without ID were addressed using a HMR as the main test. This allowed for integration of the various predictors, potential covariates, and criterion variables into the

model to determine significant associations and the magnitude and direction of the effects and variance explained. The next chapter, Chapter 4, will cover the main findings of the study.

Chapter 4: Results

Autism spectrum disorders (ASD) is a life-long chronic neurodevelopmental condition that persists throughout the lifespan. The condition is primarily managed through the planning and delivery of various interventions tailored to the individual's needs starting early in life. Although research has evaluated the effectiveness of therapeutic interventions in helping improve areas of need, assessments of effectiveness are typically in a controlled setting, based on the researcher's evaluation, have short follow-up periods, and lack a longitudinal approach (Benevides et al., 2020; Pfeiffer et al., 2018). This cross-sectional, quantitative survey study was needed to determine the association between the various therapeutic interventions used by people with autism aged 18 years and older and their QoL and mental health. The research questions were designed to answer the association between therapeutic interventions including social skills, mental health, behavioral therapies, adaptive/DLS, vocational, mindfulness, and prescribed medications, and the self- or proxy-reported quality of life (QoL) of autistic individuals aged 18 years and older without intellectual disability (ID) as measured by the WHOQOL-BREF and DASS-21.

This chapter reports the key findings from the study. The first section reviews the data collection procedures including participant demographics and how this compares to the normative population as well as the autistic population from other research studies. Next, the Results section presents testing of model assumptions and the inferential statistics relevant to the study research questions. Then, the chapter concludes with a summary.

Data Collection

Study collection and participant recruitment for the study lasted from November 202 through to February 2022. Study data were exported from the Survey Monkey platform to the SPSS 28.0 software. A total of 192 participants completed the study survey, although 10 responses were removed for the following reasons: seven participants were under the age of 18 and three only completed the demographic section of the survey and not the WHOQOL-BREF and DASS-21 questionnaires. Of these, one respondent did not complete the WHOQOL-BREF and two did not complete the DASS-21. As such, the final complete dataset comprised 182 participants. The final sample size of 182 was 121% of the originally planned 150.

Participant Demographics

Descriptive statistics were performed for the 182 participants in the study (Table 1). From survey respondents, 71.4% ($n = 130$) were autistic individuals and 28% ($n = 51$) were proxy reports (the parent or caregiver of the person with autism). One person did not answer the question of who is completing the survey. Most respondents were male (59.3%, $n = 108$) and 63.7% ($n = 116$) self-reported a Level-1 ASD diagnosis followed by Level-2 and Level-3 (23.1%, $n = 42$; 13.2%, $n = 24$, respectively). The mean age of participants was 29.1 years ($SD = 10.6$) with a range of 18 to 72 years. About half of respondents (51.1%, $n = 93$) had completed post-secondary level education, such a college or university, the majority (69.8%, $n = 127$) were single, and 66.5% ($n = 121$) lived with family or caregivers. Regarding employment status, about one third (32.4%, $n = 59$) of respondents were employed, whereas the majority (80.8%, $n = 147$) received

support from family, friends, or social groups. A lower proportion of participants (30.2%, $n = 55$) were currently ill or in poor health whereas 36.8% ($n = 67$) self-reported having a mental health condition diagnosis.

To ascertain the degree of QoL impairment in this cohort, the WHOQOL-BREF mean subscale domain scores for physical, social, psychological, and environment were compared to other reported population norms. In the absence of normative WHOQOL-BREF data for healthy Canadians, UK norms were used from the study by Skevington and McCrate (2012) from the *well* category, rather than those with various illnesses. The UK data were compiled from a total of 1,324–1,328 participants and various study sites. The QoL scores from this study were consistently lower across all domains than UK norms (Table 2). Since primary data were not available from the UK study, Cohen's d was computed for each QoL subscale showing moderate to large effect sizes between the two populations.

Table 1

Participants' Demographic Information

Characteristic	<i>N</i>	%	Mean	<i>SD</i>
Age (years)	181		29.1	10.6
Person completing survey				
Person with Autism	130	71.4		
Parent/caregivers	51	28		
Gender				
Female	74	40.7		
Male	108	59.3		
Level of autism				
Level 1	116	63.7		
Level 2	42	23.1		
Level 3	24	13.2		
Highest level of education				
High school or less	89	48.9		

Post-secondary	93	51.1
Current relationship status		
Single	127	69.8
In a relationship	54	29.7
Current living status		
Lives on own	61	33.5
Lives with family/caregiver	121	66.5
Current employment status		
Employed (full- or part-time)	59	32.4
Unemployed	71	39
Student	52	28.6
Current level of support		
Receives support from family	147	80.8
Does not receive support	35	19.2
Currently ill or in poor health		
Yes	55	30.2
No	127	69.8
Current mental health condition diagnosis		
Yes	67	36.8
No	114	62.6

Note. For each characteristic where percentages do not add up to 100%, the remaining percentage was not reported.

Table 2

WHOQOL-BREF Subscales and Normative Data for UK Cohort

Study	Mean physical (<i>SD</i>)	Mean psychological (<i>SD</i>)	Mean social (<i>SD</i>)	Mean environment (<i>SD</i>)
Social skills	57.9 (17.9)	58.1 (19.8)	54.4 (22.2)	60.4 (16.1)
UK norms ^a	76.5 (16.2)	67.8 (15.6)	70.5 (20.7)	68.2 (13.8)
Cohen's <i>d</i>	1.1	0.6	0.8	0.5

Note. ^a taken from Skevington & McCrate (2012) normative data for 'well' participants ($n = 1324-1328$). Cohen's *d*: 0.2 = small effect, 0.5 = medium effect, and 0.8 = large effect

For the DASS-21 depression and anxiety subscales, the mean depression and anxiety scores were 15.3 ($SD = 11.9$) and 13.5 ($SD = 9.6$), respectively. According to the

Lovibond & Lovibond (1995) DASS-21 manual, scores between 14–20 are considered moderate depression, whereas scores between 10–14 reflect moderate anxiety. Therefore, this cohort of autistic individuals appeared to be both moderately depressed and anxious. Of note, in this data analysis, a composite score for depression and anxiety was computed by averaging the individual depression and anxiety scores. The latter generated a composite depression and anxiety mean score of 14.4 ($SD = 10.2$).

Autism Interventions

Table 3 displays the frequencies of the seven therapeutic interventions used by the cohort of autistic individuals in this study. The following interventions were used by over 60% of participants: social skills (63.2%), mental health support (71.4%), and behavioral therapies (67%), and medications were used by the largest proportion of participants (82.4%). On the other hand, about half of participants used adaptive learning skills, employment support, and mindfulness therapies (48.4% 55.5%, and 54.9%, respectively).

Table 3

Frequencies and Percentages of Autism Therapeutic Interventions Used by Participants

Intervention	<i>N</i>	%
Social skills	115	63.2
Mental health	130	71.4
Behavioral	122	67.0
Adaptive learning	88	48.4
Employment support	101	55.5
Mindfulness	100	54.9
Medications	150	82.4

Results

Testing of HMR assumptions

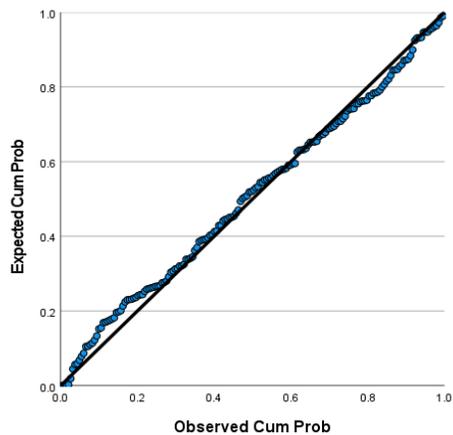
As outlined in Chapter 3, key assumptions of the HMR model were tested including (a) normality of residuals, (b) independence of residuals, (c) multicollinearity, (d) undue influence, (e) linearity, and (f) homoscedasticity (Warner, 2013).

Normality of Residuals

The normality assumption was tested graphically by computing a normal P-P plot of regression standardized residuals for observed versus expected values for each dependent variable (physical, social, psychological, environment, and anxiety-depression composite score). The normality assumption was met for all four WHOQOL-BREF domains except for the DASS-21 anxiety-depression composite score (see Figures 2-6). Given this violation, the bootstrapping technique was used in the HMR analysis and the conventional and bootstrapped 95% confidence intervals were reported for each *B* coefficient.

Figure 2

Normal P-P Plot of Regression Standardized Residuals for Physical Domain

**Figure 3**

Normal P-P plot of Regression Standardized Residuals for Psychological Domain

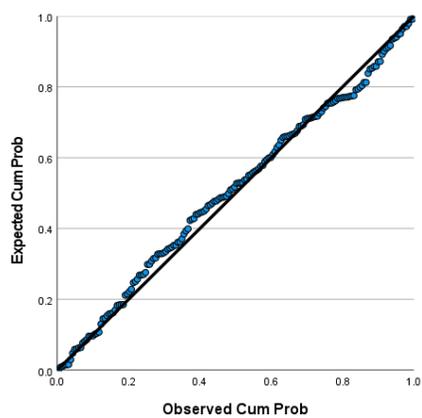
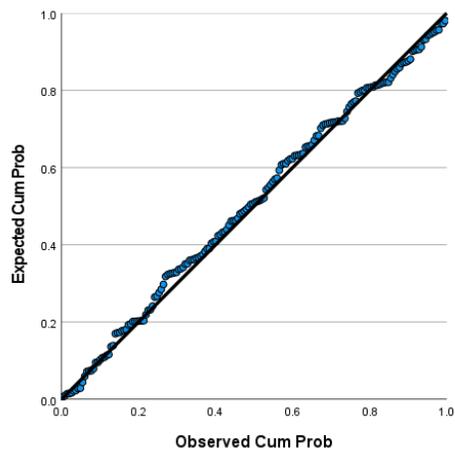
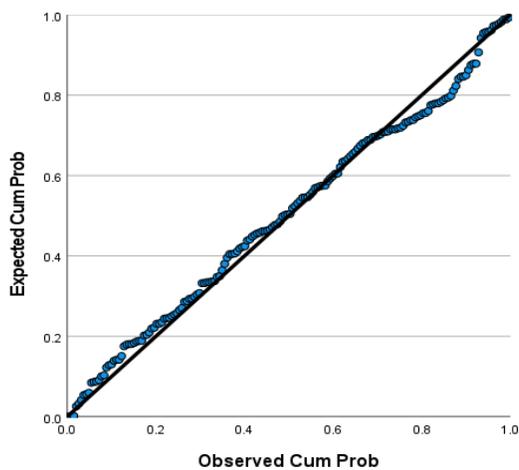


Figure 4

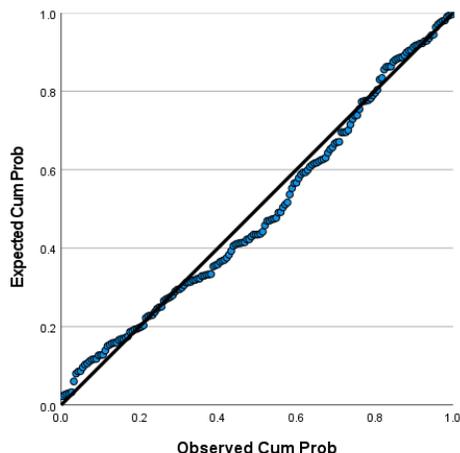
Normal P-P Plot of Regression Standardized Residuals for Social Domain

**Figure 5**

Normal P-P Plot of Regression Standardized Residuals for Environment Domain

**Figure 6**

Normal P-P Plot of Regression Standardized Residuals for Anxiety-Depression Composite Score



Independence of Residuals

This assumption was tested using the Durbin-Watson statistic to ensure the absence of autocorrelation in the data (Frankfort-Nachmias & Leon-Guerrero, 2018). Values for all five HMR models ranged between 1.79 to 1.97 indicating no autocorrelation between residuals.

Undue influence

Cook's distance was used to test the assumption of undue influence and values for all variables fell below 1.0 indicating that this assumption was also met.

Linearity

Linear regression models assume a linear relationship between the predictor and criterion variables (Frankfort-Nachmias & Leon-Guerrero, 2018). This assumption was evaluated using a scatter plot of the regression standardized residuals versus predicted values for each dependent variable to assess the fit of the estimates. All four WHOQOL-

BREF domains and the anxiety-depression composite score displayed a random pattern of plots indicating that this assumption was met (Figures 7-11).

Figure 7

Scatterplot of Regression Standardized Residuals for Physical Domain

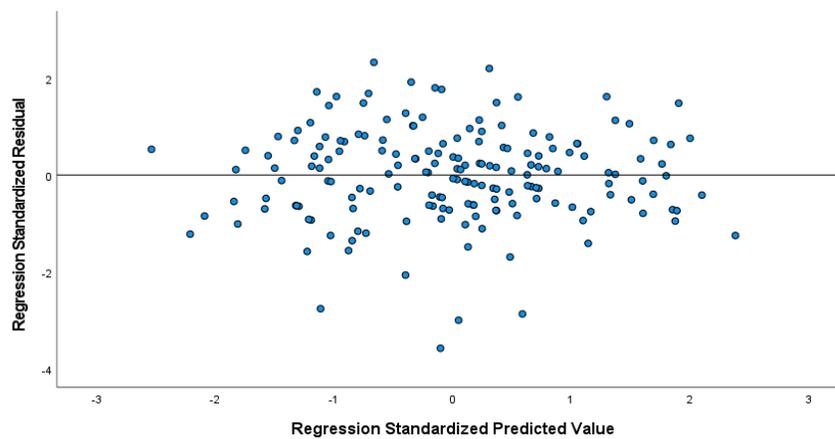


Figure 8

Scatterplot of Regression Standardized Residuals for Psychological Domain

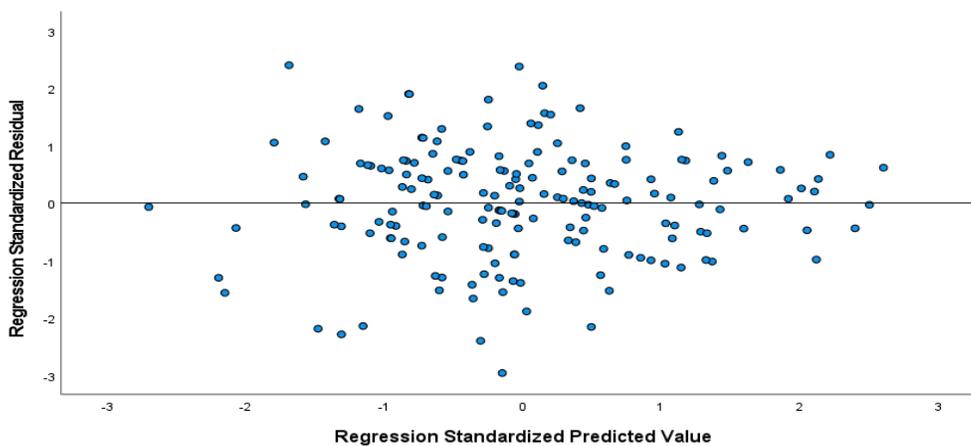
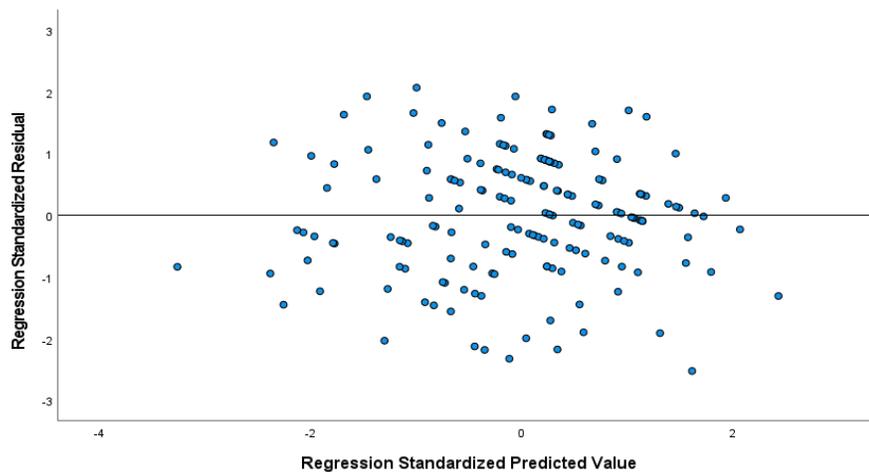


Figure 9

Scatterplot of Regression Standardized Residuals for Social Domain

**Figure 10**

Scatterplot of Regression Standardized Residuals for Environment Domain

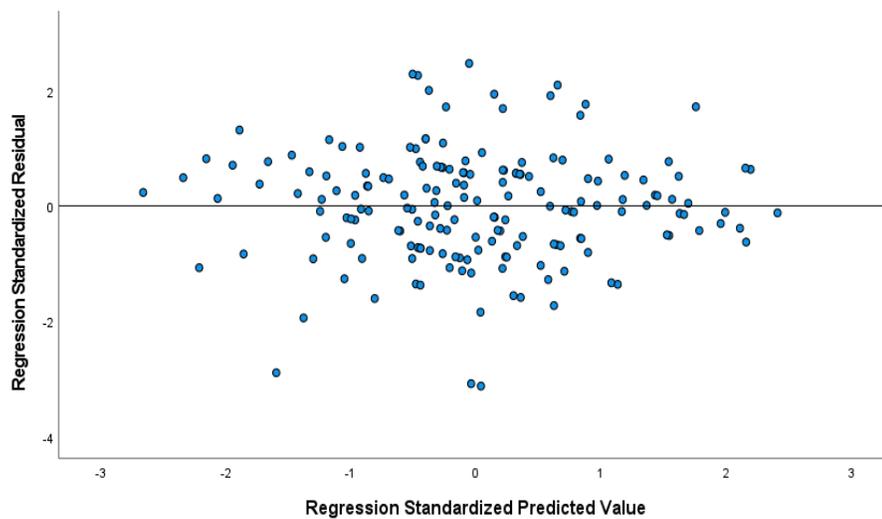
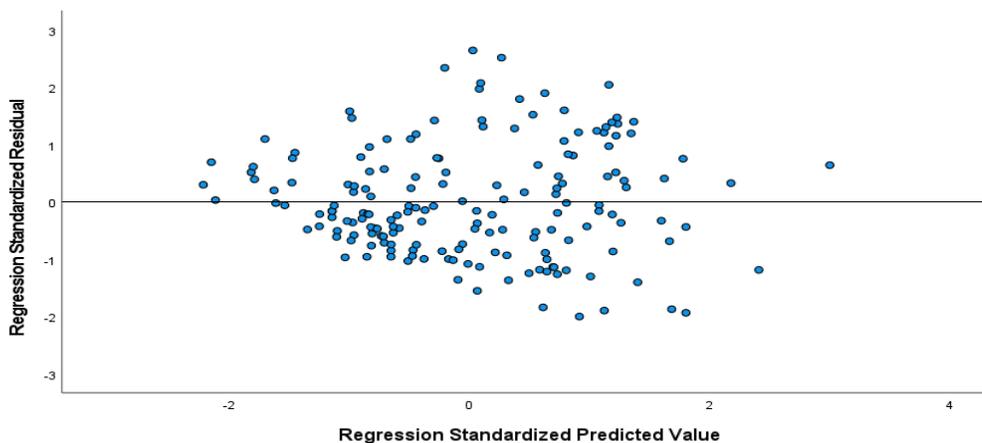


Figure 11

Scatterplot of Regression Standardized Residuals for Anxiety-Depression Composite Score



Multicollinearity

To test the assumption of multicollinearity between the eight covariate and seven predictor variables, a set of collinearity statistics were used. The variance inflation factor (VIF) was used for the predictor-covariate and covariate-covariate relationships (Hair et al., 2013). VIF values for all covariate and predictors variables were less than 2.0 indicating that this assumption was not violated. In addition, tolerance values were also evaluated to measure the influence of one independent variable on all other independent variables. All tolerance values were greater than 0.1 indicating the absence of multicollinearity (Kim, 2019). To further assure that multicollinearity was not present, collinearity diagnostics were performed. This entailed an evaluation of a matrix comprised of the standardized predictor variables and associated *eigenvalues* (λ), *Condition Indices*, and *Variance proportions*. No eigen values were close to 0 and

condition indices more than 10 to 30 for each predictor variable further confirming the absence of multicollinearity.

Homoscedasticity

This assumption was tested using the scatterplots displayed in Figures 2a-e to assess equal distribution of data plots across the regression line (Jeong & Jung, 2016). As depicted in the figures, equal dispersion of values above and below the horizontal zero line for the four WHOQOL-BREF domains (physical, psychological, social, and environment) showed no violation of this assumption, whereas there appeared to be a violation of the homoscedasticity assumption for the anxiety-depression composite score. Here again, the bootstrapping technique was used to combat violation of this assumption and the conventional and bootstrapped 95% confidence intervals were reported.

Research Question 1: Predictors of QoL

Hierarchical multiple regression (HMR) analysis was used to explore the relationship between a set of covariates/predictors and the QoL of people with autism. Block 1 (model 1) included three covariates namely, age, gender, and autism severity. Next, five additional covariates including level of education, current relationship status, current level of support, employment status, and having a mental health condition were entered into the second block (model 2). Finally, the seven predictors or interventions of interest including social skills, behavioral therapies, mental health support, employment support, adaptive/daily living skills, mindfulness therapies, and medications were entered as block 3 (model 3). Results of the HMR models for each of the WHOQOL-BREF domains (physical, psychological, social, and environment) are displayed in Table 4.

Table 4*HMR Models for Each Subscale of the WHOQOL-BREF*

Subscale	Adjusted R ²	P	Positive predictors	β	Negative predictors	β
Physical						
Model 1 ^a	.169	< .001	-		Autism severity	-.370***
Model 2 ^b	.205	< .001	Being employed	.186*	Autism severity	-.319***
Model 3 ^c	.275	< .001	Mental health support	.219**	Autism severity	-.325***
			Behavioral therapies	.161*		
Psychological						
Model 1 ^a	.095	< .001	-		Autism severity	-.196**
			-		Gender (female)	-.151*
			-		Age	-.201**
Model 2 ^b	.117	.007	-		Age	-.249**
Model 3 ^c	.269	< .001	Being employed	.194*	Autism severity	-.166*
			Mental health support	.313**	Gender (female)	-.205**
			Behavioral therapies	.283*	Age	-.206**
Social						
Model 1 ^a	.104	< .001	-		Autism severity	-.204**
			-		Gender (female)	-.174*
			-		Age	-.197**
Model 2 ^b	.199	< .001	Being in a relationship	.299**	Autism severity	-.147*
					Gender (female)	-.147*
					Age	-.293***
Model 3 ^c	.290	< .001	Being in a relationship	.352***	Autism severity	-.151*
			Mental health support	.215**	Gender (female)	-.221**
			Behavioral therapies	.167*	Age	-.239**
Environment						
Model 1 ^a	.130	< .001	-		Autism severity	-.216**
			-		Gender (female)	-.251**
			-		Age	-.153*
Model 2 ^b	.163	< .001	Being employed	.209*	Autism severity	-.178*
					Gender (female)	-.219**
					Age	-.183*
Model 3 ^c	.237	< .001	Being employed	.235*	Autism severity	-.187*
			Mental health support	.240**	Gender (female)	-.226**
					Age	-.176*

Note. ^a Predictors: autism severity, gender, and age; ^b Predictors: education level, employment status, relationship status, support status, and having a mental health condition diagnosis; ^c Predictors: social skills, mental health support, adaptive/daily living skills, mindfulness, employment status, behavioral therapies, and medications.

* $P < .05$, ** $P < .01$, *** $P < .001$

For the physical domain, all three HMR models were significant with each model predicting an increasingly higher proportion of the variance in the dependant variable.

Model 1 predicted 16.9% of the variance, while models 2 and 3 predicted 20.5% and 27.5% of the variance, respectively (model 1: $R^2 = 0.169$, $F(3, 172) = 11.7$, $p < .001$; model 2: $R^2 = 0.205$, $F(8, 167) = 5.4$, $p < .001$; and model 3: $R^2 = 0.275$, $F(15, 160) = 4.1$, $p < .001$). Of note, the change in variance from model 1 to model 2 was not significant (ΔR^2 : $p = .2$), although it was significant from model 2 to 3 (ΔR^2 : $p = .035$). When evaluating the significance of each covariate/predictor variable, autism severity remained the strongest negative predictor of physical QoL across all three models ($\beta = -.37$, $\beta = -.32$, and $\beta = -.33$, all $p < 0.001$, respectively). Additionally, in model 3, predictors which were significantly associated with physical QoL included being employed ($\beta = .19$, $p = .047$), receiving mental health support ($\beta = .22$, $p = .004$) and behavioral therapies ($\beta = .16$, $p = .045$).

For the psychological domain, all three HMR models were significant with each model predicting an increasingly higher proportion of the variance in the dependant variable. Model 1 predicted 9.5% of the variance, while models 2 and 3 predicted 11.7% and 26.9% of the variance, respectively (model 1: $R^2 = 0.095$, $F(3, 172) = 6.0$, $p = .001$; model 2: $R^2 = 0.117$, $F(8, 167) = 2.76$, $p = .007$; and model 3: $R^2 = 0.269$, $F(15, 160) = 3.92$, $p < .001$). Of note, the change in variance from model 1 to model 2 was not significant (ΔR^2 : $p = .523$), although it was significant from model 2 to 3 (ΔR^2 : $p < .001$). When evaluating the significance of each covariate/predictor variable, autism severity, gender (being female), and age (older age) were significant predictors of psychological QoL in model 1 ($\beta = -.20$, $p = .008$; $\beta = -.15$, $p = .043$; and $\beta = -.20$, $p = 0.007$, respectively). In model 2, age remained the only significant predictor of psychological

QoL ($\beta = -0.25, p = .002$). In model 3, autism severity, gender, and age remained significant negative predictors of psychological QoL as in model 1 ($\beta = -.17, p = .023$; $\beta = -.021, p = .008$; and $\beta = -.21, p = .009$, respectively), while the strongest positive predictor of psychological QoL was receiving mental health support ($\beta = .31, p < .001$), followed by behavioral therapies ($\beta = .28, p = .001$), and being employed ($\beta = .19, p = .038$).

For the social QoL domain, all three HMR models were significant, and each model predicted an increasingly higher proportion of the variance in the dependant variable. Model 1 predicted 10.4% of the variance, while models 2 and 3 predicted 19.9% and 29.0% of the variance, respectively (model 1: $R^2 = .104, F(3, 172) = 6.64, p < .001$; model 2: $R^2 = .199, F(8, 167) = 5.19, p < .001$; and model 3: $R^2 = 0.290, F(15, 160) = 4.35, p < .001$). The changes in variance from model 1 to model 2 and from model 2 to model 3 were both statistically significant ($\Delta R^2: p = .002$ and $.007$, respectively). In model 1, autism severity, gender (being female), and age (older age) were all significant negative predictors of social QoL ($\beta = -.20, p = .006$; $\beta = -.17, p = .019$; and $\beta = -.20, p = 0.008$, respectively). In model 2, all three covariates remained statistically significant, although the strongest predictor of social QoL was being in a relationship ($\beta = .30, p = 0.002$). In model 3, autism severity, gender, and age remained significant predictors of social QoL ($\beta = -.15, p = .036$; $\beta = -.22, p = .004$; and $\beta = -.24, p = .002$, respectively). In addition, being in a relationship predicted the highest proportion (35.2%, $p < .001$) of the variance for social QoL followed by receiving mental health support ($\beta = .22, p = .004$) and behavioral therapies ($\beta = .17, p = .035$).

Finally, for the environment QoL domain, all three HMR models were significant, and each model predicted an increasingly higher proportion of the variance in the dependant variable. Model 1 predicted 13.0% of the variance, while models 2 and 3 predicted 16.3% and 23.7% of the variance, respectively (model 1: $R^2 = .130$, $F(3, 172) = 8.53$, $p < .001$; model 2: $R^2 = .163$, $F(8, 167) = 4.06$, $p < .001$; and model 3: $R^2 = .237$, $F(15, 160) = 3.32$, $p < .001$). The change in variance from model 1 to model 2 was not statistically significant ($p = .257$), but was significant from model 2 to model 3 (ΔR^2 : $p = .034$). In model 1, autism severity, gender, and age were all significant predictors of environment QoL ($\beta = -.22$, $p = .003$; $\beta = -.25$, $p = .001$; and $\beta = -.15$, $p = 0.036$, respectively). In model 2, all three covariates remained statistically significant, while employment status was also a significant positive predictor of environment QoL ($\beta = -.21$, $p = .03$). In model 3, autism severity, gender, age, and employment status all remained significant predictors of environment QoL as in model 2 ($\beta = -.19$, $p = .013$; $\beta = -.23$, $p = .004$; $\beta = -0.18$, $p = .03$, and $\beta = .24$, $p = .002$, respectively). In addition, receiving mental health support intervention ($\beta = .24$, $p = .002$) significantly predicted environment QoL.

Research Question 2: Predictors of Anxiety and Depression

The same HMR analysis was used to determine whether a significant association existed between the aforementioned set of covariates/predictors and the anxiety and depression levels of people with autism as measured by the DASS-21 instrument. The set of eight covariates (block 1: age, gender, autism severity; block 2: employment status, relationship status, education level, support status, and having a mental health condition

diagnosis) and seven interventions (predictors) (block 3: social skills training, mental health support, daily/adaptive living skills, employment support, behavioral therapies, mindfulness, and medications) were all entered into the hierarchical regression analysis in the same manner as previously done for the WHOQOL-BREF outcomes. Results of the HMR models for the anxiety-depression composite score are displayed in Table 5.

As mentioned previously, it is important to note that the data did not meet all the assumptions of linear regression, namely the normality of residuals and homoscedasticity assumptions. As such, the bootstrapping approach was used and results from both the conventional and bootstrapping methods are reported herein. Consequently, non-significant associations between the predictor and outcome variables should be interpreted with caution due to the inherent potential bias which may have increased the chance of a Type II error, thus accepting the null hypothesis when in fact it should have been rejected.

Table 5

HMR Models for the DASS-21 Anxiety-Depression Composite Score

Scale	R^2	P	Negative predictors	β	B	95% CI	Bootstrapped 95% CI
Anxiety-depression							
Model 1 ^a	.152	< .001	Autism severity	-.360***	-7.67	-10.67 to -4.68	-10.62 to -4.19
			Age	-.166*	-.16	-.02 to -.30	-.02 to -.33
Model 2 ^b	.181	< .001	Autism severity	-.332***	-7.09	-10.24 to -3.95	-10.41 to -3.51
			Age	-.159*	-.15	-.006 to -.30	-
Model 3 ^c	.235	< .001	Autism severity	-.332***	-7.08	-10.22 to -3.93	-10.54 to -3.60

Note. ^aPredictors: autism severity, gender, and age; ^bPredictors: education level, employment status, relationship status, support status, and having a mental health condition diagnosis; ^cPredictors: social skills, mental health support, adaptive/daily living skills, mindfulness, employment status, behavioral therapies, and medications.

* $P < .05$, ** $P < .01$, *** $P < .001$

As seen in the WHOQOL-BREF analyses, each of the three HMR models for the anxiety-depression composite score was statistically significant and predicted an increasingly higher proportion of the variance in the dependant variable. Model 1 predicted 15.2% of the variance, while models 2 and 3 predicted 18.5% and 23.5% of the variance, respectively (model 1: $R^2 = .152$, $F(3, 172) = 10.17$, $p < .001$; model 2: $R^2 = .181$, $F(8, 167) = 4.46$, $p < .001$; and model 3: $R^2 = .235$, $F(15, 160) = 3.23$, $p < .001$). Of note, the change in variance between the three models was not statistically significant.

In model 1, significant predictors of anxiety-depression were autism severity ($\beta = -.36$, $p < .001$) and age ($\beta = -.17$, $p = .022$). The 95% confidence interval (CI) for the unstandardized B coefficient was $B = -7.67$, 95%CI: -10.67 to -4.68 for autism severity and $B = -.16$, 95%CI: -.02 to -.30 for age. The bootstrapping procedure slightly increased the length of the 95% CI (autism severity: -10.62 to -4.19; age: -.02 to -.33) compared to the traditional method. In model 2, both autism severity and age remained significant predictors of anxiety-depression with autism severity negatively predicting 33% of the variance (autism severity: $\beta = -.33$, $p < .001$; age: $\beta = -.16$, $p = .042$). No additional predictors were significant, although having a current mental health condition diagnosis almost reached statistical significance ($\beta = -.14$, $p = .05$). The 95% CI for the unstandardized B coefficient for autism severity was $B = -7.09$, 95%CI: -10.24 to -3.95 and $B = -.15$, 95%CI: -.01 to -.30 for age. With the bootstrapping procedure, only autism severity remained statistically significant in model 2 with a slightly increased 95% CI of -10.41 to -3.51 for the B coefficient. Finally, in model 3, autism severity was the only statistically significant predictor of anxiety-depression ($\beta = -.33$, $p < .001$) with an

unstandardized $B = -7.08$, 95%CI: -10.22 to -3.93. Bootstrapping slightly increased the length of the 95% CI (-10.54 to -3.60).

Summary

This quantitative, cross-sectional correlational study sought to determine the association between the various therapeutic interventions used by people with autism and their quality of life and mental health. A national sample of 182 participants aged 18 to 72 years (mean 29.1 years) completed the study survey. About 60% of respondents were male and the majority (65%) had Level 1 ASD. Concerning autism interventions, social skills training, employment support, and mindfulness were used by over 50% of participants, while behavioral therapies (67.0%), mental health support (71.4%), and medications (82.4%) were the highest types used.

In addressing the first research question, each covariate and predictor variable differentially predicted QoL across the four domains. Overall, autism severity (higher), gender (being female), and age (being older) remained consistent negative predictors of QoL across the psychological, social, and environment domains, while being employed was a positive predictor of the physical, psychological, and environment domains. Two interventions which were significantly associated with higher QoL scores in almost all domains included receiving mental health support and behavioral therapies. Of note, the strongest positive predictor of psychological QoL was receiving mental health support which explained 31% of the variance, while being in a relationship was a significant positive predictor of social QoL and explained 35.1% of the variance.

Finally, the analysis for the second research question which sought to determine the association between the seven interventions of interest and mental health of people with autism failed to show a significant relationship between the predictor and outcome variables, hence the alternative hypothesis was rejected. Indeed, the only significant negative predictor of the anxiety-depression composite score was autism severity which explained 33% of the variance. As mentioned in the previous section, these results should be interpreted with caution and may not be reflective of the true association between the predictor and outcome variables due to violations of linear regression analysis.

The next and final chapter of the dissertation, Chapter 5, will discuss the interpretation of the findings of this study and how these may corroborate or refute the results from other peer-reviewed research. Several strengths and limitations of the study including recommendations and future implications will also be discussed in the final chapter.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this quantitative, cross-sectional survey study was to evaluate the association of therapeutic interventions used by individuals with autism without intellectual disability (ID) 18 years or older living in Canada and their QoL and mental health status. Seven therapeutic interventions including socially based interventions, mental health services, behavioral interventions, adaptive/daily living skills (DLS), mindfulness, prescribed medications, and vocational interventions were evaluated in relation to QoL and depression and anxiety in the sampled population. QoL was measured using mean scores of the four WHOQOL-BREF subscales (McConachie et al., 2018; WHOQOL-BREF, 1996), and depression and anxiety were assessed using the average mean score of the DASS-21 Questionnaire (Park et al., 2020).

A Canadian national sample of 182 participants (*M* age of 29.1 years) completed the study survey with about 60% of respondents being male and 65% having a Level 1 ASD diagnosis. Regarding demographic variables, 70% were single, 80.8% received support, 51% had achieved post-secondary education, and over 70% were unemployed. Concerning autism interventions, behavioral therapies (67%), mental health support (71.4%), and medications (82.4%) were the mostly used types, whereas social skills, mindfulness, and employment support were used by just over 50% of participants. In comparison to a normative sample of people from the UK (Skevington & McCrate, 2012), the QoL of this cohort of adults with autism was lower across all four domains of the WHOQOL-BREF. Additionally, the sample had moderate levels of anxiety and

depression in accordance with the DASS-21 manual categories of severity (Lovibond & Lovibond, 1995).

In evaluating the predictors of QoL in this sample of adults with ASD, characteristics including autism severity (higher), gender (being female), and age (being older), all covariates), were consistent negative predictors of QoL across the psychological, social, and environment domains, while being employed was a positive predictor of the physical, psychological, and environment domains. Two interventions that were significantly associated with higher QoL scores in almost all domains included receiving mental health support and behavioral therapies. In addition, the strongest positive predictor of both physical and psychological QoL was receiving mental health support (explained 21.9% and 31% of the variance, respectively), and being in a relationship was a significant positive predictor of social QoL explaining 35.1% of the variance. Finally, both receiving mental health support and being employed positively predicted the environment subscale of QoL (24% of the variance explained by each).

Regarding the second research question, no significant associations were found between the seven interventions of interest and the depression and anxiety levels of people with autism, hence the null hypothesis was accepted. Autism severity was the only significant negative predictor of the anxiety-depression composite score explaining 33% of the variance in the final model. Of note, these results should be interpreted with caution due to the violations of the assumptions of linear regression.

Interpretation of the Findings

To my knowledge, this is the first quantitative, correlational study to evaluate the association between a variety of interventions used by people with autism throughout their lifespan and their QoL and mental health. Key findings from the study suggest that receiving mental health support and behavioral therapies as therapeutic interventions are significantly associated with achieving a better QoL for adults with autism. The study confirms findings from previous research in several ways. First, it is in line with the results of numerous studies that have consistently reported a lower QoL in people with autism across all domains of the WHOQOL-BREF as compared to normative samples (Bishop-Fitzpatrick et al., 2018; Hong et al., 2016; Ikeda et al., 2014; Kamio et al., 2013; Katz et al., 2015; Khanna et al., 2014; Knüppel et al., 2018; Lawson et al., 2020; Mason et al., 2018; van Heijst & Geurts, 2015). For example, Heijst and Geurts (2015) used a combined sample size of 486 people with ASD and 17,776 controls and found a significantly lower QoL in people with autism compared to controls with a quite large mean effect size (Cohen's $d = 0.96$). Similarly, in this study, moderate to large effect sizes between 0.5 and 1.1 were seen for the four QoL domains.

Second, several characteristics of this sample resembled those of recent studies conducted in the United States and Europe. In the present study, most participants (71.4%) were capable of filling out the study survey independently rather than by a proxy report (28%). This is similar to the study by Mason et al. (2018) where 78.4% of respondents did not need help to complete the study questionnaires. The latter finding may reflect the large proportion of adults in the current study with Level 1 ASD (63.7%)

and without an intellectual disability (ID) who are relatively able and can be generalizable to the broader population of autistic adults who can self-report. Next, the proportion of autistic adults in this sample who were either full- or part-time employed (32.4%) is similar to those reported by other researchers at 40% and 36.5% (Helles et al., 2017; Mason et al., 2018). Of note, the percentage of adults in the current study who had completed post-secondary education was slightly higher (51.1%) than those reported by Gotham et al. (2015) and Mason et al. (2018), who reported rates of 42% and 41.6%, respectively. The latter finding may again be reflective of the higher proportion of participants with Level 1 ASD and no ID in this cohort who are capable of higher educational achievement.

Despite epidemiological data reporting a high male to female ratio of four to one for the autistic population, the current study had a large proportion of females (40.7%, $n = 74$). This is similar to the study by Mason et al., (2018) who also reported a high proportion of females (42.7%) in their study. Moreover, the proportion of autistic adults living with their family or caregiver in this study was quite high (66.5%), although lower than the rate reported in the National Longitudinal Transition Study-2 (Roux et al., 2015) where 87% of young adults with autism were living with a parent after leaving high school compared to 21% of neurotypical young adults living in the United States. Finally, in this study, the proportion of subjects reporting a mental health condition diagnosis was substantially lower (36.8%) compared to other studies (Mason et al., 2018; Helles et al., 2017; Gotham et al., 2015) that reported much higher rates. For example, Mason et al. (2018) reported a rate of 70.8% in their cohort of autistic adults who had at least one

mental health condition, whereas Helles et al. (2017) and Gotham et al. (2015) reported 50% and 86%, respectively. The lower proportion of mental health condition diagnosis in the current study may be due to several factors including the absence of having sought a formal mental health diagnosis, the lack of self-awareness that one may have a mental health condition, and the high variability in rates of mental health conditions reported by different studies. For example, a recent systematic review and meta-analysis using a large sample of studies and participants found current and lifetime prevalences of 27% and 42% for any anxiety disorder and depressive disorder, respectively (Hollocks et al., 2018). The high variability in prevalence rates of mental disorders in the literature reflects a high degree of heterogeneity in methodology, diagnostic tools, and clinical samples used which underscore the importance of well-defined study samples, representation by non-clinical samples, and the use of validated diagnostic tools to reduce bias and heterogeneity (Hollocks et al., 2018; Wigham et al., 2017).

Demographic Predictors of QoL

Three main characteristics were negative predictors of QoL across almost all domains including higher autism severity, being female, and an older age. Conversely, several factors and interventions positively predicted QoL. Better physical QoL was predicted by receiving mental health support and behavioral therapies; greater psychological QoL was associated with being employed, receiving mental health support and behavioral therapies; higher social QoL was predicted by being in a relationship, receiving mental health support and behavioral therapies; and a better environment QoL was predicted by being employed and receiving mental health support. As such, receiving

mental health support and behavioral therapies were the two therapeutic interventions which were positively associated with all QoL domains except for the environment domain where mental health support was the only significant intervention.

These findings provide evidence-based information related to specific characteristics and interventions that should be considered for provision of supports and services to improve QoL of people with ASD. For example, older autistic women who are unemployed or single may represent a particularly vulnerable group requiring attention and support to achieve and sustain a better QoL. However, it is important to note that these findings are cross-sectional and directional associations should not be interpreted as causal relationships between the predictor and QoL variables. For example, those with a higher QoL may be more able to initiate and maintain a relationship with a partner and/or seek and maintain employment.

The results from this study are consistent with several but not all findings from other research. Like in other studies (Jennes-Coussens et al., 2006; Kamio et al., 2013; Kamp-Becker et al., 2010; Lin, 2014), social QoL was the most affected and the lowest of the four QoL domains in the current study ($M = 54.4$, $SD = 22.2$). Deficits in social skills are a core characteristic of people with ASD and impaired social skills and low social cognition, in general, have been associated with poor QoL outcomes as they often result in social isolation, anxiety, and depression (Lieb & Bohnert, 2017). These are associated with the inability to process non-verbal cues, delays in the acquisition of verbal communication skills, repetitive behaviors, and sensory issues.

In this study, characteristics such as older age, being female, and autism severity were negative predictors of QoL across almost all domains except for physical QoL, which was only associated with autism severity. Several studies have reported similar findings. For example, in a large study of 370 adults with autism, being female, older age, and autism severity were negative predictors of QoL (Mason et al., 2018). Though the effect of aging on lower QoL may not be specific to only those with autism (Skevington & McCrate, 2012), it may reflect inadequate access and provision of appropriate services to older autistics compared to children and adolescents, as well as the inability of those services to meet their unmet needs. Further, both social isolation and the loss of perceived informal support (having someone to spend time with and/or do things with) experienced in older age may be associated with the lower QoL of adults with autism (Happe & Carlton, 2012). Of note, the negative effects of ageism are likely further exacerbated in individuals with higher autism severity who may be less flexible and reluctant to try new things. In contrast to these findings, researchers like van Heijst and Greuts (2015) did not find a significant association between age, IQ, and ASD severity and QoL in a cohort of 486 people with autism across the lifespan, which highlight differences in the various subpopulations of autistics. But being in a relationship was a significant predictor of social QoL in this study, which further underscores the importance of social supports in this population.

The current study also showed lower QoL across all domains (except for physical) related to gender. Several studies have found autistic females to have a significantly lower QoL compared to their male counterparts (Kamio et al., 2013; Mason et al., 2018).

This contrasts with Bargiela et al. (2016), who found a higher QoL in autistic females compared to males. Though the latter may be related to the higher motivation levels and ability of females to better initiate and maintain friendships than males, it may also reflect the notion of “camouflaging” by autistic people, which results in long term negative effects (Hull et al., 2017). Regardless, findings around the association between autism severity and QoL of people with autism have been inconsistent. The current study found a significant association between autism severity and QoL across all three models and domains. This is in line with the results of several studies (Khanna et al., 2014; Chiang & Wineman, 2014; Knuppel et al., 2018; Lawson et al., 2020) where autism severity was significantly correlated with the QoL of both children and adults with autism. On the other hand, several studies have not found a significant association between autism severity and QoL (Kim et al., 2019; van Heijst and Greuts, 2015). The discordance in findings may result from the difference in how autism severity was captured in these studies (formal diagnosis vs. self-reported), the different QoL of instruments used, the levels of support available and accessed, and the presence of confounders.

Further, employment is a known mediator of a range of QoL components including family and life satisfaction, economic self-sufficiency, mental health, and social inclusion in the general population (Walsh et al., 2014). This is an important consideration when assessing the QoL of people with autism since over half are unemployed or underemployed (Hirvikoski & Blomqvist, 2015). Poor employment has been associated with low independence, higher rates of physical and mental problems, and poor community engagement all of which negatively impact QoL (van Rijn et al.,

2016). The current finding that being employed was a significant positive predictor of psychological and environment QoL is therefore not surprising. The psychological domain's questions ask about mental health, happiness, self-satisfaction, and having a meaningful life, while the environment domain asks about transport, access to health services, and living arrangements (WHOQOL-BREF, 1996). However, as noted previously, these positive associations should not be interpreted as causal or directional since it may well be that those with a higher QoL are better able to seek and secure employment compared to autistics with a lower QoL.

Finally, this study found that being in a relationship was a positive significant predictor of social QoL. This corroborates with the results of several studies which have shown the importance of social support, forming relationships, engaging in social interactions, and communication in achieving better mental health and well-being (Knuppel et al., 2018; van Heijst & Greuts, 2015; Khanna et al., 2014; Mason et al., 2018). Indeed, social isolation, the absence of someone to talk to and do things with, and the lack of supportive people around can all have a significant impact on QoL and mental health of people with autism (Happé & Charlton, 2011).

Therapeutic Interventions Predicting QoL

As noted previously, to the researcher's knowledge, this is the first study to evaluate the association between a set of therapeutic interventions used in autism and the QoL and mental health of adults with ASD. Of the seven interventions studied, only two, namely receiving mental health support and behavioral therapies, were significant predictors of a better QoL in this cohort of individuals with autism. These results

corroborate with several studies which have evaluated the association between single interventions using psychological interventions and health and health-related outcomes (physical, mental health, and wellbeing) (Ekman & Hiltunen, 2015; Hesselmark et al., 2014; McGillivray & Evert, 2014; Russell et al., 2013; Sizoo & Kuiper, 2017; Weiss & Lunskey, 2010). Specifically, these studies have evaluated the association between psychological interventions using cognitive behavioral therapy (CBT) and health and health-related outcomes. Deemed as the “current gold standard of psychotherapy” in the general adult population, the NICE guidelines (2011) recommend psychological therapy, in particular cognitive behavioral therapy (CBT), as first line treatment in mild to moderate presentations. In a systematic review conducted by Benevides et al. (2020), CBT interventions were considered an *emerging evidence-based approach* in improving self-reported mood and anxiety in autistic adults, although not significantly better than anxiety management or recreational groups as alternative interventions. For example, Sizoo and Kuiper (2017) reported improvements in self-reported anxiety and depression scores, rumination, and global mood in those who underwent CBT. Further, a Canadian study by Weiss and Lunskey (2010) using group CBT showed positive outcomes related to self-reported depression and anxiety symptoms. Of note, the current study did not identify the specific approaches used for the delivery of mental health interventions, although CBT was included as an example in this intervention type on the study survey. Given the high prevalence of comorbid mental health disorders in the autistic population, with depression and anxiety being the most common (Croen et al., 2015; Joshi et al., 2013), the empirical evidence generated from this study which suggests that provision of

mental health interventions may be associated with a better QoL in autistic adults is noteworthy. As such, as part of evidence-based interventions, mental health support should be prioritized as an effective therapeutic option to help achieve better long-term outcomes, satisfaction, and well-being for people with autism across the lifespan.

The second intervention type which was significantly associated with a better QoL in this study was behavioral therapies. All domains of QoL except for environment appeared to have benefited from this intervention. Applied behavior analysis (ABA) is a widely accepted and well-established approach used to strengthen and improve a broad range of skills and deficits in individuals with ASD including communication skills, behavioral, physical, and social skills, among others (Yu et al., 2020). There is strong evidence to support its use in children with ASD, although data is scarce in the adult population (Roth et al., 2014). The findings from this research are again aligned with previous research which confirm the effectiveness of ABA as a valid and evidence-based intervention to help improve a variety of skills in people with autism. For example, a meta-analysis by Roth et al. (2014) evaluating the effectiveness of behavioral interventions in various areas, such as academic skills, phobic avoidance, vocational skills, problem behaviors, adaptive skills, and social skills showed medium to large effect sizes. Similarly, a recent literature review conducted by Marcotte et al. (2020) found that behavioral interventions which comprised the majority (40%) of the articles reviewed were among the seven effective interventions identified. These interventions significantly improved activities of daily living skills, such as food and meals, shopping, and travelling in the community.

While research evaluating the long term, sustained effects of ABA specifically around improving QoL of adults with autism is scarce, the significant associations found in this study may suggest a sustained overall positive impact of this intervention on the QoL and well-being of people with ASD. Indeed, researchers have suggested incorporating long-term follow-up of ABA interventions a priori in future studies to ascertain their true effectiveness in addressing the core deficits of ASD. Given that behavioral interventions are used overtly to target a broad range of deficits in people with autism, it is plausible that this intervention alone may have compensated for the other types of interventions used in this study resulting in the spurious associations observed between the remaining therapies and QoL.

In contrast to the findings in this study, the systematic review by Benevides et al. (2020) found that mindfulness-based interventions were emerging evidence-based approaches in the adult autistic population. Mindfulness interventions focus on modifying the way a person perceives and processes their thoughts and emotions with the goal of achieving a better state of self-awareness and emotional regulation (Conner & White, 2017). Of note, this finding was based on two high-quality studies including a RCT and a pre-test-posttest quasi-experimental design (Sizoo & Kuiper, 2017; Spek et al., 2013). Both studies showed small to large effect sizes between .07 and .78 for self-reported depression and anxiety symptoms suggesting the beneficial effects of mindfulness therapies. In this study, mindfulness interventions were used by 55% of participants and were defined as yoga, meditation, breathing exercises, and physical exercise. This contrasts with how mindfulness interventions are implemented in the research setting

which include complementary/integrative medicine administered at various frequencies, duration, and intensity. Therefore, they are not implemented in the same manner as those defined in this research study which may explain the discrepant results. On the other hand, findings from this study are consistent with those reported in previous research which did not find sufficient evidence to support their effectiveness in addressing health and health-related outcomes in the autistic population (Benevides et al., 2020; Enticott et al., 2011; Gal et al., 2015; McVey et al., 2016; Nilsson & Ekselius, 2009; Roser et al., 2009; Wachtel et al., 2010). These interventions included social skills, vocational, prescription medications, and daily living skills interventions. As such, the consistency of the findings from this study with those of previous research with more rigorous designs and methods is reassuring and further strengthens the validity of these findings.

Therapeutic Interventions Predicting Anxiety and Depression

Results from this study did not find any significant associations between the seven interventions of interest and the anxiety and depression composite score as measured by the DASS-21 instrument. The only significant variable which negatively predicted depression and anxiety was autism severity which explained 33% of the variance. In this study, 37% of participants self-reported having a current mental health diagnosis. Moreover, both anxiety and depression levels were considered moderate based on the DASS-21 rating scores. As mentioned previously, estimated rates of these disorders vary considerably across studies with some reporting rates as high as 70% for depression and anxiety (Lever & Greuts, 2016; Mason et al., 2018) and others reporting rates as low as less than 1% for depression (Buck et al., 2014) and 5% for anxiety (Tsakanikos et al.,

2011). Indeed, there is high variability in the prevalence rates of mental disorders reported in the literature due to the high degree of heterogeneity in methodology, diagnostic tools, and clinical samples used. This notion of heterogeneity is also evident in this study since receiving mental health interventions was the strongest predictor of the psychological QoL domain of the WHOQOL-BREF explaining 31% of the variance, while the same association was not seen when measuring anxiety and depression using the DASS-21 instrument.

As noted above, mindfulness interventions and cognitive behavioral therapy (CBT) approaches have been shown to be effective in ameliorating anxiety and depressive symptoms in adults with autism (Sizoo & Kuiper, 2017; Spek et al., 2013), although these associations were not observed in the current study due to the potential reasons related to methodology, sampling, and instruments used. Furthermore, it is plausible that from a statistical standpoint, violations of HMR assumptions contributed to the non-significant associations between the predictor and outcome variables.

Despite these differences, autism severity was indeed a significant predictor of anxiety and depression in this study. This is in line with previous studies which have also established the association between autism traits and mental health in autistic adults (Lever & Geurts, 2016; Uljarevic et al., 2020; Lawson et al., 2015; Wallace et al., 2016). Lever and Geurts (2016) examined the occurrence of psychiatric symptoms and diagnoses across the lifespan in adults aged 19 to 79 with and without ASD. They found that ASD severity, female gender, and lower age were associated with the presence of any anxiety disorder. Similarly, another study evaluating self-reported anxiety and

depressive symptoms in a sample of 255 individuals with ASD across various age groups found that predictors of depression and anxiety included female gender and higher autism severity (Uljarevic et al., 2020). Given that these characteristics are non-modifiable risk factors, these findings along with those reported in this study emphasize the need for early and accurate diagnosis of comorbid anxiety and depression, particularly in females with severe ASD to provide timely support and interventions to help them achieve a better mental health and QoL.

Limitations of the Study

This study had several strengths and some limitations. The study recruited a relatively large sample size of autistic participants with a nation-wide sampling frame from various sources in Canada. This gave power to undertake the HMR analysis with multiple covariate and predictor variables. Moreover, it increased the generalizability of the findings. The instruments used to measure QoL (WHOQOL-BREF) and mental health (DASS-21) have been validated in the ASD population (McConachie et al., 2017; Park et al., 2020) which further strengthen the validity and reliability of the findings. The questionnaire had an excellent completion rate of 95% likely due to the sources where the study was advertised. Moreover, there was advocacy by a few autistic ambassadors who were very supportive of the research and distributed the study survey among a small group of autistics in the community to raise awareness.

The study had some limitations. The data captured pertaining to autism interventions as predictors of QoL lacked some specificity. For example, the study survey asked participants to indicate whether a given intervention was ever used in the *past* or

present. As such, the duration of the intervention, whether the intervention was administered as intended, whether it was used and fully completed, or was still ongoing were not captured in the study survey. The latter may have confounded the effectiveness of the interventions undertaken by each participant due to the heterogeneity among participants who responded ‘*Yes*’ to this question since even though the participant had used the intervention, the intended outcome may have not been achieved. Next, the data were self-reported and could not have been cross validated against formal diagnoses for variables such as autism, ASD severity, having an intellectual disability or a current mental health condition. Further, the geographic residence of participants was not captured in the survey. It is possible that regional differences in access and availability of interventions to people with ASD and the potential variability in their living circumstances may have contributed to a better or lower quality of life, although it is hoped that the nationwide sampling frame may have, in part, mitigated this limitation.

Another limitation of the study involved its cross-sectional design, limiting interpretation of causal relationships. It is feasible that those with a higher QoL in the study had a higher likelihood of seeking employment, being in a relationship, or having the motivation or state of mind to seek autism interventions. There were two additional possible limitations of the study. One included possible self-selection bias since autistic individuals who chose to participate in the survey may have been more involved in online platforms, sought and used autism interventions and services, and been more comfortable to complete surveys. These factors may have impacted the representativeness of the sample, hence generalizability of the study results (Althubaiti, 2016). Finally, the

inclusion of proxy-report responses (28%) on behalf of the autistic individuals may not have accurately reflected first person ratings given the subjective nature of QoL. Albeit, those with an intellectual disability are often excluded from self-reported research due to potential issues with obtaining valid informed consent (Hamilton et al., 2017). Despite this, studies have shown a high correlation between autistic adult self-reports and parental proxy-reports around QoL outcomes which give reassurance to the consistency of the reporting between the two groups (Hong et al., 2016; Sheldrick et al., 2012).

Recommendations

The current study has underscored an important gap in autism research related to the ways in which therapeutic interventions are associated with QoL in individuals with ASD. While a multitude of interventions are available and offered to people with ASD, they often do not consider QoL as an outcome and a long-term goal for this population (Benevides et al., 2020, Pfeiffer et al., 2017; Mason et al., 2018). As noted by Pfeiffer and colleagues (2017), autism interventions are not always coherent with the end goals and needs of people with ASD and the relationship between interventions and QoL is not well understood. This study sought to determine the association between a set of commonly used therapeutic interventions by adults with ASD and their QoL and mental health. The findings from this study should catalyze future research which focus on improving QoL as an end goal, especially across the lifespan. Researchers should include well-defined measures of QoL, health, and well-being as desirable outcomes for interventions. In addition, studies should adopt a longitudinal approach to identify how current interventions meet the identified needs of people with ASD as they age into

adulthood. Intervention methods should be guided by the meaningfulness of interventions to the individual with autism rather than solely focusing on short-term goals which aim to improve the specific gap or challenge experienced by the person. While the latter is an important first and obvious step in supporting individuals with ASD, the long-term outcomes of ASD interventions are often not considered and evaluated with a longitudinal perspective. Finally, given the significant decline in provision of services in adulthood known as the ‘service cliff’ (Anderson et al., 2018) as well as the paucity of data around the use of interventions among the adult autistic population (van Heijst et al., 2015), future research should identify the most commonly used interventions which are most suited to address the unmet needs of adults with ASD.

This study found that behavioral and mental health support interventions were significantly associated with a better QoL in adults with ASD without an intellectual disability. This provides guidance for future studies to directly evaluate the effectiveness of these interventions in improving QoL and well-being. Moreover, it suggests the importance of involving community-stakeholder partnerships when evaluating the effectiveness of autism interventions to ensure that they are accepted and are meaningful in improving QoL over time.

Implications

Findings from this study have practical importance and positive implications to social change. First, the study has helped identify the types of therapeutic interventions which are most relevant to improving QoL in adults with autism. Of note, the two types of interventions which were associated with a higher QoL, behavioral and mental health,

are evidence-based approaches which have been shown to be effective in addressing the various needs of people with autism. As such, the findings from this study further validate their effectiveness, albeit indirectly, in supporting the QoL and well-being of autistic adults. Second, results from this study have raised awareness about the importance of intervening early with subgroups of autistic individuals, namely those with higher ASD severity, women, and those who are older, as they are particularly vulnerable to a lower QoL. Third, findings from this study can raise awareness and guide decision making among policy makers and agencies regarding the allocation and prioritization of scarce resources and funding to those interventions and services which optimize long-term outcomes for people with ASD related to their QoL and better integration into the community. Finally, findings from this study may bring about positive social change by helping inform multiple stakeholders involved in the management, care, and delivery of services to people with autism to support advocacy and client-centered approaches that are associated with better long-term outcomes and overall wellbeing.

Conclusion

This is the first study, to the researcher's knowledge, to evaluate the association of a set of commonly used therapeutic interventions in adults with autism and their QoL and mental health. Rooted in the Precede-Proceed theoretical framework which posits that all interventions and programs should start with the end goal in mind – to improve QoL, the study found that behavioral based therapies and mental health interventions were significantly associated with a better QoL, but not anxiety and depression, in adults with autism without an intellectual disability. Additionally, individual characteristics

including older age, ASD severity, and being female were negatively associated with a better QoL. These findings are important since while a multitude of studies have evaluated the effectiveness of various autism interventions in improving a target behavior or psychosocial deficit, they do not consider the impact of these interventions on QoL, and their long-term sustained effect is not well known. Given that both behavioral and mental health interventions are evidence-based approaches well studied in the literature, the findings from this study are reassuring and should instigate further research to evaluate the direct effectiveness of these interventions on the QoL and well-being of people with autism, especially as they age.

References

- Akshoomoff, N., Stahmer, A. C., Corsello, C., & Mahrer, N. E. (2010). What happens next? Follow-up from the children's toddler school program. *Journal of Positive Behavior Interventions, 12*(4), 245–253.
<https://doi.org/10.1177/1098300709343724>
- Alli, K., & Priya, S. (2017). Effectiveness of exposure therapy on anxiety and sensory over-responsivity among children with autism spectrum disorder. *International Journal of Pharma and Bio Sciences, 8*, 436–439.
<https://doi.org/10.22376/ijpbs.2017.8.2.b436-439>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- American Psychological Association. (n.d.). Social skills. In *APA dictionary of psychology*. Retrieved December 15, 2021. from <https://dictionary.apa.org/social-skills>
- American Psychology Association Ethical Principles of Psychologists and Code of Conduct. (2016).
<https://www.apa.org/ethics/code#:~:text=Psychologists%20uphold%20professional%20standards%20of,lead%20to%20exploitation%20or%20harm.>
- Albantakis, L., Brandi, M. L., Zillekens, I. C., Henco, L., Weindel, L., Thaler, H., Schliephake, L., Timmermans, B., & Schilbach, L. (2020). Alexithymic and autistic traits: Relevance for comorbid depression and social phobia in adults with and without autism spectrum disorder. *Autism, 24*(8), 2046–2056.

<https://doi.org/10.1177/1362361320936024>

- Althubaiti A. (2016). Information bias in health research: definition, pitfalls, and adjustment methods. *Journal of Multidisciplinary Healthcare*, 2016(1), 211–217. <https://doi.org/10.2147/JMDH.S104807>
- Ames, M. E., McMorris, C. A., Alli, L. N., & Bebko, J. M. (2016). Overview and evaluation of a mentorship program for university students with ASD. *Focus on Autism and Other Developmental Disabilities*, 31(1), 27–36. <https://doi.org/10.1177/1088357615583465>
- Anderson, A., Moore, D. W., Rausa, V. C., Finkelstein, S., Pearl, S., & Stevenson, M. (2017). A systematic review of interventions for adults with autism spectrum disorder to promote employment. *Review Journal of Autism and Developmental Disorders*, 4(1), 26–38. <https://doi.org/10.1007/s40489-016-0094-9>
- Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of individuals with autism to adulthood: A Review of Qualitative Studies. *Pediatrics*, 141(Supp 4). <http://doi.org/10.1542/peds.2016-4300i>
- Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment*, 10(2), 176. <https://psycnet.apa.org/doi/10.1037/1040-3590.10.2.176>
- Arnold, L. E., Aman, M. G., Cook, A. M., Witwer, A. N., Hall, K. L., Thompson, S., & Ramadan, Y. (2006). Atomoxetine for hyperactivity in autism spectrum disorders: placebo-controlled crossover pilot trial. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45(10), 1196–1205.

<https://doi.org/10.1097/01.chi.0000231976.28719.2a>

Asamoah, M. K. (2014). Re-examination of the limitations associated with correlational research. *Journal of Educational Research and Reviews*, 2(4), 45–52.

<http://sciencewebpublishing.net/jerr/archive/2014/July/pdf/Asamoah.pdf>

Ashman, R., Banks, K., Philip, R. C., Walley, R., & Stanfield, A. C. (2017). A pilot randomised controlled trial of a group based social skills intervention for adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 43, 67–75. <https://doi.org/10.1016/j.rasd.2017.08.001>

Atkinson-Jones, K., & Hewitt, O. (2019). Do group interventions help people with autism spectrum disorder to develop better relationships with others? A critical review of the literature. *British Journal of Learning Disabilities*, 47(2), 77–90.

<https://doi.org/10.1111/bld.12258>

Autism Speaks. (2022). *Interventions*. <https://www.autismspeaks.ca/interventions/>

Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2018). A systematic review of quality of life of adults on the autism spectrum. *Autism: The International Journal of Research and Practice*, 22(7), 774–783.

<https://doi.org/10.1177/1362361317714988>

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., & Warren, Z. (2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report*, 67(6), 2–23.

Baker, E. K., Richdale, A. L., Hazi, A., & Prendergast, L. A. (2019). Assessing a

- hyperarousal hypothesis of insomnia in adults with autism spectrum disorder. *Autism Research: Official Journal of the International Society for Autism Research*, 12(6), 897–910. <https://doi.org/10.1002/aur.2094>
- Baker, E., Stavropoulos, K. K., Baker, B. L., & Blacher, J. (2021). Daily living skills in adolescents with autism spectrum disorder: Implications for intervention and independence. *Research in Autism Spectrum Disorders*, 83, 101761. <https://doi.org/10.1016/j.rasd.2021.101761>
- Bakken, T. L., Helverschou, S. B., Eilertsen, D. E., Heggelund, T., Myrbakk, E., & Martinsen, H. (2010). Psychiatric disorders in adolescents and adults with autism and intellectual disability: A representative study in one county in Norway. *Research in Developmental Disabilities*, 31(6), 1669–1677. <https://doi.org/10.1016/j.ridd.2010.04.009>
- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46(10), 3281–3294. <https://doi.org/10.1007/s10803-016-2872-8>
- Barker, C., & Pistrang, N. (2015). *Research methods in clinical psychology: An introduction for students and practitioners*. New York, NY: John Wiley & Sons.
- Barnham, C. (2015). Quantitative and qualitative research: Perceptual foundations. *International Journal of Market Research*, 57(6), 837–854. <https://doi.org/10.2501/IJMR-2015-070>
- Barnhill, G. P. (2007). Outcomes in adults with Asperger Syndrome. *Focus on Autism*

and Other Developmental Disabilities, 22(2), 116–

126. <https://doi.org/10.1177/10883576070220020301>

Beck, J. S. (2011). Cognitive-behavioral therapy. *Clinical Textbook of Addictive Disorders*, 491, 474–501.

Beck, A.T., Rush, A.J., Shaw, B.F., & Emery, G. (1979). *Cognitive Therapy of Depression*. New York: Guilford Press.

Bennett, K. D., & Dukes, C. (2014). A systematic review of teaching daily living skills to adolescents and adults with autism spectrum disorder. *Review Journal of Autism and Developmental Disorders*, 1(1), 2–10. <https://doi.org/10.1007/s40489-013-0004-3>

Benevides, T. W., Shore, S. M., Andresen, M. L., Caplan, R., Cook, B., Gassner, D. L., Erves, J.M., Hazlewood, T. M., King, M. C., Morgan, L., Murphy, L. E., Purkis, Y., Rankowski, B., Rutledge, S. M., Welch, S. P., & Wittig, K. (2020). Interventions to address health outcomes among autistic adults: A systematic review. *Autism: The International Journal of Research and Practice*, 24(6), 1345–1359. <https://doi.org/10.1177/1362361320913664>

Blackmer, A. B., & Feinstein, J. A. (2016). Management of sleep disorders in children with neurodevelopmental disorders: a review. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy*, 36(1), 84–98. <https://doi.org/10.1002/phar.1686>

Blainey, S. H., Rumball, F., Mercer, L., Evans, L. J., & Beck, A. (2017). An evaluation of the effectiveness of psychological therapy in reducing general psychological

distress for adults with autism spectrum conditions and comorbid mental health problems. *Clinical Psychology & Psychotherapy*, 24(6), O1474–O1484.

<https://doi.org/10.1002/cpp.2108>

Biggs, E. E., & Carter, E. W. (2016). Quality of life for transition-age youth with autism or intellectual disability. *Journal of Autism and Developmental Disorders*, 46(1), 190–204. <https://doi.org/10.1007/s10803-015-2563-x>

Binnie, J., & Blainey, S. (2013). The use of cognitive behavioural therapy for adults with autism spectrum disorders: A review of the evidence. *Mental Health Review Journal*, 18(2), 93–104. <https://doi.org/10.1108/MHRJ-05-2013-0017>

Bird, P. D. (2015). The treatment of autism with low-dose phenytoin: a case report. *Journal of Medical Case Reports*, 9(1), 1–5. <https://doi.org/10.1186/1752-1947-9-8>

Bishop-Fitzpatrick, L., Mazefsky, C. A., & Eack, S. M. (2018). The combined impact of social support and perceived stress on quality of life in adults with autism spectrum disorder and without intellectual disability. *Autism: The International Journal of Research and Practice*, 22(6), 703–711. <https://doi.org/10.1177/1362361317703090>

Brown, T. A., Chorpita, B. F., & Barlow, D. H. (1998). Structural relationships among dimensions of the DSM-IV anxiety and mood disorders and dimensions of negative affect, positive affect, and autonomic arousal. *Journal of Abnormal Psychology*, 107(2), 179. <https://doi.org/10.1037//0021-843x.107.2.179>

Buchsbaum, M. S., Hollander, E., Mehmet Haznedar, M., Tang, C., Spiegel-Cohen, J.,

- Wei, T. C., Solimando, A., Buchsbaum, B. R., Robins, D., Bienstock, C., Cartwright, C., & Mosovich, S. (2001). Effect of fluoxetine on regional cerebral metabolism in autistic spectrum disorders: A pilot study. *International Journal of Neuropsychopharmacology*, *4*(2), 119–125.
<https://doi.org/10.1017/S1461145701002280>
- Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *44*(12), 3063–3071. <https://doi.org/10.1007/s10803-014-2170-2>
- Burger-Caplan, R., Saulnier, C., Jones, W., & Klin, A. (2016). Predicting social and communicative ability in school-age children with autism spectrum disorder: A pilot study of the Social Attribution Task, Multiple Choice. *Autism: The International Journal of Research and Practice*, *20*(8), 952–962.
<https://doi.org/10.1177/1362361315617589>
- Burke, T. J., Segrin, C., & Farris, K. L. (2018). Young adult and parent perceptions of facilitation: Associations with overparenting, family functioning, and student adjustment. *Journal of Family Communication*, *18*(3), 233–247.
<https://doi.org/10.1080/15267431.2018.1467913>
- Burkholder, G. J., Cox, K. A., & Crawford, L. M. (2016). *The Scholar-Practitioner's Guide to Research Design*. Baltimore, MD: Laureate Publishing.
- Cachia, R. L., Anderson, A., & Moore, D. W. (2016). Mindfulness in individuals with autism spectrum disorder: A systematic review and narrative analysis. *Review*

Journal of Autism and Developmental Disorders, 3(2), 165–178.

<https://doi.org/10.1007/s40489-016-0074-0>

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, 48(2), 473–484. <https://doi.org/10.1007/s10803-017-3342-7>

Cappadocia, M.C., & Weiss, J.A. (2011). Review of social skills training groups for youth with Asperger Syndrome and High Functioning Autism. *Research in Autism Spectrum Disorders*, 5, 70–78. <https://doi.org/10.1016/j.rasd.2010.04.001>

Cardaciotto, L., & Herbert, J. D. (2004). Cognitive behavior therapy for social anxiety disorder in the context of Asperger's syndrome: A single-subject report. *Cognitive and Behavioral Practice*, 11(1), 75–81. [https://doi.org/10.1016/S1077-7229\(04\)80009-9](https://doi.org/10.1016/S1077-7229(04)80009-9)

Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2008). Asperger syndrome and autism: a comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders*, 38(1), 72–85. <https://doi.org/10.1007/s10803-007-0364-6>

Centers for Disease Control and Prevention. (2019). Treatment and interventions for autism spectrum disorder. <https://cdc.gov/ncbddd/autism/treatment.html>

Cereda, D., Federici, A., Guarino, A., Serantoni, G., Gruppo PRECEDE-PROCEED, Coppola, L., Lemma, P., & Rossi, P. G. (2020). Development and first application of an audit system for screening programs based on the PRECEDE-PROCEED model: An experience with breast cancer screening in the region of Lombardy

- (Italy). *BMC Public Health*, 20(1), 1778. <https://doi.org/10.1186/s12889-020-09842-8>
- Charman, T., Pickles, A., Simonoff, E., Chandler, S., Loucas, T., & Baird, G. (2011). IQ in children with autism spectrum disorders: data from the Special Needs and Autism Project (SNAP). *Psychological Medicine*, 41(3), 619–627. <https://doi.org/10.1017/S0033291710000991>
- Chiang, H. M., Ni, X., & Lee, Y. S. (2017). Life skills training for middle and high school students with autism. *Journal of Autism and Developmental Disorders*, 47(4), 1113–1121. <https://doi.org/10.1007/s10803-017-3028-1>
- Ching, H., & Pringsheim, T. (2012). Aripiprazole for autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*, (5). CD009043. <https://doi.org/10.1002/14651858.CD009043.pub2>
- Clark, B. G., Magill-Evans, J. E., & Koning, C. J. (2015). Youth with Autism Spectrum Disorders: Self- and proxy-reported quality of life and adaptive functioning. *Focus on Autism and Other Developmental Disabilities*, 30(1), 57–64. <https://doi.org/10.1177/1088357614522289>
- Clark, L. A., & Watson, D. (1991). Tripartite model of anxiety and depression: psychometric evidence and taxonomic implications. *Journal of Abnormal Psychology*, 100(3), 316. <https://doi.org/10.1037//0021-843x.100.3.316>
- Cochrane, A.L. (1972). Effectiveness and efficiency: Random reflections on health services. Nuffield Trust.
- Conner, C., & White, S. (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.

<https://doi.org/10.1007/s10803-017-3312-0>

Cooper, D., Yap, K., & Batalha, L. (2018). Mindfulness-based interventions and their effects on emotional clarity: A systematic review and meta-analysis. *Journal of Affective Disorders*, 235, 265–276. <https://doi.org/10.1016/j.jad.2018.04.018>

Cortesi, F., Giannotti, F., Sebastiani, T., Panunzi, S., & Valente, D. (2012). Controlled-release melatonin, singly and combined with cognitive behavioural therapy, for persistent insomnia in children with autism spectrum disorders: a randomized placebo-controlled trial. *Journal of Sleep Research*, 21(6), 700–709.

<https://doi.org/10.1111/j.1365-2869.2012.01021.x>

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the Autism Spectrum. *Autism: The International Journal of Research and Practice*, 19(7), 814–823.

<https://doi.org/10.1177/1362361315577517>

Crosby, R., & Noar, S. M. (2011). What is a planning model? An introduction to PRECEDE-PROCEED. *Journal of Public Health Dentistry*, 71 Suppl 1, S7–S15.

<https://doi.org/10.1111/j.1752-7325.2011.00235.x>

Cullen, J. M., Alber-Morgan, S. R., Simmons-Reed, E. A., & Izzo, M. V. (2017). Effects of self-directed video prompting using iPads on the vocational task completion of young adults with intellectual and developmental disabilities. *Journal of Vocational Rehabilitation*, 46(3), 361–375.

<https://doi.org/10.1177/2165143417752901>

David, D., Cristea, I., & Hofmann, S. G. (2018). Why cognitive behavioral therapy is the current gold standard of psychotherapy. *Frontiers in Psychiatry, 9*, 4.

<https://doi.org/10.3389/fpsy.2018.00004>

De Haan, L., Egberts, A. C. G., & Heerdink, E. R. (2015). The relation between risk-taking behavior and alcohol use in young adults is different for men and women. *Drug and Alcohol Dependence, 155*, 222–227.

<https://doi.org/10.1016/j.drugalcdep.2015.07.013>

De Leeuw, D. (2005). To mix or not to mix data collection modes in surveys. *Journal of Official Statistics, 21*(2), 233–255.

De Leeuw, E., & Berzelak, N. (2016). Survey mode or survey modes. *The Sage Handbook of Survey Methodology*, 142–156.

Dern, S., & Sappok, T. (2016). Barriers to healthcare for people on the autism spectrum. *Advances in Autism, 2*(1), 2–11. <https://doi.org/10.1108/AIA-10-2015-0020>

Doehring, P., Reichow, B., Palka, T., Phillips, C., & Hagopian, L. (2014). Behavioral approaches to managing severe problem behaviors in children with autism spectrum and related developmental disorders: A descriptive analysis. *Child and Adolescent Psychiatric Clinics, 23*(1), 25–40.

<https://doi.org/10.1016/j.chc.2013.08.001>

Dörnyei, Z. (2007). *Research methods in applied linguistics*. New York: Oxford University Press.

- Duncan, A. W., & Bishop, S. L. (2015). Understanding the gap between cognitive abilities and daily living skills in adolescents with autism spectrum disorders with average intelligence. *Autism, 19*(1), 64–72.
<https://doi.org/10.1177/1362361313510068>
- Duncan, A., Ruble, L. A., Meinzen-Derr, J., Thomas, C., & Stark, L. J. (2018). Preliminary efficacy of a daily living skills intervention for adolescents with high-functioning autism spectrum disorder. *Autism, 22*(8), 983–994.
<https://doi.org/10.1177/1362361317716606>
- Eissa, N., Al-Houqani, M., Sadeq, A., Ojha, S. K., Sasse, A., & Sadek, B. (2018). Current enlightenment about etiology and pharmacological treatment of autism spectrum disorder. *Frontiers in Neuroscience, 12*, 304.
<https://doi.org/10.3389/fnins.2018.00304>
- Ekman, E., & Hiltunen, A. J. (2015). Modified CBT using visualization for Autism Spectrum Disorder (ASD), anxiety and avoidance behavior--a quasi-experimental open pilot study. *Scandinavian Journal of Psychology, 56*(6), 641–648.
<https://doi.org/10.1111/sjop.12255>
- Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics, 5*(1), 1–4. <https://doi.org/10.11648/j.ajtas.20160501.11>
- Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*(2), 175–191.

<https://doi.org/10.3758/bf03193146>

- Fietz, J., Valencia, N., & Silani, G. (2018). Alexithymia and autistic traits as possible predictors for traits related to depression, anxiety, and stress: A multivariate statistical approach. *Journal of Evaluation in Clinical Practice*, *24*(4), 901–908. <https://doi.org/10.1111/jep.12961>
- Fombonne, E., & Chakrabarti, S. (2001). No evidence for a new variant of measles-mumps-rubella-induced autism. *Pediatrics*, *108*(4), e58–e58. <https://doi.org/10.1542/peds.108.4.e58>
- Fombonne, E. (2020). Epidemiological controversies in autism. *Swiss Archives of Neurology, Psychiatry and Psychotherapy*, *171*(01).
- Fortuna, R. J., Robinson, L., Smith, T. H., Meccarello, J., Bullen, B., Nobis, K., & Davidson, P.W. (2016). Health conditions and functional status in adults with autism: A cross-sectional evaluation. *Journal of General Internal Medicine*, *31*(1), 77–84. <https://doi.org/10.1007/s11606-015-3509-x>
- Frankfort-Nachmias, C., & Leon-Guerrero, A. (2018). *Social statistics for a diverse society* (8th ed.). Sage Publications
- Gal, E., Selanikyo, E., Erez, A. B., & Katz, N. (2015). Integration in the vocational world: How does it affect quality of life and subjective well-being of young adults with ASD. *International Journal of Environmental Research and Public Health*, *12*(9), 10820–10832. <https://doi.org/10.3390/ijerph120910820>
- Galli-Carminati, G. M., Deriaz, N., & Bertschy, G. (2009). Melatonin in treatment of chronic sleep disorders in adults with autism: A retrospective study. *Swiss*

Medical Weekly, 139(19-20), 293–296.

- Gantman, A., Kapp, S. K., Orenski, K., & Laugeson, E. A. (2012). Social skills training for young adults with high-functioning autism spectrum disorders: a randomized controlled pilot study. *Journal of Autism and Developmental Disorders*, 42(6), 1094–1103. <https://doi.org/10.1007/s10803-011-1350-6>
- García-Pérez, M. A. (2012). Statistical conclusion validity: Some common threats and simple remedies. *Frontiers in Psychology*, 3, 325.
<https://doi.org/10.3389/fpsyg.2012.00325>
- Gates, J. A., Kang, E., & Lerner, M. D. (2017). Efficacy of group social skills interventions for youth with autism spectrum disorder: A systematic review and meta-analysis. *Clinical Psychology Review*, 52, 164–181.
<https://doi.org/10.1016/j.cpr.2017.01.006>
- Gaus, V. L. (2011). Adult Asperger syndrome and the utility of cognitive-behavioral therapy. *Journal of Contemporary Psychotherapy*, 41(1), 47–56.
<https://doi.org/10.1007/s10879-010-9159-8>
- Gielen, A.C., McDonald, E.M., Gary, T.L., & Bone, L.R. (2008). Using the PRECEDE/PROCEED model to apply health behavior theories. In K. Glanz, F.M. B. K. Rimer, & K. Viswanath, (Eds.), *Health Behavior and Health Education: Theory, Research and Practice*. 4th edition, pp. 407–433. San Francisco: Jossey-Bass
- Golubchik, P., Rapaport, M., & Weizman, A. (2017). The effect of methylphenidate on anxiety and depression symptoms in patients with Asperger syndrome and

comorbid attention deficit/hyperactivity disorder. *International Clinical Psychopharmacology*, 32(5), 289–293.

<https://doi.org/10.1097/YIC.0000000000000175>

Golubchik, P., Sever, J., & Weizman, A. (2013). Reboxetine treatment for autistic spectrum disorder of pediatric patients with depressive and inattentive/hyperactive symptoms: An open-label trial. *Clinical Neuropharmacology*, 36(2), 37–41.
<https://doi.org/10.1097/WNF.0b013e31828003c1>

Gotham, K., Marvin, A. R., Taylor, J. L., Warren, Z., Anderson, C. M., Law, P. A., Law, J. K., & Lipkin, P. H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism: The International Journal of Research and Practice*, 19(7), 794–804. <https://doi.org/10.1177/1362361315583818>

Green, L.W. (1974) Toward cost-benefit evaluations of health education: Some concepts, methods, and examples. *Health Education Monographs* 2(Suppl. 1): 34–64

Green, L.W., Kreuter, M.W., Deeds, S., & Partridge, K. (1980). *Health Education Planning: A Diagnostic Approach*. Palo Alto, CA: Mayfield.

Green, L. W., & Kreuter, M. W. (1991). *Health Promotion Planning: An Educational and Environmental Approach*. Mayfield Pub. Co.

Green, L.W., & Kreuter, M.W. (2005). *Health Program Planning: An Educational and Ecological Approach*. New York: McGraw-Hill.

Gunes, S., & Ekinçi, Ö. (2019). Health-related quality of life in children and adolescent with ASD: The role of mothers' emotional symptoms. *Anatolian Journal of*

Psychiatry, 20(5), 548–555. <https://doi.org/10.5455/apd.18005>

Hagopian, L. P., & Jennett, H. K. (2008). Behavioral assessment and treatment of anxiety in individuals with intellectual disabilities and autism. *Journal of Developmental and Physical Disabilities*, 20(5), 467–483. <https://doi.org/10.1007/s10882-008-9114-8>

Hair, J. F., Ringle, C. M., & Sarstedt, M. (2013). Partial least squares structural equation modeling: Rigorous applications, better results and higher acceptance. *Long Range Planning*, 46(1-2), 1–12.

<https://psycnet.apa.org/doi/10.1016/j.lrp.2013.01.001>

Hamilton, J., Ingham, B., McKinnon, I., Parr, J. R., Tam, L. Y. C., & Le Couteur, A. (2017). Mental capacity to consent to research? Experiences of consenting adults with intellectual disabilities and/or autism to research. *British Journal of Learning Disabilities*, 45(4), 230–237. <https://doi.org/10.1111/bld.12198>

Handen, B. L., Johnson, C. R., & Lubetsky, M. (2000). Efficacy of methylphenidate among children with autism and symptoms of attention-deficit hyperactivity disorder. *Journal of Autism and Developmental Disorders*, 30(3), 245–255. <https://doi.org/10.1023/a:1005548619694>

Happé, F., & Charlton, R. A. (2012). Aging in autism spectrum disorders: A mini-review. *Gerontology*, 58(1), 70–78. <https://doi.org/10.1159/000329720>

Hare, D. J. (1997). The use of cognitive-behavioural therapy with people with Asperger syndrome: a case study. *Autism*, 1(2), 215–225. <https://doi.org/10.1177%2F1362361397012007>

- Harfterkamp, M., van de Loo-Neus, G., Minderaa, R. B., van der Gaag, R. J., Escobar, R., Schacht, A., Pamulapati, S., Buitelaar, J. K., & Hoekstra, P. J. (2012). A randomized double-blind study of atomoxetine versus placebo for attention-deficit/hyperactivity disorder symptoms in children with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(7), 733–741. <https://doi.org/10.1097/JCP.0b013e31829c764f>
- 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. <https://doi.org/10.1007/s10803-019-04145-3>
- Hatfield, M., Falkmer, M., Falkmer, T., & Ciccarelli, M. (2016). Evaluation of the effectiveness of an online transition planning program for adolescents on the autism spectrum: Trial protocol. *Child and Adolescent Psychiatry and Mental Health, 10*, 48. <https://doi.org/10.1186/s13034-016-0137-0>
- Hatfield, M., Falkmer, M., Falkmer, T., & Ciccarelli, M. (2017). Effectiveness of the BOOST-A™ online transition planning program for adolescents on the autism spectrum: a quasi-randomized controlled trial. *Child and Adolescent Psychiatry and Mental Health, 11*, 54. <https://doi.org/10.1186/s13034-017-0191-2>
- Hatfield, M., Ciccarelli, M., Falkmer, T., & Falkmer, M. (2018). Factors related to successful transition planning for adolescents on the autism spectrum. *Journal of Research in Special Educational Needs, 18*(1), 3–14. <https://doi.org/10.1111/1471-3802.12388>

- Hayes, S. C., Follette, V. M., & Linehan, M. (Eds.). (2004). *Mindfulness and acceptance: Expanding the cognitive-behavioral tradition*. Guilford Press.
- Helles, A., Gillberg, I. C., Gillberg, C., & Billstedt, E. (2017). Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity. *Autism, 21*(4), 458–469.
<https://doi.org/10.1177/1362361316650090>
- Herscu, P., Handen, B. L., Arnold, L. E., Snape, M. F., Bregman, J. D., Ginsberg, L., Hendren, R., Kolevzon, A., Melmed, R., Mintz, M., Minshew, N., Sikich, L., Attalla, A., King, B., Owley, T., Childress, A., Chugani, H., Frazier, J., Cartwright, C., Murphy, T., ... Autism Speaks Autism Clinical Trials Network (2020). The SOFIA study: Negative multi-center study of low dose fluoxetine on repetitive behaviors in children and adolescents with autistic disorder. *Journal of Autism and Developmental Disorders, 50*(9), 3233–3244.
<https://doi.org/10.1007/s10803-019-04120-y>
- Hidalgo, B., & Goodman, M. (2013). Multivariate or multivariable regression?. *American Journal of Public Health, 103*(1), 39–40.
<https://doi.org/10.2105/AJPH.2012.300897>
- Hillier, A., Fish, T., Cloppert, P., & Beversdorf, D. Q. (2007). Outcomes of a social and vocational skills support group for adolescents and young adults on the autism spectrum. *Focus on Autism and Other Developmental Disabilities, 22*(2), 107–115. <https://doi.org/10.1177/10883576070220020201>
- Hillier, A. J., Fish, T., Siegel, J. H., & Beversdorf, D. Q. (2011). Social and vocational

skills training reduces self-reported anxiety and depression among young adults on the autism spectrum. *Journal of Developmental and Physical Disabilities*, 23(3), 267–276. <https://doi.org/10.1007/s10882-011-9226-4>

Hinkle, D.E., Wiersma, W. & Jurs, S. (2003). *Applied Statistics for the Behavioral Sciences* (5th ed.)

Hirvikoski, T., & Blomqvist, M. (2015). High self-perceived stress and poor coping in intellectually able adults with autism spectrum disorder. *Autism: The International Journal of Research and Practice*, 19(6), 752–757. <https://doi.org/10.1177/1362361314543530>

Ho, B. P., Stephenson, J., & Carter, M. (2015). Cognitive-behavioural approach for children with autism spectrum disorder: A literature review. *Journal of Intellectual and Developmental Disability*, 40(2), 213–229. <https://doi.org/10.3109/13668250.2015.1023181>

Hollander, E., Soorya, L., Chaplin, W., Anagnostou, E., Taylor, B. P., Ferretti, C. J., Wasserman, S., Swanson, E., & Settapani, C. (2012). A double-blind placebo-controlled trial of fluoxetine for repetitive behaviors and global severity in adult autism spectrum disorders. *American Journal of Psychiatry*, 169(3), 292–299. <https://doi.org/10.1176/appi.ajp.2011.10050764>

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. <https://doi.org/10.1017/S0033291718002283>

- Holtgraves, T. (2017). Social desirability and the interpretation of uncertainty terms in self-report questions. *Applied Cognitive Psychology, 31*(6), 623–631. <https://doi.org/10.1002/acp.3364>
- Hong, J., Bishop-Fitzpatrick, L., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Factors associated with subjective quality of life of adults with autism spectrum disorder: Self-report versus maternal reports. *Journal of Autism and Developmental Disorders, 46*(4), 1368–1378. <https://doi.org/10.1007/s10803-015-2678-0>
- Howlin, P., & Taylor, J. L. (2015). Addressing the need for high quality research on autism in adulthood. *Autism, 19*(7), 771–773. <https://doi.org/10.1177/1362361315595582>
- Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder--a follow-up comparison in early adult life. II: Social, behavioural, and psychiatric outcomes. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 41*(5), 561–578. <https://doi.org/10.1111/1469-7610.00643>
- Howlin, P., & Yates, P.M. (1999). The potential effectiveness of social skills groups for adults with autism. *Autism, 3*(3), 299–307. <https://doi.org/10.1177/1362361399003003007>
- Hull, L., Levy, L., Lai, M. C., Petrides, K. V., Baron-Cohen, S., Allison, C., Smith, P., & Mandy, W. (2021). Is social camouflaging associated with anxiety and depression in autistic adults? *Molecular Autism, 12*(1), 13. <https://doi.org/10.1186/s13229->

021-00421-1

- Hume, K., Steinbrenner, J. R., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., McIntyre, N. S., Yücesoy-Özkan, S., & Savage, M. N. (2021). Evidence-Based Practices for Children, Youth, and Young Adults with Autism: Third Generation Review. *Journal of Autism and Developmental Disorders*, 51(11), 4013–4032. <https://doi.org/10.1007/s10803-020-04844-2>
- Ikeda, E., Hinckson, E., & Krägeloh, C. (2014). Assessment of quality of life in children and youth with autism spectrum disorder: a critical review. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 23(4), 1069–1085. <https://doi.org/10.1007/s11136-013-0591-6>
- Interagency Autism Coordinating Committee. (2016-2017). Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder. The U.S. Department of Health and Human Services Interagency Autism Coordinating Committee: <https://iacc.hhs.gov/publications/strategic-plan/2017/>.
- James, N. (2013). The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: What do carers say? *Journal of Intellectual Disabilities* 17(1), 6–23. <https://doi.org/10.1177%2F1744629512472610>
- Jennes-Coussens, M., Magill-Evans, J., & Koning, C. (2006). The quality of life of young men with Asperger syndrome: a brief report. *Autism: The International Journal of Research and Practice*, 10(4), 403–414. <https://doi.org/10.1177/1362361306064432>

- Jensen, P. S., Kettle, L., Roper, M. T., Sloan, M. T., Dulcan, M. K., Hoven, C., Bird, H. R., Bauermeister, J. J., & Payne, J. D. (1999). Are stimulants overprescribed? Treatment of ADHD in four US communities. *Journal of the American Academy of Child & Adolescent Psychiatry, 38*(7), 797-804.
<https://doi.org/10.1097/00004583-199907000-00008>
- Jeong, Y., & Jung, M. J. (2016). Application and interpretation of hierarchical multiple regression. *Orthopaedic Nursing, 35*(5), 338–341.
<https://doi.org/10.1097/NOR.0000000000000279>
- Jobski, K., Höfer, J., Hoffmann, F., & Bachmann, C. (2017). Use of psychotropic drugs in patients with autism spectrum disorders: a systematic review. *Acta Psychiatrica Scandinavica, 135*(1), 8–28. <https://doi.org/10.1111/acps.12644>
- Jones, K. B., Cottle, K., Bakian, A., Farley, M., Bilder, D., Coon, H., & McMahon, W. M. (2016). A description of medical conditions in adults with autism spectrum disorder: A follow-up of the 1980s Utah/UCLA Autism Epidemiologic Study. *Autism: The International Journal of Research and Practice, 20*(5), 551–561. <https://doi.org/10.1177/1362361315594798>
- Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Fried, R., Bolfek, A., Kotte, A., Stevens, J., Furtak, S. L., Bourgeois, M., Caruso, J., Caron, A., & Biederman, J. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. *Journal of Autism and Developmental Disorders, 43*(6), 1314–1325. <https://doi.org/10.1007/s10803-012-1679-5>

- Kabat-Zinn, J. (1994). Catalyzing movement towards a more contemplative/sacred-appreciating/non-dualistic society. In *Meeting of the Working Group*.
<https://www.contemplativemind.org/admin/wp-content/uploads/kabat-zinn.pdf>
- Kamp-Becker, I., Schröder, J., Remschmidt, H., & Bachmann, C. J. (2010). Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. *Psycho-social Medicine*, 7, Doc03.
<https://doi.org/10.3205/psm000065>
- Kamio, Y., Inada, N., & Koyama, T. (2013). A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism: The International Journal of Research and Practice*, 17(1), 15–26. <https://doi.org/10.1177/1362361312436848>
- Katz, N., Dejak, I., & Gal, E. (2015). Work performance evaluation and QoL of adults with High Functioning Autism Spectrum Disorders (HFASD). *Work (Reading, Mass.)*, 51(4), 887–892. <https://doi.org/10.3233/WOR-152001>
- Keefer, A., White, S. W., Vasa, R. A., & Reaven, J. (2018). Psychosocial interventions for internalizing disorders in youth and adults with ASD. *International Review of Psychiatry (Abingdon, England)*, 30(1), 62–77.
<https://doi.org/10.1080/09540261.2018.1432575>
- Kellems, R. O., Frandsen, K., Cardon, T. A., Knight, K., & Andersen, M. (2018). Effectiveness of static pictures vs. video prompting for teaching functional life skills to students with autism spectrum disorders. *Preventing School Failure: Alternative Education for Children and Youth*, 62(2), 129–139. <https://doi.org/>

<http://doi.org/10.1080/1045988X.2017.1393790>

- Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic Childhood Events and Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 45(11), 3475–3486. <https://doi.org/10.1007/s10803-015-2392-y>
- Kenworthy, L., Case, L., Harms, M. B., Martin, A., & Wallace, G. L. (2010). Adaptive behavior ratings correlate with symptomatology and IQ among individuals with high-functioning autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 40(4), 416–423. <https://doi.org/10.1007/s10803-009-0911-4>
- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62(6), 593–602. <https://doi.org/10.1001/archpsyc.62.6.593>
- Khanna, R., Jariwala-Parikh, K., West-Strum, D., & Mahabaleshwarkar, R. (2014). Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders*, 8(3), 157–167. <https://doi.org/10.1016/j.rasd.2013.11.003>
- Khazaal, Y., van Singer, M., Chatton, A., Achab, S., Zullino, D., Rothen, S., Khan, R., Billieux, J., & Thorens, G. (2014). Does self-selection affect samples' representativeness in online surveys? An investigation in online video game research. *Journal of Medical Internet Research*, 16(7), e164. <https://doi.org/10.2196/jmir.2759>

- Kiep, M., Spek, A. A., & Hoeben, L. (2015). Mindfulness-based therapy in adults with an autism spectrum disorder: Do treatment effects last?. *Mindfulness*, *6*(3), 637–644.
<https://doi.org/10.1007/s12671-014-0299-x>
- Kim, I., Lee, A. B., & Lei, J. (2019). Global and local two-sample tests via regression. *Electronic Journal of Statistics*, *13*(2), 5253–5305.
<https://doi.org/10.1214/19-EJS1648>
- Klinger, L. G., Cook, M. L., & Dudley, K. M. (2021). Predictors and moderators of treatment efficacy in children and adolescents with autism spectrum disorder. *Journal of Clinical Child & Adolescent Psychology*, *50*(4), 517–524.
<https://doi.org/10.1080/15374416.2020.1833735>
- Kratochwill, T. R., Hitchcock, J., Horner, R. H., Levin, J. R., Odom, S. L., Rindskopf, D. M., & Shadish, W. R. (2010). Single-case designs technical documentation. *What Works Clearinghouse*. http://ies.ed.gov/ncee/wwc/pdf/wwc_scd.pdf
- Knüppel, A., Telléus, G. K., Jakobsen, H., & Lauritsen, M. B. (2018). Quality of life in adolescents and adults with autism spectrum disorder: Results from a nationwide Danish survey using self-reports and parental proxy-reports. *Research in Developmental Disabilities*, *83*, 247–259.
<https://doi.org/10.1016/j.ridd.2018.09.004>
- Kok, T., de Haan, H. A., van der Meer, M., Najavits, L. M., & De Jong, C. A. (2015). Screening of current post-traumatic stress disorder in patients with substance use disorder using the Depression, Anxiety and Stress Scale (DASS-21): A reliable and convenient measure. *European Addiction Research*, *21*(2), 71–77.

<https://doi.org/10.1159/000365283>

- Kose, L. K., Fox, L., & Storch, E. A. (2018). Effectiveness of cognitive behavioral therapy for individuals with autism spectrum disorders and comorbid obsessive-compulsive disorder: A review of the research. *Journal of Developmental and Physical Disabilities, 30*(1), 69–87. <https://doi.org/10.1007/s10882-017-9559-8>
- Kovshoff, H., Hastings, R. P., & Remington, B. (2011). Two-year outcomes for children with autism after the cessation of early intensive behavioral intervention. *Behavior Modification, 35*(5), 427–450. <https://doi.org/10.1177/0145445511405513>
- Krieger, B., Kinebanian, A., Prodinger, B., & Heigl, F. (2012). Becoming a member of the work force: Perceptions of adults with Asperger Syndrome. *Work, 43*(2), 141–157. <https://doi.org/10.3233/WOR-2012-1392>
- Kulesa, A., Krzywinski, M., Blainey, P., & Altman, N. (2015). Sampling distributions and the bootstrap. *Nature Methods, 12*, 477–478. <https://doi.org/10.1038/nmeth.3414>
- Laerd Statistics. (n.d.). Point-biserial correlation using SPSS statistics. <https://statistics.laerd.com/spss-tutorials/point-biserial-correlation-using-spss-statistics.php>
- Lai, J. K. Y., & Weiss, J. A. (2017). Priority service needs and receipt across the lifespan with autism spectrum disorder. *Autism Research, 10*(8), 1436–1447. <https://doi.org/10.1002/aur.1786>
- Laugeson, E.A., & Frankel, F. (2010). *Social skills for teenagers with developmental and*

autism spectrum disorders: The PEERS Treatment Manual. Routledge/Taylor & Francis Group.

- Laugeson, E., Gantman, A., Kapp, S., Orenski, K., & Ellingsen, R. (2015). A randomized controlled trial to improve social skills in young adults with Autism Spectrum Disorder: The UCLA PEERS Program. *Journal of Autism & Developmental Disorders*, *45*(12), 3978–3989. <https://doi.org/10.1007/s10803-015-2504-8>
- Lawson, L. P., Richdale, A. L., Haschek, A., Flower, R. L., Vartuli, J., Arnold, S. R., & Trollor, J. N. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism: The International Journal of Research and Practice*, *24*(4), 954–967. <https://doi.org/10.1177/1362361320908107>
- Lawson, R. A., Papadakis, A. A., Higginson, C. I., Barnett, J. E., Wills, M. C., Strang, J. F., Wallace, G. L., & Kenworthy, L. (2015). Everyday executive function impairments predict comorbid psychopathology in autism spectrum and attention deficit hyperactivity disorders. *Neuropsychology*, *29*(3), 445–453. <https://doi.org/10.1037/neu0000145>
- LeClerc, S., & Easley, D. (2015). Pharmacological therapies for autism spectrum disorder: A review. *Pharmacy and Therapeutics*, *40*(6), 389.
- Leung, C. N. W., Chan, R. W. S., Yeung, M. Y. C., & Tsui, H. C. H. (2019). Applicability and Effectiveness of Social Competence Group Intervention on Adults with Autism Spectrum Disorder in a Chinese Context: A Community-Based Study with Self- and Parent-Report. *Journal of Autism & Developmental*

Disorders, 49(8), 3440–3452. <https://doi.org/10.1007/s10803-019-04066-1>

Lever, A. G., & Geurts, H. M. (2016). Age-related differences in cognition across the adult lifespan in autism spectrum disorder. *Autism Research: Official Journal of the International Society for Autism Research*, 9(6), 666–676.

<https://doi.org/10.1002/aur.1545>

Lewis, A. S., & van Schalkwyk, G. I. (2020). Systematic Review: Distribution of Age and Intervention Modalities in Therapeutic Clinical Trials for Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 50(6), 2208–2216.

<https://doi.org/10.1007/s10803-019-03942-0>

Lieb, R.W., & Bohnert, A. M. (2017). Relations Between Executive Functions, Social Impairment, and Friendship Quality on Adjustment Among High Functioning Youth with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 47(9), 2861–2872. <https://doi.org/10.1007/s10803-017-3205-2>

Lin L.Y. (2014). Quality of life of Taiwanese adults with autism spectrum disorder. *PLoS One*, 9(10), e109567. <https://doi.org/10.1371/journal.pone.0109567>

Lin, L.Y., & Huang, P.C. (2019). Quality of life and its related factors for adults with autism spectrum disorder, *Disability and Rehabilitation*, 41:8, 896–903, <https://doi.org/10.1080/09638288.2017.1414887>

Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2011). Social participation in a nationally representative sample of older youth and young adults with autism. *Journal of Developmental and Behavioral Pediatrics*, 32(4), 277–283.

<https://doi.org/10.1097/DBP.0b013e31820b49fc>

- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*(1), 3. <https://doi.org/10.1037//0022-006x.55.1.3>
- Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy, 33*(3), 335–343. [https://psycnet.apa.org/doi/10.1016/0005-7967\(94\)00075-U](https://psycnet.apa.org/doi/10.1016/0005-7967(94)00075-U)
- Lubin, A., & Feeley, C. (2016). Transportation issues of adults on the Autism Spectrum: Findings from focus group discussions. *Transportation Research Record, 2542*(1), 1–8. <https://doi.org/10.3141/2542-01>
- Maddox, B. B., & White, S. W. (2015). Comorbid social anxiety disorder in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(12), 3949–3960. <https://doi.org/10.1007/s10803-015-2531-5>
- Maras, A., Schroder, C. M., Malow, B. A., Findling, R. L., Breddy, J., Nir, T., Shahmoon, S., Zisapel, N., & Gringras, P. (2018). Long-term efficacy and safety of pediatric prolonged-release melatonin for insomnia in children with autism spectrum disorder. *Journal of Child and Adolescent Psychopharmacology, 28*(10), 699–710. <https://doi.org/10.1089/cap.2018.0020>
- Marcotte, J., Grandisson, M., Piquemal, C., Boucher, A., Rheault, M. E., & Milot, E. (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>

- 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>
- Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research: Official Journal of the International Society for Autism Research*, *11*(8), 1138–1147.
<https://doi.org/10.1002/aur.1965>
- Matson, J. L., Turygin, N. C., Beighley, J., Rieske, R., Tureck, K., & Matson, M. L. (2012). Applied behavior analysis in autism spectrum disorders: Recent developments, strengths, and pitfalls. *Research in Autism Spectrum Disorders*, *6*(1), 144–150. <https://doi.org/10.1016/j.rasd.2011.03.014>
- Matson, J. L., & Jang, J. (2014). Treating aggression in persons with autism spectrum disorders: A review. *Research in Developmental Disabilities*, *35*(12), 3386–3391.
<https://doi.org/10.1016/j.ridd.2014.08.025>
- McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the validity of a quality of life measure for autistic people. *Journal of Autism and Developmental Disorders*, *48*(5), 1596–1611.
<https://doi.org/10.1007/s10803-017-3402-z>
- McCracken, J. T., McGough, J., Shah, B., Cronin, P., Hong, D., Aman, M. G., Arnold, L. E., Lindsay, R., Nash, P., Hollway, J., McDougle, C. J., Posey, D., Swiezy, N., Kohn, A., Scahill, L., Martin, A., Koenig, K., Volkmar, F., Carroll, D., Lancor,

A., ... Research Units on Pediatric Psychopharmacology Autism Network (2002).

Risperidone in children with autism and serious behavioral problems. *New England Journal of Medicine*, 347(5), 314–321.

<https://doi.org/10.1056/NEJMoa013171>

McDougle, C. J., Holmes, J. P., Bronson, M. R., Anderson, G. M., Volkmar, F. R., Price, L. H., & Cohen, D. J. (1997). Risperidone treatment of children and adolescents with pervasive developmental disorders: a prospective, open-label study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 36(5), 685–693.

<https://doi.org/10.1097/00004583-199705000-00020>

McDougle, C. J., Naylor, S. T., Cohen, D. J., Volkmar, F. R., Heninger, G. R., & Price, L. H. (1996). A double-blind, placebo-controlled study of fluvoxamine in adults with autistic disorder. *Archives of General Psychiatry*, 53(11), 1001–1008.

<https://doi.org/10.1001/archpsyc.1996.01830110037005>

McGillivray, J. A., & Evert, H. T. (2014). Group cognitive behavioural therapy program shows potential in reducing symptoms of depression and stress among young people with ASD. *Journal of Autism and Developmental Disorders*, 44(8), 2041–2051. <https://doi.org/10.1007/s10803-014-2087-9>

McMullen, M., Lau, P., Taylor, S., McTigue, J., Cook, A., Bamblett, M., Hasani, A., & Johnson, C. E. (2018). Factors associated with psychological distress amongst outpatient chemotherapy patients: An analysis of depression, anxiety and stress using the DASS-21. *Applied Nursing Research*, 40, 45–50.

<https://doi.org/10.1016/j.apnr.2017.12.002>

- McVey, A. J., Dolan, B. K., Willar, K. S., Pleiss, S., Karst, J. S., Casnar, C. L., Caiozzo, C., Vogt, E. M., Gordon, N. S., & Van Hecke, A. V. (2016). A replication and extension of the PEERS® for young adults social skills intervention: Examining effects on social skills and social anxiety in young adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *46*(12), 3739–3754.
<https://doi.org/10.1007/s10803-016-2911-5>
- Menezes, M., Harkins, C., Robinson, M. F., & Mazurek, M. O. (2020). Treatment of depression in individuals with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, *78*, 101639.
<https://doi.org/10.1016/j.rasd.2020.101639>
- Miller, A.R., Vernon, T.W., Wu, V., & Russo, K. (2014). Social skill group interventions for adolescents with Autism Spectrum Disorders: A systematic review. *Review Journal of Autism and Developmental Disorders*, *1*, 254–265.
<https://doi.org/10.1007/s40489-014-0017-6>
- Mohammadzaheri, F., Koegel, L. K., Rezaee, M., & Rafiee, S. M. (2014). A randomized clinical trial comparison between pivotal response treatment (PRT) and structured applied behavior analysis (ABA) intervention for children with autism. *Journal of Autism and Developmental Disorders*, *44*(11), 2769–2777.
<https://doi.org/10.1007/s10803-014-2137-3>
- Monaco, S. D., & Wolfe, P. (2018). Comparison of individualized and non-specific video-prompts to teach daily living skills to students with autism spectrum disorders. *Education and Training in Autism and Developmental*

Disabilities, 53(4), 378–392. <https://www.jstor.org/stable/26563480>

- 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. <https://doi.org/10.1007/s10803-019-04020-1>
- Moshki, M., Dehnoalian, A., & Alami, A. (2017). Effect of Precede-Proceed model on preventive behaviors for Type 2 Diabetes Mellitus in high-risk individuals. *Clinical Nursing Research*, 26(2), 241–253. <https://doi.org/10.1177/1054773815621026>
- Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders*, 47(6), 1830–1837. <https://doi.org/10.1007/s10803-017-3105-5>
- Murphy, S. M., Chowdhury, U., White, S. W., Reynolds, L., Donald, L., Gahan, H., Iqbal, Z., Kulkarni, M., Scrivener, L., Shaker-Naeni, H., & Press, D. A. (2017). Cognitive behaviour therapy versus a counselling intervention for anxiety in young people with high-functioning Autism Spectrum Disorders: A pilot randomised controlled trial. *Journal of Autism and Developmental Disorders*, 47(11), 3446–3457. <https://doi.org/10.1007/s10803-017-3252-8>
- Nah, Y. H., Brewer, N., Young, R. L., & Flower, R. (2018). Brief report: Screening adults with autism spectrum disorder for anxiety and depression. *Journal of Autism and Developmental Disorders*, 48(5), 1841–1846. <https://doi.org/10.1007/s10803-017-3427-3>

National Institute of Mental Health. (2018). Autism Spectrum Disorder.

<https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/>

National Autism Spectrum Disorder Surveillance System. (2018).

<https://www.canada.ca/en/public-health/corporate/mandate/about-agency/access-information-privacy/national-autism-spectrum-disorder-surveillance-system.html>

National Autism Spectrum Disorder Surveillance System Ontario Teacher's Federation.

(n.d.). Transition Plans. <https://www.teachspced.ca/transition-plans>

National Institute for Health and Care Excellence guidelines. (2021). Autism Spectrum Disorder in adults: Diagnosis and management.

<https://www.nice.org.uk/guidance/cg142>

National Professional Development Centre on Autism Spectrum Disorders. (n.d.). What are evidence-based practices? <https://autismpdc.fpg.unc.edu/evidence-based-practices>

Nicholas, D. B., Attridge, M., Zwaigenbaum, L., & Clarke, M. (2015). Vocational support approaches in autism spectrum disorder: A synthesis review of the literature. *Autism, 19*(2), 235–245. <https://doi.org/10.1177/1362361313516548>

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., Kapp, S. K., Weiner, M., & Boisclair, W. C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism: The International Journal of Research and Practice, 19*(7), 824–831. <https://doi.org/10.1177/1362361315576221>

Nilsson, B. M., & Ekselius, L. (2009). Acute and maintenance electroconvulsive therapy

for treatment of severely disabling obsessive-compulsive symptoms in a patient with Asperger syndrome. *The Journal of Electroconvulsive Therapy and Related Treatments*, 25(3), 205–207. <https://doi.org/10.1097/YCT.0b013e31819746bc>

Odom, S. L., Boyd, B. A., Hall, L. J., & Hume, K. (2010). Evaluation of comprehensive treatment models for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 40(4), 425–436. <https://doi.org/10.1007/s10803-009-0825-1>

Odom, S. L., Duda, M. A., Kucharczyk, S., Cox, A. W., & Stabel, A. (2014). Applying an implementation science framework for adoption of a comprehensive program for high school students with autism spectrum disorder. *Remedial and Special Education*, 35(2), 123–132. <https://doi.org/10.1177/0741932513519826>

Oswald, T. M., Winder-Patel, B., Ruder, S., Xing, G., Stahmer, A., & Solomon, M. (2018). A pilot randomized controlled trial of the ACCESS Program: A group intervention to improve social, adaptive functioning, stress coping, and self-determination outcomes in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(5), 1742–1760. <https://doi.org/10.1007/s10803-017-3421-9>

Owen, R., Sikich, L., Marcus, R. N., Corey-Lisle, P., Manos, G., McQuade, R. D., ... & Findling, R. L. (2009). Aripiprazole in the treatment of irritability in children and adolescents with autistic disorder. *Pediatrics*, 124(6), 1533–1540. <https://doi.org/10.1542/peds.2008-3782>

Pahnke, J., Lundgren, T., Hursti, T., & Hirvikoski, T. (2014). Outcomes of an acceptance

- and commitment therapy-based skills training group for students with high-functioning autism spectrum disorder: A quasi-experimental pilot study. *Autism*, 18(8), 953–964. <https://doi.org/10.1177/1362361313501091>
- Palmen, A., & Didden, R. (2012). Task engagement in young adults with high-functioning autism spectrum disorders: Generalization effects of behavioral skills training. *Research in Autism Spectrum Disorders*, 6(4), 1377–1388. <https://doi.org/10.1016/j.rasd.2012.05.010>
- Park, S. H., Song, Y., Demetriou, E. A., Pepper, K. L., Thomas, E. E., Hickie, I. B., & Guastella, A. J. (2020). Validation of the 21-item depression, anxiety, and stress scales (DASS-21) in individuals with autism spectrum disorder. *Psychiatry Research*, 291, 113300. <https://doi.org/10.1016/j.psychres.2020.113300>
- Park, S. H., Song, Y., 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>
- Pérez-Fuster, P., Sevilla, J., & Herrera, G. (2019). Enhancing daily living skills in four adults with autism spectrum disorder through an embodied digital technology-mediated intervention. *Research in Autism Spectrum Disorders*, 58, 54–67. <https://doi.org/10.1016/j.rasd.2018.08.006>
- Pfeiffer, B., Piller, A., Giazzoni-Fialko, T., & Chainani, A. (2017). Meaningful outcomes for enhancing quality of life for individuals with autism spectrum

- disorder. *Journal of Intellectual & Developmental Disability*, 42(1), 90–100.
<https://doi.org/10.3109/13668250.2016.1197893>
- Porter, C. M. (2016). Revisiting Precede-Proceed: A leading model for ecological and ethical health promotion. *Health Education Journal*, 75(6), 753–764.
<https://doi.org/10.1177/0017896915619645>
- Posey, D. J., Erickson, C. A., Stigler, K. A., & McDougle, C. J. (2006). The use of selective serotonin reuptake inhibitors in autism and related disorders. *Journal of Child & Adolescent Psychopharmacology*, 16(1-2), 181–186.
<https://doi.org/10.1089/cap.2006.16.181>
- Potes, A., Souza, G., Nikolitch, K., Penheiro, R., Moussa, Y., Jarvis, E., Looper, K., & Rej, S. (2018). Mindfulness in severe and persistent mental illness: A systematic review. *International Journal of Psychiatry in Clinical Practice*, 22(4), 253-261.
<https://doi.org/10.1080/13651501.2018.1433857>
- Rausch, J. L., Sirota, E. L., Londino, D. L., Johnson, M. E., Carr, B. M., Bhatia, R., & Miller, S. (2005). Open-label risperidone for Asperger's disorder: negative symptom spectrum response. *The Journal of Clinical Psychiatry*, 66(12), 13361.
<https://doi.org/10.4088/jcp.v66n1216>
- Rayan, A., & Ahmad, M. (2016). Effectiveness of mindfulness-based interventions on quality of life and positive reappraisal coping among parents of children with autism spectrum disorder. *Research in Developmental Disabilities*, 55, 185–196.
<https://doi.org/10.1016/j.ridd.2016.04.002>
- Raymaker, D. M., McDonald, K. E., Ashkenazy, E., Gerrity, M., Baggs, A. M., Kripke,

- C., Hourston, S., & Nicolaidis, C. (2017). Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism: The International Journal of Research and Practice*, *21*(8), 972–984. <https://doi.org/10.1177/1362361316661261>
- Reichow, B., Servili, C., Yasamy, M. T., Barbui, C., & Saxena, S. (2013). Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower-functioning autism spectrum disorders: A systematic review. *PLoS Medicine*, *10*(12), e1001572. <https://doi.org/10.1371/journal.pmed.1001572>
- Richards, J. (2012). Examining the exclusion of employees with Asperger syndrome from the workplace. *Personnel Review*. <https://doi.org/10.1108/00483481211249148>
- Richards, A. L., Walstab, J. E., Wright-Rossi, R. A., Simpson, J., & Reddihough, D. S. (2009). One-year follow-up of the outcome of a randomized controlled trial of a home-based intervention programme for children with autism and developmental delay and their families. *Child: Care, Health and Development*, *35*, 593–602. <https://doi.org/10.1111/j.1365-2214.2009.00953.x>
- Rogers, S. J., Estes, A., Lord, C., Vismara, L., Winter, J., Fitzpatrick, A., Guo, M., & Dawson, G. (2012). Effects of a brief Early Start Denver model (ESDM)-based parent intervention on toddlers at risk for autism spectrum disorders: a randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, *51*(10), 1052–1065. <https://doi.org/10.1016/j.jaac.2012.08.003>
- Rosales, R., & Whitlow, H. (2019). A component analysis of job interview training for

- young adults with autism spectrum disorder. *Behavioral Interventions*, 34(2), 147–162. <https://doi.org/10.1002/bin.1658>
- Rosen, T. E., Connell, J. E., & Kerns, C. M. (2016). A review of behavioral interventions for anxiety-related behaviors in lower-functioning individuals with autism. *Behavioral Interventions*, 31(2), 120–143. <https://doi.org/10.1002/bin.1442>
- Roser, M. E., Aslin, R. N., McKenzie, R., Zahra, D., & Fiser, J. (2015). Enhanced visual statistical learning in adults with autism. *Neuropsychology*, 29(2), 163. <https://doi.org/10.1037/neu0000137>
- Rossignol, D. A., & Frye, R. E. (2011). Melatonin in autism spectrum disorders: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, 53(9), 783–792. <https://doi.org/10.1111/j.1469-8749.2011.03980.x>
- Roth, M. E., Gillis, J. M., & DiGennaro Reed, F. D. (2014). A meta-analysis of behavioral interventions for adolescents and adults with autism spectrum disorders. *Journal of Behavioral Education*, 23(2), 258–286. <https://doi.org/10.1007/s10864-013-9189-x>
- Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., Edwards, A. D., Wei, X., McCracken, M., & Yu, J. W. (2015). Characteristics of two-year college students on the Autism Spectrum and their support services experiences. *Autism Research and Treatment*, 2015, 391693. <https://doi.org/10.1155/2015/391693>
- Roy, M., Prox-Vagedes, V., D Ohlmeier, M., & Dillo, W. (2015). Beyond childhood: psychiatric comorbidities and social background of adults with Asperger

syndrome. *Psychiatria Danubina*, 27(1), 0–59.

<https://pubmed.ncbi.nlm.nih.gov/25751431/>

Russell, A. J., Jassi, A., Fullana, M. A., Mack, H., Johnston, K., Heyman, I., Murphy, D. G., & Mataix-Cols, D. (2013). Cognitive behavior therapy for comorbid obsessive-compulsive disorder in high-functioning autism spectrum disorders: A randomized controlled trial. *Depression and Anxiety*, 30(8), 697–708.

<https://doi.org/10.1002/da.22053>

Sackett, D. L., Rosenberg, W. M., Gray, J. A., Haynes, R. B., & Richardson, W. S.

(1996). Evidence based medicine: what it is and what it isn't. *British Medical Journal (Clinical Research ed.)*, 312(7023), 71–72.

<https://doi.org/10.1136/bmj.312.7023.71>

Salazar, F., Baird, G., Chandler, S., Tseng, E., O'sullivan, T., Howlin, P., Pickles, A., & Simonoff, E. (2015). Co-occurring psychiatric disorders in preschool and elementary school-aged children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 45(8), 2283–2294.

<https://doi.org/10.1007/s10803-015-2361-5>

Santomauro, D., Sheffield, J., & Sofronoff, K. (2016). Depression in adolescents with ASD: A pilot RCT of a group intervention. *Journal of Autism and Developmental Disorders*, 46(2), 572–588. <https://doi.org/10.1007/s10803-015-2605-4>

Saulle, R., Sinopoli, A., De Paula Baer, A., Mannocci, A., Marino, M., De Belvis, A. G., Federici, A., & La Torre, G. (2020). The PRECEDE-PROCEED model as a tool in Public Health screening: A systematic review. *La Clinica Terapeutica*, 171(2),

e167–e177. <https://doi.org/10.7417/CT.2020.2208>

- Seaman, R. L., & Cannella-Malone, H. I. (2016). Vocational skills interventions for adults with autism spectrum disorder: A review of the literature. *Journal of Developmental and Physical Disabilities, 28*(3), 479–494. <https://doi.org/10.1007/s10882-016-9479-z>
- Shattuck, P. T., Roux, A. M., Hudson, L. E., Taylor, J. L., Maenner, M. J., & Trani, J. F. (2012). Services for adults with an autism spectrum disorder. *The Canadian Journal of Psychiatry, 57*(5), 284–291. <https://doi.org/10.1177/070674371205700503>
- Shea, N., Payne, E., & Russo, N. (2018). Brief report: Social functioning predicts externalizing problem behaviors in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(6), 2237–2242. <https://doi.org/10.1007/s10803-017-3459-8>
- Sheldrick, R. C., Neger, E. N., Shipman, D., & Perrin, E. C. (2012). Quality of life of adolescents with autism spectrum disorders: Concordance among adolescents' self-reports, parents' reports, and parents' proxy reports. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 21*(1), 53–57. <https://doi.org/10.1007/s11136-011-9916-5>
- Shipman, D. L., Sheldrick, R. C., & Perrin, E. C. (2011). Quality of life in adolescents with autism spectrum disorders: reliability and validity of self-reports. *Journal of Developmental and Behavioral Pediatrics: JDBP, 32*(2), 85–89. <https://doi.org/10.1097/DBP.0b013e318203e558>

- Siew, C. T., Mazzucchelli, T. G., Rooney, R., & Girdler, S. (2017). A specialist peer mentoring program for university students on the autism spectrum: A pilot study. *PloS One*, *12*(7), e0180854. <https://doi.org/10.1371/journal.pone.0180854>
- Singh, N. N., Lancioni, G. E., Singh, A. D., Winton, A. S., Singh, A. N., & Singh, J. (2011). Adolescents with Asperger syndrome can use a mindfulness-based strategy to control their aggressive behavior. *Research in Autism Spectrum Disorders*, *5*(3), 1103–1109. <https://doi.org/10.1016/j.rasd.2010.12.006>
- Singh, N. N., Lancioni, G. E., Winton, A. S., Karazsia, B. T., Myers, R. E., Latham, L. L., & Singh, J. (2014). Mindfulness-based positive behavior support (MBPBS) for mothers of adolescents with autism spectrum disorder: Effects on adolescents' behavior and parental stress. *Mindfulness*, *5*(6), 646–657. <https://doi.org/10.1007/s12671-014-0321-3>
- Siu, A. M. H., Lin, Z., & Chung, J. (2019). An evaluation of the TEACCH approach for teaching functional skills to adults with autism spectrum disorders and intellectual disabilities. *Research in Developmental Disabilities*, *90*, 14–21. <https://doi.org/10.1016/j.ridd.2019.04.006>
- Sizoo, B. B., & Kuiper, E. (2017). Cognitive behavioural therapy and mindfulness based stress reduction may be equally effective in reducing anxiety and depression in adults with autism spectrum disorders. *Research in Developmental Disabilities*, *64*, 47–55. <https://doi.org/10.1016/j.ridd.2017.03.004>
- Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric

properties and results of the international field trial. A report from the WHOQOL group. *Quality of life Research*, 13(2), 299–310.

<https://doi.org/10.1023/B:QURE.0000018486.91360.00>

Skevington, S. M., & McCrate, F. M. (2012). Expecting a good quality of life in health: assessing people with diverse diseases and conditions using the WHOQOL-BREF. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 15(1), 49–62. <https://doi.org/10.1111/j.1369-7625.2010.00650.x>

Skinner, B. F. (1953). Some contributions of an experimental analysis of behavior to psychology as a whole. *American Psychologist*, 8(2), 69.

<https://doi.org/10.1037/h0054118>

Slaughter, V., Imuta, K., Peterson, C. C., & Henry, J. D. (2015). Meta-analysis of Theory of Mind and peer popularity in the preschool and early school years. *Child Development*, 86(4), 1159–1174. <https://doi.org/10.1111/cdev.12372>

Smith, S. M., Bayliss, E. A., Mercer, S. W., Gunn, J., Vestergaard, M., Wyke, S., Salisbury, C., & Fortin, M. (2013). How to design and evaluate interventions to improve outcomes for patients with multimorbidity. *Journal of Comorbidity*, 10–17. <https://doi.org/10.15256/joc.2013.3.21>

Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal of Mental Retardation: AJMR*, 105(4), 269–285.

[https://doi.org/10.1352/0895-8017\(2000\)105<0269:RTOIEI>2.0.CO;2](https://doi.org/10.1352/0895-8017(2000)105<0269:RTOIEI>2.0.CO;2)

- Smith, T., & Iadarola, S. (2015). Evidence base update for autism spectrum disorder. *Journal of Clinical Child & Adolescent Psychology, 44*(6), 897–922. <https://doi.org/10.1080/15374416.2015.1077448>
- Souders, M. C., Zavodny, S., Eriksen, W., Sinko, R., Connell, J., Kerns, C., Schaaf, R., & Pinto-Martin, J. (2017). Sleep in children with autism spectrum disorder. *Current Psychiatry Reports, 19*(6), 1-17. <https://doi.org/10.1007/s11920-017-0782-x>
- Spain, D., & Blainey, S. H. (2015). Group social skills interventions for adults with high-functioning autism spectrum disorders: A systematic review. *Autism, 19*(7), 874–886. <https://doi.org/10.1177/1362361315587659>
- Spek, A. A., van Ham, N. C., & Nyklíček, I. (2013). Mindfulness-based therapy in adults with an autism spectrum disorder: a randomized controlled trial. *Research in Developmental Disabilities, 34*(1), 246–253. <https://doi.org/10.1016/j.ridd.2012.08.009>
- Spiers, N., Brugha, T. S., Bebbington, P., McManus, S., Jenkins, R., & Meltzer, H. (2012). Age and birth cohort differences in depression in repeated cross-sectional surveys in England: The National Psychiatric Morbidity Surveys, 1993 to 2007. *Psychological Medicine, 42*(10), 2047–2055. <https://doi.org/10.1017/S003329171200013X>
- Stoddart, K. P., Burke, L., Muskat, B., Manett, J., Duhaime, S., Accardi, C., Burnham Riosa, P., & Bradley, E. (2013). Diversity in Ontario's youth and adults with Autism Spectrum Disorders: Complex needs in unprepared systems. Toronto, ON: The Redpath Centre. <https://redpathcentre.ca/publications/>

- Storch, E. A., Arnold, E. B., Lewin, A. B., Nadeau, J. M., Jones, A. M., De Nadai, A. S., Jane Mutch, P., Selles, R. R., Ung, D., & Murphy, T. K. (2013). The effect of cognitive-behavioral therapy versus treatment as usual for anxiety in children with autism spectrum disorders: A randomized, controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry*, *52*(2), 132–142.
<https://doi.org/10.1016/j.jaac.2012.11.007>
- Sung, C., Connor, A., Chen, J., Lin, C. C., Kuo, H. J., & Chun, J. (2019). Development, feasibility, and preliminary efficacy of an employment-related social skills intervention for young adults with high-functioning autism. *Autism: The International Journal of Research and Practice*, *23*(6), 1542–1553.
<https://doi.org/10.1177/1362361318801345>
- Taylor, J. L., McPheeters, M. L., Sathe, N. A., Dove, D., Veenstra-Vanderweele, J., & Warren, Z. (2012). A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics*, *130*(3), 531–538.
<https://doi.org/10.1542/peds.2012-0682>
- Tordjman, S., Anderson, G. M., Pichard, N., Charbuy, H., & Touitou, Y. (2005). Nocturnal excretion of 6-sulphatoxymelatonin in children and adolescents with autistic disorder. *Biological Psychiatry*, *57*(2), 134–138.
<https://doi.org/10.1016/j.biopsych.2004.11.003>
- Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2. (2018). https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html
- Tsakanikos, E., Underwood, L., Kravariti, E., Bouras, N., & McCarthy, J. (2011). Gender

differences in co-morbid psychopathology and clinical management in adults with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(2), 803–808. <https://psycnet.apa.org/doi/10.1016/j.rasd.2010.09.009>

Turner, T. L., Balmer, D. F., & Coverdale, J. H. (2013). Methodologies and study designs relevant to medical education research. *International Review of Psychiatry (Abingdon, England)*, 25(3), 301–310. <https://doi.org/10.3109/09540261.2013.790310>

Turner-Brown, L. M., Perry, T. D., Dichter, G. S., Bodfish, J. W., & Penn, D. L. (2008). Brief report: feasibility of social cognition and interaction training for adults with high functioning autism. *Journal of Autism and Developmental Disorders*, 38(9), 1777–1784. <https://doi.org/10.1007/s10803-008-0545-y>

Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I., Cai, R. Y., Dissanayake, C., Richdale, A., & Trollor, J. (2020). Anxiety and depression from adolescence to old age in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 50(9), 3155–3165. <https://doi.org/10.1007/s10803-019-04084-z>

Ung, D., Selles, R., Small, B. J., & Storch, E. A. (2015). A systematic review and meta-analysis of cognitive-behavioral therapy for anxiety in youth with high-functioning autism spectrum disorders. *Child Psychiatry & Human Development*, 46(4), 533–547. <https://doi.org/10.1007/s10578-014-0494-y>

Van Heijst, B.F.C., & Geurts, H.M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism*, 19, 158–167. <https://doi.org/10.1177/1362361313517053>

Van Heijst, B. F., Deserno, M. K., Rhebergen, D., & Geurts, H. M. (2020). Autism and

- depression are connected: A report of two complimentary network studies. *Autism*, 24(3), 680–692. <https://doi.org/10.1177/1362361319872373>
- Van Rijn, R. M., Carlier, B. E., Schuring, M., & Burdorf, A. (2016). Work as treatment? The effectiveness of re-employment programmes for unemployed persons with severe mental health problems on health and quality of life: a systematic review and meta-analysis. *Occupational and Environmental Medicine*, 73(4), 275–279. <https://doi.org/10.1136/oemed-2015-103121>
- Vasa, R. A., Carroll, L. M., Nozzolillo, A. A., Mahajan, R., Mazurek, M. O., Bennett, A. E., ... & Bernal, M. P. (2014). A systematic review of treatments for anxiety in youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(12), 3215–3229. <https://doi.org/10.1007/s10803-014-2184-9>
- Vitiello, M. V., McCurry, S. M., Shortreed, S. M., Balderson, B. H., Baker, L. D., Keefe, F. J., Rybarczyk, B. D., & Von Korff, M. (2013). Cognitive-behavioral treatment for comorbid insomnia and osteoarthritis pain in primary care: The lifestyles randomized controlled trial. *Journal of the American Geriatrics Society*, 61(6), 947–956. <https://doi.org/10.1111/jgs.12275>
- Vogan, V., Lake, J. K., Tint, A., Weiss, J. A., & Lunskey, Y. (2017). Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction. *Disability and Health Journal*, 10(2), 264–270. <https://doi.org/10.1016/j.dhjo.2016.11.002>
- Wachtel, L. E., Hermida, A., & Dhossche, D. M. (2010). Maintenance electroconvulsive

therapy in autistic catatonia: a case series review. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, 34(4), 581–587.

<https://doi.org/10.1016/j.pnpbp.2010.03.012>

Wallace, G. L., Kenworthy, L., Pugliese, C. E., Popal, H. S., White, E. I., Brodsky, E., & Martin, A. (2016). Real-World Executive Functions in Adults with Autism Spectrum Disorder: Profiles of Impairment and Associations with Adaptive Functioning and Co-morbid Anxiety and Depression. *Journal of Autism and Developmental Disorders*, 46(3), 1071–1083. <https://doi.org/10.1007/s10803-015-2655-7>

Walsh, L., Lydon, S., & Healy, O. (2014). Employment and vocational skills among individuals with autism spectrum disorder: Predictors, impact, and interventions. *Review Journal of Autism and Developmental Disorders*, 1(4), 266–275. <https://doi.org/10.1007/s40489-014-0024-7>

Wang, X., & Cheng, Z. (2020). Cross-Sectional Studies: Strengths, Weaknesses, and Recommendations. *Chest*, 158(1, Supplement), S65–S71. <https://doi.org/10.1016/j.chest.2020.03.012>

Wang, Y. Y., Li, X. H., Zheng, W., Xu, Z. Y., Ng, C. H., Ungvari, G. S., Yuan, Z., & Xiang, Y. T. (2018). Mindfulness-based interventions for major depressive disorder: a comprehensive meta-analysis of randomized controlled trials. *Journal of Affective Disorders*, 229, 429–436. <https://doi.org/10.1016/j.jad.2017.12.093>

Warner, R. M. (2013). *Applied statistics: From bivariate through multivariate techniques*. Sage Publications.

- Wehman, P., Schall, C. M., McDonough, J., Graham, C., Brooke, V., Riehle, J. E., Brooke, A., Ham, W., Lau, S., Allen, J., & Avellone, L. (2017). Effects of an employer-based intervention on employment outcomes for youth with significant support needs due to autism. *Autism, 21*(3), 276–290.
<https://doi.org/10.1177/1362361316635826>
- Weiss, J. A., & Lunsky, Y. (2010). Group cognitive behaviour therapy for adults with Asperger syndrome and anxiety or mood disorder: a case series. *Clinical Psychology & Psychotherapy, 17*(5), 438–446. <https://doi.org/10.1002/cpp.694>
- Welch, C. D., & Polatajko, H. J. (2016). Applied behavior analysis, autism, and occupational therapy: A search for understanding. *The American Journal of Occupational Therapy, 70*(4), 7004360020p1–7004360020p5.
<https://doi.org/10.5014/ajot.2016.018689>
- Weston, L., Hodgekins, J., & Langdon, P. E. (2016). Effectiveness of cognitive behavioural therapy with people who have autistic spectrum disorders: A systematic review and meta-analysis. *Clinical Psychology Review, 49*, 41–54.
<https://doi.org/10.1016/j.cpr.2016.08.001>
- What Works Clearinghouse. (2020). What Works Clearinghouse Standards Handbook, Version 4.1. Washington, DC: U.S. Department of Education, Institute of Education Sciences, National Center for Education Evaluation and Regional Assistance. <https://ies.ed.gov/ncee/wwc/handbooks>.
- White, S. W., Lerner, M. D., McLeod, B. D., Wood, J. J., Ginsburg, G. S., Kerns, C., Ollendick, T., Kendall, P. C., Piacentini, J., Walkup, J., & Compton, S. (2015).

Anxiety in youth with and without autism spectrum disorder: examination of factorial equivalence. *Behavior Therapy*, 46(1), 40–53.

<https://doi.org/10.1016/j.beth.2014.05.005>

Wigham, S., Barton, S., Parr, J. R., & Rodgers, J. (2017). A systematic review of the rates of depression in children and adults with high-functioning autism spectrum disorder. *Journal of Mental Health Research in Intellectual Disabilities*, 10(4), 267–287. <https://doi.org/10.1080/19315864.2017.1299267>

Williams, K., Brignell, A., Randall, M., Silove, N., & Hazell, P. (2013). Selective serotonin reuptake inhibitors (SSRIs) for autism spectrum disorders (ASD). *The Cochrane Database of Systematic Reviews*, (8), CD004677. <https://doi.org/10.1002/14651858.CD004677.pub3>

Wink, L. K., Early, M., Schaefer, T., Pottenger, A., Horn, P., McDougale, C. J., & Erickson, C. A. (2014). Body mass index change in autism spectrum disorders: comparison of treatment with risperidone and aripiprazole. *Journal of Child and Adolescent Psychopharmacology*, 24(2), 78–82. <https://doi.org/10.1089/cap.2013.0099>

Wise, J. M., Cepeda, S. L., Ordaz, D. L., McBride, N. M., Cavitt, M. A., Howie, F. R., Scalli, L., Ehrenreich-May, J., Wood, J. J., Lewin, A. B., & Storch, E. A. (2019). Open trial of modular cognitive-behavioral therapy in the treatment of anxiety among late adolescents with autism spectrum disorder. *Child Psychiatry & Human Development*, 50(1), 27–34. <https://doi.org/10.1007/s10578-018-0817-5>

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., Brock, M.

- E., Plavnick, J. B., Fleury, V. P., & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders, 45*(7), 1951–1966. <https://doi.org/10.1007/s10803-014-2351-z>
- Wood, J. J., Ehrenreich-May, J., Alessandri, M., Fujii, C., Renno, P., Laugeson, E., Piacentini, J. C., De Nadai, A. S., Arnold, E., Lewin, A. B., Murphy, T. K., & Storch, E. A. (2015). Cognitive behavioral therapy for early adolescents with autism spectrum disorders and clinical anxiety: A randomized, controlled trial. *Behavior Therapy, 46*(1), 7–19. <https://doi.org/10.1016/j.beth.2014.01.002>
- Wood, B. M., Nicholas, M. K., Blyth, F., Asghari, A., & Gibson, S. (2010). The utility of the short version of the Depression Anxiety Stress Scales (DASS-21) in elderly patients with persistent pain: does age make a difference? *Pain Medicine, 11*(12), 1780–1790. <https://doi.org/10.1111/j.1526-4637.2010.01005.x>
- Woodman, R. W. (2014). The role of internal validity in evaluation research on organizational change interventions. *The Journal of Applied Behavioral Science, 50*(1), 40–49. <https://doi.org/10.1177%2F0021886313515613>
- World Health Organization Quality of Life User Manual. (1997). https://apps.who.int/iris/bitstream/handle/10665/77932/WHO_HIS_HSI_Rev.2?sequence=1
- World Health Organization Quality of Life Assessment: Position paper from the World Health Organization. (1995). *Social Science & Medicine, 41*(10), 1403–1409. [https://doi.org/10.1016/0277-9536\(95\)00112-K](https://doi.org/10.1016/0277-9536(95)00112-K)

- World Health Organization. (2022). *Mental Health*. https://www.who.int/health-topics/mental-health#tab=tab_1
- World Health Organization. (2017). *Depression and Other Common Mental Disorders: Global Health Estimates*. Geneva.
<https://apps.who.int/iris/bitstream/handle/10665/254610/WHO-MSD-MER-2017.2-eng.pdf>
- World Health Organization. (1946). Constitution of the World Health Organization. *American Journal of Public Health Nations Health*, 36(11), 1315–1323.
<https://doi.org/10.2105/ajph.36.11.1315>
- World Health Organization Quality of Life assessment: Position paper from the World Health Organization. (1995). *Social Science & Medicine* (1982), 41(10), 1403–1409. [https://doi.org/10.1016/0277-9536\(95\)00112-k](https://doi.org/10.1016/0277-9536(95)00112-k)
- World Health Organization Quality of Life (WHOQOL-BREF). (1996). Introduction, administration, scoring, and generic version of the assessment. Field trial version.
https://www.who.int/mental_health/media/en/76.pdf
- Xu, G., Strathearn, L., Liu, B., & Bao, W. (2018). Prevalence of autism spectrum disorder among US children and adolescents, 2014-2016. *Journal of the American Medical Association*, 319(1), 81–82. <https://doi.org/10.1001/jama.2017.17812>
- Yu, Q., Li, E., Li, L., & Liang, W. (2020). Efficacy of interventions based on applied behavior analysis for autism spectrum disorder: a meta-analysis. *Psychiatry Investigation*, 17(5), 432. <https://doi.org/10.30773/pi.2019.0229>
- Zhou, M. S., Nasir, M., Farhat, L. C., Kook, M., Artukoglu, B. B., & Bloch, M. H.

(2021). Meta-analysis: Pharmacologic treatment of restricted and repetitive behaviors in autism spectrum disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, 60(1), 35–45.
<https://doi.org/10.1016/j.jaac.2020.03.007>

Appendix: Study Questionnaire

PART I: About You

Please indicate who is filling out this form:

Person with autism

Parent/caregiver of person with autism

*If you are the parent/caregiver, please fill out this form **as you believe your child would answer.***

Please answer the following questions about yourself by selecting the correct answer or by filling in the space provided.

1. What is your gender? Male Female
2. What is your age in years? _____
3. What is your level of autism?
 - Level 1 (requiring support)
 - Level 2 (requiring substantial support)
 - Level 3 (requiring very substantial support)
4. What is your highest level of education?
 - High school or less
 - Postsecondary/College/University
5. What is your current relationship status? In a relationship Single
6. What is your current living status? Live on my own Live with my
family/caregivers
7. What is your current employment status?
 - Unemployed Employed (full time or part-time) Student
8. What is your current level of support?

I receive support from family/friends/social groups

I do not receive any support from family/friends/social groups

9. Are you currently ill or in poor health? Yes No

10. Do you currently have a mental health condition diagnosis? Yes No

Autism Interventions Use

Please indicate which of the following autism interventions you have ever used (in the *past or present*) to help manage your needs (Please choose all that apply):

1. Social skills training: Yes No

2. Mental health support (eg. psychologist, therapist, social worker, cognitive behavior therapy (CBT)): Yes No

3. Behavioral therapies (eg. Applied behavior analysis (ABA)): Yes No

4. Adaptive/Daily living skills (eg. personal hygiene, dressing, meal preparation, ability to shop): Yes No

5. Employment support (eg. interview skills, job skills, keeping a job): Yes No

6. Mindfulness (eg. yoga, meditation, breathing exercises, physical exercise): Yes No

7. Medications: Yes No

PART II: Quality of Life Questionnaire

Please read the question, assess your feelings, **over the last two weeks**, and **select the number on the scale** for each question that gives the best answer for you.

		Very Poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very Dissatisfied	Fairly Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the **last two weeks**.

		Not at all	A Small amount	A Moderate amount	A great deal	An Extreme amount
3	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5
6	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	Slightly	Moderately	Very	Extremely
7	How well are you able to concentrate?	1	2	3	4	5

8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

		Not at all	Slightly	Somewhat	To a great extent	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information you need in your daily life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Not at all	Slightly	Moderately	Very	Extremely
15	How well are you able to get around physically?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life over the over the **last two weeks**.

		Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very satisfied

16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Infrequently	Sometimes	Frequently	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety or depression?	1	2	3	4	5

PART III: Depression and Anxiety Questionnaire

Please read each statement and choose a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past two weeks**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree or a good part of time

3 Applied to me very much or most of the time

1 a	I was aware of dryness of my mouth	0	1	2	3
2 d	I couldn't seem to experience any positive feeling at all	0	1	2	3
3 a	I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
4 d	I found it difficult to work up the initiative to do things	0	1	2	3
5 a	I experienced trembling (e.g., in the hands)	0	1	2	3
6 a	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
7 d	I felt that I had nothing to look forward to	0	1	2	3
8 d	I felt down-hearted and blue	0	1	2	3
9 a	I felt I was close to panic	0	1	2	3
10 d	I was unable to become enthusiastic about anything	0	1	2	3
11 d	I felt I wasn't worth much as a person	0	1	2	3
12 a	I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	0	1	2	3
13 a	I felt scared without any good reason	0	1	2	3
14 d	I felt that life was meaningless	0	1	2	3

Thank you for taking the time to complete this survey

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