

**Utilizing ACT to Promote Resilience and Empower Parents/Caregivers in Navigating a
New Diagnosis of Autism Spectrum Disorder in their Children (over 6 years old)**

by

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Abstract

This capstone explores the experiences and support needs of parents and caregivers whose children are diagnosed with Autism Spectrum Disorder (ASD) after the age of six. Despite growing awareness and earlier identification, many families still face delays in diagnosis, emotional upheaval, and difficulty accessing clear, practical support. Through a comprehensive review of the literature, this project examines the psychological and emotional impacts of an ASD diagnosis on parents and families. This Capstone explores the role of psychoeducation and the application of Acceptance and Commitment Therapy (ACT), as a therapeutic intervention and seeks to determine the strengths and gaps in current support systems. The review also considers methodological and ethical issues in existing research. Findings highlight the importance of timely, accessible, and culturally sensitive psychoeducation, as well as ongoing mental health and peer support that meets the present and ongoing support needs of families. Recommendations include a two-step model: starting with foundational psychoeducation, followed by flexible, ACT-based supports that can adapt to each family's needs. Community involvement, regular feedback, and a strong ethical foundation are emphasized as essential for keeping programs relevant and empowering. This capstone underscores the need to include families' voices in designing and evaluating support and to address barriers so that families feel seen, supported, and equipped to navigate the journey after an ASD diagnosis.

Keywords: Autism Spectrum Disorder, post-diagnosis parent and caregiver support, psychoeducation, Acceptance and Commitment Therapy, family well-being

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Chapter 1: Introduction

After years of supporting children with Autism Spectrum Disorder (ASD) and their families, I have observed that while services primarily focus on helping children develop adaptive behaviours for community, academic, and home life, parents and caregivers rarely seek support for themselves, even when overwhelmed, frustrated, and/or struggling. In British Columbia, although the Autism funding provided by the Ministry of Family and Child Development's (MCFD) now includes family counselling for children under six (since April 2021), the reduction in funding for children over six—from \$22,000 to \$6,000—significantly limits access to individual and family therapy. These observations have sparked my interest and passion in understanding and supporting parents/caregivers through their journey: their experiences with new diagnoses, life changes, and impacts of ASD. Since parents and caregivers are often their children's main advocates, providing them with tools to support both their own and their children's well-being can greatly enhance the quality of life for the whole family.

This capstone focuses on the experiences of parents and caregivers whose children are diagnosed with ASD after age six, a threshold that aligns with the Ministry of Children and Family Development's (MCFD) funding model in British Columbia, Canada (MCFD, August 23, 2021). The study explores how different aspects of the diagnostic journey, including the pre- and during-diagnosis periods, shape overall parent and caregiver experiences. While the primary focus is on three key post-diagnosis themes: parental response, impacts, and support, the capstone also briefly addresses earlier stages to provide essential context, recognizing that these experiences are interconnected and collectively influence family adjustment and access to resources.

The exploration begins by identifying the research question that will be addressed throughout this investigation, followed by a brief justification for this inquiry. Then, the impact and contribution to the counselling field are provided along with the theoretical framework that shapes this Capstone. Finally, I reflect on my position in this process by providing context and acknowledging potential biases

Research Problem Statement

While there is research on the parent/caregiver and child experience throughout the diagnosis process, little is known about how post-diagnosis therapeutic supports can minimize negative experiences stemming from ASD diagnoses. The 2019 Canadian Health Survey on Children and Youth (CHSCY) revealed that ASD prevalence was highest among children aged 5-11 (2.5%), followed by those aged 12-17 (1.9%), then finally ages 1-4 (1.1%), suggesting a considerable number of diagnoses occur after age five (Public Health Agency of Canada, June 21, 2022). Given these statistics, the reduced ASD funding for children over the age of six in BC, and literature indicating reduced accessibility to support for parents/caregivers of children with delayed diagnoses, it is important to address this significant gap in knowledge for post-diagnosis support services.

A diagnosis at any time can impact the overall parenting experience. Strong evidence indicates that many parents/caregivers face heightened distress, grief, increased demands, and financial burdens, which can cause vulnerabilities to mental health complexities like depression and anxiety (Befi et al., 2013; Elder et al., 2016; Elder et al., 2017; Karst & Van Hecke, 2012; Lai & Oei, 2024; Vasilopoulou & Nisbet, 2016; Crane et al., 2016; Hayes & Watson, 2013; Almog et al., 2023). Unsupported parents/caregivers can potentially result in inadequately supported children. Even knowing that parents/caregivers often play a primary role in supporting

their children, minimal information is known on how to effectively support them post-diagnosis, especially for later ASD diagnoses in their children.

While peer-reviewed and reputable sources and literature are vital in gaining more knowledge on how to support parents/caregivers better, it is also important to consider existing local (Victoria, BC) services/resources (e.g. Victoria Society for Children with Autism - VSCA) and online platforms (e.g. Autism Community Training – ACT Community) that could aid in enhancing this research. Therefore, this capstone aims to address the question:

What are the most important components of a post-diagnosis support program for parents/caregivers navigating an ASD diagnosis of their child after the age of 6 that can most effectively support them?

By researching literature and integrating existing local and online resources, the foundations of a potential program can be developed that equips parents/caregivers with the knowledge, tools, and strategies to help them navigate the challenges that may come with raising a child with ASD.

Rationale/justification

The literature reveals a critical gap in effective support systems for parents/caregivers of children with ASD post-diagnosis. There are significant implications that show that parents/caregivers experience higher levels of distress and parenting stress compared to those managing other developmental disorders, affecting both caregiver and child physical and mental well-being (Befi et al., 2023; McCafferty & McCutcheon, 2020; Neece et al., 2023; Gindi et al., 2024). Historical inequities in resource access particularly impact low-resource settings and racial/ethnic minority populations (Lee et al., 2023; Neece et al., 2023). Limited social support

and poor family adjustment during and post-diagnosis can severely impact the family's quality of life (Gillberg et al., 2023; Rivard et al., 2022). Furthermore, grief and loss experiences in these families remain under-researched, with traditional grief models being insufficient in capturing the complex and continuous nature of this experience (Bravo-Benítez et al., 2019). Finally, the absence of concrete guidelines for navigating resources often leaves parents feeling lost, frustrated, and distressed (Rabba et al., 2020), potentially leading to family disharmony, divorce, decreased productivity, and social withdrawal (Befi et al., 2023).

More research is needed to support parents/caregivers raising children with ASD post-diagnosis. Gindi et al. (2024), mention that this could be implementing a support intervention group during the diagnostic process or offering it immediately after, which is seen as the critical period. This additionally allows for different ways to implement systemic, family-centered, potentially tailored, culturally appropriate, and inclusive support programs/systems that may be more generalizable to diverse families. (McCafferty & McCutcheon, 2020; Jamshidian et al., 2023).

Conversely, some studies highlight protective factors that enhance the family quality of life and posttraumatic growth (PTG) in parents/caregivers of children with ASD, such as family-centered support, mental health promotion, and early behavioural training (Rivard et al., 2022). Higher resilience and positive coping were associated with greater PTG and self-efficacy, emphasizing the need for psychological and emotional support post-diagnosis (Lu et al., 2022). Additionally, Mindfulness-Based Stress Reduction (MBSR), which shares similarities with Acceptance and Commitment Therapy (ACT) and is discussed in more detail later, has demonstrated positive associations with increased mental health and well-being for families (Neece et al., 2023). These insights illuminate several approaches that can target building

resilience and overall psychological and emotional well-being for parents/caregivers (Lu et al., 2022; Rivard et al., 2022).

Families in Victoria, BC, navigating an ASD diagnosis have access to a range of local service providers and online resources, including organizations like RISE Behaviour Services, Stepping Stones, Little Steps, FIVE Behaviour and Education, and Functional Learning and the Victoria Society for Children with Autism (VSCA). While these services offer valuable programs and support groups, information is often fragmented, inaccessible, and hard to find on program websites. Additional support is available through organizations such as the Victoria Disability Resource Centre, which lists free and affordable counselling options (Victoria Disability Resource Centre, n.d.). Online resources like Autism Support BC and ACT Community provide general guidance but often lack a focus on parent and caregiver mental health. Community support can also be found through local Facebook groups. However, despite the wealth of information available, it is dispersed, and the emphasis on child-focused support can make it challenging for families, especially for those without easy online access. This creates additional barriers to accessibility in finding appropriate support, and parental well-being needs may be overlooked.

Contribution to the Field of Counselling

This capstone addresses a significant gap in immediate support services for parents and caregivers during the post-diagnosis critical period. By focusing on this understudied area, this research can contribute to developing more effective, timely, and tailored interventions for families navigating the challenges of an ASD diagnosis, especially surrounding parent/caregiver mental health and well-being. Recognizing this gap underscores the important role counsellors and psychotherapists can play in supporting families during this crucial stage.

This in-depth research provides counsellors and psychotherapists with the opportunity to gain a deeper understanding of the unique challenges and needs of families post-ASD diagnoses, to offer more tailored and effective support. By identifying points of intervention, parents/caregivers who struggle can be equipped to develop and expand the protective factors that can enhance their ability to cope and enhance their resilience. (Rivard et al., 2022; Lu et al., 2022). Previous studies focused on mothers in Western cultures, therefore, this research will aim to be more culturally diverse and inclusive, flexible, and adaptable (e.g., to fathers, grandparents, etc.) to encourage more cultural competence in counselling practices. With an emphasis on family functioning and well-being, this research can also promote a more holistic approach to counselling and supporting these families by recognizing that the whole family system is interconnected, especially in the context of a new ASD diagnosis. Additionally, counsellors and therapists can enhance their support by offering better online resources or referrals through a centralized knowledge system, decreasing the time it could take to navigate multiple platforms.

Through addressing the current research problem, immediate support to parents/caregivers may be implemented following a diagnosis, which minimizes delays, potentially reduces stress, and increases the chance of adaptation. Focusing on resilience (an aspect of PTG) and protective factors can also support shifting the perspective and narrative to positive outcomes, growth, and empowerment rather than a deficit-based model. Providing effective support to the parents/caregivers can lead to improved overall family dynamics and family functioning, which ultimately can result in benefits to raising a child with ASD. Furthermore, exploring more parent-to-parent support models can decrease the chance of social isolation, where parents/caregivers foster and create more social connections, a sense of community, and reciprocal empowerment (Lee et al., 2023). While it seems that high-quality and

centralized web-based resources are available (Rabba et al., 2020), they seem to be limited in Victoria, BC, and the surrounding BC area. Addressing the overwhelming nature of resource navigation can lead to more efficient, effective, and tailored support services (2020).

This research can potentially have a significant impact on the field of counselling and psychotherapy by addressing gaps in knowledge and understanding and offer recommendations on how to support families post-diagnosis of those children over the age of six. By providing more immediate and informed support, parents/caregivers are resourced with the information they need and can avoid navigating the unknowns (Gillberg et al., 2023). This can promote positive outcomes by fostering community and social connections and addressing mental health and well-being challenges, while also considering cultural backgrounds and diverse family structures. Ultimately, by stabilizing the family environment and taking care of the parents/caregivers, their children with ASD will also be set up for success and a positive experience.

Theoretical framework

Acceptance and Commitment Therapy (ACT) will be the theoretical framework that grounds and guides this capstone. ACT is a third-wave therapy primarily developed by Steven Hayes that stems from Behavioural Therapy (first wave), and Cognitive Behavioural Therapy (second wave) (Prochaska & Narcross, 2018). In general, ACT uses a combination of Western (behavioural and cognitive therapies) and Eastern (mindfulness, noticing, accepting, etc.) perspectives and practices to support individuals (2018). The goal of ACT is to develop psychological flexibility by bringing awareness to oneself to decrease one's denial, avoidance, and struggle with inner emotions and instead accept that one's responses and feelings about certain situations are valid and appropriate (Hayes & Lillis, 2012). Through slow changes and

the development of this new mindset, the hope is individuals can begin to accept their distress and commit to making necessary changes to increase their quality of life (2012). ACT empowers individuals to no longer hide from the lows of life or ignore their emotions but to sit with these circumstances/feelings, process them, accept them, and continue moving forward. Individuals acknowledge that they are not their emotions and problems and that they are committing to themselves so that they can face and overcome life's trials.

To develop psychological flexibility, ACT focuses on 6 core processes: acceptance, cognitive defusion, being present, self-as-context, values, and committed action (Hayes & Lillis, 2012). Along with supporting individuals in different ways to move away from suppressing and controlling their painful emotions (behavioural change), they are also learning to accept their emotions and experiences (2012). Often, these core processes do not need to be done in order; they can be done following what is most important currently to the individual (Caufield, 2023). By honouring the diverse needs and nature of families and children with ASD, parents/caregivers can decide what priorities are important presently and employ the most appropriate strategies. With MBSR having similar elements to ACT and showing improvements in family mental health and well-being (Neece et al., 2023), this can be an opportunity to equip families with the tools to increase their resilience, self-efficacy, acceptance (to what cannot be changed, i.e. an ASD diagnosis) and other limited areas of psychological inflexibility. ACT will not only bring empowerment and agency back to the parents/caregivers (choice of which strategies to use based on their experience) but also be flexible and adaptable for different cultural contexts and different types of caregivers (e.g. fathers, grandparents, etc.).

Approaching the literature review and research through the lens of Acceptance and Commitment Therapy (ACT) provides a framework that aligns with ACT's core principles, such as fostering acceptance among parents and caregivers of children with ASD. Each core process of ACT can address specific challenges faced by parents and caregivers, for example, cognitive defusion and present-moment awareness can help manage distress and fear of the unknown, while acceptance, self-as-context, and values-based processes can support coping with grief and shifts in self-identity. Furthermore, interpreting information through both Western and Eastern perspectives within ACT enhances the adaptability of program development, ensuring strategies are relevant and supportive for multicultural and diverse populations. Importantly, the goal of ACT is not to "cure" families or children of their diagnoses, but to empower them to pursue growth, gain new knowledge, and learn to coexist with circumstances that cannot be changed. By adopting ACT's strengths-based and inclusive perspective, research can facilitate empowerment, resilience, adaptability, and a growth mindset while prioritizing diversity and inclusivity.

Positioning statement

My passion for this research topic comes from nearly eight years of supporting children with ASD and their families. After starting in front-line work, I moved into administrative and management roles, working more closely with parents and caregivers. This experience exposed me to the many challenges families face after a new diagnosis, including a lack of information, difficulty accepting the diagnosis, overwhelming stress, and especially caregiver burnout due to minimal self-care. It was heartbreaking to see the primary supporters of these children neglect their own needs, ultimately impacting the quality of care their children received. Through my capstone research, I hope the insights gathered will help illuminate a path towards potential

resources and tools for parents and caregivers, by empowering them, strengthening their resilience, and enabling them to better support both themselves and their children.

Before coming into this profession, personally and academically, this was not a topic I encountered often. I am a first-generation Chinese (Hong Kongese) Canadian, cisgender, heterosexual, middle-class woman in her early thirties and settler on the lands of the Songhees, Esquimalt, and WSÁNEĆ peoples. My worldview is informed by my family teaching me through Collectivist values, while my education/schooling/social connections taught me Individualistic values. I hold a mix of both values and see myself as “in-between” (Fang & Huang, 2020). The value of education and problem-solving was one of the most significant impacts my family has had on me, and therefore, I have strived to always seek out more knowledge and learned the value of maintaining a growth mindset. Due to my family not being as emotionally expressive with each other, we have always valued problem-solving, as that has always decreased conflict. Knowing these prominent influences also guides how I approach this research, perceive and understand data and results, and interpret information.

My main influence and motivation for pursuing this topic is the experience that I have had at work, and seeing the impact of tailored support and knowledge, which sets both the parents/caregivers and children up for success. However, I am also aware that I bring biases through this experience because I truly want to find ways to support these families and may encounter some confirmation bias. My inherent drive to solve problems will also need to be reined in, as that amplifies my desire to support these families and find solutions. Additionally, I lack the lived experience of being a parent/caregiver raising a child with ASD in addition to being a service provider for this population. Furthermore, I want to acknowledge that not all families and children struggle in this population and to remember to highlight strengths while

addressing struggles. I must be mindful that while I may find many supporting articles and evidence, I must also be critical when analyzing the information, not take all findings at face value, and keep my mind open and curious about different possibilities and ways of improvement. Finally, I recognize that realistically, this capstone will only be the start of the potential impact and support I hope to bring to this population.

Definition of Key Terms

Autism/Autism Spectrum Disorder (ASD): within the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), it is classified as a lifelong neurodevelopmental disability that includes stretches in social communication and restrictive/repetitive behaviours (Autism Speaks Canada, n.d.).

Cope/Coping: thoughts and behaviours that are utilized to manage internal and external stressful situations. Coping is often considered conscious and voluntary (Algorani & Gupta, April 24, 2023).

Empower/Empowerment: promoting the process of providing the proper tools, resources, and environment to build, develop, and increase the ability and effectiveness to define and reach an individual's goals (Haddad, & Toney-Butler, 2024).

Protective factors: defined as behavioural, genetic, psychological, environmental, or other characteristics that are associated with decreased probability of a particular disease, disorder, or situation developing or occurring within an individual. It often mitigates the effects of stress (APA Dictionary of Psychology, April 19, 2018).

Psychoeducation: is a strategy for teaching individuals about mental health disorders, informing and providing knowledge about what is happening, to provide more understanding and context. This also includes treatment, personal coping techniques, and resources. (Chan, 2011).

Psychological Flexibility: is the process of contacting the present moment fully as a conscious human being and persisting or changing behaviour that is still true to one's core values. (Hayes & Lillis, 2012)

Resilience: the process and outcome of successfully adapting to difficult or challenging life experiences. This is through mental, emotional, and behavioural flexibility and adjustment to external and internal demands (APA Dictionary of Psychology, April 19, 2018).

Wellbeing: is a multi-dimensional and holistic concept that relates to one's emotions, behaviours, cognition, and relationships to their quality and satisfaction with life. (Jarden & Roache, 2023)

Outline of Chapters

In the rest of the capstone, Chapter Two will first lay out the historical context and current definition of ASD and then comprise of a comprehensive literature review, exploring current research on parental/caregiver experiences, the impacts of an ASD diagnosis, and the effectiveness of various supports (including supports locally in Victoria, BC), with particular attention to ACT- and mindfulness-based approaches. This chapter will also critically examine the methodologies and ethical considerations present in the literature and identify limitations and gaps. In Chapter Three, key findings and themes will be discussed and then transformed into practical recommendations through an ACT lens that can better aid these families. Finally, future recommendations and directions will be proposed that can inform more effective, ethical, and

inclusive support for families navigating an ASD diagnosis. This capstone will lay the foundations for developing a program that empowers parents/caregivers, enhances family well-being, and addresses current gaps in support.

Chapter Two: Literature Review

Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by persistent challenges in social communication and interaction, alongside restricted and repetitive behaviours, interests, or activities (American Psychiatry Association [APA], 2022). Over the past few decades, the understanding of ASD has evolved significantly, driven by changes in diagnostic frameworks, increased awareness of its diversity, and growing recognition of research limitations. Given these changes, it is important to contextualize how our understanding of ASD has become more nuanced over time. It is equally essential to highlight how ASD is currently defined in the fifth text revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) and the eleventh edition of the International Classification of Diseases and Related Health Problems (ICD-11). Both are standardized classification systems used by clinicians, researchers, and healthcare professionals worldwide: the DSM-5-TR for diagnosing and categorizing mental health disorders, and the ICD-11 for all diseases and health conditions (Regier et al., 2013).

This literature review will begin by outlining the historical changes in ASD definitions and current diagnostic frameworks in the DSM-5-TR and ICD-11. It will then examine the global and Canadian prevalence of ASD, before focusing on the experiences of parents and caregivers throughout the diagnostic journey (pre-, during, and post-diagnosis). This also includes the impact of diagnosis and the supports available, with particular attention to resources in Victoria, British Columbia. The review will also explore emerging research on supporting parents/caregivers, highlighting protective factors such as resilience and the application of

Acceptance and Commitment Therapy (ACT) and mindfulness-based practices. Finally, ethical and cultural considerations in supporting families affected by ASD will be discussed.

A Historical and Current Perspective of ASD

In the past seventy years, the conceptualization and understanding of ASD have changed drastically. This includes diagnostic understanding, shifts in misconceptions, emerging insights, and acknowledgment of research limitations (Skuse, 2020). Once narrowly and inaccurately defined as a rare childhood disorder, ASD is now the focus of extensive research, increased public awareness, active advocacy, and broader recognition (Lord et al., 2018). In the early 1950s, some clinicians speculated that Autism was related to childhood schizophrenia (Bender, 1946). It was not until the 1970s that Autism was considered a defined neurological disorder in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III; Volkmar et al., 2005). In the DSM-IV (in 1994), Asperger syndrome (named after Hans Asperger) and other developmental disorders existed as subtypes alongside ASD (Barhona-Correa & Filipe, 2016). However, these were taken out due to inconsistencies and difficulties between the diagnosis of Autism or Asperger's, including limited biological evidence that supported a clear distinction between the two (Macintosh & Dissanayake, 2004). There was insufficient evidence to support the distinction between Autism and Asperger's (Barhona-Correa & Filipe, 2016), even Asperger's own cases would not qualify for an Asperger's diagnosis in the DSM-IV (Miller & Ozonoff, 1997).

At the same time as the DSM, the International Classification of Diseases and Related Health Problems (ICD) also underwent several revisions regarding ASD. The ICD-8 (1967) first mentioned Autism, but it was under the schizophrenia category as "infantile autism" (Ousley & Cermak, 2015). In 1978, the ICD-9 still recognized Autism as "infantile autism" but shifted into

the category of childhood psychotic conditions (Volkmar et al., 2005). In 1994, the ICD-10 formally recognized Autism as a disorder under pervasive developmental disorders, while also including Asperger syndrome as well, being in line with the DSM-IV at the time (2005).

Presently, the DSM-5-TR (2022) and ICD-11 (2024) both describe ASD similarly: a neurodevelopmental condition with onset in early childhood (American Psychiatry Association [APA], 2022; World Health Organization [WHO], 2024). The two main core symptom domains are emphasized as (1) persistent deficits in social communication and interaction, and (2) restricted, repetitive patterns of behaviour, interests, or activities (APA, 2022; WHO, 2024). Some specific and common symptoms include difficulties in social-emotional reciprocity, challenges in nonverbal communication (e.g. recognizing social cues), difficulty developing and maintaining relationships, stereotyped movements or speech (i.e. “stimming”), rigid behaviours/routines, highly focused interests, and sensory sensitivities (APA, 2022; WHO, 2024).

Both classifications note that symptoms may not become fully noticeable until demands (e.g. social demands) exceed the individual's current capabilities (APA, 2022; WHO, 2024). This often may cause significant functional impairment and can vary in presentation across the lifespan (APA, 2022; WHO, 2024). The ICD-11 and DSM-5-TR both acknowledge the wide spectrum of the presentation of ASD, noting varying levels of severity, intellectual abilities, and language skills (APA, 2022; WHO, 2024). While there are minor differences in organization and terminology, both systems provide a consistent framework for understanding and diagnosing ASD, emphasizing its lifelong nature and other conditions that may co-occur (APA, 2022; WHO, 2024).

As more research surfaces, ASD is no longer seen as a rare condition, largely due to changes in diagnostic definitions and increased awareness of the diversity within the autism “spectrum” (Skuse, 2020). This shift has led to a more nuanced understanding of ASD, moving beyond limited and outdated definitions. As a result, stereotypes from older classification systems, such as the belief that autism primarily affects males or is always associated with intellectual disability, are being dismantled (Lord et al., 2018; Werling & Geschwind, 2013). These misconceptions have contributed to underdiagnosis in intellectually able individuals, females, and those with subtler autistic traits (Mandy et al., 2012). Other outdated ideas, such as autistic individuals lacking interest in social relationships or the overestimation of epilepsy rates, are also being challenged (Hauck et al., 1995; Lukmanji et al., 2019). In reality, many autistic individuals desire social connections, autistic traits exist on a continuum in the general population, and people may develop compensatory behaviours, such as “camouflaging” or “masking,” which is more common in females (Skuse et al., 2009; Hull et al., 2017). Despite advances, research has yet to identify a definitive genetic marker or a single symptom that confirms or rules out autism (Robinson et al., 2016). Overall, the understanding of ASD remains complex, and ongoing research continues to refine its core features and underlying biology (2016).

Prevalence

As the conceptualization of ASD has evolved, reported prevalence rates have increased. In the 1990s, combined subtypes yielded a prevalence of about 0.6% (Chakrabarti & Fombonne, 2001). This rise is largely attributed to changes in diagnostic definitions and greater awareness of the spectrum’s diversity (Skuse, 2020). The prevalence varies worldwide and tends to be higher

in regions like North America, where diagnostic services are more accessible (Fombonne, 2020; Lord et al., 2018).

According to the DSM-5-TR, 1-2% of the population (both children and adults) in the United States are reported to have a diagnosis of ASD (APA, 2022). This breaks down accordingly as African American (1.1%) and Latinx children (0.8%), prevalence appears to be lower than Caucasian children (1.3%) (2022). However, the DSM-5-TR notes that the reported prevalence of ASD may be affected by misdiagnosis, delayed diagnosis, or underdiagnosis of individuals from different cultural backgrounds (2022). Across non-U.S. countries, the prevalence approaches 1% of the population without significant variation based on geographical region or ethnicity (2022). In terms of the male and female ratio, globally, it is mentioned to be 3:1 with concerns about the under-recognition of ASD in women and girls (2022). However, as old stereotypes, such as the belief that ASD is primarily a male condition (Werling & Geschwind, 2013), are gradually dismantled, awareness of the diverse manifestations of ASD continues to grow. As recognition improves, the male-to-female ratio in reported diagnoses may shift in the future, with more females likely to be accurately identified.

For further data on prevalence, Talantseva et al. (2023) performed a three-level meta-analysis on the worldwide prevalence of ASD and found evidence suggesting that higher estimates occurred (1) when studies used a records-review surveillance design, (2) in North America compared to other geographical regions, (3) in higher-income compared to lower-income countries, and (4) that the highest prevalence rates were registered in the USA. For ages, there was a higher significant percentage in children aged between 6-12 (0.82%) compared to children under 5 (0.57%) and older than 13 (0.57%) (2023). Similarly, and specifically in Canada, the 2019 Canadian Health Survey on Children and Youth (CHSCY) revealed that ASD

prevalence was highest among children aged 5-11 (2.5%), followed by those aged 12-17 (1.9%), then finally ages 1-4 (1.1%) (Public Health Agency of Canada, June 21, 2022). This information suggests that more diagnoses occur after age five in North America and potentially worldwide. Knowing that most diagnoses occur after the age of five highlights the increased need for support, particularly for parents and caregivers during this critical period.

Current Understanding of the Parent Experience

The process of diagnosing ASD in children is a deeply complex and emotionally challenging journey for families. These challenges can influence and shape the well-being and future outcomes of both the children and their parents/caregivers. This journey begins before and during the diagnosis, where the families' experiences often affect their post-diagnosis responses, which include dilemmas around diagnosis disclosure, feelings of distress and grief, and shifts in parenting identity. The quality of support parents/caregivers receive after the diagnosis also plays a major role in shaping these impacts, as tailored support can help families properly adapt and build resilience. While local (e.g. in Victoria, BC) and many online resources are available and are meant to support families, navigating through vast amounts of information during this stressful time can cause more overwhelm and confusion.

Pre-/During Diagnosis

Pre-diagnosis and diagnosis experiences play a significant role in shaping outcomes after the diagnosis. The common theme revealed in multiple studies shows that the diagnosis process is extremely lengthy and stressful (Crane et al., 2016; Smith-Young et al., 2020; Rutherford et al., 2018). Emotional and logistical challenges are described in Crane et al. (2016) and Rutherford et al. (2018)'s research when parents/caregivers are faced with prolonged assessment

periods, while Smith-Young et al. (2020) highlight the frustration and anxiety caused by long wait times and repeated appointments.

Smith-Young et al. (2020) and Goin-Kochel et al. (2006) describe that a confirmed diagnosis typically requires numerous visits to healthcare professionals to rule out other possible conditions. Research also shows that even when parents first report suspicion about ASD sometimes as early as the first 12 months, healthcare providers say to “not worry about” common features such as delayed language or social withdrawal, attributing them to normal variation or shyness (Elder et al., 2017; De Giacomo & Fombonne, 1998; Lord et al., 2006; Elder et al., 2016). While best practice guidelines recommend a maximum wait time of 5 months between initial referral and diagnosis, studies consistently report that the average time between initial concerns and formal diagnosis is typically between 2 and 4 years (Smith-Young et al., 2020; Kalkbrenner et al., 2011; Siklos & Kerns, 2007).

In a large-scale survey conducted by Dr. Laura Crane and colleagues in 2016, researchers from Goldsmiths, University of London, examined the diagnostic experiences of over 1,000 parents of children with ASD in the United Kingdom. The sample included parents (mean age 43.4 years; 93% female; 95% white identifying) of children (mean age 11.8 years; 80% male, 18% female) diagnosed with ASD. The study found that, even when parents first noticed developmental concerns early on (with 17% noting problems by age 1, 34% by age 2, and 33% between ages 2–5), the average age at which they sought professional help was 3.9 years, with 72% seeking help before their child’s sixth birthday. These results suggest that parents typically waited at least a year after first concerns before consulting professionals. Additionally, Crane et al. reported an average delay of approximately 3.5 years from the time parents first approached a health professional to the confirmation of an autism diagnosis. The study also highlighted

widespread parental dissatisfaction with the diagnostic process and post-diagnostic support, emphasizing the emotional and logistical challenges families face

In general, research consistently shows that an earlier diagnosis of ASD is associated with higher parental and caregiver acceptance, lower stress levels, and greater opportunity to develop effective coping strategies (Woolley et al., 1989). In 1989, Woolley et al. observed that parents who received an early diagnosis reported greater acceptance and lower psychological distress. Early identification also enables families to access tailored support and interventions sooner, which can help reduce anxiety and uncertainty during the diagnostic process (Crane et al., 2016; Elder et al., 2017). These early interventions are associated with more significant improvements in children's cognition, language, adaptive behaviour, daily living skills, and social functioning (Elder et al., 2017; Zwaigenbaum et al., 2015; Dawson et al., 2010; Vivanti et al., 2016; Remington et al., 2007). For instance, Zwaigenbaum et al. (2015) and Dawson et al. (2010)'s research revealed that children who received intervention before the age of two experienced greater improvements in language and adaptive skills compared to those who started later. Therefore, earlier diagnoses not only improve outcomes for children but also provide better overall support for families navigating the challenges of ASD.

With studies showing that delays and lengthy processes of diagnoses are a reality for families, this is a problematic barrier for parents/caregivers and children to receive support (Elder, 2016; Elder et al., 2017; Webb et al., 2014). The delays in support impede intervention effectiveness and can increase parental/caregiver distress through prolonged uncertainty and insufficient support systems, potentially leading to compound negative outcomes for both parents/caregivers and children (Elder, 2016; Elder et al., 2017; Webb et al., 2014). Therefore, delayed diagnoses may lead to detrimental consequences for the children and their families.

Post-Diagnosis Parent Response

Parent/caregiver responses to their child's ASD diagnosis can manifest in various ways, each closely tied to the resulting impacts on family well-being. Several studies have reported that parents/caregivers often experience certain realizations, a sense of relief, feelings of acceptance, and sometimes denial following the diagnosis (Befi et al., 2023; Crane et al., 2016; Abott et al., 2013; Elder et al., 2017; Cappe et al., 2011; Elder & D'Alessandro, 2009; Elder et al., 2016; Elder, 2016; Hayes & Watson, 2013). Abbott et al. (2013) found that a common realization among parents is the understanding that ASD is a lifelong developmental disorder, which can evoke both relief and anxiety about what the future holds. Relief is frequently reported when families finally receive an explanation for their child's behaviours, validating concerns and alleviating uncertainty (Abbott et al., 2013; Elder et al., 2017). Crane et al. (2016) and Cappe et al. (2011) further note that, while some families readily accept the diagnosis, others may initially respond with denial or seek alternative explanations. This search for answers can leave families vulnerable to misinformation or unsupported claims about "cures" for Autism (Elder et al., 2016; Elder et al., 2017; Elder, 2016; Hayes & Watson, 2013). Overall, the literature reveals that the emotional response to an ASD diagnosis is multifaceted and can significantly influence how families adapt and seek support.

Diagnosis Impacts

The parent/caregiver responses are deeply intertwined with the impacts they experience, often giving rise to dilemmas of diagnosis disclosure, emotional distress, grief, identity shifts, and increased caregiving demands (Almog, 2023; Befi et al., 2023; Elder et al., 2016; Elder et al., 2017; Karst et al., 2012; Lai & Oei, 2014; Vasilopoulou & Nisbet, 2016). Existing literature highlights the complexity and diversity of these experiences. Elder et al. (2016, 2017) and Karst

et al. (2012) found that parents often report heightened stress, changes in family dynamics, and struggles with their own identity as caregivers. Additionally, Lai and Oei (2014) and Befi et al. (2023)'s research describes how these emotional responses can be compounded by societal stigma and limited support systems. However, it is important to recognize that these studies also identify key areas where these systems of support can be strengthened or developed to better equip families for success

Dilemmas often relate to how ASD is invisible in nature, the stigma of the diagnosis, the child's environment, the act of the disclosure itself, the child's personal narrative of how they see themselves and their developing self-concept (Almog et al., 2023). Many parents often go through a long, complex, and ongoing process of internalizing and coming to terms with their child's diagnosis (Almong et al., 2023; Crane et al., 2019). Almong et al. (2023) presents a Diagnosis Disclosure Dilemmas Model that helps individuals understand and frames the main themes as to what may hinder or promote parents in disclosing:

(1) Autism In/Visibility and the Un/Known – if one cannot see it, there is no reason to tell (hindering factor) versus if one can see it and does not know what it is, then it is a problem (promoting factor)

(2) The word “Autism” and its stigma – the generalization of the whole spectrum under one word (hindering factor) versus disclosing in a positive context before the child learns its negative connotations and stigma (promoting factor)

(3) Too early or too late – the fear of lack of maturity, child's difficulty in understanding their diagnosis and potential withdrawal and avoidance (hindering factor) versus fear of the regression in behaviour in adolescence (promoting factor)

(4) Those who already know/do not know – difficulties in disclosing to others (hindering factor) versus sharing with others to create beneficial and positive experiences (promoting factor)

(5) Why and how – often lack of professional knowledge, support, and interventions (hindering factor) versus the drive to build complete and positive narratives for their child (promoting factor).

Parents/caregivers can feel an abundance of potentially conflicting emotions and themes when dealing with disclosures. This framework can provide powerful insight to professionals and how they can potentially support these families.

On top of the distress caused by dilemmas and diagnosis disclosure, parents/caregivers also frequently experience heightened distress through increased levels of stress, fatigue, and isolation due to the extra challenges that come with raising a child with ASD (e.g. repetitive behaviours, difficulty in communication and understanding) which affect not only the child but also the whole family system (Befi et al., 2023; Elder et al., 2016; Elder et al., 2017; Karst & Van Hecke, 2012; Lai & Oei, 2014; Vasilopoulou & Nisbet, 2016). Elder et al. (2016, 2017) and Karst & Van Hecke (2012) found that parents report increased daily stress and feelings of social withdrawal, while Befi et al. (2023) and Vasilopoulou & Nisbet (2016) emphasize the burnout associated with persistent caregiving demands. These additional pressures can lead to family disharmony, disharmony in the family, and even increased risk of divorce, as shown in research by Brobst et al. (2019) and Nurhastuti & Fatmawati (2018).

Families may also experience financial burdens, as interventions and therapies cost extra (Befi et al., 2013; Elder et al., 2017). Emotional impacts are further amplified by fears about the unknown future, including vulnerability to depression and anxiety, as Fernández-Alcántara et al.

(2016), Russel & Norwich (2012), Crane et al. (2016), and Hayes & Watson (2013) describe. All of these studies provide insight into the challenges associated with raising a child with ASD, affecting not only the child but the entire family's emotional, social, and financial well-being.

Every parent/caregiver will react differently to receiving and accepting their child's ASD diagnosis. While some parents/caregivers may express relief in finally having an answer after experiencing uncertainty during the lengthy diagnosis process, other parents/caregivers may experience the grieving process of: denial, anger, depression, and acceptance (Elder et al., 2017; Elder et al., 2009; Ross & Kessler, 2007). Elder et al. (2017, 2009) and Ross & Kessler (2007) describe how parents often go through a cycle of these stages, with many reporting a sense of loss regarding their original expectations for their child's future. Elder et al. (2017) elaborate that this adjustment process often involves revisions of hopes and plans, adjustments, and considerations, like their child's potential future plans.

Anger is commonly reported, and especially intensified when parents/caregivers question, "Why us? Why our child?" Elder et al. (2017) emphasize that supportive professionals should recognize that anger is a natural part of the grieving process, rather than a sign of maladjustment. Similarly, Befi et al. (2023) and Fernández-Alcántara et al. (2016) highlight that parents must reconcile their dreams for their children with the realities of an ASD diagnosis. This process can be emotionally taxing, but can also lead to eventual acceptance and resilience (Befi et al., 2023). As these emotional responses unfold, additional challenges and responsibilities can accumulate, adding further layers to the already complex experience faced by parents/caregivers.

Another challenge that may arise is a decrease in parenting self-efficacy and/or parents/caregivers' confidence in their ability to parent successfully (Befi et al., 2023; Smart, 2016; Jones & Prinz, 2005). Befi et al. (2023) and Smart (2016) observed that lower self-efficacy

is linked to increased stress and uncertainty in managing challenging behaviors, while Jones & Prinz (2005) discuss how this can decrease parents' confidence in their ability to parent successfully. Fields (2006) reports that since children with ASD may struggle more with difficult and rigid behaviours, parents/caregivers may experience more failure and frustration when utilizing more "typical" parenting strategies. In public settings, parents may feel social pressure to have their child conform to norms and may experience criticism or blame when their child's behaviors differ (Ryan, 2010; Smart, 2016). In public, parents/caregivers may feel more socially pressured to have their child conform to public social expectations and can feel criticized and rejected when their child behaves contrary to societal norms (Ryan, 2010). This results in parents/caregivers feeling like they are to blame for these behaviours (Smart, 2016).

In contrast, higher levels of self-efficacy in parents/caregivers are often seen with more engagement and persistence in difficult situations with their children, along with it being a predictor of greater mastery of parenting beliefs, more favorable co-parenting relationships, and less psychological distress (Li et al., 2023; Bandura 2001; Almendingen & Pilkington, 2024). However, Li et al. (2023) and Bandura (2001) mention that it can be difficult to achieve this when parents/caregivers are often in a state of self-doubt, confusion, and frustration when tough behaviours arise. Overall, how an ASD diagnosis can impact a family can vary greatly, so it is essential for supporting professionals to recognize and respect the diversity of each family's experience by considering all possible factors.

Post-Diagnosis Parent Support

The quality and consistency of post-diagnosis support significantly impact the overall parenting/caregiving experience, regardless of diagnosis timing. In several studies, many parents report receiving only generic referrals (e.g. general list of service providers) and minimal

guidance, with some encountering inattentive professionals (Crane et al., 2016; Elder et al., 2017; Elder, 2016). As described by Crane et al. (2016) and Elder et al. (2017), the lack of individualized support can potentially amplify parental distress and grief, which leaves families feeling overwhelmed and isolated. Insufficient post-diagnostic guidance may contribute to more uncertainty and difficulty accessing appropriate resources in an already frustrating circumstance (Elder, 2016).

In comparison, research consistently shows that tailored support, like family counseling, specialized interventions like Applied Behaviour Analysis (ABA), and strong parent-professional relationships can improve outcomes for both parents and children. Crane et al. (2016) and Elder et al. (2017) observed that parents who accessed collaborative care teams and received individualized intervention plans reported greater satisfaction and reduced stress. Befi et al. (2023) and Osborne et al. (2008) emphasize the importance of ongoing professional guidance and peer support, which help families develop adaptive coping strategies and foster resilience. Furthermore, Solomon & Chung (2012) and Brogan & Knussen (2003) demonstrate in their studies that access to evidence-based interventions, such as ABA, can optimize the intervention environment and promote overall family functioning.

In addition to professional support, community engagement (online or in-person), spirituality, support groups, and informal networks (e.g. respite care), play a crucial role in reducing isolation and strengthening family resilience. Clifford & Minnes (2013) and Mandell & Salzer (2007) found that parents who participated in peer support networks reported improved emotional well-being and a greater sense of belonging. Additionally, Ingersoll & Hambrick (2011) and Tway et al. (2007) emphasize that these informal supports can complement formal interventions, helping families adapt to ongoing challenges and unexpected circumstances.

Tailored and community support can have a significant positive impact on families and set them up for success in raising their children (Elder et al., 2017)!

Local (Victoria, BC) and Digital Supports

In Victoria, BC, families navigating an ASD diagnosis with their children have access to various local service providers and online resources, though navigating so many resources at once can be challenging. Common providers include RISE Behaviour Services, Stepping Stones, FIVE Behaviour and Education, Little Steps, and Functional Learning; however, most offer limited, easily accessible information on their websites, with Little Steps being an exception in providing more context for parents (Little Steps Therapy Services, n.d.). Support organizations like the VSCA offer resources for families with newly diagnosed children (Victoria Society for Children with Autism, n.d.), while the Victoria Disability Resource Centre lists free and affordable counseling options in the area (Victoria Disability Resource Centre, n.d.).

Online, many websites such as Autism Support BC, Autism Outreach, Autism Speaks, and ACT Community provide guidance on understanding Autism and navigating the diagnosis and system but often lack resources focused on parents/caregivers' mental health. Community support is available through local Facebook groups like the Victoria Autism Parent Social/Support Community and the Vancouver Island ASD/Autism Parent Support Network. Despite the wealth of information, accessing multiple web-based sources can be extremely overwhelming (Rabba et al., 2020). While resources are out there, it can be difficult to know what information is relevant and beneficial to families processing a new diagnosis.

Emerging Supports for Parents

While there have been many findings on the complex and stressful nature of the journey of an ASD diagnosis, emerging literature offers promising insights into effective ways professionals can support families during this process. These findings emphasize strategies such as identifying protective factors that enhance family quality of life, fostering posttraumatic growth (PTG) to build resilience, and guiding parents and caregivers toward acceptance and resolution of their child's diagnosis to improve overall well-being. Additionally, accessing peer parent-to-parent support has been shown to foster a sense of community and shared understanding, while incorporating therapeutic approaches like Acceptance and Commitment Therapy (ACT) and mindfulness practices can strengthen coping skills, improve mental health, and boost confidence and self-efficacy in caregiving roles. The following section will investigate these prospective approaches in greater detail.

Some studies have explored protective factors influencing family quality of life and PTG in parents/caregivers of children with ASD (Rivard et al., 2022; Lu et al., 2022). PTG is defined as the process of meaning-making following a stressful situation and can be positively expressed through feelings of strength and power, improvements in interpersonal relationships, development in spirituality, and finding meaning in life (Tedeschi & Calhoun, 2004; Linley & Joseph, 2004; Taubman-Ben-Ari et al., 2020). Rivard et al. (2022) suggest several key supportive elements: (1) family-centred diagnostic support with accessible resources and support team members, (2) promotion of family psychological, emotional, and mental health wellbeing, and (3) early behavioural management training and coaching. Additionally, Lu et al.'s (2022) research demonstrated that higher parent/caregiver resilience was associated with increased PTG and self-efficacy, with positive coping styles influencing this relationship. While Lu et al.'s study

addressed developmental disabilities broadly, both studies provide important insights for developing programs to support parents/caregivers of children with ASD post-diagnosis, emphasizing psychological, emotional, fostering resilience, and overall well-being (Lu et al., 2022; Rivard et al., 2022).

Naiker et al. (2023), describe that acceptance and resolution in parents/caregivers of their child's autism diagnosis allows them and their children to reach an optimal level of well-being, which includes a greater capacity to cope with stress, decreasing psychological distress, and depression, higher levels of marital satisfaction, and more willingness to seek and access social support (Kazak et al., 1997; Da Paz et al., 2018) Through a systematic review, Naiker et al. (2023) found patterns where 6 common factors impact a parent/caregivers' resolution of their child's autism: child characteristics (severity of autism), religion, belief and culture, knowledge and uncertainty, negative emotions (e.g. denial, shame, guilt), positive emotions and factors (e.g. family support and emotional availability), and attunement and insightfulness. Therefore, taking into account these factors ensure there is greater support, for psychoeducation on autism, while adopting a strength-based approach may support overcoming obstacles and help facilitate acceptance of autism diagnoses (Naiker et al., 2023; Brown et al., 2021).

Newer insights on parent-to-parent support are continually emerging. Lee et al. (2024) found trends through a scoping review that having parents/caregivers support each other, not only fills the gap for decreased instances of social isolation but also creates opportunities for social connections, a sense of community, and empowerment (Lee et al., 2024). These findings show the value of community and social support, which can help bridge the gap of the unknown, connect parents/caregivers in common situations, and provide them with more relevant resources and information (Gillberg et al., 2024).

Incorporating ACT and Mindfulness

There have been more studies being published where ACT is utilized to support parents with children with ASD (and other disabilities). Initially, Blackledge & Hayes (2006) utilized ACT to support parents/caregivers of children with ASD through a 2-day workshop consisting of 20 participants, and it significantly improved depression, general distress, and perceived control. Improvements were maintained at their 3-month follow-up as well (2006). Their future suggestions included incorporating more focused diffusion and acceptance techniques focused on specific and unique challenges of the parents/caregivers (2006). This early study highlights the potential of ACT as a supportive intervention for parents/caregivers during challenging periods. Building on these promising results, subsequent research has continued to explore and expand the use of ACT in this context.

In more recent years, Holmberg Bergman et al., (2022) evaluated the feasibility and preliminary outcomes of using ACT group intervention for parents in Sweden's outpatient habilitation services. With 80% of participants completing the program, Bergman et al.'s (2022) initial analysis showed significant improvements in parental well-being, including reduced experiential avoidance, increased mindfulness, and decreased depression and anxiety. Improvements in children of participating parents/caregivers were also observed as reduced emotional and behavioural problems and increased prosocial behaviours (2022). Maughan et al., (2023) conducted a randomized controlled trial on brief (3-session) group-based ACT for parents/caregivers with children, adolescents, and adults with ASD, where improved aspects of parent/caregiver mental health, including reduced depression, and family distress, compared to the waitlist control group were observed. The improvements were also still present at the 4-month follow-up period where parents/caregivers reported greater short-term improvements in

affect and personal goal attainment and improvements in family distress, but with no significant changes in general family functioning or child mental health (2023).

Additionally, Marino et al. (2021), conducted a randomized controlled trial to compare parent/caregiver outcomes with children with ASD participating in ACT interventions versus a standard parent training program and observed that ACT intervention led to more significant improvements. These improvements included parents/caregivers acquiring new strategies to cognitively reframe their emotional reactions, psychological flexibility, awareness, aligned personal values, and reduced parental stress and perceptions of their child's disruptive behaviours, compared to the control group that received standard parent training (2021). To evaluate the effectiveness of ACT-based interventions on improving the mental health of parents/caregivers of children with special health care needs, Li et al., (2023) conducted a systematic review and meta-analysis of available and relevant English and Chinese journals. The trends observed found positive effects of ACT-based interventions on mental health, psychological flexibility, mindful awareness/mindfulness abilities, and confidence/self-efficacy in parents/caregivers (2023). Additionally, it was suggested that group-based ACT combined with a parenting program was identified as the most optimal and effective strategy to provide support (2023).

Most recently, Leadbitter et al. (2025) developed and piloted the Empower-Autism program, a novel group-based intervention integrating manualized autism psychoeducation with ACT-based therapeutic content. This program was delivered in both in-person and online models to 29 caregivers with children (ages 4-15) recently diagnosed with ASD to increase accessibility. Through quantitative (i.e., attendance) and qualitative (i.e., satisfaction) assessment, the program was reported to be well attended (76%) and that it was acceptable and accessible (2025).

Feedback from the participants shows that there were perceived benefits from the program, including improved well-being, social connection, Autism positivity, and more attuned parenting (2025). This program shows promise, as it is now being evaluated within a large randomized controlled trial (2025).

Finally, as ACT incorporates aspects of mindfulness, it can also be helpful to include studies that focus on mindfulness. Neece et al. (2023) compared mindfulness-based stress reduction (MBSR) versus psychoeducation supports in longitudinal samples of families with autistic preschoolers and found that both produced better outcomes, especially MBSR compared to no supports (Neece et al., 2023). Yesilkaya & Magallon-Neri (2024) conducted a systematic review of the existing literature on the relationship between parental stress and the severity of ASD symptoms, as well as the potential benefits of mindfulness-based interventions for reducing parental stress. It was observed that the severity of ASD symptoms is positively associated with increased parental stress, but also mindfulness-based interventions can help reduce parental stress overall (2024). Parents/caregivers with a greater tendency to practice mindful parenting and report lower affiliate stigma experienced less parenting stress which is associated with fewer behavioural issues (Yesilkaya & Magallon-Neri, 2024; Cheung et al., 2019). Overall, increasing mindfulness practices and training mothers in mindfulness-based positive behaviour support helps decrease overall stress and reduce aggressive and disruptive behaviours in adolescent children with ASD (Yesilkaya & Magallon-Neri, 2024).

Current Reality and Considerations

A diagnosis at any time can impact the overall parenting experience. Strong evidence indicates that many parents/caregivers face heightened distress, grief, increased demands, and financial burdens which can cause vulnerabilities to mental health complexities, like depression

and anxiety (Befi et al., 2013; Elder et al., 2016; Elder et al., 2017; Karst & Van Hecke, 2012; Lai & Oei, 2024; Vasilopoulou & Nisbet, 2016; Crane et al., 2016; Hayes & Watson, 2013; Almog et al., 2023). Unsupported parents/caregivers can potentially result in inadequately supported children. However, bringing more awareness and acknowledgment to these parents/caregiver's experiences can encourage more tailored and meaningful support from service providers and other professionals. From emphasizing family-centred and accessible support and team members, promotion of family overall well-being, early behavioural management training, and coaching, building parent/caregiver resilience and self-efficacy, supporting them through the acceptance and resolution process, to connecting them to a community of other parents/caregivers that understand and can provide the value of community can potentially make all the difference (Rivard et al., 2022; Lu et al., 2022; Naiker et al., 2023; Kazak et al., 1997; Da Paz et al., 2018; Brown et al., 2021 Lee et al., 2024; Gillberg et al., 2024).

Through exploring the environment of current and emerging literature around potential effective ways to better support parents/caregivers with ASD children, especially through an ACT-based and mindfulness-based framework, while studies seem to point towards positive results, there is still extremely limited research. Within the newer studies noted in this review, all studies that conducted trials had small sample sizes (cognitive bias), which may skew data and lack generalizability to the broader population, and mainly included cross-sectional data (cross-sectional bias). While studies included follow-ups (5 months being the longest), it is hard to determine if maintenance of benefits can be assumed beyond, for example, one-year post-study/intervention. Holmberg Bergman et al.'s (2023) study did not include randomization and a control group (selection and sample bias), and Maughan et al.'s (2024) recruitment of participants came only from families already receiving services at agencies (selection and sample

bias); this excludes families that are not currently receiving services (lack of generalizability). Of the systematic reviews, specific demographics were not considered, and while Li et al. (2025) indicated reviewing both English and Chinese journals, only English ones were used (publication bias). Li et al.'s study also is not specific to parents/caregivers with only ASD children, so generalizability to parents/caregivers specifically with ASD children is limited.

It is also important to consider in the general context when reviewing literature that the world is culturally diverse and parenting struggles, social standards, ASD diagnoses etc., can present differently, and what is reported from one family as a struggle may not be for another. Many of these experiences are subjective and dependent on culture, language, understanding, societal norms, and more. Therefore, using the current literature to generalize across different cultures is quite limiting and may not be respectful and fully representative of different families' lived experiences. Many studies also mainly included mothers (and some fathers) as main parents/caregivers and do not represent different family structures across the world, where there may be other caregivers like aunts, uncles, or grandparents. Finally, the diagnosis of ASD and the use of the DSM-5TR and ICD-11 to define ASD may vary across cultures, and therefore, reflexivity and awareness of cultural and diversity factors should be considered when using those frameworks.

When working with families of children with ASD, ethical considerations must not be overlooked in research and practice. In Canada, all research involving human participants must follow the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), which emphasizes respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2022). Researchers and clinicians

need to be especially attentive to how consent is obtained, making sure that information is provided in clear, accessible language and that children, especially those who may be nonverbal or have communication differences, are included in the process as much as possible. Informed consent should be ongoing, and not just a one-time event. As professionals, we must ensure that families, children, and participants feel heard, can ask questions, or withdraw at any point.

Privacy and confidentiality are also vital, particularly when families are sharing sensitive information about their personal experiences, mental health, and/or family dynamics. This can be especially relevant in smaller communities or in group-based programs where anonymity can be more difficult to guarantee. As professionals, we also must ensure that data is stored securely, that identifying details are protected, and that families know exactly how their information will be used. In addition to upholding privacy and confidentiality, it is equally important to consider how ethical practice extends to respecting and valuing the diverse cultural backgrounds and perspectives of the families we support.

Cultural safety and inclusion are other key ethical priorities. As mentioned previously, much of the existing research and many interventions have been developed from a Western perspective, which may not always reflect the experiences, values, or needs of all families. Therefore, being aware of our own biases, while using strengths-based and affirming language, and making space for the voices and preferences of families from diverse backgrounds are extremely important. It is also important to avoid pathologizing language or approaches that reinforce stigma or suggest there is only one “right” way to be or to parent.

Finally, ethical practice means being mindful about the potential risks and benefits of any intervention or support and continuously welcoming and reflecting on feedback. For example, while programs like ABA or group-based ACT can be helpful for some, they must be delivered

in ways that respect autonomy, are adapted to individual needs, and do not pressure families or children to conform to norms that do not fit their values; they choose what is best for them.

Digital and online supports should also be evaluated for privacy and accessibility. Ultimately, the goal is to create environments where families feel respected, included, and empowered at every step.

Conclusion

Through Chapter 2, the current understanding and emerging information on the experiences of parents/caregivers with ASD children and how to better support them was explored and discussed. The main themes of emphasizing tailored, family-centred, and holistic well-being factors were noted that can better support these families during their difficult circumstances. Through ACT-based and mindfulness-based programs, these factors can be potentially targeted to ensure that these families do not fall through the cracks. However, one must be mindful when applying study findings and generalizing them across different families, as every family can come with different diversity, culture, and lived experiences that must be considered when striving to provide the best quality of care and support.

Chapter 3: Discussion and Application

Over the past seventy years, the awareness and understanding of ASD have developed significantly, luckily leading to better access to diagnosis and information for children and their families. However, as prevalence rates continue to rise, many families, especially parents and caregivers, still experience challenges in finding the proper support they need, with resources often limited or difficult to navigate. The literature continues to show gaps in meeting these needs, from diagnostic delays to the emotional impacts on families and a lack of consistent post-diagnosis support.

In this final chapter, the initial research question will be discussed: What are the most important components of a post-diagnosis support program for parents and caregivers navigating an ASD diagnosis for their child after the age of six? By bridging together the key findings from the literature review, practice recommendations will be offered, highlighting limitations in the current research and suggesting directions for future studies. The hope is to help move toward more effective, accessible, and family-centred support for those navigating this journey.

Discussion

The literature demonstrates that receiving an ASD diagnosis after the age of six can impact families in a multitude of ways (Crane et al., 2016; Elder et al., 2017). While each family's experience is unique, several common themes consistently emerge as areas requiring greater attention in post-diagnosis support.

Timely and Accessible Psychoeducation

Delays in diagnosis and support are common and can amplify stress and uncertainty for families (Smith-Young et al., 2020; Kalkbrenner et al., 2011). Providing timely, accessible

psychoeducation is essential to help families understand what ASD is, how it may impact their child and family, and how to distinguish accurate information from misinformation (Crane et al., 2016; Befi et al., 2023). Tailored information about next steps, available resources, and practical guidance on navigating systems can empower families, giving them a sense of direction and control during a challenging time (Rabba et al., 2020).

Tailored Advocacy Assistance

The literature highlights the importance of individualized advocacy and support in reducing barriers to services and improving family outcomes (Crane et al., 2016; Elder et al., 2017). Support professionals who are attentive, empathetic, and able to build a strong rapport with families can help alleviate accessibility challenges, particularly following a lengthy and stressful diagnostic process (Karst & Van Hecke, 2012). Taking a family-centered, neurodiversity-affirming, and culturally sensitive approach is critical to ensuring that families feel understood and supported (Almog et al., 2023; Vasilopoulou & Nisbet, 2016). Appropriate referrals to family counselling, specialized interventions, and community resources can help families begin to establish effective support systems (Osborne et al., 2008).

Mental Health and Well-being supports

Parents and caregivers often face emotional distress, grief, identity shifts, and increased demands following their child's diagnosis (Befi et al., 2023; Elder et al., 2016; Karst et al., 2012). Access to mental health support is crucial for addressing these challenges properly. Evidence suggests that therapeutic approaches such as ACT and mindfulness practices can help parents build resilience, strengthen coping skills, and improve overall well-being (Blackledge & Hayes, 2006; Marino et al., 2021; Holmberg Bergman et al., 2022; Li et al., 2023). Supporting

families through their grief and the process of acceptance can further promote psychological adjustment and family functioning (Fernández-Alcántara et al., 2016).

Emotional and Peer Support

Parenting a child with ASD can be isolating, making social connections an important protective factor. Facilitating opportunities for parents to connect with peers through support groups, community organizations, or informal networks can reduce feelings of isolation and helplessness (Clifford & Minnes, 2013; Mandell & Salzer, 2007). Peer parent-to-parent support allows parents to share experiences, gain practical advice, and build supportive circles with others who understand similar challenges (Twyo et al., 2007; Ingersoll & Hambrick, 2011).

Skills Training and Coaching

The literature also indicates that parent coaching and skills training are effective in increasing parenting self-efficacy, confidence, and coping skills (Osborne et al., 2008; Brogan & Knussen, 2003; Ho et al., 2014). By equipping parents with strategies to address their child's behaviors, families are empowered to advocate for themselves and navigate challenges more effectively (Li et al., 2023; Befi et al., 2023).

Limitations and Interpretation

It is important to be aware that much of the literature is limited by small sample sizes, cross-sectional designs, and a focus on Western populations, which may affect generalizability (Holmberg Bergman et al., 2022; Maughan et al., 2023; Li et al., 2023). Many studies primarily included mothers, with less representation from fathers or other caregivers, and cultural diversity was often underexplored. These methodological limitations should be considered when interpreting the findings and applying them to practice.

Recommendations for Practice

Drawing from the literature review, the most effective post-diagnosis support for families with children diagnosed with ASD after age six should be flexible, family-centered, and responsive to the needs and voices of both parents/caregivers and the community (Crane et al., 2016; Befi et al., 2023; Almog et al., 2023). The main components can be organized into two key steps, with the understanding that not all families will require the same level or type of support at every stage.

Step 1: Psychoeducation – So, what now?

Providing timely, accessible, and accurate psychoeducation is foundational for families navigating a new ASD diagnosis (Rabba et al., 2020; MCFD, 2023a). This step should be delivered in a neurodiversity-affirming, culturally sensitive, non-judgmental, and gender-neutral manner (Almog et al., 2023). This can be structured around three key areas: (1) offering clear information about Autism as a diagnosis, (2) outlining the next steps following diagnosis, and (3) setting realistic expectations for parents. Below is a simple example of how this curriculum might be organized:

Section 1 – What is Autism?

- a) Common Symptoms and their diverse nature
- b) Misconceptions and Stereotypes

Section 2 – What can be expected now?

- a) Journey of parents and caregivers
 - i) Normalizing experience
 - ii) Grief – identity shifts, the cycle; Relief, denial, and acceptance

- iii) Diagnosis disclosure – dilemmas: stigma, social norms, narratives, etc.
- iv) Potential emotional distress
- v) Other impacts: influences on relationships, increased caregiving demands, effects on work productivity, etc.

Section 3 – What do we do now?

- a) First steps
 - i) Apply for Autism Funding (if applicable to that area)
 - ii) Who to connect to and how to apply
 - iii) Potential information on wait times
- b) What are common services?
 - i) Support from the ministry (e.g. social workers)
 - ii) Specialized services
 - (1) SLP, OT, Physio, ABA services – BCBA's, etc.
 - iii) Family or individual counselling
- c) When do we need certain services?
- d) List of local resources

Step 2: ACT – Taking Care of the Caregivers

After establishing a strong foundation through psychoeducation, ongoing support should be made accessible and sustainable, ideally through a flexible, long-term, drop-in style program. This step would focus on supporting mental health, well-being, family dynamics, and grief, using evidence-based approaches like ACT and mindfulness (Blackledge & Hayes, 2006; Marino et al., 2021; Holmberg Bergman et al., 2022; Li et al., 2023). After a mandatory introductory session to ensure a shared foundation and understanding, families could choose sessions based on their

needs and schedules. The program would be neurodiversity-affirming, culturally inclusive, non-judgmental, and family-centered, fostering community and social connections. Both in-person and online options would be available, with potential childcare offered for in-person sessions. The curriculum, based on ACT's six principles, would cover diverse topics with practical activities, though further development is needed to comprehensively address families' varied challenges. The following are session examples with brief explanations:

Mandatory session – Introduction to ACT

In this mandatory introductory session, the parents/caregivers will learn about what ACT is, how it can be helpful, and how they can best utilize this program.

Session 2 – Grief, denial, & changes in expectations

This session will be based around ACT's Acceptance principle, and can potentially address parents/caregivers' grief, denial, their child's tough behaviours, changes in family dynamics, changes in their expectations, and so on. A potential activity can be the "I Accept" activity (Caufield, 2023)

Session 3 – Unhelpful thoughts & behaviours; Breaking patterns

This session will be based around ACT's Defusion principle, and can potentially address parents/caregiver's unhelpful thoughts, behaviours, and habits that arise. It will teach them a strategy to break patterns. A potential activity can be the "What fires together, wires together" activity (Caufield, 2023).

Session 4 – But... What if?

This session will be based around ACT's Being Present principle and can potentially address parents/caregivers' tendencies to easily get caught in the "What ifs" in life and bring mindfulness practices into their everyday life. A potential activity can be the "Leaves, Streams & Clouds" activity (Caufield, 2023.)

Session 5 – Parenting self-efficacy

This session will be based around ACT's Self-as-Context principle and can potentially address parents/caregivers' doubts about their parenting abilities. This can help with their self-efficacy in parenting and increase their confidence. A potential activity can be the "Self as a process of ongoing self-awareness" (Caufield, 2023).

Session 6 – Who am I as a parent/caregiver?

This session will be based around ACT's Values principle and can potentially address parents/caregivers' self-efficacy as a parent while identifying and re-aligning with their values. This can help with becoming clearer about who they want to be as a parent, caregiver, partner, friend, etc., and staying true to that. A potential activity can be the "Picking Core Values" activity (Caufield, 2023).

Session 7 – Who's on my team?

This session will be based around ACT's Committed Action principle and can address the potential social isolation parents/caregivers may experience. With the program being group-based, this also fosters a sense of community and social connection through parent-to-parent peer support. A potential activity can be "Finding an accountability partner" to continue motivating each other (Caufield, 2023).

Recommendations for Future Research

Looking to the future, ongoing collaboration with families and the broader community should be at the heart of any support program for parents and caregivers navigating an ASD diagnosis (Rabba et al., 2020; Almog et al., 2023). Future programs should be co-created with regular opportunities for feedback, such as advisory panels, surveys, and open forums to ensure they remain responsive, relevant, and inclusive. Weaving in ongoing evaluation using both quantitative and qualitative data will allow for continuous adaptation and improvement as family needs evolve, while transparent sharing of findings with families and stakeholders will further strengthen trust and accountability. Flexibility in program design is also essential, with a range of delivery formats (in-person, online, hybrid) and attention to barriers related to accessibility, language, and technology.

Ethical standards must remain central to all program development and research. Adhering to the Tri-Council Policy Statement (TCPS2) and Canadian Psychological Association guidelines ensures respect for informed consent, privacy, and cultural safety at every stage (Canadian Institutes of Health Research et al., 2022). Involving autistic individuals and caregivers in both design and evaluation upholds the principle of honoring lived experience and autonomy. To address current gaps in the literature, future research should prioritize greater diversity in family structures, cultural backgrounds, and underrepresented caregiver groups, such as fathers, grandparents, and extended family members (Li et al., 2023; Holmberg Bergman et al., 2022). Longitudinal studies are also needed to better understand the long-term effectiveness of interventions like ACT and psychoeducation, ensuring that supports remain effective, equitable, and empowering for all families navigating an ASD diagnosis (Marino et al., 2021).

Conclusion

In summary, this capstone set out to better understand and address the unique needs of parents and caregivers whose children receive an ASD diagnosis after the age of six. The study highlighted the challenges families face, from navigating delays and uncertainty to coping with emotional impacts and finding accessible, meaningful support. By exploring the current literature and existing resources, it became clear that there is a significant gap in post-diagnosis support, and that families benefit most from timely, practical, and culturally sensitive guidance that recognizes both their strengths and struggles.

The main takeaway from this research is that families do best when support is flexible, family-centered, and grounded in both accurate information and genuine care for their well-being. Combining strong psychoeducation with ongoing mental health supports like ACT, opportunities for advocacy, peer connection, and skills-building can make a real difference in how families adjust and thrive after a diagnosis. Just as importantly, involving families and the community in shaping these programs and keeping ethical standards ensures that supports stay relevant, respectful, and empowering as needs change.

Ultimately, these findings echo and build on previous research, reinforcing that while progress has been made, there is still much to do to make post-diagnosis support more accessible, inclusive, and effective. By continuing to listen to families' voices and adapting our approaches, we can help create a landscape where every family navigating an ASD diagnosis feels seen, supported, and equipped for the journey ahead.

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