Applied Intersectionality: Supporting Families of Children with Autism Spectrum Disorder from Racial, Ethnic, and Cultural Minority Groups

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ABSTRACT

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Paul De Luca

Having a child with special needs may incur a tremendous toll on the family unit, a reality that is significantly more pronounced for members of marginalized (i.e., racial and ethnic minorities) communities. Examples of these disparities include more pronounced barriers to healthcare, delayed diagnoses, and difficulty accessing critical services. The present study had two aims. Firstly, to conduct a needs assessment exploring the types of services ethnically diverse parents rely on to support their children and families, as well as their satisfaction with the quality of these services. Secondly, to test the efficacy of a culturally adapted parent training program, 'Parents Taking Action (PTA)', with the goal of: *a.* Increasing parents' knowledge of ASD *b.* Reducing parental stress *c.* Increasing parents' perceived competence and self-efficacy beliefs. Five parents (*n* = 5*)* were recruited. The findings indicate that parents rely on several services offered by healthcare providers (e.g., pediatricians), education specialists, professionals (e.g., speech pathologists, occupational therapists, ABA therapists) to support their children from both the private and public sector to varying degrees of satisfaction. Several challenges to accessing services emerged: long waitlists, absence of information following a diagnosis, inaccessibility of private care (i.e., financial constraints) and language barriers, and issues within the public sector (e.g., lack of resources, poorly trained specialists, overcrowded services within the child's school). Furthermore, all parents' knowledge of ASD increased, half the parents saw a reduction of stress, and half of the parents' self-efficacy beliefs improved. Taken together, the findings from the present study continue to support a burgeoning literature in support of culturally-adapted materials to support ethnically diverse parents of children with special needs.

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Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder with observed deficits in communication and social interaction skills, repetitive behaviours, and restricted interests (American Psychiatric Association, 2013). The effects of ASD may not only be distressing to the child but can negatively impact the family as well. For example, parents of children with ASD may incur tremendous costs to support their children through therapy and other specialized services (Lavelle et al., 2014). This issue is further exacerbated by caregiving duties to support children with ASD, which can impede employment opportunities (Houser et al., 2014). Moreover, the literature overwhelmingly suggests parents of children with ASD report higher levels of stress (DePape & Lindsay, 2015; Tomiyama et al., 2018; Van Esch et al., 2018). These mental health-related outcomes for parents of children with ASD have been exacerbated by the current COVID-19 pandemic (Lee et al., 2021). Siblings of children with ASD may also be adversely affected compared to siblings of typically developing (TD) children (Shivers et al., 2019; Smith & McQuade, 2021). For example, siblings of children with ASD are more likely to report turbulent sibling relationships, greater propensity towards internalizing behaviour problems, and psychological and social functioning difficulties (Shivers et al., 2019). Thus, the role of contextualized family care in supporting children with ASD represents a promising opportunity to mobilize parents, empower children, and strengthen the family unit.

Rationale

The Autism and Developmental Disabilities Monitoring (ADDM) Network estimates that one in fifty-four children will be diagnosed with ASD (Maenner et al., 2020). In the absence of early intervention and critical services such as psychoeducation and clinical support, ASD symptomology may severely inhibit children’s ability to reach developmental and educational milestones. Moreover, the pervasive nature of ASD means symptoms will persist across the child's lifespan into adolescence and eventual adulthood. Developmental disorders in general appear to be on the rise. Using data collected from the National Health Interview Survey, Zablotsky et al. (2019) estimates 1 in 6 North American children will be diagnosed with a developmental disability. These figures are based on parent reports spanning nearly a decade of research. They include reports from thousands of parents disclosing whether a doctor or health professional had formally diagnosed their child with a developmental disability. When observing the rates of ASD specifically, the data reveals a significant increase suggesting the rates of ASD have been steadily increasing since the start of this study in 2011. To iterate how drastic these increases have been, the prevalence rates of ASD from 2011-2013 was 1.25% compared to 2.24% just a year later in 2014. Given the growing rates of ASD observed in North America and the myriad of ways ASD symptomology disparages children, these statistics are not negligible.

Examples of the adverse outcomes children with ASD may be subjected to include low academic achievement, higher rates of stress, sleep problems, and poor emotion regulation (Dillenburger et al., 2010; Dillenburger et al., 2012; Keen et al., 2015; McDougal et al., 2020). In a review by Hoover and Kaufman (2018), the literature suggests children with ASD are up to four times more likely to experience victimization and bullying than their non-disabled peers. Moreover, their study also found these children are at risk for other psychiatric health problems such as mood disorders (i.e., depression) and anxiety disorders (Generalized Anxiety Disorder and even Post-Traumatic Stress Disorder in cases where the child experienced extreme physical peer victimization). Children with ASD are also disadvantaged in terms of educational outcomes, as reported in a literature review by Keen and colleagues (2015). Academic achievement is generally poor for children with ASD, due in part to deficits in attention which is an important mechanism that modulates their ability to reach their academic potential (Keen et al., 2015; McDougal et al., 2020). ASD may also impede the quality of life for these children. For example, children with ASD are more likely to have issues related to sleep, conduct disorder problems, aggression, general stress, and emotion regulation problems (Dillenburger et al., 2012; Dillenburger et al., 2010). Correlational studies have also found that children with ASD are more likely to have gastrointestinal health problems (Chaidez et al., 2014; Wang et al., 2011).

An Intersectional Approach

For members of marginalized communities (i.e., racial and ethnic minorities), these inequities are more pronounced (Magana et al., 2013). The process of seeking and accessing appropriate supports for their children can be difficult due to ubiquitous systemic barriers. These obstacles may be exacerbated by language barriers and cultural differences (Kang-Yi et al., 2018; Sritharan & Koola, 2019). For example, cultural taboos or negative attitudes (i.e., stigma) towards having a child with ASD will impact caregivers' willingness to have their child assessed by a professional, as well as seek the proper supports (Kang-Yi et al., 2018; Sritharan & Koola, 2019). Taken together, racial and ethnic minority families who have a child with ASD may be disproportionately affected by systemic and cultural barriers, making it difficult for their child to receive the proper resources they require. As is the case for neurodevelopmental disabilities at large, early and consistent intervention is crucial. In the face of these systemic barriers, the process by which children seek, access, and benefit from specialized care may therefore become delayed or halted altogether. These pitfalls may prevent children with ASD from attaining critical educational and developmental milestones. Thus, the rationale for this thesis project is to equip families from racial, cultural, and ethnic minority groups with increased self-efficacy and perceived self-competence through a parent training intervention. At the macro-level, there are several shortcomings from the government and policymakers that address the needs of these groups (Eriksson et al., 2018). However, much can be done in terms of groundwork so that parents can feel confident in their ability to oversee the provision of their children's care.

Literature Review

Theoretical Frameworks

Bronfenbrenner's Bioecological Model

Bronfenbrenner's seminal theory for human development, originally titled the Ecological Systems Theory, is a framework for understanding development within the context of the child's broader ecology (Hayes et al., 2017). This entails studying children across multiple contexts and systems to comprehensively and thoroughly contextualize their developmental trajectory. It is essentially important to maintain that, while the child is impacted by these unique yet interrelated systems, they also impact individuals and systems within their proximal ecology.

Despite the impact and implications for Bronfenbrenner's early model, many critiques emerged as outlined by Elliot and Davis (2018). Firstly, the ecological model largely ignores human-nature interconnections by failing to recognize it as a bidirectional transaction. While the individual may be impacted by their environment, one cannot ignore that the individual may also impact their environment and the individuals within the environment's social network. Another critique is that the ecological model was too anthropocentric (Elliot & Davis, 2018). While many of the core tenants of anthropocentrism (e.g., improving human welfare) represent a noble objective, it positions humankind as the most central element of existence. Moreover, an anthropocentric lens to conceptualizing development would have been at odds with the popular post-humanist lens, an emerging school of thinking (Elliot & Davis, 2018). Post-humanism has had profound implications for the way development is studied, as it frames the human condition within the broader context of their environment. Thus, in 1983 Bronfenbrenner amended his theory to include the concept of the person (i.e., interpersonal variation, individual characteristics, attitudes, beliefs, behaviour) to propose what is now known as the Bioecological Model. This transition has resulted in a more complex, dynamic, and robust framework for understanding development in the current contemporary context.

The Bioecological Model encompasses multiple levels of the environment such as family, culture, laws and customs, school, mass media, government, and sociohistorical events (e.g., war, pandemic, living under a dictatorship) (Hayes et al., 2017; Elliot & Davis, 2018). The interaction between levels and the child interacts bidirectionally to modulate developmental and educational outcomes. The ecological model comprises five different levels: the microsystem, mesosystem, exosystem, macrosystem, and the chronosystem.

The Microsystem and Mesosystem. The microsystem comprises individuals within the child's proximal social ecology such as family members (e.g., caregivers, siblings, extended family), teachers, friends, and classmates. Those within this social network may play an integral role in shaping the child which may modulate the attainment of certain developmental, educational, and psychological milestones. For example, in a recent study by Campos et al. (2020) 114 children were recruited from a low-income neighbourhood and the quality of their home environment (i.e., quality of housing, degree of household chaos, and the school environment), levels of stress, educational quality as measured by classroom environment, and executive functioning (i.e., decision making and planning ability) was assessed. The results yielded suggest that environmental quality at the microlevel plays a critical role in modulating stress and executive functioning performance. When children had poorer environmental quality, they were likely to report greater stress levels and poorer executive functioning ability.

Conversely, children with nurturing relationships with their caregivers were more likely to attain critical developmental milestones and observe higher levels of well-being.

The importance of the role individuals play within the child's proximal ecology is particularly concerning when considering the contemporary COVID-19 context (Zhang, 2022). Household chaos is a family environment characterized as overcrowded and noisy, as well as deficient in both order and routine which may precede the onset of mental health problems for caregivers and their children. Research shows that 'household chaos' disproportionately affects racial and ethnic minority families. Most notably, depression has steadily increased among ethnic/racial minority families since the beginning of the pandemic. For young children, growing up in this environment has drastic implications for behaviour. These children are more likely to exhibit externalizing behaviours (e.g., acting out) and internalizing behaviours (e.g., depression, fearfulness, social withdrawal). The degree of household income determines ones' SES, whereby income loss due to the pandemic's impact on employment predicts higher levels of household chaos. Thus, taken together it is quite clear that the child's caregivers and home environment has dramatic implications for human development.

It is paramount to recognize that, while the child is affected by others, the relationship within the microsystem is largely bidirectional. The child will also influence the behaviour, beliefs, and attitudes of those around them (Hayes et al., 2017; Huang, 2013). Within the context of ASD, for example, children often have unique social skills that make it difficult to foster relationships with their classmates (Huang, 2013). For example, many children with ASD observe deficits in identifying and understanding the emotions of others through their facial expressions (Chasson & Jarosiewicz, 2014). These children may also have distinguishable nonverbal social impairments such as maintaining eye contact and appropriate gaze. Research by

Campbell and Barger (2014) finds that many of these children are therefore likely to become the target of peer victimization resulting in lower levels of social acceptance among school-age peers, poorer relationship quality as measured by frequency of social reciprocity, and fewer opportunities to establish companionship. These studies iterate that the child's own behaviours may elicit differential behaviours (i.e., bullying, victimization) from their peers, thus showing the bidirectional nature of relationships within the microsystem (Hayes et al., 2017).

The mesosystem links the microsystem to the exo-system through direct interaction (Bronfenbrenner, 1977). At this level, the focus is on the relationships between settings that contain individuals (e.g., relationships between home and school). The mesosystem is a conceptualization of social networks that explains how individuals begin to understand norms, behaviours, and expectations across settings by activating contacts within the system (Hayes et al., 2017; Newman, 2020). By participating in multiple settings, the child achieves cognitive complexity by attaining resources, participating in activities, and interacting with others (Newman 2020). The mesosystem is essential for individuals to construct oneself in terms of identity, expectations, and values. In interacting with a variety of patterns and expanding interpersonal relationships across the mesosystem, the individual becomes realized.

Within the context of ASD specifically, it is important to remember the child's own cognitive and social capacities will influence their behavioural patterns. Therefore, many interventions such as Applied Behaviour Analysis (ABA) are targeted at the individual level. The goal of these interventions is to support the child as they adjust to their external environment. Embedded within the microsystem and mesosystem is the child's family and, given the extent to which ASD may impact the family dynamic, it is critical to consider the bidirectional relationship between individuals within these systems (Bekhet et al., 2012; Hayes & Watson, 2013). Thus, while caregivers exert their influence over the child, the child's own behaviour (i.e., clinical symptomology) will also impact caregivers and siblings of children with ASD. As such, it is important to not only focus on providing support at the individual-level but also to those within the child's proximal social ecology (Eriksson et al., 2018; Newman, 2020).

The Exosystem. The exosystem reflects both formal and informal societal variables (e.g., government, the role of media, education system, etc.) (Hayes et al., 2017; Elliot & Davis, 2018). While the child is not contained within this system, they are directly influenced. For families of children with ASD, the types of services and educational policies is regulated at the government level (Eriksson et al., 2018; Nicholas et al., 2018). These policies are critical for ensuring that the child and their family's rights are protected and to provide the proper resources (e.g., facilities, services). This may entail providing financial compensation for families whose employment has been impacted by having a child with ASD or offering insurance premiums that include therapy (Nicholas et al., 2018; Predescu et al., 2018). Outside of the economic and clinical spheres, schools may also play an important role by providing educational support and specialized, differentiated instruction so these children are attaining key educational milestones (Eriksson et al., 2018; Predescu et al., 2018). This entails being equipped with the requisite infrastructure such as support staff (e.g., technicians, psychologists, counsellors), resources, teaching training, and open communication with parents to accommodate a breadth of diverse learners (Grigorenko et al., 2019; Reardon et al., 2021).

The Macrosystem. The macrosystem represents norms and values shared by the larger culture and the sub-cultures embedded within it (Hayes et al., 2017). By extension, the culture's constituents impact the individual who belongs to that culture. The history of autism, for example, highlights how cultural beliefs about neurodevelopmental disabilities impact the ways children with these conditions are treated (Kirkham, 2017). Autism was once viewed as a 'disease' that is a by-product of poor parenting practices, or something innate within the child that can be 'trained' out of them with punitive measures (Dillenburger et al., 2010; Kirkham 2017). These cultural beliefs about ASD have resulted in the horrific maltreatment of children with special needs. Fortunately, the advocacy work of professionals, caregivers, and individuals with ASD has veered our understanding of ASD from a medical, brutalist perspective to a more inclusive and accepting attitude (Sandoval-Norton et al., 2021). This has had profound implications for these children. As new attitudes and beliefs about ASD have emerged to challenge antiquated preconceptions of this disorder, more services and supports across various sectors (e.g., family, educational, professional, governmental) have been provided to support these children.

The Chronosystem. Lastly, the chronosystem explains how environmental changes and sociohistorical events (e.g., war, famine, a pandemic, living under a dictatorship, etc.) may also shape development (Hayes et al., 2017). The COVID-19 pandemic has negatively impacted many in terms of mental health outcomes, employment, and general well-being (Hwang et al., 2020; Mukhtar, 2020). These outcomes are particularly concerning when considering those with special needs at the margins who are often an underrepresented population in the discourse on the impact of the pandemic. Many services were moved to online platforms to be offered remotely which, as the literature suggests, is problematic as telehealth does not necessarily work for all (Costa et al., 2022; Lee et al., 2021; Ingersoll et al., 2017). In some cases, services to support those with ASD were suspended indefinitely to comply with government-mandated protocols to curb the spread of the COVID-19 virus (Costa et al., 2022; Lee et al., 2021). Thus, the pandemic has set back children with ASD and their families back tremendously (Lee et al., 2021). This is especially concerning considering early intervention is crucial (Sone et al., 2021). With many services delayed or suspended indefinitely, it is likely many young children at the height of the pandemic were not being diagnosed or given therapeutic interventions in a timely, consistent manner.

For families of children during the pandemic, their employment prospects were affected in two ways (Craig & Churchill, 2020; Woolbridge et al., 2021). Firstly, many parents lost their jobs during the pandemic which created a tremendous degree of household instability (Clark et al., 2021; Farre et al., 2021). Moreover, income loss and poverty are significant predictors of a myriad of adverse outcomes such as higher levels of stress, lower levels of social security, and fewer opportunities to access resources (Archibong et al., 2021; Holmes et al., 2020). With literature showing that providing for a child with ASD may be a costly endeavour (Lavelle et al., 2014), it is especially critical to consider how caregivers of these children who have reported income loss have been impacted. The second way the pandemic has affected employment is by transitioning to a work-from-home format (Craig & Churchill, 2020; Woolbridge et al., 2021). This presented many unique challenges, as parents were required to not only meet their professional obligations but to now oversee the provision of their children's care and education at home. For children with special needs, access to school also means access to services, technicians, and support staff that will help support the child. In the absence of these vital resources, many parents have found themselves overworked as they attempt to support their children while working from home (Costa et al., 2022; Craig & Churchill, 2020).

Family Systems Theory

Family systems theory (FST) aims to understand the human experience within the broader context of the family dynamic (Priest, 2021). This framework posits that the family context plays a critical role in shaping individuals. The theory is derived from three distinct yet interrelated epistemologies (Brown, 1999; Umberson & Thomeer, 2020). Firstly, the emotional system which allows the individual to integrate and respond to their environment. Secondly, the feeling system which refers to the specific labels ascribed to internal states (e.g., guilt, sadness, shame, etc.). Lastly, the intellectual system which refers to individuals' propensity to know and understand phenomenon. FST suggests that the underlying epistemologies that explain the individual's behaviour do not occur in a vacuum, but are instead attenuated by the family context. This includes individuals within the family unit, the context the family is embedded within, and interactions of people between families (Priest, 2021; Schermerhorn & Cummings, 2008). As suggested by Smith (2016), the underlying core tenant of FST is that the sequence of interactions that occurs between family members reveal a great deal about human behaviour and development. Thus, in terms of its clinical implications a FST lens posits the family should be regarded as a singular causative system containing an intricate web of complementary communication in which the nature of the interaction is reinforced. It is then critical to consider the rules within such a system that govern the overall family ecology. It is therefore the job of clinicians to understand these 'rules' so that they can have a better understanding of the family's functioning holistically (Johnson & Ray, 2016). Additionally, patterns of interactions embedded within the family are important to consider. Targeting maladaptive behaviours and interactions may then attenuate negative outcomes and thus promote the strengthening of the family unit overall. Taken together, the interactions between members of the family are especially crucial to understand why individuals display certain emotions or behave the way they do.

Family Systems Theory has well-documented applications for the family with the core goal of strengthening the family unit. For example, FST has informed interventions that decrease marital distress, depression, and promote adaptive functioning (e.g., coping with a chronic illness) (Cridland et al., 2014; Priest, 2021). With respect to ASD specifically, FST has also been found to support children with ASD and their families (Cridland et al., 2014). The existing literature overwhelmingly finds providing supports for families of children with ASD yields positive benefits such as improved psychological and emotional functioning, improved communication skills, and higher rates of both empathy and patience (Cridland et al., 2014).

Despite its novelty, FST's success as a lens to inform clinical intervention is promising as it hinges on several underlying mechanisms that characterize effective clinical intervention: ambiguous loss, resilience boundaries, and traumatic growth (Bradford, 2010). Ambiguous loss encompasses a change in one's psychological state. In considering ASD, for example, this may refer to how the brunt of caring for a child with ASD can incur mental health tolls for parents (e.g., fatigue, anxiety) and siblings (e.g., low self-esteem, perceived loneliness). Resilience refers to one's ability to circumvent and work through challenges (e.g., physical, emotional, social, and psychological in nature). Thus, many interventions aim to bolster the family's resilience so that they feel competent and empowered to work through some of the challenges that may accompany caring for a child with ASD. Boundaries are conceptualized borders that define the family in relation to other systems. Lastly, traumatic growth refers to the process by which coping with trauma leads to positive change (e.g., personal strength, family solidarity, improved relationship quality). Families who face trials and learn to overcome these obstacles may observe positive benefits which improves the well-being of the family unit (Banda, 2015; Shivers & Plavnick, 2015). For parents who participate in clinical interventions and workshops related to ASD, many report increased knowledge about ASD, greater perceived emotional support, stronger response to grief, improved family capacity, and improved acceptance and appreciation for the family's situation (Bradford, 2010; Cridland et al., 2014; Samios et al., 2012).

From an FST lens, therapy can also integrate members of the family into the child's therapy plan (Wright et al., 2019). For example, involving siblings in the treatment of the child's ASD yields positive results (Banda, 2015; Shivers & Plavnick, 2015). This entails making the TD sibling the co-recipient of the intervention or making the TD sibling the target of the intervention (Shivers & Plavnick, 2015). There are several benefits to doing this, such as improving functional communication and fostering optimal social communication skills between siblings. To a large extent, the success of this approach can be attributed to the notion of horizontalization (Finke, 2016). This means putting TD children and their sibling with ASD in comparable roles (i.e., the agent of therapy) creating equal status and fosters egalitarianism.

Research has also found that integrating parents into the child's intervention plan yields positive results, as doing so leverages caregivers as the primary agents of change, which hinges on a transactional model of development (Brian et al., 2022; Sone et al., 2021). This means that, as parents become acclimated with the process of therapy, they can transition to parent-delivered modalities of treatment at home. This may yield several benefits such as allowing therapy to occur in a naturalistic context, improving parent-child interactions (i.e., parental synchrony), and ultimately leads to improved self-efficacy and empowerment (Tomeny et al., 2020). An added benefit of parent-led therapy in the home is that it also promotes healthy patterns of social interaction, which may facilitate social cohesion by increasing family time and promotes togetherness outside of the context of therapy (Boyd et al., 2014).

Taken together, both Bronfenbrenner's Bioecological Model of development and Family Systems Theory show the extent to which the family context is critical to support children

(Hayes et al., 2017; Johnson & Ray, 2016; Thomson & Priest, 2016). The role of contextualized family care in particular represents an opportunity to support families of children with ASD (Priest, 2021; Thomson & Priest, 2016). This may not only help to ensure optimal development for the child, but may strengthen the overall family unit which may mitigate the potential negative outcomes that have been associated with having a child with ASD.

Impact of ASD on the family

Parents

Given the life-long, pervasive nature of ASD, many parents experience unique challenges as caregivers that persist throughout the lifespan (DeGrace et al., 2004; DePape & Lindsay, 2015). The root of parental stress is largely due to the adjustment period between the initial ASD diagnosis and the point where families can settle into a routine. For example, literature shows that parental stress and frustration is highest after the initial diagnoses (Aylaz et al., 2012; DeGrace et al., 2004). Many parents felt overwhelmed by the increased demands to support their children and decreased time they had for both themselves and other family members in the home. Additionally, many parents did not have the requisite knowledge to understand the child's behaviour and could not predict certain triggers that elicit tantrums (Aylaz et al., 2012; DeGrace et al., 2004; DePape & Lindsay, 2015). For example, children with ASD are typically sensitive to changes in routine (Ludlow et al., 2011). Additionally, these children may also have sensory issues that can trigger outbursts (DePape & Lindsay, 2015). Being unable to accurately identify, assess, and act to support their children is distressing and may leave parents feeling incompetent in their ability to oversee the provision of childcare and symptom management (Aylaz et al., 2012; DePape & Lindsay, 2015). A scoping review by Lee et al. (2021) has also found that caregivers of children with ASD experienced heightened levels of stress due to the ongoing COVID-19 pandemic which may incur long-term consequences for both the child and family.

The literature suggests that ill-equipped parents caring for a child with ASD for the first time may observe adverse mental health outcomes (DePape & Lindsay, 2015; Fletcher et al., 2012). Parents of children with ASD were more likely to report feeling exhaustion and stress, with some going on to suffer stress-related health problems such as high blood pressure (Altiere & Von Kluge, 2009). Many parents also lacked the requisite coping mechanisms to manage their new role as caregivers of children with ASD. For example, a study by Fletcher et al. (2012) found that some parents turned to medication while others spiralled further into feelings of self-doubt. A common thread across the literature discussed is that feeling stressed with the workload required to care for a child with ASD often led to negative self-appraisals of parental competence and ability, with many parents beginning to view themselves as inadequate (DePape & Lindsay, 2015). In some cases, this internal dialogue may manifest as resentment towards the child. For example, a study by Tomiyama et al. (2018) found that mothers of children with ASD between 5- to 8-years old were more likely to view their child less positively than mothers of typically-developing children. However, it must be noted that these effects were mediated by mothers' existing knowledge of ASD. Mothers who understood ASD were less likely to have unfavourable perceptions of their child than mothers who did not. Regardless, these findings are especially concerning when considering that social interactions between mother-child dyads is important for the development of the 'social mind' of the child (Tomiyama et al., 2018). If children's social capacity is low, they are at a significantly higher risk of later behavioral and developmental disorders. Recent research has also shown that negative mother-child social interactions may result in aversive child behaviour that puts these children at risk for later adjustment and regulatory problems (Moed et al., 2017).

Caring for a child can either bring couples closer or, in severe cases, fragment the relationship to the point of divorce (Aylaz et al., 2012; Meirscchaut et al., 2010). The dissolution of the family unit in these instances, is largely attributed to mothers feeling resentful that their partner did not provide enough support, speaking to the time- and resource-intensive nature of caring for a child with ASD (DePape. & Lindsay, 2015; Luong et al., 2009). In extreme cases where parental knowledge of ASD is especially low, resentment and strain between parents was harboured when one accused the other for causing the child's diagnosis (Fletcher et al., 2012).

However, literature has shown that as parents settle into their newfound roles as caregivers for a child with special needs, many of the aforementioned outcomes dissipate (Van Esch et al., 2018). This is likely because parents become more attuned to their needs and feel more competent in their ability to support their children. In a study by Van Esch et al. (2018), mother-adolescent interactions were observed to compare differences between parents of children with ASD and typically-developing children. The findings from the self-reported questionnaire revealed that mothers of children with ASD were more adaptable compared to the control group. Moreover, during observations of mother-adolescent interactions, the findings also show that mothers in the ASD group exhibited more creativity and sensitivity to the needs of their children. Thus, while the transition period is markedly arduous, parents eventually achieve a level of competence and adaptability that may alleviate their previous hardships.

Siblings

Siblings of children with ASD may also be impacted in unique ways (Smith & McQuade, 2021). These relationships are also especially critical since positive sibling relationships are associated with sibling involvement in later life (Burke et al., 2016). Given that ASD is a lifelong disorder, fostering strong sibling relationships ensures support for the individual with ASD in adulthood. However, siblings of children with ASD often face a myriad of adverse outcomes. For example, the literature shows that parents have differential treatment between children with ASD and their siblings whereby the former receives more attention (Aylaz et al., 2012; Divan et al., 2012). This has resulted in many siblings of children ASD feeling neglected and underappreciated because their parents invest much of their time elsewhere. Additionally, research by Shivers et al. (2019) has found these siblings are more likely to exhibit higher rates of internalizing behaviour, poorer psychological and social functioning, and they held more negative beliefs about disability compared to groups of siblings of typically-developing children. The beliefs siblings held about disability were more negative; they were more likely to view people with disabilities as aggressive and incomprehensive, as well as view them as a hindrance to their family. Similarly, Smith and McQuade (2021) also report that siblings of children with autism experience internalizing behavioural problems at higher rates than siblings of typically developing children. These siblings are also more likely to feel forgotten and have trouble fitting into the family because their sibling with ASD is typically the focal point of parental attention.

However in some cases, having a sibling with ASD yielded positive benefits. For example, a study by Markoulakis et al. (2010) found that siblings of children with ASD assisted their parents with caring for their sibling and as a result, developed increased patience and maturity. Taken together, having a sibling with autism presents unique challenges but it also has the propensity to create a nurturing positive relationship between siblings bolstered by love and affection, as well as an appreciation for the unique interests and qualities their sibling with ASD has (Smith & McQuade, 2021; Leedham et al., 2020).

Family Income and Resources

One of the most pervasive barriers to healthcare and social services is cost (Lavelle et al., 2014). There are two mechanisms that reinforce socioeconomic and financial barriers, which ultimately disparage caregivers and parents of children with ASD. Firstly, the exorbitant costs of therapeutic and medical services that having a child with ASD may require (Lavelle et al., 2014). Secondly, parents of children with ASD report lower income, likely due in part to the fact that caring for a child with ASD can negatively impact parental employment opportunities (Houser et al., 2014; Montes & Halterman, 2008).

Research by Lavelle et al. (2014) aimed to produce estimates of cost outcomes, service use, and caregiver time associated with ASD in children between 3-17 years old in the United States. Data was gathered from national data sets (National Health Interview Survey and the Medical Expenditure Panel Survey). The researchers also used a measure created specifically for the study to measure healthcare costs, school-service use, family-coordinated services, therapy use, and caregiver time. Based on the analyses in this study, the average cost of supporting one child with ASD is $17,081 USD per year. To iterate the magnitude of this issue, the researchers applied this statistic to the estimated 673,000 children in the United States with ASD in 2011, which totals $11.5 billion USD. With the rates of ASD steadily increasing, this figure is likely much larger in present day time (Maenner et al., 2020). In terms of cost breakdown, school services incurred the greatest costs for families, although healthcare services (e.g., doctor visits, therapy, etc.) and caregiving costs also had exorbitant costs (Lavelle et al., 2014). These findings suggest caregivers are more likely to spend more money on children with ASD to support their needs, well-being, and general development compared to caregivers of typically developing children. A similar pattern has been found in other countries, instilling greater confidence in the validity of these findings (Lavelle et al., 2014). For example, in the U.K. and Sweden the average cost of caring for a child with ASD is approximately $44,063 USD and $68,000 USD respectively. Thus, this evidence suggests that the crude costs incurred to support children with ASD is a pervasive barrier for caregivers and parents. Research has also shown financial costs are worsened by reduced employment opportunities and income loss (Montes & Halterman, 2008). Even when controlling for extraneous variables (e.g., parental level of education, ethnicity, etc.), parents of children with ASD reported an average loss of annual income of 14%. Thus, parents not only have to spend more money to support their children with ASD, but also make less money on average (Lavelle et al, 2014; Montes & Halterman, 2008).

To understand why parents of children with ASD earn less money than parents of typically developing children, Houser et al. (2014) sought to identify the specific obstacles caregivers of children with ASD face that affect their employment opportunities. Using a phenomenological study design, 37 children with ASD and their parents were recruited for this study. Interviews were conducted and families were followed up at 3- and 9-month intervals. In addition to sociodemographic information, parents were asked about the types of supports and social services they used for their children, some of the barriers to care they experienced, and what challenges they face with respect to employment and childcare arrangements. From the data collected, several response patterns emerged. Firstly, most parents reported having to adapt their work schedule to reduce the amount of time their children spent in nonparental care (i.e., daycares). They also had to alter their schedule to account for the time-consuming, variable nature of therapy. Secondly, nearly a quarter of parents reported having to miss work, with some having to miss up to 36 days in a year. A small percentage of respondents also noted that they quit work or dropped out of their school program after their child's diagnosis because the balance between work and arranging for suitable care was too difficult to manage. These parents also felt they had less support from extended family. This was a result of family members feeling overwhelmed or ill-suited to provide childcare for children with ASD, largely due to behavioural challenges that accompany this disorder. Parents felt uncomfortable leaving their children with caregivers because they did not feel they had the requisite skillset and professional competence to care for children with ASD. The most concerning finding is that the majority of parents viewed caring for children with ASD as a full-time job, with many feeling frustrated by having to complete demanding (yet unpaid) work. Taken together, some of the central issues to emerge are that families affected by ASD report employment problems because of how difficult it is to find appropriate and stable childcare. They also reported financial stress, difficulty accessing (i.e., incurring costs, scheduling, maintaining) services, and family stress in comparison to families of typically developing children. A limitation from Houser et al.'s (2014) study is that participants were only recruited from two service providers in an urban city center. As such, participants were predominantly middle- and upper- socioeconomic status and White. On the other hand, this highlights that families in more privileged circumstances (in terms of socioeconomic status and race) still struggle immensely with balancing employment and childcare for children with ASD. This brings into question how marginalized populations (e.g., ethnic and racial minorities) fare in terms of navigating these barriers.

An Intersectional Perspective

Navigating Systemic Barriers

Children with ASD who belong to racial or ethnic minority groups are negatively impacted by systemic barriers in several ways. Firstly, non-White children are more likely to be diagnosed with ASD at significantly later ages compared to their White counterparts (Lopez et al., 2020;

Mandall et al., 2002; Stahmer et al., 2019). Secondly, research has shown issues of accessibility and subpar care are further exacerbated by language barriers (St. Amant et al., 2017; Stahmer et al., 2019; Timmins, 2002). Lastly, the current medical framework does not account for cultural differences, thus ignoring the group-specific needs of racial and ethnic minority groups (Sritharan & Koola, 2019; Stahmer et al., 2019).

To maximally benefit children with ASD, early intervention is crucial (Wallace & Rogers, 2010). However, several studies in the United States have found children from racial and ethnic minority groups are likely to be diagnosed considerably later than their White counterparts (Lopez et al., 2020; Mandall et al., 2002). Magana et al. (2013) explored this issue further in their study in which they aimed to find differences between White and Latinx children regarding age diagnosed and parental attitudes towards accessibility (Magana et al., 2013). Forty-seven Latina mothers of children diagnosed with ASD between ages 2 and 22 were recruited for the study. They were given the Autism Diagnostic Interview to measure treatment satisfaction, attitudes towards accessibility, and parental stress levels. Consistent with previous findings, Magana et al. (2013) found that Latino children with ASD are diagnosed later (i.e., one year) than White children. Additionally, Latino immigrant caregivers report fewer options and resources to obtain a second opinion when diagnosing their child. Compared to White middle-class caregivers, Latino parents have reduced access to resources (e.g., Internet, books) and are unable to afford services from specialty clinicians. In terms of service use, the researchers reported two findings. Firstly, Latinx children received fewer services. Additionally, the services they did access were not sufficient to meet their needs compared to non-Latino White children (i.e., caregivers were dissatisfied with the quality of services provided). The study had a few methodological flaws. Participants were recruited on a volunteer basis and the researchers were unable to determine whether the effects were due to ethnicity or level of parental education. Additionally, Latina mothers were given in-person interviews while White mothers answered via mail-in survey, thus leading to a potential effect of differences in response. Lastly, the sample consisted of Mexican and Puerto Rican mothers, which does not represent all Latinx groups. Despite these limitations, the findings from this article have appeared in other studies from the emerging literature on this topic. For example, Lopez et al. (2020) also found Latinx children (and other minority groups) were diagnosed later and had less access to resources (i.e., social service programs, treatments, etc.) compared to their White counterparts (Lopez et al., 2020). There are several mechanisms driving this effect (e.g., socioeconomic status, neighbourhood), but one of the most salient effects is that of language barriers (Lopez et al., 2020; Stahmer et al., 2019; Timmins, 2002). While these studies were conducted in the United States, it is reasonable to expect a similar pattern in Canada. Recent literature has shown that Anglophones and non-official language speakers (i.e., individuals whose language is not English or French) are less likely to access medical services (Ngwakongnw et al., 2012). This effect has become especially pronounced during the COVID-19 pandemic as the literature shows an imbalance exists in the ratio of physicians to non-official language speakers (Ariste & Matteo, 2021). At present, there is an alarming paucity of research exploring whether disparities in service-seeking for parents of children with ASD among non-official language speakers exists. However, based on the discrepancies that exist in the Canadian medical system at large (Ariste & Mateo, 2021; Ngwakongnw et al., 2012), it is reasonable to expect a similar phenomenon to the US studies (Lopez et al., 2020; Stahmer et al., 2019; Timmins, 2002).

Language Minority Groups

The effect of race and ethnicity on access to healthcare-related services may be worsened by language barriers (Stahmer et al., 2019; Timmins, 2002). Since Timmins (2002) published one of the first studies suggesting language barriers are a prominent barrier to healthcare, and a breadth of literature investigating this issue has emerged. Within the context of ASD, Stahmer et al. (2019) explored cross-cultural disparities in accessing autism services. Qualitative data was gathered from focus groups and interviews with 58 caregivers of children with ASD. These caregivers belong to diverse ethnic groups (e.g., Latino, Black, and Korean), and approximately half spoke English. Fifty-five service providers and administrators who specialized in ASD (e.g., educators, pediatricians, speech pathologists, etc.) were interviewed. A persistent theme that emerged across providers' and caregivers' responses was that language barriers were still a ubiquitous impediment to accessing services and information (Stahmer et al., 2019). Many caregivers were not bilingual or proficient enough in English to communicate with their child's therapist. Additionally, the research has shown an alarming absence of bilingual service providers equipped to work with English as a Second Language (ESL) speakers. This has resulted in delayed diagnosis and access to services that are crucial for supporting children with ASD. Additionally, when caregivers had concerns or felt the services provided were inappropriate, they reported feeling helpless because they did not have the language skills to advocate for their child. Thus, the findings support the notion that language barriers manifest in inadequate healthcare. For example, practitioners are more likely to dismiss developmental concerns of language delay in children who belong to a non-English speaking family. Taken together, language barriers harm children with ASD and their families by delaying diagnoses and subsequent access to essential services, as well as negatively impacting the quality of care they receive (Stahmer et al., 2019). The study also had a few limitations; participants were recruited from four sites and only three prominent ethnic groups were considered in the analysis. However, the themes to emerge from this study are consistent with the broader literature. As reported by St. Amant et al. (2017), social skills and communication improvement were overrepresented in the child's individualized education plan (IEP) suggesting that language can also impact the diagnosis and treatment plan of ESL children. In addition to language, cultural differences have also been found to produce the same effects (Kang-Yi et al., 2018).

Cultural Attitudes: Taboos, Attitudes, and Beliefs

The issue of race and ethnicity is further exacerbated by cultural differences, as explored in an article by Kang-Yi et al. (2018). Using a qualitative study design, the researchers' objective was to understand how differences in community (i.e., cultural beliefs) impact how children with ASD receive care in immigrant communities (Kang-Yi et al., 2018). Through snowball sampling, members of the Korean-American community in New York City were recruited. These members included youth workers and members of churches (e.g., pastors, leaders, staff). Semi-structured interviews between 45 to 60 minutes were conducted, transcribed, and analyzed for patterns of response. The findings suggest that members within different cultural communities have their own beliefs about autism, that in turn influence the type of support they receive. For example, parents believed ASD is caused by poor parenting, poor attachment, pregnancy complications, and low parental intelligence (Kang-Yi et al., 2018). The presumption that abusive or poor caregiving leads to ASD has resulted in many Korean children being misdiagnosed as having Reactive Attachment Disorder. The stigma associated with ASD is due in part to the absence of disclosure, openness, and accessible resources to explain child education, development, and parenting. The participants noted that it is difficult to get informed (i.e., attend parenting seminars, learning developmental milestones, visiting early childcare centers) because many Korean parents are required to work long hours. The researchers also highlighted a paucity of specialized strategies to educate and support members within immigrant communities, thus reinforcing systemic barriers to proper care. Despite the study's limitations (e.g., small sample size, few demographic characteristics, etc.), the findings from this article are consistent with the broader literature. Sritharan and Koola (2019) reported the same narrative; cultural beliefs about ASD may act as a barrier that manifests as delayed or inaccurate diagnosis, negative perceptions of ASD and negative perceptions of healthcare and social services.

Contextualized Family Care: Family-Based Interventions

Despite many of the barriers that disparage families of children with ASD, there are many possible avenues for professionals, clinicians, educators, and advocates alike to intervene (Mazzoni et al., 2018). One of the most salient yet effective ways to support these families is through initiatives that aim to educate, empower, and support families as they learn to ensure they are meeting the needs of their children (Mazzoni et al., 2018; Prendeville & Kinsella, 2019). Family-based interventions may comprise clinical interventions, but they can also include informal supports (e.g., workshops, psychoeducation) (Mazzoni et al., 2018) and learning to work with key members within the child's proximal ecology (e.g., educators) (Azad et al., 2018).

Parent Training

Parent training has demonstrated consistent efficacy and continues to show 'informal' strategies to mitigate the potential impact of having a child with ASD are promising (Mazzoni et al., 2018; Prendeville & Kinsella, 2019). Many of these strategies are centered around educating parents and equipping them with the requisite skills to support their children (Mazzoni et al., 2018). As reported by Begum and Mamin (2019), many caregivers attribute their distress to disruptions in their daily routine and having to adjust their lifestyle to accommodate the needs of their children. Thus, if parents are equipped with the skills to feel competent and empowered when caring for their children with ASD, many of these negative emotions may be alleviated. Additionally, the distress experienced by parents is often due to disruptions in the family's routine (DeGrace, 2004; Durán-Pacheco et al., 2022). For example, disturbances in the child's sleep schedule, whereby caregivers of children with ASD who have difficulty sleeping reported increased strain, further contributing to a destabilized home environment. At present, it must be noted that there is a paucity of research demonstrating evidence-based interventions that target improving children with ASD's sleep quality specifically (Durán-Pacheco et al., 2022). Outside of the context of sleep, there are other informal supports parents can utilize to establish routines and, by extension, foster family togetherness in other areas of the home. For example, informal supports in the form of education, parental coaching, and improving knowledge of their children's symptoms are effective strategies to mobilize caregivers (Wallace & Rogers, 2010). This entails teaching parents how to establish routines and foster naturalistic opportunities for social interaction, which has a protective function for family cohesion (Boyd et al., 2014). Naturalistic opportunities for social interaction are especially critical, as they decentralize the child's disorder which creates a sense of normalcy within the family unit (Boyd et al., 2014). Establishing routines is merely one type of strategy Another effective mitigation technique that can be used is parent coaching (Brian et al., 2022; Little et al., 2018; Wallace & Rogers, 2010).

Parent coaching consists of training parents to be more responsive and sensitive to the specific needs of their children with ASD (Brian et al., 2022; Little et al., 2018; Wallace & Rogers, 2010). It educates parents on how to understand the behaviours of their children with ASD by becoming acclimated to the specific characteristics and behavioural cues that the child frequently exhibits (Little et al., 2018). Parents who undergo this form of coaching are not only better at identifying the needs of the child with greater accuracy, but they are therefore more likely to respond appropriately (Little et al., 2018). Parent coaching can also include functional communication training (Moes & Frea, 2002). This entails training parents to foster optimal communication in the parent-child dyad, which may reduce challenging behaviours (Moes & Frea, 2002). One of the ways this is achieved is by teaching the child how to communicate their needs. This ensures that their needs are being sufficiently met, as well as grants the child a sense of autonomy by enabling them to represent themselves (Moes & Frea, 2002; Little et al., 2018). Being attuned to the needs of children with ASD as early as infancy is particularly critical for parents, as early intervention for ASD typically precludes better long-term developmental outcomes (Wallace & Rogers, 2010). As parents become confident in their ability to support their children, they can transition to accessing telehealth services remotely which not only improves accessibility, but also grants them greater flexibility in their schedule as time-intensive commutes are eliminated (Ingersoll et al., 2017; Little et al., 2018). This allows professionals (e.g., occupational therapists, speech pathologists) to provide education and coaching to parents in remote areas (Little et al., 2018). Given the present COVID-19 pandemic, this also represents an opportunity to reach caregivers during government-mandated quarantines where on-site services have been suspended to prevent the spread of the virus (Alhoumaizi et al., 2021). However, it must be noted that telehealth does not necessarily work for all families, and access to technological resources is still regarded as a luxury in some areas of North America (Ingersoll et al., 2017). Thus, the success of telehealth is largely contingent on the family's circumstances.

The research also supports the notion that family coordination is a critical skill (Mazzoni et al., 2018). Examples of strategies to improve family coordination include joint focalization, equal participation of all members of the family, and organization (Little et al., 2018). Joint focalization refers to organized activities that the family can participate in to improve affect sharing their feelings (Favez et al., 2017). While this is intended to improve communication, an added benefit is that it also promotes empathy and perspective-taking between family members (Favez et al., 2017). It is also important to ensure that these activities are not centred solely around therapy or intervention strategies so that the child's disorder is decentralized when appropriate (Smith & McQuade, 2021). Equal participation of all members of the family unit refers to delegating tasks and caregiving responsibilities to ensure that one sole caregiver does not assume the brunt of caregiving responsibilities and work (Begum & Mamin, 2018; Mazzoni et al., 2018). This is an important aspect of family coordination, as disruptions in coparenting and unequal provision of childcare can be additional risk factors for marital stress and general household disharmony (Mazzoni et al., 2018). While there is a paucity of research explaining why these associations exist, it is speculated that there are differences in how mothers and fathers support their children with ASD (Griffith et al., 2015; Mazzoni et al., 2018; Taylor & Warren, 2012). For example, fathers tend to focus more on the child's performance and attainment of both developmental and educational milestones, while mothers focus more on fostering a positive emotional environment (Mazzoni et al., 2018; Taylor & Warren, 2012). Thus, parents must work together to reconcile their differences to ensure the child's welfare takes precedence.

Collaborating With Educators

In addition to working directly with families, a goal of interventions should be to bridge the gap between the home life and school to support the child and work towards building a more inclusive community (Azad et al., 2018; Pellicano et al., 2014). Existing literature suggests that parents and teachers have fragmented communication when it comes to supporting children with

ASD (Azad et al., 2018). Despite many teachers valuing feedback and input from parents, parents attributed their lack of involvement to feeling insecure in their level of expertise and lack confidence (Azad et al., 2018; Simpson et al., 2017). Despite feeling inept, parents should continue to strive to be active agents in their children's education as doing so will yield many positive benefits (Azad et al., 2018; Kurth et al., 2018). In addition to psychoeducation, parent training, and attending workshops to learn about ASD, parents can also participate in their child's Individualized Education Program (IEP). IEPs consist of a multidisciplinary team of professionals (e.g., educators, psychologists, therapists) whose aim is to assess the child's scholastic achievement, develop goals, evaluate progress, recommend specially designed instruction and accommodations if necessary, and make adjustments as the child progresses (Kurth et al., 2018; Ruble et al., 2010). Establishing an effective IEP where all parties can deliberate the best possible strategy to support the child has been associated with positive outcomes. For example, in a study by Kurth et al. (2018), several predictors of parental satisfaction with the child's IEP were identified. In general, parents who had a greater input in their child's education and greater perceived support from school personnel were more likely to report satisfaction with their child's school experience. It is therefore critical that parents oversee the provision of their children's not just at home, but in other settings as well. However, it also important to mention that parents in the study shared some of the barriers that impeded their ability to work with schools and the school system at large, thus requiring them to seek privatized care. For example, some schools do not use existing resources to offer inclusive programs or to hire personnel that will support the child's learning objectives. Additionally, parents may not have the time to make meaningful contributions to their children's IEP or maintain consistent correspondence with the child's educators due to professional work obligations. Thus, while parents could be encouraged to get more involved in their child's IEP and education to support their children's attainment of developmental and educational goals, this is not plausible for all families (Azad et al., 2018; Kurth et al., 2018; Ruble et al., 2010).

Outside of the school environment, parents access and participate in more community-based activities (Smith & McQuade, 2021). Existing literature shows that parents of children with ASD often feel overwhelmed when planning activities for their children due to the time-intensive nature of preparing for these activities (Galpin et al., 2018; Smith & McQuade, 2021). For example, children with ASD may report deficits in self-care skills, diet, and communication which requires parents to make additional accommodations to ensure the optional environment and activity for their child (Smith & McQuade, 2021). Additionally, these environments can sometimes become too overstimulating which results in outbursts that may ostracize the child and their parents from the rest of the community (Zapata-Fronseca, 2018). As a result, some parents become withdrawn out of fear of being scrutinized. Parents who become disengaged from their community due to parental anxiety that stems from others' perceptions of them are ultimately doing a disservice to the child and broader family context (Galpin et al., 2018; Smith & McQuade, 2021). For example, studies have shown that parents who are inhibited by the pressure of accommodating their children with ASD can become socially withdrawn from the community at large (i.e., parents who centralize their children's condition) are less adaptable, inflexible, and are less likely to participate in spontaneous events (Smith & McQuade, 2021). Thus, parents should aim to strike a balance between attention and coordination, so that all members of the family are attended to. In considering the benefits of participating in community-based activities such as increased family cohesion and reduce parental anxiety, getting involved in family-based activities is a worthwhile endeavour (Smith & McQuade, 2021).

Cultural Sensitivity: The Case for Adapted Interventions

Existing literature has established several possible avenues for caregivers of children with ASD to pursue to get educated, improve their self-efficacy and competence, and improve the overall functioning of the family unit (Bearss et al., 2015; Kalalo et al., 2021; Mukhtar et al., 2018). However, there is an alarming paucity of research exploring interventions attuned to the specific needs of families who belong to racial, ethnic, and cultural minority groups (Kaiser et al., 2022). This is especially problematic considering that many interventions for these families are tested with predominantly White families identified as middle class or higher (West et al., 2016). Thus, it is critical to consider culture through the lens of the ecological validity framework, and how interventions must therefore be adapted to support those at the margins.

The Ecological Validity Framework

The Ecological Validity Framework (EVF) is an eight-dimensional model that enhances the ecological validity of an intervention with a target (i.e., culturally different) group (Magana et al., 2017). This framework emphasizes the core tenets of cultural diversity which have been divided into eight unique but interrelated components (Bernal et al., 2009; Magana et al., 2017): (1) *Language*: Ensuring that the intervention is developed and made available to a plethora of diverse language speakers. (2) *Persons*: Considering the characteristics of both the participant and interventionist, as well as the relationship between them. For example, peer-led interventions from individuals within the same community, or allowing an 'outsider' who is made aware of cultural differences to run the intervention. (3) *Metaphors*: Understanding unique symbols and concepts that are shared within the community of interest. (4) *Content and (5) Concepts*: Knowledge of the individual's culture (e.g., traditions, values, etc.). (6) *Goals*: Ensuring that the goals of the intervention are culturally sensitive and developed alongside members of the community to ensure that their needs and interests are properly addressed. (7) *Methods:* Considering the methods for achieving the outcomes of a given intervention, and whether they are accessible, feasible, and culturally sensitive. (8) *Context*: Considering both the social context of the intervention and the individual context of the participants (e.g., acculturative stress).

Cultural Adaptation

Cultural adaptations to interventions must consider both the individual and systemic barriers that give rise to discord and duress for families of children with ASD (Magana et al., 2021a). At present, a standardized procedure for cultural adaptation does not exist. However, strides have been made by advocates (Kuhn et al., 2020; Nguyen et al., 2021) to identify the core tenets of a rudimentary cultural adaptation process. There are profound implications for doing so, such as promoting more inclusive research practices that engages both the individual and stakeholders to foster equity, thus reducing health disparities (Magana et al., 2021a).

There are six phases that encompass the cultural adaptation process outlined by Magana et al. (2021a): (1) Creating an alliance between the researchers and interventionist to create knowledge with stakeholders. (2) Deciding on an intervention and ensuring that it has been tested with diverse groups. If key factors such as sample recruitment and retention, engagement with the intervention, and participant outcomes vary as a function of the group the individual belongs to, cultural adaptation is needed. (3) Determine what the needs of the individuals are prior to both administering the intervention or making adaptations. (4) Pilot any adaptations to the intervention. (5) Evaluate the efficacy of this pilot study by discussing the results with stakeholders for insight and feedback. (6). Update, adapt, and implement based on whether refinement is needed. Whether or not refinement is needed is based on the results of the pilot study and the feedback provided by stakeholders and participants.

Parents Taking Action (PTA): A Culturally Adapted Intervention

In line with the EVF and six phases to design a culturally-sensitive intervention, Magana and colleagues developed the "Parents Taking Action" (PTA) intervention (Magana et al., 2017; Magana et al., 2021a). The PTA intervention offers parent training to families of children with special needs, including ASD. The manual, modules, and protocol were all developed in consultation with social workers who work with Black, Indigenous, and/or People of Colour (BIPOC) families as well as developmental specialists (e.g., pediatricians and educational consultants). After completing the eight (8) week intervention, parents reported statistically significant differences on the following target outcomes: knowledge of autism, understanding their children's symptomology, competence accessing community-based resources, self-efficacy to help support their children attain developmental and educational milestones, knowing their rights, having support systems, and total score family outcomes (Magana et al., 2017). Additional data was collected to measure the feasibility and efficacy of this intervention. The findings revealed statistically significant differences for efficacy in use of strategies at pre- and post-test intervals, suggesting that parents find the intervention practical. This original pilot study was conducted with 20 mothers of Latin American descent.

PTA – Robustness and Flexibility

Since this original pilot study, PTA has been tested in several other settings with other racial and culturally diverse groups. For example, PTA was used with Chinese immigrant families and Black families and yielded successful results indicating PTA can be used with different ethnic groups beyond the Latinx population (Dabanah et al., 2021; Magana et al., 2021a). Beyond North America, PTA has also been tested in Colombia which speaks to not only its robustness but flexibility (Magana et al., 2021b). Despite its novelty, PTA is beginning to build substantial evidence in support of its efficacy both in terms of its clear, clinical objectives but also for its practicality. Across the pilot studies, parents overwhelmingly view PTA as a feasible intervention that yields positive results (Dabanah et al., 2021; Magana et al., 2021a).

PTA can also be delivered using different modalities. For example, the original pilot study (Magana et al., 2017) consisted of a fourteen-week intervention with trained interventionists, or *promotoras*, completing the intervention during weekly home visits. Since this pilot project, Dabanah et al. (2021) conducted a follow-up study with results that show PTA could be run in group settings as opposed to one-on-one sessions. Additionally, Magana et al. (2017) found that PTA could also be delivered remotely through Zoom. An added benefit in doing so is that families from different cities (e.g., Chicago and New York) were recruited to participate in the same group study which allowed the researchers to increase their sample size (Magana et al., 2017). The duration of the intervention can also be altered depending on the needs and goals of the researcher (Garcia-Torres & Magana, 2019; Magana et al., 2021b). For example, in one study that assessed the efficacy of PTA in Bogotá, Columbia (Garcia-Torres & Magana, 2019), only nine (9) topics of the intervention were administered out of a possible 14. Additionally, these topics were condensed into four three-hour sessions. Thus, the literature shows that PTA can be easily adapted and tweaked to fulfill different purposes.

At present the PTA intervention has only been tested on one ethnic group at a time. It has not been tested on a heterogeneous cultural, racial, and/or ethnically diverse sample of participants (Magana et al., 2021a). This therefore represents a novel opportunity to test the efficacy of PTA on a mixed group with the hope of supporting parents achieve PTA’s objectives (e.g., increased knowledge, improved self-efficacy, etc.) while also potentially building support groups and social cohesion between different ethnic groups.

The Present Study

Given the extent to which contextualized family care has been shown to be an effective intervention modality (Cridland et al., 2014; Spain et al., 2017; Wright & Benigno, 2019), it was especially important to consider an intersectional approach when exploring the efficacy of a novel parent training workshop. As such, the present study had two primary objectives. Firstly, to conduct a needs assessment to identify the types of supports diverse parents of children with ASD rely on, and whether they were satisfied with the quality of these supports. The questions asked were, *a. What types of services do parents of children with ASD from racial, ethnic, and cultural minority backgrounds rely on in Montreal, Quebec, Canada? b. Are these parents satisfied with the quality of care they receive?*

Secondly, the aim was to assess whether an adapted version of the PTA workshop [1]is effective. Questions asked were, *a. Does this adapted version of PTA increase parents' knowledge of ASD? b. Does this intervention reduce or alleviate parental stress? c. Will parents become more confident in their caregiving abilities and report higher rates of self-efficacy?*

Methodology

Sample and Recruitment

Sample Inclusion/Exclusion Criteria

Age. Given the extent to which early intervention is crucial (Sone et al., 2021), parents of young children with ASD (i.e., less than 12 years old) were recruited. The literature suggests that the average age of diagnosis in Canada is varied. A study by Oullette-Kuntz et al. (2009) sought to measure the average age of diagnosis across four regions in Canada. The results ground inter-regional differences in the average age of ASD diagnosis with Southeastern Ontario having the

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[1] Expressed permission to use a modified version of the 'Parents Taking Action' workshop was granted by Dr. Sandy Magana from the University of Texas at Austin, Steve Hicks School of Social Work.

oldest age (55 months), a stark contrast to Newfoundland and Labrador who boasted the lowest age (39 months). At present, research that explains potential factors driving these differences is lacking. A recent metanalysis by Van Hof et al. (2020) measured the average age of diagnosis for ASD from 55 studies published between 2012 and 2019. The findings suggest a mean age of 43.18 months for children under the age of 10 years old. On the lower end of this range, children were diagnosed as young as 30.90 months and on the higher end, 74.70 months. Thus, it is difficult to select a target age especially when considering that children from cultural, racial, and ethnic minority backgrounds may also receive a diagnosis later (Lopez et al., 2020; Mandall et al., 2002; Stahmer et al., 2019). Parents of children under the age of 10 were eligible to participate. However, this age was later increased to 14 years old to improve participation rates.

ASD Diagnosis. Caregivers of these children must have received a formal evaluation and diagnosis from a professional (e.g., a registered psychologist, psychiatrist, pediatrician) based on observation, criteria from the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), and the child's developmental and medical history (American Psychiatric Association, 2013). The DSM-V notes three tiers to ASD severity. Children in Level 1 require support as they may have difficulty with social communication and often exhibit maladaptive, inflexible behaviour that impair the quality of their daily lives. Children in Level 2 have marked impairments in communication ability (i.e., verbal and nonverbal). These children also have difficulty adapting to changes in their routine and may become distressed when tasked with changing action or focus on a given task. As such, these children require substantial support. Children in Level 3 require very substantial support as they experience severe communication skills deficits (e.g., low frequency social interaction initiation, few social responses to others, only responds to direct social approaches). These children have marked behavioural impairments that severely inhibit their ability to function in a variety of spheres. Parents of children with ASD, regardless of severity, were recruited and eligible to participate in this study. Parents were not asked the severity of their child's diagnosis, nor were they included or excluded on the basis of the level of severity of their child's diagnosis.

Sociodemographic Characteristics. One of the goals of this study was to determine the efficacy of a psychoeducational intervention that helps families of children with ASD from racial, ethnic, and cultural minority groups. As such, only parents from racial, ethnic, and cultural minority groups were initially eligible to participate in the study on the basis of whether they self-identify as Black, Latinx, Arab, and/or Asian. However, due to the unique context of Quebec (i.e., language laws that instate French as the primary language of the province), the inclusion criteria were later expanded to include immigrants and first-generation Canadians (i.e., children of immigrants). No limitations were placed on socioeconomic status or education level. Previous work has focused primarily on mothers (Magana et al., 2021a). While mothers carry substantially more childcare-related responsibilities (DePape & Lindsay, 2015; Luong et al., 2009), fathers undoubtedly may have a lot to gain from participating in an intervention whose core tenets promote education, self-efficacy, and perceived competence to support their children.

Recruitment Sites

After receiving ethical approval**,** parents were recruited in the Montreal area using a purposive sampling method in two ways. Parents were solicited from various centres, organizations, and community-based organizations that aim to support individuals from different ethnic backgrounds. Parents were also recruited on social media. This entailed joining specific Facebook groups (e.g., 'Parent support group for parents of children with ASD in Montreal') and advertising a call for participants. A breakdown of the research questions, the project's phases and the intervention's objectives were outlined. A comprehensive list of potential recruitment sites and copy of the recruitment poster is provided in Appendix A. Examples of these sites include the *Cote-Des-Neiges Black Community Association*, is a community-led group aimed at promoting educational, social, and cultural prosperity in Montreal's Black community. Another example is the *Centre d'aide aux familles latino-américaines* which supports Latinx families integrate into Quebec society by familiarizing them with social services and resources.

Sample Composition and Procedure

Five participants (*n* = 5) expressed interest in the present study and participated in *Phase I*. However, one participant (Parent 1) was lost to attrition and did not participate in *Phase II* (*n* = 4). The parents represent a range of ethnicities. Regarding their children, the average age was 10.2 and the average age of diagnosis was 4.6 years of age and there were four boys and one girl. Firstly, parental consent was obtained prior to data collection (Appendix B). Secondly, semi-structured interviews with parents were conducted remotely on Zoom. In this Zoom session, parents were asked various questions about the types of services they rely on to support their children (e.g., diagnostic resources, interventions, supports within the public and private sector, etc.). At the end of the interviews, parents completed all pre-test scales and measures. This procedure comprises Phase I. In Phase 2, parents attended eight sessions of the adapted PTA workshop. During these sessions, parents were given presentations covering various topics related to ASD, accessing services and supports, stress management techniques, and how to become better advocates. They were also asked to complete anchoring activities during these sessions and, at times, were encouraged to complete additional self-guided activities (e.g., activities in which they were asked to reflect on their child's behaviour, therapy goals, and current challenges they face as caregivers). Once the workshop was completed, parents completed the same measures at post-test.

Parent 1. Parent 1 was a Latina mother of an 11-year-old boy. Her child was mixed ethnicity (Cuban-Italian) and was diagnosed with ASD at the age of 3 years old by a neuropsychologist. Parent 1 only participated in Phase I of the present study.

Parent 2. Parent 2 was an immigrant from the United States. He was White and a dual citizen of both Canada and the United States. His child was a 14-year-old boy, the oldest of the five participants in the present study. He was diagnosed at 10 years of age, the oldest in age of diagnosis of all the children, by educational specialists in Vermont.

Parent 3. Parent 3 was an immigrant of Irish-Canadian descent. Her child was a 4-and-a-half-year-old boy, the youngest child. Her child had just turned 4 when he received his ASD diagnosis from a specialist at a health centre in Montreal.

Parent 4. Parent 4 was Asian-Canadian. At the time of the interview, her daughter was 10, though she turned 11 during the study. She received a formal ASD diagnosis at the age of 4 from a pediatrician at a children's hospital.

Parent 5. Parent 5 was Afro-Latina. Her child was a 10-year-old boy and received a diagnosis at the age of 2 from a team of psychologists at a children's hospital. At 2 years of age, he was the youngest to receive a formal ASD diagnosis of the children whose parents participated in the study.

Protocol For Phase I

Semi-Structured Interview

In *Phase I* of this study, the supports of families of children with ASD from cultural, racial, and ethnic minority groups were explored by conducting semi-structured interviews. This phase aimed to identify the types of supports these parents relied on and whether they were satisfied with the supports they received. A qualitative design lent itself well to this inquiry as it provided parents with the opportunity to shed light on their unique, lived experiences in a way that a quantitative design could not. While use of scales and questionnaires is methodologically sound (Srinivasan et al., 2021; Zorec & Pop-Jordanova, 2020), a qualitative design often grants a greater degree of agency to parents and can be empowering by allowing them to share (Saldana et al., 2021). Prompts and questions were taken from the Family Outcome Survey (FOS) - Revised (Bailey et al., 2008). This measure includes five subscales in total but only items from one subscale were used. The subscale of interest focused on caregivers' social supports and their satisfaction accessing services and resources offered at the community level, as well as challenges they may face. For example, question 7 asks, "After receiving the diagnosis, which types of supports and resources (e.g., referral to a specialist, referral to support groups, information brochures or literature on the topic, intervention services) did you receive?". The follow-up questions asked whether these services were accessible (e.g., easy to get to, covered by insurance, etc.). The complete set of interview questions and prompts can be found in Appendix C. The semi-structured interviews with the participants took approximately one hour and were conducted through Zoom. This method allowed for rich data to be captured via interview transcripts. Per Brinkmann (2018), a semi-structured interview allows for a greater degree of leeway and flexibility to follow up on themes that are deemed important. Additionally, interviewers can focus the conversation on specific issues that arise without being confined to a set script. The data collection procedure was informed by the steps for conducting narrative research outlined in Cresswell and Poth (2017). This entailed selecting subjects and ensuring their story is properly situated within their personal experience (e.g., job, role within the family context, etc.), culture (i.e., racial and ethnic background), and historical context (i.e., the current COVID-19 pandemic).

Data Coding and Analysis

Transcripts were coded using first cycle (In Vivo and Emotion) coding and second cycle (Pattern) coding. ‘In Vivo’ coding is an appropriate method to preserve the participants’ meaning, views, and actions (Charmaz, 2014; Saldana, 2021). This is particularly important considering one of the primary objectives of the study was to explore the subjective experience of parents of children with ASD. This method also allows one to amplify the voice of the participant which, from an advocacy standpoint, was an intended benefit (Saldana, 2021). ‘Emotion’ coding was also employed concurrently to explore the interpersonal experiences of participants (Liu, 2015). Pattern coding was used during second cycle coding to contextualize participants’ experience within the broader context of their social networks, patterns within interpersonal relationships, and experience with systemic forces at large (Saldana, 2021). It allows one to analyze the directional processes of a given phenomenon. This had positive implications for this study as it allowed us to see not only how participants engaged with community-based services, but how barriers that existed within these systems may have impeded both the access and quality of supports parents received.

Several strategies were used to ensure the trustworthiness and validity of the data. Firstly, analytic memos were written throughout the first phase of the project to reflect upon the ongoing research process. This provided an opportunity to compartmentalize existing biases. Analytic memos also allowed for reflection and the writing of descriptive summaries of data collected (Mason, 2002; Thornberg & Charmaz, 2014). It served as a rudimentary way to summarize and reflect on salient ideas from the data without reducing it, thus allowing for a rich analysis

(Saldana, 2021). Secondly, debriefing was used with my supervisor to discuss the themes extrapolated from the data. Additionally, a colleague within the department was asked to code one of the transcripts. They were made aware of the coding strategies to use when analyzing the transcripts. Codes derived from these transcripts were compared to ensure a degree of reliability. This entails comparing codes, subsequent categorization, themes extrapolated, and whether both raters tapped into the same constructs.

Moreover, attention was also devoted to ensuring the interview process itself did not influence the participants' answers. This phenomenon, known as research reactivity, is a threat to validity (Maxwell, 2013). While it is impossible to extricate research reactivity completely, certain strategies were used to minimize its effect. For example, asking questions using non-judgmental verbal and body language so the participant felt comfortable and at ease is critical. Another important strategy employed was ensuring empathic neutrality (Hays & Singh, 2012). This encompasses three key components to maintain the study's integrity and validity: communication, understanding, and care (Hays & Singh, 2012).

Additional strategies to improve the study's validity were implemented. For example, ensuring the transcriptions were accurate so the meaning from the transcriptions were the same as when spoken orally. To do this, check-ins with the participants were conducted to ensure their intended meaning was accurately understood during the interview. Thus, active listening and consistent engagement during this process were crucial.

In addition to transcribing the interview, notes were taken. These notes consisted of details regarding the participant's story, as well as the participant's body language and intonation during the interview to not only understand what the participant said, but how they did so.

Protocol For Phase II

In *Phase II,* a pre- and post-test design was used to test the efficacy of an adapted PTA intervention. Due to time and sampling constraints, changes were made to the original protocol such as: administering the intervention remotely on Zoom, recruiting a mixed sample consisting of multiple ethnic groups rather than soliciting one group, and delivering the intervention in a group-based setting rather than on an individual basis. With the exception of recruiting a heterogenous, ethnically diverse sample, these modifications have been validated by existing research (Magana et al., 2021a). During these eight weeks, parents were given the opportunity to not only learn about ASD and strategies to support their children, but also to complete anchoring activities (e.g., listening to simulated radio program, viewing a video, completing "home assignments") where they were asked to try implementing a strategy throughout the week. At the start of each session, parents were given the opportunity to share their week in review and experience implementing the strategies in the intervention. A comprehensive schedule of the program including objectives, content, and activities is outlined in Appendix D.

The intervention consisted of an eight-week long program. Starting from the first week, the primary goal was to equip parents with knowledge of ASD, to promote advocacy, and to help parents feel competent and confident navigating the system. Parents received an introduction to the program (e.g., schedule, overview of the goals, introduction to the materials). Parents were then trained to understand their child's behaviour by learning to understand the development of social and play skills, as well as communication in children. Parents were also trained to recognize the signs of ASD and understanding the diagnostic criteria of ASD. The aim of this was to not only improve parent's knowledge, but to dispel common myths about ASD. Parents also learned how to advocate for their child at school, which was especially critical to ensure that they were receiving the services they need. In this module, ASD and the child's behaviour with others were explained to build social support. Parents were also equipped with strategies to reduces stress. Additionally, parents were made aware of evidence-based interventions to improve their child's functioning (e.g., social and play skills, communication ability) and decrease problematic behaviour. Parents learned about current practices and strategies to encourage communication with their children. Parents also learned strategies to improve their children's play and social skills with other children. Finally, parents learned to understand the root of problem behaviour(s), as well as how to prevent and address them.

Measures

Three measures were administered at pre- and post-test intervals: The *Caregiver Burden, Satisfaction, and Efficacy* scale (Heller et al., 1999) (Appendix E), the *Autism Parenting Stress Index* (*APSI*) developed by Silva and Schalok (2012) (Appendix F), and the *Autism Spectrum Knowledge Scale – General (ASKS-G)* (McClain et al., 2019) (Appendix G). These measures were used to determine whether the intervention improved parents' knowledge of ASD and alleviated parental stress. It also allowed us to observe whether parents become more confident in their caregiving abilities, whether this resulted in greater self-efficacy beliefs.

Caregiver Burden, Satisfaction, and Efficacy. There are three dimensions to this self-report questionnaire (Heller et al., 1999). A higher score on this measure means higher levels of caregiver's perceived self-efficacy and competence, satisfaction with their relationship with the child, and degree of burden. Firstly, caregiver burden explores the effects of caring for a child with ASD on employment, personal time, social opportunities, caregivers' relationship, etc. (e.g., caring for my child places a financial strain on my family). Caregiver satisfaction includes items that look at the relationship between the caregiver and child (sample item: helping my child helps me feel close to him/her). Finally, caregiver efficacy is designed to measure the caregiver's perceived self-efficacy, competence, and ability to effectively parent a child with special needs (e.g., I can manage my child's behaviour). This measure uses a 4-point Likert scale where the participant can rank whether they strongly disagree (1) or strongly agree (4) with a statement. As we were primarily concerned with self-efficacy and parents' perceived competence, only one subscale was included in the final analysis though parents completed the entire questionnaire. While the entirety of the scale was administered, only the dimension exploring parental efficacy was included in the findings of the present report, as constructs such as caregiver burden and satisfaction were not target outcomes included in the present study's research questions.

Autism Parenting Stress Index. The *APSI* identifies where parents of children with ASD need support (Silva & Schalok, 2012). It was also used to assess the success of an intervention whose target is to reduce parenting stress (DesChamps et al., 2019). It is a self-report questionnaire where parents were asked to rate how stressful the event described in a given item is ranging from 'not stressful' to 'so stressful that sometimes we feel we cannot cope'. Sample items include rating the following events or situations: tantrums/meltdowns, self-injurious behaviour, concern for the future of your child being accepted by others. This measure is not only important for measuring the cumulative volume of stress parents of children with ASD experience, but can also be used to identify which factors specifically trigger stress.

The Autism Spectrum Knowledge Scale – General. The *ASKS-G* general population version is a measure to assess the knowledge the general population has of ASD (McClain et al., 2019). While there are many autism knowledge scales, many have been developed and validated using samples consisting of clinicians and professionals (Benallie et al., 2019; McClain et al., 2019). The *ASKS-G* is therefore an important measure, as it was developed and validated using parents. This measure is a 31-item true/false questionnaire assessing caregivers' knowledge and understanding of ASD. There are five subsections: *Etiology and prevalence* (e.g., vaccines can cause ASD), *symptoms/associated behaviours* (e.g., all individuals with ASD have low IQs), *assessment/diagnosis* (ASD can only be diagnosed after the age of 4), *treatment* (e.g., restricting certain foods is an effective treatment for ASD), and *outcomes/prognosis* (e.g., individuals with ASD will never learn to speak). This measure is critical, as ASD knowledge is associated with higher advocacy, likelihood of seeking support, and being better equipped to identify the early signs of ASD (Benallie et al., 2019).

Data Collection & Analysis

Data collected from the questionnaires administered at both pre- and post-test intervals was compared to determine whether the adapted intervention was successful. This consisted of a single-subject comparison between the caregiver's scores before and after the intervention. Additionally, individualized case studies were compiled and presented to demonstrate both similarities and differences in how parents benefited from participation in this intervention.

Results

Research Aim I

The first aim of the present study was to understand the types of supports ethnically diverse parents of children with ASD rely on and whether they are satisfied. Firstly, we asked what supports parents of children with ASD from racial, ethnic, and/or cultural minority backgrounds rely on to support their children. Secondly, we asked parents whether they were satisfied with the quality of support they received.

Data Analysis

Transcripts (*n* = 5) were coded using first cycle (In Vivo and Emotion) and second cycle (Pattern) coding. 'In Vivo' coding was used to preserve the participants' intended meaning, views, and actions related to the phenomenon of interest (Charmaz, 2014; Saldana, 2021). 'Emotion' coding was used concurrently to explore the interpersonal, subjective experiences of participants (Liu, 2015). Pattern coding was also used during second cycle coding to contextualize parents' experience within the broader context of their social ecology (Saldana, 2021). The aforementioned strategies to improve trustworthiness and validity of the data were implemented (e.g., analytic memo writing, peer debriefing, reducing researcher reactivity).

Summary

Service Access & Quality. Across all the interviews, the parents explained how they solicited help from a suite of services across different sectors (e.g., healthcare, education, social service programs) to support their children. There are two dimensions to service access and quality to support their children: diagnosis and subsequent therapy/intervention. Moreover, parents were asked about the services they use to support themselves (e.g., parent training workshops, counselling, therapy) in the face of possible caregiving-related challenges. Regarding initial diagnoses, the most common service accessed was from specialized psychoeducational centres that conducted formal ASD evaluations. Only two out of the 5 parents had their child diagnosed by professionals through the medical system. For all parents, however, their pediatrician was their first point of contact. Parents initially met with their pediatrician to discuss their concerns and were referred to external services to obtain a formal evaluation and diagnosis for their child. Getting in contact with a pediatrician did not pose any problems for parents. However, the most challenging and distressing period occurred when parents tried to meet a specialist to obtain an evaluation. Regarding therapy/intervention modalities, the majority of parents (60%) used a mix of services from both the public and private sectors. Parents mostly sought services from the private sector in the interim as they were placed on a waitlist for government-subsidized services in the private sector. Examples of these services include help from specialized professionals, such as ABA therapists, speech therapists, and occupational therapists. Parents also sought help from special education technicians. Within the public sector, parents relied on the services the school provided. The children received therapy from ABA therapists, speech therapists, occupational therapists, and benefited from having a school psychologist and team of special education technicians on staff. However, many of these professionals had a large case load and rarely met with the children one-on-one. Instead, they often offered group-based interventions to meet the high volume of diverse learners and students with neurodevelopmental disorders. These services were only offered once per week which was largely insufficient for parents. Finally, the parents in the present study did not access services to support them directly. Only one of the five parents joined a support group on social media.

Quality and Frequent Challenges. Across all five participants who participated in the interviews, many of the same challenges emerged. Firstly, long waitlists made it difficult for parents to obtain a diagnosis and subsequent resources to support their children. Secondly, after obtaining a diagnosis, two parents in the study did not receive guidance on how to proceed. In the absence of information from their healthcare provider or professional responsible for diagnosing their child, many of these parents were forced to conduct their own research independently. Thirdly, accessing private healthcare was not only inaccessible for the parents in this study, but language barriers made it difficult to find services in English. With Quebec being a Francophone province, many parents were required to settle for services they were not always content with. The source of this dissatisfaction was due to language barriers that made it difficult to not only find suitable services, but also maintain consistent and clear communication with specialists. A fourth challenge to emerge in the interviews was the pitfalls of public services, namely those within the education sector. These pitfalls were often derived from one central issue: a lack of resources to adequately supply diverse learners and children with special needs with the care they need and deserve. The parents in this study overwhelmingly agreed that there are few specialized professionals (e.g., ABA therapists, speech therapists, occupational therapists, special education technicians) available for free within the school, and even fewer professionals who were appropriately trained. A common critique of these professionals was that they were either inexperienced or under-supported, often forcing children to either settle for group-based interventions or fewer (i.e., < 2) hours of therapy per week.

Parent 1

Parent 1 noticed several alarming behaviours that led her to conduct her own research on child development and ASD. After consulting with her pediatrician, she was placed on a waitlist to obtain an evaluation. She remained on a waitlist for one year before electing to obtain private care from a neuropsychologist who evaluated and diagnosed her child. The long wait times created feelings of anxiety and distress in Parent 1, ultimately driving her to seek therapy for her child before obtaining a formal diagnosis. Without a formal diagnosis, therapy came at exorbitant costs since Parent 1 needed to seek private healthcare to support her child. Obtaining a formal diagnosis also proved to be tricky for Parent 1, as she stated her pediatrician initially dismissed her child's problematic behaviours by attributing it to his 'Cuban ethnicity'.

Regarding the types of services accessed, Parent 1 met with her child's pediatrician, therapists from government-funded programs, educators, a speech therapist, physiotherapist, and an occupational therapist. Despite access to a multi-disciplinary team, the quality of these services varied immensely. In terms of consulting with health professionals, Parent 1 did not feel supported by her child's pediatrician. Her child's pre-existing health condition required an aggressive steroid treatment with side effects that affected the child's mood and behaviour. As a result, her pediatrician did not initially believe his behaviour was indicative of ASD, but rather a by-product of the medication. This experience proved to be very frustrating for Parent 1, as she stated, "Even the doctors weren't really taking me serious".

Regarding the team of therapists working with her child, Parent 1 is currently pleased despite the immense challenges and obstacles that preceded the present intervention plan for her child. The first of many challenges emerged when she first enrolled her child in a special, private daycare before beginning elementary school. Here, she described the therapists as ill-equipped to handle the demands and needs of children with special needs. Secondly, after an immense wait time, Parent 1 was able to obtain government-subsidised therapy from an educator offered through a provincial social service program. This experienced posed many problems. Firstly, as the educators were not able to communicate effectively in English, Parent 1 had difficulty maintaining communication between herself and the team of therapists. She stated, "They pretend that it's services in English, but the educators are not able to hold the conversation in English". Additionally, the therapists themselves did not effectively help her child. One therapist told her, "Madame you have more experience than I do. I don't think I'll be able to help you". This same therapist eventually dropped her case because she claimed both the child and the mom were too demanding to work with. At the time of the interview, Parent 1 had hired two therapists from the private sector to support the needs of her child. While private therapy was expensive, Parent 1 deemed it necessary due to the aforementioned challenges associated with seeking care from public, social service programs.

Regarding the educational context, the school where her child was enrolled did not have the resources to provide individualized intervention. However, her child was offered free group speech therapy, physiotherapy, and occupational therapy. Parent 1 did not have any critiques for these services. However, she did feel frustrated by the experience of navigating systemic barriers (i.e., underfunded schoolboards). For example, Parent 1 was deemed ineligible for a government-funded program on the basis that her child was enrolled in an English school in a Francophone province. The inability to access critical services on the basis of language laws (i.e., Bill 96) left Parent 1 angry. This eventually culminated in her taking legal action, which had been covered by major media outlets (e.g., CTV) in the country. At the time of the study, her case had been taken up by politicians and a legal case was being built due to the view that it violated the Charter of Rights.

Taken together, Parent 1's experience as a caregiver had provided several interesting findings. Firstly, a multidisciplinary team consisting of therapists, educators, and specialists was needed to support her child's learning. Secondly, there were several challenges associated with seeking these supports as an ethnic, racial, and/or cultural minority in Quebec. While many of these challenges were due to poor government planning and resource management (e.g., long waitlists, fewer qualified and competent professionals in the public sector than in the private sector, less individualized intervention offered within the school), some were due to systemic barriers and perceivably discriminatory legislation such as those that deny access on the basis of language services available in the province.

Parent 2

Parent 2 first developed an inkling that his child may have a neurodevelopmental disorder based on their early behaviours (e.g., language processing, sensory processing). The process of obtaining a formal diagnosis proved to be exceptionally difficult. The long wait times in the public sector and tremendous cost to obtain a formal diagnosis drove Parent 2 to seek help in the United States where the costs for a diagnosis were comparable to Canada, but wait times were considerably shorter. The assessment was conducted by a team of psychologists at an educational centre in Vermont. On one hand, Parent 2 felt considerable relief after obtaining a diagnosis but the reality of having a child with special needs with little information about available resources incurred a tremendous toll on their mental health. As an immigrant from the United States, Parent 2 felt out of his depth trying to identify available services to support his child. Parent 2's process of obtaining information was conducted entirely independently. He conducted his own research on the Internet and joined social media support groups to get connected with other parents of children with special needs.

Regarding the types of supports Parent 2 relied on to support his child, he initially sought out the help of a speech pathologist to address his child's speech delays prior to obtaining a formal ASD diagnosis. At the time of the interview, his child was receiving support from a speech therapist, an occupational therapist provided by the schoolboard, a psychiatrist, and two psychologists. Overall, Parent 2 was pleased with the quality of these supports. Not only did he believe his child was receiving proper support, but communication between him and the team of specialists was open, clear, and available when needed. Between specialists, there was also communication in the form of yearly evaluations where, "they share notes, work on strategies together”. Additionally, the treatment modality was flexible and his child was able to attend either in person or online.

However, despite the strides his child has made receiving therapy, there were still many difficulties and challenges to accessing this care. Parent 2 was not able to obtain a formal diagnosis or referral from a family doctor because they did not have a family doctor and were still on a waiting list to receive one. Additionally, none of the services received were subsidized because the Quebec government did not deem his needs severe enough. As a result, Parent 2’s child did not receive weekly care, but rather operated on a needs basis. Each 45-minute session was $100 and, after an 18-month process to have the costs recuperated, Parent 2 and his family had his request denied. Many of the gaps in his child’s intervention plan, however, were filled by the services offered by his child’s school since it was a special needs school. Despite the school’s commitment to supporting neurodiverse learners, there was still an alarming lack of resources. For example, there was only one speech pathologist in a school of approximately 300 students.

To summarize, Parent 2 was generally content with the quality of services (i.e., speech therapy) received, though long wait times and convoluted criteria made it difficult to access and afford special care. His child’s enrolment in a school catered to children with special needs may have offset the lack of private services accessed, though it must be noted that the school had many of its own challenges (e.g., deficient in resources to provide enough support to its student body).

Parent 3

Parent 3 obtained a diagnosis for their child in a process that lasted almost three years, due in part to the COVID-19 pandemic, as well as systemic factors, such as waitlists, the need for referrals, and extensive testing to obtain a diagnosis. This was a pervasive barrier, as obtaining a diagnosis that was recognized by the government as a critical step so parents may access specialized services at a subsidized rate. The process of triaging for Parent 3 proved to be tedious, as she was initially referred to a pediatrician by a specialist at a rehabilitation centre. Here, she was referred to the CLSC who then referred her back to the rehabilitation centre. After being diagnosed, she was finally referred to the CLSC to learn about her next steps. On one hand, receiving the diagnosis was affirming for Parent 3 because she had an inkling that her child might have ASD. However, the process of obtaining supports and information as a parent of a child with special needs was a markedly difficult period for Parent 3.

At the time of the study, Parent 3 was on a waitlist for a speech therapist and occupational therapist. As stated, “He hasn’t received any treatment yet. Like literally none. I advocated very, very actively over the last year with the CLSC to get therapy for him”. In the interim, Parent 3 paid for private care with a special education technician, although this was not a feasible long-term option for two reasons. Firstly, the cost of therapy was expensive and unstainable for Parent 3. Secondly, “it was hard to know what to invest in because no one would give us a clear answer of what the right kind of therapy was”. In the absence of accessible and high-quality information, Parent 3 was essentially forced to conduct her own research about the various types of therapy available for her child.

Outside of therapy, Parent 3 had tremendous difficulty navigating services within the education sector. While special education and related resources (i.e., programs, supports) were a big part of Quebec’s plan to support children with special needs, Parent 3’s experience with these services shows that there was still ample work necessary to strive towards inclusion and equality. For example, she placed her son in three early childhood education centres. At the first daycare, her child worked with a special education technician who put together a behaviour plan. When asked about the quality of this service, Parent 3 said, “There was some progress but there were no resources to support it, so it didn’t do much”. At the second daycare, Parent 3 had an issue with overcrowding due to the ‘double classroom’ model adopted by the educators. When describing the environment, Parent 3 said, “It was very noisy because there were two teachers, two clusters of kids all in the same space. He had trouble with that”. Additionally, one of the educators was ill-equipped to handle such a large class size including students with special needs, as this daycare was her first job. As Parent 3 stated, “She did not have the skills to support him. No specialized training, working with special needs populations or anything, no training working with toddlers at all. She had been a secondary school teacher”. Finally, her son was transferred to another daycare. During this time, Parent 3 faced tremendous turmoil and discrimination. While she believed obtaining an official diagnosis would serve her child well, the inverse appeared to happen. The policy of the daycare stated that children formally diagnosed with ASD must be accompanied by an aid. However, the shortage of specialized educators (i.e., aids) meant that they could not arrange for the child to return to the daycare. In essence, her child was removed from the daycare because the educators could not accommodate him in a timely manner.

To summarize, the types of services that Parent 3 accessed for her child were a team of specialists (e.g., education professionals, pediatricians, support staff affiliated with the CLSC), a private therapist, and staff at the various daycares she enrolled her child in. Many challenges associated with navigating these services had to do with long waitlists and staff who, in the words of Parent 3, were “ill-equipped and undertrained to work with children with special needs”. On one hand, obtaining a diagnosis provided a degree of comfort for Parent 3. However, the events that followed the diagnosis were not only distressing, but incredibly destabilizing for her family. With her child removed from several daycares and access to help blocked behind arbitrary regulations and long waitlists, she was forced to keep her child at home while juggling a full-time job. Parent 3 attributes the dissolution of her marriage partly to the stress she experienced during this time. She stated, “I got divorced during the pandemic – it’s not the only reason, but it was an additional stressor”.

Parent 4

Parent 4’s child was diagnosed with ASD after approximately two years on a waitlist by a pediatrician. Similarly to the other parents in this study, the diagnosis brought a great degree of relief as it provided an explanation for their child’s problematic behaviours. However, many of the challenges began shortly after the diagnosis was given. As Parent 4 stated, “I have answers but then I don’t have solutions. I don’t know what to do”. Her pediatrician did not refer her to an organization or resource where she could learn about ASD, evidence-based therapies to support children with ASD, or who to contact regarding next steps. She said, “We applied to get information but never get an answer until she was removed from the list because she was too old”. Additionally, getting specialized care in the form of subsidized therapy, support from a speech and/or occupational therapist, special education aids, etc. has not been possible for Parent 4. At the time this study was conducted, Parent 4’s child had not received any care outside of the supports offered through her school. As stated, “She is not working with anyone at the moment. She has help at school”.

The only support Parent 4 relied on was from her child’s teachers. Regarding the quality of this support, there were both strengths and weaknesses addressed. Regarding the positives, Parent 4 maintained consistent communication with her child’s teachers. “The teacher is very helpful and very professional. I get religiously informed and aware of what’s going on at school”. However, there were several weaknesses that came up when Parent 4 was asked about teacher support. While she was happy that teachers were helpful, she did not believe that they always provided the best strategy that worked for her child. Relative to her child’s ASD presentation (e.g., behavioural and social issues), she felt her child was not receiving enough services.

Thus, Parent 4’s interview revealed that long waitlists made it difficult to obtain specialized care to support children with ASD. At the time of the interview, her child was only receiving support from her teachers at school. She was not receiving any educational, social, or clinical/therapeutic services to ensure she was attaining critical developmental and educational milestones. Moreover, little was being done to effectively address her child’s ASD symptomology. While communication between her and the teacher had been positive, there was still a lot to be done to fill in the gaps.

Parent 5

Parent 5 had their child diagnosed by a team of psychologists and specialists at a hospital specializing in pediatric care. After 8 months on a waitlist, her child received a thorough and comprehensive assessment, spanning two days. Initially, she was informed the wait time would be two and a half years but Parent 5’s unrelenting commitment to supporting her child expedited the process. She stated, “I’m the mom that keeps calling and calling and calling. They had told me the wait time was two and a half years. I was the mom calling every month and I think they just got irritated with me that they sent my file to see things”.

After obtaining a diagnosis, Parent 5 recalled, “I did all the work by myself. We were on a waiting list for parent workshops. There’s no services given, we waited like three, four months and then went to a workshop to explain what autism was”. The quality of this workshop left a lot to be desired, as Parent 5 stated the content of the workshop spanned topics she already knew based on her extensive research conducted independently. The workshop itself did little to equip her with concrete strategies and skills to cope with raising a child with special needs.

Parent 5's child received private support from a speech therapist, an occupational therapist, and an ABA therapist. At the time of the interview, her child was in the process of transitioning to public care, to be enforced by a team of specialists within his school. Parent 5 overall seemed pleased with the quality of the private services, though several issues came up. For example, the owner of one of the therapy centres became less hands-on as her business grew. As Parent 5 said, "She's no longer on hand. There's no more empathy. I find that my son became a number". Overall, however, she reportedly felt pleased with the quality of services available in private care. For example, triaging her child to a different therapist was a more seamless process in private care. For example, one of the ABA therapists her child was seeing recommended she find help from another therapist at the centre since her child was not progressing as quickly as they wanted under their intervention plan. Additionally, one of the occupational therapists had to drop her case after being diagnosed with breast cancer. Finding a replacement proved to be very difficult, as Parent 5 said, "It's very hard to get English services", though the centre did their best to accommodate her. In terms of the challenges associated with private care, "There was no insurance at all. Everything's paid out of pocket".

Since her child was eligible for services within his school, many of the challenges associated with public healthcare and social services came to light. For example, her child was eligible for ABA therapy, but the school only had enough resources to provide up to two hours of therapy per week. As a result, "he's not really learning much in two hours". With regards to the quality of the services available publicly, Parent 5 was largely dissatisfied. She shared, "The workers just came out of school, and it changes all the time. Are they competent? I don't know". Another major issue to arise within the public and educational sector was fragmented communication. For example, Parent 5 stated that there was no communication between herself and the teacher. She did not know what program her child was doing, nor the therapy goals set by the school psychologist and team of therapists.

To summarize, Parent 5 recruited help from both the private and public sectors. Within the private sector, she was quite pleased by the services (e.g., speech therapy, occupational therapy, ABA therapy) offered and the ability to circumvent long times spent on a waitlist. However, language barriers and exorbitant costs were two significant barriers to staying within the private sector. In the public sector, the child had access to a team of specialists (e.g., school psychologist, ABA therapist, speech, and occupational therapists), but there were simply not enough resources to meet the therapy needs of the child. Additionally, fragmented communication between Parent 5, the educator, and team of specialists working with her child was cited as an especially distressing challenge that characterized her experience.

Research Aim II

The second aim of this study was to assess whether an adapted version of PTA is effective. There were three central questions investigated in the present study. *I. Does this adapted version of PTA increase parents' knowledge of ASD? II. Does this intervention reduce or alleviate parental stress? III. Will parents become more confident in their caregiving abilities, become greater advocates, and observe greater satisfaction post-intervention?*

Data Analysis

Data was derived from questionnaires administered at both pre- and post-test intervals to determine whether the adapted intervention was successful. The present design is a single-subject comparison of caregivers' scores before and after the intervention. Due to the small sample size, inferential statistics were not used. Instead, simple descriptive statistics and participants' sum scores were tabulated. Additionally, in the descriptive case studies the participants' changes were calculated as a percentage to show the size and direction of change effects where relevant.

After the eight-week workshop, post-test data was collected to measure the success of the target outcomes: increasing parents' knowledge of ASD, reducing parental stress, and improving parental self-efficacy beliefs. All questionnaires were scored and the results were compiled into Tables 1-3. When comparing pre- and post-test data collected using the ASKS-G (Table 1), all participants performed better at post-test, suggesting parental knowledge increased following the completion of the workshop. In some cases, the differences were more pronounced (e.g., Parent 3) and in other cases, the differences were marginal (e.g., Parent 2).

Table 1

Autism Knowledge Scale-General (ASKS-G) higher scores indicates greater ASD knowledge*

	Parent 2		*Parent 3*		*Parent 4*		*Parent 5*	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*
Etiology/ Prevalence	3	4	1	2	5	6	6	5
Symptoms/ Associated Behaviours	6	6	6	7	6	7	6	7
Assessment/ Diagnosis	3	4	5	6	6	6	5	6
Treatment	4	3	4	4	4	4	3	4
Outcomes/ Prognosis	4	5	4	5	4	5	5	5
Total	*20*	*22*	*20*	*24*	*25*	*28*	*25*	*27*

As measured by the APSI, parenting stress (APSI) yielded more variability in the pre- and post-test results (Table 2). For two of the participants, parenting stress decreased after completing the workshop. For one parent, pre- and post-test results were the same. Notably, parenting stress increased for one parent.

Table 2

Autism Parenting Stress Index (APSI) **higher score indicates greater levels of parental stress*

	Parent 2		*Parent 3*		*Parent 4*		*Parent 5*	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*
Score	19	12	36	33	19	19	47	49

Regarding data collected using the 'Caregiver Burden, Satisfaction, and Efficacy' scale, three dimensions were measured (Table 3). The first dimension, 'Caregiver Burden' yielded mixed results. A higher score on this dimension implies that parents feel a greater degree of burden related to caring for a child with special needs. For parents who scored lower on 'Caregiver Burden' at post-test, this implies they felt less burdened by the workload associated with children with ASD. For half of the participants, parents' perceived burden increased after the workshop. For one of these parents, the increase was noticeably higher (i.e., a 5-point difference). In the case of parents whose perceived burden decreased, the decrease at post-test was marginal (i.e., a difference of approximately 2 points). Caregiver satisfaction remained relatively consistent at pre- and post-test intervals. A higher score on this dimension implies that parents view their relationship with their child as positive, and generally feel content in their role as a caregiver for a child with special needs. For half the parents, their pre- and post-test scores were the same. For the other half, points either increased (i.e., Parent 3) or decreased (i.e., Parent 4) by one point. Finally, self-efficacy also yielded mixed results, whereby half the parents observed an increase while the other half had decreased self-efficacy at post-test. A higher score on self-efficacy suggests parents felt a greater sense of perceived self-competence and confidence in their ability to effectively support their children with special needs. While data was collected for all three subscales, self-efficacy is the primary variable of interest, as it was one of the target outcomes the workshop aimed to improve.

Table 3.

Caregiver Burden, Satisfaction, and Efficacy (CBSE)

**higher score indicates greater levels of perceived caregiver burden, caregiver satisfaction, and self-efficacy*

	Parent 2		*Parent 3*		*Parent 4*		*Parent 5*	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*
Caregiver Burden	13	18	17	18	11	10	22	20
Caregiver Satisfaction	16	16	16	16	13	14	13	12
Self-Efficacy	12	11	12	13	9	12	9	6

Parent 2

According to the summative scores on the various measures used, Parent 2 appeared to have benefited from the workshop, having improved tremendously across three of the target outcomes (Table 4). Regarding the ASKS-G, Parent 2's composite score improved by a total of two points. The percentage of correct responses at pre-test was 66.7% compared to 73.3% at post-test, indicating Participant 1's knowledge of ASD improved by 6.6% after completing the workshop. Across all five subsections of the scale, Parent 2 either improved or remained the same at post-test data collection. However, it must be noted that for one of the categories (Treatment), Parent 2 performed slightly below at post-test. Though the difference between pre- and post-test scores were marginal, they dropped by one point (i.e., a decrease of 3.33%). Based on these results, Parent 2's knowledge of ASD had improved greatly in general, having an improved total score. Improvements were noted specifically for the following categories: etiology/prevalence, assessment/diagnosis, and outcomes/prognosis.

Regarding parent anxiety, Participant 2 also appeared to have benefited from the content of the workshop, as pre- and post-test figures suggest. In comparing their total score on the APSI, their post-test score was lower indicating that Parent 2 felt less anxious related to caregiving responsibilities, their children's disability, and/or about their future. Overall, parent anxiety appears to have decreased by 11% after completing the workshop.

Participants' performance measured by the CBSE yielded a great degree of variability. For example, while certain metrics (i.e., caregiver burden) increased, others (i.e., self-efficacy) decreased. Notably, caregiver satisfaction remained the same at pre- and post-test intervals. Firstly, caregiver burden has increased by 5 points (21% increase). This indicates that Parent 2's perceived burden associated with caring for a child with special needs has increased after completing the workshop. Secondly, caregiver satisfaction has remained consistent. This means that Parent 1's attitudes (i.e., love, affection, appreciation) for their child did not change after the workshop. Finally, Parent 1's self-efficacy decreased by one point (6% decrease). Though this difference is small, this suggests that their assessment of their own competence and ability to effectively care for their child with special needs has decreased after completing the workshop.

Table 4. Summary of Parent 2's ASD Knowledge, Stress, and CBSE

	Autism Knowledge Scale – General	
	Pre	*Post*
Etiology/ Prevalence	3	4
Symptoms/Associated Behaviours	6	6
Assessment/Diagnosis	3	4
Treatment	4	3
Outcomes/Prognosis	4	5
Total	*20*	*22*

	Autism Parenting Stress Index	
	Pre	*Post*
Score	*19*	*12*

	Caregiver Burden, Satisfaction, & Efficacy (CBSE)	
	Pre	*Post*
Caregiver Burden	*13*	*18*
Caregiver Satisfaction	*16*	*16*
Self-Efficacy	*12*	*11*

Parent 3

Parent 3 also benefited from the workshop, having improved across the aforementioned target outcomes (Table 5). Regarding the ASKS-G, Parent 3's score improved by a total of four points. Across all participants, Parent 3 observed the greatest gains in autism knowledge at post-test, having increased by 13%. For all five subsections, their performance at post-test either improved or stayed the same. Specifically, they improved on etiology/prevalence, symptoms/associated behaviours, assessment/diagnosis, and outcomes/prognosis. However, they performed the same when assessing their knowledge of available treatments for ASD. Participant

3’s levels of anxiety also decreased at post-test, having originally scored 33 and decreasing by 3 points at post-test. Parent 3 yielded the second-best gains regarding parental anxiety, suggesting they benefited from learning about stress and using strategies to reduce it.

With respect to CBSE, Parent 3 also had a great deal of variability in their post-test results, having improved in one outcome, staying consistent in another, and finally regressing for another outcome. In terms of improvements, self-efficacy improved by one point (6%) after the workshop. This suggests that Parent 3’s perceived self-appraisal of their caregiving abilities increased after the workshop. Caregiver satisfaction remained the same at pre- and post-test intervals. Notably, caregiver burden increased by one point (6%) at post-test, indicating that they have a greater degree of perceived burden associated with caring for a child with special needs.

Table 5. Summary of Parent 3’s ASD Knowledge, Stress, and CBSE

	Autism Knowledge Scale - General	
	Pre	*Post*
Etiology/ Prevalence	1	2
Symptoms/Associated Behaviours	6	7
Assessment/Diagnosis	5	6
Treatment	4	4
Outcomes/Prognosis	4	5
Total	*20*	*24*

	Autism Parenting Stress Index	
	Pre	*Post*
Score	*36*	*33*
	Caregiver Burden, Satisfaction, & Efficacy (CBSE)	
	Pre	*Post*
Caregiver Burden	*17*	*18*
Caregiver Satisfaction	*16*	*16*
Self-Efficacy	*12*	*13*

Parent 4

Parent 4's knowledge increased after the eight-week workshop by 3 points, indicating that they benefited from participating (Table 6). Their performance at pre- and post-test remained the same for two of the five subsections (treatment and assessment/diagnosis), however they improved in the other subsections by one point in each domain. Overall, their knowledge of autism increased by 10% after completing the program. Regarding parental stress, their post-test scores did not change from their pre-test scores. This suggests that they did not benefit from the stress management techniques and strategies outlined in the program.

Their performance on the CBSE scale at post-test was generally positive across three target measures. Regarding caregiver burden, their score decreased by one point (4.2%). Though marginal, this difference reflects a shift in Parent 4's perception of the burden of caring for a child with special needs. For caregiver satisfaction, they improved by one point (5.5%) suggesting they felt more satisfied with their role as a caregiver for a child with ASD. Finally, their self-efficacy appraisal increased by three points (16.7%). This difference shows that Parent 4 generally felt more competent and confident in their ability to care for a child with special needs. Notably, Parent 4 is the only participant in the sample to yield improvements across all three measures of the CBSE scale. While other parents in the study yielded more variability (i.e., benefiting in some areas, regressing in others), Parent 4's CBSE score indicates that participating in the workshop was successful at bolstering their confidence, competence, and overall perception of their role as caregivers of children with special needs.

Table 6. Summary of Parent 4's ASD Knowledge, Stress, and CBSE

	Autism Knowledge Scale – General	
	Pre	*Post*
Etiology/ Prevalence	5	6
Symptoms/Associated Behaviours	6	7
Assessment/Diagnosis	6	6
Treatment	4	4
Outcomes/Prognosis	4	5
Total	*25*	*28*

	Autism Parenting Stress Index	
	Pre	*Post*
Score	*19*	*19*

	Caregiver Burden, Satisfaction, & Efficacy (CBSE)	
	Pre	*Post*
Caregiver Burden	*11*	*10*
Caregiver Satisfaction	*13*	*14*
Self-Efficacy	*9*	*12*

Parent 5

Parent 5's knowledge of autism increased by two points, indicating a growth of 6% (Table 7). Overall, the results suggest that they benefited from participating in the workshop, particularly for the subsections assessment/diagnosis, symptoms/associated behaviours, and treatment. For these three competencies, they improved by one point each. Their sub-score for outcomes/prognosis remained the same at both pre- and post-test intervals. Notably, their performance at post-test was worse for the etiology/prevalence subsection. However, the difference is marginal, as Parent 4 only regressed by one point.

Regarding parental stress, their performance increased by two points at post-test. Despite the small difference, this is especially notable considering none of the other participants in the present study performed worse at post-test on the APSI scale. This suggests that their levels of stress were heightened following exposure to the content covered in the workshop. It also suggests that the techniques aimed at reducing parental stress were likely not effective for Parent 4. Though difficult to ascertain why, it may be a content-related issue (i.e., the content covered in the program was not rigorous enough to effectively manage Parent 4's anxiety). It may also be because exposure to novel information about the best ways to support her child highlighted existing gaps in her parenting, and thus created additional stress. A final explanation for why this may be is because the content covered the signs of parental stress and activities to reflect on daily stressors. Perhaps through completing this activity, Participant 4 became more aware of stressors in her life, thus resulting in a higher post-test on the APSI.

Finally, their performance on the CBSE scale indicates that they benefited along one dimensions but regressed in two. The area in which they improved was 'caregiver burden', having observed a reduction of 12 (50%) points at post-test which suggests the perceived burden of caring for a child with special needs was alleviated following participation in the workshop. Unfortunately, 'caregiver satisfaction' and 'self-efficacy' were worse at post-test. The former decreased by one point (5.5%) and the latter by 3 points (16.7%) This speaks to two things. Firstly, parents felt less satisfied in their role as a parent to a child with special needs. Secondly, they had worse self-efficacy beliefs following the workshop. Thus, their perceived self-competence, confidence, and overall self-assessment of their ability to care for a child with ASD was worse following the intervention.

Table 7. Summary of Parent 5's ASD Knowledge, Stress, and CBSE

	Autism Knowledge Scale – General	
	Pre	*Post*
Etiology/ Prevalence	6	5
Symptoms/Associated Behaviours	6	7
Assessment/Diagnosis	5	6
Treatment	3	4
Outcomes/Prognosis	5	5
Total	*25*	*27*
	Autism Parenting Stress Index	
	Pre	*Post*
Score	*47*	*49*
	Caregiver Burden, Satisfaction, & Efficacy (CBSE)	
	Pre	*Post*
Caregiver Burden	*22*	*10*
Caregiver Satisfaction	*13*	*12*
Self-Efficacy	*9*	*6*

Discussion

The present study had two aims. Firstly, to conduct a needs assessment by identifying the suite of services recruited by ethnically, racially, and/or culturally diverse parents to support their children with special needs. Parents were also asked questions to assess the quality of support received, as well as the challenges involved in accessing these supports. Secondly, we aimed to test the efficacy of a culturally adapted parent training workshop with three target outcomes: Increase parents' knowledge and understanding of ASD, reduce parental anxiety, and improve their CBSE scores (i.e., caregiver burden, satisfaction, and efficacy beliefs).

Research Aim I

Interviews conducted with parents revealed a great deal about the types of services recruited by parents to support their children. It also provided an evaluative component, as parents were asked to provide feedback on the quality of these services and the challenges associated with them. Five main challenges emerged based on the data collected: Long wait times, cost of private care, lack of information for parents of newly diagnosed children with ASD, language barriers associated with navigating services in a predominantly Francophone province, and sub-par professionalism (e.g, undertrained staff) within the public sector.

Types of Services

Regarding the types of services and supports solicited by parents, there are two dimensions that must be considered. The first related to supports used by parents that directly support their children (e.g., therapy, medication). The second referred to supports and services aimed at supporting the parent (e.g., seeking social supports within the community, soliciting help from a mental health professional, seeking information about ASD and its related impact).

Within the first dimension, parents recruited a suite of services to support their children. This included medical professionals (e.g., pediatricians), psychologists, educational specialists (e.g., behavioral technicians, special educators), and therapists (e.g., ABA, speech, occupational). The parents in this study who solicited these services never recruited just one, but rather had their child benefit from a team of specialists working in tandem to design and implement intervention plans. Parents elected to target the behavioral and psychosocial aspects of ASD symptomology, which is consistent with existing literature that has found behavioral intervention is one of the most sought-after treatment modalities in parents of children and adolescents with ASD (DeFilippis, 2016). These treatments, which aim to improve children’s social skills, reduce instances of challenging behaviours, and improve the social consequences of ASD symptomology (Warren et al., 2011), accurately reflect the list of services utilized by the parents in this study. Interestingly, none of the parents in the present study pursued medical intervention in the form of pharmacological treatment. Despite the well-chronicled efficacy of some of these medications (e.g., Risperidone, Aripiprazole), particularly as it relates to treating behavioral symptoms, the parents in the present study only pursued psychosocial, behavioral interventions (e.g., ABA, SLP, OT) (Aishworya et al., 2022; DeFilipis & Wagner, 2016).

For the second dimension, it is important to note that none of the parents in the study sought support from a therapist, counsellor, or other mental health professional for their own stress. This is largely inconsistent with the literature that has explored the types of supports parents of children with special needs utilize. For example, one study conducted by Marsack-Topoloewski (2020) found that nearly a quarter (27.5%) of parents participated in ASD support groups, nearly half (48.8%) solicited psychiatric services, and 40.6% sought help from a counsellor. This is a stark contrast to the parents in the present study, where only one parent out of five (20%) searched for support for themselves in the form of a Facebook support group to connect with other parents of children with special needs.

Challenges

Long wait times. Long wait times proved to be one of the most pervasive issues among parents in the present study. Throughout the entire process (i.e., obtaining a diagnosis and seeking services), parents were faced with long waitlists. In terms of getting a diagnosis, wait times ranged from eight months, on the shorter end, to three years. Despite these long wait times, parents remained active and resourceful by trying to get informed about ASD and seeking privatized care to support their kids, even in the absence of a formal diagnosis. Two parents in the study tried to circumvent the wait times. Parent 2, for example, ventured to the United States where wait times were considerably shorter due to the privatized healthcare system. Parent 5 also managed to advocate for her child by calling the center daily, eventually getting the two and a half year wait time to eight months. Across the five parents who participated in the interview portion of the study, the average time to receive a diagnosis was 20.4 months (1.7 years).

This is especially concerning, considering the literature on wait times in Canada has ranged from 7 months (Penner et al., 2018) to 12 months (Bernie et al., 2021). There are two potential confounds explaining why the average time to receive a diagnosis was higher in the present study than those reported in the literature. Firstly, there is a breadth of literature showing that belonging to a cultural, racial, and/or ethnic minority group has been associated with a later age of diagnosis (Lopez et al., 2020; Mandall et al., 2002; Stahmer et al., 2019). The literature points to two possible reasons for this: cultural taboos that reinforce cycles of denial within families (Kang-Yi et al., 2018), and language barriers (St. Amant et al., 2017). Given that Quebec is a Francophone province whose services are offered mostly in French, the latter is a more plausible explanation for the results obtained in the present study. This is especially likely considering the majority of parents in the present study are Anglophones who either do not speak French or do not speak it well enough to confidently navigate various services.

Additionally, one must also consider the impact of the COVID-19 pandemic. As emerging research has shown, individuals with disabilities in Quebec had tremendous difficulty accessing services during the pandemic (Fortin-Bedard et al., 2023). The novel nature of the virus represents an issue in its own right, as the Government did not know how to properly adapt to reliably support individuals with disabilities. Moreover, the inability to respond effectively and in a timely manner was further exacerbated by insufficient resources, structural weaknesses (e.g., poor coordination between medical professionals, stakeholders, and policymakers), and the Quebec government's choice to prioritize other groups over individuals with neurodevelopmental disabilities (Fortin-Bedard et al., 2023; Valderrama et al., 2022).

Taken together, the long wait times reported by parents in the study speak to a larger systemic issue, whereby individuals with special needs are often cast aside and not accounted for. While long wait times are not a novel phenomenon, many of the longstanding issues have since been exacerbated by the COVID-19 pandemic (Lee et al., 2021).

Private Care. Four out of five parents in the present study (80%) solicited help from the private sector. This figure is considerably high, considering the tremendous strides made by the Quebec government to divest funds and support individuals with disabilities. Quebec offers a unique context to explore disparities in access to privatized versus public healthcare. The results from the present study support the notion that much is required from the Quebec government to ensure parents do not have to seek private care out of necessity. Legislation and public policy governing health policies are a provincial matter. Services that support the needs of individuals with disabilities are mandated by the Quebec Health and Social Service System (Alami et al., 2021). At present, there are 22 social service centres that support individuals with disabilities, four hospitals, and three universities (MSSS, 2018, as cited in Alami et al., 2021). While the depth of support offered is promising, the reality is that this is simply insufficient for parents of children with special needs in Quebec. However, despite these seemingly abundant services, many of the parents in this study did not rely on government-subsidized services.

There are several reasons why parents pursued psychosocial intervention within the private sector in lieu of the public. One parent, for example, was not eligible for government-funded programs because their child was enrolled within the English sector. Another parent had to seek services in the private sector because his needs were not deemed significant enough to qualify for government-subsidized services. As a result, this parent had to pay for private care and, after an 18-month battle seeking reimbursement, he was unsuccessful. While the majority of the parents in the study relied on some form of privatized care, many did so to circumvent long wait times associated with pursuing services in the healthcare sector. In many ways, parents simply had no choice and did not pursue privatized care of their own volition. While the parents were overall satisfied with the quality of services in the private sector, the majority of parents did not feel it was financially feasible to continue pursuing privatized care. One parent, for example, could only afford private care from a special education technician on an ad-hoc basis.

These findings are therefore consistent with existing literature which shows the exorbitant cost of healthcare to support children with special needs are a pervasive barrier for most families (Lavelle et al., 2014; Maener et al., 2020). Given the unique context of Quebec and Canada at large, it is difficult to reliably draw comparisons between the Canadian context and studies conducted in the United States where healthcare services are commodified. We therefore look to two countries whose governance and regulation of healthcare services mirrors Canada: the United Kingdom (U.K.) and Sweden. In situating the findings from the present study within the global context, it is quite clear that the results remain consistent (Lavelle et al., 2014). For example, parents in the U.K. have cited healthcare costs for children with special needs are not only a major barrier, but a significant stressor. In Sweden, where healthcare costs are largely subsidized by the government much like Quebec, parents spend approximately $73,700 during childhood and adolescence on therapy (Lavelle et al., 2014).

The literature also shows financial hardship is exacerbated by income loss associated with parents reducing their work hours or quitting altogether to support their children (Houser et al., 2014; Montes & Halterman, 2008). While this did not appear to be a common issue among the parents in the present study, one parent reported she had to quit her job after her child was denied services at an early childhood education centre. There may be two possible explanations for this. The first corresponds to government-mandated quarantines imposed at the height of the COVID-19 pandemic, whereby parents were able to work remotely from home while still undertaking caregiving responsibilities. A second, and more likely, explanation is that Quebec funds programs and services that directly support children of different abilities (Ministère de l'Éducation et de l'Enseignement Supérieur [MEES], 2013). Special education programs in schools and daycares, for example, may have technicians, resource teachers, and other skilled professionals (e.g., occupational therapists, ABA therapists, speech therapists). Additionally, affordable daycare in Quebec may alleviate some of the financial burden, as parents can afford daycares with a curriculum adapted to neurodiverse children. As a result, there is less pressure for them to quit their job to assume caregiving responsibilities because they can afford to send their children to daycare.

Taken together, it is quite clear that the cost of supporting children with ASD remains a pervasive barrier that is consistent with scope of literature on this issue. Despite the efforts made by the Quebec government to expand its suite of services to support individuals with disabilities and diverse learners, there are still many structural and systemic issues (e.g., poor financial planning) that have tremendous financial repercussions for parents.

Lack of Information. Another challenge to emerge in the interviews was lack of information for parents of newly diagnosed children with ASD. Upon receiving a diagnosis, many parents did not receive adequate information from their healthcare provider (i.e., pediatrician) or specialist conducting the assessment. Instead, they were referred to external resources like parent workshops and information sessions. The quality of such services left much to be desired, as the parents who attended these workshops felt that the content was not comprehensive enough and did not introduce new material that they had learned during the independent research they conducted. This had repercussions for parents. For example, one parent had delayed seeking therapy for her child because she did not know the best therapy to invest her time and money into. Another parent, for example, was placed on a waitlist for a parent workshop and was eventually removed because her daughter exceeded the age of four. Unfortunately, the results of the study are in line with the typical experience of parents seeking information upon receiving an ASD diagnosis for their children. Existing literature has found that receiving an ASD diagnosis is the source of emotional turmoil and incurs tremendous stress (Banach et al., 2010; McStay et al., 2014). While parents in this study did not feel frustrated or upset by a formal ASD diagnosis, they did feel overwhelmed because they did not know how to effectively proceed with the next steps. This is therefore consistent with existing literature that has shown parents incur a tremendous emotional toll educating themselves and learning about ASD, an issue that has since become more pronounced in the digital age (Rabba et al., 2020).

Participants in the present study stated that they had conducted their own research independently instead of seeking help from resource centers and parent workshops. This is consistent with current trends in the literature that has shown individuals are turning to Internet-based health services in droves (Rabba et al., 2020). For example, users accessing health-related services or research grew from 22% in 2014 to a staggering 46% in 2016-2017 based on one study conducted by the Australian Bureau of Statistics (Australian Bureau of Statistics, 2016). While these results are based on Australian participants, many of the same trends have persisted within the global context. For example, studies have shown parents of children with ASD rely on the Internet to learn about the disorder, its symptomology, strategies to support their children, and the different types of treatment modalities (Rabba et al., 2020). The shift towards digital aid has also impacted the types of supports parents themselves rely on. For example, a study of 674 parent volunteers found that of all the types of supports designed to support parents of children with special needs (e.g., workshops, parent training), informal socials supports, and social media were rated as the most helpful (Shepherd et al., 2020).

To conclude, the parents in the present study cited difficulties accessing reliable, current, and relevant information. Only a select few elected to pursue traditional forms of parent education in the form of parent workshops and coaching programs, though these experiences were not rated favorably. In the absence of accessible programs that aim to educate parents, the parents in the present study turned to the Internet which is in line with current research showing web-based health research has been trending upwards (Rabba et al., 2020). There are two possible explanations for this. Firstly, the long waitlists to receive education and information has left parents with no other choice than to conduct their own research independently. Secondly, one may ascertain that the COVID-19 pandemic and sudden closure of key social services left parents struggling to seek information to better understand their child's condition.

Language Barriers. Language barriers were another challenged cited by parents in the present study. The parents in the study were primarily Anglophone and, as Quebec's official language is French, the services are offered mostly in French, posing many challenges to surface in the interviews. These challenges manifested in two ways. Firstly, it was difficult for parents to communicate with the educators and specialists working with their children, as the language barriers made it hard for parents to discuss their children's needs, progress, and establish goals for intervention plans. Secondly, for parents in the process of obtaining specialized care, there was a shortage of services that cater to English-speaking parents. Many of the services were offered in French and, within the English sector, there were few therapy centers or specialized clinics and even fewer sites with available space for new clients.

Language barriers are a well-chronicled obstacle to navigating the healthcare system for minority groups who do not speak the primary language of the region they inhabit (Stahmer et al., 2019; Timmins, 2002). Thus, as the parents in the present study comprise a language-minority group, experiencing language barriers is in line with existing research that has highlighted cross-cultural disparities in accessing critical services (Stahmer et al., 2019). While there is a paucity of literature that has explored the experience of language-minority groups in Quebec specifically, we look to trends in the United States to ascertain language barriers are a consistent challenge experienced by many ethnic, racial, and/or cultural minority groups. For example, Latinx families in the United States who speak English as a second language (ESL speakers) share similar struggles to the parents in the present study. It is difficult to communicate with therapists, specialists, and doctors to work in tandem to support the child's needs (Stahmer et al., 2019; St-Amant et al., 2017). The literature suggests that language barriers not only have implications for navigating and accessing services, but can also result in delayed diagnoses though the latter was not an issue that arose among participants in this study.

Professionalism and Competence Within the Public Sector. The parents in the present study raised several issues related to the quality of professionalism and competence in the public sector. One of the major critiques of professionals within the public sector is feeling as though they were not competent. For example, parents raised concerns over the inexperience of young professionals, as in some cases, they had never worked with children with special needs before. At present, there is no literature evaluating the quality of services within the public sector in

Quebec specifically. However, the results yielded in the present study are consistent with existing literature that shows there is a great need for improved training for aspiring therapists working with children with ASD. For example, one study found several serious gaps in the training curricula of professionals working with children with ASD, mainly related to lack of knowledge and skills to effectively address the symptoms of ASD and related comorbidities (Read & Schofield, 2010). Additionally, a recent study of 498 psychotherapists found that many specialists working with special needs populations had little knowledge about ASD (i.e., etiology, prevalence, prognosis), held outdated beliefs about the disorder, and/or had little experience conducting therapy with this group (Lipinski et al., 2022). Thus, it is quite clear that the pitfalls inexperienced technicians and poorly trained therapists lacking specialized training to work with individuals with special needs is not exclusive to Quebec.

With regard to professionalism, the literature suggests parents of racial, ethnic, and cultural minority groups are more likely to face racism from healthcare providers in the form of outward discrimination, neglecting patients' needs, and disregarding patients' consent by subjecting them to harmful and unnecessary procedures (Perera et al., 2018; Yalley et al., 2023). Within the context of ASD, Latinx children were diagnosed later than White children for a myriad of reasons (Lopez et al., 2020). There are many social determinants responsible for this discrepancy (e.g., socioeconomic status, geographical location, language barriers) (Lopez et al., 2020; Stahmer et al., 2019; Timmins, 2002). Another explanation, however, suggests stereotyping and covert racism from healthcare providers. While the parents in the present study identified as ethnic, racial, and/or cultural minorities, only one reported discrimination. This parent stated her pediatrician told her child's problematic behaviour was likely due to his Cuban ethnicity, and not because of a neurodevelopmental disorder.

Thus, it is quite clear that there are still many challenges associated with pursuing support within the public sector, even with the promise of subsidized, accessible services. These challenges are largely systemic and due to an overcrowded, underfunded healthcare system. Based on the results of the present study, the challenges described are not due to participants' minority status, though it is difficult to ascertain whether this is the case based on one interview.

Research Aim II

A second objective of the present study was to assess whether an adapted version of PTA is effective at improving parents' knowledge of ASD, reduce parental stress, and increase parents' confidence in their caregiving ability. After completing the eight week-long workshops, parents were given the same questionnaires they were given prior to the commencement of the study. Overall, parents' knowledge increased following the completion of the workshop. For parental stress, half the participants (50%) experienced less stress post-workshop, 25% remained the same, and 25% observed an increase in parent stress. For parental efficacy, mixed results were obtained. Half (50%) of the sample's self-efficacy beliefs increased at post-test whereas the other half decreased.

Knowledge of ASD

Across all four parents in the study, knowledge of ASD increased, suggesting that the content of the program, structured activities, and take-home anchoring activities were successful at increasing parents' knowledge of ASD across the five dimensions: *Etiology and prevalence*, *symptoms/associated behaviours, assessment/diagnosis*, *treatment*, and *outcomes/prognosis*.

Overall, the findings are consistent with existing studies that have shown parent workshops are successful at increasing parents' knowledge of ASD, particularly from families of racial, ethnic, and cultural backgrounds who may hold preconceived notions about ASD (Wang et al., 2022). In light of the COVID-19 pandemic, there is little literature exploring whether remote intervention (i.e., parent training) is as effective as traditional training programs at increasing parents' knowledge of ASD. However, a recent study by Wilkes-Gillan and Lincoln (2018) found that parent interventions delivered remotely are just as effective at improving parents' knowledge of ASD, specifically with respect to understanding their children's problematic behavioural and communication skills.

The success of this target measure may be attributed to the program's emphasis on understanding ASD, their children's behaviour, and learning evidence-based strategies to become more responsive and attuned to the needs of these children, which is consistent with the literature that has identified these as core tenets of successful interventions (Brian et al., 2022; Little et al., 2018; Wallace & Rogers, 2010). Specifically, parents are not only educated on ASD and related symptomology, but they can understand the behaviours of their children and learning their behavioural triggers through structured, reflection-based anchoring activities where parents synthesize and apply the concepts they have learned.

Regarding the PTA workshop specifically, several studies exploring its implications for caregivers' knowledge have been shown (Dabanah et al., 2021; Garcia-Torres & Magana, 2019; Magana et al., 2021a; Magana et al., 2021b). The findings of the present study are therefore consistent with the broader literature showing the PTA workshop may be an effective resource for improving caregivers' knowledge and understanding of ASD.

Parental Stress

The results yielded for parental stress were less unanimous, with half the participants (50%) experiencing less stress post-workshop, 25% reporting the same level of stress, and 25% increasing in post-test stress levels. Parental stress is a common occurrence among caregivers of children with special needs (DePape & Lindsay, 2015; Tomiyama et al., 2018; Van Esch et al., 2018). Thus, decreasing parental stress by teaching parents' effective strategies at managing the challenges associated with caring for a child with special needs should be an essential goal of a successful parent training program (Magana et al., 2017a).

On one hand, 50% of the parents in the present study appeared to have benefited from the strategies outlined in the PTA program to manage parental stress. This suggests that, for these parents, learning about ASD, related strategies to manage their children's behaviour, and understand possible behavioural triggers were all instrumental at reducing parental anxiety. These results are at least partially consistent with existing literature on the efficacy of PTA, which has shown participants who participate in this workshop report lower levels of stress at post-test intervals (Magana et al., 2021a; Magana et al., 2021b). However, there is still variability in parents' parental stress. It is notable that the children of Parent 3 and 4 received the least amount of services of the parents in the present study. It is therefore likely that parent stress will not be reduced in the absence of reliable services that address their children's behaviour.

Regarding the parents whose stress levels either stayed the same or increased at the post-test interval, there are several possible explanations. Firstly, the content of the program did not target parental stress specifically, but rather taught parents how to effectively address their children's behaviour which, theoretically, should reduce stress levels. For example, the 'Hizen Parenting Skills Training' program aims to support parents of children with special needs by providing therapy, consultation, and education-based workshops (Iida et al., 2018). Despite its novel origins, the literature has shown it is successful at reducing paternal stress in caregivers of children 4-11 years old. Thus, it is possible that more specialized intervention is required to effectively reduce parental stress. Secondly, with government-mandated lockdowns and restrictions, it is possible that parents were not able to effectively implement many of the strategies outlined in the program. For example, a common source of stress for parents of children with ASD is learning how to integrate the child into everyday social activities (Boyd et al., 2014). Thus, with lockdowns being implemented parents could not effectively implement these strategies. Finally, it is difficult to ascertain whether the program's content was not successful at reducing parental stress in light of the ongoing COVID-19 pandemic. The pandemic led to a tremendous increase in household stress (Costa et al., 2022; Xu et al., 2021; Zhang, 2022), the likes of which have differentially impacted caregivers of children with special needs (Valderrama et al., 2022). It is possible that the contents of the program are insufficient at modulating the impact of the pandemic, which would explain why some of the parents in this study did not have less anxiety at post-test. Additionally, as parents become more knowledgeable about ASD and its related outcomes (i.e., prognosis, life-long and consistent intervention required) it is possible that parents may have begun feeling overwhelmed.

Taken together, it is difficult to determine why parental stress outcomes were variable among the participants in the present study. On one hand, half of the parents in the present study appeared to have benefited from the contents outlined in the PTA program. However, with half the group either performing the same or worse at post-test, we must consider how PTA and related programs fail to account for the current context of a pandemic. Specifically, with respect to the shift to remote work, suspended services, and increased destabilization within the home (Costa et al., 2022), future interventions should account for changes in the home.

Efficacy Beliefs

The 'CBSE' scale administered at pre- and post-test intervals contained three subscales: caregiver burden, satisfaction, and self-efficacy. Of relevance is their performance on the self-efficacy subscale, which notably saw two parents improve at post-test intervals. For one parent, their self-efficacy beliefs decreased by one point and for another, by a staggering 3 points.

Parents whose self-efficacy beliefs improved at post-test are in line with the current literature on PTA's efficacy. Across several studies in the United States (i.e., Chicago and New York) and Columbia, PTA has shown to increase parents' self-efficacy beliefs (Dabanah et al., 2021; Magana et al., 2017a; Magana et al., 2017b). Thus, parents who complete the program not only feel more confident and competent in their caregiving ability, but they also have the requisite skillset to effectively advocate for their children across various sectors. Even when accounting for differences in how PTA is delivered (i.e., remotely versus on Zoom, fourteen weeks versus eight weeks, group-based versus individual sessions) (Garcia-Torres & Magana, 2019; Magana et al., 2021b), the literature suggests that parents who complete PTA have improved self-efficacy beliefs. Thus, the results are partially consistent with the scope of literature on PTA (Dabanah et al., 2021; Magana et al., 2017a; Magana et al., 2017b). However, for parents who performed worse, there are several possible explanations.

While parents' knowledge increased, parents becoming aware of gaps in their knowledge may have reduced their perceived ability to effectively care for their child. Given the existing link between parents' knowledge and self-efficacy beliefs, it is reasonable to suspect that the PTA program made participants cognizant of gaps in their own knowledge and strategies, which in turn incurred a negative toll on their self-efficacy beliefs (Bearss et al., 2015; Kalalo et al., 2021; Mukhtar et al., 2018). Another potential explanation for this outcome is that the program does not allow for parents to employ mindfulness strategies, which the literature has shown improves emotion regulation, emotion intelligence, the quality of interpersonal relationships, and self-efficacy beliefs in parents of children with special needs (Curl & Hampton, 2023). The findings from a study conducted by Curl and Hampton (2023) aimed to evaluate the efficacy of the ‘Mindful Self-Compassion’ workshop. After completing the brief (i.e., 3-day), virtual workshop, parents observed improvements in mindfulness and self-compassion, which allowed them to have greater self-efficacy beliefs at post-test intervals. Thus, while the PTA workshop has anchoring activities intended to elicit reflection from parents, it is possible these activities were too open-ended and parents would, instead, benefit from more structured intervention that targets mindfulness and self-efficacy beliefs. For example, activities that focus on mindfulness and self-compassion which, according to existing literature (Curl & Hampton 2023; Kurzok et al., 2021; Lunsky et al., 2021), are critical skills implicated in self-efficacy beliefs.

Limitations

Despite strategies employed to account for methodological limitations of qualitative inquiry, several limitations to the present study persist. Firstly, only one semi-structured interview with each parent was conducted prior to beginning the workshop. In this interview, parents were asked a great deal about the services they relied on, their satisfaction with these services, and any related challenges. However, they were not asked about COVID-19 and how this may have accounted for some of these challenges. Secondly, findings from qualitative inquiry are often context-specific and, at times, interpretations and explanations of a participant’s experience are unique to them (Khankeh et al., 2015). On one hand, this individualization is a strength when amplifying the voices of those in need, however it brings into question the validity of the findings and their subsequent generalizability (Anderson, 2010).

Another limitation of the present study refers to the sampling technique employed. The use of purposive sampling to recruit participants presents an issue with respect to accessibility. As no compensation was offered, the participants in the present study therefore had the resources (i.e., time) to participate in the present study which may have been a barrier for other parents who might not have the same resources and were therefore not able to participate. Additionally, while flyers were distributed through local social centres within the city, the bulk of participants in the present study were recruited from a Facebook support group for parents of children with special needs. As a result, they may not entirely be representative of the population of interest (i.e., ethnically parents of children with special needs). The parents in this study were also recruited from Montreal, a metropolitan city with access to a myriad of services. This is therefore not inclusive of all parents of children with special needs in Quebec, especially those from rural communities, who may have their own unique challenges with stigma and accessibility.

With respect to *Phase II*, the descriptive statistics conducted suggest that PTA is an effective intervention modality to support parents' knowledge growth, reducing parental stress, and improving self-efficacy beliefs. However, whether these findings were statistically significant is to left unknown, as the small sample size does not lend itself to inferential statistics.

It also must be noted that being a member of a racial, ethnic, and/or cultural minority group is not a monolith. Within each ethnic group is unique challenges that differentially impact members of these groups. For example, the literature suggests children of Asian descent often have different challenges (e.g., misconceptions about ASD etiology that impact the likelihood of seeking support) (Kang-Yi et al., 2018; Sritharan & Koola, 2019) compared to those of Latinx descent (e.g., language barriers associated with a later age of diagnosis) (St. Amant et al., 2017).

Future Directions

There are several recommendations to consider for future research. Firstly, future studies should explore the efficacy of PTA using a homogeneous ethnic sample. This is because, as discussed, ethnic and racial minorities do not comprise a monolith and it is critical to ensure the needs of specific ethnic groups are addressed properly. Secondly, future research should also aim to recruit parents from both urban and rural geographical regions. At present, PTA has been conducted in major metropolitan cities (e.g., Chicago, New York). For residents in rural communities, there is much to learn about their needs and whether they would benefit from a parent training program in the same way parents from more urban communities would. Thirdly, regarding *Phase I,* future research should conduct more interviews and focus groups with participants both at pre- and post-test intervals. For pre-test, it would be beneficial to understand the role of COVID-19 and how this phenomenon has impacted parents and the services they relied on at the time of the study. It would also allow researchers to determine what the specific needs and expectations of parents are prior to beginning the program. Thus, modifications, if any, could be made to maximally benefit participants. For post-test, conducting focus groups with parents would be beneficial to identify their satisfactions with the program, as well as document any recommendations for future PTA sessions.

A fourth recommendation regarding *Phase I* would be to increase the sample size so that inferential statistics can be conducted to determine effect size and power. This is especially critical to ensure that the outcomes associated with the PTA workshop are statistically significant. A fifth recommendation would be to consider social determinants that may attenuate outcomes. For example, the social determinants of health (e.g., socioeconomic status, family size, education level, housing situation, and food security) may mediate the effectiveness of the PTA workshop (Islam, 2019). Without controlling for these variables, it is difficult to determine which groups benefit most from parent training. A sixth, and final, recommendation is to pilot the effectiveness of PTA as a self-guided workbook. For many parents, associated time and resource constraints with accessing a live parent training program presented a barrier. Self-guided self-help programs, especially in the digital age, are a relatively new phenomenon that has yielded promising results (Kumar et al., 2017). It would therefore be beneficial to pilot PTA as a workbook so that parents who do not have the means to attend weekly sessions could also benefit from the program.

Implications

The present study has several implications for research, practice, and public policy. In terms of research, the results suggest that there is still significant work needed to be done in the field of parent training, specifically as it relates to cultural adaptation and intersectionality. As we begin to employ an intersectional lens to support families of different racial, ethnic, and cultural orientations, it is critical to contribute to literature that aims to understand how certain groups may be differentially impacted. Thus, a hope of this study is that it will inform future studies exploring the efficacy of PTA by integrating the results to identify which areas of the program can be improved upon. Specifically, a hope is that future studies will troubleshoot the shortcomings of the workshop so that it may maximally benefit different types of families.

Regarding practice, the present study demonstrates the importance of employing materials that are culturally adapted to different ethnic groups. The findings from the study have implications for clinical, applied practice as professionals ought to think about the types of materials they use to support families and whether they are attuned to the needs of ethnically diverse groups. As the findings reveal, parents from different ethnic, racial, and cultural minority groups benefit a great deal from parent training that is developed for and by people who understand the plight of belonging to a marginalized group. Thus, while social determinants of health may result in differential health outcomes and disparities in service access, the results of the present study speak to the importance of addressing these disparities directly by providing equitable, culturally-sensitive resources.

Finally, this study has implications for public policy, as many of the challenges associated with accessing services have been identified. The results clearly support the notion that there is not enough being done to mobilize caregivers, stakeholders, and advocates. Parents have worked diligently to advocate for their children and, in most cases, compromise financially to ensure their children are receiving services in the private sector that the government should be providing for free within the public sector. A hope is that the findings from this study will, at the very least, generate a discourse on the importance of investing in special education and policies that promote inclusivity. Specifically, we hope that the government will recognize the need for more services that are culturally attuned to the needs of ethnically diverse groups. There is much to be done in terms of improving coordination between policymakers, advocates, and stakeholders but we hope the findings from the present study indicate the need for this overhaul.

Conclusion

The present study had two central aims. Firstly, to identify the types of supports ethnically diverse parents of children with ASD rely on, the quality of these services, and the challenges they face when navigating these services. Secondly, to test the efficacy of a culturally-adapted parent training program with three target objectives: (*i*) Increase parents' knowledge of ASD, (*ii*) Reduce parental stress, (*iii*) increase parents' self-efficacy. In all, five parents elected to participate in *Phase I*, with one parent dropping out in *Phase II*.

The findings from *Phase I* indicate parents rely on several services offered by healthcare providers, education specialists, and social service programs to support their children. The most common service access to obtain a diagnosis was from a specialized psychoeducational centre, not by a healthcare provider through the medical system. Once a diagnosis was obtained, parents solicited help from several specialists, including ABA therapists, speech therapists, occupational therapists, and special education aids. The majority of parents in this study relied on a mix of both private and public services, with only two parents relying exclusively on free, government-subsidized educational programs through the child's school. However, it must be noted that most parents opted for private care in the interim waiting for space in the public sector. With respect to the challenges that emerged, many parents shared the same issues: long waitlists, absence of information following a diagnosis, inaccessibility of private care (i.e., financial constraints) and language barriers, and issues within the public sector (e.g., lack of resources, poorly trained specialists, overcrowded services within the child's school).

In *Phase II*, all four parents' knowledge of ASD increased at post-test, suggesting the content of the PTA workshop is an effective tool to improve parents' understanding of ASD symptomology, etiology and prevalence, prognosis and outcome, and treatment. These findings are consistent with not only the literature that has shown structured workshops are an effective way to improve parents' knowledge of ASD (Deb et al., 2020), but also speak to PTA's efficacy (Magana et al., 2017a; Magana et al., 2017b). Regarding parent stress, half the parents in the present study improved at post-test, suggesting that parents benefited from PTA either directly from the stress management strategies provided, or from their increased knowledge and understanding of ASD. However, one parent remained the same at post-test and another parent performed worse (i.e., felt more stressed after completing the program). Though difficult to ascertain why this may be, it is possible the stress management techniques outlined in the PTA program were simply not enough, or the impact of the COVID-19 pandemic made it so the content attuned to the needs of parents within the context of a pandemic. Finally, self-efficacy yielded similar mixed results, with half the parents in the present study having improved self-efficacy and the other group regressing. It is possible that the content in the PTA program does not emphasize self-efficacy directly, instead focusing on teaching parents new skills rather than building their confidence and perceived self-competence of their current skillset through mindfulness. Finally, it is likely that parents' exposure to new content, strategies, and information about ASD highlighted gaps in their own skillset and knowledge, which would have incurred negative repercussions for their self-efficacy beliefs.

To conclude, the present study has illuminated a great deal about the types of supports caregivers of children with ASD rely on, as well as their satisfaction with these services. In interviewing these parents, many of the challenges associated with accessing healthcare services in Quebec have come to light. To better support these parents, an adapted version of the PTA workshop was administered. With PTA in its infancy, the findings from the present study overall are consistent with the literature exploring its efficacy. This suggests a positive, bright direction for PTA and culturally-adapted services in general.

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Appendices

Appendix A - Recruitment Sites & Flyer

The Black Community Resource Centre (BRC)	https://bcrcmontreal.com/
West Island Black Community Association	https://wibca.org/
The South Asian Women's Community Centre	https://www.sawcc-ccfsa.ca/EN/about-sawcc/history/
Service De La Famille Chinoise Du Grand Montreal	https://www.famillechinoise.qc.ca/fr/
Black Healing Fund	https://www.blackhealingfund.com/therapists-and-healers
Canadian Council of Muslim Women (CCMW)	https://www.ccmw.com/
Centre d'aide aux familles latino-américaines	https://cafla.ca/
Carrefour d'Intercultures de Laval	https://www.carrefourintercultures.com/
Centre d'appui aux communautés immigrantes (CACI)	https://caci-bc.org/

Recruitment Poster

Free Parent Workshop!

I am seeking participants for a research study I am conducting as part of my graduate thesis at Concordia University. We are looking for parents of children with autism spectrum disorder (ASD) to participate in a free eight-week workshop.

Phase 1

Needs Assessment: What are your needs as parents?

We want to hear from you! You will be asked to share the types of supports and services you rely on, and whether you are happy with these services in terms of their quality, accessibility, availability.

Parents Taking Action (PTA)

Phase 2

Parents will be invited to participate in a free workshop. The workshop is eight weeks and will be conducted remotely on Zoom. Through this workshop, we hope to:

- Increase knowledge of ASD
- Promote self-efficacy and confidence in your caregiving ability
- Offer a list of services, resources, and evidence-based practices available in Quebec
- Equip you with the requisite terminology and knowledge to advocate for your child in a variety of settings (e.g., schoolboard, hospital, social services).

Am I eligible?

We are looking for parents who are:

- Located in Quebec and fluent in English.
- Able to commit at least eight weeks.
- Are a parent of a child with ASD under 12 years old.
- Identify as either...
  - A racial/ethnic minority (e.g., Black, Latinx, Arab, Asian).
  - An immigrant.
  - A child of immigrants (i.e., a first generation Canadian).

Interested? To register, contact:

ConcordiaPTAStudy@gmail.com

Appendix B - Sample Consent Form

INFORMATION AND CONSENT FORM

Study Title: Applied Intersectionality: Supporting Families of Children with Autism Spectrum Disorder from Racial, Ethnic, and Cultural Minority Groups
Researcher: Paul De Luca
Researcher's Contact Information:
Phone: 514-291-1513
Email: p_delu@live.concordia.ca
Faculty Supervisor: Dr. Miranda D'Amico
Faculty Supervisor's Contact Information:
Phone: 514-848-2424 ext. 2040
Email: miranda.damico@concordia.ca
Source of funding for the study: N/A

You are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

A. PURPOSE

The purpose of the research is twofold. Firstly, to identify what the needs of parents of children with Autism Spectrum Disorder (ASD) from cultural, racial, and ethnically diverse backgrounds are. This entails exploring the types of supports that parents rely on and whether they are satisfied with these systems. Secondly, we aim to assess whether an adapted version of the 'Parents Taking Action' psychoeducational intervention is effective.

The intervention aims to equip you with knowledge of autism, promote advocacy, and help you feel competent and confident navigating healthcare and school systems. You will be coached to understand your child's behaviour by learning to understand the development of social and play skills. You will also learn to recognize the signs and causes of ASD to not only improve your knowledge of ASD, but to dispel common myths. You will also learn how to advocate for your child at school to ensure that they are receiving the services they need. You will also be equipped with strategies to reduces stress. Additionally, you will be made aware of evidence-based interventions to improve your child's functioning (e.g., social and play skills, communication ability) and decrease problematic behaviour. You will also learn about current research-based strategies to improve communication with your children.

B. PROCEDURES

If you participate, you will be asked to complete two phases. In the first phase, we will conduct an interview to understand the types of supports you rely on to support your children and whether they are satisfied. In the second phase, you will complete questionnaires both before and after the 8-week intervention. The 8-week intervention consists of a one-hour weekly workshop on Zoom. The format of this intervention is group-based, meaning other parents will be present during the Zoom sessions completing the workshop with you. You will be given information about ASD, complete anchoring activities, and have the opportunity to share your experience as caregivers of children with special needs.

In total, participating in this study will take 8-10 weeks. The semi-structured interview will take between 30 minutes to one hour and will be conducted on Zoom. Interviews via phone or in person are available per the participant's request. The intervention will span 8 weeks to reflect 8 topics. Each session is between 45 minutes to one hour.

C. RISKS AND BENEFITS

You might face certain risks by participating in this research. These risks include discussing and viewing content that may be sensitive. For example, discussing some of the systemic barriers that parents from ethnically diverse backgrounds and their children face which may be particularly distressing to hear for some. Additionally, in some cultures having a child with special needs may be regarded as taboo, and members of the community may be ostracized if it is discovered they have a child with autism spectrum disorder. In participating in this group-based intervention, a potential risk is members within your community discovering your circumstances. While we will do our best to ensure that other participants do not disclose any information regarding the other participants in the study, we cannot guarantee that they will respect your confidentiality.

Potential benefits include an opportunity for you to become empowered by sharing your experience as caregivers of children with ASD. For parents who participate in the intervention, the intended benefits are:
Increased knowledge of ASD.
Increased understanding of their children's symptoms and how to better identify and assess their behaviours.
Increased confidence and competence in accessing resources and supports within the community.
Increased self-efficacy to ensure children are attaining developmental and educational milestones.
Learning what your rights are as caregivers of children with special needs and how to advocate for your children at school.

D. CONFIDENTIALITY

We will gather the following information as part of this research:

Interviews. You will be asked about the types of supports you currently rely on to help and guide your child with ASD, and whether you are content with the current resources, supports, and systems in place.

Responses to three questionnaires that will be administered before and after the intervention. These questionnaires are intended to measure your knowledge of ASD, caregiver satisfaction, efficacy and burden, and parental stress.

We will not allow anyone to access the information, except people directly involved in conducting the research. We will only use the information for the purposes of the research described in this form. The information gathered will be anonymous. That means that it will not be possible to make a link between you and the information you provide.

We will protect the information by storing all data on a password-protected computer that can only be accessed by me, the principal investigator. We intend to publish the results of the research. However, it will not be possible to identify you in the published results. To account for delays in writing, submitting, and presenting/publishing the data (e.g., interviews, scores on the questionnaires, responses), it will be stored up to two years following the completion of the study to ensure ample time is granted.

By signing this form, you agree to respect the confidentiality of the other participants in the study with you. In signing this form, you also agree to not disclose the identity of the other participants outside of the study. Moreover, your signature means you consent to having your identity known to other participants in the group intervention. Finally, in signing this form you agree that the researcher cannot guarantee others participants will respect your confidentiality.

F. CONDITIONS OF PARTICIPATION

You do not have to participate in this research. It is purely your decision. If you do participate, you can stop at any time. You can also ask that the information you provided not be used, and your choice will be respected. If you decide that you don't want us to use your information, you must tell the researcher up until one month after the final workshop session is completed.

There are no negative consequences for not participating, stopping in the middle, or asking us not to use your information.

G. PARTICIPANT'S DECLARATION

I have read and understood this form. I have had the chance to ask questions and any questions have been answered. I agree to participate in this research under the conditions described.

NAME (please print)

____

SIGNATURE

____

DATE ____

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.

Appendix C - Semi-structured interview script

1 – How old is your child and when were they first diagnosed with ASD?

2- Who diagnosed your child (e.g., pediatrician, psychologist, psychiatrist)?

3- How long did it take to receive a diagnosis?

4- How did you feel upon first learning your child had ASD?

5- Did the professional who diagnosed your child offer any information about where you can access services and the types of services you will receive?

6- After receiving the diagnosis, which types of supports and resources (e.g., referral to a specialist, referral to support groups, information brochures or literature on the topic, intervention services) did you receive?

7- Which services do you rely on now?

8 – Are these services accessible?

- a. How frequently do you access these services? Are they easy to get to?
- b. Are they covered by insurance?

9 – How satisfied of these services are you?

- a. Do you feel like the professionals you are working with are competent?
- b. Do you feel these services are meeting your child's needs? In what way?
    - a. If not, why?
- c. Do you feel these services are meeting the needs of your family? In what way?
    - a. If not, why?
- d. Do you feel supported by these professionals? For example, do you feel as though you can seek additional information or ask questions?

9 – What are some of the challenges you face accessing services?

10 – Do you feel as though there are enough services offered to support your child and your family?

11 – At school, does your child have the support they need to succeed?

   a. What types of services are offered at your child's school?
   b. Are you satisfied with these supports?

Appendix D - Weekly Intervention Schedule, Objectives, & Activities

(Adapted from Magana et al., 2017a; Magana et al., 2017b).

Session One: Introduction to the Program & Understanding Child Development

This is an opportunity for interventionists and parents to get to know each other. It is important in this first session that interventionist emphasize what they have in common with the parent. This will improve their bond and give credibility to the advice they give because of their shared experience as parents of children with autism.

Objectives of Session Two:

- Introduction.
- Talk about child development.
- Review information from the Center for Disease Control.
- Talk about the M-CHAT.

Key activities in Session Two:

- Read Tom's story.
- Practice the stages of child development with a picture dictionary.

Additional Points for Session Two:

- Tell interventionists to allow parents time to answer questions: It's okay to sit in silence for a moment.
- Have printed information sheet from the CDC available for interventionists to bring to give to parents after the session.

Session Two: Understanding the Autism Spectrum and Your Child's Needs (1-2 hours)

Objectives of Session Two:

- Review key terms about autism.
- Talk about myths and realities.

Key activities in Session Two:

- Talk about your reaction when your child was diagnosed with autism.
- Review and practice the activity about the 12 signs of autism.
- Complete the activity about your child's needs.
- Read Miguel's story.

Additional points for Session Two:

- You can have participants talk to each other about their experiences around diagnosis, but be sure to set and keep time-limits.
- Be sure participants are familiar with the 12 signs of autism.
- You can create a game where they separate myths from realities.

Session Three: What Works to Address the Symptoms of ASD

Objectives of Session Three:

- Understand what "evidence-based practices" means.
- Recognize the types of therapies that have evidence supporting their use.
- Recognize the types of therapies that are unproven or potentially harmful.
- Recognize the advantages of using evidence-based interventions.
- Recognize whether your child is using evidence-based therapies or programs.
- Evaluate the effects of using unestablished therapies or treatments.
- Provide parents will resources and services in the Montreal area.

Additional Points for Session Three:

- Be sure that participants have a strong understanding of "evidence-based practices," and that they will not promote alternative and unproven therapies when they support parents.

Session Four: How to be an Effective Advocate

Objectives of Session Four:

- Review the concept of how to advocate.
- Review "tips" or ideas for how to be an effective advocate.

Key activities in Session Four:

- Listen to Mateo's Story.
- Practice with an activity about how to advocate.

Additional points for Session Four:

- Present a "bad" example of advocacy through role play and have the group discuss what went wrong and how to be a more effective advocate.
- Write down their "tips" or ideas for how to be an effective advocate on a whiteboard or large piece of paper.

Session Five: Advocacy in the School System

Objectives of Session Five:

- Learn key terms relevant to the school system.
- Review five ideas or tips to advocate in the school system.
- Discuss IEPs.

Key activities in Session Five:

- Listen to a short story about advocating in the school system.

Session Six: Play Together Learn Together

Objectives of Session Six:

- Understand common difficulties experienced by children with autism pertaining to play.

- Analyze the diverse ways in which children play alone and with others.
- Understand the characteristics of play in children with autism.
- Learn how to arrange the environment for successful play with parents, siblings, or other children.
- Learn ways to interact with your child to promote meaningful engagement with toys and other materials.
- Learn how you can facilitate peer interactions during a scheduled play time.

Additional points for Session Six:

- Allow parents to understand and express common difficulties experienced by children with autism pertaining to play.
- Discuss how to arrange the environment for successful play. Interventionists should emphasize the following:
    - Turn off the television and try to minimize any distractions/interruptions.
    - Maintain organized play for a short and successful time period (start off with 5 minutes and then gradually increase).
    - Show a video that shows participants how to promote meaningful engagement of children with toys and other materials. Point out how the adult in the video:
        - Gets the child's attention.
- Shows the child a new way to play with a toy.
- Waits and prompts.
- Rewards the child.

Session Seven: Creating Everyday Opportunities to Encourage Communication

Objectives of Session Seven:

- Understand the communication difficulties that children with autism often have.
- Learn the different forms of communication: verbal, augmentative and alternative communication such as: picture exchange communication.
- Analyze how children communicate and the purposes of communication.
- Expand your child's communication skills.
- Learn how to arrange the environment in order to promote communication during everyday situations.

Key activities in Session Seven:

- Complete the communication chart.

Additional points for Session Seven:

- Provide participants access to different forms of augmentative and alternative communication such as: picture exchange communication and voice output devices to familiarize them with commonly-used options.
- Review the purposes of communication.
- Show a video of naturalistic teaching and point out when the adult is using expansions, following the child's lead and communication temptations.

- Show a video that shows how mother and sibling prime the child on how to greed a friend.

Session Eight: Stress Management & Building Support

Objectives of Session Eight:

- Talk about the symptoms of stress.
- Share suggestions on how to control stress.
- Listen and talk about a short story about encouraging community acceptance of disability.
- Review the Circle of Friends.
- Talk about and engage in some activities about how to talk to others about your child with autism.
- Discuss how and when to tell your child about his condition of autism.

Key activities in Session Eight:

- Practice a relaxation activity.
- Listen and talk about a short story about family issues of families of kids with disabilities.
- Listen to short story and facilitate discussion.
- Review Circle of Friends Model and explain the components.
- Discuss issues and challenges with talking about children with ASD.
- Review the chart, "Explaining ASD to others" and encourage parent to fill in the blanks.

Appendix E - Caregiver Burden, Satisfaction, and Efficacy (CBSE) Scale (Heller et al., 1999)

For each item, please tell what number best reflects how strongly you agree or disagree with the following statements and if it applies to your life with your child. For each sentence, answer the best way you can depending on the coding scale.

	Strongly Disagree	**Somewhat Disagree**	**Somewhat Agree**	**Strongly Agree**
1. Caring for my child hurts my job	0	1	2	3
2. I would make a fine model for a parent of a child with a disability	0	1	2	3
3. I feel I can manage my child's behavior	0	1	2	3
4. Caring for my child places a financial strain on the family	0	1	2	3
5. I worry a lot about my child's future	0	1	2	3
6. I meet my own expectations in caring for my child	0	1	2	3
7. Caring for my child leaves me with little time to be me	0	1	2	3
8. Caring for my child leaves me physically exhausted	0	1	2	3
9. If anyone can find the answer to what is troubling my child, I can	0	1	2	3
10. I honestly believe I have the skills necessary to be a good parent to my child	0	1	2	3
11. Caring for my child limits my social life	0	1	2	3
12. My child's pleasure over some little thing gives me pleasure	0	1	2	3
13. Caring for my child means fewer vacations for me	0	1	2	3
14. Caring for my child does not leave enough time to do things I like	0	1	2	3
15. My child shows real appreciation for what I do for him/her	0	1	2	3
16. Taking responsibility for my child gives my self-esteem a boost	0	1	2	3
17. Caring for my child hurts my chances for a good marriage	0	1	2	3

18. Helping my child helps me feel close to him/her	0	1	2	3
19. I really enjoy being with my child	0	1	2	3
20. I feel that what I can do can help improve my child’s situation	0	1	2	3

Appendix F - Autism Parenting Stress Index (APSI) (Silva & Schalok, 2012)

Date: ____ Person completing checklist:_________________

	Stress Ratings				
Please rate the following aspects of your child's health according to how much stress it causes you and/or your family by placing an X in the box that best describes your situation.	**Not stressful**	**Sometimes creates stress**	**Often creates stress**	**Very stressful on a daily basis**	**So stressful sometimes we feel we can't cope**
Your child's social development	0	1	2	3	5
Your child's ability to communicate	0	1	2	3	5
Tantrums/meltdowns	0	1	2	3	5
Aggressive behavior (siblings, peers)	0	1	2	3	5
Self-injurious behavior	0	1	2	3	5
Difficulty making transitions from one activity to another	0	1	2	3	5
Sleep problems	0	1	2	3	5
Your child's diet	0	1	2	3	5
Bowel problems (diarrhea, constipation)	0	1	2	3	5
Potty training	0	1	2	3	5
Not feeling close to your child	0	1	2	3	5
Concern for the future of your child being accepted by others	0	1	2	3	5
Concern for the future of your child living independently	0	1	2	3	5
Subtotal					
Total					

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Appendix G - Autism Spectrum Knowledge Scale, General Version (APKS-G) (McClain et al., 2019)

*Participants choose *True, False,* or *Don't Know*

> *Please answer the following questions. If you do not know an answer, select* Don't Know. *Please refrain from looking up the correct responses.*

Etiology/Prevalence

1. Less than 2% of people in the US have autism spectrum disorder.
2. Vaccines can cause autism spectrum disorder.
3. Boys are four times as likely than girls to have autism spectrum disorder.
4. Children who have a brother or sister with autism spectrum disorder are more likely to develop the disorder.
5. Autism spectrum disorder is caused by a lack of motherly warmth.
6. Advanced paternal (father) age is a risk factor for autism spectrum disorder.
7. There are no differences in the identification rates of autism spectrum disorder across racial and ethnic groups.

Symptoms/Associated Behaviors

1. All individuals with autism spectrum disorder have low intellectual quotients (i.e., IQs).
2. Children with autism spectrum disorder may not play with toys the way they are intended.
3. Individuals with autism spectrum disorder may have strict routines or rituals.
4. Individuals with autism spectrum disorder have difficulties interacting socially with others.
5. Some individuals with autism spectrum disorder may be uncoordinated or clumsy.
6. Many individuals with autism spectrum disorder have difficulties expressing themselves.
7. Symptoms of autism spectrum disorder do not appear before the age of 2 years.

Assessment/Diagnosis

1. Diagnosis of autism spectrum disorder is primarily based on behavioral observations and parent interviews.
2. Autism spectrum disorder can only be diagnosed after the age of 4 years.
3. If a teacher believes a student has autism spectrum disorder, they can make a diagnosis.
4. Autism spectrum disorder can be diagnosed with brain imaging.
5. For a diagnosis of autism spectrum disorder, symptoms must be present from early childhood.
6. It is possible for autism spectrum disorder to develop in adulthood.

7. A diagnosis of autism spectrum disorder can only be made by a medical doctor.

Treatment

1. There are no beneficial treatments available for individuals with autism spectrum disorder.
2. Restricting certain foods (e.g., gluten) is an effective treatment for autism spectrum disorder.
3. Social skills training is an effective treatment for some individuals with autism spectrum disorder.
4. Intellectual quotient (i.e., IQ) and age affect treatment success for children with autism spectrum disorder.

Outcomes/Prognosis

1. Most individuals with autism spectrum disorder will never learn to speak.
2. Symptoms of autism spectrum disorder do not change throughout an individual's life.
3. Autism spectrum disorder only affects children.
4. Many individuals with autism spectrum disorder have difficulties living and working independently in adulthood.
5. Up to 70% of individuals with autism spectrum disorder also have an additional mental health diagnosis (e.g., anxiety).
6. Many children with autism spectrum disorder are at risk for academic difficulties.