

## Lived Experiences of Children with Autism Spectrum Disorder in Canada and Pakistan

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### Abstract

*The present paper represents a qualitative cross-cultural comparison of the lived experiences of Canadian and Pakistani 2-5-year-old children with Autism Spectrum Disorder (ASD). A brief overview of disability law and policies in Canada and Pakistan is provided, followed by information gathered through direct contact with ASD professionals and families via social media. It appears that, contrary to common wisdom, a wealthy developed nation such as Canada, provides few guarantees for quality education and care for such children. At the same time, developing nations such as Pakistan find their own unique ways to address the needs of young children with ASD, often building upon cultural strengths. The efforts in raising such children in both wealthy and developing nations meet both successes and failures.*

Key Words: Autism Spectrum Disorder, culture, COVID-19 pandemic, daycare, legislation, parenting

### 1. Introduction

Examining the lived experiences of children who have Autism Spectrum Disorder (ASD) is important to better understand how, across culture and wealth, nations differentially address the needs of young children with ASD. Lived experiences include individuals' unique experiences specific to their context, and engagement with their everyday environments. Various factors contribute to an individual's lived experiences.

#### 1.1 What is Autism Spectrum Disorder?

The US National Institute of Mental Health defines ASD as "a developmental disorder that affects communication and behaviour" (NIMH, 2018). Symptoms typically appear by two years of age and include communication difficulties, repetitive behaviours and limited interests. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) ASD is diagnosed in young children if they demonstrate persistent social communication and interaction deficits in each of the following areas: socio-emotional reciprocity, nonverbal communicative behaviours; and developing, maintaining, and understanding relationships. The child must also display a minimum of two of four forms of repetitive behaviours: repetitive motor movements, insistence on sameness, fixated interests, and hyper- or hypoactivity to sensory input. Diagnosis is a two-stage process: a general developmental screening during well-child checkups; and an exam measuring a child's growth and development to identify or prevent problems at the 18- and 24-month milestones using screening tools such as parent questionnaires (US Centers for Disease Control and Prevention, 2021). If the screening stage shows evidence of developmental problems, the evaluation proceeds with a cognitive assessment of thinking skills, social reasoning, language skills, and age-appropriate skills required to independently complete daily activities such as personal hygiene, eating, dressing, etc. This formal diagnosis is usually conducted by a team including a child psychologist and/or psychiatrist, a neuropsychologist, a speech-language pathologist, and a developmental pediatrician.

Current treatments for ASD involve medications such as Risperidone - to reduce behavioural symptoms, as well as Intensive Behavioural Intervention (IBI), which is based on principles of Operant Conditioning (DeFilippis & Wagner, 2016). The provision of adequate resources and family support is essential to maximize the progress of children with ASD during this critical period of development, when cortical circuits in the brain are being refined according to individuals' experiences (LeBlanc and Fagiolini, 2011).

Diagnosis and treatment for ASD vary significantly according to time and place. Cultures differ in diagnostic criteria, service options, applications of technology, accessibility to treatment, and societal perceptions (Ennis-Cole et al., 2013).

## **2. Method**

We provide a cross-cultural comparison of the lives of Canadian and Pakistani children with ASD, focusing specifically on the unique factors that contribute to their well-being. Fundamental federal laws and constitutional rights are discussed, however, due to the great scope of demographic and health-related variation occurring within both nations, we narrowed our sociocultural analysis to the province of Ontario in Canada and Punjab in Pakistan – the largest provinces of their respective countries by population, home to their capital cities, and diverse multilingual and economic hubs. We provide a brief overview of the current state of ASD services and their impact on children's well-being in both regions, by examining government records and policies, and engaging directly with ASD professionals, such as special education teachers, psychologists, pediatricians, early intervention workers, and registered behavioural therapists and caregivers of preschool children (aged 2-5) with ASD. Within Ontario, we focused on posts from individuals in the Canadian Greater Toronto Area as well as the remote Northern Ontario community of Thunder Bay. We joined social media Facebook communities including *Autism Parents Support Group for Families in Ontario, Canada*, and *Northern Autism Families Matter*, a group which not only provides help and advice but also appeals for the right to non-discriminatory services, sufficient funding, and a culturally-sensitive National Autism Strategy that ensures appropriate resources while respecting indigenous values. Our Pakistani social media analysis included posts, in both Urdu and English, from the Facebook communities *Autism Resource Group Pakistan* and *Autism super moms*, online platforms enabling individuals to ask questions, seek advice, and receive support from others such as family members, professionals, and educators. There were no separate Pakistani Facebook groups catering specifically to remote communities, as most of these populations seek knowledge and resources from professionals affiliated with large cities. Sharing online groups can provide them with the most accurate and up-to-date information. In fact, therapists and other professionals even offer free online services via the *Autism Resource Group Pakistan* to families who cannot afford or access them.

## **3. Background**

### **3.1 ASD in Different Societies**

Perceptions, attitudes, and behaviours towards children with ASD vary considerably between countries. Current views on ASD are not only focused on treatment, but also on how individuals learn to live with their condition, which is influenced by the surrounding culture and even by area of residence within a country – often due to differences in socioeconomic status (SES) and access to support. In developed and affluent countries such as Canada, federal and provincial laws are in place to ensure that services are accessible to children with ASD through various social programs. Limitations include long waitlists for services for children (Shepherd & Waddell, 2015) and high levels of unemployment and social isolation for adults with ASD (Howlin et al., 2013; Roux et al., 2013;). In collectivistic developing nations such as Pakistan, with widespread poverty and polarization of wealth, only the middle and upper classes can afford extensive services for children with ASD (Rathore et al., 2011). Additionally, although the term 'disability' holds a negative connotation in both countries, within Pakistan this belief makes ASD highly stigmatized, and death by neglect fairly common (Rathore et al., 2011). ASD is often undiagnosed or improperly managed in rural areas due to the lack of formal support systems, placing a greater need for support by extended family members (Hamdani et al., 2014).

### **3.2 The Impact of the Developmental Context**

Like all children, the experiences of a child with ASD are shaped by interactions with both micro- and macro-level social structures. Macro-level social structures form the broadest level of the child's rearing environment and include social norms, attitudes, policies, legislation, living arrangements, religious beliefs, and daycare and service options. Micro-level social structures are small-scale interactions at the individual level, including the roles of parents and immediate family members, sleeping patterns, and daily routines such as mealtime and diet. Both macro- and micro-level social structures vary considerably between different nations and consequently result in different lived experiences for Canadian and Pakistani children with ASD.

## **4. Findings**

Through a cross-cultural comparison of the role that legislation and religion play in the lived experiences of children with ASD followed by a shift to a micro-level focus on families through a discussion of childcare, services for children with ASD, classroom structure, the role of parenting, daily routines, and the impact of COVID-19, we provide a macro-level analysis of differences in living with ASD in Canada and Pakistan.

#### 4.1 Legislation

Canada is a wealthy, democratic, multicultural nation with strong humanistic laws such as the Canadian Human Rights Act and the Canadian Charter of Rights and Freedoms which protect individuals with disabilities from discrimination by guaranteeing them equal rights under the law. Provincial legislation such as the Ontario Human Rights Code also guarantees equal rights in housing, employment and services. Additionally, the government-run Ontario Health Insurance Plan (OHIP) and Ontario Disability Support Program (ODSP) cover the cost of many health-related emergency, preventative, and rehabilitation services for eligible Ontario residents. In 2005, the Accessibility for Ontarians with Disabilities Act (AODA) became a key milestone for disability rights as it implemented accessibility standards in facilities, accommodation, technology, services, infrastructure, and goods, to make Ontario “barrier-free” by 2025 (Government of Ontario, 2016).

Pakistan is a poor country with limited healthcare facilities and, as such, struggles to provide related services to its large population of approximately 229 million people. Nevertheless, it has similar laws for the protection of individuals with disabilities. Pakistan’s 1981 Disabled Persons’ (Employment and Rehabilitation) Ordinance advocates for the rights of individuals with disabilities by providing them with welfare, rehabilitation and employment opportunities (Kizilbash, 2020). Furthermore, in 2020 the (then) Prime Minister of Pakistan signed the Islamabad Capital Territory Rights of Persons with Disability Act 2020; the first federal law guaranteeing the inclusivity of individuals with disability and demanding the establishment of ‘special disability courts’ for speedy trials and the discontinuation of derogatory terms such as ‘disabled’ and ‘mentally retarded’ (Kizilbash, 2020). Both Canada and Pakistan have ratified the United Nations *Convention on the Rights of Persons with Disabilities (CRPD)*, which advocates for change towards viewing individuals with disabilities as ‘subjects’ with rights and active and equal roles in society rather than as ‘objects of charity’ (United Nations, 2006).

Although both countries have similar laws protecting the rights of people with disabilities, there are discrepancies in the extent to which they are enforced due to societal attitudes and resources. A law normally reflects societal values and requires its support to be effective. National laws in most countries tend to be utilitarian (i.e., Bentham, 1789) where maximum benefit to the maximum number of people is prioritized, on the understanding that marginalized members of society may not receive what they need. However, the enforcement of laws is not always utilitarian, and securing ASD-related resources has always been a struggle when utilitarian allocation of resources is made. Both Canada and Pakistan have competing priorities such as healthcare & education, economic affairs; agriculture, energy, mining, and transport. Canada’s greatest expenses also include social protection; family and child benefits, old age security, disability payments, and unemployment benefits (Statistics Canada, 2021). Pakistan’s top expenses include general public services; servicing of foreign and domestic debt, foreign loan repayment, superannuation allowances and pensions, defence affairs, and public order and safety affairs (Government of Pakistan Finance Division, 2020).

A poor country in which adequate food, shelter, and security may be in short supply has greater difficulty prioritizing disability rights, let alone costly services for children with ASD. Canada’s GDP per capita stands strong at 52,051.4 USD in comparison with 1,537.9 USD for Pakistan, which explains why the latter has a much harder time enforcing its disability laws and protecting citizens with disabilities (World Bank, 2021). As a result, children with ASD in Pakistan receive fewer services due to an inadequately funded public health system that lacks universal coverage, placing most of the financial burden on the patient’s family (Imran and Azeem, 2014). It is important to note that although children in Canada might have better access to resources and funding, the struggle to secure financial support and services is still ongoing for Ontario parents (to be discussed later). Legislation and allocation of resources underlie health outcomes, rights, and integration of individuals with ASD into mainstream society, and Canada is clearly at an advantage due to its per capita wealth.

#### 4.2 Regional Differences

The lived experiences of children with ASD are also influenced by regional differences that occur within a country. Such differences include ease of access to services due to distance from institutional/medical support, SES (i.e., wealth disparities between different geographic areas), and cultural differences. For example, Indigenous communities living on reserves in Northern Ontario have long battled against systemic racism in healthcare, employment, education, and other aspects of life.

Joyce Echaquan, a 37-year-old mother of seven and Indigenous inhabitant of Quebec (Canada’s predominantly French-speaking and second most populated province) was verbally abused by healthcare providers moments before her death on September 28, 2020 (Nerestant, 2021). Echaquan was confined to her hospital bed after being admitted due to stomach pains and was administered morphine despite concerns of adverse side effects. It was later revealed that Echaquan had faced multiple incidents of mistreatment and racial discrimination at the hands of healthcare workers

during her on-and-off visits to the hospital for prior heart complications. Sadly, there are likely many additional cases of systemic racism in Canadian healthcare, and many may not even be reported. Moreover, Indigenous Canadians are at higher risk of facing food insecurity and mental and chronic illnesses as a result of health inequities (Kim, 2019). Fortunately for Canadians, access to healthcare can be referred to as a 'passive method' of prevention of risk, as healthcare services are free for everyone, and protective measures such as well-child checkups allow for early detection of ASD are provided by the government and include visits to physicians and specialists (Government of Canada, 2021). Nevertheless, remote Northern communities continue to experience inferior access to such services.

At the national level, due to widespread poverty within Pakistan, most individuals seeking services for their children with ASD belong to the middle and upper-middle classes and live in cities with easy access to resources. Parents living in rural areas lack awareness of and access to diagnostic facilities and may need to travel hours every day to big cities such as Lahore and Karachi for treatment (Furrukh & Anjum, 2019). For example, one mother posted on the Facebook group *Autism Resource Group Pakistan*:

I am a mother of a 4 years autistic daughter. We are based in [rural] Bahawalpur [Punjab, Pakistan, located 5 hours from Lahore] which lacks Autism related resources. I have visited a speech therapist here once and she said I should visit Lahore (which is difficult for me). I am left with the options of 1) visiting Multan [Pakistan's 7th largest city and economic capital of Southern Punjab], or 2) online consultation.

Hence, it is not uncommon for parents to travel far distances to enrol their children in good and renowned institutions. However, most rural families cannot afford the expensive transportation fares and accommodation costs required for such travel. Thus, lack of access to adequate services deprives rural families of opportunities to provide the best care for their children with ASD. Since money is the principal determinant of access to healthcare in Pakistan; those who earn more have better access to health services. ASD services represent an active method of prevention of risk. Parents are entirely responsible for seeking services for their children with disabilities and paying for it. As such, Pakistanis face greater inequality than Canadians where ASD services are, for the most part, funded by provincial governments. While in Canada access to healthcare is more uniform, it does not eliminate inequalities for remote regions where Indigenous minority communities live. In Pakistan, access to healthcare is less equitable and uniform across the entire country, including within large cities themselves. Access to services for children with ASD can be challenging in both countries, but the challenge is greater in Pakistan.

#### 4.3 Religion

In many developing countries, religion plays an important role in shaping attitudes towards individuals with disabilities, including ASD. Some individuals use religion to explain or rationalize *why* a child has ASD (e.g., why 'bad' things happen to good people). Religion is also employed as a coping mechanism, where individuals seek community support through organized religious activities, prayer, and trust in God. Harnessing religion as a coping strategy post diagnosis can have both positive and negative effects on the psychological well-being of families of children with ASD (Tarakeshwar & Pargament, 2001). Positive religious coping such as seeking God for support and guidance is associated with both improved religious outcomes (e.g., sense of closeness/connection with God, spiritual growth) and increased stress-related growth (i.e., positive changes in social relationships, personal resources and coping skills). Muslim parents of children with neurological illnesses in Jordan even use religious practices, such as reciting the Quran and seeking religious healers as complementary and alternative medicine (CAM) (Aburahma et al., 2010). However, negative religious explanations such as feelings of abandonment by and anger towards God are associated with greater depressive affect and negative religious outcomes (Tarakeshwar & Pargament, 2001). Religious coping is not just limited to the Islamic faith. Hindus, Buddhists, and Sikhs use the religious concept of karmic attribution to explain the cause of disability, either negatively, as a punishment for sins in a past life or positively, as an opportunity for enhancing good deeds in the present life through righteous action (Gupta, 2011). Thus, religious beliefs may influence the everyday lived experiences of children with ASD in both Canada and Pakistan – countries that differ in the role religion plays in coping with disability. Pakistan is a monocultural, monotheistic country whereby most people are Pakistani born and identify as Muslims. Religion is a key area of concern amongst Muslim families, as many live their lives in line with their Islamic faith. This was reflected in a common trend in the *Autism Resource Group Pakistan* Facebook group, where religious beliefs played a pivotal role in explaining why a child has a disability. Some respondents in this group claimed that such children represent a blessing from God, whereas others feel that they are a curse or punishment for the mother's sins. Such divergent views often result in online debates. For instance, one commenter responded that pleading for God's forgiveness would improve a child's mental health, when her mother asked for suggestions for affordable therapy services. In response, group members expressed their disappointment by arguing that children with ASD are God's gift, not punishment. Hence, in times of distress religion provides relief to some parents while discomfort to others in a country like Pakistan.

In contrast, Canada is a highly secular society where diverse religions are practiced at different levels. Religion does not play an equal role for Canadian families and healthcare professionals in understanding ASD. This was reflected in certain posts in the Canadian *Autism Parents Support Group for Families in Ontario, Canada* which did not see religious beliefs as a cause of ASD, and instead relied on the biomedical approach.

In Pakistan, religion is not only used to explain Autism and guide parents after their child's diagnosis but is also manifested in the lives of children through religious observances and celebrations. Muslims (who form 96% of the population) may visit their local mosque every day for the five daily prayers, and most unite every Friday for communal prayers. The month of Ramadan is spent fasting from sunrise to sunset, and it is common for families to host gatherings to break fasts together. Apart from fasting and prayers, *Zakat* (almsgiving) is another pillar of Islam under which it is mandatory for Muslims to donate a certain portion of their wealth to help the poor and needy. Closely linked is the concept of *Sadaqah*, which is a form of voluntary charity (not obligatory as per religious commandments) people perform not just in the form of donating money, but also through an act of kindness, a smile, or a helping hand. These various religious traditions highlight the beauty and importance of helping others and maintaining a strong communal connection. Despite being a poor country, Pakistan contributes over 1% (more than \$2 billion annually) of its GDP to charity, in line with far wealthier countries including Canada with its 1.2% contribution (Amjad & Ali, 2018). Hence, a collectivistic Pakistani culture, deeply driven by religious sentiments and practices that foster a sense of connection with the larger group and develop empathy and compassion by supporting the less fortunate within that group, may be better at providing a rich and nourishing environment for a young child with Autism when religion is used in a positive manner.

#### 4.4 Childcare

Another major difference between Canada and Pakistan is the cost and availability of childcare services for children with ASD. A 2011 survey revealed that more than 56% of Canadian parents used childcare for children aged four years and younger, especially when both parents were employed outside their home (Sinha, 2014). Parents primarily choose between daycare centres, home daycares, and private arrangements such as grandparents, other relatives, nannies, etc. Many factors influence their choice and include quality, convenience, accessibility, and cost. Through its Early Years Division, the Ontario Ministry of Education monitors and grants licenses to regulated childcare centres and administers relevant legislation. The 2014 Child Care and Early Years Act sets forth the rules and guidelines for the regulation of childcare services in Ontario, covering areas such as staff qualifications, health supervision, nutrition programs, safety standards for home childcare centres, etc. (Friendly et al., 2020). According to the Licensed Child Care Survey provided by the Government of Ontario (2019), the median daily home-based childcare fees ranged from \$66 for infants to \$22 for school-aged children. To provide context, the minimum wage in Ontario is \$15.50 per hour (\$2,325 per month), making Ontario the most expensive province for childcare (Friendly et al., 2020). For those who cannot afford childcare, the Ontario Child Care Subsidy Program may provide families with full or partial subsidies. All provinces/territories in Canada provide similar subsidies to eligible low-income families to assist them in childcare costs, except for Quebec, which directly funds regulated childcare programs. Ontario recently became the last province to partner with the federal government to introduce a national childcare program costing families \$10-a-day per child (Government of Canada, 2022).

Traditional gender parental roles in Pakistan encourage mothers to care for their children. Most married women in Pakistan function as housewives; raising children, cooking, cleaning, and managing all other household chores. According to the World Bank (2021), 60% of females aged 15 or above participate in the labour force in Canada, compared to only 22% in Pakistan. In addition to the small proportion of working women, Pakistan's extended family social structure also provides parents access to childcare provided by relatives, thereby reducing their reliance on paid services. This structure was reflected in the 8,300 member Facebook community for Autism families in Pakistan, where only one post mentioned daycare centres as a tool for parents.

Similar to Canada, Pakistan also has federal and state-level policies outlining standards for daycare centres, however, there are few government-led programs to provide parents with financial support to cover the cost of childcare. The Government of Punjab's Guidelines and Standards for Daycare provide the standards for building requirements, staff management, health and safety, nutrition, etc. for daycare centres. The 2019 Day Care Centres Bill of the National Assembly Standing Committee on Human Rights of Pakistan mandates that every office, private or public, with 25 or more employees must establish a daycare centre to increase women's active participation in the workforce and potentially raise the country's GDP by 30% (Junaidi, 2019). However, according to social media activists and professionals, this policy is applied sporadically only by some wealthy organizations such as multinational corporations and educational institutions, whereas many large-scale textile, sports, and garment manufacturing industries have gotten away with non-compliance.

#### 4.5 ASD Services

Different services and governmental assistance are available for children with ASD in both countries. The Ontario Ministry of Children, Community and Social Services' *Ontario Autism Program* provides services, guidance and financial support in the form of interim one-time funding for children under 18 years formally diagnosed with ASD (Ministry of Children, Community and Social Services, 2021). The funding is determined according to the child's age. As of April 2022, children between 1-5 years are eligible for \$22,000 once through the intervening time whereas those between ages 6-17 can receive up to \$5500. This money can be used to purchase sensory equipment, respite and recreational activities, and intervention services such as speech and occupational therapy. The new funding program was enacted in 2018 to allow parents to choose which services to purchase. The overall impact was, however, a reduction in the funds available for ASD support (Schnurr, 2019). The Ontario Health Insurance Plan (OHIP) does not cover ASD services despite its neurological aetiology.

Punjab lacks a centralized program for Autism services. Families either receive services from government-funded hospitals or private treatment centres. Although provincial-level hospitals such as *The Children's Hospital*, Lahore, provide assessment and therapy sessions free of charge, via social media groups professionals report that these centres experience high patient turnover due to the limited number of publicly funded hospitals that provide free services to a large number of families.

#### 4.6 Classroom Structure

Public schools in Canada are free and employ Individual Education Plans (IEPs), which tailor the curriculum according to the individual strengths and needs of the child, setting annual learning goals and assessment measures. The child's placement is guided by the principle of the Least Restrictive Environment (LRE), which promotes as much inclusion with other students within a regular classroom as is beneficial to the student (Rueda et al., 2000). Classroom structure can vary across institutions and includes inclusive classrooms, resource room models, self-contained classrooms, and special schools which only serve children with special needs. One common theme suggested among many professionals on various online Facebook groups was the need for shorter wait times to enrol in schools and more spots for children requiring special education.

The typical classroom offered to children with ASD in Punjab is a regular classroom with segregated resources for children with special needs, or separate schools providing special education. In 2012, the Punjab School Education Sector plan implemented an inclusive education framework whereby children with mild and moderate disabilities would be enrolled in regular classrooms at the primary and middle school level to maximize inclusion and teachers would receive special training from the Department of Special Education for this purpose (Government of Punjab, 2013). However, online members protested that teachers still lack basic training, and the curriculum follows the same pattern for all students, starting with basics such as the alphabet and numbers, rather than catering to the individualistic learning needs of each student with ASD. A prevalent suggestion was the need to make the educational environment more inclusive to provide students with a stimulating environment to develop their social skills, and to sensitize other students and peers towards their needs. Professionals also stressed the need for lower fees for families who cannot afford private schooling, and effective education plans specific to the child's strengths and abilities.

#### 4.7 Role of Parenting

Parents play a significant role in a child's experience of ASD, as they are the primary caregivers and thus responsible for the child's healthy upbringing. Receiving an ASD diagnosis for a child is difficult for any parent. Grief occurs in five stages: denial and isolation, anger, bargaining, depression, and acceptance (Kübler-Ross, 1969). Parents undergo 'cyclical grieving,' which is when one or more of the initial stages of the cycle and related emotions recur intermittently throughout the child's development and lifespan (Bravo-Benitez et al., 2019). However, there are also cross-cultural differences in the way Canadian and Pakistani parents process and cope with such information. For example, our search from the *Autism Parents Support Group for Families in Ontario, Canada* revealed that the initial reaction upon diagnosis involved significant distress for Canadian parents, but their overall response was generally more positive in comparison with Pakistani parents.

A cross-cultural study on parenting stress and social style in parents of school-age children (5-12 years) with ASD in Italy (an individualistic culture) and Japan (a collectivistic culture) revealed that Japanese parents demonstrated significantly higher levels of stress and that their stress was positively correlated with ASD severity (Giannotti et al., 2021). Japanese parents reported feeling less competent and supported, and more restricted, conflicted, and depressed in their parental role.

The connection between a collectivistic mindset and parental stress is driven by a strong desire to ‘adjust’ their child to acceptable societal standards, deviations from which may impede community harmony and conformity to group norms due to socio-communicative impairments. This cultural difference in response may also be due to variability in access to counselling, resources, access to services and funding.

Societal acceptance of people with disabilities further helps parents accept and embrace their child’s diagnosis. On social media, parents claimed that the biggest factor affecting their initial response was awareness/knowledge of ASD and exposure to children who have it. Some parents reported that having a relative with ASD, learning about it and connecting with other ASD families through online communities provided them with comfort and reassurance. Online discussions suggest that Canadian parents place a greater emphasis on respite care, dedicating leisure time towards self-care.

According to Facebook posts, upon their child’s ASD diagnosis, many Pakistani parents shared emotions of shock, confusion, distress, and frustration and didn’t know where to seek support. A general trend was that mothers usually played the primary role in the upbringing of the child, whereas grandparents, neighbours, and extended relatives offered to babysit in their absence. Many commenters advised parents to watch videos to educate themselves and provide their child with occupational and speech therapy at home. Examples include motor development using therapy balls, and joint massages. Pakistani parents of children with ASD rarely seek respite and instead meet with friends, watch television, and go on walks. Even if a child is non-verbal, parents report that they learn from siblings by observation and imitation; a strategy which parents support. Parents suggested establishing sensory-friendly places including restaurants, parks, and cinemas to make these environments comfortable for their children to participate in.

Pakistan’s collectivistic culture, encompassing core values such as family loyalty, strong social ties, and constructive interdependence may provide a 24/7 warm and receptive environment for young children with ASD. Since most mothers are homemakers and joint family systems (where extended family members share a household with the nuclear family) are prevalent, children can benefit from increased time spent with mothers, grandparents, cousins, and even neighbours. Low labour costs present hiring maids to tend to household chores (which mothers are normally expected to do) as a convenient and affordable option for most middle/upper class families. Not only do maids help with child-rearing duties, allowing greater leisure time for mothers, they can also free up more time for them to invest in educating their child (e.g., reading books, helping them complete homework) and providing parent-directed therapy. Regardless of country of residence, parent-mediated intervention may actually be better for the development of the child’s social and communication skills and can even reduce their levels of anxiety. For example, Green et al. (2010) implemented the parent-mediated Preschool Autism Communication Trial (PACT) intervention, which provides parents of children with ASD with training on how to optimize the responsiveness, timing, and sensitivity of their communicative patterns, plans interactive activities, and encourages strategies such as action routines and pauses during conversations. In their study, 2 to 4-year-old children with ASD were placed into one of two groups: one group received their usual intervention/therapy whereas another group received a combination of their usual intervention and PACT. The latter group demonstrated improvements in parent-child dyadic communication (improvements in their ability to interact with their child and vice versa), as well as reduced ASD-related symptoms such as repetitive behaviours. Since Pakistani parents, especially those living in areas that lack affordable or accessible therapy options, learn to provide therapy to children themselves, more one-on-one parent-child time may optimize their child’s learning. Hence, Pakistani family structure may ultimately aid in the social and interpersonal development of young children with ASD by allowing them increased quality family involvement.

As for families belonging to the lower class, unfortunately most parents are not aware that their child has Autism and do not seek professional help. Instead, they resort to religious explanations and raise them as ‘abnormal’ children. Recently and thanks to social media’s warm and supportive Pakistani online community, many families seek advice and guidance from their online peers. Even a parent living in a remote town, devoid of adequate professionals and services, can join online groups and access up-to-date webinars, resource links, question/answer sessions, live discussions, and additional resources provided in their native tongue of Urdu. It is awe-inspiring to see parents stand against terms referring to their children as ‘ill,’ ‘abnormal,’ and ‘retarded,’ and suggest correct alternatives such as ‘neurodiverse,’ and ‘differently abled.’ Whereas in Canada the former terms are more likely to be recognized as derogatory, in Pakistan parents do not always grasp their negative connotations. Parents with no internet access obtain guidance from hospitals, charitable organisations, and their own social networks. One father, for example, connected with his childhood teacher who is also an occupational therapist. Living in a rural community with few available services, he used videos sent by his mentor to provide occupational therapy to his son.

In conclusion, Pakistani and Canadian parents are the primary caregivers of preschool children with ASD and receive varying levels of support from extended family and neighbours in child rearing, mostly in the form of babysitting. While family demographics are comparable, nations differ in parental responses towards their child's diagnosis, with Canadian parents being more proactive in the long run. Pakistani mothers make greater use of one-on-one time with their children by implementing direct intervention strategies. Despite these differences, a promising and powerful trend consistently observed by all parents was a strong sense of advocacy, ownership, and pride in their children. While navigating through services and learning about their child's needs, many parents became professional counselors themselves, obtaining certification, training, and customizing individualized intervention plans of their own accord. As one determined parent expressed in a post, "you are your child's own therapist" –parenting is significant and those parents who are active on social media groups take ownership over raising their child with ASD.

#### 4.8 Daily Routine

Parenting is a principal determinant of children's daily routine and is greatly influenced by culture which, in turn, shapes the child's lived experiences. Key areas of daily routine of children who have ASD (e.g., sleeping patterns) have been studied but also include areas such as leisure behaviours (i.e., screen time) and dietary patterns. For example, researchers found that children with ASD spend more time using technology (i.e., longer screen time) than non-ASD children, even though longer screen time was associated with more severe symptoms of ASD, especially in the language domain (Dong et al., 2021). Although ASD diets is a controversial topic, some research has reported that gluten-free diets are often used as alternative (and successful) therapy for ASD (Pennesi & Klein, 2012; Rubenstein et al., 2017) and is also discussed by parents on social media.

In Ontario, leisure time for children with ASD is spent playing games, solving puzzles, working with blocks, or watching cartoons on a tablet or television (i.e., longer screen time). In fact, one parent commented that she uses educational apps such as *ABC Kids* instead of reading books to her son because he prefers practical, hands-on activities over theory-based learning. Dietary patterns suggest a heavier reliance on processed and packaged foods such as chicken nuggets, sugared cereals, *Nutri-Grain* bars, popcorn, *Goldfish* crackers, with a general dislike of fruits and vegetables. Such children also eat toast, peanut butter, oatmeal, drink milk regularly, and take Vitamin D and Iron supplements. Therapy and daycare are a common part of their everyday routine.

Punjabi children with ASD spend their leisure time at a local park, visit relatives, and spend significant but relatively less time than their Western counterparts on technology (i.e., screen time). Diets also vary greatly among children; but most parents generally try to incorporate rice and roti (a type of South Asian flatbread) into their meals. A common issue that families sought advice for via social media was their child's narrow dietary preferences and tendency to be 'picky eaters.' In response, many group members recommended a GF/CF (gluten-free and casein-free) diet, because they held a common belief that casein and gluten are 'top offenders' that may worsen the eating habits and trigger behavioural problems in children with ASD. This is a controversial topic because there is no scientific consensus, with some professionals suggesting that diets free of casein and gluten are more apt for children who have pain and discomfort from underlying digestive disorders. During playtime, children enjoy activities such as colouring and watching cartoons, with some showing a special interest in playing with textured items such as sand or play dough. One prevalent concern parents sought advice for was their child's irregular sleep patterns which include, delayed sleep-onset and sleeping/waking at odd hours after short durations.

Although the routine of every child varies significantly, there are underlying sociocultural factors that can potentially explain general trends. For instance, vitamin D deficiency is common across numerous countries, including Canada and Pakistan. A significant number of Canadians (34% of the population) regularly take Vitamin D supplements due to long winters that deprive individuals from receiving it naturally through exposure to sunlight (Statistics Canada, 2015). Comparable national statistics are not available for Pakistan, however, it also has alarmingly high rates of Vitamin D deficiency estimated to be over 70% of the population (Siddiquee, 2021). Risk factors for Vitamin D deficiency in Pakistan include illiteracy, decreased sun exposure and lack of multivitamin intake (Junaid et al., 2015). Vitamin D is not only important for bone health, but also plays a role in circadian rhythm and sleep-wake cycles (Romano et al., 2020). Vitamin D deficiency is also found to be associated with sleep disorders including a decreased quality of sleep amongst children and adolescents (Priono et al., 2022). Children with ASD demonstrate a greater prevalence of sleep disturbances compared to non-ASD children. They have higher rates of insomnia, bedtime resistance, sleep anxiety, nighttime wakings, and parasomnias (Guler et al., 2016).

Pakistanis are less likely to be tested for Vitamin D deficiency compared to Canadians, since Canada's prevention-based approach to healthcare is better funded and encourages routine medical bloodwork, supplementary intake of essential vitamins, and regular exercise alongside a healthy, balanced diet.



This is one reason which might explain why sleep-related problems are mentioned more frequently by Pakistani parents even though they are common in children with ASD from both countries. Canadian and Pakistani parents try to limit their child's screen time to a couple of hours per day as they believe it is detrimental to their speech development and encourage them to exert physical energy and foster social connections in other ways. In addition to greater family time, factors such as daily power outages to conserve electricity and Pakistan's high electricity costs naturally reduce the frequency and duration of technology use. Another factor to consider is the leverage Canadian parents can obtain from their interim funding, which may be used to cover costs of technological devices including tablets, computers, smart phones, and specific computer applications or software that can help their child reach their goals. The funding even covers a white noise machine to help the child sleep soundly, an aid few Pakistani parents know of or use. Such funds can be used directly to shape and improve the daily routines of children with ASD in Ontario, a form of support not available to families in Pakistan and may therefore explain cultural differences in lived experiences in these domains. Pakistani children have more limited dietary choices as gluten and casein-free alternatives are only easily available at high-end supermarkets, whereas in Canada they are common at grocery stores and may even appear on restaurant menus.

All in all, the child with ASD is a part of a larger household linked by social ties through kinship and informal networks which reflects the local environment and services available to them, and is governed by the broader economic, social, and political environment.

#### **4.9 COVID-19 and Unprecedented Challenges for ASD**

The COVID-19 pandemic had a detrimental impact on children with ASD as it disturbed the social, emotional, and physical well-being of individuals all over the world. Studies have identified stressors such as the duration of quarantines and lockdowns, financial challenges, feelings of boredom and frustration resulting from isolation, associated stigma, and fear of catching COVID-19 that have negatively impacted the mental health of families (Brooks et al., 2020). Arguably, the effect of COVID-19 on children with ASD has been greater than on others, as they tend to be routine-oriented and any deviations from their routines can cause significant emotional and behavioural distress (Eshraghi et al., 2020). Social distancing, online classes, and the use of masks disrupted everyone's lives but may have been especially difficult for children with ASD. Both Canadian and Pakistani Facebook users reported feeling that their children regressed verbally and socially and found it difficult to sit in one place when attending online classes or therapy. Additional restrictions such as the closure of public parks and recreational activities during lockdowns also prevented children from enjoying their regular outdoor activities, depriving them of mediums to channel their energy and emotions. A recent study by Amorim et al. (2020) compared the lived experiences of children with ASD to those without neurodevelopmental disorders amidst the pandemic and found that the former reported a more negative effect of COVID-19 on emotion management. Children with ASD also had greater levels of anxiety, and those whose routines had been disrupted due to the pandemic reported relatively higher anxiety than those whose routines were less affected. In addition, social distancing measures restricted face-to-face therapy services and shut down schools and day care centres, limiting avenues for professional and social support for children with ASD (Eshraghi et al., 2020). Many treatment centres in Canada restricted in-person services to one-on-one, eliminating the option for group therapy and interaction, resulting in greater costs, longer waiting times, and fewer available options for parents. Counsellors and other staff help parents adjust to these changes by advising them on less expensive alternatives that may benefit their child, for instance, though specialized services are critical intervention techniques for children with ASD (Elder et al., 2017). One major issue reported by teachers in Pakistan is the shortage of resources and supplies, including toys, games, and stationery due to pandemic related supply delays. Teachers worked around this by switching towards "Do it Yourself" (DIY) crafts such as using scrap household materials.

The challenges children with ASD faced varied in part due to differential government-imposed restrictions related to the pandemic. For instance, a Pakistani child may have still been able to enjoy large family dinners on weekends, local parks were still open to the public, the requirement to wear masks indoors was lenient (especially for children), and families were free to visit the neighbourhood mosque for communal prayers. In Canada extensive lockdowns and restrictions on indoor social gatherings resulted in very limited, if any, interactions outside of one's household. It may be argued that despite school closures in both countries, the pandemic affected children with ASD in Pakistan to a lesser extent by allowing them more opportunities to socialize.

Table 1.

*Broad Overview of Factors Influencing Lived Experiences of Children with ASD in Canada and Pakistan*

	Ontario, Canada	Punjab, Pakistan
Developmental Context	<p><b>Legislation:</b> Explicit consideration of the rights of people with disabilities (e.g., Accessibility for all Ontarians with Disabilities Act (AODA) implemented accessibility and accommodation as a priority in Ontario).</p> <p><b>Regional Differences:</b> Remote communities (e.g., northern Indigenous communities) have less access to ASD support and face discrimination/racism from the healthcare system.</p> <p><b>Religion:</b> Highly secular society, religiosity differs across diverse groups.</p> <p><b>Childcare:</b> Canadian parents rely on external childcare (i.e., daycare centers) which are expensive.</p>	<p><b>Legislation:</b> Disabled Persons' (Employment and Rehabilitation) Ordinance of Pakistan, 1981.</p> <p><b>Regional Differences:</b> Lower-income individuals, and those in smaller communities at large distances from cities have poor access to private ASD services, and often rely on poorly funded public resources</p> <p><b>Religion:</b> Monotheistic country. Religion brings individuals a community, social support, and cause for ASD. Also used as a coping mechanism.</p> <p><b>Childcare:</b> Mothers are primary caretakers of children with ASD, due to traditional gender parental norms, and culture of work in Pakistan whereby workforce is primarily composed of men.</p>
ASD Services	ASD services provided by the government to each family. One-time funding determined by various factors (e.g., age, income) resulting in caps on the number of available therapy hours leading to poor care for some children.	Poorly funded government services overall, although some major city hospitals (e.g., The Children's Hospital, Lahore) provides therapy free of cost. High-income families use private resources, often travelling long distances, whereas low/middle-income families rely on public resources. Complete lack of awareness and acceptance of ASD in poor, uneducated populations.
Classroom Structure	Education is most often tailored to the individual child's needs (e.g., using Individual Education Plans), prioritizing the least restrictive environment. Families often experience long wait times to access special education services.	Education is not often tailored to student's needs at the institutional/government level. More responsibility is placed on individual teachers. Families and professionals in Pakistan push for education services to be less costly, especially for those who cannot afford private care.
Parenting	Parents have greater awareness and acceptance of ASD, and greater access to ASD services that inform their style of parenting.	Mothers are the primary caregivers of children with ASD but lack access to at-home resources that help their child. Despite this, many are actively engaged in their child's well-being and report becoming the therapist themselves.
Daily Routines	Children often have longer screen time, primarily due to easy access to technology for most families, and their dietary patterns demonstrate a heavier reliance on processed and packaged foods such as chicken nuggets and sugary cereals, despite greater access to healthier alternatives	Children often have less screen time, primarily due to lack of access to such technology, a greater time spent outdoors and frequent power outages. Dietary patterns of children with ASD in Pakistan have been recommended to include casein and gluten-free diets, but access to these is limited primarily to higher-income families

**5. General Discussion**

Overall, the factors discussed differentially affect the lived experiences of children with ASD in both countries. These areas exist in an interconnected network that makes up the child's environment and determines their lived experience. At the broadest level, both countries have laws and policies set in place to secure the rights of individuals with disabilities and help them lead a safe and productive lifestyle. Canadians rely more heavily on daycare, whereas Pakistani parents may receive assistance from hired household help and relatives who might share a roof under a joint family system. Regional differences in Canada result in poorer access for Indigenous and other communities to

healthcare, including ASD services. In Pakistan such differences are more robust due to greater polarization of wealth and few passive methods of prevention of risk, due to lack of government assistance and involvement. Generally, children with ASD in individualistic cultures enjoy greater freedom to express their uniqueness but have smaller networks of social ties. Such children brought up in collectivistic cultures benefit from rich stimulating large family environments along with greater parental stress and stigmatization due to the pressure to keep up with society's rigid expectations that determine their sense of self-worth and competency as a parent.

Are children with ASD who live in a Western cosmopolitan city with access to high quality healthcare and services better off than those raised by a middle-class family living in a collectivistic country with tight-knit social networks and a strong cultural connection? It's hard to say. A Canadian family living in a big city such as Toronto might wait several years on a waitlist to secure funding and access to services for their child. Their individualistic mindset and small nuclear family structure may constrict community ties and social bonds that are conducive to their child's speech and behavioural development. Many Pakistani ASD families are desperate to emigrate to developed nations such as Canada to receive the best care for their child. However, that often results in foregoing respectable jobs and comfortable lifestyles they have spent years working hard towards, only to end up being lonely and homesick parents who are anxiously awaiting access to ASD services for their child, struggling financially to make ends meet in very expensive cities. This scenario reiterates the impact of culture and nationality on the lived experiences of children with ASD, each with pros and cons for the child. Choosing between the two, when possible, is often simplistic and biased towards the West, dismissing the important contribution large collectivistic families make to raising children.

This review, despite its consideration of multiple factors, may be rather simplistic as it has employed only a limited ethnographic approach. A more comprehensive ethnography would yield multiple volumes of information concerning differences between and within cultures. Health inequities across regions, ethnicity, age, sex, financial status, religion, and other factors interact to determine the lived experiences of children with ASD. Cross-cultural comparisons are complex and despite narrowing our focus to one province from each country while drawing on both remote and urban communities using multiple social media groups, the data is still insufficient to draw broad conclusions. Analyzing qualitative data from languages other than English and Urdu would also yield a more accurate cultural representation and classify data further by demographic variables such as education level, family status, ethnicity/cultural background, and religiosity of ASD families, perhaps to a greater extent in Pakistan than in Canada. Each country faces its unique challenges accessing services, with wealth and geographic location serving as limiting factors in both countries, though to a greater extent in Pakistan. While information was obtained from hundreds of social media posts, the experiences of families belonging to the lowest classes could not be obtained since they lack access to technology and social media. It is specifically difficult to obtain direct data from remote communities that may not be active on social media due to lack of awareness (about ASD), low literacy (in Pakistan), and a lack of an effective means of virtual communication. Future studies may overcome this using ethnographic methods involving in-person conversations with affected families.

## 6. Conclusion

The holistic approach of this paper, relying on anecdotal examples, government documents, and empirical literature suggests that the lived experiences of a child with ASD in a wealthy developed nation are not necessarily better than that of a child growing up in a poor, developing country, due to the many factors that determine the child's experience. It is important to avoid ethnocentrism and rather recognize that different societies can learn from one another to improve the lives of children growing up with ASD. Families in Western countries, including Canada, can embrace collectivistic attitudes emphasizing extended family and community support to create a warm environment for children with multiple avenues of interpersonal support.

Developing countries must continue to build social structures that are tolerant of differences as well as develop economically to provide Western style ASD services for all children, consistent with the laws they have in place. What ultimately matters is that the child grows up in a loving, caring, and supportive environment that stimulates their social, emotional, and behavioural well-being and accepts them as they are. As one parent summed it up "My son is not different because he cannot learn what others do, he is different because he just learns it differently."

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