EXPLORING THE CULTURAL PERCEPTIONS OF AUTISM SPECTRUM DISORDERS (ASD)

Kaneez Mustary

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SUMMARY

The aim of this thesis was to explore the impact of cultural constructions, generational perspectives, social stigma, daily living experiences, and patterns of help-seeking and access to ASD-related services across different global communities, by employing qualitative and quantitative research.

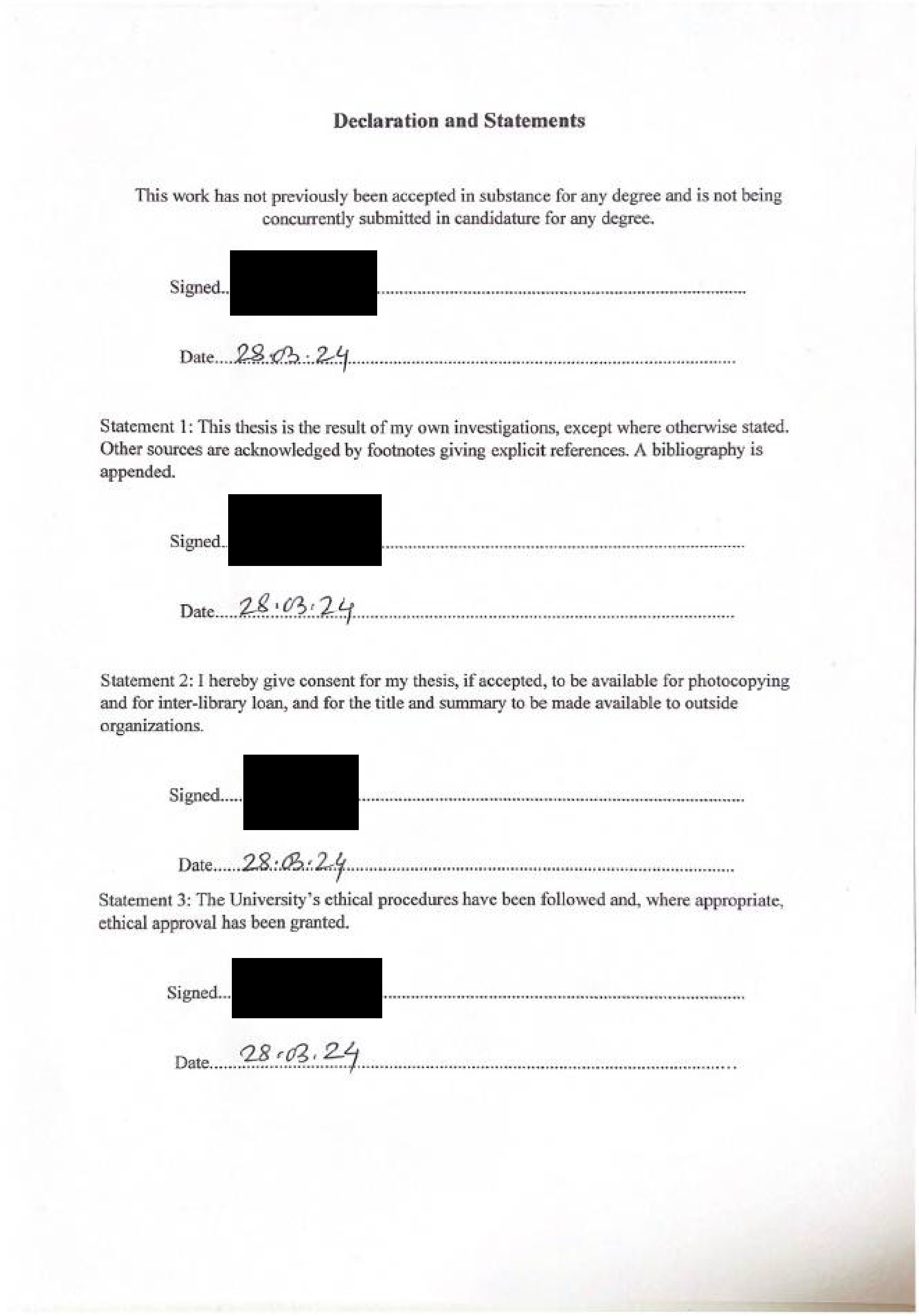
The first qualitative study encompassed the first cross-country exploration of professionals' views of a range of key areas related to ASD provision in Bangladesh, Indonesia and the UK. Professionals from each country expressed common concerns regarding the insufficiency of specialised support and training in effectively managing populations with ASD.

The second qualitative study explored the parental perceptions of diagnosis, understanding of ASD, its associated behaviours, and experience of familial reactions to ASD, in Bangladesh, Indonesia, and the UK. The results suggest similarity across countries, and that different beliefs may be related to different cultural concerns, rather than differences in knowledge. It also highlights the need for more support for families, mental and financial, more training regarding ASD and interventions available, and support with inclusion into the society.

The first quantitative study examined parent perceptions of ASD and its diagnosis, school provision, and predictors of satisfaction of school provision in Bangladesh, Zambia, Kenya, Greece and the UK. The results indicate significant cross-cultural variations in responding to research questions.

The second quantitative study investigated parenting stress and coping to provide some exploratory data across five different countries: the UK, and Greece in Europe; Kenya, and Zambia, in Africa; and Bangladesh in Asia. The aim was to allow levels of parenting stress, the adoption of coping styles, and the impact of coping style on parenting stress for parents of children with ASD to be compared across the countries.

This study could mark a starting point of developing understanding of ASD and their care needs and supporting professionals and parents to empower themselves, within their cultural contexts.



Declaration and Statements

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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ABBREVIATIONS

ABA	Applied Behaviour Analysis
ABC	Autism Behavior Checklist
ASD	Autism Spectrum Disorder
ADI-R	Autism Diagnostic Interview-Revised
ADOS	Autism Diagnostic Observation Schedule
ANOVA	Analysis of Variance
APA	American Psychiatric Association
DSM	Diagnostic and Statistical Manual
ICD	International Classification of Diseases
PDD-NOS	Pervasive Developmental Disorders Not Otherwise Specified
QRS	Questionnaire on Resources and Stress
QRS-F	Questionnaire on Resources and Stress - Friedrich Short Form
SDQ	Strengths and Difficulties Questionnaire
SDQi	Strengths and Difficulties Questionnaire (internalising problem)
SDQe	Strengths and Difficulties Questionnaire (externalising problem)
F-COPES	Family Crises Oriented Personal Evaluation Scales
FRI	Family Routines Inventory
FBI	Family Burden Ichthyosis
NICE	National Institute for Clinical Excellence
PIASC	Parent-Mediated Intervention for Autism Spectrum Disorders
WHO	World Health Organisation
WMA	World Medical Association
WEIRD	Western, Educated, Industrialised, Rich, Democratic

CHAPTER 1

GENERAL INTRODUCTION

1.1 INTRODUCTION

Autism Spectrum Disorder (ASD) refers to a range of complex neurodevelopmental conditions characterised by challenges and differences in social communication and interaction, as well as restricted interests, repetitive behaviours, and difficulties adjusting to change (APA, 2013). Current best estimates, based on epidemiological data, suggest that approximately 1 in 54 children meet diagnostic criteria for autism, with a higher prevalence among boys than girls, at a ratio of around 3-4:1 (Rivera-Figueroa, Marfo, & Eigsti, 2022). In recent decades, the reported rates of autism diagnosis have increased substantially across many nations worldwide. In the United States, for example, the Centers for Disease Control estimates that less than 1 in 150 children were identified with autism in the year 2000, compared to 1 in 44 today (Rivera-Figueroa, Marfo, & Eigsti, 2022). While heightened awareness and improved screening and diagnostic processes have contributed, the rise has prompted debate regarding how much of this increase reflects a true increase in prevalence, versus changing diagnostic criteria, surveillance methods, and access to services (Gordillo, Chu, & Long, 2020). However, the increased rates underscore the urgent need to advance services, supports, and societal understanding of autism.

In examining global patterns, marked disparities have also emerged in autism identification rates, and estimated prevalence, between different cultural groups and national regions. For instance, current estimates for ASD prevalence in many Western nations, such as Canada, the United States, and Northern Europe, range around 1-2% of the population. This contrasts with estimates of only 0.1-0.2% in some parts of Africa, Asia, and Latin America (Gordillo, Chu, & Long, 2020). A proportion of these differences stem from limitations in diagnosis and surveillance infrastructure in lower-resourced countries, but it must be acknowledged that cultural and social factors also play a substantial role in shaping understandings, experiences, and societal responses to autism worldwide (Angell, Meadan, & Stoner, 2020). Such differences are not widely explored or understood, and contribute to a major gap in the knowledge base.

Autism is considered to have a genetic component, but the precise underlying aetiology remains unclear, and may well involve family, social, and wider cultural influences (Lord et al., 2020). For example, differences in cultural values and social norms, along with variabilities in language and communication patterns, will influence whether a child's early developmental behaviours raise concern, and whether this translates into seeking or receiving a diagnosis (Gordillo, Chu, & Long, 2020). The extent of knowledge about autism among parents, educators, healthcare providers, and the general public, may also vary cross-culturally, which could impact symptom recognition (Rivera-Figueroa, Marfo, & Eigsti, 2022). Furthermore, differing belief systems about the causes of autism may shape perceptions, and influence parents' decisions about choices of interventions, therapies, and/or services (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Dardennes et al., 2011). Together, these diverse social and cultural factors may well contribute to global variability in how the characteristics of autism are constructed, interpreted, and identified across settings.

While progress has certainly occurred in autism research, and in the development of evidence-based services, globally over recent decades, the majority of this work to date still reflects Western scientific perspectives, and most usually biomedical models of disability. Far less is known regarding the cultural constructs, societal beliefs, lived experiences, daily functioning, and long-term outcomes associated with autism in non-Western cultural contexts (Angell, Meadan, & Stoner, 2020). Even within multicultural Western nations, the sociocultural and ethnic dimensions of autism remain relatively understudied, with a particular dearth of evidence on ASD features and experiences among racial, ethnic, cultural, and linguistic minority groups (Castillo et al., 2020). Thus, extensive gaps persist in understanding the complex interplay between culture and ASD across diverse global settings. Cross-cultural or cross-country research is urgently needed to elucidate cultural perspectives, representations, values and practices related to autism worldwide. Developing culturally-informed understandings is critical for shaping more equitable and effective practices, policies and systems to improve inclusion, functioning, quality of life, and positive lifelong outcomes for all those navigating autism.

This thesis aims to provide a start in addressing these knowledge gaps by employing a variety of methods and procedures (qualitative and quantitative) to explore the impact of cultural constructions, generational perspectives, social stigma, daily living experiences, parental stress, coping strategies and patterns of help-seeking and access to autism-related services across different global communities. For example, by grasping how the lived experience of autism is shaped by cultural ecology and context, findings can help inform more compassionate societal systems that embrace neurodiversity, and allow affected individuals and families to reach their full potential worldwide. Overall, this research seeks to give voice to diverse cultural perspectives on autism that have often been overlooked, advancing conceptualisations of neurodiversity in ways that foster greater equity, understanding, and global cooperation.

It is acknowledged that the terminology ‘autism spectrum disorder (ASD)’ is not universally accepted by in the autism community, but ASD is the term of choice in the DSM, and it is in wide use in many of the countries in the current study. At the same time, it is crucial to use the terminology accepted by the autism community. Research has shown that “autism” or “on the autism spectrum” were the most acceptable terms, both for persons on the autism spectrum as well as professionals working with this population (Bury et al., 2020; Kenny et al., 2016; Singer et al., 2022; Taboas et al., 2022). Therefore, the terms ‘autism’ and ‘ASD’ were used interchangeably in this paper.

1.2 BACKGROUND

Autism comprises a range of behaviours and different cognitive characteristics that are broadly characterised by challenges in two core domains: 1) social communication and social interaction, and 2) restricted, repetitive patterns of behaviours, interests or activities (APA, 2013). Symptoms emerge early in childhood during key developmental periods, typically becoming apparent between 12-24 months of age, and persist throughout the individual's lifetime, although considerable heterogeneity in presentation and severity exists across the spectrum (Lord et al., 2020).

Distinctions or ongoing struggles with social-emotional reciprocity are part of the social communication and interaction impairments category in the DSM-5-TR diagnosis criteria. This includes things like not engaging in conventional two-way discussion or taking an unusual attitude to social situations (Castillo et al., 2020). Nonverbal communication difficulties are also a part of it. These include things like trouble interpreting and using nonverbal cues for social interaction, problems with eye contact and body language, and a lack of integration between verbal and nonverbal communication. Last but not least, it involves problems with understanding, creating, and sustaining relationships, such as a lack of interest in or ability to adapt conduct to specific social situations (APA, 2013).

The second diagnostic domain encompasses restricted, repetitive patterns of behaviour, interests or activities. This can include stereotyped or repetitive speech or motor movements, excessive adherence to routines and ritualised patterns, highly restricted interests of abnormal intensity or focus. Additionally, there can be hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (APA, 2013). Such behaviours frequently serve a regulatory function for individuals with autism.

As well as its core symptoms, a range of co-morbidities also often accompanies autism, although intellectual disability and language impairment co-occur in many individuals with autism, they are no longer required for diagnosis in DSM-5. Approximately 25-30% of people with autism have average to above average intellectual ability, while around 30% have minimal language skills (Lord et al., 2020). Autism occurs across all racial, ethnic and socioeconomic groups, and is around four times more common in boys than girls. High rates of co-occurring mental health conditions, such as anxiety, ADHD and depression, are also consistently reported (Antezana et al., 2019).

1.2.1 Historical Developments

The first formal diagnostic criteria for autism appeared with the introduction of Infantile Autism as a category in the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1980, under the broad class of Pervasive Developmental Disorders (Castillo et al., 2020). Prior to this time, autism was conceptualised primarily through psychoanalytic theory, which attributed symptoms of autism solely to poor parenting practices, particularly a lack of maternal warmth (Safi, Alshamsi, & Opoku, 2022). Subsequent revisions to the DSM criteria evolved toward a greater neurodevelopmental focus, aiming to delineate the core features of autism, while removing aspects now considered nonspecific, such as lack of attachment or aloofness.

In its most current version, DSM-5, released in 2013, merged four subcategories from the DSM-IV-TR—Childhood Disintegrative Disorder, Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise specified—into a single diagnosis of ASD. The adjustment was made in response to substantial data showing that these categories could not be consistently distinguished in clinical practice. Instead, all signs and severity levels of autism spectrum disorder (ASD) are now grouped together under a single diagnosis (Lord & Jones, 2012).

While DSM criteria are commonly used for diagnosis in the United States and other high-resourced Western nations, the World Health Organisation's International Classification of Diseases (ICD) is more widely used globally. In the previous ICD-11 guidelines, a differentiation was made between Childhood Autism, Atypical Autism, and Asperger's Syndrome as distinct entities under Pervasive Developmental Disorders, as in the DSM-IV-TR. Whereas the new ICD-11 aligns more closely with DSM-5 in using the unified ASD diagnosis (Kulage, Smaldone, & Cohn, 2014). Adaptation and validation of international diagnostic criteria across cultures remains an active area of study.

The conventional medical approach searches for impairments and functional deficits in autism and often has the unintended consequence of drawing attention away from the particular strengths of autistic people and focusing entirely on limitations, whether perceived or real. It detracts, in other words, from an account of what autistic people can do and stresses what they cannot (Frith & Happé, 1994; Hermelin & Frith, 1971; Hermelin & O'Connor, 1975; Mottron & Belleville, 1993; Shah & Frith, 1983). This tendency to interpret autistic performance negatively is seen further in the research literature on autistic intelligence, which demonstrates that it is often the research design itself that is the cause of the issue. Autistic scientist, Michelle Dawson, has long argued that the habit of casting autistic people as ‘less than’ has resulted in autism being subject to medical and other interventions that are not as fully supported by evidence as they should be (Dawson, 2004).

Three recognised difficulties with the conventional medical approach to autism – an overfocus on deficits, an overwhelming emphasis on the individual as opposed to their social context and a narrowness of perspective – have provoked the emergence of the neurodiversity movement in the 1990s and marked an important evolution in perspectives on ASD and other forms of neurocognitive divergence (Lord & Jones, 2012). In contrast to the predominant medical model view of autism as an impairment or pathology to be cured or eliminated, some constructions of neurodiversity propose that autism reflects a natural and meaningful human variation (Walker, 2014). From this viewpoint, societal efforts should focus less on trying to 'fix' people with autism, and focus more on fostering accommodating environments that respect and embrace neurological differences.

The social model of disability presents a similar conceptual counterpoint to the medical model by locating disability, not as inherent to a person, but as predominantly arising from social, structural, and attitudinal barriers that restrict opportunities for those with mental or physical differences (Shakespeare, 2017). Through this lens, equipping individuals with adequate supports, and removing environmental obstacles, provides a more constructive approach than attempting to remediate people to conform to arbitrary norms (Valencia et al., 2022). However, neither model in isolation fully captures the multifactorial nature of disability for complex conditions like autism. While the neurodiversity paradigm helpfully challenges deficit-focused assumptions, and values positive identity, it risks minimising real challenges that accompany autism (Lord & Jones, 2012).

1.2.2 Global Disparities

In examining worldwide patterns, notable disparities have emerged in estimated ASD prevalence and identification rates across cultural groups and national regions. For instance, according to de Leeuw, Happé, and Hoekstra (2020), the prevalence of ASD is approximately 1.5% in North America, 0.15% in South America, and 0.14% in Africa, according to recent systematic assessments of epidemiological data. Japan and South Korea had higher rates, whereas portions of Southeast Asia had lower rates; this disparity in estimations was more pronounced among Asian nations. While methodological factors contribute, these patterns strongly suggest socio-cultural influences shape global identification.

Several factors likely contribute to the differences between autism identification or classification between higher-income Western countries and lower-resourced nations in Africa, Latin America, Eastern Europe, and South/Southeast Asia (Adams, Dadabhay, & Neille, 2021). Firstly, limited awareness and knowledge regarding autism among the general public, educators, and healthcare providers in many countries, directly impedes recognition of early symptoms (Valencia et al., 2022). Fewer trained clinicians, coupled with inadequate screening tools and diagnostic infrastructure, also delayed identification. Additionally, cultural variability in social norms and expectations around child development and behaviour influence interpretation of early signs of autism (Safi et al., 2022). For example, in Iranian society, people are less informed about the symptoms and nature of autism. Unfortunately, after recognising the child's differences and feeling the need to seek a doctor, families do not know what to do and where to go. In this research by Safi et al. (2022), one parent said, *"Despite being suspicious of some of my child's behaviours, I attributed them to his childish playfulness until one day when he knocked his head on a wall, I took him to the doctor. He wrote some tests. It was not normal. They said he had autism. I thought it was a temporary illness and it would get better"*

A study by Adams, Dadabhay, & Neille (2021), on feeding difficulties in children with autism in South Africa, highlighted that practitioners providing feeding management for autistic children need to be responsive to the family's context and culture. This research showed that many families were unable to implement the practitioners' recommendations and this calls for a more family-centred approach to intervention.

Across diverse global societies, sociocultural stigma and misconceptions have profoundly impacted public attitudes and inclusion for those with autism. Early psychoanalytic theories blaming emotionally cold "refrigerator mothers" fostered misplaced stigma, until disproven by research (Safi et al., 2022). A study conducted in Taiwan in 2017, reported the increased burden, isolation, and blame on the mother for having a child diagnosed with autism and these findings were linked to the cultural and contextual understanding of autism and that the mother is the reason for their child's difficulties. (Hsu, Tsai, Hsieh, Jenks, Tsai & Hsu, 2017).

To diagnose ASD in Africa and non-Western countries, the most commonly used diagnostic tools still include the DSM-5 criteria, the ADOS and the ADI-R (Samadi et al., 2022). However, Western diagnostic tools are typically based on observing social communication, interaction and repetitive behaviours and interests (Sharma et al., 2018).

The diagnosis of autism in Africa and non-Western countries present significant challenges due to cultural beliefs and attitudes towards neurodivergent people, including mental health disorders, influence the diagnosis of ASD in Africa and other countries (Ruparelia et al., 2014). Neurodivergence is often viewed as a punishment or curse in some cultures, for example, in Turkey, this perception is leading families to avoid seeking a diagnosis or treatment for their child (Karaca et al., 2019). This avoidance is often driven by the fear of social stigma, which may result in isolation and discrimination. Moreover, variations in social communication and interaction in African and other cultures further complicate the diagnosis of autism (Golson et al., 2022). For example, direct eye contact and social interactions are not always highly valued in some cultures, while repetitive behaviours and interests may be considered normal (Uno et al., 2015). These cultural differences often make it difficult for Western diagnostic tools to capture the full range of behaviours associated with autism in African and other non-western cultures (Aderinto et al., 2023).

Inequities in autism identification intersect with disparities in access to services and supports globally. In high-income countries, children from disadvantaged or ethnic/racial minority groups face more barriers accessing early screening, diagnosis, and evidence-based interventions, contributing to poorer outcomes (Hernández-González et al., 2022). Insufficient infrastructure, long waiting lists and delayed diagnosis contribute to inadequate treatment, exacerbating the challenges faced by autistic individuals and their families (Khanlou et al., 2017). In addition, insufficient awareness and understanding of autism in the general population create stigma and discrimination, hindering access to essential support and resources (Germain et al., 2015). In lower-resourced nations, few evidence-based services may exist at all, outside limited private clinics in major cities, leaving many families without basic supports (Angell, Meadan, & Stoner, 2020). The financial burden of treatments and therapies poses a significant challenge to many families, particularly those from low-income communities (Norris et al., 2016). This financial burden can limit access to evidence-based interventions, forcing them to rely on alternative therapies with unproven efficacy, which can further exacerbate the challenges of providing appropriate and effective treatment for individuals with autism. Thus, poverty, discrimination, and lack of understanding of the need of neurodivergent population, may all obstruct equality of access worldwide. These issues have been recognised, and pressure is placed on governments to address inequities under Articles 24 and 25 of the United Nations Convention on the Rights of Persons with Disabilities, which recognise healthcare, rehabilitation, education, and reasonable accommodation as fundamental rights (United Nations, 2006). However, major gaps remain between rights on paper and realities around the globe, making this an area in need of further investigation.

1.3 PROBLEM STATEMENT

A global perspective on autism is of urgent importance as the vast majority of the world's autistic population today is severely overlooked and neglected (de Vries, 2016; Durkin et al., 2015). In low and middle-income countries, most individuals with autism remain undiagnosed. Late or no diagnosis disadvantages individuals with autism in distinct cultural or socioeconomic settings, and bars them from effective early intervention or educational support (Bakare & Munir, 2011; Bello-Mojeed, Omigbodun, Bakare, & Adewuya, 2017; Montiel-Nava, Chacín, & Gonzálezvila, 2017; Ruparelia et al.,2016). Moreover, little is known about the cultural and contextual adaptations required to make interventions feasible, acceptable, and effective across low-resource settings (Al Maskari, Melville, & Willis, 2018; Franz, Chambers, von Isenburg, & de Vries, 2017; Guler, Vries, Shabalala, & Franz, 2017). A better understanding of the cultural and contextual dimensions of autism may inform strategies to better support underserved communities within high-income, as well as low resourced countries.

Despite the problem being clear, there are numerous barriers obstructing progress in this critical area of inquiry. For example, limited research funding and infrastructure in lower-resourced nations severely constrain opportunities to conduct locally-driven, culturally-relevant autism research in these settings. Additionally, lack of cultural and linguistic competency in research design, clinical practice, and policy realms perpetuates Western-centric cultural biases that overlook diverse perspectives (Yolanda et al., 2017). The researchers have reported that African-American and Hispanic populations are less likely to be diagnosed with autism, often receive the initial diagnosis at later ages, and experience differences in access to services in comparison to other racial and ethnic groups. Studies have also documented lower participation rates of minorities in research studies of autism. These differences have contributed to disparities in services for children with autism from culturally, linguistically, and economically diverse backgrounds. The complexities of navigating community entry, cultural prohibitions, stigma surrounding disability, and historic marginalisation of affected populations in many societies also impedes investigation. For example, Black children are less likely to be diagnosed with autism spectrum disorder (ASD) than White children (Mandell et al., 2009), despite Black and White parents reporting first concerns when their children are of similar ages (Jang et al., 2014), and Black autistic children are often misdiagnosed with other psychiatric disorders (Mandell et al., 2007). Among those diagnosed with autism, clinical presentation is more severe, on average, than that of White children, suggesting that Black children with less impairing symptoms are missed altogether (Jarquin et al., 2011). These diagnostic disparities may reflect providers' racial biases; many Black caregivers of autistic children state that their provider has expressed doubts about the parents' knowledge of autism or made racist assumptions about their family structure or income (Dababnah et al., 2018). These assumptions may cause providers to dismiss Black caregivers' concerns about ASD (Magaña et al., 2015; Pearson & Meadan, 2018). A meta-analysis of intervention studies found that most failed to report the racial and ethnic demographics of participants; the few studies that included this information reported overwhelmingly White participants (West et al., 2016). These disparities highlight a broader culture of exclusion and ignoring people of colour in autism research.

Stigma toward individuals with autism and their families occurs globally and crosses culture and context (Grinker et al., 2012; Ha, Whittaker, Whittaker, & Rodger,2014; Hsu et al., 2017; Manor-Binyamini & Shoshana, 2018; Mitter, Ali, & Scior, 2019; Someki, Torii, Brooks, Koeda, & Gillespie-Lynch, 2018; Tilahun et al., 2016). A clear example of affiliate stigma is reported in a study of South Korean caregivers, who described the stigmatizing consequences of having a child with autism, including reduced career opportunities,and marginalisation from socially desirable networks (Grinker et al., 2012). In South Korea as well as in India (Daley, Singhal, & Krishnamurthy, 2013; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Grinker et al., 2012), the high heritability of autism adds a source of stigma; in both countries having a relative with autism may decrease marriage prospects due to a"genetic taint" on the family. In a study among Ethiopian caregivers, reported stigma was found to be associated with the type of causal explanations provided by caregivers (Tilahun et al., 2016). Caregivers providing a spiritual explanation for their child's condition or seeking help from spiritual institutions.

Gender inequality can form a barrier to accessing services in some cultural contexts. A study among Bedouin mothers of children with autism in Israel (Manor-Binyamini & Shoshana, 2018) describes how in the strongly patriarchal society of the Bedouins, mothers are often unable to access services for their children by themselves and require the father as mediator. One mother was quoted: *"We missed many treatments because his father was* *busy, and I can't travel without him, and sometimes he didn't want to take us because he said it was useless."*

Language barriers may be especially relevant in multilingual countries where the diagnostician has a different mother tongue or dialect to that of the family. Latino parents living in the United States with poor proficiency in the English language report receiving poorer primary healthcare services than those with good English language proficiency (Pippins, Alegría, & Haas, 2007).

Across different geographical contexts, the access to and quality of autism services is associated with income (Alnemary, Aldhalaan, Simon-Cereijido, & Alnemary, 2017; Bishop-Fitzpatrick & Kind, 2017; Colbert, Webber, & Graham, 2017; Dickersonet al., 2017), with parents of lower socioeconomic status reporting poorer access (Bishop-Fitzpatrick & Kind, 2017) and poorer quality (Magaña, Parish, & Son, 2015) of care for their child with autism.

Furthermore, the general absence of participatory frameworks that meaningfully involve community members and people with lived experience as research partners risks producing knowledge and services misaligned from cultural priorities.

It is important to recognize that "culture" does not follow country borders; large cultural differences may be observed within countries, and the cultural similarities may be smaller between neighbours than between diaspora groups living on different continents. Moreover,"culture" is not static, and cultural differences or similarities may change over time (Kirmayer & Swartz, 2014). Kang-Yi et al. (2018), for example, highlight adversity in attitudes within the Korean community in New York City, with some community members openly discussing autism and treating families with a child with autism like other families, while others are reluctant to talk about autism and are inclined to hide it.

1.4 PURPOSE OF THE STUDY

The purpose of this thesis is to elucidate cultural perspectives of parents and professionals associated with autistic population, their values, practices, experiences, and understandings related to autism across diverse global settings through in-depth qualitative, as well as quantitative, research methodologies. The aims are to address major gaps in awareness regarding the complex sociocultural ecologies that shape their experiences worldwide, and to generate insights that can inform more equitable and effective practices, systems, policies and supports to improve quality of life for the rising number of individuals and families affected by autism globally.

On a scholarly level, findings promise to enrich theoretical paradigms by uncovering previously overlooked cultural dimensions of autism. For applied domains, results can directly inform more appropriate, accessible policies, services, and supports tailored to cultural settings.

Significant disparities continue to exist regarding the sociocultural experiences, insider viewpoints, traditional practices, and long-term consequences linked to autism around the globe, even though attention to autism is increasing on a global scale due to its increasing incidence, little is known about the intricate cultural eco systems that influence disability on a worldwide scale. However, most of the existing paradigms for autism research and therapy are based on Western cultural contexts, which may limit their applicability in other, more diverse environments. Investigating the cultural circumstances of autism on a worldwide scale is crucial in order to add to the existing body of knowledge. There are significant knowledge gaps about the cultural aspects of autism among marginalised racial, ethnic, cultural, and language groups, even in multicultural Western countries. Their omission from studies compromises generalisability and exposes researchers to cultural prejudice. So, although autism has become more of a global public health concern, there are still a lot of dark spots when it comes to understanding the cultural norms and social reality of autistic people around the world. This makes things worse for everyone and makes it harder to get the help that people need.

Greater understanding of the cultural contexts influencing autism experiences and neurodiversity cross-culturally is increasingly imperative, both for informing equitable policy and practice reforms as well as advancing conceptual paradigms. The need for qualitative and quantitative, participatory research focused on marginalised sociocultural settings and standpoints is urgent. Ultimately, illuminating diverse voices and experiences related to autism worldwide can catalyze change towards more just, equitable societies that celebrate neurodiversity.

This research was done across six countries, the UK, Indonesia, Bangladesh, Kenya, Greece and Zambia. Whilst the researcher was not present in all the countries of interest due to covid but she was previously been to these countries or have contacts there. The researcher has over 25 years of experience working with autistic people and can speak multiple languages involved in this study.

1.4.1 Research Aim

The primary aim of this research is to identify the services exist for people diagnosed with autism across diverse global settings, starting from their diagnosis and to explore the cultural perspectives, barriers and experiences and expectations of parents and professionals associated with autistic population through qualitative and quantitative investigation.

1.4.2 Research Objectives

- Explore cultural constructions, social stigma, generational attitudes, and causal models associated with autism in the UK, Indonesia, Bangladesh, Kenya, Greece and Zambia.
- Examine daily living experiences, family impacts, functioning, quality of life, and long-term outcomes related to autism within these countries, with different cultural contexts.
- Investigate cultural factors influencing autism identification, help-seeking, disclosure, and access to services and supports.
- Identify sociocultural strengths, priorities, and unmet needs among individuals with autism and their families in these countries
- Inform development of culturally-attuned practices, policies, and systems to promote equity and inclusion for those with autism globally.

1.5 SUMMARY

As discussed above, the cultural factors influencing autism remain understudied among ethnic, racial, and linguistic minority groups - severely limiting generalisability. These gaps contribute to disparities in identification, stigma, and access to appropriate autism services worldwide.

This thesis intends to help meet these needs through exploring diverse insider cultural perspectives on autism across international settings. Autism is a rising public health priority, now estimated to affect around 1% of children but with marked variation in reported prevalence between cultural groups and national income regions. Contributing factors likely include heightened awareness and diagnostic resources in high-income countries versus extremely limited autism identification in lower-resourced regions. Sociocultural influences on norms and stigma also mediate symptom interpretation and identification patterns cross-nationally. Yet despite escalating global prioritisation, most autism research and clinical paradigms still emerge from Western cultural contexts, with minimal focus on non-Western settings or insider perspectives. These gaps surrounding cultural contexts, experiences, insider perspectives, traditional practices, and long-term outcomes associated with autism globally persist, fueling inequities and limiting validity of supports. But the complex sociocultural ecologies shaping autism worldwide remain poorly understood, necessitating more inclusive qualitative and quantitative research to advance conceptual models and inform appropriate reforms tailored to community priorities.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The purpose of this chapter is to provide a comprehensive synthesis of existing literature at the intersection of culture and disability that is relevant to the field of autism spectrum disorder (ASD). A rigorous review of prior research is crucial to situate the significance of the present study within the context of current knowledge and remaining gaps in understanding the cultural dimensions of autism globally. Particular attention will be given to illuminating research on sociocultural factors related to autism arising from non-Western paradigms, as well as examining representation of racial, ethnic, cultural, and linguistic minorities within autism research in multicultural Western settings. Analysis of gaps, limitations, and ethical considerations for conducting cross-cultural research will also be discussed.

This literature review begins with essential background information defining autism, diagnostic criteria, epidemiology, etiology, clinical presentation, and prognosis. This will then explore current understandings of the complex features and heterogeneity encompassed within autism. The state of cross-cultural autism research will then be examined regarding: representation of cultural groups such as, Bangladesh, Indonesia, Kenya, Zambia, Greece, and UK, settings studied, paradigms and methods employed, ethical considerations, and limitations. Evidence on relevance of cultural context to outcomes will also be analyzed. Finally, the chapter will synthesise key gaps identified through this literature review to situate the rationale and significance of the present study, which intends to help address current knowledge gaps through in-depth qualitative and quantitative exploration of diverse insider cultural perspectives on ASD globally.

2.2 AUTISM SPECTRUM DISORDER

The background information regarding autism and diagnostic criteria is covered in detail in the previous chapter.

Formal diagnostic criteria for autism spectrum disorder (ASD) has evolved over recent decades, starting with the introduction of Infantile Autism as a category in the 1980 Diagnostic and Statistical Manual of Mental Disorders. This represented a shift away from previous psychoanalytic concepts of autism origins toward a more evidence-based diagnostic framework (Manning et al., 2021). Contemporary ASD diagnosis continues to be based on behavioural descriptions outlined in the DSM criteria, though debate persists around boundaries and subgroups within the autism spectrum (Sikich et al., 2021).

The diagnostic evolution across successive revisions to the DSM and International Classification of Diseases (ICD) aimed to better delineate the core features of the autism spectrum while removing nonspecific aspects and acknowledging its neurodevelopmental origins (Raj & Masood, 2020). Nonetheless, controversies remain around distinguishing specific ASD phenotypes (Chiarotti & Venerosi, 2020). The most recent diagnostic criteria delineated in the DSM-5 reflect a conceptual shift to a unitary autism spectrum disorder diagnosis. This merges the previous subcategories of Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified from the DSM-IV under one encompassing diagnosis (Salari et al., 2022). Proponents argued this better captures the continuous nature of the autism spectrum and improves diagnostic sensitivity and specificity. However, critics raise concerns about the loss of meaningful clinical information given the extensive heterogeneity within ASD (Dietz et al., 2020). The ICD-11 criteria maintain distinct categories along the spectrum. Ongoing refinements aim to optimise clinical utility of diagnoses.

2.2.1 Prevalence and Epidemiology

The estimated prevalence of autism spectrum disorder has risen substantially over recent decades worldwide, as discussed in the previous chapter. Similar patterns are documented globally, with current best prevalence estimates indicating around 1% of children worldwide are affected by ASD, equating to tens of millions globally based on population figures (Lord et al., 2020). However, significant disparities and variations emerge in ASD prevalence estimates between geographic regions and sociocultural contexts. For example, a 2012 systematic review estimated ASD prevalence at over 1% in North American and European epidemiological studies, compared to estimates ranging from 0.1-0.9% in some parts of Asia and Latin America and less than 0.1% in Africa (Lockwood Estrin et al., 2021).

Likewise, rural regions often have lower reported rates than urban metropolises, perhaps reflecting discrepancies in diagnostic infrastructure. Boys are diagnosed at four times the rate of girls, although gender differences may be narrower for those requiring maximal support (Solmi et al., 2022). Debate continues whether true variation exists in prevalence across cultures or discrepant estimates simply reflect differences in identification patterns.

2.2.2 Etiology

The precise etiologies underlying autism remain incompletely understood at present. However, current evidence strongly indicates autism spectrum disorders result from a complex interplay of genetic, epigenetic, and environmental risk factors that impact early brain development (Raj & Masood, 2020). While a distinct unifying cause is unlikely to account for all cases, significant progress has been made in identifying contributing mechanisms that increase liability (Willsey et al., 2022). Genetically, autism is among the most heritable psychiatric conditions, with concordance rates between identical twins of 60-90%, compared to only 0-30% in fraternal twins and siblings (Dietz et al., 2022). Yet no single autism risk gene exists. Rather, findings implicate diverse variants spanning the genome that converge on common pathways, essential for typical neurodevelopmental trajectories (van't Hof et al., 2021). The identified genetic architecture involves both common variants of small effect, along with rare mutations of larger effect, often shared across neurodevelopmental disorders. Over 100 autism risk genes are now identified. Some known syndromes caused by highly penetrant mutations, like Fragile X, Tuberous Sclerosis, and Angelman Syndrome have high rates of ASD comorbidity as well (Rylaarsdam & Guemez-Gamboa, 2019). Still, much of the genetic contribution remains unexplained.

According to Lord et al. (2020), beyond strictly genetic factors, environmental variables also alter risk, reflecting the fluid interplay between genes and experience. Advanced parental age, maternal obesity, gestational diabetes, prenatal valproate exposure, and difficult birth complications all associate with increased autism risk, suggesting prenatal origins (Manning et al., 2021). No evidence supports vaccine relationship theories. Postnatally, psycho-social adversity, institutional rearing, and nutrition influence likelihood of autism features emerging (Raj & Masood, 2020). Teasing apart causal mechanisms requires integrating biological, psychosocial, and cultural levels of analysis. While this complex etiology causes heterogeneity, it also provides diverse potential footholds for intervention (Lockwood Estrin et al., 2021). Precision public health approaches leveraging risk markers aim to optimise prevention, treatment, and functional support.

Although genetic factors contribute significantly to ASD liability based on twin studies, no single cause is identified to account for rising prevalence. Instead complex gene-environment interactions are likely at play (Hyman et al., 2022). Proposed risk factors range from advanced parental age and prenatal nutrition to air pollution and pesticide exposures, but further etiologic investigation is needed (Sikich et al. 2021). This complex epidemiologic profile underscores the need for continued surveillance and monitoring of population trends across sociocultural contexts. It also foregrounds the role that broader cultural variables likely play in mediating how ASD manifests and is recognised across settings (Chiarotti & Venerosi, 2020).

However, more research is urgently needed, particularly inclusive of diverse populations and sociocultural contexts, to elucidate etiologic mechanisms and subgroups that can inform individualised care tailored to each person's needs across the autism spectrum worldwide (Solmi et al., 2022).

2.2.3 Clinical Presentation and Associated Features

The clinical presentation of autism varies substantially across individuals but invariably involves some degree of difficulty with social communication and interaction as well as restricted interests and/or repetitive behaviours (Genovese & Butler, 2020). Within these core symptom domains, myriad patterns of strengths and challenges emerge across the developmental trajectory (Dietz et al., 2020). Many infants later diagnosed with autism exhibit subtle deviations in social engagement, communication, motor control, and sensory reactivity that become more apparent as reciprocal social demands increase (Manning et al., 2021). Common early signs include reduced orienting to name and eye gaze, diminished shared affect, and atypical vocal patterns and gestures. However, wide heterogeneity exists (Aishworiya et al., 2022). Declining language, social interest, play, and self-care skills between 12-24 months often prompts evaluation.

In childhood, difficulties with reciprocal conversation, friendships, pretend play, adjusting behaviour across settings, and transitions are common. Yet some have precocious vocabularies and speech patterns. Around a third remain minimally verbal (Solmi et al., 2022). Many experience medical comorbidities like gastro-intestinal distress and sleep disorders as well (Genovese & Butler, 2020). Above-average abilities are also possible, masking underlying challenges. Sensory sensitivities, insistence on sameness, and motor stereotypies frequently emerge. Symptom presentation evolves across adolescence and adulthood in heterogenous patterns (Chiarotti & Venerosi, 2020). While some gain skills and independence, others require extensive lifelong supports. Mental health disorders like anxiety are prevalent (Raj & Masood, 2020). Social disconnect and post-high school transition challenges are common but not universal. Adopting a life course perspective focusing on individual developmental trajectories is recommended (Willsey et al., 2022). In all cases, clinical presentation reflects an interaction between underlying neurocognitive differences in the autism spectrum and contextual factors. No single profile universally defines an autistic person. While uncertainty around long-term prognosis persists, personalised supports maximising resilience and self-determination enable positive individual trajectories.

Understanding clinical features through a culturally informed lens remains essential. Manifestations of autism characteristics can vary based on cultural norms around communication, social interaction, restricted interests and behaviours (Solmi et al., 2022). For instance, in cultures that emphasise interdependence and social reciprocity, deficits in social communication skills may be more overt and problematic for individuals with autism. Sensory sensitivities similarly may diverge based on cultural differences related to food, clothing, noise levels, etc. Interpreting autism symptoms thus requires nuanced understanding of cultural backgrounds (Dietz et al., 2020).

2.2.4 Prognosis and Outcomes

Historically, autism carried a poor overall prognosis, with the assumption individuals would require extensive lifelong care and limited education or vocational opportunities (Manning et al., 2021). However, as per Alallawi, Hastings, and Gray (2020), contemporary evidence paints a far more hopeful picture. While heterogeneous, outcomes for many with autism now reach into normative ranges on dimensions like social relationships, mental health, and career (Hyman et al., 2020). However, disparities remain worldwide. Several large cohort studies document that between 3-25% of individuals with autism achieve positive social and vocational outcomes by adulthood, although precise rates depend on definitions (Lord et al., 2020). More acquire speech by age 5 and develop friendship networks over time. Yet a subgroup show cognitive, social and adaptive declines, underscoring heterogeneity (Hodges, Fealko, & Soares, 2020).

As per the study of Sikich et al. (2021), myriad factors influence individual trajectories, including autism severity, intellectual ability, verbal skills, and availability of educational and social supports. Co-occurring conditions like intellectual disability and language impairments predict greater support needs. However, even nonverbal individuals make progress with alternative communication systems (Dietz et al., 2020). Early behavioural intervention and family involvement facilitate gains too. Thus, while autism confers lifelong challenges, positive adaptation is possible for many, contingent on accessing tailored supports and accommodations (Manning et al., 2021). Enhancing quality of life requires moving beyond a deficit-focused lens to foster environments enabling self-determination. However, major disparities in outcomes persist globally based on socio-economic status and access to services (Chiarotti & Venerosi, 2020).

2.3 CULTURAL DIMENSIONS OF AUTISM

2.3.1 Cultural Constructs and Social Stigma

All human phenomena, including developmental disabilities and neurocognitive differences, inherently have cultural dimensions shaped by societal contexts. As per Alallawi, Hastings, and Gray, (2020), autism is no exception. While universal features of information processing differences and genetic risks underlie autism neurobiology, the sociocultural ecology profoundly shapes resulting constructs, lived experiences, and accommodation of divergence for those across the spectrum worldwide. Grasping insider cultural perspectives on autism is therefore profoundly important yet lacking in much autism research to date (Park et al., 2020). Attitudes, assumptions, values, and stigma surrounding autism and developmental disabilities remain heavily mediated by sociocultural influences within any community. For example, in many nations across Africa, autism continues to be shrouded in mystery and stigma, frequently associated with folk beliefs around curses, witchcraft, or parental faults as causes (Samadi, 2020; Hodges, Fealko, & Soares, 2020), and lacking biomedical diagnostic and infrastructure supports (Giannotti et al., 2021). Much work remains not only in boosting identification mechanisms on the continent but also reducing stigma through awareness campaigns attuned to cultural perspectives. This contrasts sharply with cultures like South Korea that have actively promoted acceptance and understanding of developmental disabilities in recent years through nationwide advocacy campaigns (Giannotti et al., 2021).

Likewise, certain patterns of behaviour, learning, or interaction associated with autistic profiles in Western clinical contexts may be more tolerated or even valued as diversity in some collectivist or indigenous cultures under positive rubrics like interdependence, humility, or spirituality (Zhao & Fu, 2022). Cross-cultural interpretation requires avoiding reflexive judgment through an open, compassionate cultural relativist lens. Seeking out and listening to insider perspectives on autism from within diverse communities through qualitative research is vital yet sorely lacking (Samadi, 2020). Even within multicultural societies in the West, mainstream autism advocacy culture has frequently centered voices and constructs arising predominantly from white, educated, middle-class parental perspectives (de Leeuw, Happé & Hoekstra, 2020). Self-advocacy groups spearheaded by parents have played central roles in reducing stigma through awareness campaigns and publicly counteracting damaging cultural myths wrongly linking autism to poor parenting or personal deficits. For example, Autism Speaks in the United States has disseminated multilingual toolkits challenging erroneous claims that link autism to immigration status (Kuhn et al., 2020). However, the diverse narratives highlighted often implicitly reinforce standardising biomedical models rather than embracing pluralistic cultural experiences with autism (Aylward, Gal-Szabo, & Taraman, 2021). Well-meaning universalist communication risks cultural erasure or appropriation, obscuring meaningful variability in how the autism spectrum is understood, experienced, and valued across diverse sociocultural traditions (Enea & Rusu, 2020). More critical examination of cultural tropes and power dynamics is warranted within both autism research and advocacy realms.

Research reveals that cultural stereotypes and societal attitudes toward autism often lack nuance and propagate stigma (Samadi, 2020). For instance, anthropological studies examine how reductive tropes like the unfeeling, socially-avoidant autistic person or the tireless autism parent-therapist fail to reflect the true day-to-day complexity of living with autism (Samadi, 2020). Qualitative investigations documenting first-hand accounts find that across the spectrum, individuals frequently report rich inner lives, meaningful relationships, and moral experiences of empathy when provided opportunities to share subjective standpoints in accessible ways (Zhao & Fu, 2022). Such empirical insights highlight lived complexities that contradict potential cultural misconceptions. Broader evidence indicates that dismantling stigma requires moving beyond dehumanising stereotypes through relation, dialogue, and compassionate diversity embracement (Smith et al., 2016). Additionally, sociocultural forces shape the very construction of disability versus human cognitive diversity (Alallawi et al., 2020). Studies demonstrate that in educational contexts, traits associated with autism spectrum neurotypes, like monotropic focus, may be judged problematic deviations from narrow classroom behavioural norms. Whereas similar traits, like perseverance, are praised when manifested in revered groups like scientists (Park et al., 2022). Disability results not from within-child deficits alone but from interaction with environments that valorise certain ways of thinking over others. Through a neurodiversity paradigm that values diverse minds, new possibilities emerge (Giannotti et al., 2021).

Expanding cultural assumptions about gender entails embracing expressions and strengths across the spectrum that transcend reductive stereotypes. Furthermore, conceptions of autism as an inherently biological medical condition rather than dimension of natural human diversity carry cultural roots (Aylward, Gal-Szabo & Taraman, 2021). Western biomedical frameworks have tended to locate disability within the individual, not societal barriers that disable those with atypical skills and minds (Giannotti et al., 2021). The medical model has improved diagnostic precision and services, but also risks defining people by deficits alone. Holistic cultural perspectives recognising epigenetic interactions between environments and neurodiversity can foster fuller humanity (Park et al., 2020).

In general, while autism spectrum disorders as patterns of neurological difference certainly exist cross-culturally, sociocultural experiences with and responses to ASD remain complex and heterogeneous. No singular narrative defines “autistic culture.” Yet the dearth of qualitative and quantitative research illuminating diverse insider cultural perspectives on autism worldwide obscures this richness. Understanding insider attitudes, assumptions, values, and beliefs is profoundly needed to appropriately contextualise developmental disabilities and design equitable, empowering systems (Samadi, 2020). Progress relies on compassionate cultural bridging.

2.3.2 Generational Perspectives and Family Dynamics

According to Giannotti et al. (2021), marked intergenerational differences frequently emerge in cultural outlooks, values, and attitudes toward disabilities and developmental differences like autism, reflecting shifting sociocultural norms across time periods. While younger generations in diverse societies often demonstrate more acceptance of concepts like neurodiversity, older generations within communities more commonly grapple with enduring stigma and shame surrounding autism and other developmental disabilities (Alallawi, Hastings & Gray, 2020). However, traditional practices developed over generations that foster interdependence and collective responsibility may also offer valuable protective and coping benefits for families facing challenges – illustrating the nuanced layers across generations (Solmi et al., 2022). These complex multi-layered generational dynamics related to sociocultural perspectives on autism often play out across family systems worldwide in deeply context-specific ways. For example, in many individualistic Western nuclear family structures, mothers in particular face cultural expectations to take on disproportionate caregiving burdens for a child with high support needs, frequently resulting in heightened psychological distress, social isolation, and financial strain (Salari et al., 2022). However, some more collectivist cultures may share caregiving responsibilities more broadly across extended kinship networks and community supports to foster greater parental resilience when navigating disabilities (Willsey et al., 2022). Parenting stress is typically very high for parents of autistic children (Barroso et al., 2018; Bonis, 2016; Dabrowska & Pisula, 2010; Hayes & Watson, 2013). In fact, patenting stress for this population is often reported as much higher than for parents of children with other conditions (Hayes & Watson, 2013; Pastor-Cerezuela et al., 2021; Osborne & Reed, 2010; Spratt et al., 2007). It may be that cultural and familial perceptions and expectations may impact parenting stress and coping styles linked to having a child with autism (Dyches et al., 2004; Matson et al., 2017; Rahman et al., 2021).

Likewise, ingrained cultural values like filial piety and family honor may function as motivators for extended family members volunteering to support care and therapy tasks related to raising a child with autism in some Asian cultural contexts, whereas similar obligations may function as burdensome strains that contribute to shame or resentment in other communities if supports feel imposed (de Leeuw, Happé, & Hoekstra, 2020). These complexities underscore the need to elicit direct input from diverse family members across generations (Enea & Rusu, 2020). Too often, families are treated as monolithic entities in cultural research as opposed to the complex adaptive systems they are. Similarly, commonly proposed interventions for supporting families touched by autism also require nuanced modification and tailoring based on generational considerations within cultural contexts (Park et al 2020). For example, parent education programs aiming to reduce stigma by sharing accurate science on neurobiology and dispelling myths may have wider benefit if adapted to also include psychoeducation components targeted to grandparents and extended relatives, who exert strong influences on family attitudes and may require differing messaging (Manning et al., 2021). Alternatively, offering community-based respite programs embracing traditional recreational or spiritual activities with respected elders could empower families across generations. Understanding these generational subtleties and varied learning needs across family members is the key (Dietz et al., 2020).

As per the study of Lord et al. (2020), while parenting any child with high support requirements related to disabilities like autism understandably poses universal challenges for caregivers across cultures, the particular nature of stressors and supports that resonate most strongly are also filtered through the lens of cultural values, social organisation, gender norms, and community roles. For instance, interview research with mothers of children with autism in India reveals extreme social isolation and painful lack of practical and emotional support from husbands and extended family members – a finding sharply contrasting cultural ideals of interdependence and cohesiveness within South Asian joint families (Raj, & Masood, 2020). Within Middle Eastern family contexts, studies indicate high prominence of cultural values around shame associated with inability to control one’s child’s socially unexpected behaviours in public spaces – spotlighting needs for parenting supports tuned to this priority (Aishworiya et al., 2022). These examples underscore how even universal impacts of autism on family wellbeing reflect through the prism of cultural systems in context-specific ways, illustrating the vital need for qualitative and quantitative research and tailored supports embracing insider perspectives (Zhao & Fu, 2022).

2.3.3 Explanatory Models and Help-Seeking

For families to access appropriate and timely services when developmental disabilities like autism first emerge, they must navigate a complex sequence of steps. Samadi, (2020) argued the pathway ranges from initially noticing differences in a child's development or behaviour, to interpreting and making meaning of the symptoms through available cultural explanatory frameworks, deciding whether to seek help based on internalised models, and ultimately connecting with resources if pursued. This entire help-seeking process is profoundly shaped by sociocultural contexts, belief systems, values, and structural factors embedded in the surrounding ecology. For example, whether parents will interpret delays or differences as atypical depends heavily on internalised cultural norms around child development (Aylward et al., 2021). The cultural salience placed on milestones differs. In Western nations like the United States, intensive early intervention services target even subtle lags in reaching speech, motor or social targets out of concern such delays risk cascading impacts if not promptly treated. Whereas in many Latin American contexts, more flexible, family-oriented outlooks on child development timelines prevail (Juarez et al., 2018). These contrasting cultural perspectives clearly emerge when comparing developmental expectations between the United States and Guatemala. American parents endorsed more rigid norms around age-based skills in survey data, while Guatemalan caregivers emphasised individual variation and downplayed comparisons in qualitative interviews. Such internalised cultural norms influence how similar behaviours might be perceived as either within expectations or warranting intervention referral.

Likewise, the explanatory models drawn upon by families and communities to understand the underlying reasons or causes of symptoms marked as atypical – ranging from biomedical to supernatural – critically influence associated meanings, stigma, and resulting help-seeking actions. Causal models attributing autism to fate, divine will, karma, evil spirits, curses, or strictly Western biomedical neurocognitive explanations each carry different implications that will evoke very different care seeking responses and experiences of stigma (Chiarotti & Venerosi, 2020). For instance, a family who believes their child's behavioural challenges reflect spiritual forces like demonic possession will likely not first seek psychiatric care and early intensive behavioural interventions as recommended in Western treatment models (Sikich et al., 2021). Their cultural explanatory framework guides them elsewhere. Yet, biomedical help-seeking in accordance with Western paradigms may not only fail to resonate, but directly conflict with traditional explanatory models that might alternatively frame autism as supernatural possession only curable through indigenous ritual healing (Hodges, Fealko & Soares, 2020). These clashes underscore complexity. Additionally, practical barriers embedded within healthcare, education, and social systems heavily intersect with sociocultural forces to shape whether vulnerable groups will face delays in recognising emerging developmental delays or ultimately fail to access needed supports entirely. For example, families in rural settings globally, as well as those facing poverty, discrimination, and marginalisation nearly everywhere, are at profoundly increased risk of delayed or missed diagnoses of autism and other developmental conditions, reflecting compounded barriers (Genovese & Butler, 2020).

According to Manning et al. (2021), culturally embedded determinants like health beliefs, attitudes toward disability, trust in institutions, stigma, and conceptual models of developmental difference can exert strong influences on help-seeking choices and engagement with services for autism, independent of objective availability or means. For instance, ethnographic research suggests some African community perspectives may consider delays in functional independence or intellectual disability as more worrisome in a child than delays in social communication prioritised by many Western autism diagnostic frameworks – creating potential disconnects (Giannotti et al., 2021). Or in other cultural settings, beliefs that autism reflects a curse on the family meant to isolate them may motivate concealing the child's symptoms rather than pursuing care. These examples underscore risks of well-intentioned but overly simplistic awareness campaigns surrounding autism that fail to address the timely help-seeking behaviors (Zhao & Fu, 2022). With the expansion of diagnostic criteria and the introduction of new disorders in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), more behaviours are being classified as disorders. This cultural shift towards pathologizing normal behaviours also impacts how society views autism. As more behaviours are labeled as disorders, there is a risk of fostering a culture of dependency on medical solutions rather than promoting resilience and coping strategies (Julie et al., 2022).

To meaningfully improve access and service pathways requires engaging in more ground-up qualitative and quantitative research directly with diverse communities to grasp insider cultural paradigms from within (Kuhn et al., 2020).

Cultural competency cannot be achieved through top-down education models alone but requires patient partnership. Seeking to understand family explanatory frameworks, belief systems, lived realities, and complex structural barriers from their direct perspectives can begin highlighting leverage points to guide reforms and promote more equitable access (Enea & Rusu, 2020). But driving change ultimately requires walking alongside communities to co-create systems carefully tailored to integrate cultural values, practices, and priorities of those most impacted (Alallawi, Hastings & Gray, 2020).

2.3.4 Identification Patterns and Disparities

It is important to note that higher prevelance is noted where autism is more recognised and valued, . For example, in the North American context, concerted advocacy efforts over recent decades promoting autism awareness and acceptance have coincided with systemic changes enabling earlier identification and access to services (Smith et al., 2020). Significantly higher autism knowledge and openness scores emerge among the cultures' educators in survey findings. Qualitative data further demonstrates complex stigma barriers restricting autism identification in many Asian communities (Kim et al., 2011). However, cultural developmental expectations and norms surrounding social behaviour also affect appraisal of symptoms. In societies highly valuing social conformity and interpersonal harmony, subtle early traits of autism like reduced eye contact draw less concern than conditions threatening group participation (Freeth et al., 2013). Parents may not perceive challenges warranting help-seeking, and clinicians may have higher diagnostic thresholds for milder social differences versus behavioural disruptions.

Stigma, taboos, and limited vocabulary to describe social-communication differences can also delay recognition and label use. Qualitative research highlights how Indonesian parents frequently emphasizised emotional regulation and tantruming behaviours before mentioning social deficits when discussing diagnostic processes, reflecting salient concerns (Grinker, Yeargin-Allsopp & Boyle, 2012). Political and structural factors further mediate healthcare priorities. Within diverse nations, similar disparities in early screening access, timing of diagnosis, and unequal receipt of ASD services persist across racial, ethnic, cultural, linguistic, and socioeconomic lines. For instance, in the United States, African American and Latino children tend to be evaluated and diagnosed at much older ages than white middle-class children, despite controlling for risk factors, with cascading consequences for long-term prognosis (Zuckerman et al., 2018). Drivers of these intractable disparities include gaps in cultural competency of diagnostic tools, differing conceptual models and developmental expectations, mistrust and stigma surrounding disability, and compounding structural inequities in healthcare.

2.3.5 Access to Services and Supports

Just as sociocultural forces shape autism identification patterns, they also mediate access to and uptake of autism-related services and supports globally. Gaps certainly exist in resource infrastructure across less-resourced nations (Smith, Maenner & Seltzer 2019).

However, cultural variables related to stigma, explanatory models, and locally-relevant priorities also affect engagement with services at household, provider, and systems levels, independent of objective availability. Understanding barriers through insider perspectives is the key. For instance, interview studies with Chinese American and Somali American immigrant parents of children with autism highlight how cultural stigma surrounding developmental disabilities reduces families' intentions and willingness to seek out or participate in early intervention therapies, due to fear of social isolation and shame (Li, 2015; Fox et al., 2017). Directly addressing such sociocultural taboos through participatory methods is required to enable ethical, compassionate care.

Even in well-resourced settings like Western Europe, families from immigrant or ethnocultural minority subpopulations report marginalisation from formal autism systems, resulting in care disparities. Specialised services often reflect the cultural paradigms of dominant groups. Navigating care systems is challenging for any family, but acculturative stress compounds barriers without cultural humility from providers. Beyond limited availability, existing autism services may not provide culturally responsive family-centered care aligned with marginalised community values, communication styles, and social norms. Redesign requires qualitative and quantitative inputs from diverse insider perspectives to guide appropriate, accessible programs.

2.3.6 Daily Living Experiences and Quality of Life

The daily lived experiences and quality of life for individuals with autism and their families cannot be divorced from cultural and contextual factors which differ dramatically worldwide (Fox et al., 2017). Yet a dearth of research exists elucidating how neurodiverse traits manifest within routine activities and social relationships outside Western cultural frameworks. Filling this gap is an urgent priority with ethical implications. Social ecology shapes disability experience. For example, in many collective societies, social rituals around maintaining harmony through polite greetings, eye contact, and small talk carry heightened importance during daily public activities compared to some Western autonomous settings. Navigating ubiquitous social expectation therefore poses amplified and qualitatively different challenges that require locale-specific accommodations, supports, and coping knowledge (Angell, Meadan & Stoner, 2020). Evidence shows local childrearing goals intersect with functional expectations in ways that may evoke distress for neurodiverse youth. For example, Brazilian toddler playgroups emphasising rigid social skills like turn taking over child-led play cause overwhelming pressure for autistic children (Stubbe, 2020). Such premature demands rooted in cultural norms provoke disability per se, causing over-pathologize everyday behaviors and experiences. (Julie et al., 2022).

Coping strategies associated with autism like structured routines, special interests, and solitary play to overwhelmed individuals, often contradict norms in cultures where interdependence is sacrosanct (Uljarević et al., 2016). Yet neurodiversity possibilities like appreciating mathematical strengths non-pejoratively as "nerdy", or leveraging hyperfocus in high technology careers, are often not recognised either (De Jaegher, 2013). Expanding opportunity hinges on embracing insider perspectives on diverse living realities. While autism is simply a descriptive category for grouping behaviour by definition, quality of life ultimately reflects a dynamic co-creation between person and environment. Cultural forces shape the environmental contingencies. Even basics like family sleep practices, diet and nutrition patterns, built landscapes, and default communication modalities facilitate or obstruct participation.

2.3.7 Long-Term Trajectories and Outcomes

Among the more definitive conclusions emerging from decades of autism research is the recognition that long-term developmental trajectories and life outcomes among individuals across the autism spectrum are remarkably heterogeneous and contingent on contextual factors. While intrinsic characteristics like intellectual abilities, communication skills, and co-occurring conditions undoubtedly help shape long-term prognosis, external sociocultural variables also play critical roles in determining functioning across the lifespan for those with autism. However, the majority of longitudinal studies tracking outcomes through adulthood have been conducted in Western nations, substantially limiting generalisability. For instance, a systematic review synthesising findings from longitudinal cohort studies in the United States and Europe found that between 3-25% of individuals with autism attained favourable social functioning and/or vocational outcomes by adulthood. However, the variability in estimates depended heavily on how constructs were operationalised and which assessment measures were applied across the samples (Howlin & Moss, 2012). In broad terms, outlooks on long-term prognosis have gradually improved over recent decades in these nations as societal awareness, service access, and family supports for autism have expanded.

However, such patterns clearly cannot be presumed to automatically represent the inherent potentials, needs, or experiential realities of all individuals across the autism spectrum worldwide. Comparative research increasingly highlights how profound sociocultural variables profoundly shape family systems, transition supports, vocational accommodations, assistive technologies, community inclusion, and public attitudes that fundamentally enable or obstruct optimal developmental trajectories (Jang et al., 2013). While emerging neuroscience evidence does indicate that some features and information processing patterns appear consistently associated with autism neurocognition across the human population, a child or adult's functional abilities and access to social roles cannot be divorced from the cultural ecology and context in which they are embedded.

This carries profound risks of promoting deterministic and ablest judgments about potential based on the rigid application of culture-bound outcome measures developed in Western nations to other societal settings which lack comparable educational, vocational, healthcare, and social infrastructures. For example, intensive early behavioural interventions predicated on training young autistic children expected social communication benchmarks derived from typical toddler development norms common in suburban U.S. settings may hold less relevance or feasibility in cultures where family structures prioritise fostering interdependence, respect for elders, and conformity to hierarchies over individual assertiveness, autonomy, and independence often valued in Western middle-class contexts. Thus, the need for far more diverse global research investigating long-term developmental trajectories and life outcomes associated with autism across different sociocultural environments is extremely urgent. Cross-cultural understandings are critically needed to illuminate particular sociocultural variables and practices that may foster positive adaptation, self-determination, and social inclusion across settings.

To date, applied behaviour analysis (ABA) is proven to be the most scientific intervention for autistic population. Behaviour-analytic interventions may increase client independence, increase a client's indices of happiness (Green & Reid, 1996; Reid, 2016), increase a client’s range of preferences (Dutt et al., 2014; Winborn-Kemmerer et al., 2009), increase positive and reciprocal interactions between caregivers and their children (Ala'i-Rosales et al., 2013; Solomon et al., 2008), and decrease self-reported depression and anxiety (Hillier et al., 2011; Schiltz et al., 2018). In each instance we recognize that neurodivergent individuals struggle to achieve, not because they are neurodiverse, but because our institutional and social environments privilege neurotypicality.

Behaviour analytic training programs should be redesigned so that “neurodiversity-informed pedagogy . . . [becomes] embedded into existing clinical programs to enhance the training of professionals and ensure they are capable of serving as the ‘neurodiversity advocate’ when working with autistic individuals and their families across various cultural contexts” (Schuck, Tagavi, et al., 2022).

Large collaborative international cohort studies tracking children with autism into adulthood through consistent methodologies but across diverse cultural settings hold great potential to unpack complex gene-environment interactions and better inform equitable policy reforms to optimise functioning and combat ableism worldwide. However, the selection of the target behaviour within the research design needs to be readjusted. Many group designs could benefit from understanding the value in single-case designs.

2.3.8 Perspectives of Affected Individuals

Too often absent from scientific discourse, clinical practice, policy development, and autism research worldwide are the authentic first-person perspectives of individuals living with autism themselves. The UK report *A Future Made Together* (Pellicano et al., 2013) sought the views of autistic people and their families, researchers and practitioners (including people identifying with multiple such categories) about their experiences of being involved in research. One key finding from the report was that research funding and output in the United Kingdom does not align with the views of autistic people, family members and practitioners on what research questions should be prioritised – a clear barrier to translation. Views on the prevalence of participatory research were contrasting – while researchers perceived themselves to be engaged with the autism community in both dissemination and discussions about their research, community members, most notably autistic people and their families, did not share this view (Pellicano et al., 2014b). Therefore, intentionally including and amply elevating such experiential insider voices and standpoints is a foundational imperative for conducting ethical, empowering research and shaping anything designed to serve this community. While certain pragmatic barriers to participation exist across the spectrum, specially with sensory and rigid behaviour patterns and communication difficulties, thoughtfully adapting research designs through practices like providing longer timeframes, visual supports, experienced mentors, and alternative communication modalities can greatly foster far more active inclusion of people with autism than presently achieved – with invaluable benefits (Fletcher-Watson et al., 2019). The researchers in this study came from the UK and international autism community.

When enacted conscientiously, such accommodated approaches provide profound experiential insights and subjective perspectives simply unavailable through purely third-party accounts, no matter how well-intended. They allow moving from research merely about autistic people, toward inquiry by and for this community. For example, an anthropological study by De Jaegher (2013) focused directly on how adolescent and young adults on the autism spectrum in both India and Belgium constructed meaning and narratives surrounding the challenges they face in achieving self-determination, pursuing vocations aligned with their talents, living independently, and realising other aspirations to participate fully in community life.

Centering analysis expressly on making sense of lived insider experiences navigating real-world barriers illuminated novel perspectives often marginalised, but essential for guiding reforms in transition supports, accessibility, accommodation practices, and policies. This could address systemic limitations through heeding firsthand insights too frequently overlooked by outside "experts." Such participatory approaches intentionally recognise autistic people as equal partners and valuable generators of knowledge who deserve opportunities to actively shape priorities in research, services, supports, and policies concerning their lives, rather than remaining positioned as passive objects of study or recipients of externally-imposed interventions designed without their input. However, the vast majority of autism research across nearly all disciplines globally still remains conducted "on" or "about" people on the spectrum, rather than meaningfully "with" or genuinely "by" members of the autism community themselves – especially for projects situated outside Western cultures (Pellicano, Dinsmore & Charman, 2014).

Changing this longstanding exclusionary paradigm will require embracing more inclusive and equitable research methods that actively re-center insider stakeholder voices and dismantle entrenched power imbalances that have marginalised people with lived experience. But the benefits for knowledge and ethics are immense. Going further to intentionally seek out and amplify firsthand perspectives also allows moving completely beyond reductive deficit-focused framings that objectify autistic traits or differences as inherently pathological. Instead, it validates strengths, creativity, and self-insights too often overlooked when external paradigms dominate both academia and practice. For instance, research initiatives led by self-advocates and participatory projects partnering with communities powerfully underscore how developmental differences in social motivation or communication styles associated with autism need not intrinsically preclude meaningful participation, relationships, empathy, accomplishment, and valued roles – given adequate structural accommodations centered on lived priorities (Ratto et al., 2017). Inclusive, participatory research holds tremendous yet untapped potential to more richly elucidate cultural standpoints, experiences, goals, and supports subjectively needed to enable those with autism to flourish that remain overlooked and unheeded when deficit-focused external paradigms continue dominating research and practice worldwide.

2.4 CROSS-CULTURAL AUTISM RESEARCH

2.4.1 Representation of Cultural Groups

A robust literature over recent decades has substantially advanced biological understanding of autism as a complex condition with strong neurodevelopmental origins across populations worldwide. However, much of this accumulating evidence continues to be constrained by profound limitations in representation that jeopardise external validity and generalisability of findings across human diversity. The vast majority of foundational autism research has focused on cohorts from Western, educated, industrialised, rich, and democratic (WEIRD) societies, especially North American and European settings, with insufficient inclusion of participants from diverse racial, ethnic, cultural, or linguistic backgrounds (Harrison et al., 2017). For example, a 2011 review found only 2% of total participants in autism studies were African American, despite epidemiological evidence then already indicating higher autism prevalence among African Americans relative to Caucasians in the United States (Tek & Landa, 2012). Low representation fails to reflect sociodemographic realities.

Asian and African individuals have also remained profoundly underrepresented, constituting only around 3% of autism study samples on average, compared to comprising over 15% of the U.S. population and around 25% of public school autism special education enrollments (West et al., 2016). These mismatches limit generalisability. Similar disparities exist for indigenous groups and peoples. In Canada, a 2021 review found less than 1% of autism research participants were indigenous, even though communities report concerns over increasing prevalence (Nicholson et al., 2021). Lack of disaggregated data by ethnicity or culture commonly persists elsewhere as well. Underrepresentation spans basic science, clinical trials, epidemiological surveillance, and intervention studies. But downstream consequences are most acute for psychological, diagnostic, and educational research used to create clinical tools then applied across populations. For example, foundational studies establishing autism screening methods, caregiver report questionnaires, and gold-standard diagnostic measures like the ADOS and ADI-R overwhelmingly recruited white middle-class children from suburban U.S. and U.K. samples (Cuccaro et al., 2007). This risks cultural bias in defining behavioural norms.

Likewise, fundamental psychological theories explaining autism's core features through concepts like "theory of mind" deficits emerge from experiments with homogenous WEIRD children (Kreiser & White, 2014). However, social cognition develops through cultural contexts. Inattention to diversity also characterised seminal early behavioral intervention research. Maenner et al, original 2021 study included only one non-White participant in the experimental sample of 19 (Maenner et al., 2021). Such gaps powerfully shape standards of care and outcomes. In general, lack of cultural representativeness across foundational autism research risks both perpetuating disparities and limiting generalisability of insights for diverse populations. Prevailing gaps require continued critical analysis. However, solutions rest on accelerating more inclusive, equitable participant recruitment and community partnerships going forward to ensure justice.

2.4.2 Settings Studied

In addition to lack of participant diversity, cross-cultural research requires examining diverse settings and environments using contextualised methods. However, the overwhelming preponderance of autism research continues conducted in Western Europe, North America, and Australia. Far less investigates non-Western sociocultural contexts despite over 80% of humanity residing outside WEIRD nations. For example, a 2020 systematic review on autism in India, the world's second most populous nation, found only 130 relevant studies over the prior decade, most following Western designs (Kalra, Agarwal & Tandon, 2020). China, despite extensive research capacity, produced under 500 autism studies total between 1982 and 2011 using homegrown approaches (Sun et al., 2013).

Autism research remains nascent across Africa. A 2020 scoping review on ASD in Africa found only 56 studies over the previous 15 years, noting profound dearth of evidence (Harrison et al., 2017). Similar patterns characterise Latin America, South and Southeast Asia, and Eastern Europe, though some nations like Brazil and South Korea show recent growth. Global mapping of research landscapes consistently reveals massive under-prioritisation of autism studies contextualised for or emerging from low and middle-income country settings relative to prevalence. This holds for basic science, screening tools, cultural constructs, and interventions.

The lack of non-Western autism research cannot be attributed solely to resource constraints. Even brief targeted inquiry elucidating cultural perspectives requires minimal funding but yields high value. Dearth of partnerships, deficit paradigms, and WEIRD biases that dismiss contextual insights as irrelevant more likely drive gaps. Absence of locally-attuned research limits generalisability of Western findings. It also inhibits culturally-appropriate policy and practice reforms in underrepresented settings. Autism's cultural dimensions are dismissed. For example, norms for child interaction and play contrast across cultures, holding implications for judging impairment, support needs, and targets of early intervention (Ratto et al., 2017). In general, the settings studied in autism research remain concentrated in high-income Western, Educated, Industrialised, Rich, Democratic (WEIRD) nations despite rising prioritisation of autism globally (Harrison et al., 2021). Building sustained research collaborations grounded in diverse cultures and contexts worldwide is an urgent priority with ethical implications. Focus must shift to rectify erasure of understudied populations. The countries encompassed across the studies in this thesis - Bangladesh, Zambia, Kenya, Indonesia, Greece, and the United Kingdom, - reflect diverse and underrepresented groups in efforts toward addressing representation gaps and inclusive understanding of autism worldwide. Each cultural context shapes unique lived realities for those within its autism community. By examining insider perspectives from these settings, this research aims to document vital ethnographic insights while analyzing comparative quantitative and quatitative patterns across cohorts. Such inclusive approaches can inform appropriately adapted policies and supports.

2.4.3 Research Paradigms and Methods

In additional to lack of diversity in participants and settings, cross-cultural autism research requires expanded paradigms and methods. Much current work imposes extrinsic assumptions and measures versus generating insights through participatory processes co-designed with communities. That is, building a culture where autistic people and their allies can take on active, meaningful roles in research. These include: changing the language we use to describe autism (Gernsbacher, 2017; Kenny et al., 2016); modifying or identifying physical spaces to enable autistic participation; and adapting the structures and bureaucracy of academia to facilitate autistic involvement and leadership in research. Another challenge is how to capture the voices of autistic people who are not easily integrated into even the fledgling participatory research structures available at current time. This includes autistic children, those with intellectual disabilities and those who do not speak. While innovative practices are being developed (Gaudion et al., 2014; McDonald and Stack, 2016; Ridout, 2014 & Pellicano, 2018), we remain far from achieving meaningful, integration of these voices into research. This will reduce the risks of harm despite good intent. For example, an anthropological critique of standard autism research in Africa found parents objectified as data points rather than collaborators (Valentine, 2010). "Helicopter research" by outside experts seeking to assess prevalence or needs often exploit more than empower (Akombi, Gwarzo, & Balogun, 2021). Similarly, psychological assessments measuring behaviours against U.S. norms without grasping lived realities can pathologise difference (Norbury & Sparks, 2013). Deficits get essentialised as inherent rather than reflecting interacting social and biological factors.

Much of autism research in lower-resource nations also remains grounded in colonialist "medical model" paradigms localising all disability within the individual versus understanding influences of social barriers, inequities, stigma, and lack of resources. It is widely accepted that acknowledging cultural differences and biases can positively affect the quality of the relationship between practitioners and consumers, and the success of behavior change programs (Brodhead et al., 2014; Fong et al., 2016) .

In contrast, participatory paradigms elevating community priorities, qualitative methods capturing insider perspectives, and cultural frameworks illuminating lived realities can catalyze ethical research on the boundaries of science and society (Jivraj et al., 2014). For example, the Cultural-Clinical model integrates cultural assessment into diagnostic processes through contextualised, collaborative practices (Franz et al., 2017).

2.4.4 Ethical Considerations

Conducting rigorous, compassionate, and ethical autism research across cultural settings poses profound challenges but remains a moral imperative. Guiding principles endorsed by the UN Declaration of Human Rights, Declaration of Helsinki, and Belmont Report, including respect for autonomy, justice, beneficence, and non-maleficence, provide foundational anchors (UN General Assembly, 1948; World Medical Association, 2013). However, operationalising research ethics requires nuanced considerations of potential exploitation, harm, imbalanced power dynamics, and lack of direct benefit for vulnerable participants that emerge distinctly when engaging communities across conditions of global inequality. Well-meaning intentions insufficiently safeguard. Foremost is the need to redress historic exclusion through active partnership with affected individuals, families, advocates, providers, and scholars in the Majority World to co-create priorities, methods, and equitable infrastructure as collaborators, not subjects (Durkin et al., 2021).

The procedures encompass informed consent processes adapted across languages, cultures, and accessibility needs to ensure comprehension without coercion or deception. Confidentiality measures require diligence. Question design warrants care to avoid resurrecting stigma and trauma. Interpreting results also deserves prudence and cultural humility to prevent harm from misjudging practices. Nuance matters; selective hearing risks damaging misconceptions. Legitimising pluralism, not imposing universality, is advised (Angell, Meadan, & Stoner, 2020). Community review and member-checking of conclusions strengthens trustworthiness and avoids misrepresentation. Sharing data ownership, authorship, and training opportunities upholds justice. There are no shortcuts to partnership ethics; but the rewards are lasting. In general, navigating ethics in autism research across the unequal terrain of global communities demands reflexive attention, courage, patience, and moral imagination. Guiding principles provide direction when internalised. But lasting progress requires relationships of care, trust, and mutual empowerment.

2.4.5 Gaps and Limitations

This synthesis reveals critical gaps and limitations common across much contemporary cross-cultural autism research that demand urgent redress. Problematic patterns include: insufficient cultural representativeness; concentration in high-income Western settings; exportation of Northern paradigms and measures; lack of qualitative and quantitative, community-based participatory methods; ethics lapses; interpretive blindspots; and researcher-driven agendas that re-inscribe inequities. Consequently, current understandings of cultural dimensions of autism experiences, perspectives, strengths, and needs remain profoundly constrained. The complex sociocultural realities shaping disability and neurodiversity for a majority of the global population affected by autism remain eclipsed and erased.

Addressing representation gaps in autism research requires embracing alternative ways of knowing through mixed methods that re-center inclusive partnerships (Jivraj et al., 2014). This thesis encompasses complementary qualitative and quantitative approaches to balance lived experience insights with epidemiological patterns across understudied cultural contexts. Ethnographic data contextualises participant perspectives, while surveys enable broader generalisation. Formative research facilitated community collaboration to shape socially-valid study design. Analyses anchor inquiry in cultural conceptual frameworks of each setting to equitably extend quality autism research beyond WEIRD samples. Such community-based participatory approaches depart entrenched ruts in existing literature through on-the-ground insights toward inclusive advance.

2.5. RELEVANCE OF CULTURAL CONTEXT TO OUTCOMES

2.5.1. Evidence Linking Culture and Outcomes

While the sociocultural construction of disability is complex and multifactorial, a growing body of evidence affirms that cultural variables play pivotal roles in shaping developmental trajectories, daily living experiences, access to supports, and long-term outcomes associated with autism across the lifespan (Hyun, 2011). Although much remains unknown regarding specific causal pathways, associations point to the profound influence of societal contexts. For example, large-scale studies reveal marked disparities in age of first evaluation, age of diagnosis, and lag time to access early interventions between racial, ethnic and cultural groups even within some high-resourced countries like the United States.

One analysis of over 8000 children with autism in the United States found the average age of diagnosis was over six months later for Hispanic versus non-Hispanic white children. African American children were 2.6 times less likely to have a documented autism diagnosis than non-Hispanic whites, and waited on average nine more months for interventions after concerns emerged (Zuckerman et al., 2018). While gaps in awareness contribute, systemic biases and structural barriers also cause disadvantages for minority groups (Walton & Gabriels, 2020). Evidence-based early intervention during pivotal windows can shift trajectories. Similar ethno-racial disparities emerge in quality of life outcomes between groups in diverse societies. For example, a Canadian study found South Asian children with autism had substantially lower adaptive functioning than White peers despite controls. Family cultural factors partially explained gaps (Jang et al., 2013). Broader comparisons reveal wide variations in long-term outcomes internationally that exceed differences merely tied to service access or income. For instance, cigarette smoking, obesity, post-secondary education participation, and independent living attainment diverge across cohorts with autism in Japan, Australia, Europe, and Canada (Howlin & Magiati, 2017), though influenced by culture and policy. Even fundamental realms like stigma reveal cultural variability. A multi-country study found U.S. respondents expressed less stigma towards autistic children than Korean or Sri Lankan peers (Werner, Shulman, & Turnbull, 2013). Positive media portrayals and inclusive policies may shift attitudes. Perceived quality of life for parents of children with autism also shows differences between cultural settings, with higher stress reported in Singapore versus Switzerland, partially reflecting family expectations and supports (Ho et al., 2019). Other factors also contribute, but culture mediates adaptation. In totality, accumulating outcome research affirms autism as a universal neurocognitive condition, while lived experiences remain situated within societal systems and structures shaped by cultural values. Building equitable societies requires fostering supportive ecologies that move beyond "fixing" individuals to removing obstacles limiting potential based on arbitrary norms. Solutions tailored through understanding cultural strengths and barriers are required.

2.5.2 Implications for Research and Practice

Recognition that cultural factors critically shape lived experiences and outcomes associated with autism spectrum disorders carries profound implications for priorities in research and clinical practice. Most fundamentally, it demands embracing approaches that illuminate sociocultural dimensions through participatory paradigms. Objective measures alone are insufficient. Understanding complex nuances begins by making diverse global contexts, insider perspectives, and marginalised populations central in setting agendas, not appendages. For instance, qualitative methods are vital to capture themes on stigma, explanatory models, and coping unavailable through clinical assessments or caregiver surveys alone (Angell, Meadan, & Stoner, 2020). Cross-cultural mixed methods research can link systemic and individual levels. Practically, findings emphasise urgency for reforms ensuring earlier access to culturally-competent screening, diagnosis, and family supports tailored to diverse populations. Disparities result from incongruence between programs and cultural priorities. Addressing gaps requires partnering with communities to guide appropriate systems, not quick fixes.

Improving adaptation and functioning also hinges on modifying environments, not just training persons with autism to fit narrow molds. Cultural strengths like interdependence can be leveraged in designing accommodations. But insights must inform practices. One-size-fits-all interventions overlook needs. Remedies must be grounded in cultural competence. At policy levels, equitable reforms to education, healthcare, and social service systems are incomplete without understanding family values, structural barriers, and lived realities within local cultural ecologies. Even basic variables like terminology require localisation. Global advocacy partnerships can accelerate progress by illuminating diverse voices. Finally, participatory paradigms that meaningfully involve impacted communities, families, and autistic individuals as equitable partners and directors in research offer profound potential to open doors to best practices and lasting solutions tailored to cultural contexts. But this hinges on humility to follow their lead. Listening and seeking to understand diverse realities can catalyze justice.

2.6 SUMMARY

This integrative literature review affirms that while universal patterns underlie the neurobiology of autism across humanity, the sociocultural ecology profoundly shapes resulting lived experiences, responses to difference, and developmental outcomes associated with autism worldwide. However, pervasive gaps persist regarding in-depth understandings of cultural constructs, social integration, daily functioning, services access, and long-term trajectories related to living with autism outside dominant Western cultural paradigms. Even within multicultural societies, the cultural dimensions of autism remain understudied for racial, ethnic, and linguistic minority groups. Problematic disparities in representation within autism research, exportation of Western assumptions, and lack of qualitative and quantitative, participatory methods, risk perpetuating cultural biases that fuel stigma and inequities in care. Significant reform is needed to redress these imbalances through inclusive practices elevating diverse global voices and standpoints.

Still, building evidence affirms that cultural context plays pivotal roles in shaping autism identification patterns, service disparities, family systems impacts, and adaptation across settings worldwide – even as neurodiversity remains universal. Progress equitably improving outcomes, dismantling barriers, and fostering inclusive societies that embrace all people across the spectrum demands nuanced research illuminating sociocultural forces, beliefs, and lived realities. But this requires moving beyond etic outsider accounts alone to purposefully center emic insider perspectives from affected individuals, families, communities, and scholars in the majority world positioned to elucidate overlooked realities.This review examines current literature regarding cultural dimensions of disability, and autism specifically, to situate the rationale for the proposed thesis research qualitatively and quantitatively exploring underrepresented insider global perspectives on navigating the autism spectrum. Findings promise to enrich scholarship while informing practices and policies to uphold dignity.

CHAPTER 3

QUALITATIVE FINDINGS - PROFESSIONALS' PERCEPTIONS

3.1 INTRODUCTION

As discussed in the previous chapters, a person with autism commonly exhibit comorbidities (McPheeters et al., 2011; Myers, 2009) including but not limited to intellectual difficulties (Elsab-bagh et al., 2012), seisure disorders (Bolton et al., 2011), and hyperactivity and anxiety (Shephard et al., 2019). Moreover, individuals with autism frequently encounter unaddressed medical requirements (Lu et al., 2013; Zhang et al., 2020).

Due to this array of challenges, substantial demand exists for a range of services to address specific behavioural and developmental concerns (Copeland & Buch, 2013), and manage concurrent problems (Zablotsky et al., 2015). Provision of this assistance is often constrained in terms of accessibility, adequacy, and overall satisfaction for parents (Crane et al., 2018; Galpin et al., 2018; Hebron & Bond, 2017; Preece, 2014), and professionals express a desire to provide more comprehensive and extensive assistance (Rogers et al., 2016; Unigwe et al., 2017). This is especially true when tailoring educational services for autistic children (Tissot, 2011), which can present challenges intensified by increased demand for such services (Reed, 2016), and limited comprehension regarding autism (Donnellan et al., 2012; Galpin et al., 2018; Preece, 2014; Roberts & Simpson, 2016).

More affluent nations have had extensive access to information on autism and related services for a considerable period (Chiarotti & Venerosi, 2020; Salari et al., 2022), but research on mental and behavioural health concerns has had comparatively limited emphasis within low-to-medium-income countries (Hossain et al, 2017; Makino et al., 2021; Preity et al., 2018). Limited awareness and service provision for autism in low-and middle-income countries has been attributed to such a dearth of understanding, as well as financial constraints (Collins et al., 2011; Hossain et al, 2017; Viljoen et al., 2021). Moreover, identification of autism may be limited due to societal stigma surrounding mental and behavioural health issues, specifically in the context of children (Rahman et al., 2019; Yamin et al., 2015). Such factors make a necessity of gathering data on autism in low-to-middle-income nations, while acknowledging the significant variations in their cultures, education systems, and economies (Daulay, 2018; World Bank, 2021; Yamin et al., 2015).

The objective of this study is to examine perceptions of professionals regarding provision for autistic individuals in Bangladesh, Indonesia and in the UK. These countries were selected based on the presence of favourable conditions to collect data, along with their representing countries at different stages of development of provision for autistic population. Bangladesh and Indonesia are low-to-medium-income countries at different stages of implementing laws and national services related to autism, whereas the UK has well established services.

Bangladesh is formulating policy for autism through passing two legislative acts, The Disability Rights Law (2013), and The Neurodevelopmental Disability Protection Trust Act (2013) to safeguard rights and assure safety of individuals with disabilities (Mahabuba et al., 2023). These address concerns about provision of comprehensive support and assistance fostering a nurturing and secure environment for neurodiverse individuals to promote their rehabilitation and social empowerment. This Act underscores the significance of developing education systems relevant to the needs of this population, and ministries have committed to implementing programs to address community-based needs associated with autism through establishment of the Advisory Committee on Autism and Neuro-developmental Disorders, a cooperative and collaborative multi-ministry committee involving representatives from all stakeholders, supported by an Autism Technical Guidance Committee. The commencement of the National Disability Complex took place in 2014 to offer support and assistance to students with additional needs including autism. Additionally, Protibondhi Sheba O Sahajya Kendro, established in 2009, provides individuals with disabilities a range of services including physiotherapy, occupational therapy, counselling, and the provision of assistive devices (assisted) by the 'One Stop Mobile Service' for individuals in rural areas with limited access to medical services. Thus, Bangladesh has implemented initiatives aimed at providing assistance to the neurodiverse population, but it is imperative to acknowledge that Bangladesh has not implemented a comprehensive social care and monitoring system for the programs, and the extent of the impact generated by these initiatives remains uncertain (Mahabuba et al., 2023).

In juxtaposition, Indonesia and the UK exemplify nations exhibiting varying degrees of development in their national approach to neurodiversity; In Indonesia, a recent educational program has been implemented to facilitate the mainstream inclusion of children with special needs with the aim of providing equal opportunities compared to typically developing peers, and provides training and informative pertaining to optimal teaching methodologies. For example, some educational institutions offer designated break rooms to cater to the diverse learning needs, alongside provision of psychologists and teaching assistants. Families have autonomously established regional organisations and educational institutions for mutual assistance, although this is in its early stages, and is a local rather than central-government initiative, which has not established a cohesive and complete approach, in terms of creating pathways to receive valid diagnosis, evidence based intervention provisions and inclusivity into the mainstream education (Pratama, 2020).

On the opposite end of the continuum, UK provisions for neurodiverse children has existed since the early and mid-20th century (Osborne & Reed, 2023). Services tailored specifically for autism were established during the 1960s through the efforts of parents. Recognition of the necessity for the health, social care, and education sectors to adopt a proactive approach for autistic individuals was officially acknowledged during the late 1990s, with the establishment of the Department for Education and Employment, Autism Working Group, in 1998 (Osborne & Reed, 2023). The National Health Service (NHS) in the UK plays a vital role in the comprehensive and continuous management and support of individuals with autism and their families/caregivers, and encompasses primary, secondary, and tertiary services, both directly and in collaboration with education, social care, and voluntary sectors (NICE, 2021). The Autism Education Trust (2007) for England and Wales identifies exemplary practices, and focuses on development of formal competencies and training programs for educational practitioners. The Autism Act (2009) imposes an obligation on the Secretary of State for Health to formulate a comprehensive plan for individuals with autism (irrespective of their cognitive capabilities) and outlines the legal obligations that local authorities and NHS entities must fulfil. Additionally, it entails establishment of a well-defined diagnostic process, designation of lead professionals responsible for diagnosis and assessment, development of explicit transition plans, appointment of a senior commissioner responsible for joint efforts, and the formulation of localised commissioning plans.

Thus, these countries offer a chance for a comparative analysis of autism services and provisions, contributing to the expansion of knowledge on the global landscape of autism, whilst acknowledging differences in low-to-medium-income countries. Despite differences in the development of legislation, differences in actual provision of diagnostic services may be less pronounced than expected across these countries. It is widely stated that there is a lack of knowledge about autism in low-to-medium-income countries (Hossain et al, 2017; Makino et al., 2021; Preity et al., 2018), although it may be that this is not so much a lack of knowledge, but a different understanding of autism, in some regards, attributable to cultural differences and beliefs (Reed et al., 2024). However, there are very few studies that have compared across countries directly using the same methodology, making any such claims difficult to substantiate, and it may be that knowledge varies within countries to the same extent as between countries. To commence such a comparative analysis, the perspectives of professionals who offer these services were deemed important to ascertain, and inquiries were conducted into three domains involving perspectives on: the nature of ASD; the key ASD-related behaviours and corresponding interventions; and assistance provided to family by services.

It is well established for the UK that knowledge about autism is variable, and a significant factor determining professionals' capacity and willingness to offer provision (Able et al., 2015; Baglieri & Shapiro, 2012; Busby et al., 2012; Crane et al., 2016; Jones et al., 2014; Jung et al., 2011; Segall & Campbell, 2012; Unigwe et al., 2017). Similarly, Biswas et al. (2018) examined understanding of autism among special educators in Bangladesh, and noted that teachers exhibited a lack of awareness regarding autism and misconceptions about its underlying causes, which are shared by parents (Reed et al., 2024) There is limited research available on perceptions of Indonesian teachers, with only one study partially exploring opinions of Indonesian teachers. Febrian and Widavant (2015) demonstrated nearly 90% of teachers demonstrated unfamiliarity with autism, and those with a certain degree of knowledge and expertise held autism to be synonymous with mental instability.

In respect to ASD related behaviours and their treatment, there is a great deal of evidence relating to outcome-effectiveness studies derived from higher-income countries (Reed, 2016), but less from low-to-medium-income nations (Gómez-Marí et al., 2022). However, this does not mean that this scientific base is translated in professionals' understanding in any country. In the UK, and other economically-prosperous countries, professionals providing services for autistic individuals often have a sense of inadequacy in effectively addressing challenging behaviours and distress (Weiss, 2020). Gómez-Marí et al. (2022) & Reed (2016), noted that the learning strategies and cognitive characteristics exhibited by individuals with autism pose a challenge to established pedagogical principles and practices. Previous research has proposed that the way teachers perceive the causes of problematic behaviours influence decisions to provide assistance for such behaviours (Lambrechts et al., 2008; Whitaker, 2009). Tabib (2011) noted that medical professionals in Bangladesh exhibited a lack of knowledge on the clinical characteristics and treatment strategies for ASD. Efa et al. (2015) found a majority of teachers lacked comprehension of challenging behaviours associated with autism; while they could identify short-term tactics for reactive management, they did not describe named or intricate tactics often employed to effectively handle problematic behaviours. In Indonesia, Tucker et al. (2013) concluded most teachers have not received specific training in how to educate students with autism and challenging behaviours, and Paramita et al. (2020), indicated Indonesian teachers mainly attribute challenging behaviour to family-related factors (which may, or may not, be the case; Osborne & Reed, 2009). Ashar et al. (2019), studied an inclusive setting, and reported teachers were able to understand the triggers of challenging behaviours, but were only able to apply minor interventions when challenging behaviours were at an early stage.

Although there exists a widespread recognition of autism in the UK by families (Reed et al., 2024), Crane et al. (2018) noted a widespread absence of post-diagnostic assistance for both individuals with autism and their families (Jones et al., 2014; Rogers et al., 2016). Guldberg (2021) revealed significant disparities in rates of school exclusions between those with autism, indicating that autistic pupils are twice as likely to experience such exclusions compared to their non-SEN peers.

Given all of the above, the present study encompassed the first cross-country exploration of professionals' views of a range of key areas related to Autism provision. It employed semi-structured interviews that explored professionals' perceptions of autism, selection of interventions, and views on support within the context of their cultural traditions and the resources accessible to them. The adoption of a qualitative approach was motivated by several factors: firstly, the potential emergence of issues was not clearly defined; secondly, there is a lack of established quantitative tools capable of effectively capturing these issues; and thirdly, it was deemed crucial to provide participants with ample freedom to express cultural differences that may not have been initially considered by the researchers.

3.2 METHOD

3.2.1 Participants and Recruitment

Participants were recruited via advertising on social media groups, social media pages, and organisations working with people with autism, and targeted GPs, Consultants, Social Workers, Psychologists, Occupational Therapists, and Teachers working with autistic people, and with knowledge of behavioural difficulties that people with autism can present. Thirty-seven professionals agreed to participate and were interviewed across Bangladesh (*n* = 12), Indonesia (*n* = 18), and the United Kingdom (*n* = 7). Table 3.1 gives details of the participants, including genders and occupations. Most were teachers in special education, but other professionals included Speech and Language Therapists (SLTs), Occupational Therapists (OTs), Psychologists, Behaviour Analysts (BCBAs), and Intensive Interaction practitioners. Reflecting the development of national policies and practices in the countries, the Bangladeshi professionals worked in both public and private sectors, those in Indonesia worked in the private sectors, and those in the UK worked in the NHS and public sectors.

Table 3.1: Participant Characteristics

	N	**Gender**		**Occupation**		**Sector**		**Years Experience**
Countries		**M**	**F**	**Special Ed**	**Other**	**Public**	**Private**	
Bangladesh	12	6	6	9	3	5	7	10+
Indonesia	18	3	15	16	2	0	18	10+
UK	7	1	6	4	3	2	5	10+

3.2.2 Ethical Issues

This study obtained ethical approval from the Ethics Committee of the Department of Psychology at the University. Prior to conducting the interview, all participants were provided with a comprehensive explanation of the goal and nature of the interview, and gave their consent by signing a consent form. Verbal consent was also recorded for each participant at the start of the interview. All participants were informed of their right to withdraw from the study at any given moment.

Table 3.2: Participating Countries

Country	Location	Area	Population	Main Language	Ethnic Diversity	Main Religion (% of adherents)	Free Health Service	Free Social Service
Bangladesh	South Asia	148,460km^2	170 Million	Bengali	Bengali - 99% Other – 1%	Islam (91%)	No	No
Indonesia	Southeast Asia and Oceania	1,904,569km^2	270 Million	Bahasa Indonesia	Javanese 40% Ethnic Groups- over 1300	Islam (87%)	No	No
UK	Northwestern coast of Europe	242,500km^2	68 Million	English	White- 87% Asian- 7% Black- 3% Mixed- 2% Other- 1%	None (52%) Christianity (36%) Islam (7%) Other (5%)	Yes	Yes

3.2.3 Procedure

The same researcher conducted each interview, which were performed through individualised interactions, utilising various communication mediums, such as telephone, messenger, or audio conversations. Prior to the interview, participants were given opportunities to discuss their experiences and expectations, etc., on several occasions_with the researcher. These conversations prior to interview is what helped to develop the research questions. An introduction to the study to establish a sense of comfort inside the research environment was also given to each of the participants, prior to interview. This additionally ensured that all participants were prepared in a comparable manner. The duration of each interview ranged from 30 to 40 min, but participants were not discouraged or inhibited from discussing matters in as much detail as they deemed suitable for each question.

The interviews were conducted in a systematic manner, following a predetermined set of instructions and questions. The script delineated the specific inquiries and prompts to be employed for the purpose of eliciting responses. The implementation of this protocol meant that similar inquiries were posed in each interview, inside a consistent and standardised environment, in order to maintain uniformity and consistency. There were 10 questions, divided into three sections: perceptions of ASD; perceptions of behaviours and treatment; and perceptions of family, care, and support issues. These areas were selected for this study after consultations with professionals from the participating countries prior to interview as mentioned above. It is important to mention that not all professionals involved in the initial discussions, participated in the study. Researcher asked questions in English to the professionals working in the UK and Indonesia, an interpreter was used for Indonesian professionals to translate the research questions into Bahasa and then translate back into English for the researcher. For Bangladeshi professionals, the researcher asked the questions in the participants' native language. Table 3.3 displays the actual questions that were asked during the interviews.

Table 3.3: Actual Questions discussed during the interviews

About ASD

1. Tell me what 'autism' means to you.
2. What causes ASD?
3. What behaviours are key in diagnosis?
4. How do challenging behaviours develop?

Behaviours in ASD

5. Behaviours you are concerned about.
6. Why do people with ASD behave the way they do?
7. What interventions actually work or should be tried.

Family and care issues

8. Comments/concerns from family members, and/or members of the public, made regarding the behaviours of an individual with ASD, that are concerning.
9. Future expectations for people with ASD.
10. Who should take primary responsibility for the wellbeing of this person long term?

3.2.4 Content Analysis

The interviews were captured using a conventional tape recorder, and stored on audiotapes, which were then transcribed. Subsequently, the transcripts of the interviews underwent content analysis to derive overarching themes that would encapsulate the remarks made during the interviews. The aforementioned methodology has been previously employed to get a deeper understanding of the outcomes derived from interviews, as well as to facilitate the conversion of qualitative themes into quantitative data. In order to achieve these objectives, the content analysis was carried out in accordance with the guidelines proposed by Vaughn et al. (1996), Frederickson et al. (2004), and Osborne and Reed (2008). The processes involved in doing content analysis are delineated in Table 3.4. As the content analysis was done only by the researcher, step 4 of the table 3.4 was not completed.

Table 3.4: Outline of content analysis

1. Identification and highlighting of units of information (words, phrases and/or sentences) relevant for research purposes.
2. Selection of category headings to sort and group these units of information.
3. Coding of units of information according to category headings, to enable most of the units to be placed within a category.
4. Negotiation between the researchers to agree the category headings that most economically accommodate the relevant units of information.
5. Categories generated in the first phase of data analysis are reviewed and revised.

Note: Based on Vaughn et al. (1996); Osborne & Reed (2008)

Following transcription, statements made by participants were deconstructed into the most basic units of information that could be interpreted independently as meaningful and instructive utterances. The statements that formerly comprised many units of information, such as lengthy phrases encompassing multiple points, were separated into distinct units. A representative subset of the interview transcripts was chosen, with one transcript taken from each country. The interview transcripts were thoroughly examined multiple times, and, as a result of these examinations, category headings were created for the statements provided in response to each question. The selection of these category headings was made with the intention of facilitating the classification of all units of information pertaining to a specific question, based on the headings generated for that question. Once the categories were determined, the researcher proceeded to categorise all the units of information generated during each interview.

3.3 Results

The cumulative quantity of information generated by each group in relation to each question was computed. The percentage of units of information falling into each category for a given question was also computed for participants from each country.

3.3.1 ASD

Question 1:Tell me what 'autism' means to you.

Table 3.5: What Autism means. Percentage (number of participants) in different categories.

Country	Lifelong Disability	Neuro-developmental delay	Different ability
Bangladesh	0	75% (3)	25% (1)
Indonesia	9% (1)	91% (10)	0
UK	0	33% (4)	67% (6)

Table 3.5 summarises professionals' responses about their understanding of ASD. Professionals from all countries noted that ASD was a neuro-developmental delay, with this response being more prevalent from Bangladesh and Indonesia.

One Indonesian professional expressed, *"As a practitioner, I think of autism as a label of a neurological condition, this label is only useful for the parents to understand their children and to have a realistic expectations about their children."* Thinking of ASD as a different ability was mentioned by UK and Bangladeshi professionals (no such explanation was recorded by Indonesian participants).

One Bangladeshi professional stated, *"Autism means a different lifestyle to me, we live in one way and they live in a different way. We communicate in one way and they communicate in a different manner. If we can follow their lifestyles, then we can understand and communicate with them functionally. Autism is not a disease."*

One UK professional said, "Autism is an umbrella name, where no one is the same, there are lots of turns in it and every individual has different needs and abilities, and requires support in different areas."

Only small numbers of comments suggested ASD was a lifelong disability.

Question 2: What causes ASD?

Table 3.6: Percentage (number of participants) in different categories for what causes ASD.

Country	Medication, nutrition, & depression during pregnancy	MMR vaccine	Mercury & chemical	Neurodivergence	Genetics	Pollution/ Environment
Bangladesh	29% (4)	0	14% (2)	14% (2)	14% (2)	29% (4)
Indonesia	20% (6)	3% (1)	17% (5)	6% (2)	42% (13)	13% (4)
UK	9% (1)	0	0	27% (3)	55% (6)	9% (1)

Table 3.6 summarises responses regarding professionals beliefs about the causes of ASD. The majority of comments from UK professionals (> 80%) suggested either a genetic or neurodivergence as the cause of ASD. These suggestions were also made, to a lesser extent, by Indonesian professionals (~50%), and to a more lesser extent by Bangladeshi professionals (~30%).

One UK professional stated, *"I never thought anything ever caused autism. I thought it was something to do with the wiring of the brain, they hear and perceive things differently than us. I thought it was a condition that they were born with. The degrees of difficulties varies."*

One Indonesian professional expressed, *"The root cause is genetical, but I believe that genetical predisposition with environmental factors are responsible. For example, if a child spends 8 to 9 hours in a day in front of a phone or tab, he has no opportunity to socialise or to learn anything new. These environmental factors play a vital role in childhood development."*

Bangladeshi (~60%) and Indonesian (>30%) professionals' comments were also likely to mention environmental pollutants, and mother's behaviours during pregnancy as potential causes; certainly, more often than UK professionals (~20%).

One Bangladeshi professional stated, *"During pregnancy, if a mother is not taking care of herself and/or not maintaining good diet, this could cause her child to be autistic."* This was echoed by an Indonesian professional, she said, *"Autistic child is born because of a mother's mental and physical difficulties during pregnancy."* Another Bangladeshi professional said, *"We are seeing increase in autism diagnosis because of our environmental pollution."*

Question 3: Key signs of ASD during diagnosis

Table 3.7: Percentage (numbers of participants) in different categories for signs first noticed among children with *ASD*.

Country	Deficits noticed in Speech	Deficits noticed in Socialisation	Deficits noticed in play skills	Deficits noticed in Behaviour
Bangladesh	24% (4)	35% (6)	6% (1)	35% (6)
Indonesia	23% (7)	19% (6)	6% (2)	52% (16)
UK	27% (3)	27% (3)	18% (2)	27% (3)

Table 3.7 summarises the responses made by the participants regarding deficits professionals noticed among children before their diagnosis of ASD was confirmed. Deficits in speech and socialisation were identified as key symptoms noticed similarly by professionals across all three countries. Deficits in socialisation and play skills were noticed more by professional in Bangladesh and the UK.

One UK professional stated, *"The signs that I noticed were lack of socialisation, for example, not playing with other children in the nursery, lack of eye contact and lack of imagination when playing with toys. There were also some noticeable rigid patterns of behaviour."*

Similarly, one Bangladeshi professional said, *"I noticed the lack of eye contact, and repetitive movements and echolalia as the initial signs among ASD children."*

Another UK professional expressed, *"The signs I noticed first were repetitive motor movement, and the way they might use their words. They might know the word and meaning of it, but they might not use it to request. Again, they don't play in a meaningful way, they could be lining up toys rather than playing with them."*

However, Indonesian professionals tended to report deficits in behaviour more compared to other two countries. Most of the reported behaviour were self-stimulatory in nature.

One Indonesian professional stated, *"First I will look for eye contact, then look to see if the child is aware of his surroundings, and if he is doing any stimming behaviour, and lastly I notice their interactions with their family members and peers. They tend to live in their own world."*

Question 4: How did the person with ASD develop challenging behaviours?

Table 3.8: Percentage (number of participants) in different categories for how the person with ASD developed challenging behaviours.

Country	Learned behaviour	Lack of functional skill	Develop due to ASD	Lack of person-centred plan and inconsistent Intervention
Bangladesh	37% (4)	27% (3)	18% (2)	18% (2)
Indonesia	69% (11)	13% (2)	6% (1)	12% (2)
UK	40% (4)	30% (3)	0	30% (3)

Table 3.8 illustrates what professionals believe to be the reasons for developing challenging behaviour. A high number of comments suggest that problematic behaviours are learned, with this number being highest for Indonesian professionals.

One Indonesian professional said, *"They do those behaviours to get a response from another person, that is how they learn to behave."*

Similarly, one UK professional stated, *"There are lack of opportunities to explore appropriate activities or objects for sensory related behaviours, whereas, the self-injurious and aggressive behaviours are learned behaviour."*

Professionals from all three countries identified that lack of functional skills is responsible for developing challenging behaviour.

Indonesian professional expressed, *"They develop challenging behaviour because of not having functional skills to control their environment, as they spend majority of their time in front of a tab."*

A higher number of UK professionals and carers believe that lack of person-cantered plan and inconsistent behaviour management are the cause of developing challenging behaviour.

One UK professional stated, *"These behaviours start because of the people who work with them, who hasn't had a good plan for them, hasn't built up a good relationship with them. Unfortunately, in line of work, we get people who lack empathy, understanding and patience. These are the characteristics that are crucial in people working in this field. If we have not got the right person, support or plan and consistent implementation, it is very easy for the behaviours to escalate."*

Similarly, one Bangladeshi professional said, *"The challenging behaviours are a result of not having person-centered intervention."*

Few comments from professionals working in Bangladesh and Indonesia suggested that the challenging behaviours are integral to ASD.

3.3.2 Behaviours and ASD

Questions 5: Behaviours you are concerned about.

Table 3.9: Percentage (number of participants) in categories for ASD-related behaviours that are concerning.

Country	Self-injury	Lack of Skills	Aggression	Sexualised Behaviour	Stereotypical Behaviour
Bangladesh	18% (2)	27% (3)	27% (3)	18% (2)	9% (1)
Indonesia	36% (8)	0	41% (9)	0	23% (5)
UK	57% (4)	0	29% (2)	14% (1)	0

Table 3.9 describes a range of behaviours that professionals find challenging. A higher number of UK, and to a lesser degree Indonesian, professionals' comments expressed worries about self-injurious behaviours, compared with Bangladeshi participants. Aggressive and ritualistic behaviours were noted more often by Indonesian and Bangladeshi professionals, although aggressive behaviours were also noted by UK professionals.

One UK professional expressed concerns about self-injurious and aggressive behaviour. He stated, *"These behaviours increase fear among staff and family members, and decrease opportunities for staff and families' ability to socially engage with that person, it creates a vicious circle. It increases the social isolation for the person."*

Lack of functional skills were reported by Bangladeshi professionals. No such concerns were reported by Indonesian and UK professionals. One Bangladeshi professional stated, *"If an autistic child does not know how to cross the road, and runs aimlessly on the road, he could put himself and others in danger."*

A small percentage of Bangladeshi and UK professionals' comments expressed concern regarding individual's sexualised behaviours, whereas Indonesian professionals noted ritualistic behaviours as a concern. One Indonesian professional said, *"I am mostly concerned about self-stimulatory behaviour, as parents want us to eliminate their child's stimming behaviour."*

A study by Hattier et al. (2011), demonstrated a higher percentage of challenging behaviour for people with autism, compared with those with atypical development. The data yielded the occurrence of challenging behaviour as aggression was 56%, stereotypies was 24.5%, and self-injurious behaviour was 22.9%, for autistic group.

Question 6: Why people with ASD behave the way they do.

Table 3.10: Percentage (number of participants) in different categories for why people with ASD behave the way they do.

Country	Lack of Meaningful Engagement	Lack of family Support	Communication Difficulties	Sensory difficulties associated with autism	Lack of understanding of social expectation
Bangladesh	8% (1)	8% (1)	46% (6)	23% (3)	15% (2)
Indonesia	14% (3)	5% (1)	57% (12)	24% (5)	0
UK	0	0	50% (5)	40% (4)	10% (1)

Table 3.10 summarises the responses of professional's perception regarding why people with autism behave the way that they do. Communication difficulties were identified by the professionals from all three countries as a cause of challenging behaviours, along with the nature of autism.

One UK professional added, *"I think its frustration, a bit of anxiety and not being able to express or not being understood properly by other people. That can trigger some sort of reactions of that person."*

Similarly, one Indonesian professional expressed, *"They behave differently as they have their own ways of thinking and it is not understood by others, that's why they display those types of behaviour."*

Professionals from all three countries identified sensory difficulties associated with autism as a cause of behaving inappropriately.

One UK professional stated, *"A person engaging in the sensory stimulation type behaviour, either to gain control or blocking out all those unwanted sensory input. It is like a life boat in the stormy sea, a person needs to do the behaviour to cope with stormy unpredictable situations they find themselves in. The behaviour towards other people or towards themselves is a way of processing or coping with very unpleasant sensations within that person's body and mind. "*

A very small number of Bangladeshi and Indonesian professionals and carers comments suggested lack of family support is the cause of challenging behaviour, compared to none from UK participants.

One Indonesian professional stated, *"I believe these children do not get appropriate support from their family, so they act out to get attention."*

Similarly, one Bangladeshi professional expressed, *"Parents do not give quality times to their children, also, do not teach them how to play or communicate. Children tend to watch TV or play with a phone for most of the time. This lack of engagement creates behavioural issues and they communicate through challenging behaviour."*

A small number of Indonesian and Bangladeshi professionals' comments indicated lack of engagement, and lack of understanding of social expectation, as causes of challenging behaviour.

Question 7: What interventions work or should be tried.

Table 3.11: Percentage (number of participants) in different categories for what interventions actually work or should be tried.

Country	Applied Behaviour Analysis	Bio-medical Interventions	Occupational/ Speech therapy	Eclectic Approach
Bangladesh	53% (9)	6% (1)	29% (5)	12% (2)
Indonesia	70% (12)	12% (2)	18% (3)	0
UK	40% (2)	0	40% (2)	20% (1)

Table 3.11 illustrates what professionals believe to be the ideal intervention for ASD. Professionals in all countries suggested ABA and occupational therapy as important interventions, with ABA being more highly commented about in Indonesia and Bangladesh, and occupational therapy being more commented upon in the UK, as were eclectic approaches.

One Bangladeshi professional said, *"Occupational therapy should be used first and if we do not deal with a student's sensory diet at the beginning, we cannot teach that student. ABA should be the second choice of intervention."* Another Bangladeshi professional stated, *"In my opinion, ABA is the most scientific intervention."*

One Indonesian professional expressed, *"The choice of intervention should be based on child's needs, some may need speech therapy to communicate, and some may need occupational therapy to deal with sensory issues, along with ABA."*

Similar response was received from one UK professional, *"interventions should be chosen according to the child's needs."* Another UK professional added, *"The Positive Behaviour Support, Proactive strategies and Active Support, all work if doing it right. Encouraging staff, regular evaluation and staff training are also required for an intervention to be successful."*

3.3.3 Family and care issues

Question 8: Concerns from family members and/or members of the public regarding the behaviour of an autistic individual.

Table 3.12: Percentage (number of participants) in different categories for comments from family members and/or members of the community about ASD that are concerning.

Country	Family members	Friends	Community	School/College
Bangladesh	23% (4)	12% (2)	65% (11)	0
Indonesia	6% (1)	0	82% (14)	12% (2)
UK	38% (3)	0	50% (4)	12% (1)

Table 3.12 summarises comments about ASD heard by professionals that were concerning. Similar number of professionals experienced negative comments about the individual that they were supporting from the community as a whole.

One Bangladeshi professional commented, *"Name calling is still the usual way of identifying a person with autism within our community."*

Similarly, one Indonesian professional stated, *"The people in our society often identify autistic individuals as 'crazy' and parents have to apologise to the public for the behaviour of their children in the community."*

One UK professional reported, *"There is a common attitudes among staff members that the autistic person is doing the behaviour on purpose or to wind them up to see their reactions."*

Another Indonesian professional said, *"The only thing I get upset about when an autistic person talking or making noises in the community, the look they get from others. I witnessed that many times. I think that is very rude!"*

Some Bangladeshi and UK professionals' comments suggested family members made negative comments. One Bangladeshi professional expressed, *"We often hear comments from the family members and common people in our society that these autistic children were born because of their parents' sins."*

Most of Indonesian professionals reported negative comments from the community and very less from the family members, compared with other two countries. This could be due to their strong family values and bonding, other cultural factors, that was not explored during the interview.

Question 9: What future expectations for people with ASD.

Table 3.13: Percentage (number of participants) in different categories for future expectations for person with ASD.

Country	Independent living	Communication/skill development	Supported Living	Social Inclusion
Bangladesh	6% (1)	69% (11)	25% (4)	0
Indonesia	5% (1)	40% (8)	5% (1)	50% (10)
UK	14% (1)	43% (3)	14% (1)	29% (2)

Table 3.13 describes the future expectations of professionals regarding individuals with ASD they are working with. A similar number of professionals in all three countries expect the individual to develop communication skills in all three countries. A higher number of Bangladeshi professionals expect that, in future, the individual will function with supported living, and those in Indonesia and the UK suggested inclusion in society as a future goal.

One UK professional said, *"I expect them to live in Independent accommodations with right assistance. It needs to be reviewed regularly for better options so that we can give them a better life."*

One Indonesian professional stated, *"The autistic people can be included into the society, so that they can go out in the community and also be accepted by their families. The schools in Indonesia are not truly 'inclusive'. They struggle to understand the context of inclusion, and they expect the autistic child to be behaving normally to be included. "*

Similarly, one UK professional expressed *"The main focus should be their integration into the society."*

Regarding skill development, one Bangladeshi professional said, *"Students should learn to work on various skills, for example, computer skill, baking, cooking, jewellary* *development, etc., so that they can earn a living. Without these skills, one cannot live a dignified life in the society."*

There were no comments from the Bangladeshi professionals on social inclusion, because they did not perceive this is something realistically achievable in the short to medium term.

Question 10: Primary long-term responsibility for the wellbeing of people with ASD.

Table 3.14: Percentage (number of participants) in different categories for who should take primary responsibility for the wellbeing of people with ASD in the long-term.

Country	Family member	Autism Community/ Trust	Government/Social Services	Unsure	Key worker /Advocate/ Registered Person
Bangladesh	27% (4)	13% (2)	53% (8)	7% (1)	0
Indonesia	80% (16)	10% (2)	10% (2)	0	0
UK	11% (1)	11% (1)	22% (2)	11% (1)	44% (4)

Table 3.14 summarises professionals' expectations about who should take the primary responsibility for people with ASD in the longer term. Family members were chosen by the majority of the Indonesian professionals, compared with smaller number of Bangladeshi and UK participants.

One Indonesian professional said, *"As the Government of Indonesia is not showing much awareness about autism, family members will have to take the responsibility."*

A higher number of Bangladeshi professionals and carers expect the government to take the responsibility.

One Bangladeshi professional stated, *"Bangladesh Government alone will not be able to take this huge responsibility, therefore, we need other private organisations or autism community to bear this responsibility jointly with the Government."*

Similarly, another Bangladeshi professional expressed, "*There are many autistic individuals live in orphanages, who do not have anybody to support them or look after them. The Government should take the initiatives to set up a system to take care of these individuals, despite the fact that no such structure of support currently exist in this country."*

Only a fewer UK participants expect the social services to take the full responsibility, while most of them preferred services led by key workers.

One UK professional mentioned, *"This is a collective responsibility of all involved with the autistic person, and should be led by a key worker."*

Another UK professional said, *"A familiar person should be included in person's daily life with a plan, so that they become a family member as well as having professional relationship. They should be understanding their role and will support the individual when parents are no longer there."*

3.4 Discussion

This study examined the experiences of professionals in two low-to-medium-income countries to address the limited data base on service provision for ASD in those nations (Hossain et al, 2017; Makino et al., 2021; Preity et al., 2018). Interviews explored professionals' views about the nature of ASD and it services, ASD-related behaviours and interventions, and future expectations for the ASD individuals. This comparative approach acknowledges the significant variations in culture, education systems, and economies of countries (Daulay, 2018; Yamin et al., 2015). There were few differences observed between the countries in terms of professionals' views of ASD, the key behaviours, and their perceptions of care. There were recurring themes across cultures concerning the needs for support, and concerning stigma and social inclusion. These themes may be important in understanding differing approaches and understandings of ASD cross culturally around the world (Rahman et al., 2019; Yamin et al., 2015).

Individuals with autism have many difficulties within inclusive educational environments, encompassing challenges related to social interactions, academic performance, and behavioural patterns (Allen & Yau, 2019). Additionally, difficulties with play and learning have been observed in this population (Mody & Belliveau, 2013), and certain behaviours associated with autism may hinder active participation in classroom activities and engagement with peers (Conallen & Reed, 2017). For example, verbal outbursts and challenging behaviours can lead to disturbances within inclusive educational settings (Mody & Belliveau, 2013). The heterogeneity among students with autism poses extra obstacles for professionals in inclusive educational settings (Finlay et al., 2022; Leonard & Smyth, 2022). The researchers included in this study expressed their apprehension regarding the incorporation of individuals with autism, not only inside the conventional educational framework but also within their own communities (see table 3.12 and 3.13).

Despite the presence of well-defined guidelines for the provision of services to individuals with autism, there exists considerable variation in the execution of these services in the UK. The implementation of practices exhibits considerable variation contingent upon the availability of resources and money. In contrast to the well-established advice provided in the UK, provision of ASD services in Bangladesh and Indonesia is still in its early stages of development (Ahmed et al., 2011; Ahmed et al., 2015; Aldana et al., 2001; Kancee, 2009; Fransisca, 2017).

This study was limited by a few factors. For example, only a small number of professionals were interviewed, and the representativeness of this sample, must be considered. The professionals interviewed were mostly special educators that posed another limitation. Other professionals were not available due to their work commitments. The duration of the interviews was also limited, only 30–45 min, due to the professional' availability. We must recognise another important limitation of not having an inter-observer agreement for the contents and results, as the content analysis was conducted by the researcher alone.

Despite those limitations, the current study attempts to explore the perception and practice of professionals working in three different countries with completely different framework or structures. Future research should investigate what specific framework and training for professionals working with students with autism would be most useful and effective in supporting them in creating an inclusive environment for students with autism in the mainstream environment. It might also be interesting for future studies to compare the responses of professionals with different occupations. We did not have enough professionals of any given occupation to make those contrasts meaningful, therefore we did not attempt to do it.

In summary, there were few differences of note observed between the countries in terms of professionals' views of autism, the key behaviours, and their perceptions of care. Where there were differences in the conception of ASD, these tended to suggest that low-to-medium-income countries placed a greater emphasis on parental and societal factors in the development of ASD than professionals in the UK, which has been noted in previous studies of professionals (Daulay, 2018; Yamin et al., 2015), and carers (Rahman et al., 2019). These views may be linked to cultural beliefs in these countries (Daulay, 2018). However, while there may be such differences, they appeared not to impact what professionals explored during the diagnoses, nor, to any striking extent, the types of interventions that were suggested (Ehsan et al. 2018; Preity et al., 2018). Thus, similarity, rather than difference, characterised these responses, and it may be that resources, rather than cultural beliefs, are a key determinant of service provision – within as well as between countries.

CHAPTER 4

QUALITATIVE FINDINGS - PARENTS' PERCEPTIONS

4.1 INTRODUCTION

Considerable variation exists in the estimated prevalence of Autism Spectrum Disorder (ASD); a global incidence figure of 0.6% conceals a significant disparity ranging from 0.02% to 3.7% across nations (Chiarotti & Venerosi, 2020; Salari et al., 2022). Several Western European nations and the USA report prevalence rates ranging from 1.5% to 3% (McConkey, 2020; Xu et al., 2019). Conversely, some Asian and African countries have reported notably lower rates (Salari et al., 2022). Multiple factors contribute to this variability, including cultural and familial perceptions and expectations that may impact seeking diagnosis, understanding, and treatment for ASD (Dyches et al., 2004; Durkin et al., 2015; Matson et al., 2017; Rahman et al., 2019). However, although less than 20% of the world's population reside in high-income Western countries (Durkin et al., 2015; World Bank, 2015), this group is predominantly featured in research (de Vries, 2016; Durkin et al., 2015; Viljoen et al., 2021), with only limited data available for low-to-middle income countries (Hossain et al, 2017; Makino et al., 2021; Rahman et al., 2019; Viljoen et al., 2021). To help address this identified gap, the present study investigates parental perceptions of the pre- and post-diagnosis experiences, their understanding of autism, its associated behaviours, and their experience of familial reactions to autism, across three distinct countries: Bangladesh, Indonesia, and the UK, with diverse cultural traditions and autism services.

Cultural practices may influence a wide range of aspects of parenting perceptions and experiences related to autism (Dyches et al., 2004; Rahman et al., 2019), such as: the processes of seeking and obtaining a diagnosis (Dyches et al., 2004; Durkin et al., 2015; Matson et al., 2017; Rahman et al., 2019); the extent to which behaviours are seen as important, relevant priorities, which may then determine interventions and strategies (Ehsan et al., 2018; Hossain et al, 2017); and societal acceptance of individuals with autism (Ennis-Cole et al., 2013; Rahman et al., 2019; Samadi et al., 2011). Although there is a growing literature from low-to-middle-income country regrading parent perceptions (Hossain et al, 2017), there are few comparative investigations of parental perspectives on the full trajectory from diagnosis to intervention and impact, across countries differing in cultural values, resources, and constraints.

The nature of autism and associated behavioural issues were discussed in the previous chapters.

It is probable that understanding how symptoms are reported and assessed, the impact that these symptoms have on parental expectations for their child, and how interventions are implemented, are all influenced by cultural and contextual biases (Durkin et al., 2015; Freeth et al., 2013; Matson et al., 2017). For example, Dyches et al. (2004; Reyes et al., 2018) suggested certain cultures exhibit greater hesitancy towards seeking assessments for disabilities, stemming from societal shame (Michele et al., 2021; Rahman et al., 2019) and/or perceptions of the symptom's significance (Daley & Sigman, 2002). Hence, perceptions and attitudes towards autism may be influenced by views about customary behaviours and normal growth. For instance, African American families with strong religious beliefs, and Native cultures within the USA, exhibit more positive evaluations of disability, attributed to a prevailing optimism and an idea that all children hold inherent value (McCubbin et al., 1998; Rogers-Dulan & Blacher, 1995). Whereas Michele et al. (2021) noted that individualistic Italian communities perceived children with disabilities as if they had typical development, and Japanese collectivist communities viewed disabilities as a source of stigma and shame for the family reflecting poor parenting ability.

There are some literatures aimed at understanding the diagnostic process, and parental expectations, for autism from low-to-middle-income countries, such as Bangladesh and Indonesia, where significant numbers of individuals with autism go unsupported through formal means, and the majority have insufficient availability of evidence-based support or educational resources (Hossain et al, 2017; Kieling et al., 2011; Viljoen et al., 2021). In Bangladesh, much parent-focused research suggests a lack of knowledge about autism (Preity et al., 2018), although this is defined by holding a different conception of autism to that prevalent in Western professionals. Nevertheless, a sense of shame and stigma is reported by such parents (Eshan et al., 2018; Rahman et al., 2019), suggesting the behavioural and processing differences associated with autism are not viewed as positive. This sense can reduce the likelihood of seeking support and interventions (Rahman et al., 2019), including engagement in digital forms of support that could otherwise be cost effective for that country (Ehsan et al. 2018; Preity et al., 2018). For example, Ehsan et al. (2018) examined the difficulties associated with developing mobile assistive technology to support care practices for individuals with autism in Bangladesh. Likewise, Riany et al. (2016) investigated cultural beliefs surrounding autism in Indonesia, and noted that, in addition to the range of emotions and experiences typically reported in Western literature, parents also discussed traditional beliefs about behaviour during pregnancy, karma, and God's plan. Daulay (2018) also noted this range of views and experiences, but also that traditional beliefs within Indonesia differ between Batak (more community based) and Javanese (more individualistic) cultures. Fransisca et al. (2017) examined diagnostic procedures, requirements, and difficulties faced by practitioners in Indonesia when diagnosing individuals with autism, and found barriers to the development of these services based on shame and stigma. Thus, while this literature is growing, it is typically focused on one community rather than allowing cross-country comparisons using the same methodology, which is the focus of the current study.

Comparing these countries, along with the UK, represents an opportunity to compare parent perceptions of autism and services to expand the knowledge base regarding the world situation for autism across a range of different cultures and preparational levels. In addition to the cultural and economic variations between these countries, Bangladesh represents a low-to-middle-income country with a developing policy for autism, as discussed in the previous chapter. Indonesia and the UK, respectively, represent countries with a less and more developed national response to neurodiversity (albeit one is low/middle income and the other higher income). In Indonesia, the situation with regards to national co-ordinated autism policies and services is less developed than in Bangladesh, and substantially less so than the UK. Autism services were set up by private initiatives than federal government (Pratama, 2020). At the other end of the spectrum, the first services for neurodiverse children in the UK date from the early 20th Century (Osborne & Reed, 2023). Health and social care needs are nationally recognised in The Autism Act (2009), and are financially supported at a national level (Osborne & Reed, 2023).

The study encompassed semi-structured interviews that explored experiences before and after diagnosis, their comprehension of difficult behaviours, their selection of interventions, and their hopes for the future, all within the context of their cultural traditions and the resources accessible to them. The adoption of this flexible qualitative approach was motivated by several factors: firstly, the potential emergence of issues was not clearly defined; secondly, there is a lack of established quantitative tools capable of effectively capturing these issues; and thirdly, it was deemed crucial to provide participants with ample freedom to express cultural differences that may not have been initially considered by the researcher.

4.2 Method

4.2.1 Participants and Recruitment

Participants were recruited via social media groups, advertising on social media pages, through organisations working with people with autism in all three countries. The recruitment criteria were: having a child diagnosed with autism; being aged over 25 years old; having experience seeing or dealing with challenging behaviour; and being involved from diagnosis in the up-bringing of child with autism. The exclusion criteria included any parent aged below 25 years, and only one parent per child was allowed to participate in the research. Twenty-seven parents were interviewed across Bangladesh, Indonesia and United Kingdom. Table 4.1 illustrates the number of participants from each country, parent's and children's mean age, and mean length of diagnosis.

Table 4.1: Ages and Diagnosis Periods

Countries	**Number of Parents**		**Mean Age**		**Time to get a Diagnosis of ASD**
	Mother	Father	Parent (Year)	Child (Months)	(Mean time in Months)
Bangladesh	11	2	45	18	25
Indonesia	5	0	46	18	27
UK	11	1	53	23	35

4.2.2 Ethical issues

The procedures followed to obtain the ethical approval from the University and the informed consent from the parents were identical as described in chapter 3.

4.2.3 Participating Countries

Same countries as identified in chapter 3.

4.2.4 Procedure

The researcher, who had dedicated time to practicing the questions outlined in the script, performed each interview. The interview questions were developed and interviews were carried out through individualised interactions using the same procedure described in chapter 3, with the exception of the interview time, as some interviews exceeded one hour.

Table 4.2 displays the actual questions that were asked during the interviews.

Table 4.2: Actual questions asked during the interviews.

Diagnosis 1. Can you please share your experience of the pre-diagnosis stage of autism spectrum disorder? For example, what signs do you notice among children before their diagnosis of autism spectrum disorder? 2. Tell me about the diagnostic process of ASD. For example, how long does it take to get an appointment, diagnosis, etc.
About ASD 3. Tell me what ‘autism’ means to you. 4. In your opinion, what causes autism spectrum disorder? 5. Why do you think the people with autism behave the way they do?
Behaviours in ASD 6. Tell me about the behaviours you are concerned about. 7. How do you respond when you see an autistic person displaying inappropriate behaviours? 8. From your experience, tell me what interventions actually work or should be tried.
Family and care issues 9. Tell me about any comments/concerns from family members, and/or members of the public, made regarding the behaviours of an autistic individual in the community, that you felt bad about. 10. What future expectations do you have for this person with autism? 11. Who should take primary responsibility for the wellbeing of this person when you are no longer around?

4.2.5 Content Analysis

The same methodology for content analysis was conducted as seen in Chapter 3.

4.3 Results

The cumulative quantity of information generated by each group in relation to each question was computed. The percentage of units of information that fell into each category for each group was also computed.

4.3.1 Diagnosis

Question 1: Can you please share your experience of the pre-diagnosis stage of autism spectrum disorder? For example, what signs do you notice among children before their diagnosis of autism spectrum disorder?

Table 4.3: Percentage comments (number of participants) in different categories for parental experience of the pre-diagnosis stage of Autism Spectrum Disorder

Country	First noticed sign of ASD (months)	Deficits noticed in Speech	Deficits noticed in Socialisation	Deficits noticed in Play skills	Deficits noticed in Behaviour
Bangladesh	34	41% (9)	10% (2)	16% (3)	33% (6)
Indonesia	18	39% (4)	15% (1)	10% (1)	37% (4)
UK	23	36% (7)	17% (5)	4% (2)	43% (10)

Table 4.3 summarises the responses made by the participants in each country regarding the mean age of the children when signs of autism were first noticed by parents, which was higher amongst Bangladeshi parents. A one-way between-subject analysis of variance (ANOVA) revealed that this difference was marginally significant, $F(2,26) = 2.85$, $p = 0.76$, $\eta^2_p = .180$[*95%CI* = .000:.387]. Tukey's Honestly Significant Difference (HSD) tests revealed that the difference between time to noticing in Bangladesh was greater than both the UK and Indonesia, both *p*s < .05. The participants identified four key areas of deficits that lead to this noticing. Parents in all countries commented often on noticing behavioural and speech differences.

One Bangladeshi parent said, *"my child was talking and asking for things whenever he wanted something, but he could not answer any question without help. He was playing* *by himself but never showed any interest about playing with any of his peers in school. That's the time I got worried and took him to a doctor for the first time."*

One UK parent shared her experience and said, *"My child was exceptionally well behaved when he was young, but when he was around 6 months old, I first noticed him playing with his fingers in front of his face. He started babbling but didn't develop any speech. I became suspicious when he was around 11 months old and took him to the health visitor. Things went progressively worse, he started banging his head and was shaking his shoes in front of his eyes. He was doing that all the time."*

Similarly, one Indonesian parent added, *"I first noticed the signs when my child was two and half years old, she was in a preschool. She used to have tantrums and was rolling on the floor. Her teacher could not handle her. She also had speech delay and very little eye contact."*

Socialisation was highlighted more than play in Indonesia and the UK, but the reverse relations between these two categories held in Bangladesh.

Another UK parent expressed, *"My boy had practically everything you see in a book linked to autism. He had no speech, he had no sense of danger, he didn't understand what you saying to him, he would make high pitch screaming noises all day, he would bite people and hit them. We have autism in the family so I kind of knew about autism."*

Question 2: Tell me about the diagnostic process of ASD. For example, how long does it take to get an appointment, diagnosis, etc.

Table 4.4: Percentage (number of participants) falling into categories for the diagnostic process of ASD.

Country	Time to get the diagnosis of ASD (Mean months)	Negative experience with professionals	Parents were blamed	Lack of Family support	Had Stressful time
Bangladesh	25	54% (7)	38% (3)	8% (1)	0%
Indonesia	27	44% (2)	0%	21% (1)	35% (2)
UK	35	30% (2)	17% (2)	0%	53% (4)

Table 4.4 summarises the responses made by the participants regarding the average time taken to get the diagnosis from the period of noticing the first signs of autism. In UK, it took nearly three years to get the diagnosis, whereas it took just over two years in Indonesia and Bangladesh. However, a one-way between-subject ANOVA revealed no statistical difference between the countries, $F < 1$, $\eta^2_p = .025[.000:.163]$. There were four categories of comments in response to questioning about the diagnostic experience. Negative experiences with professionals were reported more in Bangladesh and Indonesia, including inconsistencies regarding recommendations, lack of clear guidance and support.

One Bangladeshi parent reported that they had the worst experience visiting the doctor, as the doctor said to both parents, *"Please don't smile, you have no idea what kind of trouble you are in with your child. He will never be alright, and will be a lifelong burden for you. We both got depressed since then."*

Whereas Bangladeshi parents reported more parental blaming, a higher proportion of comments were connected to stress in Indonesia and the UK. It may be somewhat surprising that nobody from Bangladesh mentioned stress during the diagnostic period.

One UK parent stated, *"I took my child to the GP when he was about 18 months old. I would say it was very stressful as a family because it completely took over my life. I had to get my son diagnosed and I didn't care. We had lots of appointments and got the diagnosis. I was suffering from depression and had a breakdown in the middle of it, as it was extremely stressful for the whole family."*

One Indonesian parent expressed similar concern and said, *"It was a stressful time as we had no idea about autism and she was our first child. We went from doctor to doctor and therapist to therapist, to get a diagnosis. But they didn't want to diagnose our child as she was too young. We started to look for a diagnosis after her second birthday, and finally got the diagnosis when she was seven years old."*

Family support was noted minimally in all countries, specially in the UK and in Bangladesh.

4.3.2 ASD

Question 3: Tell me what 'autism' means to you.

Table 4.5: Percentage comments (number of participants) in different categories for what 'autism' means to parents.

Country	Lifelong disability	Neuro developmental delay	Hate the word	Different ability	Lifestyle changes and Social Isolation
Bangladesh	10% (3)	0%	6% (1)	46% (8)	38% (7)
Indonesia	0%	50% (1)	0%	50% (1)	0%
UK	4% (1)	33% (6)	3% (1)	40% (8)	20% (4)

Table 4.5 summarises the responses made by the participants about their perception of autism. Overall, six categories of comment emerged, with the most common response in all countries being that of a different ability.

One Indonesian parent said, *"My child express things differently. She has little empathy and sometimes, we parents or our family get affected by her words, but I keep telling her younger siblings that she is different, but not less in any way. We just need to be more understanding of her."*

Autism being a lifelong disability was noted more by parents in Bangladesh, whereas it was identified as a neuro-developmental delay more by parents in Indonesia and the UK. A smaller number of comments suggested parents hated the diagnosis.

One UK parent stated, *"I absolutely hate the word autism. It stole my son from me, it stole his voice. I can cope with his autism and the fact that he has no voice, kills me."*.

Question 4: In your opinion, what causes autism spectrum disorder?

Table 4.6: Percentage comments (number of participants) in different categories for what causes autism spectrum disorder?

Country	No idea/ God's wish	Mother's health during pregnancy	MMR/ vaccines	Mercury & other chemicals	Neurodivergence	Genetic
Bangladesh	41% (5)	27% (3)	8% (1)	0%	8% (1)	15% (2)
Indonesia	40% (2)	19% (1)	14% (1)	0%	10% (1)	19% (1)
UK	0%	4% (1)	8% (1)	13% (2)	8% (1)	67% (8)

Table 4.6 summarises the responses made by the participants regarding the parental perception about the causes of autism. There were a wide range of suggestion to this question. A higher number of Indonesian and Bangladeshi parents commented that they had no idea or considered it as God's wish, with UK parents tending to comment about the genetic causes.

One UK parent expressed, *"It is definitely genetic. I wouldn't have said this some time ago, but I can see traits in myself and definitely in all the family members."*

Another Indonesian parent added, *"One doctor told me that it could be genetic. My husband's gene and my gene did not match and it caused autism. I kind of believe it, because some of her habits or behaviours are more or less similar to me and my husband, but in a extreme way."*

A higher number of Bangladeshi and Indonesian parents believe that the mother's behaviour and mental state during pregnancy (nutritional deficiencies, medication level, and depression) was responsible for causing ASD. Smaller numbers of comments across the countries noted neurodivergence, vaccinations, or environmental toxins as a cause.

One Bangladeshi parent said, *"My child was absolutely fine before having the MMR vaccine. I can clearly remember that he had a rash on his leg after getting the vaccine. He used to engage in imaginary play, could answer my questions, waved bye to people. He progressively lost his skills after having the vaccine. He never recovered from it. At the end, I think of it as God's will."*

Question 5: Why do you think the people with autism behave the way they do?

Table 4.7: Percentage comments (number of participants) in different categories for why people with autism behave the way they do.

Country	Lack of engagement	Lack of family support	Communication Difficulties	Gut problem	Lack of understanding of social expectation
Bangladesh	40% (6)	13% (3)	47% (7)	0%	0%
Indonesia	0%	0%	0%	20% (1)	80% (4)
UK	3% (4)	0%	78% (10)	6% (1)	10% (3)

Table 4.7 summarises the responses made by the participants regarding the cause of their children's behaviour. Bangladeshi and UK parents' responses indicated the behaviours associated with autism were connected to attempts of communicate, with a lack of reciprocal engagement within the child's environment being noted by parents in Bangladesh.

One Bangladeshi parent stated, *"My child used to hit himself and I didn't understand how to support him at that time. Later on, I realised that he only hit himself when he was in pain, so the hitting was an effort to express his discomfort. Now understand what he is trying to say and can manage his behaviour."*

Similarly, one UK parent added, *"I think when they have no way to communicate, they lash out. Once they have little bit of speech, it gets better. I think also, something in his brain needs repetitive actions. He needs to flap hands or flick a straw endlessly and I think that's just part of autism."*

Parents in Indonesia noted a lack of understanding of social expectations on the part of the child was responsible for their behaviour.

4.3.3. ASD Behaviours

Question 6: Tell me about the behaviours you are concerned about.

Table 4.8: Percentage comments (number of participants) in different categories for behaviours that are concerning.

Country	Self-injury	Lack of Skills	Aggression	Sexualised Behaviour	Absconding	Sleep Problem	Ritual Behaviour
Bangladesh	15% (1)	47% (4)	15% (2)	15% (2)	8% (1)	0%	0%
Indonesia	35% (2)	65% (4)	0%	0%	0%	0%	0%
UK	28% (4)	30% (7)	16% (3)	0%	4% (1)	14% (4)	8% (2)

Table 4.8 summarises the responses made by the participants about the behaviours of concern. Lack of skills and self-injurious behaviours were moted commonly by parents in all countries. Most comments across the countries related to a lack of skills and self-injury as the key behaviours of concern.

One Indonesian parent commented, *"We are most concerned about my child's self-help skills. She cannot brush her hair properly, cannot wash her hair or body properly. If I tell her, she gets annoyed. Sometimes, she starts to yell, and sometimes just ignore."*

One Bangladeshi parent expressed similar concern and said, *"I am mostly concerned about my child's sitting habit. He doesn't have the skill to sit down or wait for a short period. He gets aggressive at times and pushes other children and spits at others"*

Bangladeshi parents' comments also noted concerns about aggressive behaviour (as did comments from the UK), and sexualised behaviour.

One UK parent said, *"He would bite people, he would head bang people even when the tiniest thing didn't go in his way. If he wasn't allowed to have three chocolate bars, he would head bang on the floor, or pinch people, bite people, he would punch his own head, and other's head. So, that's self-injury and aggression. He would try to flood the house by running the tap. He would eat things that is dangerous, he would not understand any risks, like if he saw a dog, and he is afraid of the dog, he would run out in front of a car to get away from that dog. The list will go on and on."*

There were a range of other suggestions, but only sleep disturbance was a notable concern for UK parents.

Question 7: How do you respond when you see an autistic person displaying inappropriate behaviours?

Table 4.9: Percentage comments (number of participants) into different categories for parental response when an autistic person displays inappropriate behaviours.

Country	Withdraw demand	Verbal reprimand/ Counter instruction	Attention extinction	Delivery of reinforcer	Physical Intervention	Distraction
Bangladesh	15% (2)	38% (5)	23% (3)	23% (3)	0%	0%
Indonesia	0%	45% (5)	0%	28% (2)	27% (2)	0%
UK	4% (1)	41% (9)	4% (1)	20% (3)	4% (1)	28% (4)

Table 4.9 summarises the responses made by the participants about parental responses to inappropriate behaviour. There were large similarities in the strategies used

by parents across the countries. Issuing verbal reprimand or a counter instruction was commonly noted as a response by parents in all counties.

One Indonesian parent said, *"Sometimes, I snap at her at that time and sometimes, I wait till I calm down. Then I talk to her about being nice to others."*

One Bangladeshi parent stated, *"I ask him to stop immediately and always make my child say sorry to others."*

Using reinforcers to stop inappropriate behaviours was also noted often by parents in all countries. Perhaps the parent are not aware of the functions of their children's inappropriate behaviour. They deliver reinforcers to stop the behaviour. Similarly, a smaller number of Bangladeshi and UK parents noted withdrawing demands from the child following challenging behaviour, and withdrawing unwanted attention following a behavioural incident. Again this could be related to not knowing about the functions of behaviour or not having appropriate interventions in place. Many more Indonesian parents suggested they used physical intervention. UK parents reported use of a distraction procedure after a behavioural incident.

One UK parent said, *"Now we have lots of tools in our box since doing ABA for long time. For example, if he hits his head, we give him gesture prompt to put his hands together in front of him and ask him to squeeze his hands together to redirect him from the aggression. That way, he gets the same sensory feedback as he was getting from punching his head but it is not that damaging."*

Question 8: From your experience, tell me what interventions actually work or should be tried.

Table 4.10: Percentage comments (number of participants) in different categories for the interventions that work or should be tried.

Country	Applied Behaviour Analysis	Bio-medical Intervention	Physical activities	Occupational/ Speech therapy	Eclectic Approach	Son-Rise/DIR
Bangladesh	33% (4)	8% (1)	8% (1)	8% (1)	25% (3)	8% (1)
Indonesia	76% (4)	0%	24% (1)	0%	0%	0%
UK	40% (7)	6% (1)	7% (2)	23% (4)	17% (2)	7% (2)

Table 4.10 summarises the responses made by the participants to the question on parental preferences about the intervention available for autism. Applied Behaviour Analysis was the chosen method reported by the majority of comments by parents in all countries.

One UK parent confirmed, *"Only ABA works, nothing else works. The rest of it is placebos. We tried lots of therapies, nothing worked. My child needed behavioural therapy to retrain how it was okay for him to behave even when he is stressed."*

One Indonesian parent made a similar comment, *"I think ABA is more convenient, because it is individualised. She is comfortable with her therapist and I think it also depends on the personality of the therapist."*

Parents in Indonesia suggested physical activities, whereas parents in Bangladesh and the UK commented more about other approaches. Few parents' comments suggested biomedical approaches would be favoured.

4.3.4 Family and care issues

Question 9:Tell me about comments/concerns from family members, and/or members of the public, made regarding the behaviours of an autistic individual that you felt bad about.

Table 4.11: Percentage comments (number of participants) in different categories for comments/concerns from family member, and members of the public.

Country	None	Family member	Friends	Community	School
Bangladesh	20% (3)	30% (4)	0%	50% (7)	0%
Indonesia	0%	0%	0%	50% (1)	50% (1)
UK	8% (1)	12% (2)	12% (2)	67% (10)	0%

Table 4.11 summarises the responses made by the participants in relation to the negative comments and concerns raised by the family members or members of the public regarding the behaviour of an autistic person. Parents from all counties made a substantial

number of comments about comments made from the community about the behaviour of the person with autism.

One UK parent shared, *"There was one time when my child was little and we went swimming. There was a lady with a small child kept moving away from him, as if he had a disease. I lost my temper at that situation and told that lady that he was not infectious."*

Bangladeshi parents' responses indicated receiving negative experiences from family members, and parents in Indonesia reported negative comments from schools.

One Bangladeshi parent said, *"I heard my family members call another autistic child crazy, in a family picnic. That hurt me as my child is also autistic." Another Bangladeshi parent added, "I could not rent a house, as the landlords won't rent a place as I have an autistic child. I was also been denied by a rickshaw puller to take us in his rickshaw because of my child's challenging behaviour. Parents are extremely helpless in this country."*

Question 10: What future expectations do you have for this person with autism?

Table 4.12: Percentage comments (number of participants) in different categories for future expectations for the person with ASD

Country	Independent living	Manageable behaviour	Communication/skill development	Supported Living
Bangladesh	0%	26% (3)	48% (6)	26% (3)
Indonesia	15% (2)	10% (1)	24% (3)	50% (5)
UK	0%	0%	40% (6)	60% (12)

Table 4.12 summarises responses made by the participants to the question related to parental expectations for their children in the future. A high number of parental responses in all countries suggested that better communication or functional skill development, and supported living, were the expectations that they have for the person with autism.

One UK parent said, *"He is always going to be living with us at home. He is trying few little work experience jobs. He is going to an office and doing jobs like emptying their dishwasher, filling papers in their printer. I think he will be able to get a job like that, may* *be in a kitchen. I want him to have a full life rather than just sitting in front of a tele all day."*

Parents comments in Bangladesh highlighted more manageable behaviour as an expectation, and those in Indonesia suggested independent living (which was not an expectation in Bangladesh or the UK).

One Bangladeshi parent expressed, "All we want for our boy to be living a happy life without any challenging behaviour."

On the other hand, one Indonesian parent expressed, *"Future expectation would be for her to be independent so that she can support herself, financially also life skill wise. She can contribute to her society, she can help others, and be happy and healthy."*

Question 11: Who should take primary responsibility for the wellbeing of this person when you are no longer around?

Table 4.13: Percentage (number of participants) responses falling into the different categories for who should take primary responsibility for the wellbeing of the person with autism.

Country	Family member	Autism community/trust	Government/Social Services	Unsure	God
Bangladesh	25% (2)	8% (1)	15% (2)	38% (5)	15% (2)
Indonesia	60% (3)	0%	0%	40% (2)	0%
UK	48% (7)	10% (2)	32% (5)	10% (1)	0%

Table 4.13 summarises the responses made by the participants regarding choosing primary carer for the child when they no longer will be around to support them. A similar number of Indonesian and UK parents wished their children would be looked after by the family members, which is much higher than the wishes of Bangladeshi parents. A higher number of UK parents' responses expressed preferring their children's wellbeing to be looked after by Government or social services.

One UK parent stated, *"We got deputyship for him and when my husband and I die, my daughter will be the official deputy or power of attorney for him. I don't want her to be burdened with him, so I think he will probably have to go to a residential care, but his* *sister would be the person best placed to have his best interest at heart. Because the best will in the world, the state will want him to have the cheapest care on earth and we will want him to have the best care in the world, and that's why we have the deputyship in place."*

Indonesia and Bangladesh parents were unsure of their children's future.

One Indonesian parent said, *"That we have not thought about, really need to think about it. In Indonesia, there are no such facilities."*

Some of the Bangladeshi parents believe God to be responsible for the wellbeing of their autistic children when parents are no longer available to support them.

4.4 Discussion

To help increase the data available from low-to-middle income countries regarding parental views and experiences of autism (Hossain et al, 2017; Makino et al., 2021; Viljoen et al., 2021), parental perceptions of diagnosis, understanding of autism, its associated behaviours, and experience of familial reactions to autistic people, in Bangladesh, Indonesia, and the UK were investigated. It has been suggested that differences across countries may lead to variations in responses to autism (de Vries, 2016; Durkin et al., 2015; Dyches et al., 2004; Matson et al., 2017; Viljoen et al., 2021). However, this expectation was only partially confirmed by analysis the present data across a range of topics. It also has been suggested that there is a lack of knowledge of about autism in non-Western counties (Hossain et al, 2017; Preity et al., 2018). However, the current results, viewed in the light of previous literature, suggest this is not entirely the case, but that different beliefs may be related to different cultural concerns.

There were some differences in parental experiences of diagnosis for autism across the three countries studied that was consistent with previous reports (Eshan et al., 2018; Rahman et al., 2019). However, these differences in parental perceptions were not concerned with the behaviours seen as critical for autism (although there was a slightly greater focus on socialisation in Indonesia and the UK), but rather with the reactions to the child with ASD and the parents, which were perceived as more negative in Bangladesh

(Rahman et al., 2019). It is worth noting, however, that parents from all countries noted some negative experiences with professionals during the diagnostic process, mirroring work conducted in Western countries (Chamak et al., 2011; Osborme & Reed, 2009). However, the clearest differences were in the conception of the nature and cause of autism across the countries, which does accord with previous suggestions (Durkin et al., 2015; Dyches et al., 2004). It was the case that the majority of parents comments in all countries suggested autism was a ‘different ability’, rather than a ’disability’, suggesting a concordance with contemporary thinking across the world. However, parents in the UK thought of autism as genetic in basis, with differences in behaviour being related to communication. In contrast, many parent comments from Bangladesh and Indonesia suggested autism was caused by God, with behaviours resulting from either communication problems (Bangladesh), or a lack of appreciation of societal expectations (Indonesia).

Despite these differences in conception of autism, it is striking that there were few differences in what parents thought about the associated behaviours in terms of their appropriate treatment, or the familial and social reactions to their child. Although there was a great level of concordance in these responses, it should be noted that greater emphasis was placed on the role of mothers’ behaviours during pregnancy by parents in Bangladesh (see also Rahman et al., 2019), which has previously also been noted for Indonesian parents (Riany et al., 2016). This is in line with greater proportion of comments from parents in Bangladesh being related to blame.

In addition to the above, it is possible to discern some themes that were common across questions, and which differ across the countries. These themes may be important in understanding differing approaches and understandings of autism cross culturally. In particular, there were recurring themes of blame, knowledge, support and acceptance, which will be discussed in turn.

Parents in all countries had negative experiences in terms of interaction with the professionals. Parents from Bangladesh and the UK reported little help from friends and family, but parents from Bangladesh more often reported that they were blamed for their child’s autism diagnosis and difficulties. Often family members blamed parents, especially mothers, for not managing their children effectively. These findings reflect some previous reports from Bangladesh. Ehsan et al. (2018) found that 76% of the Bangladeshi caregivers felt directly impacted by stigma in their ability to openly talk about autism, while 24% felt there were other kinds of stigma that denied them full access to social support. There are numerous cases of divorce after receiving a diagnosis of autism in Bangladesh, as mothers are blamed by their in-laws, and are abandoned by their husband and the society. The lack of awareness about autism and willingness to accept the child as an equal member of the family or society, play important roles in blaming parents in Bangladesh. In the context of social support, this was also true for UK parents who reported becoming socially isolated, as they were unable to attend social events due to the child's challenging behaviour. For the same reason, they felt excluded from receiving invitation from friends and family. In contrast, parents from Indonesia reported support from their families and friends during and after the diagnostic period.

Parents from all three countries expressed their views on autism causes, and behaviour of concern for their children, and these were mixed, as noted above. It is disappointing that, to date, there are only few easily available training programmes available for parents of newly diagnosed children in all three countries. There are no government training programme available for the new parents in Bangladesh and in Indonesia, and parents reported that the understanding of symptoms of autism and their management is worryingly different between parents, professionals and in the community services. Fransisca et al. (2017) highlighted the urgency of training to improve quality and accuracy of autism diagnosis. In the UK, parents rely on social and education services for their children's care and education. There are significant shortages of this kind of specialist services in the UK, but they are entirely absent in Bangladesh and Indonesia, perhaps causing parents, professionals, and community services to remain untrained and unskilled. Indonesian parents reported getting training and intervention privately. Rainy et al. (2016) reported that a large percentage of Indonesians still have little understanding about autism (and other disabilities) due to limited access to media and other health information. This is particularly likely to apply to those who live in small cities and rural areas. However, it is important to consider whether a difference in conception of autism reflects a lack of understanding, which it may, or whether it reflects a different cultural conception. It is important not to dismiss such differences in conception, as they can sometimes be very beneficial to prognosis (McCubbin et al., 1998; Rogers-Dulan & Blacher, 1995).

The inclusion of a person with autism still faces significant challenges in the community settings or in a mainstream setting. The support from the authorities and education providers are non-existent in Bangladesh and Indonesia, where there are no state services available for these children. Concerns were also raised by parents in Bangladesh and the UK regarding accessing specialist support for their children. In contrast, parents in Indonesia privately pay for the services they need. However, in other studies it has been reported that most Indonesian people with disabilities (including ASD), particularly those who live in rural areas of Indonesia, are not able to afford appropriate services (Adioetomo et al., 2014; Irwanto et al., 2010).

The results suggest that, despite celebrating the autism awareness worldwide and talking about inclusive society, there are still significant challenges that exist in all countries, especially in low-to-medium-income countries. There are number of things that need to be considered in this context: support for parents in terms of respite or breaks, mental health support, training on autism and evidence based interventions, and support with inclusion of the autistic people into the society.

As with any study, there are several limitations to the present study that need to be discussed. The relatively small sample size, especially for the Indonesian parents, and the representativeness of this sample, must be considered. The current study did not examine the correlation between state funded diagnosis procedures and their duration in the UK with privately paid diagnosis procedures and their duration in other two countries. Also, it is important to explore whether those parents who received training after a diagnosis had a better understanding and management of their children diagnosed with autism. This study did not determine whether the children received state funding and support in UK, and private funding and support in Indonesia and Bangladesh, made better progress than those who received no funding and support. Finally, it was important to find out whether the parents who received support from their family, friends and professionals were more content with the diagnosis and management of their children than those parents who had no support. It would also be beneficial to compare the perceptions regarding challenging behaviour of autistic individuals and the approaches used by parents and professionals on the management of those behaviour in future studies. Another limitation was mentioned in the last chapter regarding not having an inter observer agreement, as the researcher was the only person did the content analysis, also applicable to this chapter.

Regardless of these limitations, the current study aimed to understand the cultural perceptions of autism and related difficulties in three different countries. This study may not provide a solution to better understanding and management of challenging behaviours, but this could a starting point of developing an understanding of the autistic individuals, and their care needs and supporting parents to empower themselves, withing their cultural contexts.

CHAPTER 5

QUANTITATIVE FINDINGS-PARENTS' PERCEPTIONS

5.1 INTRODUCTION

As discussed in the previous chapters, prevalence estimates for autism have risen over the last 10 years, and currently are around 1.6 to 1.8% of the population (Chiarotti & Venerosi, 2020; Knopf, 2020). However, such estimates differ across the world, and figures are mainly based on higher-income countries (Chiarotti & Venerosi, 2020; Salari et al., 2022), with much less information being available for prevalence in low-to-medium-income countries (Aderinto et al., 2023; Qiu et al., 2020). Although there are differences in prevalence, strategies to provide help for children with ASD remain largely within the remit of education across the world (Gómez-Marí et al., 2021), with schools often taking the lead in providing help for children with ASD (Osborne & Reed, 2023; Ye, 2022).

Much of the information that is easily available about the impact of these educational strategies on children with autism is based on data from higher-income countries (Reed, 2016). Although there are sometimes severe financial, social, and political barriers to the application of educational practices for autism across the world (de Leeuw et al., 2022; Liu et al., 2021), many local communities have found ways of adapting these educational approaches (Choueiri et al., 2023; Jani et al., 2021). As a result, educational strategies for autism are not dissimilar for low-to-medium income countries to those applied in higher-income countries (Alnusayri, 2021; Choueiri et al., 2023; Kopetz, & Endowed, 2012). Yet, whereas a growing amount is known about the ways in which autism services are experienced and perceived by parents from higher-income countries (Locke et al., 2020; Marsack-Topolewski & Weisz, 2020), few data are available for these purposes from lower-and-middle income countries (Ayinla, 2019; Makino et al., 2021; Viljoen et al., 2019; 2021).

Not only does this lack of knowledge represent a barrier to the development of evidence-based strategies in low-to-medium income countries (Bakare & Munir, 2011; Hossain et al, 2017), it prevents comparison across countries that may be of importance when developing scales that are of wide usefulness (Matson et al., 2017). This study provided some exploratory data on the perceived educational situation for children with autism across five different countries: the UK, and Greece in Europe; Kenya, and Zambia, in Africa; and Bangladesh in Asia. This approach follows from a similar comparison across a different set of countries by Matson et al. (2017), but which focused on key aspects of behaviour indicated as important in the diagnosis of autism. However, adding to the knowledge base is vital at this early stage of cross-country comparisons (Bakare & Munir, 2011; Hossain et al, 2017; Nyoni, 2022). In addition, the current set of countries, although partially reflecting opportunity, also allows some interesting comparisons between the level of development of service and knowledge about autism, as well as reflecting countries in which there has already been some study of ASD.

The European countries studied in this report both represent higher-income nations, with a relatively well-developed, although different, educational provision for children with autism, and about which much is known. The UK is one of the leading centres for autism research, and has provided innumerable research papers on the topic. Similarly, autism provisions in Greece are well known (Kossyvaki, 2021; Makrygianni et al., 2018; Ntre et al., 2018; Sevaslidou et al., 2019). However, despite both being higher-income European countries, with some level of state run developed health and educational provision for autism, there are differences between these nations: a much greater proportion of the population in Greece identifies with a religion (overwhelming Grek Orthodox), and reports suggest greater levels of stigma around having a child with autism in Greece, relative to the UK, where it is a key barrier for many parents (Gemegah et al., 2012; Veroni, 2019).

In both the African and Asian continents (although neither should not be regarded as homogenous), there is much less literature available. The effects of autism provision in African countries is not well explored (Bakare & Munir, 2011), nor has this received great attention in Asia (Hossain et al, 2017). Nevertheless, there is a nascent qualitative literature on parents' and educators' perceptions of ASD in both Zambia (Nyoni, 2022; Washington-Nortey & Serpell, 2021), Kenya (Gona et al., 2015; Kamau, 2017; Masaba et al., 2012), and Bangladesh (Reed et al., 2024; Rahman et al., 2019). A range of autism provisions are available in all of these countries, but public knowledge remains generally poor (Masaba et al., 2012; Nyoni, 2022), and social stigma is an issue (Nyoni, 2022; Washington-Nortey & Serpell, 2021; Rahman et al., 2019). Culturally, ethnically, and religiously Kenya represents a more diverse population than Zambia, but both have autism provisions in the first stages of development, in terms of raising awareness, diagnostic services and placement development. Bangladesh is a relatively culturally and religiously monolithic society, with a developing provision for autism (Mannan, 2017), but one which remains uneven across the country (Hossain et al, 2017; Rahman et al., 2019).

There are clearly many areas that could be examined in regard to parent perceptions of autism provision, but three main areas were chosen as of interest to this study, based on their apparent importance in the developed literature. Firstly, the diagnosis system was thought important, as parents' perceptions of this have been investigated widely in higher-income countries (Chamak et al., 2011; Goh et al., 2021; Reed & Osborne, 2019). Based on such findings, a number of factors have been identified as important for child and parent functioning, especially: when parents first noticed a difference or problem with their child's behaviour that leads them to seek a diagnosis (Reed et al., 2019), the age of the child at diagnosis (Chamak et al., 2011), and the length of time between the two (Osborne et al., 2008; Reed et al., 2019). In addition, the perceived severity of autism in the countries is also of interest, as is the relative severity of the behaviours that comprise autism, which has been examined for some countries (Matson et al., 2017), and may have importance for the development of scales that capture the autism experiences thought important (Viljoen et al., 2021). There is some literature that is relevant to these topics in each of the studied countries (Kamzu, 2017; Reed et al., 2024; Nyoni, 2022; Reed et al., 2019; Veroni, 2019). However, the procedures involved in each survey have been widely different making it useful to have the same types of data and procedure applied in each context to facilitate comparisons.

Secondly, it is of importance to understand the types of provision that the various counties are providing to the children, such as type of school (mainstream and special), as this has been found to impact satisfaction (Osborne & Reed, 2023). As well as having legal implications with respect to the UN in regard to issues such as whether the child spends time in school, and are included, with children who do not have special needs (Buchner et al., 2021). Moreover, the current study evaluated how this provision is perceived by the parents in the various countries included. As noted above in terms of diagnostic services, there are varying amounts of data available from each of the countries, but they are not in a form that can be easily compared, and originate from very different methods of survey. Finally, there may be differences in the ways in which the school provision is perceived by the parents across the countries, but it is important to determine whether there are any common predictors of this satisfaction (or lack thereof), which may be present across countries. These factors include teacher training and experience with autism (Osborne & Reed, 2011).

In summary, the study examines parent perceptions of autism and its diagnosis, school provision, and predictors of satisfaction of school provision, across five different countries. It was hoped that the use of a single procedure to collect such data would facilitate comparisons, of use in subsequent development of cross-country comparisons. The countries chosen also allow some comparison between a range of different factors that may play a role, and offer a start for such comparisons.

5.2 METHOD

5.2.1 Participants and Recruitment

Participants were recruited via advertising on social media groups, social media pages, and organisations working with people with ASD, in all five countries. The recruitment criteria were: having a child diagnosed with ASD using the DSM-5; being aged over 18 years old; having experience seeing or dealing with challenging behaviour; and being involved from diagnosis in the up-bringing of child with ASD. The exclusion criteria included any parent aged below 18 years; any comorbid psychiatric diagnosis; and only one parent per child was allowed to participate in the research. Ethical approval was obtained from the Psychology Department Ethics Committee of the University.

G-Power calculations indicated that for a medium effect size (r = .3), a rejection criterion of p < .05, and 80%, that 67 participants would be needed for Pearson correlations. For an analysis of variance (ANOVA) between the five countries, with a medium effect size (f' = .25), rejection criterion of p < .05, and 80% power, that 200 participants would be needed. For a multiple regression with three predictors, for a medium effect size (f^2 = .15), rejection criterion of p < .05, and 80% power, then 77 participants would be needed.

Two hundred participants (40 from each country) were given full information about the study, and agreed to participate. Of these participants, 196 (98%) completed the questionnaires; 2 participants from Zambia, and 2 from Greece, did not supply the full data set, and were excluded.

5.2.2 Family Characteristics/background: Of the participants, there were 134 mothers (55 fathers), with a mean age of 39.9 (SD ± 8.1; range 18 – 65) years. Of the sample: 26/183 (14%) were single; 141/183 (77%) were married; 10/183 (5%) were widowed; and 15/183 (8%) separated. The number of family members in the families of the participants were given as: 2 = 10/181 (6%), 3 = 38/181 (21%), 4 = 72/181 (40%), 5 = 39/181 (22%), 6/181 = 13 (7%), 7/181 = 4 (2%), 8 = 3/181 (2%), 10/181 = 2 (1%). The number of siblings of the child with autism about whom the questions were answered were given as: 0/186 = 36 (19%), 1 = 84/186 (45%), 2 = 51/186 (27%), 3 = 11/186 (6%), 5 = 3/186 (2%), 6/186 = 1 (5%). Of the participants 47/181 (32%) reported that a family member had a similar problem to autism. The fathers' education was reported as: up to 16 years = 11/186 (6%); up to 18 years = 27/186 (15%); college/university = 98/186 (53%); postgraduate = 50/186 (27%). Mothers' educational levels were reported as: up to 16 years = 13/182 (7%); up to 18 years = 31/182 (17%); college/university = 110/182 (60%); and postgraduate = 28/182 (15%). The fathers' occupations were reported as: labourer/clerical = 35/188 (19%); skilled/technical = 27/188 (14%); managerial/professional = 105/188 (56%); and unemployed/houseworker/strike = 21/188 (11%). The mothers' occupations were reported as: labourer/clerical = 26/187 (13%); skilled/technical = 11/187 (6%); managerial/professional = 91/187 (49%); and unemployed/houseworker/strike = 59/187 (32%). The breakdown of the family demographics by country can be seen in Table 5.1.

Table 5.1: Mean (standard deviation) demographic characteristics of the parents in each country

	Age	Family	Sibs	Married	Father degree	Mother degree	Father skill/prof	Mother skill/prof
Bangladesh	40 (8)	4.1 (0.9)	1.3 (1.0)	80%	97%	87%	76%	86%
Zambia	38 (9)	5.4 (1.7)	1.3 (1.2)	84%	60%	63%	73%	88%
Kenya	36 (8)	4.1 (1.2)	1.6 (1.1)	81%	85%	76%	82%	83%
Greece	39 (5)	3.8 (0.8)	0.9 (0.6)	91%	51%	65%	70%	57%
UK	46 (6)	3.8 (1.2)	1.2 (0.8)	52%	87%	82%	47%	81%

5.2.3 Children's characteristics: Of the 196 children with a DSM-5 ASD diagnosis about whom the questionnaires were completed, 150 (77%) were male, and they had a mean age of 8.9 (± 3.7; range = 3 – 16) years. Of the parents who responded to the question, 70/178 (40%) reported that this child also had a physical medical diagnosis, 87/183 (48%). The parents reported that they had first noticed an issue with their child when the child was 2.3 (± 1.9; range = birth – 9) years old, that a DSM-5 ASD diagnosis was received when the child was 3.8 (± 1.4; range = 1 – 9) years old, with a mean time from noticing to diagnosis of 1.4 (± 1.2; range = 1 – 7) years. The children's characteristics for each country can be seen in Table 5.2.

Table 5.2: Mean (standard deviation) demographic characteristics of the children in each country

	N	Gender (male)	Mean Age, (Standard deviation; Range)
Bangladesh	40	34 (85%)	9.7 (3.3; 5 – 16)
Zambia	38	27 (71%)	8.6 (4.1; 3 – 16)
Kenya	40	31 (78%)	9.1 (4.2; 3 – 16)
Greece	38	31 (82%)	7.5 (3.4; 3 – 16)
UK	40	27 (68%)	9.3 (3.0; 4 – 16)

Table 5.3: Participating Countries

Participating Countries	Location	Area	Population	Main Language	Ethnic Diversity	Main Religion (% of adherents)	Free Health Service	Free Social Service
Bangladesh	South Asia	148,460 km^2	170 million	Bengali	Bengali - 99% Other – 1%	Islam (91%)	No	No
Zambia	Southern Africa	752,617 km^2	2 million	English	73 Ethnic Groups	Christianity (95%)	No	No
Kenya	East Africa	580,367 km^2	47.6 million	English and Swahili	Over 10 Ethnic Groups	Christianity (85.5%)	No	No
Greece	Southeast Europe	131,957 km^2	10.5 million	Greek	Greek - 91.56% Other - 8.44%	Christianity (93%)	Yes	Yes
UK	Northwestern coast of Europe	242,500 km^2	68 million	English	White- 87% Asian- 7% Black- 3% Mixed- 2% Other- 1%	None (52%) Christianity (36%) Islam (7%) Other (5%)	Yes	Yes

Table 5.4: Quantitative Research Questions for Parents

1. Time to Diagnose ASD
2. Parent perception of ASD severity
3. Perceptions on school provision
4. Help reported by parents from school and local authority
5. Parents′ perceptions of school support and satisfaction

5.3 MATERIALS

Demographic/Background Questions: There were questions relating to the gender and age of the parent who was completing the form: whether they were married, the number of family members, the numbers of siblings of the child with autism, and whether any family members had similar problems. They were asked about the father's and mother's educational levels and current occupations. In terms of the child, they were asked about their age, gender, when they first noticed a problem with the child, and when the diagnosis occurred. They were asked what sort of school the child attended, when they had started the school, whether the parents were satisfied with the school (0 = 'not at all' and 4 = 'very satisfied'), about the quality of the school (0 = 'poor' and 4 = 'very good'), and whether the parents had any problems or difficulties with the teachers.

Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1979, 1980) is a widely used instrument (Bodfish, Symons, Parker, & Lewis, 2000; Tamanaha, Perissinoto, & Chiari, 2008), easy to administer, and suitable from 18 months to 35 years. It contains a list of behaviours associated with autism which the parents tick if they have ever been shown by the child. Each behaviour gives a weighted score indicative of autism (4 indicates the highest predictor, and 1 the lowest). The behavioural descriptors are grouped into five symptoms areas:

1. Sensory: this domain assesses an individual's responses to various sensory stimuli, including visual, auditory, tactile, and olfactory inputs. It may include items related to unusual sensitivities or apparent lack of response to certain stimuli.

2. Relating: this section evaluates how the individual interacts with others, including eye contact, social responsiveness, and ability to form relationships. It's crucial in identifying the social challenges often associated with autism.

3. Body and object use: this component focuses on repetitive or stereotyped movements, unusual body postures, and atypical use of objects. These behaviours are often characteristic of individuals on the autism spectrum.

4. Language: the language domain assesses both receptive and expressive language abilities, including the presence of echolalia, unusual speech patterns, or delayed language development.

5. Social and self-help: this section evaluates the individual's ability to perform age-appropriate self-care tasks and navigate social situations. It may include items related to toileting, dressing, and following social norms. (Miranda-Linne, & Melin, 2002).

The intra-rater reliability (*r*) of the test is 0.94, and the intra-rater reliability agreement score is 95%. Its validity is satisfactory (Eaves, Campbell, & Chambers, 2000; Krug et al., 1980). For each country the ABC was translated from English to the needed language, and was then back translated by an independent person competent in both languages to ensure that the translation did not affect the integrity of the checklist. The internal reliability (coefficient alpha) ranged between 0.81 and 0.88 for the different countries.

Parent Satisfaction Scale (Clare & Pistrang, 1995) is a measure of parent satisfaction with specific teaching services for children with special needs. Parents rate their satisfaction with the school on 8 items, each scored on a 5-point scale (0 = 'strongly disagree to 4 = strongly agree). Clare and Pistrang (1995) suggest that the measure may be considered to have adequate face and content validity because it appears to be acceptable to parents, easy to complete, and contains questions related to the educational services (Harris, & Poertner, 1998). For the current data, the alpha coefficient was calculated, and ranged from 0.89 to 0.93 for the countries.

5.4 PROCEDURE

If parents wished to participate, they clicked a consent button, and were taken to the online survey. There was no set time limit to complete, but the survey generally took about 15 min. Once completed parents were shown a debrief page on-screen. Prior to analyses, data were cleaned and screened for missing values and outliers. Missing data were replaced using the person-mean substitution method for any questionnaire measure where ≤ 10% of the items were missing (Hawthorne & Elliott, 2005). Visual inspection of histograms and Q-Q plots demonstrated the data were normally distributed on all variables.

The data was screened for missing data which were replaced by mean subtitution. The data was screened for outliers and any points falling three standard deviations away from the mean were removed. The data was examined for normality. None of the variables demonstrated significant skewedness or ketosis.

5.5 RESULTS

5.5.1 Time to diagnosis

Table 5.5: Mean (standard deviation) years old when parents first noticed an issue with the child, when the child was diagnosed with ASD, and the time between the two, along with the ANOVA analyses.

	First Noticed	Diagnosed	Time to diagnose
Bangladesh	2.5 (0.8)	3.3 (1.0)	0.8 (0.8)
Zambia	2.4 (1.9)	4.2 (1.9)	1.8 (1.3)
Kenya	2.4 (0.9)	4.1 (1.7)	1.6 (1.8)
Greece	1.5 (0.6)	2.6 (0.7)	1.1 (0.6)
UK	2.8 (0.7)	4.5 (0.8)	1.7 (0.9)
ANOVA	$F = 7.04, p < .001$ $\eta^2_p = 0.134$ Tukey's HSD: Greece lower than all	$F = 12.07, p < .001$ $\eta^2_p = 0.211$ Tukey's HSD: Greece lower than Zambia, Kenya, and UK; Bangladesh lower than Zambia and Kenya	$F = 5.34, p < .01$ $\eta^2_p = 0.106$ Tukey's HSD: Bangladesh quicker than Zambia, Kanya, and UK.

Table 5.5 presents the mean (standard deviations in brackets) for the child ages when the parents first noticed a difference, issue, or problem; the child age when the DSM-5 ASD diagnosis was given; and the time delay between these two points. Inspection of these data reveals some differences between the countries, with parents in Greece noticing an issue earlier than parents in the other countries, diagnosis taking place at an earlier age in Greece and Bangladesh, and the time between first noticing and diagnosis being shorter

in Bangladesh compared to the other counties. There were no significant differences except for those highlighted above.

5.5.2 Parent perception of ASD severity

Table 5.6: Mean (standard deviation) of total ABC score, along with the mean (standard deviation) of percentage of subscale scores possible. ANOVA results are presented for each scale.

	Total	Sensory	Relating	Body	Language	Social
Bangladesh	62.4 (17.9)	37.2 (16.9)	44.2 (17.1)	36.8 (18.8)	36.9 (20.7)	42.1 (22.6)
Zambia	61.7 (30.9)	41.0 (24.2)	36.7 (24.6)	37.7 (25.7)	39.4 (22.8)	42.2 (27.1)
Kenya	83.0 (33.4)	45.2 (26.6)	53.9 (27.1)	56.5 (25.1)	48.3 (26.0)	57.2 (24.3)
Greece	59.4 (23.5)	29.3 (21.4)	37.9 (18.2)	33.2 (22.1)	37.7 (21.3)	52.3 (20.2)
UK	127.8 (12.6)	75.6 (10.4)	73.0 (14.2)	79.6 (8.4)	88.8 (10.9)	83.7 (8.6)
ANOVA	$F = 3.23$, $p < .001$ $\eta^2_p = .535$ Tukey's HSD: UK higher than all; Kenya higher than rest	$F = 28.81$, $p < .001$ $\eta^2_p = .384$ Tukey's HSD: UK higher than all; Kenya higher than Greece	$F = 19.99$, $p < .001$ $\eta^2_p = .302$ Tukey's HSD: UK higher than all; Kenya higher than Zambia and Greece	$F = 33.95$, $p < .001$ $\eta^2_p = .423$ Tukey's HSD: UK higher than all; Kenya higher than rest	$F = 43.65$, $p < .001$ $\eta^2_p = .486$ Tukey's HSD: UK higher than all	$F = 24.91$, $p < .001$ $\eta^2_p = .350$ Tukey's HSD: UK higher than all; Kenya and Greece higher than Zambia and Bangladesh

Table 5.6 presents the mean total ABC score for each country (Higher score means more 'severe' symptoms), along with the mean percentage of the total scores possible for each subscale. Inspection of these data and analyses, reveals that the autism severity was rated highest in the UK relative to all other countries, and this was true for all of the subscales. Parents in Kenya tended to rate the symptoms as more severe than in the other countries. Comparison of the relative importance of the different subtypes of symptoms in the five countries was analysed through a two-factor mixed-model ANOVA (country x subscale), which revealed a significant main effect of country, $F(4,185) = 51.78$, $p < .001$, $\eta^2_p = .528$, a main effect of subscale, $F(4,740) = 9.88$, $p < .01$, $\eta^2_p = .051$, and a significant interaction between the countries, $F(16,740) = 3.72$, $p < .001$, $\eta^2_p = .075$. Separate pairwise analysis for each country between the symptoms revealed that there was no difference between the importance for Zambia, that Bangladesh and Greece rated relating and social symptoms as

more severe than the others, Kenya rated relating and body symptoms as more severe, and the UK rated social and language symptoms as more severe.

5.5.3 Perceptions of school provision

Table 5.7: Percentage pupils in special school, mean (standard deviation) days per week and hours per day in school, percentage teachers with ASD training and experience, as well as percentage of pupils included with nonspecial needs children and having LSA support.

	Special %	Days /week	Hours /day	Teach Train %	Teach Exp %	Inclusion %	LSA %
Bangladesh	97	4.9 (0.3)	4.7 (0.8)	60	82	3	79
Zambia	6	5.1 (0.7)	5.0 (1.1)	57	73	60	43
Kenya	38	5.1 (0.5)	7.0 (0.9)	80	80	53	90
Greece	78	4.6 (0.5)	4.4 (0.7)	76	74	76	27
UK	38	5.0 (0.1)	5.1 (0.7)	75	73	72	82
Test	$X^2 = 97.77$ B & G > UK & K > Z	$F = 4.78$ $\eta^2_p = .099$ G < Z, K, UK	F = 42.73 $\eta^2_p = .499$ K > Rest	X^2 = NS	X^2 = NS	$X^2 = 44.67$ G & UK > rest; Z > B	$X^2 = 44.31$ Z & G < Rest

Inspection of Table 5.7 shows that the majority of pupils were educated in special schools in Bangladesh and Greece, with the opposite being true for Zambia, Kenya, and the UK. This was also the case for children included with non-special needs pupils. In all countries there was near full time (5 days/week) and over 4 hours a day at school for the children with autism, with only some minor (although significant) differences between the countries. There was no difference in the levels of teachers with training and experience with autism across the countries.

Table 5.8: Types of help reported by the parents of the children with ASD across the five countries.

	Augmented communication %	Help from school %	Help from local authority %
Bangladesh	20	70	6
Zambia	16	31	0
Kenya	22	66	0
Greece	43	27	53
UK	40	35	20
X^2	NS	20.65 K & B > rest	41.06 G > UK > rest

Table 5.8 shows that the percentage of pupils who used augmented communication across the five countries was not significantly different (although higher percentages in Greece and the UK used some form of augmented communication). There were higher reported levels of help available from the school for the parents in Bangladesh and Kenya than in the other countries. No country except Greece reported very high levels of help available from the local authority (other than the school).

Table 5.9: Parents' perceptions of school support and satisfaction.

	Difficulties %	Satisfaction	Quality	School Satisfaction
Bangladesh	3	2.5 (0.3)	1.8 (0.5)	24.7 (3.8)
Zambia	11	2.1 (0.6)	1.9 (0.6)	22.2 (4.6)
Kenya	15	2.1 (0.8)	1.9 (0.7)	23.4 (7.4)
Greece	51	3.1 (0.7)	2.8 (0.7)	26.7 (3.3)
UK	65	2.4 (0.8)	2.7 (0.7)	24.9 (4.3)
Test	$X^2 = 54.79$ UK > G > K & Z > B	$H = 54.39$ G > rest	$H = 60.97$ G & UK > rest	$F = 4.71$ $p < .05$ $\eta^2_p = .096$ Tukey's HSD: G > Z & K

Table 5.9 shows the parents' perceptions of the school provision for their children with ASD. A higher percentage of parents in the UK and Greece report having difficulties with their children's teachers than in the other countries. However, parents in Greece report greater satisfaction with their child's school (on a 0 to 4 scale) than any other country, as well as thinking the quality of the school (along with the UK) as being higher than the other countries. In terms of the school satisfaction scale, parents in Greece reported being more satisfied than parents in Zambia and Kenya.

5.5.4 Predictors of school satisfaction

In addition to analysis by country, separate correlation analyses were conducted to determine if any of the autism, background, or school characteristics were related to the school satisfaction score. Relationships were taken to be meaningful and are reported only if they had a significance level of $p < .001$ (given the large number of correlations involved).

The level of autism severity (as measured by the total ABC score) was not related the School Satisfaction Scale score. This lack of a relationship between perceived autism severity and satisfaction with the school held true for each country when tested separately.

Of the parent and child background factors (parent age, child age, parent and child genders, child age at first noticing an issue, age at diagnosis, and noticing to diagnosis time) only parent age was related to School Satisfaction (r = .116). However, the relationship between parent age and school satisfaction was true in Bangladesh (r = .341) but not in the other countries.

A number of school factors were important in determining school satisfaction, which did not differ across countries. There were positive relationships between school satisfaction scores and teacher training (r_{pb} = .268), receiving parent support from the school (r_{pb} = .190), and receiving local authority support (r_{pb} = .157). We can certainly conclude that teacher training helps, but we do not have data to know the certain types help more. The type of school (special or mainstream) and being included with children with no special needs were not predictors of satisfaction.

5.6 DISCUSSION

The study examined parent perceptions of autism diagnosis, school provision, and predictors of satisfaction of school provision, across five different countries, and the most notable feature to emerge highlighted similarity rather than difference. The study was conducted in response to a range of studies suggesting a relative paucity of such data for low-to-medium income countries, which may inhibit development of services (Bakare & Munir, 2011; Hossain et al, 2017). Although there is a developing literature in some of the countries included (e.g., Kamau, 2017; Masaba et al., 2012; Reed et al., 2024; Nyoni, 2022; Rahman et al., 2019; Washington-Nortey & Serpell, 2021), most comes from higher-income countries (Chiarotti & Venerosi, 2020; Salari et al., 2022). Moreover, the procedures used in the former studies are widely different from one another, making comparison difficult, and it was hoped that the use of a single procedure to collect such data would facilitate cross-country comparisons (Matson et al., 2017). The current striking similarities give some cause for optimism in terms of generalisation of results and techniques.

In terms of the autism diagnostic systems and their perceived workings and characteristics, parents across all countries tended to report first noticing an issue of difference for their child at the same age (around 1.5 years), although parents in Greece reported noticing such differences earlier. That there were few differences in time to recognising difference suggests that apparent discrepancies in ASD knowledge in the countries (Nyoni, 2021), does not translate into lack of recognition of a potential problem on the part of the parent. Following first noticing, there were some differences in time to receive a formal diagnosis, with their being a speedier process in Greece and Bangladesh. That low-to-middle income countries do not seem to lag behind their higher-income European counterparts in this regard tends to argue against any lack of effective provision, even though there may be lack of data (Bakare & Munir, 2011; Hossain et al, 2017). The reasons for such differences are unclear, and could reflect demand on, and availability of, healthcare systems in the various countries; as less demand and greater availability could both speed the process. One thing in common between Bangladesh and Greece is a greater presence of a monolithic religion, widely shared among the population, compared to Kenya, the UK, and Zambia, which tend to be religiously more diverse. Whether this feeds into experienced stigma, which is high in both Bangladesh and Greece (Rahman et al., 2019; Veroni, 2017), could be investigated in subsequent studies. High experienced stigma and consequent shame may lead to a rush to diagnosis, which is not always helpful (Reed et al., 2019).

The severity of autism was rated as highest by parents in the UK, relative to all other countries, and this was true for all of the subscales. Following the UK, parents in Kenya rated symptoms as more severe than in the other countries. In terms of the key symptoms that were perceived as important, both Bangladesh and Greece rated relating and social symptoms as more severe than the other countries. Whether this is related to speed of diagnosis is unclear. Kenyan parents rated ‘relating and body symptoms’ as more severe, and parents in the UK rated social and language symptoms as more severe. These data reflect and extend what has previously been suggested by Matson et al. (2017) to be the case, and contribute to the understanding of the key areas that parents find challenging in those different cultures.

As this was a parent-rated scale, there is no way of knowing whether the symptoms were objectively higher in individuals with autism in the UK. All children did have a diagnosis based on the DSM-5 criteria, which provides some form of baseline, but not necessarily any insight into level of functioning. It could be that strain of services means only the most severe cases receive a diagnosis in the UK, and other countries with less demand, or more available services, give diagnoses more liberally. This would be important to establish going forward. It may be that parents in the UK, because of putative greater awareness of autism, may over-interpret the severity of the symptoms – certainly having greater levels of stress can be related to perceptions of having a problem (Fong, 1991), and such greater stress can increase ratings of behavioural challenges (Reed & Osborne, 2013). Challengingly, this may imply that awareness is not always a good thing, if coupled with a lack of understanding of the consequences of having autism. Alternatively, anxiety may be higher in the UK than in the other counties, making parents less resilient to challenge, as this has been found to range from around 5% in African cultures to over 10% in Euro/Anglo cultures (Baxter et al., 2103).

In terms of education and provision, there was remarkable similarity across the countries – and sometimes marking similarities is as vital as marking differences. No country except Greece reported very high levels of help available from the local authorities, other than the school. This mirrors what has been claimed previously, that the main burden of support for autism, irrespective of country, falls on the school and parents (Gómez-Marí et al., 2021; Osborne & Reed, 2023; Ye, 2022). There were differences in the place of provision for this help, with the majority of pupils being educated in special schools in Bangladesh and Greece, with the opposite being true for Zambia, Kenya, and the UK. Further information on the precise provision on offer would be very helpful to explore in further studies. Unfortunately, we did not have that level of detail information in this study. This also may be related to the speed of diagnosis in those countries, and a disturbing possibly is that it implies a need to remove the child from typically developing peers; alternative it may just imply better special school provision. However, whatever the place of training, parents perceived no difference in teacher training and experience. Data on parents' perceptions of the quality of school were clear in that the higher-income countries felt more satisfaction with the school provision, but also reported having more difficulty with the teachers. This may reflect greater levels of both expectation and involvement with the education process. The concept of involvement might usefully be further explored to what extent does it have to involve the parents or could it involve other family members, or to what extent do the families have an active voice in determining level of involvement. These are the issues the future work could explore.

Across all countries a number of factors predicted satisfaction such as level of teacher training, level of received support from the school, and from local authorities. The type of school (special or mainstream) and being included with children with no special needs were of no consequence to the parents' satisfaction. The latter finding suggests a misplaced focus on inclusion for its own sake may be harmful to parents' relationships with the school.

The current report provided some indicators of comparative perceptions of autism provision across five countries, of very diverse natures. The results suggested more similarities than differences, with key concerns being the lack of support on offer from authorities, and the quality of the provision provided, irrespective of how that provision was provided. There were some differences between the countries in terms of speed of diagnosis, and the factors relating to those could be interestingly explored in terms of social and religious attitudes to disability.

CHAPTER 6
QUANTITATIVE FINDINGS
PARENTING STRESS AND COPING STRATEGIES

6.1 INTRODUCTION

Parenting stress is the perceived cognitive and emotional state arising from the challenges of parenting, and is typically very high for parents of children with Autism Spectrum Disorder (ASD) (Barroso et al., 2018; Bonis, 2016; Dabrowska & Pisula, 2010; Hayes & Watson, 2013). In fact, parenting stress for this population is often reported as much higher than for parents of children with other conditions (Hayes & Watson, 2013; Pastor-Cerezuela et al., 2021; Osborne & Reed, 2010; Spratt et al., 2007). Such parenting stress co-varies with key child characteristics, such as the level of behavioural problems (Postorino et al., 2019; Osborne & Reed, 2009a; Tomanik et al., 2004), as well as ASD symptom severity (Eisenhower et al., 2005; Hall & Graff, 2011; Pastor-Cerezuela et al., 2021).

It has long been suggested that the impact of an event (stressor) on perceived stress is mediated by coping strategies (Vernhet et al., 2019). The strategies which were directly related to the behaviours causing the stress, such as ‘disengagement’ (strategies that avoid or deny stressors), ‘distraction’ (strategies directing thoughts away from stressors), and ‘engagement’ (strategies aimed directly at stressors) were associated with greater parenting stress for parents of children with autism; but ‘cognitive reframing’ strategies that allowed re-appraisal of stressors lowered that stress (Benson 2014; Benson, 2010; Reed, 2020). Similarly, Obeid and Daou (2015) noted disengagement was harmful for the psychological wellbeing of parents of children with autism, and several other studies also have noted ‘engagement’ strategies are negatively related to parenting stress (Pottie & Ingram, 2008; Shepherd et al., 2018). In contrast, Dardas and Ahmad (2015; see also Dunn et al., 2001; Reed, 2020) found reframing and reappraisal were beneficial to parents of children with autism. Seeking social support has also been noted to produce some benefits (Zablotsky et al., 2013). Moreover, the severity of the child behaviour problems moderates the effectiveness of passive reappraisal (Reed, 2020; Shepherd et al., 2018) and seeking social support (Reed, 2020).

These data are almost exclusively related to parents in higher-income countries, which account for less than 20% of the world's population (World Bank, 2015), and only limited data available for low-to-middle income countries (Hossain et al, 2017; Makino et al., 2021). It may be that cultural and familial perceptions and expectations may impact parenting stress and coping styles linked to having a child with autism (Dyches et al., 2004; Matson et al., 2017; Rahman et al., 2021).

Findings from the UK (Reed, 2020) and Greece (Ntre et al., 2022) are highly similar to one another, and to other higher-income countries, in terms of reported stress and the impact of coping strategies; with high stress being helped by cognitive reappraisal strategies, but not by disengagement (Ntre et al., 2022; Reed, 2020). High levels of stress for this population have also been noted in Bangladesh (Akter et al., 2020), Kenya (Masaba et al., 2021), and Zambia (Ncube, 2020). Many of the factors that produce stress for parents of children with autism are also similar across several studied low-to-medium income countries (Aktar et al., 2020; Ncube, 2020; Washington-Nortey & Serpell, 2021). However, there are some unique factors for particular countries (Washington-Nortey & Serpell, 2021), with very high proportions of parents noting stigma and childcare burden as key stressors (Cloete & Obaigwa, 2019; Gona et al., 2016; Haque et al., 2022; Masaba et al 2021). Additional factors that emerge uniquely among low-to-medium income countries concern the use of supernatural powers, prayers and spiritual healing (Gona et al., 2016), although this can also be noted in more highly religious higher-income countries. However, these findings are often based on qualitative reports (Cloete & Obaigwa, 2019; Gona et al., 2016), which are insightful and helpful, but do not offer a chance for comparison with established psychometric assessments often conducted in higher-income countries. Moreover, there are few, if any, data on how coping styles impact stress for such nations.

To help address this knowledge gap, the present study investigated parenting stress and coping to provide some exploratory data across five different countries: the UK, and Greece in Europe; Kenya, and Zambia, in Africa; and Bangladesh in Asia. This approach follows from a similar cross-country comparison (Matson et al., 2017; Reed et al., 2024). However, adding to the knowledge base is vital at this early stage of cross-country comparisons (Bakare & Munir, 2011; Hossain et al, 2017; Nyoni, 2022). The current set of countries, although partially reflecting opportunity, also allows some interesting comparisons between parents' stress and coping.

To collect data on stress and coping the same psychometric assessments were employed across the five countries, with the aim of allowing levels of parenting stress, the adoption of coping styles, and the impact of coping style on parenting stress to be compared across the countries. Based on various research discussed above, a clear hypothesis can be drawn that the coping strategies, including acquiring social support, reframing stressors positively, seeking spiritual support, mobilising family to secure resources, and passive appraisal will significantly mediate the relationship between behaviour and parental stress. This will allow a first comparison of such countries and it will provide much needed data on these important aspects of parenting wellbeing in relation to having a child with autism.

6.2 METHOD

6.2.1 Participants and Recruitment

The participants are the same as those in Chapter 5

Table 6.1: Quantitative Research Questions about Parenting Stress and Coping Strategies

1. Correlations between parenting stress, perceived autism severity, child behaviour problems, child internalising problems, and child externalising problems
2. Parenting Stress for each country
3. Correlations between stress subtypes and autism severity and total child behaviour problems for each country
4. Correlations between coping types and total parenting stress (QRS), autism severity (ABC), and total child behaviour problems (SDQ) for each country
5. Coping Strategies for each country

6.3 MATERIALS

The Demographic/Background Questions and Autism Behaviour Checklists are the same as those in Chapter 5.

Strengths and Difficulties Questionnaire (Parents; SDQ, Goodman, 2001**)** is a brief measure covering emotional symptoms, conduct problems, hyperactivity-inattention, and peer problems, as well as prosocial behaviour). It can be completed by parents, and comprises 25 items, describing positive and negative attributes of children and adolescents that can be allocated to 5 subscales. Each item is scored on a 3-point Likert scale, with higher scores on the prosocial behaviour subscale reflect strengths, whereas higher scores on the other four subscales reflect difficulties. The four problem subscales can be combined to provide an internalising and externalising behaviour score. The internal consistency (0.51 to 0.76), and test-retest reliability (0.70-0.85), of the SDQ are satisfactory (Goodman, 2001). The criterion validity was assessed, and found to be acceptable (Goodman, 2001). The internal reliability of the scale ranged from 0.68 to 0.88 for the different countries.

Questionnaire on Resources and Stress - Friedrich Short Form (QRS-F; Friedrich, Greenberg, & Crnic, 1983) is a measure of perceived stress about parenting, and explores the impact of a child's disability or illness on other family members. The QRS-F has been used to study stress in families of children with disabilities, including ASD. It contains 52 items, and assesses four factors: parent and family problems (stressful aspects of the impact of the child with disability on parents and the wider family), pessimism (parents' pessimistic beliefs about the child's future), child characteristics (features of the child that are associated with increased demands on parents), and physical incapacity (the extent to which the child is able to perform a range of typical activities). It is self-administered, and it has a true/false response format. It provides four factor scores, and a total scale score. Higher scores are taken to be indicative of greater distress within a family. The reliability of the total scale is 0.95 (Friedrich et al., 1983). The internal reliability was estimated at between 0.897 and 0.935 for the countries in the current study.

Family Crises Oriented Personal Evaluation Scales (F-COPES; McCubbin, Olson, & Laresen, 1981) is a 30-item scale identifies problem-solving attitudes and strategies employed by families to problematic situations. There are five sub-scales of different coping strategies: reframing (cognitively making events more manageable); passive appraisal (minimisation of responses to events); acquiring social support; seeking spiritual support, and mobilising family to acquire help. Each item is scored from 1 (strongly disagree) to 5 (strongly agree). The instrument has been used successfully in the relation to coping and stress of parents of children with ASD. Each sub-scale reduces a score, which varies from X to Y, which is the sum of the items relating to the sub-scales. The internal reliability (Cronbach α) for the total scale is .86, and the sub-scales range from .63 to .86 (McCubbin et al., 1981).

Family Routines Inventory (FRI; Fiese, Tomcho, Douglas, Josephs, Poltrock, & Baker, 2002) assesses family routines and rituals. The FRI is a parent-report inventory, which measures 28 positive, strength-promoting, family routines. These are observable, repetitive behaviours, which involve two or more family members, and which occur with predictable regularity in the daily life of a family. It consists of two subscales: the frequency scale, and the importance scale, from which only the first was used, because of the already large number of questions that the parents had to answer. The frequency scale is rated on a five-point scale, ranging from 0 to 4, with a total frequency score range from 0 to 84. The FRI appears to be a reliable and valid measure of family cohesion, solidarity, order, and overall satisfaction with family life. It has adequate internal consistency (α= 0.67-0.78; Sytsma et al., 2001), and the one-month test-retest reliability was estimated to be from 0.74 to 0.79.

6.4 Procedure

If parents wished to participate, they clicked a consent button, and were taken to the online survey. There was no set time limit to complete, but the survey generally took about 15 min. Once completed parents were shown a debrief page on-screen. Prior to analyses, data were cleaned and screened for missing values and outliers. Missing data were replaced using the person-mean substitution method for any questionnaire measure where ≤ 10% of the items were missing (Hawthorne & Elliott, 2005). Visual inspection of histograms and Q-Q plots demonstrated the data were normally distributed on all variables.

6.5 Results

6.5.1 Overall Sample

Table 6.2: Means (standard deviation and range) for sample parenting stress (QRS), perceived autism severity (ABC), child behaviour problems total (SDQ), child internalising problems (SDQi), and child externalising problems (SDQe). Pearson correlations are also displayed.

	Mean (SD; range)	ABC	SDQ	SDQi	SDQe
QRS	29.5 (8.6; 5 – 48)	.438***	.462***	.472***	.388***
ABC	79.7 (35.9; 0 – 177)		.697***	.602***	.661***
SDQ	19.2 (6.8; 0 -24)			.907***	.840***
SDQi	9.3 (3.7; 0 – 17)				.608***
SDQe	9.9 (3.6; 2 – 19)				

*p<.05; **p<.01; ***p<.001

Table 6.2 displays the means (standard deviation) for parenting stress (QRS), perceived autism severity (ABC), child behaviour problems total (SDQ), child internalising problems (SDQi), and child externalising problems (SDQe). The Pearson correlations between the variables are also displayed. There were strong positive correlations between all variables. This pattern of relationships was also seen in each country separately, except for the UK, which did not show any relationship between autism severity and parenting stress (Table 6.6).

6.5.2 Parenting Stress

Table 6.3: Means (standard deviations) for parenting stress total for each country, as well as mean (standard deviation) for the average response per item on each of the parenting stress subscales. Results of one-way ANOVAs between countries for each scale and subscale are also shown.

QRS	Total	Family	Pessimism	Child	Physical
Bangladesh	30.7 (8.2)	.52 (.22)	.83 (.14)	.61 (.17)	.12 (.09)
Zambia	28.7 (8.7)	.51 (.24)	.73 (.21)	.54 (.21)	.13 (.10)
Kenya	28.5 (8.9)	.48 (.24)	.72 (.22)	.59 (.18)	.14 (.11)
Greece	25.7 (3.0)	.40 (.29)	.62 (.22)	.54 (.21)	.18 (.09)
UK	33.8 (3.0)	.67 (.10)	.65 (.12)	.64 (.08)	.24 (.06)
ANOVA	F = 5.12 p < .001 η^2_p = .10 Tukey's HSD: UK > Z, K, G	F = 7.81 p < .001 η^2_p = .145 Tukey's HSD: UK > rest	F = 7.65 p < .001 η^2_p = .142 Tukey's HSD: B > K, G, UK	F = NS	F = 10.38 p < .001 η^2_p = .183 Tukey's HSD: UK > rest

Table 6.3 shows the means (standard deviations) for parenting stress totals for each country, as well as mean (standard deviation) for the average response per item on each of the parenting stress subscales. These data reveal that total parenting stress was highest for parents in the UK. Parents in the UK also reported higher parenting stress than parents in other countries relating to all QRS subscales, except child related difficulties, and pessimism, which was highest in Bangladeshi parents.

Further analysis determined any differences in the most stressful subscale for each country. A two-factor mixed model ANOVA (country x stress type) revealed significant main effects of country, $F(4,185) = 4.24$, $p < .001$, $\eta^2_p = .084$, and stress type, $F(3,555) = 592.60$, $p < .001$, $\eta^2_p = .762$, as well as a significant interaction between the two factors, $F(12,185) = 9.56$, $p < .001$, $\eta^2_p = .171$. Separate one-way repeated-measures ANOVAs performed on the stress types for each country revealed significant differences between the stress types for all countries, smallest $F(3,102) = 56.04$, $p < .001$, $\eta^2_p = .622$. Paired t-tests conducted on the stress types for each country, separately, using a Bonferroni correction ($p = .05/30 = .001$), revealed significant differences for parents in all low-to-medium-income countries (Bangladesh, Kenya, Zambia), with pessimism being highest, and physical problems lowest. For parents in Greece, pessimism was also high, as was child limitations. However, for UK parents the pattern was different, with stress due to physical limitations being lower than the others, but no other differences being significant.

Table 6.4: Significant correlations between stress subtypes and autism severity (ABC) and total child behaviour problems (SDQ) for each country.

	Autism Severity (ABC)	Behaviour Problems (SDQ)
Family	Bangladesh (+ve) Zambia (+ve) Greece (+ve)	Bangladesh (+ve) UK (+ve)
Pessimism	Bangladesh (+ve) Kenya (+ve) Greece (+ve)	Bangladesh (+ve) Zambia (+ve) UK (+ve)
Child	Bangladesh (+ve) Kenya (+ve) Greece (+ve)	Bangladesh (+ve) Zambia (+ve) Kenya (+ve) Greece (+ve) UK (+ve)
Physical	Bangladesh (+ve)	Bangladesh (+ve) UK (+ve)

When correlations between autism severity (ABC), as well as total behaviour problems (SDQ), and parenting stress were calculated for each country, using Bonferroni correction (*p* = .05/40 = .001), quite different patterns of relationships were seen for each country (as indicated in Table 6.4). All relationships between autism severity, child behaviour problems, and stress types were significant for parents in Bangladesh. For parents in Zambia, autism severity only correlated with family problems, and behaviour problems correlated with pessimism and child problems. For Kenyian parents, autism severity correlated with pessimism and child problems, and behaviour problems correlated with child problems. For parents in Greece, autism severity correlated with most stress types except physical limitations, but behaviour problems only correlated with child stress problems. In the UK, autism severity correlated with no aspects of stress, and behaviour problems correlated with pessimism.

6.5.3 Coping Strategies

Table 6.5: Means (standard deviation and range) for sample coping strategies (FCOPES) and family routines (FBI), along with the Pearson correlations between these variables and parenting stress (QRS), perceived autism severity (ABC), child behaviour problems total (SDQ), child internalising problems (SDQi), and child externalising problems (SDQe).

Strategy	Mean (SD; range)	QRS	ABC	SDQ	SDQi	SDQe
Reframing	.68 (.18; .05 – 1.0)	-.134	-.258***	-.162	-.199	-.180
Appraisal	.71 (.18; .25 – 1.0)	.100	-.249***	-.158	.060	.247***
Social	.66 (.16; .20 – 1.0)	-.044	.131	.022	.032	.009
Spiritual	.64 (.24; .20 – 1.0)	-.311***	-.442***	-.430***	-.353***	-.445***
Family	.75 (.17; .20 – 1.0)	-.189	-.058	-.174	-.174	-.177
Routines	.49 (.11; .25 - .79)	.154	-.190	-.100	-.110	-.223

$^{*}p<.05$; $^{**}p<.01$; $^{***}p<.001$

Table 6.5 displays the whole sample means (standard deviation and range) for the five coping strategies (FCOPES), and family routines (FBI), along with the Pearson correlations between these variables and parenting stress (QRS), perceived autism severity (ABC), child behaviour problems total (SDQ), child internalising problems (SDQi), and child externalising problems (SDQe). These data show that mobilising family support and passive appraisal tended to be used to a greater extent than the other strategies across the sample. A one-way repeated measured analysis of variance (ANOVA) revealed a significant different between these scores, $F(4,712) = 9.78$, $p < .001$, $\eta^2_p = .052$. Paired t-tests with a Bonferroni correction ($p = .05/10 = .005$) revealed that passive appraisal was used more than all other strategies except mobilising family, and the mobilising the family was used more than social support. No other comparisons were significant.

Pearson correlations between coping strategies revealed few significant relationships, with the exception of negative relationships between both reframing and passive appraisal with autism severity; and negative relationships between spiritual support and parenting stress (QRS), autism severity (ABC), and child behaviour problems (SDQ).

Table 6.6: Significant correlations between coping types and total parenting stress (QRS), autism severity (ABC), and total child behaviour problems (SDQ) for each country.

	Parenting Stress (QRS)	Autism Severity (ABC)	Child Behaviour Problems (SDQ)
Reframing		UK (+ve)	
Appraisal	Greece (+ve) UK (+ve)		
Social			
Spiritual	Greece (-ve)		
Family	Greece (-ve)		Zambia (-ve)
Routines			

This pattern was not displayed across all countries as shown in Table 6.6. There were no reported relationships between coping strategies and parenting stress (QRS), autism severity (ABC), and child behaviour problems for parents in Bangladesh or Kenya. For parents in Zambia, passive appraisal was positively associated with behaviour problems, and mobilising the family was negatively associated with child behaviour problems. For parents in Greece, passive appraisal was positively associated with parenting stress, whereas spiritual support and mobilising family support were negatively associated with parenting stress. In the UK, passive appraisal was positively associated with parenting stress, and reframing was negatively associated with autism severity (ABC).

Table 6.7: Means (standard deviations) for average response per item on each of the coping strategies for each country. Results of one-way ANOVAs between countries for each scale and subscale are also shown.

	Reframing	Passive	Social	Spiritual	Family
Bangladesh	.89 (.11)	.54 (.14)	.67 (.12)	.69 (.17)	.74 (.16)
Zambia	.71 (.14)	.77 (.19)	.60 (.14)	.81 (.16)	.71 (.19)
Kenya	.81 (.14)	.71 (.18)	.55 (.16)	.77 (.19)	.76 (.21)
Greece	.49 (.12)	.73 (.13)	.75 (.16)	.64 (.17)	.86 (.13)
UK	.53 (.08)	.79 (.13)	.74 (.08)	.35 (.18)	.75 (.12)
ANOVA	$F = 53.94$ $p < .001$ $\eta^2_p = .549$ Tukey's HSD: B & K > Z > G & UK	$F = 14.93$ $p < .001$ $\eta^2_p = .253$ Tukey's HSD: B < rest	$F = 14.24$ $p < .001$ $\eta^2_p = .244$ Tukey's HSD: Z < B; K < rest	$F = 39.81$ $p < .001$ $\eta^2_p = .378$ Tukey's HSD: UK < rest; G & B < Z & K	NS

Table 6.7 shows the average response per item on each of the coping strategies for each country, as well as the results of one-way ANOVAs between countries for each scale and subscale are also shown (using a Bonferroni correction, $p = .05/6 = .008$). These data show that there were significant differences for each coping strategy across the countries, with parents in Bangladesh and Kenya using reframing more often than parents in other countries. Parents in Bangladesh used passive appraisal less than parents in other countries. Kenyan parents tended to use social support less than those in other countries. Zambian and Kenyan parents used spiritual support more often than parents in other countries, with this strategy not being utilised often by parents in the UK.

Further analysis determined any differences in the most used coping styles for each country. A two-factor mixed model ANOVA (country x coping style) revealed significant main effects of country, $F(4,174) = 10.50$, $p < .001$, $\eta^2_p = .194$, and coping style, $F(4,696) = 16.28$, $p < .001$, $\eta^2_p = .086$, as well as a significant interaction between the two factors, $F(16,696) = 27.64$, $p < .001$, $\eta^2_p = .388$. Separate one-way repeated-measures ANOVAs performed on the stress types for each country revealed significant differences between the stress types for all countries, smallest $F(4,132) = 7.63$, $p < .001$, $\eta^2_p = .168$. Paired t-tests conducted on the stress types for each country, separately, using a Bonferroni correction ($p = .05/50 = .001$), revealed reframing was higher than all types, and passive appraisal lower than all types, for parents in Bangladesh. For parents in Zambia and Kenya using social support was lower than all other coping strategies. For parents in Greece reframing was used less than any other style, and mobilising the family used more than any other style. In the UK, seeking spiritual support and reframing were used less often than other strategies.

6.5.4 Coping as mediator between autism, behaviour problems and parenting stress

Figure 6.8: Schematic representation of mediation analysis relating autism severity (ABC) to parenting stress (QRS) mediated by five coping styles (FCOPES) and family routines (FBI). The solid lines connecting boxes represent significant relationships. The dotted lines represent insignificant relationships. The strength of the relationship is indicated by the figure close to the line, and whether the relationship is positive or negative is indicated by the sign of the value.

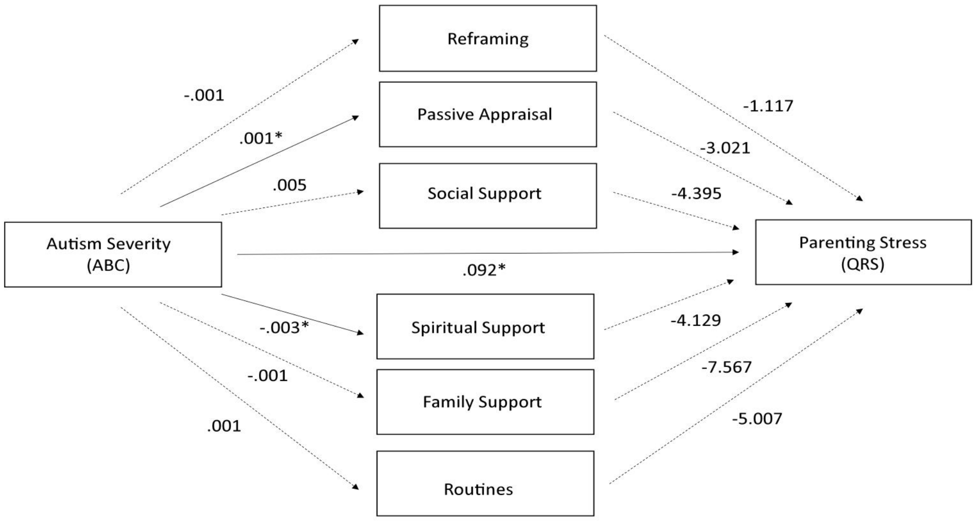


Figure 6.8 shows the results of a mediation analysis using PROCESS Model 4 (Hayes, 2023) for SPSS v26. This analysis shows that there was a significant direct relationship between autism severity and parenting stress (effect = .092, t = 4.81, p < .001), which was not mediated by any coping styles.

Figure 6.9: Schematic representation of mediation analysis relating child behaviour problems (SDQ) to parenting stress (QRS) mediated by five coping styles (FCOPES) and family routines (FBI). The solid lines connecting boxes represent significant relationships. The dotted lines represent insignificant relationships. The strength of the relationship is indicated by the figure close to the line, and whether the relationship is positive or negative is indicated by the sign of the value.

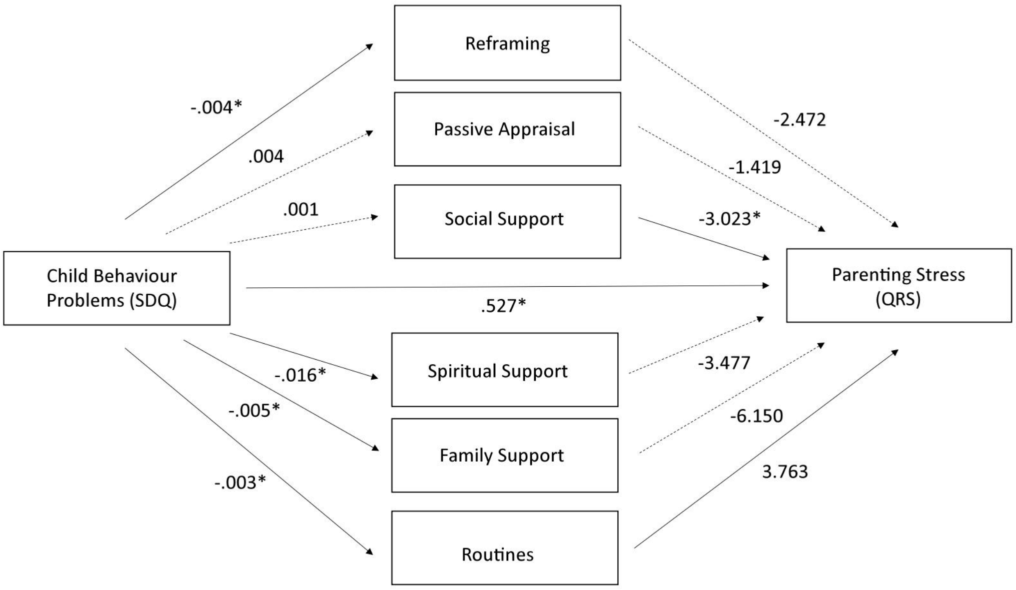


Figure 6.9 shows the results of a mediation analysis using PROCESS Model 4 (Hayes, 2023) for SPSS v26. This analysis shows that there was a significant direct relationship between child behaviour problems and parenting stress (effect = .523, t = 4.81, p < .001), which was not mediated by any coping styles.

6.6 DISCUSSION

The current study collected cross-sectional data on stress and coping across five diverse countries, with the aim of allowing levels of parenting stress, the adoption of coping styles, and the impact of coping style on parenting stress for parents of children with ASD to be compared across the countries. This study was conducted to help redress the imbalance in data on this topic from higher-income and low-to-middle income countries (Hossain et al, 2017; Makino et al., 2021). It was thought that cultural and familial perceptions and expectations may impact parenting stress and coping styles linked to having a child with autism (Dyches et al., 2004; Durkin et al., 2015; Matson et al., 2017; Rahman et al., 2019).

The study replicated findings from higher-income countries that parenting stress for parents of children with autism was high (Barroso et al., 2018; Dabrowska & Pisula, 2010; Osborne & Reed, 2010). In addition, not only was parenting stress high for Greece and the UK (Osborne & Reed, 2010; Ntre et al., 2022), but there were just as high levels of stress in Bangladesh (Akter et al., 2020), Kenya (Masaba et al., 2021), and Zambia (Ncube, 2020). The only cross-country finding of note was that parenting stress was highest in the UK. All countries reported high levels of parenting stress related to pessimism. This was highest in Bangladesh, and lowest in Greece and the UK, which may reflect the presence of better developed health and social care in the higher-income countries buffering (to some extent) against future concerns. Stress in the UK was also more related to the impact of the child on the rest of the family, which was also present in other countries but to a lesser degree. Physical limitations of the child were not a great source of stress for parents in any country, but this was most felt by parents in the UK. There were also cross-country differences in whether parenting stress was related to autism severity or behaviour problems. Aspects of parenting stress (albeit different ones) were related to autism severity in all countries, except for the UK. The lack of impact of autism severity on parenting stress has previously been noted for the UK and the USA (Lecavalier et al., 2006; Osborne & Reed, 2009b). However, the relationship between autism severity and parenting stress (Eisenhower et al., 2005; Pastor-Cerezuela et al., 2016) was present for other countries suggests that autism severity may have greater worldwide significance than for higher-income countries. It may be that greater knowledge of autism in the UK mitigated stress connected to the symptoms of autism per se. In contrast, the behaviour problems were related to parenting stress for the UK to a greater extent (Lecavalier et al., 2006; Osborne & Reed, 2010), which was also the case for the other countries. There are various aspects of this issue that will need consideration. It could be the stress in itself, which is important or it could be what the stress produces. It is not necessarily just a child having a behaviour problem, but it could be the lack of coping skill to deal with the behaviour. A coping skill could be active, that means one has the skills to manage the behaviour issues, like in ABA, or it could be that one has the cognitive resources to be able to reframe the issues.

With regard to coping strategies, across the sample, passive appraisal was used most often, with mobilising family being used more than social support. There were negative relationships between both reframing, and passive appraisal, with autism severity; and negative relationships between spiritual support and parenting stress (QRS), autism severity (ABC), and child behaviour problems (SDQ). The only cross-country differences were that reappraisal strategies were used less in higher-income countries (Greece, UK) than in low-to-medium-income countries (Bangladesh, Kenya, Zambia), and seeking spiritual support was used less in the UK than any other country. Coping styles were not greatly related to parenting stress in any low-to-medium-income country, but both passive appraisal and reframing were related to higher stress in the higher-income countries. There were few relationships between coping style and autism severity (passive approval in the UK) and behaviour problems (mobilising family in Zambia).

The direct relationship between autism severity and parenting stress was significant, revealing higher autism impairment predicted more parenting stress, aligning with prior research (Pastor-Cerezuela et al., 2016). However, counter to hypotheses, this effect was not mediated by any examined coping strategy or household routines. The direct relationship between child behaviour problems and parenting stress was significant, indicating higher levels of child behaviour issues predicted increased parenting stress, as would be expected. The effect size was moderate-large (effect = .523), and aligns with substantial literature documenting challenging behaviours among children with autism commonly increase caregiver stress across cultural settings (Pastor-Cerezuela et al., 2016). However, as with autism severity, results indicated none of the five examined coping strategies, including acquiring social support, reframing stressors positively, seeking spiritual support, mobilising family to secure resources, and passive appraisal significantly mediated this relationship between behaviour and stress. This contrasts some prior studies suggesting certain adaptive coping styles may buffer parenting stress for autism caregivers (Zaidman-Zait et al., 2020).

The reasons behind the non-significant mediating effects are unclear. Potentially coping styles captured variance directly associated with behaviour severity, overlapping rather than buffering impact. The restricted range and cultural specificity of coping measures may obscured effects as well. It is also possible child behavioural fluctuations superseded usual benefits of routines. Replication with larger, more diverse groups is warranted. To interpret the mediational findings related to coping and family routines appropriately, the study's limitations must be transparently acknowledged as well. The small convenience sample risks bias. Absence of a functional assessment in understanding and managing challenging behaviour, could have contributed to non-effective management strategies. The coping strategies could have been supplemented with an assessmet of parental skills in doing a functional assessment and their skills in detecting mentalistic explanations that misinform the solution to managing behaviour problems. Broader cultural contexts surrounding parenting an autistic child were unexamined. Such factors likely influence conceptualisations, responses to stressors, and perceived social supports.

These results allow a first comparison of such countries, and provide much needed data on these important aspects of parenting wellbeing in relation to having a child with autism. These data suggest a degree of similarity across most aspects of parenting across diverse countries, although some atypical results from the UK may mean caution is needed in drawing generalised conclusions from such higher-income countries. However, further inquiry is imperative exploring sociocultural determinants and processes that may exacerbate or mitigate how core features of autism translate into caregiver outcomes over time and settings. Such knowledge can inform contextualised supports to aid diverse families navigating autism worldwide.

CHAPTER 7

DISCUSSION

This multi-national study provided a rich cross-cultural perspective on the experiences, beliefs, and challenges faced by families and professionals dealing with autism across six countries – Bangladesh, Indonesia, Zambia, Kenya, Greece, and the United Kingdom. While the core defining features of autism transcend cultures, the findings highlighted how the specific ecological contexts and resource landscapes surrounding this condition can profoundly influence its identification, perceived causations, interventions utilised, support available, associated stressors, coping strategies employed, and long-term outlooks. This discussion aims to synthesise the key similarities and differences observed, interpreting them through a cultural lens while drawing meaningful comparisons to extant literature on autism across the globe.

7. 1 THE DIAGNOSTIC JOURNEY

The path to receiving an autism spectrum disorder (ASD) diagnosis involves a complex interplay of factors, including parental awareness, societal attitudes, and access to screening and diagnostic services. This study revealed notable cross-cultural variations in the age at which parents first noticed atypical development and the subsequent time lag until a formal autism diagnosis was established. Impairments in social communication and the presence of restricted, repetitive behaviors are hallmark characteristics that typically prompt initial parental concerns about autism (Adioetomo et al., 2014). Aligning with this, deficits in speech, socialisation skills, and behavioral patterns emerged as the commonly reported first signs noticed by parents across all countries in this study. However, there were stark differences in the average age when families first became aware of these developmental issues.

Bangladeshi parents tended to notice atypical development around 34 months on average, which was substantially later compared to an average of 18-23 months reported in Indonesia, Kenya, and the UK. This delayed recognition of early signs in Bangladesh could be attributed to multiple factors, including limited societal awareness about autism, stigma surrounding developmental disabilities, and a lack of robust developmental screening programs in the country's healthcare system (Boehm et al., 2015). In contrast, parents in higher-income nations like the UK displayed greater awareness, likely due to better access to educational resources, routine developmental monitoring, and increased public discourse around neurodevelopmental conditions (Dabrowska, & Pisula, 2010). The relatively earlier age of parental concern in Indonesia and Kenya, despite being lower-income countries, could potentially be explained by cultural factors or the specific sample characteristics in this study.

Beyond the initial recognition of atypical development, significant cross-cultural disparities were observed in the time taken to receive a formal autism diagnosis after initial concerns were raised. In Bangladesh, the average delay between first parental concerns and receiving a diagnosis was just under a year, which was shorter compared to 1.5-1.8 years reported in Indonesia, Kenya, and the UK (except for Greece, which had a remarkably shorter delay of 1.1 years). The relatively shorter diagnostic delay in Bangladesh could be attributed to a combination of factors, including expedited referral pathways for those families who did manage to navigate the healthcare system or potentially reflect the limited availability of comprehensive diagnostic services, leading to quicker (but potentially less rigorous) evaluations (Daulay, 2018).

In contrast, the longer diagnostic odyssey observed in higher-income nations like the UK, despite their well-established healthcare infrastructure, may be partly explained by complex referral pathways, strains on the National Health Service system, and a greater emphasis on comprehensive evaluations involving multiple professionals (Chamak et al., 2011). The remarkably short lag between first concerns and diagnosis in Greece could be facilitated by various factors, including relatively higher societal awareness, mandated developmental screening programs, and better access to evaluation resources through their public healthcare system (Daley, & Sigman, 2002).

The cross-cultural differences in age of first parental concern and diagnostic delays uncovered in this study broadly mirror previous findings from systematic reviews and epidemiological studies across multiple nations (Ehsan et al., 2018). For instance, a systematic review across 13 Asian countries, including Bangladesh, found the median age of autism diagnosis ranged from 38 to 62 months, well beyond the optimal window for early intervention (Fransisca et al., 2017). Delayed diagnosis is particularly concerning given the growing emphasis on early intervention as a crucial determinant of long-term outcomes in autism. Prompt detection and access to appropriate services during the critical early developmental window can help optimise skill acquisition, adaptive functioning, and overall family well-being. Conversely, late diagnosis can deprive children of the benefits of timely intervention, exacerbate associated challenging behaviors, and heighten family stress and burden.

Efforts to enhance autism screening, streamline diagnostic pathways, and reduce stigma through widespread awareness campaigns could help bridge this cross-cultural divide in timely identification. Capacity-building initiatives, such as training frontline healthcare workers in developmental screening and establishing regional diagnostic hubs, could help address resource constraints in lower-income settings (McConkey, 2020). Furthermore, leveraging innovative technological solutions, such as web-based screening tools and tele-medicine consultations, could help overcome geographic barriers and improve access to diagnostic services in remote or underserved areas. Ultimately, timely and accurate diagnosis is the crucial first step in ensuring that individuals on the autism spectrum can access the support and interventions they need to reach their full potential, regardless of their cultural or socioeconomic background (McStay et al., 2014).

7.2 PERCEIVED CAUSATIONS AND MEANING OF ASD

The beliefs held by parents and professionals regarding what causes autism and how they conceptualise this condition appeared to be deeply rooted in cultural and socioeconomic contexts. In the UK and Greece, the majority of participants viewed autism as stemming from genetic or neurobiological factors, aligning with the widely accepted scientific perspectives prevalent in Western societies (Quintero, & McIntyre, 2010). A substantial proportion of responses from these higher-income nations reflected this from a non-medical, neurodiversity viewpoint, implicating the natural variations in the human brain that affect how individuals think, process information and behave. In contrast, medical models for autism featured more prominently among participants from lower-income nations like Bangladesh, Zambia, and Kenya. For instance, while some Bangladeshi and Kenyan parents acknowledged potential genetic links, many also attributed autism to nutritional deficiencies during pregnancy, maternal stress or depression, environmental pollutants or toxins, and even childhood vaccinations (Richdale, & Schreck, 2009).

In Indonesia, several participants expressed uncertainty about the causes, also viewed autism as "God's wish," reflecting a spiritual attribution In contrast, supernatural factors, perceived parental faults, and exposure to various real or mythical environmental agents as purported causes of autism (Vaughn et al., 1996). Such cross-cultural divergence in etiological explanations can be understood through the lens of theoretical models like the Health Belief Model (Chaidez et al., 2018). In socioeconomically disadvantaged communities with limited access to scientific knowledge and quality healthcare, people may develop alternate belief systems around the causation of autism to make sense of their experiences (Samadi, & McConkey, 2011). These explanatory models are often shaped by cultural philosophies, exposure to traditional practices, and personal circumstances – for instance, a mother faced with the bewildering challenges of raising a child with autism may understandably grapple with self-blame tendencies without proper psycho-education.

Etiological beliefs were found to be intricately woven with how a condition like autism is perceived and given meaning within a cultural context. The Western conceptualisation of autism as a neurodivergence was reflected in responses like "different ability" from many UK participants. This viewpoint aligns with the neurodiversity paradigm, which acknowledges the inherent variations in human neuro-cognition and emphasises promoting acceptance, accommodations, and supports tailored to the unique needs of individuals on the autism spectrum (Viljoen et al., 2021). On the other hand, some Bangladeshi parents expressed a more negative connotation toward the term "autism," with a few even stating their dislike for the label itself. Previous studies have documented autism being viewed through the prism of abnormality, divine curses, or even possession across various Asian, African, and Middle Eastern cultures, often emanating from limited awareness and deeply entrenched spiritual attributions (Xu et al., 2019).

These cross-cultural variations in the perceived meaning and societal attitudes toward autism can have profound implications. If autism is predominantly viewed through a supernatural or parental-deficit lens within a community, it may foster shame, secrecy, and avoidance of professional services. The manner in which autism is perceived and understood can profoundly impact the associated stigma, help-seeking behaviors, and acceptance of evidence-based interventions within a community. Therefore, developing tailored approaches that respectfully integrate scientific psychoeducation within relevant cultural narratives could be an important step in dispelling stigma, misinformation, and promoting prompt access to care (Barroso et al., 2018). Conversely, a neurodiversity paradigm rooted in accurate scientific knowledge could promote acceptance, autonomy, and leveraging developmentally appropriate accommodations and supports for individuals with autism and their families (Akter et al., 2020).

Indeed, there are encouraging examples of culturally-attuned intervention models being adapted and implemented successfully across underserved regions. For instance, the Parent-Mediated Intervention for Autism Spectrum Disorders in South Asia (PIASC) is a promising approach that blends evidence-based behavioral strategies with cultural values and belief systems to enhance engagement and outcomes among families (Koly et al., 2021).

Similarly, the Natured Kids conceptual framework, developed in Kenya, emphasises leveraging local metaphors, storytelling, and community-based support networks to promote autism awareness and inclusive practices within existing socio-cultural structures (Benson, 2010). By embracing a culturally sensitive and collaborative approach, researchers and clinicians can work toward bridging the gap between scientific knowledge and local belief systems, ultimately fostering greater acceptance, support, and equitable access to resources for individuals with ASD across diverse global communities (Scott et al., 2000).

7.3 INTERVENTION APPROACHES AND SUPPORT LANDSCAPE

The choice of intervention approaches for individuals with ASD is influenced by multiple factors, including cultural beliefs, availability of resources, and compatibility with local contexts. Applied Behavior Analysis (ABA) interventions and occupational therapy emerged as favoured intervention choices across all countries in this study. The prominence of ABA is understandable given its well-established evidence base, structured pedagogical techniques, and increasing global dissemination, particularly through the efforts of organisations like Autism Speaks and the World Health Organisation's push for scalable interventions (Cloete, & Obaigwa, 2019). At the same time, the notable preference for occupational therapy could stem from efforts to address the pervasive sensory processing difficulties experienced by many individuals with autism, which can significantly impact their daily functioning and participation. However, the degree of implementation of these Western-developed approaches likely varied based on availability, affordability, and cultural compatibility across the diverse settings studied (Dabrowska, & Pisula, 2010). For instance, while ABA has gained traction in higher-income nations like the UK, its accessibility and implementation fidelity may be limited in resource-constrained regions due to a lack of trained professionals, infrastructural barriers, and potential mismatches with local belief systems. Even in the UK, there are widespread misconceptions of ABA being spread by a national UK-based charity, the National Autistic Society (NAS, 2022). On their website, they posted that cruel punishment methods were currently being used in the UK by ABA practitioners. Nearly all of North America has laws to mandate that ABA-based interventions are available through their health care systems. In contrast, across Europe there are no such laws. In fact, the National Institute for Health and Care Excellence (NICE), the body guiding health and social policy in the UK, concluded that it could not find any evidence to support ABA, and therefore could not recommend it. Moreover, emotive terms such as “barbaric, cruel, traumatizing” (NAS, 2022, p. 1) were paired with a description of ABA. implying that such practices significantly contribute to people's opposition to ABA (Keenan et al., 2024).

The utilisation of other intervention modalities displayed some cross-cultural variations. For instance, eclectic or developmental approaches, which integrate elements from various theoretical frameworks, were more frequently cited in Bangladesh and the UK compared to the other nations studied. Also, the government departments across Europe have heavily invested in eclectic, ‘treatment as usual’, or ‘general special education methods’ (Dillenburger, 2011). Biomedical interventions like special diets or supplements garnered relatively little endorsement across countries, potentially due to limited scientific evidence, inaccessibility, and cost barriers, except among a few families with greater resources (Gemegah et al., 2021). Notably, the prominence of traditional, cultural, and spiritual healing practices was not prominently captured in this study, though previous research in regions like South Asia has documented the uptake of modalities like herbal remedies, gemstones, dietary restrictions, and faith-based rituals as complementary or alternative approaches for managing autism. This discrepancy could be attributed to the study's focus on professional perspectives or potential reporting biases among participants (Haque et al., 2022).

Access to comprehensive, evidence-based care for autism can present a significant challenge, especially in resource-constrained nations. While most families in this study reported receiving some support from schools, reliance on government or social services revealed stark cross-cultural disparities. UK participants reported the highest utilisation of governmental support systems, which is expected given the establishment of legal and financial provisions for children with special needs within the National Health Service and educational frameworks (Hossain et al., 2017). In contrast, the lack of structured societal support resonated strongly in Kenya and Bangladesh, with a majority of participants reporting no assistance at all from government agencies.

Interestingly, Indonesian parents uniquely highlighted private specialist services as a key source of support, potentially reflecting this nation's growing private healthcare industry and cultural tendencies toward out-of-pocket expenditures for specialised services. It is increasingly becoming an acceptable way of accessing ABA services, even in higher resourced countries, like the UK and Northern Ireland. Greece occupied a middle ground, with parents highlighting benefits from the public healthcare infrastructure but also reporting challenges in accessing resources, potentially due to system strains or service gaps. These findings are unfortunately unsurprising given the vast infrastructural inequalities that exist across countries for accessible, quality, and affordable services for neurodevelopmental conditions like autism (Makino et al., 2021). The disproportionate burden on families in lower-income nations can exacerbate existing socioeconomic disparities and perpetuate cycles of disadvantage.

The large number of children enrolled in mainstream educational settings in Zambia, Kenya, and the UK represents an encouraging trend of inclusion, aligning with the global push for inclusive education. However, Greek and Bangladeshi families displayed a far greater dependence on specialised educational facilities or institutions for children with autism. While cultural preferences could partially influence these disparities, the availability and quality of appropriate inclusive programs within mainstream settings likely play a significant role (Ncube, 2020). Additionally, parental reports of inadequately trained teachers and inconsistent behaviour management approaches surfaced across nations, underscoring the need for comprehensive capacity-building initiatives within educational systems globally. Equipping educators with evidence-based strategies, fostering positive attitudes, and developing robust support structures are crucial for creating truly inclusive learning environments that meet the diverse needs of students with autism (Obeid, & Daou, 2015).

Overall, the cross-cultural discrepancies in service accessibility and gaps in support structures poignantly highlight the substantial systemic and resource barriers many families face when seeking appropriate care for their children with autism, especially in socioeconomically disadvantaged regions. These disparities not only impede timely access to interventions but can also exacerbate family stress, perpetuate stigma, and limit the potential outcomes for individuals with autism. Promoting collaborative, multi-sector initiatives involving policymakers, care providers, community stakeholders, and cultural liaisons could help mitigate these disparities (Osborne, & Reed, 2010). Such initiatives could focus on evidence-based resource allocation, context-sensitive service adaptation while preserving fidelity, and infrastructure development informed by the needs and realities of diverse settings.

Furthermore, leveraging innovative service delivery models, such as task-sharing, tele-health, and community-based participatory approaches, could help overcome geographical barriers and promote sustainable capacity building. For instance, the Parent-Mediated Intervention for Autism Spectrum Disorders in South Asia (PIASC) has demonstrated promising outcomes by training non-specialist facilitators to coach parents in evidence-based strategies while respecting local cultural contexts (Postorino et al., 2019). Ultimately, addressing the stark disparities in intervention access and support requires a multi-pronged approach that combines policy reforms, resource mobilisation, capacity building, and cultural attunement. By embracing a collaborative, equity-focused lens, stakeholders can work towards ensuring that individuals with autism and their families, regardless of their socioeconomic or cultural backgrounds, can access the care and support they need to thrive (Reed, 2020).

7.4 CHALLENGING BEHAVIOURS AND CONTRIBUTING FACTORS

Individuals with autism spectrum disorder (ASD) often exhibit a range of challenging behaviours that can significantly impact their daily functioning, social participation, and overall quality of life. Self-injurious behaviours, such as head-banging, skin-picking, or self-hitting, emerged as a prominent concern voiced by parents and professionals across all countries in this study. Physical aggression towards others, which can manifest as hitting, kicking, biting, or property destruction, was another frequently cited challenging behaviour (Tomanik et al., 2004). Additionally, repetitive or ritualistic tendencies, often referred to as stereotypies or restricted interests, were commonly reported as disruptive patterns exhibited by individuals with autism. These findings align well with existing literature documenting elevated rates of self-injury, aggression, stereotypies, and other disruptive behaviours among individuals with autism across cultures. While there were some variations in the specific prevalence and breakdown of these topographies across countries, the broad pattern underscores the global pervasiveness of such challenges in ASD (Veroni, 2019).

Deficits in communication and diminished understanding of socially appropriate conduct were frequently cited by participants across countries as prime reasons underlying challenging behaviours among people with autism. Communication impairments are recognised as a core feature of autism, and the inability to effectively express needs, emotions, and desires through conventional means may manifest through dysfunctional behaviours serving as an alternative mode of communication or a means of attaining desired outcomes (Salari et al., 2022). Similarly, the social cognitive deficits characteristic of autism, including difficulties with perspective-taking, understanding social norms, and interpreting contextual cues, could predispose individuals to engage in behaviours considered inappropriate or disruptive by societal standards. These proposed mechanisms resonate with well-established theoretical frameworks, such as the frustration-aggression hypothesis and the social skills deficit model, which have been extensively studied and applied in the context of autism spectrum across diverse populations (Preity et al., 2017).

While these core mechanisms were universally highlighted, some notable cross-cultural differences emerged when examining supplementary explanatory factors for challenging behaviours. Parents in lower-income nations like Bangladesh tended to emphasise insufficient engagement and lack of reciprocity in the child's environmental milieu as contributors to adverse behaviours. This perspective could be shaped by cultural views surrounding child-rearing practices, socioeconomic constraints limiting enrichment opportunities, and inadequate dissemination of scientific behavioural principles within these communities (Matson et al., 2017). Interestingly, a few Indonesian participants alluded to "gut problems" as a potential reason for challenging behaviours, reflecting alternative etiological belief systems that have been gaining attention in some circles, such as the controversial hypotheses linking gut micro biome disruptions to autism symptomatology. While the scientific evidence remains inconclusive, such beliefs highlight the need to respectfully acknowledge and integrate culturally-embedded narratives when tailoring intervention approaches (Holingue et al., 2018).

Lack of consistent behavioural supports from extended family networks also surfaced as an issue among some Bangladeshi respondents, which could stem from cultural conventions surrounding child-rearing responsibilities and persisting stigmatisation surrounding developmental disabilities within this region. These findings underscore the importance of considering the broader socio-cultural milieu when examining the etiology and maintenance of challenging behaviours in ASD (Ennis-Cole et al., 2013).

Examining the strategies used to manage challenging behaviours also revealed a mix of cross-cultural similarities and differences. Verbal reprimands, delivery of reinforcers for shaping adaptive behaviors, and withholding attention contingent on behavioural incidents were among the more common strategies endorsed across countries. These approaches share conceptual parallels with principles of Applied Behaviour Analysis (ABA), which has gained traction as an evidence-based intervention for addressing core deficits in autism worldwide (Dyches et al., 2004). However, UK participants uniquely highlighted redirection and distraction-based techniques, potentially reflecting greater access to professional behaviour therapy services and dissemination of contemporary strategies within this higher-income nation. In contrast, several Indonesian parents reported using physical interventions like restraint or containment – an ethically concerning practice that may be linked to a lack of exposure to modern, humane behaviour management strategies in these settings (Ehsan et al., 2018). While not extensively probed in this study, the incidence of certain cultural rituals, faith-based healing practices, and antiquated belief systems informing behaviour management approaches cannot be ruled out in certain regions, as documented previously in various ethnographic and qualitative investigations across Asia, Africa, and other developing contexts.

Collectively, these findings underscore the need for holistic, culturally-sensitive initiatives that not only disseminate evidence-based behavioural strategies for addressing the core deficits in autism but also acknowledge the experiential realities and entrenched philosophies that may be shaping maladaptive behaviours and responses across diverse communities. Evidence based behavioural interventions need to acknowledge cultural diversity while conducting assessment, planning and implementing individualised behaviour strategies. Stakeholder involvement, provider training, and thoughtful cross-integration of compatible traditional wisdom into modern care models could potentially enhance receptivity, fidelity, and sustainable adoption of effective practices worldwide (Dabrowska, & Pisula, 2010). For instance, the Parent-Mediated Intervention for Autism Spectrum Disorders in South Asia (PIASC) has demonstrated promising outcomes by blending evidence-based behavioural strategies with culturally-resonant metaphors, storytelling, and collaborative problem-solving approaches. Furthermore, leveraging community-based participatory research frameworks and engaging local leaders, healers, and caregivers as active partners can facilitate the co-creation of culturally-attuned interventions that harmonise modern scientific knowledge with deep-rooted belief systems and practices (Baranek, 2002). Ultimately, addressing the complex interplay of challenging behaviours, cultural narratives, and evidence-based practice in autism requires a concerted, multi-stakeholder effort grounded in mutual respect, ethical practice, and a genuine commitment to promoting equitable access to effective support for individuals and families affected by autism across the globe (Allen et al., 2007).

7.5 PARENTING STRESS, COPING, AND FAMILY IMPACT

The findings of this study highlight the significant psychological burden and challenges faced by parents raising children with autism across diverse cultural contexts.

Consistent with existing literature, the degree of parenting stress experienced emerged as a product of the child's autism severity and the extent of externalising behaviour problems. Higher endorsements of sensory issues, socialisation difficulties, repetitive behaviours, and disruptive conduct patterns all contributed to elevated stress levels among caregivers (Freeth et al., 2013). This overarching pattern resonates with previous findings documenting the formidable psychological burden and quality of life challenges faced by parents raising children with autism globally. However, a more nuanced examination revealed some cross-cultural variations in how specific autism manifestations mapped onto different parenting stress domains. For instance, pessimistic views and low confidence in managing behaviours were more pronounced among Bangladeshi parents (Kieling et al., 2011). This could be attributed to various factors, such as cultural belief systems, caregiving philosophies, and a lack of access to educational resources and support infrastructures. In contrast, stress linked to limitations in their child's autonomy emerged as a specific flashpoint for UK participants, potentially reflecting different caregiving priorities or expectations (Lloyd et al., 2013).

Notably, parents in lower-income nations like Bangladesh and Kenya displayed stronger correlations between autism severity indicators and heightened stress across multiple domains compared to their counterparts in higher-income countries like the UK. Socioeconomic disadvantages, lack of educational resources, and inadequate systemic provisions may exacerbate the strain experienced by families navigating autism-related challenges without structured formal supports (McStay et al., 2014). In contrast, the absence of a relationship between autism severity and parenting stress in the UK potentially suggests a buffering influence of existing family empowerment services, respite care provisions, and psycho-educational resources that may assist families in coping more adaptively.

Cross-cultural disparities were also observed regarding the specific coping strategies leveraged by families. Bangladesh and Kenya reported higher utilisation of faith, spirituality, and integrating autism care into broader family routines. These coping mechanisms align with cultural philosophies and belief systems that emphasise the role of spirituality and family cohesion in dealing with adversity. In contrast, UK parents endorsed more cognitive reframing and external support systems, mirroring the overall diminished reliance on spiritual explanations and greater established infrastructure for mobilising professional and governmental assistance in the caregiving process (Quintero, & McIntyre, 2010). Contrasting cultural philosophies, institutional trust, and monetary constraints may account for these differences in coping responses when confronted with the immense challenges of raising a child with autism.

Importantly, irrespective of coping approaches, higher utilisation of spiritual, family integration, and reframing-based strategies was associated with lower reported parenting stress across cultures, underscoring their potentially universal buffering influence. Indeed, previous literature has highlighted the constructive role of positive religious/spiritual coping, harnessing family strengths, and adaptive cognitive reappraisals in mitigating caregiver burden for various disabilities (Rahman et al., 2019). These coping strategies may provide parents with a sense of meaning, emotional support, and a more positive outlook, which can help alleviate the stress associated with caring for a child with autism.

These findings carry significant clinical implications surrounding the need for comprehensive, culturally-tailored psycho-education and family empowerment programs to equip caregivers with a diverse toolkit of coping mechanisms while providing tangible skill-building and respite resources. Since the evidence based intervention, such as ABA, focus on identifying target behaviour based on individual needs, the science itself will not change, but the cultural diversity issues will need to be considered to make the intervention successful. Interventions that incorporate spiritual and family-based components, as well as cognitive-behavioural techniques for reframing and stress management, may be particularly beneficial for parents across diverse cultural backgrounds. However, it is crucial that such interventions remain sensitive to the unique ecological barriers, philosophical belief systems, and intersectional stressors that may be operative across diverse communities dealing with autism (Riany et al., 2016). For instance, programs designed for families in lower-income nations should consider the socioeconomic challenges, lack of educational resources, and limited access to formal support systems that may exacerbate caregiver strain.

Simultaneously, concerted efforts must be directed at addressing the core systemic inequalities that contribute to resource deprivation and lack of adequate support infrastructures – factors that appeared to disproportionately amplify caregiver strain in many lower-income nations examined here. Sustainable investment in evidence-based services, capacity-building initiatives, and multi-sectorial policy reforms could provide a much-needed foundation for promoting family resilience and quality of life globally (Benson, 2010). Moreover, it is essential to recognise the diverse cultural perspectives and belief systems that shape families' experiences and coping mechanisms. Interventions that acknowledge and incorporate these cultural nuances, rather than imposing a one-size-fits-all approach, are more likely to resonate with families and promote sustainable engagement and positive outcomes.

In addition to addressing the psychological and emotional needs of caregivers, it is crucial to consider the broader family impact of raising a child with autism. The findings suggest that caregiving responsibilities can lead to career disruptions, social isolation, and strained relationships within the family and broader community. Providing respite care, facilitating peer support networks, and fostering inclusive community attitudes could alleviate some of these burdens and promote better quality of life for families (Dardas, & Ahmad, 2015). Overall, the study underscores the importance of a holistic, culturally-sensitive approach to supporting families raising children with autism. By addressing the complex interplay of psychological, socioeconomic, and systemic factors, and leveraging culturally-relevant coping strategies, policymakers, healthcare professionals, and community organisations can collaborate to create a more supportive and empowering environment for these families, ultimately promoting better outcomes for both caregivers and individuals with autism (Eisenhower et al., 2015).

7.6 FUTURE OUTLOOK AND LONG-TERM CONSIDERATIONS

The study's findings shed light on the diverse perspectives and expectations held by parents regarding the long-term outlook and future considerations for their children with autism across different cultural contexts. While enhanced communication skills and overall functional development emerged as common aspirations, nuanced cultural differences surfaced regarding expectations of independence and long-term care provisions (Goodman, 2001). Independent living featured more prominently in the long-term visions expressed by parents from higher-income nations like the UK. This outlook may be influenced by the availability of vocational training opportunities, supported employment programs, and residential support systems that facilitate greater independence for individuals with disabilities in these countries. In contrast, a substantial proportion of parents from

Bangladesh voiced apprehensions about future self-sufficiency, anticipating that supported living arrangements or institutionalised care may be more realistic longer-term prospects (Hayes, & Watson, 2013). This perspective is potentially shaped by socioeconomic disadvantages, lack of vocational training opportunities, and limited residential support systems in resource-constrained settings.

These discrepant outlooks towards independence likely reflect the vast infrastructural and systemic gaps in disability-related policies, transition services, and community-based rehabilitation programs that exist across different parts of the world. The development of comprehensive, context-sensitive transition models that prioritise functional skill development, supported employment opportunities, residential assistance, and promotion of self-advocacy within high-need communities could play a pivotal role in reshaping optimistic long-term visions globally (Lecavalier et al., 2006). Moreover, questions surrounding guardianship and custodial responsibilities for individuals with autism after parental mortality emerged as a major source of uncertainty and anxiety across cultures, albeit with some variations in inclinations. Bangladesh parents displayed relatively higher reliance on spiritual philosophies, leading some to express beliefs about divine intervention serving as a caregiving source – a position likely rooted in cultural and religious value systems within this region. UK respondents voiced stronger expectations of caregiving transitioning to governmental agencies or social services, reflecting the availability of such support systems in higher-income countries (Mannan, 2017). In contrast, family-based succession of custodial duties featured as a more common theme across Indonesia, potentially reflecting traditional collectivistic value systems surrounding kinship caregiving in these communities.

These cross-cultural disparities surrounding long-term care and guardianship underscore the complex interplay of systemic, community, and belief-based factors that may influence the futures envisioned by families dealing with autism internationally. Developing cultures of empowerment, self-determination, and human rights for individuals with disabilities could help reshape societal narratives away from perspectives of dependency and burden (Masaba et al., 2021). Concurrently, capacity-building initiatives focused on equipping families with skills surrounding future planning, financial management, and legal provisions are essential to cultivate a confident long-term outlook. At a broader level, sustainable governmental policies and legislative reforms promoting community inclusion, equal opportunity, and accessible long-term care options are vital to ensuring individuals with autism can experience self-actualised and dignified futures regardless of cultural context (Ntre et al., 2022). Financial assistance schemes, incentivised community-based service provider networks, public-private partnerships, and caregiver support cooperatives could represent important policy directions to meet the long-term needs of these marginalised populations worldwide.

Additionally, the uncertainty expressed by many participants points to the need for comprehensive, culturally-sensitive family psycho education surrounding autism-specific considerations pertaining to areas like guardianship, estate planning, and exploring residential pathways. Integration of such elements within holistic family empowerment curricula could help mitigate anxieties and equip caregivers with crucial knowledge for future preparation (Pottie, & Ingram, 2008). Importantly, all efforts towards reshaping long-term visions and fortifying support systems must remain rooted in the core principles of autonomy, community integration, and upholding human rights. Participatory approaches that amplify the voices of individuals with autism themselves in directing service prioritisation and policy advocacy could forge a transformative path towards equitable, self-determined futures across cultures (Rahaman et al., 2021). To address the diverse long-term considerations and future outlooks for individuals with autism, a multi-faceted and comprehensive approach is necessary. This approach should encompass the following key elements:

Development of context-sensitive transition models: These models should focus on functional skill development, vocational training, supported employment opportunities, residential assistance, and promotion of self-advocacy within communities. By tailoring these models to the specific cultural and socioeconomic contexts, they can better address the unique needs and challenges faced by individuals with autism and their families in different regions (Vernhet et al., 2019).

Capacity-building initiatives for families: Equipping families with skills in areas such as future planning, financial management, legal provisions, and navigating guardianship options is crucial. These initiatives should be culturally sensitive and aim to empower families to make informed decisions and develop a confident long-term outlook for their loved ones with autism.

Sustainable governmental policies and legislative reforms: Promoting community inclusion, equal opportunity, and accessible long-term care options through policies and legislative reforms is vital for ensuring individuals with autism can experience self-actualised and dignified futures. This may include financial assistance schemes, incentivised community-based service provider networks, public-private partnerships, and caregiver support cooperatives (Washington-Nortey, & Serpell, 2021).

Comprehensive and culturally-sensitive family psycho education: Providing families with psycho education on autism-specific considerations, such as guardianship, estate planning, and residential pathways, can help mitigate anxieties and equip caregivers with crucial knowledge for future preparation. These educational programs should be tailored to the cultural beliefs and values of different communities.

Participatory approaches and amplifying voices: Ensuring that the voices and perspectives of individuals with autism themselves are amplified and incorporated in directing service prioritisation and policy advocacy is essential. Participatory approaches that involve individuals with autism and their families can help shape more inclusive and equitable long-term support systems.

Promoting autonomy, community integration, and human rights: All efforts towards reshaping long-term visions and fortifying support systems must be rooted in the core principles of autonomy, community integration, and upholding human rights for individuals with autism. This includes challenging societal narratives of dependency and burden, and fostering an environment that celebrates diversity and empowers individuals with disabilities (Fransisca et al., 2017). By addressing the diverse long-term considerations and future outlooks through a multi-pronged approach that involves policymakers, healthcare professionals, community organisations, and individuals with autism themselves, it is possible to create a more inclusive and supportive environment that promotes self-determination, dignity, and quality of life for individuals with autism across different cultural contexts (Emerson et al., 2007).

7.7 STUDY LIMITATIONS AND FUTURE DIRECTIONS

While the present study offers a rare glimpse into the cross-cultural similarities and differences surrounding autism across diverse global contexts, some key limitations must be acknowledged. The qualitative exploratory nature of this investigation, coupled with the relatively small sample sizes from each participating country, precludes any definitive conclusions or generalisability of the findings. Additionally, the recruitment strategies employed may have introduced sampling biases, wherein participants self-selected based on existing affiliations with professional networks, autism support organisations, or personal motivations – potentially under-representing more marginalised families disconnected from such systems (Durkin et al., 2015). Future large-scale, epidemiological investigations are needed to quantify the precise prevalence and socio-demographic distributions of autism and capture more representative portraits across diverse cultures and resource settings. Such studies could incorporate advanced methodologies like random cluster sampling and community-based participatory frameworks to enhance ecological validity.

The cross-sectional design of this study presents another limitation, providing only a snapshot of the ASD experience at a single time point. Given the dynamic, evolving nature of this condition across the lifespan, longitudinal explorations tracking developmental trajectories, shifting needs, and family impact over extended periods would generate richer insights into the lived experiences encapsulated herein. Prospective cohort designs examining diverse international samples could shed light on critical junctures like early childhood, adolescent transitions, and post-parental planning phases – offering a developmental lens into the cross-cultural nuances unearthed through the present inquiry

(Chiarotti, & Venerosi, 2020). From a conceptual standpoint, the inherent subjectivity and potential influences of English language proficiency on qualitative participant responses across cultures represent methodological considerations. While efforts were undertaken to ensure semantic equivalence of terms and concepts, variations in linguistic and conceptual framing of psychological constructs cannot be discounted entirely. The incorporation of advanced techniques like translation/back-translation protocols, cultural consultants, and mixed qualitative-quantitative hybrid methodologies could enhance the robustness and cultural validity of future cross-national studies (Boehm et al., 2015). Additionally, as the researcher was the only person interviewing participants and also analysing contents, it was not possible to validate the results through the interobserver agreements.

Further, the present investigation predominantly captured parental and provider perspectives, but lacked direct insights from the individuals with autism themselves - an important dimension that could shed invaluable experiential light on topics like intervention preferences, coping strategies, and future outlooks. As a key tenet of the neurodiversity movement, prioritising first-person accounts of autistic individuals in research endeavors must become a focal priority moving forward. Participatory and emancipatory paradigms, rooted in philosophies of nothing about us without us, could help elevate the narratives of this stakeholder community, who have historically been systemically excluded from many decision-making arenas (Chiarotti & Venerosi, 2020). Lastly, while the current study captured a geographically and economically diverse swathe of countries, its scope was still restricted to the included regions. Expanding such cross-cultural investigations to encompass other under-represented territories in the Asia Pacific, Eastern Europe, Caribbean, Middle East, and indigenous communities worldwide would generate a truly panoramic understanding of the global landscape surrounding autism. Collaborative multinational research networks and community engagement initiatives could facilitate recruitment of participants across these multifarious settings (Ballaban-Gil & Tuchman, 2000).

Despite these limitations, the present work provides an important cross-cultural foundation that future studies could build upon. Potential future directions could examine specific areas of need identified herein through a more granular, mixed-methods lens – for instance, in-depth explorations of transition service gaps, community-based rehabilitation models, and spirituality-integrated autism support paradigms across diverse settings

(Adioetomo et al., 2014). Ultimately, bidirectional translation between global research and culturally-responsive action must become the driving force in catalyzing real-world change, empowering marginalised communities, and realising a truly inclusive, equitable vision worldwide for individuals with autism.

7.8 CONCLUSION

Within cross-cultural psychology, this research greatly expanded conceptual perspectives on autism and neurodevelopment. The majority of extant psychological theory on autism derives from Western settings, potentially limiting validity in non-Western contexts. For instance, foundational notions of "theory of mind" deficits in autism originated from studying mostly Caucasian, middle-class children in the United States (Oberman & Kaufmann, 2020). However, social interaction expectations vary substantially across cultural settings based on norms, communication styles, and collective versus individualistic orientations. Thus behavioural indications of challenges in social-emotional reciprocity and inference may manifest differently across cultures.

By illuminating insider perspectives on social-communication development within diverse communities, this research uncovered alternative cultural models of autism and benchmarks of development. The patterns emerged in this study suggesting currently defined characteristics of autism carry reduced salience in certain cultural settings, this prompts re-evaluation of dominant paradigms. Understanding variation in features and interpretation of autism internationally is critical for advancing diagnostic equity and tailoring supports globally (Botha & Gillespie-Lynch, 2022). Also, this research greatly expanded the scant literature concerning sociocultural constructions of autism and neurodiversity. Most medical anthropological scholarship on autism to date focuses narrowly on parental explanatory models, cultural stigma, and service access, without conveying broader societal integration or insider perspectives of affected individuals (Waubant et al., 2019).

The field lacks ethnographic studies examining cultural roles, strengths, and lived realities associated with autism outside Western society. This research intended to help fill this void through immersive qualitative and quantitative approaches illuminating conceptualisations, values, and disability experiences related to autism within diverse global communities. For sociology of neurodiversity, the insider cultural perspectives promises to diversify notions of normality and critically examine boundaries society draws around acceptable neurological functioning. Capturing diverse framings of autism can inform more inclusive paradigms that privilege functionality over normativity (Lakkis et al., 2023). Finally, within disability studies, this research aimed to advance conceptual models of disability as a complex phenomenon shaped by reciprocal interactions between health conditions and environmental contexts across settings. Findings highlight sociocultural variables mediating disability experiences related to autism worldwide, challenging purely biomedical paradigms (Gianola & Losin, 2021). Centering insider standpoints aligns with mandates to make research participatory, accessible, and empowering.

APPENDICES

Appendix 1

Participant's Information Sheet

EXPLORING THE CULTURAL PERCEPTIONS OF AUTISM SPECTRUM DISORDERS (ASD)

A Qualitative Study of Professionals', and Parents' of People Diagnosed with Autism Spectrum Disorder

The study you are being invited to participate in aims to explore your experience associated with diagnostic process of Autism Spectrum Disorder and your understandings of the terms 'challenging behaviour' and their management and the barriers that you face bringing up or working with a child with ASD. This is important as parents, and professionals play a vital role in managing challenging behaviour and teaching appropriate behaviour, and ultimately these changes can make significant differences to the quality of lives of people affected with Autism Spectrum Disorder.

Who is Running this Research?

The study is being conducted by Kaneez Mustary, under the supervision of Prof. Phil Reed in the Department of Psychology at Swansea University. The research has been approved by the departmental Research Ethics Committee.

Your Participation

You do not have to proceed with the interview if you do not wish to, and you do not have to justify why you don't want to continue to the researcher. At any point during the interview, you may withdraw from the study without penalty. If you do not wish to answer certain questions but carry on with the study, you may do so.

What Happens if I Participate?

You will be asked a series of questions concerning the ASD diagnosis, your understanding regarding challenging behaviour associated with ASD and their management options. You will also be asked your opinion on these therapies and interventions, and whether you think they are beneficial in any way. Your experience on any restriction placed on your family life or an individual due to a child with autism, will also be recorded. Your views and long-term expectations will also be considered. The interview will be recorded. If you have any questions, feel free to ask at any point before, during, or after the interview.

Possible Risks

As you are being asked about the ASD diagnosis, challenging behaviour and long-term expectations, there may be some discomfort in answering the questions. It is entirely up to you what information you choose to divulge if any.

Confidentiality

Your personal details will not be recorded, and the audio of the interview will not be heard by anyone other than the researcher.

Contacts

You can contact the researcher, Kaneez Mustary by emailing at: [redacted]

Appendix 2

Participant’s Information Sheet

EXPLORING THE CULTURAL PERCEPTIONS OF AUTISM SPECTRUM DISORDERS (ASD)

A Quantitative Study of Parents’ of People Diagnosed with Autism Spectrum Disorder

The study you are being invited to participate in aims to explore your experience associated with diagnostic process of Autism Spectrum Disorder, your perceptions of school provision, parenting stress, the adoption of coping styles, and the impact of coping style on parenting stress.

Who is Running this Research?

The study is being conducted by Kaneez Mustary, under the supervision of Prof. Phil Reed in the Department of Psychology at Swansea University. The research has been approved by the departmental Research Ethics Committee.

Your Participation

You do not have to proceed with the online survey if you do not wish to, and you do not have to justify why you don’t want to continue to the researcher. At any point during the online survey process, you may withdraw from the study without penalty. If you do not wish to answer certain questions but carry on with the study, you may do so.

What Happens if I Participate?

You will be asked a series of questions concerning the ASD diagnosis, your perceptions of school provision, parenting stress, the adoption of coping styles, and the impact of coping style on parenting stress. If you have any questions, feel free to ask at any point before, during, or after the interview.

Possible Risks

As you are being asked about the ASD diagnosis, school provisions and parenting stress, there may be some discomfort in answering the questions. It is entirely up to you what information you choose to divulge if any.

Confidentiality

Your personal details will not be recorded, and the survey result will not be seen by anyone other than the researcher.

Contacts

You can contact the researcher by emailing at: [redacted]

Appendix 3

Consent Form

Title of Research:

EXPLORING THE CULTURAL PERCEPTIONS OF AUTISM SPECTRUM DISORDERS (ASD)

Contact details of the researcher: [redacted]

1	I have read the Participant Information Sheet which is attached to this form.	Yes	No
2	I agree to take part in the study.	Yes	No
3	I understand that participation is voluntary and also that I am free to withdraw from the research, for any reason and without prejudice.	Yes	No
4	I understand what my role will be in this research, and all my questions have been answered to my satisfaction.	Yes	No
5	I understand that I am free to ask any questions at any time before and during the study.	Yes	No
6	I have been informed that the information I provide will be safeguarded.	Yes	No
7	I am happy for the information I provide to be used (pseudonymously) in academic papers and other formal research outputs.	Yes	No
9	I agree to the researchers processing my personal data in accordance with the aims of the study described in the participant information sheet.	Yes	No
10	I declare that I am 18 years or older.	Yes	No

Thank you for your participation of this study.

Name...

Signature.......................................

Date...

(Note: under Name, participants will be asked to put their initials only).

Appendix 4

Ethical Approval Letter

10 December 2019

Dear KANEEZ MUSTARY, , , PHIL Reed, Dr IRENE Reppa,

Re: 1552 , Parents’, Professionals’, and Special Educators’ understandings of challenging behaviours associated with Autism Spectrum Disorders, and the impact of training in managing these behaviours

Your application - https://swansea.forms.ethicalreviewmanager.com/ProjectView/Index/1552 - has been reviewed and approved by the Department of Psychology Ethics Committee.

The list of additional students (if any) are included in the table below:

Other student applicant - first name Other student applicant - Surname Other student applicant - email

additional researcher or student - first name additional researcher or student - surname additional researcher or student - email

The conditions of this approval are as follows:

1. To conduct your study strictly in accordance with the proposal that has been approved by the committee, including any approved amendments
2. To advise the ethics committee chair of any complaints or other issues that may warrant ethical review of the project
3. To submit for approval any changes to the approved protocol before implementing any such changes
4. To keep any information obtained from your participants absolutely confidential

Please note that failure to comply with these conditions of approval may result in the withdrawal of approval for the project.

To advertise your study on the departmental Participant Pool: You will need to send send a request for your study to be made visible, via the link on the Experiment Management System website (see Researcher Documentation for details). Please ensure that you attach this letter to your request. (If you are unable to attach the Ethics approval, send it in a separate email to Dr. Phil Tucker [redacted].

For students: Please ensure that the signed copy of this Ethical Approval, together with any other paperwork associated with your research, is included in your final write up.

Yours Sincerely,

Dr GABRIELA JIGA-BOY (Reviewer of Application)

Dr Gabriela Jiga-Boy (Committee Chair)

Appendix 5

RECRUITMENT EMAIL

Dear Parents and Colleagues,

My name is Kaneez Mustary and I am a doctoral student in Department of Psychology, College of Human and Health Sciences at Swansea University. As part of my dissertation research, I am conducting an interview to learn about your experience related to autism diagnosis and your understandings of the terms ‘challenging behaviour’. I would also like to explore your opinions of managing challenging behaviours of people with Autism Spectrum Disorder, and whether the training in Positive Behaviour Support has any impact on the management of challenging behaviour and quality of lives of those affected and their families. The results of the interview will be used to develop understanding of gaps in perception, care and wellbeing of individuals including parents and professionals across different cultures and countries.

Your participation in this study will take approximately 20 minutes. Your personal detail will not be recorded.

I am attaching the participant information sheet and a consent form for your consideration. If you wish to take part, please contact myself at [redacted] or my Supervisor, Professor Phil Reed, Department of Psychology, College of Human and Health Sciences, by emailing at [redacted] Alternatively, please fill in the consent form and send it back by post or email.

This research has been approved by the Research Ethics Committee, College of Human and Health Sciences, Swansea University.

Thank you for your consideration,

Kaneez Mustary, M.A.(Autism), BCBA
Doctoral Student in Department of Psychology
College of Human and Health Sciences,
Swansea University,
SA2 8PP

Appendix 6

DEBRIEF FORM

EXPLORING THE CULTURAL PERCEPTIONS OF AUTISM SPECTRUM DISORDERS (ASD)

Thank you for taking part in our research. Now that your contribution has finished, let me explain the rationale behind this work.

We are interested in exploring parents', professionals', and special educators' understandings of the terms 'challenging behaviour', and their opinions of managing challenging behaviours of people with Autism Spectrum Disorder. We will also be exploring the restrictions faced by parents and professionals dealing with an individual with ASD and their experiences during pre-diagnosis and diagnostic processes of Autism Spectrum Disorder.

Previous research has shown that as parents, professionals and special educators play a vital role in managing challenging behaviour and ultimately these changes can make significant differences to the quality of lives of people affected with Autism Spectrum Disorder. In this research, I am looking at a series of concerns regarding ASD diagnosis, your understanding of challenging behaviours, your opinions of the therapies/interventions and your expectations for the future.

Your information will be analysed and will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related media. Note that all information presented in any reports or publications will be anonymous and unidentifiable. Your personal details have not been recorded, and the audio recording of the interview will not be heard by anyone other than the researcher. Data will be preserved and accessible for a minimum of 10 years after completion of the research.

If you feel affected by issues raised by this research and would like to discuss any concerns, please contact the study Supervisor on the details provided below. If you feel this piece of research may have health implications for you, we advise you to contact your GP (family doctor). Other sources of support may be found at: National Autistic Society, E-mail: nas@nas.org.uk, website: www.nas.org.uk

Principal Researcher: KANEEZ MUSTARY

Department of Psychology
College of Human and Health Sciences
Swansea University
E-[redacted]

Supervisor: PROFESSOR PHIL REED
Department of Psychology
College of Human and Health Sciences
Swansea University

Appendix 7

Questionnaire for professionals working with people diagnosed with Autism Spectrum Disorder:

1. Tell me what ‘autism’ means to you.
2. In your opinion, what causes autism?
3. What behaviours are key in diagnosis?
4. How do challenging behaviours develop?
5. Tell me about the behaviours you are concerned about.
6. Why do you think the people with autism behave the way they do?
7. From your experience, tell me what interventions actually work or should be tried.
8. Comments/concerns from family members, and/or members of the public, made regarding the behaviours of an individual with ASD, that are concerning.
9. What future expectations do you have for this person with autism?
10. Who should take primary responsibility for the wellbeing of this person long term?

Appendix 8

Questionnaire for parents with people diagnosed with Autism Spectrum Disorder:

1. Can you please share your experience of the pre-diagnosis stage of autism spectrum disorder? For example, what signs do you notice among children before their diagnosis of autism spectrum disorder?
2. Tell me about the diagnostic process of ASD. For example, how long does it take to get an appointment, diagnosis, etc.
3. Tell me what ‘autism’ means to you.
4. In your opinion, what causes autism spectrum disorder?
5. Why do you think the people with autism behave the way they do?
6. Tell me about the behaviours you are concerned about.
7. How do you respond when you see an autistic person displaying inappropriate behaviours?
8. From your experience, tell me what interventions actually work or should be tried.
9. Tell me about any comments/concerns from family members, and/or members of the public, made regarding the behaviours of an autistic individual in the community, that you felt bad about.
10. What future expectations do you have for this person with autism?
11. Who should take primary responsibility for the wellbeing of this person when you are no longer around?

Appendix 9

Questionnaire for professionals working with people diagnosed with Autism Spectrum Disorder in Bangla (For Bangladeshi participants):

অটিজম স্পেকট্রাম ডিসঅর্ডারযুক্ত লোকদের সাথে কাজ করা বিশেষজ্ঞদের জন্য প্রশ্ন:

1. আপনার কাছে ‘অটিজম বলতে কী বোঝায় তা বলুন।
2. আপনার মতে অটিজমের কারণ কী?
3. অটিজম বর্ণালী ডিসঅর্ডার সনাক্তকরণের আগে আপনার শিশু / শিক্ষার্থীর লক্ষণগুলি বর্ণনা করুন।
4. আপনার মতে, কিভাবে অটিস্টিক ব্যক্তি ঐ আচরণে গড়ে তুলেছিলেন?
5. আপনি যে আচরণগুলি সম্পর্কে উদ্বিগ্ন তা সম্পর্কে বলুন।
6. অটিজমযুক্ত লোকেরা কেন এই জাতীয় আচরণ করে?
7. আপনার অভিজ্ঞতা থেকে, আমাকে বলুন যে কোন চিকিত্সা / থেরাপিগুলি আসলে কাজ করে বা চেষ্টা করা উচিত।
8. .সম্প্রদায়ের কোনও অটিস্টিক ব্যক্তির আচরণ সম্পর্কে আপনার পরিবারের সদস্য এবং / অথবা জনসাধারণের সদস্যদের কাছ্ থেকে নেওয়া কোনও মন্তব্য / উদ্বেগ সম্পর্কে আমাকে বলুন, যা সম্পর্কে আপনি সত্যই খারাপ অনুভব করেছেন।
9. অটিজম আক্রান্ত ব্যক্তির কাছে আপনার ভবিষ্যতের কোন প্রত্যাশা রয়েছে?
10. এই ব্যক্তির সুস্থতার জন্য প্রাথমিক দায়িত্ব কার নেওয়া উচিত?

Appendix 10

Questionnaire for parents with people diagnosed with Autism Spectrum Disorder in Bangla (For Bangladeshi participants):

অটিস্টিক লোকের পিতামাতাদের জন্য প্রশ্ন:

1. অটিজম বর্ণালী ডিসঅর্ডার সনাক্তকরণের আগে আপনার শিশু / শিক্ষার্থীর লক্ষণগুলি বর্ণনা করুন। উদাহরণস্বরূপ, আপনি প্রথমে কোনটি লক্ষ্য করেছেন, আপনি এটি কার সাথে আলোচনা করেছেন ইত্যাদি?
2. এএসডি-এর ডায়াগনস্টিক প্রক্রিয়া সম্পর্কে বলুন। উদাহরণস্বরূপ, অ্যাপয়েন্টমেন্ট, রোগ নির্ণয় ইত্যাদি নিশ্চিত করতে কোন সময় নিয়েছিল এবং সেই সময়কালে আপনার অভিজ্ঞতা কী ছিল?
3. আপনার কাছে ‘অটিজম বলতে কী বোঝায় তা বলুন।
4. আপনার মতে অটিজমের কারণ কী?
5. অটিজমযুক্ত লোকেরা কেন এই জাতীয় আচরণ করে?
6. আপনি যে আচরণগুলি সম্পর্কে উদ্বিগ্ন তা সম্পর্কে বলুন।
7. আপনি যখন অটিস্টিক ব্যক্তিকে অনুপযুক্ত আচরণে জড়িত দেখেন তখন আপনি কীভাবে প্রতিক্রিয়া জানান?
8. আপনার অভিজ্ঞতা থেকে, আমাকে বলুন যে কোন চিকিত্সা / থেরাপিগুলি আসলে কাজ করে বা চেষ্টা করা উচিত।
9. সম্প্রদায়ের কোনও অটিস্টিক ব্যক্তির আচরণ সম্পর্কে আপনার পরিবারের সদস্য এবং / অথবা জনসাধারণের সদস্যদের কাছ্ থেকে নেওয়া কোনও মন্তব্য / উদ্বেগ সম্পর্কে আমাকে বলুন, যা সম্পর্কে আপনি সত্যই খারাপ অনুভব করেছেন।
10. অটিজম আক্রান্ত ব্যক্তির কাছে আপনার ভবিষ্যতের কোন প্রত্যাশা রয়েছে?
11. এই ব্যক্তির সুস্থতার জন্য প্রাথমিক দায়িত্ব কার নেওয়া উচিত?

Appendix 11

Questionnaire for professionals working with people diagnosed with Autism Spectrum Disorder in Bahasa (For Indonesian participants):

Pertanyaan untuk orang tua dari orang tua dengan Gangguan Spektrum Autisme dan pengasuh, dan profesional yang bekerja dengan orang yang didiagnosis dengan Gangguan Spektrum Autisme:

1. Beri tahu saya apa arti 'autisme' bagi Anda.

2. Menurut Anda, apa penyebab autisme?

3. Bisakah Anda berbagi pengalaman tentang tahap pra-diagnosis gangguan spektrum autisme?

4. Ceritakan tentang perilaku yang Anda khawatirkan.

5. Menurut Anda, mengapa orang dengan autisme berperilaku seperti itu?

6. Menurut Anda, bagaimana orang autis mengembangkan perilaku tersebut?

7. Dari pengalaman Anda, beri tahu saya intervensi apa yang benar-benar berhasil atau harus dicoba.

8. Ceritakan tentang komentar / keprihatinan dari anggota keluarga, dan / atau anggota masyarakat, yang dibuat tentang perilaku individu autis di komunitas, yang membuat Anda merasa sangat buruk.

9. Harapan masa depan apa yang Anda miliki untuk orang dengan autisme ini?

10. Siapa yang harus mengambil tanggung jawab utama untuk kesejahteraan orang ini?

Appendix 12

Questionnaire for parents with people diagnosed with Autism Spectrum Disorder in Bahasa (For Indonesian participants):

Pertanyaan untuk orang tua dari orang tua dengan Gangguan Spektrum Autisme dan pengasuh, dan profesional yang bekerja dengan orang yang didiagnosis dengan Gangguan Spektrum Autisme:

1. Bisakah Anda berbagi pengalaman tentang tahap pra-diagnosis gangguan spektrum autisme? Misalnya, apa yang Anda perhatikan pertama kali, dengan siapa Anda mendiskusikannya, dll.?

2. Ceritakan tentang proses diagnostic ASD. Misalnya berapa lama waktu yang dibutuhkan untuk membuat janji berkonsultasi dengan professional, proses diagnostic, apa yang anda alami atau lakukan selama proses diagnostic itu, dll.

3. Beri tahu saya apa arti 'autisme' bagi Anda.

4. Menurut Anda, apa penyebab autisme?

5. Ceritakan tentang perilaku yang Anda khawatirkan.

6. Menurut Anda, mengapa orang dengan autisme berperilaku seperti itu?

7. Bagaimana Anda merespons ketika Anda melihat orang autis menunjukkan perilaku yang tidak pantas?

8. Dari pengalaman Anda, beri tahu saya intervensi apa yang benar-benar berhasil atau harus dicoba.

9. Ceritakan tentang komentar / keprihatinan dari anggota keluarga, dan / atau anggota masyarakat, yang dibuat tentang perilaku individu autis di komunitas, yang membuat Anda merasa sangat buruk.

10. Harapan masa depan apa yang Anda miliki untuk orang dengan autisme ini?

11. Siapa yang harus mengambil tanggung jawab utama untuk kesejahteraan orang ini?

Appendix 13

Quantitative Research Questions for Parents

1. Time to Diagnose ASD
2. Parent perception of ASD severity
3. Perceptions on school provision
4. Help reported by parents from school and local authority
5. Parents’ perceptions of school support and satisfaction

Appendix 14

Quantitative Research Questions about Parenting Stress and Coping Strategies

1. Correlations between parenting stress, perceived autism severity, child behaviour problems, child internalising problems, and child externalising problems
2. Parenting Stress for each country
3. Correlations between stress subtypes and autism severity and total child behaviour problems for each country
4. Correlations between coping types and total parenting stress (QRS), autism severity (ABC), and total child behaviour problems (SDQ) for each country
5. Coping Strategies for each country

Appendix 15

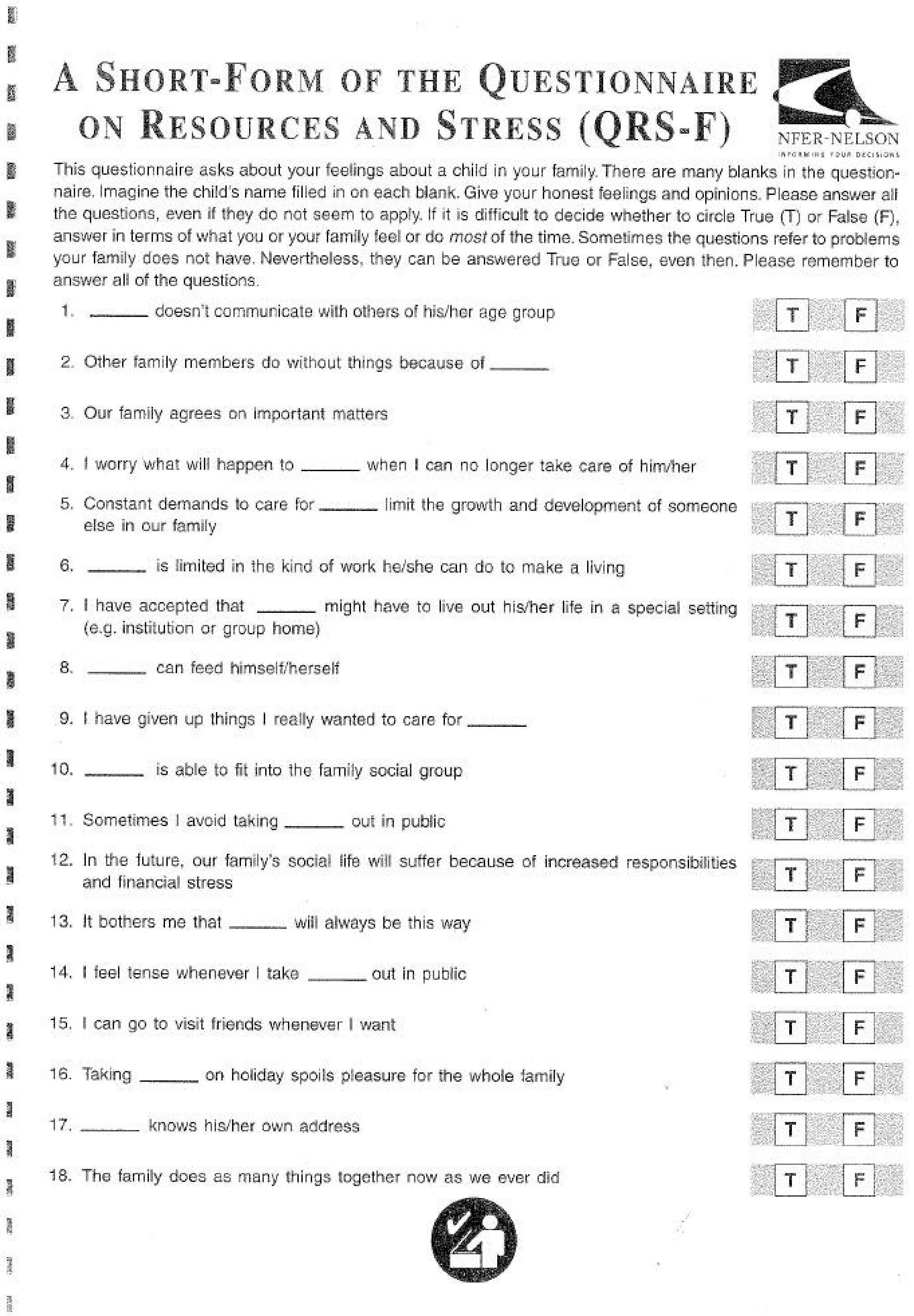
Family Routine Questionnaire

	Is this a routine in your family?			
	Always/ every day	3-5 times per week	1-2 times per week	Almost never
1. Parent(s) have sometimes each day for just talking with the children.				
2. Parent(s) have certain things they do every morning while getting ready to start the day.				
3. Working parent(s) have a regular play time with the child after coming home from work.				
4. Working parent(s) take care of the child sometime almost every day.				
5. Child does the same things each morning as soon as he/she wakes up.				
6. Parent(s) and child play together sometime each day.				
7. Non-working parent and child do something together outside the home almost every day (e.g. shopping, walking)				
8. Family has a 'quiet time' each evening when everyone talks and plays quietly.				
9. Family goes some place special together each week.				
10. Family has a certain 'family time' each week when they do things together at home.				
11. Parent(s) read or tell stories to the child almost every day.				
12. The child has some time each day for playing alone.				
13. Child takes part in regular activities after school / nursery school.				
14. Child goes to play-group the same day each week.				
15. Child does specific activities / play at the same time each day or night during the week.				
16. Child has special things he/she do or ask for each night at bedtime (e.g. a story, a good-night kiss, a drink of water).				
17. Child goes to bed at the same time almost every night.				
18. Family eats at the same time each night.				
19. At least some of the family eats breakfast together almost every morning.				
20. Whole family eats dinner together almost every night.				
21. At least one parent talks to his/her parents regularly.				
22. Family regularly visits the relatives.				
23. Family checks in or out with each other when someone leaves or comes home.				
24. Working parent(s) come home from work at the same time each day.				

This questionnaire has a number of questions about your family's routines. Please, read carefully and put a √ on the answer that corresponds to the routines of your family. Remember to answer all the questions. .

Appendix 16

A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-F)



A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-F)

NFER-NELSON
INFORMING YOUR DECISIONS

This questionnaire asks about your feelings about a child in your family. There are many blanks in the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all the questions, even if they do not seem to apply. If it is difficult to decide whether to circle True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please remember to answer all of the questions.

1. ______ doesn't communicate with others of his/her age group T F
2. Other family members do without things because of ______ T F
3. Our family agrees on important matters T F
4. I worry what will happen to ______ when I can no longer take care of him/her T F
5. Constant demands to care for ______ limit the growth and development of someone else in our family T F
6. ______ is limited in the kind of work he/she can do to make a living T F
7. I have accepted that ______ might have to live out his/her life in a special setting (e.g. institution or group home) T F
8. ______ can feed himself/herself T F
9. I have given up things I really wanted to care for ______ T F
10. ______ is able to fit into the family social group T F
11. Sometimes I avoid taking ______ out in public T F
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress T F
13. It bothers me that ______ will always be this way T F
14. I feel tense whenever I take ______ out in public T F
15. I can go to visit friends whenever I want T F
16. Taking ______ on holiday spoils pleasure for the whole family T F
17. ______ knows his/her own address T F
18. The family does as many things together now as we ever did T F

2

19. ______ is aware of who he/she is T F

20. I get upset with the way my life is going T F

21. Sometimes I feel very embarrassed because of ______ T F

22. ______ doesn't do as much as he/she should be able to do. T F

23. It is difficult to communicate with ______ because he/she has difficulty understanding what is being said to him/her T F

24. There are many places we can enjoy ourselves as a family when ______ comes along T F

25. ______ is over-protected T F

26. ______ is able to take part in games or sports T F

27. ______ has too much time on his/her hands T F

28. I am disappointed that ______ does not lead a normal life T F

29. Time drags for ______, especially free time T F

30. ______ can't pay attention for very long T F

31. It is easy for me to relax T F

32. I worry what will happen to ______ when he/she gets older T F

33. I get almost too tired to enjoy myself T F

34. One of the things I appreciate about ______ is his/her confidence T F

35. There is a lot of anger and resentment in our family T F

36. ______ is able to go to the bathroom alone T F

37. ______ can't remember what he/she says from one moment to the next T F

38. ______ can ride on a bus T F

39. It is easy to communicate with ______ T F

40. Constant demands to care for ______ limit my growth and development T F

3

41. ______ accepts himself/herself as a person T F

42. I feel sad when I think of ______ T F

43. I often worry what will happen to ______ when I can no longer take care of him/her T F

44. People can't understand what ______ tries to say T F

45. Caring for ______ puts a strain on me T F

46. Members of our family get to do the same kinds of things that other families do T F

47. ______ will always be a problem to us T F

48. ______ is able to express his/her feelings to others T F

49. ______ has to use a bedpan or a nappy T F

50. I rarely feel blue T F

51. I am worried much of the time T F

52. ______ can walk without help T F

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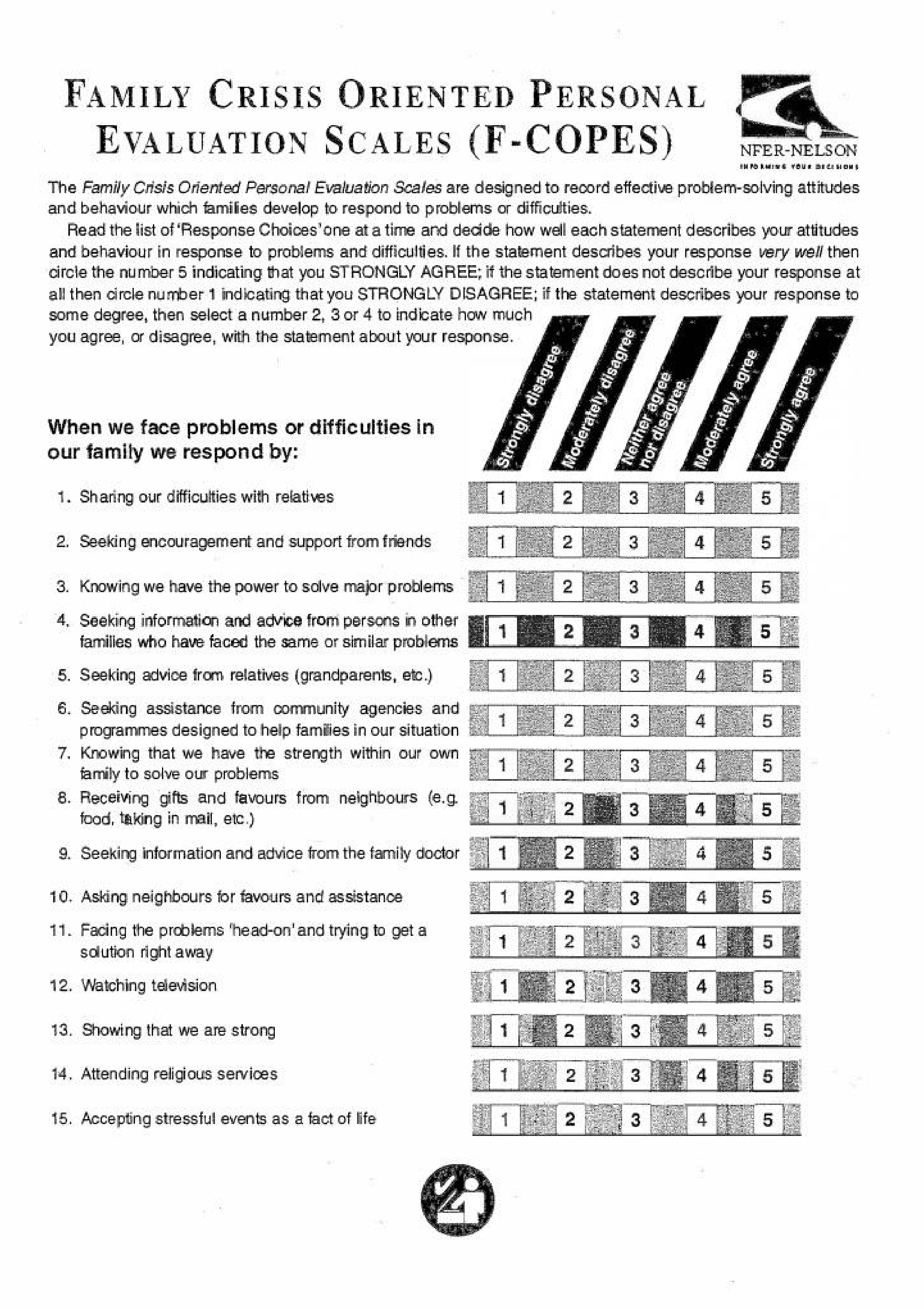
Appendix 17

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES (F-COPES)



FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES (F-COPES)

NFER-NELSON
INFORMING YOUR DECISIONS

The *Family Crisis Oriented Personal Evaluation Scales* are designed to record effective problem-solving attitudes and behaviour which families develop to respond to problems or difficulties.

Read the list of 'Response Choices' one at a time and decide how well each statement describes your attitudes and behaviour in response to problems and difficulties. If the statement describes your response *very well* then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all then circle number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3 or 4 to indicate how much you agree, or disagree, with the statement about your response.

When we face problems or difficulties in our family we respond by:

	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programmes designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favours from neighbours (e.g. food, taking in mail, etc.)	1	2	3	4	5
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbours for favours and assistance	1	2	3	4	5
11. Facing the problems 'head-on' and trying to get a solution right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending religious services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5

2

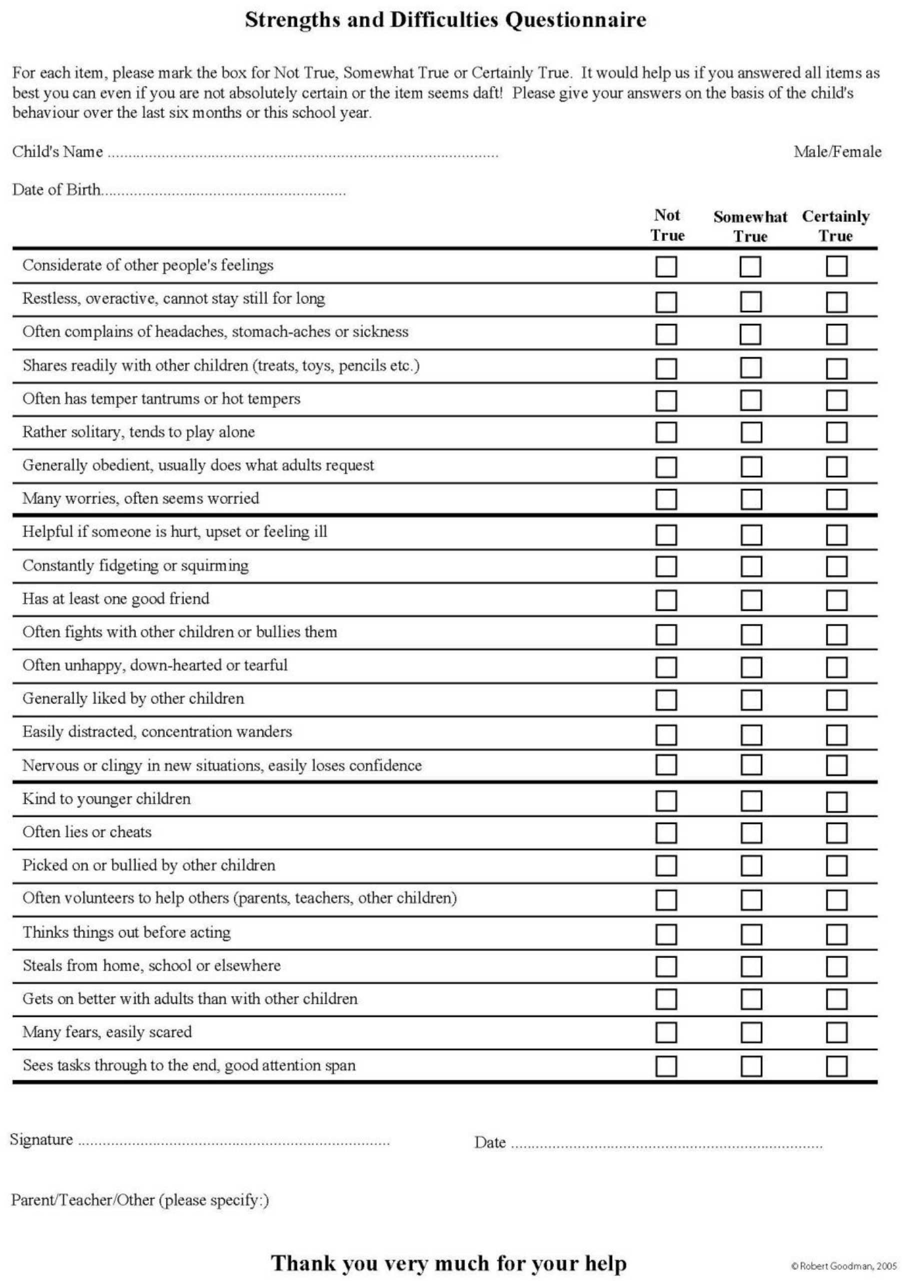
When we face problems or difficulties in our family we respond by:

	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5
21. Seeking professional counselling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in church activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty in handling problems	1	2	3	4	5
27. Seeking advice from a religious leader	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbours	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

Note: In the use of this instrument the clinician/researcher may need to obtain more complete information about the instrument, its conceptualization and the total theoretical framework as well as standard scores, reliabilities and validities from the original source of the instrument.

Appendix 18

Strengths and Difficulties Questionnaire



Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

Child's Name .... Male/Female

Date of Birth..

	Not True	**Somewhat True**	**Certainly True**
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children (treats, toys, pencils etc.)	☐	☐	☐
Often has temper tantrums or hot tempers	☐	☐	☐
Rather solitary, tends to play alone	☐	☐	☐
Generally obedient, usually does what adults request	☐	☐	☐
Many worries, often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, down-hearted or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often lies or cheats	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Steals from home, school or elsewhere	☐	☐	☐
Gets on better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Sees tasks through to the end, good attention span	☐	☐	☐

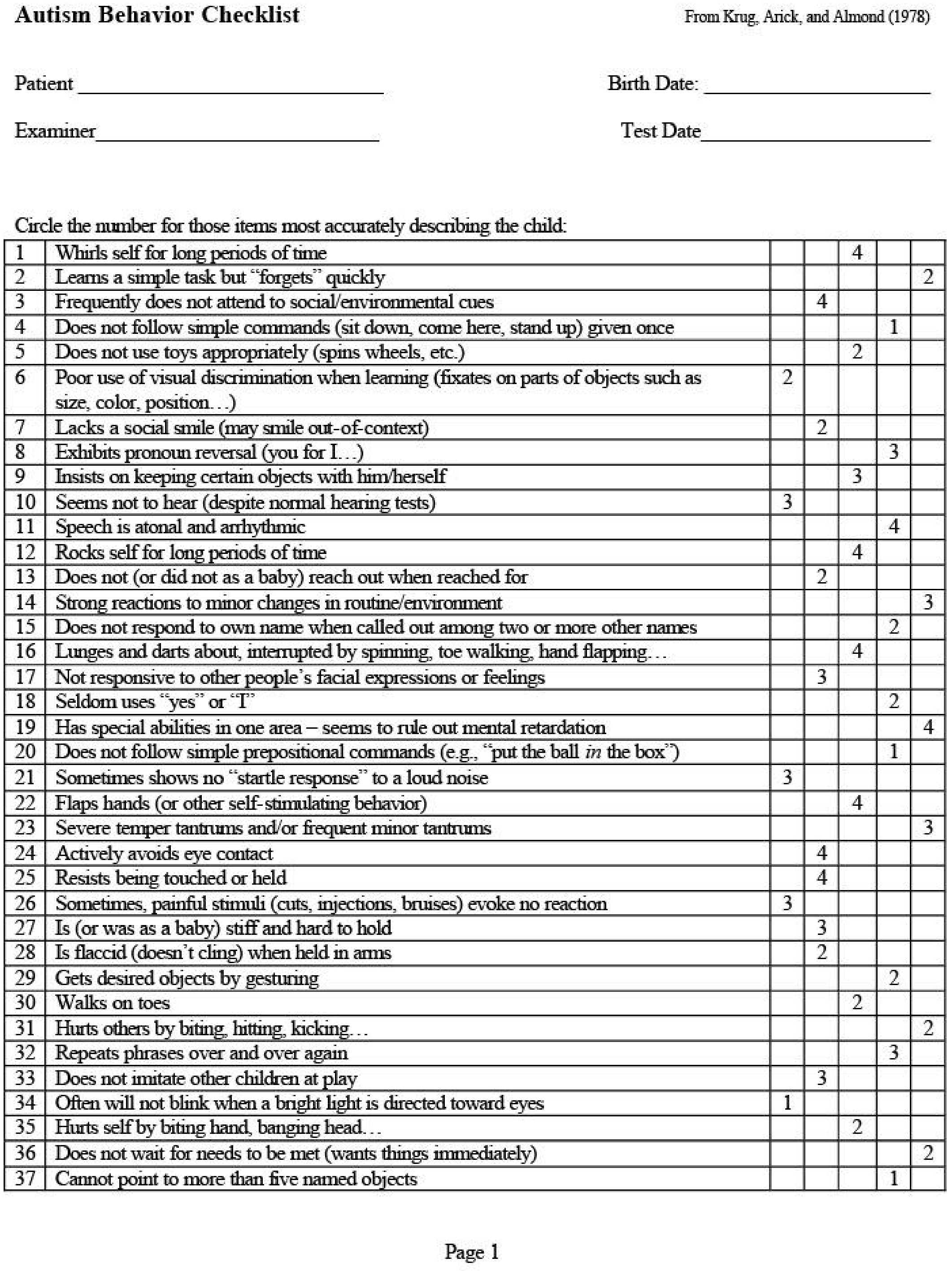
Signature .... Date ....

Parent/Teacher/Other (please specify:)

Thank you very much for your help

Appendix 19

Autism Behaviour Checklist



Autism Behavior Checklist

From Krug, Arick, and Almond (1978)

Patient ____________________________ Birth Date: _____________________

Examiner__________________________ Test Date_____________________

Circle the number for those items most accurately describing the child:

1	Whirls self for long periods of time			4		
2	Learns a simple task but "forgets" quickly					2
3	Frequently does not attend to social/environmental cues		4			
4	Does not follow simple commands (sit down, come here, stand up) given once				1	
5	Does not use toys appropriately (spins wheels, etc.)			2		
6	Poor use of visual discrimination when learning (fixates on parts of objects such as size, color, position…)	2				
7	Lacks a social smile (may smile out-of-context)		2			
8	Exhibits pronoun reversal (you for I…)				3	
9	Insists on keeping certain objects with him/herself			3		
10	Seems not to hear (despite normal hearing tests)	3				
11	Speech is atonal and arrhythmic				4	
12	Rocks self for long periods of time			4		
13	Does not (or did not as a baby) reach out when reached for		2			
14	Strong reactions to minor changes in routine/environment					3
15	Does not respond to own name when called out among two or more other names				2	
16	Lunges and darts about, interrupted by spinning, toe walking, hand flapping…			4		
17	Not responsive to other people's facial expressions or feelings		3			
18	Seldom uses "yes" or "I"				2	
19	Has special abilities in one area – seems to rule out mental retardation					4
20	Does not follow simple prepositional commands (e.g., "put the ball *in* the box")				1	
21	Sometimes shows no "startle response" to a loud noise	3				
22	Flaps hands (or other self-stimulating behavior)			4		
23	Severe temper tantrums and/or frequent minor tantrums					3
24	Actively avoids eye contact		4			
25	Resists being touched or held		4			
26	Sometimes, painful stimuli (cuts, injections, bruises) evoke no reaction	3				
27	Is (or was as a baby) stiff and hard to hold		3			
28	Is flaccid (doesn't cling) when held in arms		2			
29	Gets desired objects by gesturing				2	
30	Walks on toes			2		
31	Hurts others by biting, hitting, kicking…					2
32	Repeats phrases over and over again				3	
33	Does not imitate other children at play		3			
34	Often will not blink when a bright light is directed toward eyes	1				
35	Hurts self by biting hand, banging head…			2		
36	Does not wait for needs to be met (wants things immediately)					2
37	Cannot point to more than five named objects				1	

Page 1

Autism Behavior Checklist

From Krug, Arick, and Almond (1978)

Patient ______________________________ Birth Date: ______________________

Examiner____________________________ Test Date______________________

38	Has not developed any friendships		4			
39	Covers ears at many sounds	4				
40	Twirls, spins, and bangs objects a lot			4		
41	Difficulties with toilet training					1
42	Uses 5 or less words per day spontaneously to communicate wants or needs				2	
43	Often frightened or very anxious		3			
44	Squints, frowns, or covers eyes when in the presence of natural light	3				
45	Does not dress self without frequent help					1
46	Repeats sounds or word over and over again				3	
47	"Looks through" people		4			
48	Echoes questions or statements made by other people				4	
49	Frequently unaware of surroundings and may be oblivious to dangerous situations					2
50	Prefers to manipulate and be occupied with inanimate objects					4
51	Will feel, smell, or taste objects in the environment			3		
52	Frequently has no visual reaction to a "new" person	3				
53	Gets involved in complicated "rituals" such as lining things up…			4		
54	Is very destructive (toys and household items are quickly broken)			2		
55	A developmental delay was identified at or before 30 months of age					1
56	Uses at least 15 but less than 30 spontaneous phrases daily to communicate				3	
57	Stares into space for long periods of time	4				
	Totals:					

Overall Total: ______________

Comments:

Appendix 20

QUESTIONNAIRE FOR PARENTS

Today's date:…../…../

QUESTIONNAIRE FOR PARENTS
Name of investigator: Kaneez Mustary
Contact address: Department of Psychology, University of Wales-Swansea, Singleton Park, Swansea, SA2 8PP
e-mail address: [redacted]

Instructions

This questionnaire contains questions about your child, who is participating in this study, as well as about his/her history, your family, the support you received as parent and the transactional period between early and primary education of your child.

It would be very helpful for us if you answer all the questions. Please, read carefully and answer properly according to the type of question (either putting a √ or writing down your answer). There are no 'right' and 'wrong' answers.

We wish to stress that your responses will be treated in strict confidence by the investigator. No information concerning any individual child will be used in any way that could identify that child or their family. Your family's privacy will be protected and respected at all times.

Name of the child ………………………………………………………..

Name of the School/other facility: ………………………….. …………

Area:……………………………………………………………………………….

A) About the person completing form

a) Name : ……………………………………………………… … b) Gender: male female

c) Date of birth:……/……./…….. d) Relationship to child :……………………………….

B) About the child

a) Name : ………………………………………………………………. b) Gender: male female

c) Date of birth:……/……./……. d) Ethnic origin:……………………..………………………...

e) Nationality: …………………………… ……… f) Religion: …………………………………………

g) School or other facility:………………………………….……………………… h) Grade:…………..

i) Has your child changed primary school from the 1rst grade until now? Yes No

If Yes, clarify in which schools did your child enrolled in the past and for how long.

Name of the school	Child's age at start	Child's age at end

i) Present classification or diagnosis:…………………………………………………

Data from other Tests:

j) Intelligence :…………………………………………………………………………………….

……………………………………………………………………………………………………

k) Achievement :…………………………………………………………………………………….

……..

l) Adaptive behaviour: ……………………………………………………………………………

……………………………………………………………………………………………………….

m) Other :…………………………………………………………………………………………

……………………………………………………………………………………………………….

C) About the family

a) Number of family member: ………… b) Number of siblings: ………………..

c) Marital status: single married widowed separate/divorced

d) Father’s education: …………..………….. primary school incomplete secondary school completed secondary school college/university postgraduate studies

e) Mother’s education: …………………..….. primary school incomplete secondary school completed secondary school college/university postgraduate studies

f) Father’s occupation: Labour, clerical, or service (farm, office, domestic, etc)
Skilled labour, technical (crafts, trades, electronics, etc)
Managerial, professional (business, law, teaching, etc)
Unemployed/ on strike

g) Mother’s occupation: Labour, clerical, or service (farm, office, domestic, etc)
Skilled labour, technical (crafts, trades, electronics, etc)
Managerial, professional (business, law, teaching, etc)
Unemployed / on strike

D) Child's History

a) At what age did you first notice or suspect that your child who is in this study may have problems?

b) At what age was your child who is in this study *diagnosed* as having Autistic Spectrum problems?

c) Does your child who is in this study have any siblings?
Do any of these siblings have problems (e.g., Autistic Spectrum Problems, Down's Syndrome, Dyslexia, learning Difficulties, etc.)? Do any other family members have similar problems?

d) Did your child who is in this study have any medical problem in the past, or does the child have any medical problems now?

e) Does your child who is in this study use any type of augmented communication system (e.g., British Sign Language, Makaton, Picture Exchange Communication System, etc.)? If so, please specify.

f) Do you, or any of your family members, use more than one spoken language (e.g., bilingual or multilingual)?

g) Could you outline which interventions/therapies/treatments (e.g., A.B.A., Early Bird, Nursery placements, Portage, Secretin, Speech and Language Therapy, etc.) and supplementary treatment (diet, vitamins, sensory treatment, homeopathy preparation etc.) your child received ***in the past,*** and those treatment/treatment your child ***currently*** receives? Please indicate when your child received these interventions/therapies/treatments, approximately how long each lasted, with what intensity and where.

E) Support

a) Is there any available support to you in your child's school? ……………………………………
If yes, what kind?

b) Is there any available support to you in local authority? ……………………………………….
If yes, what kind?

c) Do you use any of the available supports? ………………………………………………………………………..
If yes, what kind?

d) Did you look for information about your child condition, in the past? ………………………………..

f) If yes, did anybody help you / give you guidance? No Yes Who?…………………………….
did you do it on your own? Yes No

F) At the transitional period
from the Early Intervention Programme/treatment programme/nursery school
to primary mainstream/special school …

a) …was there any contact and **cooperation between** the treatment/nursery school staff **and** the staff of the primary mainstream/special school?
If yes, please give more details.

b) …did your child receive any **preparation** for this transition to a different school environment (e.g., gradual transition, changes in his/her previous normal programme)?
If yes, please give more details.

G) Satisfaction from the Early intervention Programme

a) How satisfied are you with the service you received by the Early Intervention Programme (ABA, LEAP, etc)?

Quite dissatisfied   Indifferent or middle satisfied   Most satisfied   Very satisfied

b) How would you rate the quality of the service you was receiving?

Poor   Indifferent   Fair   Excellent

[Please indicate how far you agree or disagree with each of the following statements]

c) The service helped my child to progress.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

d) The service helped me as a parent.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

a) The service helped me to understand my child's difficulties.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

f) I learned new ways of helping your child.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

g) My child's worker was always reliable.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

h) I could express my feelings about my child's difficulties to my child's worker(s)

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

i) My child's worker was acting as a link to other professionals.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

j) I told to my child's worker(s) about other family or personal problems.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

k) I was enjoying doing activities with my child.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

l)My child's worker (s) used to keep me informed of plans for my child.

Strongly disagree   Disagree   Neither agree, nor disagree   Agree   Strongly agree

m) Did you have any difficulties with your child's worker(s)? Yes   No

If Yes, please describe these difficulties.

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