AN INVESTIGATION INTO PARENTAL UNDERSTANDING OF AUTISM AND THE DEVELOPMENT OF AN INDIVIDUALISED AUTISM PROFILING TOOL

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Abstract

Raising a child with autism can be extremely challenging for parents and families due to the complex nature of autism and the wide variation in the type and severity of symptoms children experience. Several factors may influence parent perceptions about autism and their understanding of the child's unique traits related to autism. To date, there is no research to identify the particular pattern of parental understanding of autism as related to their child's individual strengths and challenges. Research into specific parent factors is critical to help inform intervention strategies that can meet the needs of children with autism and their families. The main aim of this research is to provide an investigation of the basic elements comprising parental understanding of their child's presentation of autism and their pre-existing knowledge about the condition. In exploring this, an evidence-based tool, the 'Individualised Autism Profiling' (IAP) tool was developed in conjunction with key stakeholders and specialists in the field of autism. The first research objective was to determine whether there are differences between parents' understanding of the general nature and characteristics of autism and the characteristics of their child with autism. The second research objective was to identify distinct parent profiles based on their child's individual characteristics and unique needs. Findings from this research support the notion that parental understanding of autism in general and in relation to their child with autism might not be theoretically distinct constructs, and that parents of children with autism may recognize as common the characteristics of their child as related to all children with autism. Moreover, the present research provides novel evidence for the proposal of three distinct profiles of parental understanding of autism: a high, a moderate, and a poor level of autism understanding. These findings could lead to a better understanding of how parents understand their child's potential and unique needs in the context of autism and would be important for informing decisions for intervention strategies to optimize child, parent, and family outcomes.

Dedication

I dedicate this work to my parents, Dimitrios and Ioanna, who have provided me with their encouragement, love and understanding. To my brother Antony and my sister Maria for their whole-hearted support, and to my partner Theodore who has inspired me all the time.

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Publications and Presentations

Publications

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East Midlands Doctoral Network Conference, September 2018. Poster presentation, *'An Individualised Autism Profiler (IAP): Investigation into parental understanding of autism and the individual differences of children with autism'* Karousi A, Bignell S, Barnes C, Lipka S.

Autistica Discover Conference, June 2019. Oral presentation, *'How Parents Understand Autism: An Individualised Autism Profiler for Children and Young Adults'* Karousi A, Bignell S, Barnes C, Lipka S.

Chapters

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CHAPTER 1

INTRODUCTION TO THE RESEARCH

“Εν μόνον αγαθόν είναι, την επιστήμην, και εν μόνον κακόν, την αμαθίαν” – There is only one good, knowledge, and one evil, ignorance (Socrates, 469–399 BC) – as quoted in Diogenes Laertius, Lives of Eminent Philosophers, 2.31.

Thesis Outline

Section 1.1. The Main Aim and Objectives of the Research

Autism Spectrum Disorder (ASD) is a complex, multidimensional condition with different phenotypic presentations and developmental trajectories. The wide variation and severity of symptoms that children with autism experience can make parenting extremely challenging and demanding. Previous research has shown that several factors may influence parenting experiences of raising a child with autism, and in turn, their understanding of the disorder. These factors may include family-related characteristics such as socioeconomic status and socio-cultural values, as well as specific characteristics of children with autism and their caregivers. However, no previous studies have investigated the particular pattern of parental understanding of autism as related to the strengths and unique differences of their children with autism. Identifying how parents understand their child’s strengths, abilities and special needs in the context of autism is critical to help inform decisions for intervention strategies that can meet the needs of children with autism and their families.

The main aim of this thesis is to lead to a better understanding of how parents perceive their child’s behaviour in the context of autism and individual differences, and subsequently to help inform decisions for intervention strategies to optimize child, parent, and family outcomes.

The broader aim of this research is to provide an investigation of the basic elements comprising parental understanding of their child's presentation of autism and their pre-existing knowledge about the condition. In exploring this, a tool was developed in conjunction with key stakeholders and specialists in the field of autism, to help identify distinct parent profiles based on their child's individual characteristics and unique needs.

The following objectives are more directly explored in this thesis. The first objective was to investigate whether there are differences between parents' understanding of the general nature and characteristics of autism and the characteristics of their child with autism. To achieve this, an initial questionnaire was developed in conjunction with parents of children with autism to evaluate parental understanding of the general nature and characteristics of all children with autism and the characteristics of their autistic child. The questionnaire development process and evaluation are presented in separate phases in the respective chapters (Chapters 3 and 4). The second research objective was to identify distinct profiles of parental understanding of autism based on their child's individual characteristics and unique needs. To address this, a latent profile analysis was used to identify different profiles of parental understanding of autism within the data (Chapter 5). Limitations, interpretation of findings, conclusions, and future research directions are reported in the final chapter (Chapter 6).

The following chapters describe work that utilises a sample of parents of children and young adults diagnosed with autism for the exploration of parental understanding of autism. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM–5) (American Psychiatric Association, 2013), Autism Spectrum Disorder (ASD) encompasses both Autism and Asperger syndrome. Throughout this thesis, the term 'autism' will be used interchangeably unless stated otherwise.

Section 1.2. Overview of Chapters

Chapter 2 provides a review of the published literature that has informed the current understanding of autism as it relates to parenting. This chapter is divided into several sections including an overview on the current understanding of autism, a review of the major theoretical accounts of autism, a review on factors that influence parental understanding of autism, an overview on the impact of autism on parents and families, an overview of autism interventions and parent involvement, the theoretical framework that guides and informs the studies presented within this thesis, and a chapter conclusion.

Chapter 3 describes the item selection process of a pool of 229 items for the development of an initial questionnaire to explore parental understanding of autism. The item selection process involved two steps: an evaluation by the academic research team and a stakeholder consultation. A hundred and thirty items were eliminated resulting in the revised version of the first questionnaire on parental understanding of autism with 99 items.

Chapter 4 describes the rationale behind the first evaluation study aiming to determine whether there are differences between the understanding of autism in general and in relation to the individual child with autism, and in particular to examine how parents understand the general nature and characteristics of all children with autism as related to the characteristics of their autistic child; as well as to describe the rationale behind the development of a new profiling tool for parental understanding of autism. An online survey was conducted among parents of children with autism using the 99-item questionnaire, followed by a series of interviews with stakeholders and specialists in the field of autism to help define the number of appropriate items for use in the new profiling tool. The final revisions being made to the questionnaire were based on both the results of the statistical analysis and input by stakeholder and expert consultation resulting in a provisional instrument with 20 items, called the Individualised Autism Profiling (IAP) tool.

Chapter 5 describes the rationale behind the second evaluation study aiming to identify distinct profiles of parental understanding of autism based on their child's individual characteristics and unique needs. An online survey was conducted among parents of children with autism using the 20-item IAP tool, followed by a latent profile analysis to identify different profiles of parental understanding of autism within the data. Further, it was examined whether the profiles identified in the latent profile analysis differed in their levels of parenting self-efficacy, well-being, and severity of autism symptoms to better understand the nature of these profiles.

Chapter 6 provides an overall discussion of the studies presented within this thesis that explored how parents understand the potential and unique needs of their autistic children via the development of an Individualised Autism Profiling tool (IAP). In this final chapter, the findings from this research are considered together and a theoretical model for parental understanding of autism is proposed. The chapter offers a general discussion, research implications, strengths, limitations, directions for future research, and conclusions.

CHAPTER 2

REVIEW OF THE LITERATURE

Chapter Overview

The purpose of this chapter is to provide a review of the literature that illustrates the wide-ranging theoretical and research-based literature that has informed the current understanding of autism as it relates to parenting. This chapter is divided into several sections. Section 2.1. aims to introduce the reader to the chapter’s rationale. Section 2.2. provides an overview of the current scientific understanding of autism. Section 2.3. presents the major psychological accounts of autism. Section 2.4. presents a review of existing literature on factors that influence parental understanding of autism. Section 2.5. looks more generally on the impact of autism on parents and families. Section 2.6. provides an overview of autism interventions and parent involvement. Section 2.7. presents the theoretical framework that guides and informs the studies presented in later chapters. Section 2.8. concludes the chapter highlighting the importance and the purpose of this research.

Section 2.1. Introduction

Over the past few years, there has been remarkable progress in our understanding of autism. The medical model of disability is considered to be the dominant model in autism and currently, autism can be understood and defined by a certain set of behaviours with broad variations in the type and severity of symptoms. Autism has a large public health impact and extensive research in the field has contributed to advances in early identification and diagnosis that can help improve outcomes for individuals with autism and their families by providing effective interventions and targeted approaches (Mintz, 2017). This chapter provides an overview of the current scientific understanding of autism as related to its definition and prevalence, the classification system and clinical assessment, early signs and symptoms, as well as the co-occurrence with other conditions and its multifactorial aetiology. This critical review of the literature will guide the development of a tool for the evaluation of parental understanding of autism.

Given the heterogeneity of autism, various psychological theories have been developed attempting to explain the psychological processes and experiences of individuals with autism based on neurobiological research findings. Classic literature traditionally describes autism under four prevailing cognitive theoretical accounts including the theory of mind hypothesis, the weak central coherence theory, the executive dysfunction hypothesis, and the hyper-systemizing theory, each of which is based on findings that individuals with autism perform differently in specific psychological tasks compared to typically developing individuals (Pellicano, 2010). Additionally, an extension of the empathizing-systemizing theory of typical sex differences, the extreme male brain theory, suggests that autism is an extreme expression of the male brain (Baron-Cohen, 2002, 2005). These psychological models have contributed to the conceptualisation of autism by giving insight into the strengths of individuals with autism, as well as the challenges they face due to autism, but major puzzles remain. Chapter 2 provides an overview of the major theoretical accounts of autism and proposes the consideration of parental understanding of autism in connection with autism interventions to bridge the gap between theory and practice and enhance the efficacy and effectiveness of interventions.

Early identification and understanding of autism are crucial, as research has demonstrated that interventions for young children with autism are associated with improved outcomes (Zwaigenbaum et al., 2013, 2015). However, several factors may influence the way parents understand their child’s behaviour in the context of autism and individual differences. Socioeconomic and sociocultural differences, as well as the individual characteristics of children with autism and their caregivers, are the most essential factors that Chapter 2 discusses. In this review, the impact of autism on parents and family, as well as the medical and behavioural intervention approaches to autism, are discussed in some detail. Lastly, the Early Childhood Outcomes (ECO) framework (Wainer et al., 2017) provides a theoretical and contextual setting for this research by helping identify appropriate child and family level outcomes to increase the efficacy of early interventions in autism. The focus of this research is on the framework's family-level outcome: *'families understand their child's strengths, abilities, and special needs*.' The present review of the literature highlights the emerging need for investigating how parents understand their child's unique characteristics in the context of autism and individual differences, to help inform decisions for intervention strategies to optimize child, parent, and family outcomes.

Section 2.2. Autism Spectrum Disorder

2.2.1 Definition and Prevalence of Autism

Autism Spectrum Disorder (ASD) is a group of neurodevelopmental disorders, characterised by qualitative impairments in social interaction and communication, along with restricted, repetitive patterns of behaviour and interests (American Psychiatric Association, 2013b). The onset of autism symptoms usually occurs in the first three years of life and persist throughout an individual's lifespan (Lyall et al., 2017). The word autism is derived from the Greek word αὐτός (autos), which means 'self', used by the Swiss psychiatrist Bleuler, in 1912 to describe individuals with schizophrenia. However, Kanner was the first who distinguished the disorder from Childhood Schizophrenia in 1943, using the term to describe eleven case studies of children – eight boys and three girls – with withdrawal behaviour and an 'insistence on sameness'. Kanner's description is also known as 'early infantile autism' and together with the work of Asperger, formed the basis of the modern study of autism (Park et al., 2016; Yates & Le Couteur, 2016).

The prevalence of autism has increased significantly in recent decades. The World Health Organization (WHO) estimated that 1 in 160 children globally has autism; however, this estimate was based on studies in developed countries (Baxter et al., 2015; Lyall et al., 2017). In 2016, the Centers for Disease Control and Prevention (CDC) estimated that about 1 in 54 children in the US had received a diagnosis of autism by the age of 8 years (Maenner et al., 2020); a prevalence estimate which is approximately 2.8 times higher than the first estimate reported in 2002 (Centers for Disease Control and Prevention, 2007). In the UK, prevalence estimates in 8-year-old children have shown a significant increase in the number of children diagnosed with autism in the 1990s which thereafter remained steady for the period 2004–2010 (Taylor et al., 2013).

The rising prevalence of autism might be a result of changes in the diagnostic criteria to include a spectrum of disorders, as well as improved recognition and greater public awareness (Frith, 2014; King & Bearman, 2009). Although, the inclusion of children who might have been identified with an intellectual disability (ID) or another type of disability in the past might have contributed to this rise (Shattuck, 2006); an increase in known or suspected risk factors might also be associated with high incidence in the frequency of autism (Park et al., 2016).

Autism is three to four times more common in boys than girls, with a strong male bias in the high functioning group (Yates & Le Couteur, 2016). Gender differences, however, appear to decrease with increasing symptom severity (Lyall et al., 2017). Epidemiological studies suggest that females with autism might have been under-recognized due to ascertainment bias and issues of diagnostic instruments. Females who are of average to above-average intellectual ability are more likely to camouflage their underlying difficulties related to autism and in turn, to be diagnosed later than males (Lai et al., 2015; Masi et al., 2017). Research also suggests that the existence of an inherent mechanism in females, the so-called ‘female protective effect’, reduces the likelihood of developing autism (Masi et al., 2017; Park et al., 2016). Nevertheless, while boys with autism show more externalising behaviour problems, girls with autism seem more likely to mask and internalize their difficulties which may result in decreased understanding and support with catastrophic lifelong implications (Carpenter et al., 2019).

2.2.2. Classification and Clinical Assessment of Autism

At present there are two main international classification systems for diagnosing autism: 1) the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association (American Psychiatric Association, 2013b), and 2) the International Classification of Diseases (ICD) published by the World Health Organisation (World Health Organization, 1992). The DSM-5 was published in 2013 and proposed revisions which include the use of an umbrella term Autism Spectrum Disorder (ASD) with two core domains of impairment: 1) social and communication impairments, and 2) restricted, repetitive patterns of behaviour, interests, and activities (Chaste & Leboyer, 2012; Lai et al., 2014; Lord & Jones, 2012; Park et al., 2016; Yates & Le Couteur, 2016). The umbrella term ASD encompasses the previously distinct diagnostic subtypes of Autistic Disorder (AD), Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), Asperger’s Syndrome, and Childhood Disintegrative Disorder (Chaste & Leboyer, 2012; Khalifeh et al., 2016; Lyall et al., 2017; Matson & Goldin, 2014; Volkmar & McPartland, 2014; Williams et al., 2014; Yates & Le Couteur, 2016), while Intellectual Disability (ID) and Social Communication Disorder (SCD) are now recognised as separate diagnoses (Lyall et al., 2017; Williams et al., 2014).

A substantial change DSM-5 brought is the inclusion of levels of severity to address the individual’s profile of strengths and needs. Three levels of severity have been added, namely, (i) requiring support; (ii) requiring substantial support; and (iii) requiring very substantial support, based on degree impairment in the two domains of function (Constantino & Charman, 2016; Lord et al., 2018; Lyall et al., 2017; Masi et al., 2017; Yates & Le Couteur, 2016). The diagnostic criteria for autism defined by the International Classification of Disease (ICD) version-10 adopt the approach of a 'triad of impairments' described by the DSM-IV (Constantino & Charman, 2016). However, the new revision, ICD-11, released in 2018, closely mirrors the criteria outlined by the DSM-5 on core features of autism (Yates & Le Couteur, 2016).

In the absence of biological markers for autism, the clinical diagnosis is made based on an assessment of symptoms and diagnostic tests (Lord et al., 2018). According to the DSM-5, a child should meet at least three symptoms in the social-communication domain, and two in the restricted, repetitive behaviour domain to receive a formal diagnosis (Khalifeh et al., 2016; Lord et al., 2018). The strategy in the UK, following the National Institute for Health and Care Excellence (NICE) guidelines on assessment and diagnosis, utilizes a multidisciplinary approach with a combination of professional observations and parental reports to obtain the most reliable outcomes (Levy et al., 2009; Yates & Le Couteur, 2016). To assess the child's profile and range of symptoms, the information should be gathered from various settings including home and school environments, observations of behaviour in daily interactions with peers, and friendships (Constantino & Marrus, 2017). Diagnostic assessment should also consist of the family's medical and psychiatric history-taking if other psychopathological conditions along with the autism core symptoms are suspected. All the above information should be ideally obtained with the use of evidence-based screening tools, such as the Modified Checklist for Autism in Toddlers (M-CHAT) (McConachie et al., 2015).

The most frequently used diagnostic assessment tools include: the Autism Diagnostic Observation Schedule (ADOS), for diagnosing individuals with different language levels and ages (Lord et al., 2000); the Autism Diagnostic Interview-Revised (ADI-R), which includes semi-structured interviews for caregivers of suspected cases of autism (Lord et al., 1994); and the Diagnostic Instrument for Social Communication Disorders (DISCO) or the computer-generated Developmental, Dimensional, and Diagnostic Interview (3di), which are broadly used in the UK (Lord et al., 2018).

2.2.3. Early Signs and Symptoms of Autism

The onset of the symptoms of autism typically occurs by the age of three years (Dietert et al., 2011; Levy et al., 2009), even though parents may express concerns about their child's development before that age (R. J. Landa, 2008; Levy et al., 2009; Matson & Goldin, 2014). Despite this, a formal assessment is most frequently made between the age of four and five years, or in some cases even later (Guinchat et al., 2012; Ozonoff et al., 2009; Richards et al., 2016; Yates & Le Couteur, 2016). Current research suggests that there are two different patterns for symptom onset (Landa, 2008). The most common pattern of onset is called 'early-onset' and includes atypical social and communicative development which is apparent in early childhood. This pattern is thought to occur in the majority of children with autism (Ozonoff et al., 2008, 2010). The second pattern involves a period of seemingly typical early development or mild symptoms, followed by the emergence of autism-related atypical behaviours and gradual loss of previously acquired skills (R. J. Landa, 2008; Ozonoff et al., 2008, 2010; Stefanatos, 2008). This regressive autism affects mostly social and communication skills, while the loss of cognitive abilities is still arguable (Kalb et al., 2010; R. J. Landa, 2008; Ozonoff et al., 2008, 2010). Other studies suggest a mixed onset pattern, with evidence of both early delays and regression in children with autism (Ozonoff et al., 2010).

Early identification and diagnosis can facilitate early intervention with positive outcomes for the affected child and the family (Dawson, 2008). Therefore, an increasing emphasis is being placed on the detection of early signs of autism (Kishore & Basu, 2011). Retrospective studies of high-risk infants have shown a range of early indicators for autism; however, the earliest reported signs are delays in social engagement, communication, and lack of symbolic play (Kishore & Basu, 2011; Levy et al., 2009). Other early symptoms of autism often observed within the first year include delayed speech and language skills, deficits in joint attention, motor delays, eye gaze, and extremes of temperament (Lai et al., 2014; Park et al., 2016; Yates & Le Couteur, 2016). By the age of three years, the delays or atypical functioning must be present for a clinical diagnosis (Yates & Le Couteur, 2016). It is evident that due to the heterogeneous nature of the disorder and the possible co-occurrence of other conditions, there is variability in age of symptom onset, severity, type and frequency of symptoms, and timely diagnosis. Children with more severe symptoms, however, are more likely to be diagnosed earlier than those less impaired (Herlihy et al., 2015; Landa, 2008; Lyall et al., 2017; Matson & Goldin, 2014; Zablotsky et al., 2017).

2.2.4. Comorbid Conditions Associated with Autism

The existence of comorbid conditions alongside autism is well recognised (Lord et al., 2018). Autism is commonly associated with psychiatric and medical conditions including Intellectual Disability (70 per cent of the cases), Attention-Deficit/Hyperactivity Disorder (ADHD) (over 50 per cent of the cases), gastrointestinal problems, sensory sensitivities, epilepsy, aggression, anxiety, depression, mood disorders, tics, seizures, self-injurious and disruptive behaviours, food selectivity and sleep problems (Huguet & Bourgeron, 2016; Khalifeh et al., 2016; Lyall et al., 2017; Matelski & Van de Water, 2016; Park et al., 2016; Yates & Le Couteur, 2016). In some cases (some estimates suggest 15 per cent) autism has been associated with a known genetic condition, such as Fragile X syndrome, tuberous sclerosis, and Timothy Syndrome (Lord et al., 2018; Lyall et al., 2017).

The presence of one or more of these comorbid conditions may influence symptom severity and impact children with autism (Masi et al., 2017). For instance, 10 per cent of children who had first received a diagnosis of epilepsy were later diagnosed with autism (Mannion et al., 2013). Epilepsy is more prevalent in children with more severe intellectual disability (Amiet et al., 2008), while it is more common in girls (30 per cent) than boys (18 per cent) (Bolton et al., 2011). Sleep disturbances are also prevalent and have been reported to occur in 80 per cent of children with autism (Mannion et al., 2013). Furthermore, sleep problems are associated with the presence of challenging behaviours in young children with autism, including aggression, hyperactivity, language deficits, and feeding problems (Goldman et al., 2011). Also, a co-occurrence of sleep problems, gastrointestinal disturbances, and mood disorders has been found in children with autism (Ming et al., 2008). Buie et al. (2010) suggest that children with autism who present gastrointestinal symptoms may also exhibit sleep disturbances, increased irritability, and non-compliant behaviour. Nonetheless, the identification and diagnosis of co-occurring psychopathology in autism are particularly challenging due to the heterogeneity in symptom presentation and lack of diagnostic tools to screen for these conditions in individuals with autism (Mannion & Leader, 2013).

2.2.5. Aetiology of Autism Spectrum Disorder

Autism is a complex, heterogeneous disorder, with multiple aetiologies and risk factors; however, the interaction between genetic and environmental factors has been widely linked to the development of autism. Several studies suggest that there are high rates of heritability among twins, with up to 50 per cent concordance in monozygotic twins and about 10 per cent in dizygotic twins (Huguet & Bourgeron, 2016; Modabbernia et al., 2017; Park et al., 2016). Data from family aggregation studies, that refers to the occurrence of a given trait within families, have demonstrated that siblings of children with autism have a 20 to 50 times greater risk of developing autism (Huguet & Bourgeron, 2016). Moreover, a milder manifestation of cognitive or behavioural features associated with autism, such as social or language impairments, is common in parents and siblings of children with autism. This has been called the 'broader autism phenotype' and is further indicative of the high heritability of the disorder (Piven, Palmer, Jacobi, et al., 1997).

Extensive genetic research has revealed that 400 to 1000 genes may be related to autism (De Rubeis et al., 2014; Iossifov et al., 2014). Genes' variation, inherited or de novo, increases the potential risk of passing autism across generations. Approximately 10-15 per cent of cases of autism are associated with a known genetic cause via monogenic syndromes. Such syndromes include the Fragile X syndrome (about 2 per cent), Tuberous sclerosis (about 3 per cent), Rett syndrome, and Timothy syndrome (Chaste & Leboyer, 2012; Lyall et al., 2017; Ornoy et al., 2016; Yates & Le Couteur, 2016). Additionally, cytogenetic research concerned with the study of chromosome aberrations, such as maternal duplication of chromosome 15q11–q13, identified that chromosomal abnormalities occurred in up to 3 per cent of cases of autism (Chaste & Leboyer, 2012; Wegiel et al., 2012). Other studies report that up to 40 per cent of cases of autism could be linked to a known genetic cause (Froehlich-Santino et al., 2014; Hallmayer et al., 2011), suggesting that environmental causative elements may account for the remaining cases (Gardener et al., 2011; Tchaconas & Adesman, 2013).

Environmental factors associated with the prenatal, perinatal, and postnatal periods have been investigated in several studies for their role in autism risk (Wang et al., 2017). During the prenatal period, maternal exposure to environmental chemicals, including heavy metals such as arsenic, lead, cadmium, mercury, and pesticides has been reported to be a risk factor for autism (Dietert et al., 2011). Furthermore, prenatal exposure to teratogenic drugs, such as valproic acid (antiepileptic drug and mood stabilizer) and thalidomide, as well as certain infections (i.e., congenital rubella infection), may be associated with increased risk of autism (Dietert et al., 2011; Lyall et al., 2017). Potential perinatal factors include advanced maternal and paternal age, maternal infection/inflammation, maternal metabolic disorders (i.e., diabetes, gestational weight gain, and hypertension), low birth weight, premature birth, low 5-minute Apgar score, and cesarean delivery (Chaste & Leboyer, 2012; Duchan & Patel, 2012; Guinchat et al., 2012; Lyall et al., 2017; Wang et al., 2017). Several postnatal events may increase the risk of autism in some children. Recent studies have found that complications during labour that cause fetal distress, such as delayed birth cry and birth asphyxia; neonatal immune abnormalities, such as autoimmunity and brain inflammation; as well as gestational infections, such as respiratory tract infections (RTI), have been significantly associated with autism (Hadjkacem et al., 2016; Mamidala et al., 2013; Ng et al., 2017). Prenatal, perinatal, and postnatal factors could interact or contribute in combination with other factors for developing autism (Wang et al., 2017).

Several other factors have been identified to contribute to autism aetiology, the main being socioeconomic status, maternal stress, and the gender of the child. It has been suggested that socioeconomic factors play a key role in the early detection and diagnosis of autism. In particular, lower levels of parental education and family income are significantly related to underdiagnosis for children from low socioeconomic status families (Chaste & Leboyer, 2012; Duchan & Patel, 2012; Ng et al., 2017). In line with this view, a Swedish study highlighted that migration could be a potential risk factor for autism. The researchers have shown that migrant parents from countries with low human development index ranking, when migrated to Sweden during pregnancy, were at increased risk of having an offspring with autism. One possible mechanism that could explain these results is the elevated levels of maternal stress occurring during the process of migration and settlement (Magnusson et al., 2012).

Exposure to environmental stressors during critical periods of prenatal brain development has also been linked with autism aetiology (Ng et al., 2017). Though there have been conflicting studies examining the relationship between prenatal maternal stress and autism, Mueller and Bale (2008) suggested that maternal stress during early pregnancy may affect placental gene expression towards a sex-specific pattern of expression with the male genes being linked to neurodevelopmental disorders. The above-mentioned relationship may also help explain the 'extreme male brain' approach and the involvement of sex-specific biological factors in the development of autism (Baron-Cohen et al., 2011).

The gender of the child is also considered a potential contributor to autism, with a high gender bias toward males (Masi et al., 2017; Zhang et al., 2020). Several theories have argued about the effect of fetal testosterone on brain development, and therefore the incidence of gender differences in autistic traits; as well as the involvement of sex chromosomes (X- or Y-linked genes) in the aetiology of autism (Baron-Cohen et al., 2011). However, none of these theories has succeeded to explain which underlying mechanisms lead to the emergence of autism (Hassan & Mokhtar, 2019). Even if biological factors exist to reduce the likelihood of autism in females, evidence suggests that there is a gender-bias in the current diagnostic criteria which could explain why females may be less likely to meet these criteria, resulting in the underdiagnosis of autism in females (Carpenter et al., 2019).

The complex and heterogeneous nature of autism has made it particularly challenging to determine precise aetiology. While it is commonly recognised that the interrelation between environmental and genetic factors plays a significant role in the development of autism, the causal relationships between these factors need to be investigated through further research (Amaral, 2011). Advances in scientific understanding of the different phenotypes of autism could broaden the understanding of autism and help in early diagnosis and effective intervention planning, with a hope for improved child and family outcomes and quality of life.

Section 2.3. Theoretical Approaches to Understand Autism

2.3.1. The Theory of Mind Deficit Account of Autism

Theory of Mind (ToM) refers to the ability to attribute mental states to others, to interpret and predict their behaviour (Baron-Cohen et al., 1985, 1994). This ability also referred to as mentalizing, is essential for social interaction and has been claimed to lack in children with autism (Frith & Happé, 1999). A particular aspect of ToM that appears to be impaired in children with autism is the ability to understand false beliefs (Baron-Cohen et al., 1985). False-belief understanding usually occurs by the age of four years in typically developing children. It is considered to be a critical cognitive developmental milestone as it reflects the child's ability to understand that a person's belief about the world may differ from reality (Tager-Flusberg, 1999). The most widely used ToM tests in individuals with autism are false-belief tasks. Baron-Cohen et al. (1985) researched children diagnosed with autism, Down syndrome, and typically developing children to test their performance in the 'Sally-Ann' false-belief task, which was developed by Wimmer and Perner (1983). The task involved two dolls, Sally and Ann, and a hidden object. The children were presented a sequence of events, where Sally initially placed an object in one location, and later Ann moved the object to a different location, while Sally was absent. The children were then asked to predict where Sally will look for the object. To give the correct answer, the children had to represent Sally’s mental state (what the doll knows) and predict her behaviour (she will look at the location she initially placed the object), and therefore, be able to distinguish between their knowledge of the object’s real location and that of the doll. The researchers found that 80 per cent of children with autism, who were all older than four years, failed to pass this false-belief task, concluding that children with autism have an impaired ability to represent mental states. These results have been replicated by other researchers using similar or analogous tests, such as the Strange Stories test, the Eye Test, and the Recognition of Faux Paus test, attempting to explain the deficits in reciprocal social interaction and communication that characterise autism (Rajendran & Mitchell, 2007).

Happé (1994) argued about the universality of the impairment in ToM on the grounds that 20 per cent of children with autism passed the false-belief task in the original experiment and hence were able to attribute mental states to self and others. To address the issue of universality in his theory, Baron-Cohen proposed an alternative account, being that the development of a theory of mind, in children diagnosed with autism, is delayed rather than completely absent. A subsequent study has been conducted to test the performance of individuals with autism in second-order false belief tasks. Baron-Cohen (1989) found that none of the participants with autism was able to pass the second-order tasks and concluded that while some individuals with autism could successfully pass first-order false belief tasks, they fail to pass second-order tasks and therefore did not have a fully developed theory of mind. Other researchers argued, however, that some young adults with autism and Asperger Syndrome were able to pass second-order false belief tasks (Ozonoff, Pennington, et al., 1991; Ozonoff, Rogers, et al., 1991b), findings that convinced many supporters of the view that ToM deficits are not universal among individuals with autism.

The ability of some individuals with autism to pass standard false-belief tasks has been further researched by Happé (1995) which showed a strong relationship between language ability and false belief task performance. More specifically, it was shown that autistic children with higher verbal mental age (12 years old and above) were able to pass standard false-belief tasks compared to typically developing children with lower verbal mental age (4 years old). It is clear although, that even older high-functioning individuals with autism exhibit a less spontaneous ability to mentalize, a pattern which is often evident in the early social interactions of typically developing children, and have particular difficulties with non-literal language use such as understanding metaphor, irony, lies, pretence, jokes, and sarcasm (Happé, 1993, 1994; Minshew & Siegel, n.d.; Pellicano, 2010).

The Theory of Mind hypothesis of autism has been challenged by several researchers, given the fact that ToM impairments have also been found in individuals with other neurodevelopmental disorders such as specific language impairment, oral deafness, and congenital blindness (Pellicano, 2010), as well as psychiatric disorders including schizophrenia, bipolar affective disorder, psychopathy and dementia (Brüne & Brüne-Cohrs, 2006). Although the theory of mind hypothesis has attempted to find a causal explanation for the profound social and communication impairments that characterize autism, it has struggled to provide a more comprehensive account of the disorder (Pellicano, 2010). Nowadays, it is unlikely that many people still believe that impairment in the ability to attribute mental states to self and others (ToM) is the sole cause of autism. Current research suggests that rather than focussing on teaching ToM skills to individuals with autism, ToM abilities and deficits should be taken into account in understanding autistic individuals and in designing appropriate support strategies (Livingston et al., 2019).

2.3.2. The Theory of Weak Central Coherence

The Weak Central Coherence theory was proposed by Frith (1989) and reflected upon an inherent tendency of individuals with autism to focus on local information over the global whole. Typical information processing is the tendency to process complex and diverse information into an overall meaning or gist, referred to as ‘drive for meaning’ (Bartlett & Bartlett, 1995). Frith termed this tendency for typically developing individuals ‘central coherence’ and suggested that individuals with autism exhibit a ‘weak’ drive for central coherence, a cognitive bias to process information piecemeal rather than in context. The notion of weak central coherence in autism attempts to explain features of the condition that have been relatively neglected by other theories. These distinctive features are the ‘autistic aloneness’ and the ‘obsessive insistence on sameness’, which have been highlighted by Kanner in his initial clinical observations (Kanner, 1943).

According to Frith & Happé (1994), children with autism tended to perform better on tasks where attention to local information was required, but poorly on tasks requiring the recognition of global meaning. This relative superiority or ‘islet of ability’ of autistic children, was evident in early perceptual processing research. For example, Shah and Frith tested children’s performance on visuospatial tasks such as the Children’s Embedded Figures Test (CEFT, Shah & Frith, 1983; Witkin, 1971); a task that requires to locate a simple part hidden in a complex and larger figure, and the Block Design Test (Shah & Frith, 1993); a task that benefits from an enhanced object processing ability to see the whole design in terms of its segmented parts. They found that children with autism demonstrated better than controls in both tasks, findings that led Frith to formulate the hypothesis of weak central coherence in autism (Frith, 1989, 2003).

Several other studies confirmed and extended these findings with research in central coherence at the verbal-semantic level. Indeed, evidence has shown that children with autism were less likely to use sentence context to determine the meaning and correct pronunciation of a word (Frith & Snowling, 1983; Happé, 1997; Jolliffe & Baron-Cohen, 1999; Snowling & Frith, 1986). This suggests that they might read sentences like a list of unconnected words without interpreting the context of the whole sentence; a cognitive profile of weak coherence that may explain some of the social difficulties seen in autism.

Subsequent research has questioned the presence of weak central coherence in both visual and verbal tasks. For example, Lopez and Leekam (2003) combined visual and verbal tasks in a replication of the homograph reading test, introduced by Frith and Snowling (1983) as a measure of reading comprehension, and they found that autistic participants were committing errors only on the verbal level. Hence, the authors argued that weak central coherence is not a global deficit in autism, but a specific deficit of processing complex verbal information (Lopez & Leekam, 2003). Other studies have found that individuals with autism were able to process information at a global level when specific instructions are given (López et al., 2004; Plaisted et al., 1999), or when differences in language ability were controlled (Hoy et al., 2004; Norbury, 2004, 2005). These results have challenged the universality of the weak central coherence hypothesis in individuals with autism.

The contradictory and complex results from many studies have led Happé and Frith (2006) to propose some changes to the Weak Central Coherence theory. As opposed to Frith's (1989) original account, the modified approach suggested that (1) weak coherence is a secondary outcome of superior local processing which aims to explain only one part of the cognition in autism; (2) weak coherence is not a deficit or dysfunction, instead is considered a cognitive style; and (3) the processing bias that individuals with autism show can be overcome through effort. Nonetheless, the ‘weak’ central coherence notion has been highly influential, attracting attention not only by researchers but also by parents and individuals diagnosed with autism (Happé & Booth, 2008). Empirical research exploring the links between central coherence and autistic children’s performance using dynamic assessment approaches (i.e., dynamic assessments methodology emphasises the assessment of gains in performance on cognitive tasks after mediation is provided) argued that weak central coherence may undermine the gains that might be made in dynamic assessment tasks by children with autism; however, further studies are needed to determine the specific mediational strategies that can accommodate the effects of weak central coherence in children with autism (Aljunied & Frederickson, 2013).

2.3.3. The Theory of Executive Dysfunction

The Executive Dysfunction hypothesis in autism is linked to frontal lobe dysfunctions which often occur after brain injury (Ozonoff, Pennington, et al., 1991). The broad term ‘executive function’ includes functions such as working memory, initiation, inhibition, impulse control, and planning (Denckla, 1996). Executive dysfunction, and particularly insistence on sameness, difficulties in inhibition, lack of impulse control, and flexibility of thought, could explain the core deficiencies that characterize autism both in social and non-social domains (Hill, 2004; Joseph & Tager–Flusberg, 2004). The theory of executive dysfunction in autism posits a primary domain-general deficit, as opposed to a domain-specific deficit of the theory of mind (Rajendran & Mitchell, 2007).

One of the first studies of executive functions that tried to identify the primary deficit in autism was conducted by Ozonoff et al., (1991). The performance of high-functioning children with autism and Asperger Syndrome was compared with typically developing children on the theory of mind (ToM) and executive functions (EFs) tasks. The executive functions tasks involved the Tower of Hanoi (ToH), which measures planning ability, and the Wisconsin Card Sorting Test (WCST), which measures mental flexibility. The researchers found that the autistic group performed poorly in the executive function tasks as related to the comparison group. In reverse, the executive function impairments were present in the entire group, and thus, EFs tasks were better at distinguishing individuals with autism than were ToM tasks. This evidence suggests that executive function deficits might be a primary deficit in autism (Hughes & Russell, 1993; Ozonoff, Pennington, et al., 1991; Russell, 1997).

Alternative accounts, though, have challenged the universality of executive dysfunction across individuals with autism. Liss et al. (2001), reported that executive deficits were found in 57 per cent of their group; a finding which was consistent with Pellicano et al.'s (2006) report of executive problems in 50 per cent of their sample. Executive function impairments are also present in Attention-Deficit/Hyperactivity Disorder (ADHD), Tourette Syndrome, and Obsessive-Compulsive Disorder; hence, the uniqueness of the executive dysfunction hypothesis in autism is questioned (Hill, 2004). Moreover, the challenges the executive dysfunction account in autism has faced were due to the absence of an operational definition of executive function (Hughes & Graham, 2002), and failure to replicate the results of other studies (Hill, 2004; Hill & Bird, 2006).

Numerous studies have attempted to elucidate the nature of executive function by measuring task-specific executive skills. For example, researchers have consistently found that planning ability, assessed by Tower tasks (e.g., Tower of Hanoi/London), is impaired in individuals with autism (Bennetto et al., 1996; Ozonoff, Pennington, et al., 1991; Ozonoff, Rogers, et al., 1991; Ozonoff & Jensen, 1999; Ozonoff & McEvoy, 1994). However, Mari et al. (2003) assessed the performance of autistic children with different levels of intelligence in a kinematic reach-to-grasp task and found negative results. Hence, the researchers suggested that planning ability was associated with IQ rather than autism.

Mental flexibility (set-shifting) has been measured by several studies using the Wisconsin Card Sorting Test (WCST) (Grant & Berg, 1993). While autistic individuals showed high perseverative responses in this task, there was variability in the performance of those with IQ in the normal range (Hill, 2004). For inhibition, the Stroop Colour and Word Test (SCWT) and the Windows task have been extensively used to assess inhibitory control in children and adults with autism. In two studies, the Stroop test showed that performance was more likely related to task requirements since both the autism and control groups displayed similar interference control problems (Eskes et al., 1990; Ozonoff & Jensen, 1999). Conversely, the Windows task that has been replicated in several studies (e.g., Hughes & Russell, 1993; Russell et al., 1991, 2003) consistently showed impairments in prepotent response inhibition in individuals with autism.

Studies of executive dysfunction in autism have also examined the ability to produce novel responses on generativity tasks. In such studies, individuals with autism show impaired generativity on tests of word fluency (Minshew et al., 1992; Rumsey & Hamburger, 1988), imaginative drawing tasks (Lewis & Bouchet, 1991), and in spontaneous pretend play (Jarrold et al., 1996). Another component of executive functions is self-monitoring, a cognitive process that refers to the ability to evaluate others' social cues and adjust one's behaviour accordingly. Studies examining self-monitoring in autism have produced mixed results, due to the lack of evidence to support a specific deficit in self-monitoring in autistic individuals when compared with matched control groups (Hill & Russell, 2002; Russell & Hill, 2001). Nonetheless, the theory of executive functioning offers a compelling framework for an investigation into the nature of executive impairments in autism, however, further research is needed to test the underlying pattern of executive dysfunction in children with autism.

2.3.4. The Hyper Systemizing Theory

The hyper-systemizing theory was proposed by Baron-Cohen (2002) in an attempt to explain why individuals with autism resist change or have a strong preference for lawful or predictable systems, such as calendars or train timetables (Hermelin, 2001). According to the theory, individuals with autism have a high systemizing mechanism that enables them to process information that is highly law-governed or ‘systemizable’, at a superior level than the typically developing individuals (Baron-Cohen, 2006). Moreover, research suggests that strong systemizing could explain the non-social features of autism, such as repetitive behaviours, obsessional interests, and insistence on sameness (Baron-Cohen, 2006; Wheelwright & Baron-Cohen, 2011).

According to Baron-Cohen’s theory, in the general population, there are four levels of systemizing: Level 1 corresponds to individuals who have little or no drive to systemize, and therefore they can cope with rapid, unlawful change; Levels 2 and 3 correspond to individuals who have some interest in lawful systems, though research suggests that more females in the general population are at Level 2 and more males are at Level 3 (Baron-Cohen et al., 2003; Lawson et al., 2004; McClure, 2003); and at Level 4 individuals are talented at understanding highly lawful systems and their ability to systemize is above average (Baron-Cohen, 2005).

Baron-Cohen (2006) argued that individuals with autism have a different systemizing mechanism that is higher than average, ranging from levels five to eight. Experimental evidence supporting this view has shown that individuals with autism demonstrate superior systemizing abilities on the Systemizing Quotient (SQ) (Baron-Cohen et al., 2003). Moreover, autistic individuals present a normal to high performance on intuitive physics tasks (Baron-Cohen, Wheelwright, Spong, et al., 2001; Jolliffe & Baron-Cohen, 1997; Lawson et al., 2004; Shah & Frith, 1983), while they demonstrate savant abilities in domains such as mathematics, physics, or computer science (Jolliffe & Baron-Cohen, 1999), have extraordinary talent in art

(Myers et al., 2004) and great attention to detail (O’riordan et al., 2001; Plaisted et al., 1998). Baron-Cohen (2006) concluded that high-functioning individuals with autism would be rated a level six in the continuum, while medium- and low-functioning individuals would be rated a level seven and level eight accordingly.

The hyper-systemizing theory has further proposed to explain the underlying behavioural patterns of individuals with autism. An individual with a hyper-systemizing mechanism would focus on rule-governed or predictable systems (such as mathematics, objects that spin, collections), and they become disabled when they have to deal with the complex and rapidly changing social world that cannot be easily systemized. The hyper-systemizing theory can also explain the social isolation, the need for sameness, as well as the language and cognitive differences among individuals with autism. Additionally, the generativity deficits observed in autism can be explained from a hyper-systemizing viewpoint; it may be due to an inability to understand and follow rules that are arbitrary and unpredictable. Finally, some individuals may have a superior talent in areas that are ‘systemizable’, which can explain the extraordinary abilities of some individuals with autism (Baron-Cohen, 2006).

The hyper-systemizing theory can account for both weak central coherence and executive dysfunction theories as the tasks used in both approaches require the ability to process information that is not highly systemized. Hence, if children with autism are approaching these tasks with a systemizing lens, this may explain the observed differences in following arbitrary and unpredictable rules. Baron-Cohen's (2006) theory has higher explanatory power than other cognitive theories of autism, however, further research is necessary to understand the unique ways of how children with autism process and utilize information.

2.3.5. The Extreme Male Brain Theory

A growing body of evidence indicates that there are important differences in the brains of males and females. Sex differences in the empathizing and systemizing skills within the general population, have led theorists to investigate the possibility of an extreme cognitive pattern in autism (Baron-Cohen, 2002). Empathizing is the ability to understand other people's thoughts and feelings and react appropriately, also referred to as affective empathy (Davis, 1994). Systemizing is the ability to recognize complex patterns and understand lawful systems (e.g., computers or maths). Prior research suggests that females show a stronger tendency to empathize than males, and males show a stronger systemizing tendency than females (Geary, 1998; Maccoby, 1999). These findings led Baron-Cohen (2002) to the hypothesis that autism is an extreme expression of the male brain, a notion that has become known as the theory of the Extreme Male Brain in autism (EMB) (Baron-Cohen, 2002; Baron-Cohen et al., 2003).

According to the EMB theory, both males and females with autism tend to have a strong systemizing drive, while they experience delays or deficits in empathy. Such a cognitive profile explains the severe social difficulties in autism pertaining to impaired affective Theory of Mind, as well as the obsessional interests pertaining to intact or even enhanced abilities in systemizing (Baron-Cohen, 2002; Baron-Cohen et al., 2003). Two self-report questionnaires have been developed (Baron-Cohen et al., 2003), to assess an individual's ability to empathize and systemize: the Empathy Quotient (EQ) and the Systemizing Quotient (SQ). Findings from Baron-Cohen et al.'s (2003) study showed that women tended to score higher than men in the EQ, whereas men tended to score higher than women in the SQ in the general population. Individuals with autism of both sexes performed lower than control groups in the EQ. Goldenfeld et al. (2005) further suggested that there are five brain 'types', given the gender differences in brain structure and connectivity. The 'empathizing' (type E) individuals with a stronger drive to empathize than to systemize (E>S). The 'systemizing' (type S) individuals with a stronger drive to systemize than to empathize (S>E). The 'balanced' (type B) individuals whose empathy and systemizing are balanced (E=S), also called as 'balanced brain'. Individuals whose empathy is above average but systemizing is average or below average, have a brain type of 'Extreme type E' (E>>S); the 'Extreme type S' individuals who systemize at an average or above-average level, but their drive to empathize is below average (E<<S), also known as 'mind-blindness' (Baron-Cohen, 1997, 2002, 2010; Baron-Cohen et al., 2003). The Empathizing-Systemizing (E-S) model has been used to describe the gender difference in the general population. On average, females have a type E brain, while males have a brain of type S. The E-S model provided further evidence to confirm the EMB theory in autism, as the majority of autistic individuals have an Extreme type S cognitive profile (Goldenfeld et al., 2005).

Proponents of the EMB theory have also suggested that individuals with autism tend to show superior performance on cognitive tests on which males typically outperform females. More specifically, on tests of attention to detail, including the *Embedded Figures* test (Jolliffe & Baron-Cohen, 1997) and the *Block Design* task (Shah & Frith, 1993), autistic individuals score above average compared to typical males. In contrast, on tests of empathy that females tend to perform better than males, such as the *faux pas test* (Baron-Cohen et al., 1999) and the *Reading the Mind in the Eyes Test* (Baron-Cohen et al., 1997), individuals with autism score below average compared to typical males. Moreover, findings from a study by Auyeung et al. (2009) have shown that elevated levels of fetal testosterone in utero may alter the brain structure and cause hyper-masculinization. Levels of fetal testosterone are on average, higher in the male fetus than in the female, therefore there might be a link between excess fetal testosterone and the development of autism.

Taken together, the EMB theory attempted to explain the male predominance in autism (Baron-Cohen & Hammer, 1997), however, the account as to whether autistic traits should be viewed as an extreme expression of the systemizing type or male intelligence has not yet been confirmed. Moreover, the EMB theory has been criticized for gender stereotyping underlying Baron-Cohen's brain profiling, which could have serious implications for support and services for both girls and boys with autism (Krahn & Fenton, 2012). Nevertheless, further investigations are needed to better understand sex-related profiles among individuals diagnosed with autism.

2.3.6. The Link Between Theory to Research and Practice

The abovementioned theoretical accounts have contributed to a deeper understanding of how individuals with autism might process the world, as well as the various challenges they might face in everyday life. Each of these theories has had a significant influence on research and practice, by informing the design and delivery of interventions to support the educational, health, and social needs of autistic individuals (Prizant & Fields-Meyer, 2015; Silberman, 2015). However, none of the psychological models of autism has taken into account parent-related factors in connection with autism interventions, and specifically, the way parents understand the unique characteristics of their children with autism.

Early identification, diagnosis, and intervention can optimize the child's development and lead to improved outcomes for children with autism and their families (Bailey et al., 2006). However, while there is a recognition that parent integration into the intervention process is crucial for both the efficacy and effectiveness of an intervention, integrated research frameworks invariably overlook parent-related factors that may influence both the short-term and long-term effects of the intervention (Karst & Van Hecke, 2012). The current research is aiming to promote knowledge about how parents understand the potential and unique needs of their autistic children by developing an evidence-based profiling tool that can be used to inform decisions for intervention strategies that are tailored to the specific needs of the child with autism and their caregivers, and thus bridging the gap between research and practice.

Section 2.4. Factors that Influence Parental Understanding of Autism

2.4.1. Socioeconomic Factors

Early identification and diagnosis are vital for children with autism to facilitate earlier intervention and appropriate support services (Rhoades et al., 2007; Rutter, 2006). Research has shown that early intervention can lead to improved outcomes for children with autism and their families (Rogers et al., 2012; Wainer et al., 2017). However, factors such as socioeconomic characteristics (i.e., family income, parent education level), may influence parental recognition of early signs of autism and therefore, the age of the diagnosis (Fountain et al., 2011). Most previous studies have reported a positive association between high socioeconomic status (SES) and higher rates of autism diagnosis or prevalence (Dickerson et al., 2017; Durkin et al., 2010; Fountain et al., 2011; Tek & Landa, 2012). This positive association might be due to different levels of educational and financial resources (Fountain et al., 2011), as well as various opportunities to access health services, with the most advantaged groups being able to secure access to healthcare earlier (Fujiwara, 2014; Mazurek et al., 2014). Therefore, it has been suggested that diagnostic delays are more likely to occur in children from poorer households and with less-educated parents (Durkin et al., 2010). Moreover, healthcare providers in low SES areas may lack adequate training, or may not have as much time per patient to accurately diagnose children with autism (Thomas et al., 2012).

Many of the studies examining diagnostic disparities have focused on the relationship between SES and delayed access to evaluation, diagnosis, and health services (Hrdlicka et al., 2016). However, results are contradictory regarding the impact of SES on autism prevalence. Studies in the United States have shown that children from families with higher SES levels (Durkin et al., 2010; Fountain et al., 2011; P. Thomas et al., 2012) as well as children whose parents have higher levels of educational attainment (Dickerson et al., 2017; Mazurek et al., 2014), are more likely to receive a diagnosis of autism at a younger age. A study in the Czech

Republic is in agreement with the US findings, that a higher parental education level is associated with a younger age of their child’s diagnosis, however, no link was found between SES and an earlier diagnosis of autism (Hrdlicka et al., 2016). Opposite results have also been reported in countries with universal healthcare systems. In a study from Canada, it was found that family income support was associated with a greater autism risk, which possibly reflects a relationship between different income groups and risk of autism (Dodds et al., 2011). Similarly, results from a Swedish study showed that lower SES was associated with higher rates of autism diagnosis (Rai et al., 2012). Moreover, a population-based study in Japan reported a higher prevalence rate of suspected autism in toddlers whose mothers had lower levels of education attainment (Fujiwara, 2014).

In the United Kingdom, studies that focus on the impact of SES on autism prevalence have shown contradictory results. For example, a large study in South Thames has demonstrated that lower levels of parental education were associated with lower rates of autism diagnosis. This was the first study to report socioeconomic differences in autism diagnosis in the United Kingdom (Baird et al., 2006). Conversely, Sun et al. (2014) conducted a smaller study in Cambridgeshire and found no link between SES and the diagnosis of autism. However, the discrepancies between the results of the two studies may be related to other factors, such as different study designs, sample size, or geographic location. In a more recent study in Bradford City, Kelly et al. (2019) reported that higher levels of maternal education were strongly related to the probability of having a child who has received a diagnosis of autism. The authors suggested that socioeconomic factors, and in particular, the education level of a parent may affect timely diagnosis.

Several studies have also examined the relationship between early recognition of autism symptoms and socioeconomic differences. For example, Fountain et al. (2011) indicated that socioeconomic factors might contribute to parent identification of early autism signs. Most notably, the researchers found that parents with lower levels of education might be less likely to identify symptoms of autism in their children, or might be less able to navigate healthcare systems to obtain an earlier diagnosis (Fountain et al., 2011). Likewise, another study found that parents of low income and educational backgrounds were less likely to view autism as a medical condition. That is, families living in poverty may be having difficulties understanding and interpreting their child's behaviour in a medical context. Families living near poverty may feel less able to seek professional advice and support for their child's condition. Parents with lower levels of education may hold both of these beliefs (Zuckerman et al., 2015). Conversely, it has been suggested that SES does not appear to affect identification for children with higher levels of autism symptom severity, as parents of children with more severe communication and social deficits and more severe autistic symptoms can recognize signs of autism earlier and seek a diagnosis (Mazurek et al., 2014).

Other studies have examined the association between autism prevalence and SES, race, ethnicity, and immigrant status. Individuals from minority racial groups are more likely to experience higher rates of poverty and profound barriers to quality education and learning resources (Gradín, 2012). Disparities across socioeconomic and ethnic groups in the identification, diagnosis, or prevalence of autism are consistently reported. Within the Centers for Disease Control (CDC) samples a higher incidence of autism is indicated in children from white backgrounds compared to children from non-white backgrounds (Centers for Disease Control and Prevention, 2014; Dickerson et al., 2017; Durkin et al., 2010; Mandell et al., 2009; Tek & Landa, 2012). For example, a recent review highlighted that race and ethnicity may have a significant impact on a timely and accurate diagnosis of autism. Specifically, children from traditionally underserved populations tend to receive a significantly delayed diagnosis of autism as regards age and time spent in treatment before diagnosis, compared to children from Caucasian backgrounds and those from higher SES areas (Nowell et al., 2015).

A study examining the relationship between maternal race/ethnicity and nativity, and autism prevalence in the United States reported that immigrant black, Filipino, and Vietnamese mothers have higher risks of having a child with autism, intellectual disability (ID), and expressive language impairment compared to white US-born mothers (Becerra et al., 2014). However, other US studies have found no link between race/ethnicity and autism prevalence (Kogan et al., 2009; Thomas et al., 2012; Yeargin-Allsopp et al., 2003). Conversely, a population-based study in France reported a significantly higher prevalence of autism with intellectual disability (ID) among individuals living in poverty, unemployed, people without qualifications, immigrants, and single-parent families. Moreover, a higher prevalence of autism without ID was found in areas with the highest number of immigrants. The authors have suggested that in countries with universal and free healthcare systems, immigrant families generally appear to be at higher risks of having an offspring with autism, with ID or without ID, regardless of SES or equity in health care (Delobel-Ayoub et al., 2015).

The reasons for disparities in prevalence and diagnosis for minority children with autism are numerous and may also include cultural differences and communication barriers. Tek and Landa (2012) reported that although minority and non-minority children in their sample were from similar SES groups, minority children had more profound delays in language and communication. This finding suggests that parents from different cultural groups with similar SES backgrounds may interpret child behaviour problems within their cultural context (Tek & Landa, 2012). Communication barriers between minority parents and healthcare providers may further interfere even when parents note developmental differences in their children. Language barriers may arise in non-English-speaking parents; cultural barriers may influence parent-professional communication. Additionally, parents from different cultural contexts may be less willing to discuss openly their concerns due to respect to professionals' authority (Nowell et al., 2015; Tek & Landa, 2012). As can be concluded from the above, the results are conflicting regarding the impact of SES on autism; however, given that socioeconomic factors may be associated with autism prevalence, as well as access to services and therapy, in the current research it was deemed important to consider these factors as related to parental understanding of autism.

2.4.2 Sociocultural Factors

The ways parents view autism and the decisions they make for the child with autism and the family interrelate with their cultural background (Ennis-Cole et al., 2013). Culture is a broad set of behaviours, beliefs, values, attitudes, and customs shared by a group of people or community and passed from one generation to another (Helms & Cook, 1999). Given the sparse literature concerning autism and culture, broad descriptions will be used to describe the impact of culture on how one perceives and explains disability in general, and autism in particular (Adams et al., 2007).

According to Gray (1994), parents develop their own explanatory models of autism to help them interpret and construct meanings about the disorder. Previous studies have demonstrated that parents attribute autism to several causes including genetic factors, pregnancy-related events, vaccinations, and environmental factors (Goin-Kochel et al., 2015; Hebert & Koulouglioti, 2010). However, parental causal beliefs are different in Western and Eastern cultures. In the Western world, people are generally defined by individualism, leading parents to foster independence in their children; whereas Eastern cultures are more collective, and people are defined by their family and social connections above all else (Hofstede et al., 2005). In some Asian societies, for example, having children with genetic/genomic disorders is considered a stigma (Sleeboom-Faulkner, 2010). Shyu et al. (2010) explored parental explanatory models about autism in Taiwan and found that parents attributed their child's condition to both traditional biomedical and supernatural explanations without apparent conflict. However, findings from a more recent study on Taiwanese parents’ beliefs indicated that while parents perceived genetics as the cause of their child’s autism, they tended to favour non-genetic causal explanations to avoid social stigma and discrimination (Chen et al., 2015). Similarly, studies in other Asian settings such as Korea, China, and Vietnam have shown that autism is socially constructed upon stereotypes of mental illnesses, and children with autism and their families usually experience various forms of stigma as a consequence of misunderstandings about the disorder (Ha et al., 2014; Kang-Yi et al., 2013; Mak & Kwok, 2010; Sun et al., 2013).

Many studies have examined the role of religion in the understanding of autism for parents from different cultural groups. For example, parents who take a fatalistic view of their child’s condition are more likely to attribute autism to fate or destiny. As such, results from a study of Muslim parents from South Asia showed that autism was perceived as a ‘gift from God’ or that it was ‘God’s will to raise a special child’ (Jegatheesan et al., 2010). Similarly, data from a pair of case studies of families from two different cultural backgrounds revealed that Asian American families held more religious beliefs about autism compared to European American families (Sage & Jegatheesan, 2010). Also, a study in Saudi Arabia exploring how parents’ religious and cultural beliefs influence their understanding of autism, revealed that parents were more likely to attribute autism to non-medical causes (i.e., the evil eye) to be less stigmatized (Alqahtani, 2012). Within the Hispanic population in the US, studies have reported that cultural and religious beliefs may influence parents’ interpretation of the development of autism. In particular, Hispanic/Latino families may perceive autism as temporary or that their child would be treated through prayer and God’s intervention (Ijalba, 2016; Tek & Landa, 2012).

Religion has also emerged as a contributing factor in the parental understanding of autism in African cultures. For example, a study conducted on the Kenyan Coast revealed that parents of children with autism held both preternatural and biomedical beliefs about the causes of autism. In particular, it has been found that preternatural beliefs involved evil spirits, witchcraft, and curses. In contrast, biomedical beliefs that included exposure to harmful organisms and genetic elements were embraced mostly in urban areas (Gona et al., 2015). Burkett et al. (2017) found that strong faith in God and religion positively influenced African American parents' beliefs about caring for their children with autism. Parents believed that having a child with autism was a blessing from God which promoted the family's spiritual growth. On the contrary, it has been suggested that African immigrant parents tend to accept western medical explanations about their child's autism to avoid blame and stigmatisation within the African community, with a tremendous impact on their traditional cultural and religious beliefs (Munroe et al., 2016). Thus, the cultural and religious background of a family and community seems to play an essential role in parents' beliefs about their child's condition, but there are issues of generalisability.

Cultural factors may also influence parents' interpretation of early symptoms of autism (Bernier et al., 2010; Matson, Worley, et al., 2011). For example, in Japanese culture, children may avoid direct eye contact with adults as a sign of respect. However, in many Western cultures, reduced eye contact is considered one of the early signs of autism (Freeth et al., 2013). Respectively, other characteristics of autism, such as echolalia or question repetition, can be viewed as more challenging for Asian parents than parents from Western countries (Dyches et al., 2007). It has further been suggested that in some African cultures, certain behaviours such as pointing gestures, are considered inappropriate and thus, may influence parental interpretation of autism-related social symptoms (Perepa, 2014). Hence, specific characteristics of autism that are generally recognised earlier in some cultures may not be perceived as problematic by parents in other cultures (Daley, 2004; Daley & Sigman, 2002; Liu, 2005; Matson, Worley, et al., 2011; Norbury & Sparks, 2013; Perepa, 2013, 2014).

Sociocultural differences in parental recognition of early signs of autism and lack of knowledge and awareness about autism may be potential barriers to early assessment and intervention services (Freeth et al., 2013). For example, a study indicated that within the Latino community, many parents of typically developing children had not heard the word ‘autism’ or had little information about it. Moreover, some parents perceived early signs of autism as in the normal range or as due to parent-child relationship problems (Zuckerman et al., 2014). More recent research in White and Latino mothers of children with autism, however, revealed that understanding about autism might vary in linguistically diverse groups. In particular, Latino mothers with limited English proficiency may misunderstand autism due to limited knowledge or access to resources, compared to English proficient White and Latino mothers (Reyes et al., 2018).

A cross-sectional study of Chinese parents of kindergarten children showed that while parents have heard of autism (93.9 per cent), only 57.8 per cent of all participants could correctly recognise it (Wang et al., 2012). These findings, were consistent with previous research exploring the knowledge and beliefs about autism across multiple healthcare professions in the US (Heidgerken et al., 2005), suggesting that misconceptions about autism may hamper early identification and intervention. Huang and Zhou (2016) highlighted that Chinese parents of children with autism tend to perceive autism as temporary and hope that their child may ‘grow out’ of it. This misinterpretation was reinforced by the child’s actual behaviour which was notably different from parents’ preconceived notions of the nature of autism. For example, parents’ perceptions of autism often involved the presentation of much more severe behavioural symptoms or repetitive behaviours, however, they believed that their child had the capability or the potential to engage socially and interact with others if they were properly engaged or if the social interactions were initiated by another adult (Huang & Zhou, 2016). Accordingly, Desai et al. (2012) found that parents of autistic children in Goa, India, had never heard of the term ‘autism’ or perceived it as temporary before their child’s diagnosis. Moreover, the authors highlighted that parents often overlooked the early signs of autism despite noticing particular disruptive behaviours in their children (Desai et al., 2012).

Research on parents’ and professionals’ understanding of autism in rural and urban Nepal has revealed a worrying lack of awareness about autism and limited understanding of the condition as a distinct named entity especially in rural areas (Heys et al., 2017). Similarly, a general lack of knowledge and understanding of autism has been documented in the UK Somali community. In particular, Somali parents faced challenges to describe and explain autism due to the lack of a Somali word for autism and the stigma associated with mental illness and disability within the Somali community (Fox et al., 2017). Additionally, a study conducted in Canada by Pondé and Rousseau (2013) on immigrant parents’ perceptions of their children with autism, revealed that mothers from Arab countries and North America were more likely to mention autism-related symptoms compared to Asian, Latino and Caribbean mothers, who considered that their child had a ‘developmental delay or communication problem’ or ‘no problem at all’. The authors suggested that parents’ perceptions were influenced both by their cultural background and by the prevalent representations of autism in the host country (Pondé & Rousseau, 2013).

Relevant research suggests that a family’s cultural background directly influences the decisions that parents make about intervention services and resources available for their children (Ennis-Cole et al., 2013). For example, Chinese parents rarely seek professional help (Huang & Zhou, 2016); possibly due to limited knowledge about the appropriate health professionals whom they should contact for diagnosis and treatment (Wang et al., 2012). Shyu et al. (2010) suggest that parents in Taiwan tend to select treatments based on their attribution of causes, the effect of the treatment plan on the child, the closeness of the relationship to the therapist, accessibility, and affordability. Moreover, Taiwanese parents prefer to combine traditional medical therapy and alternative therapies (such as sensory integration, acupuncture, and diet) (Shyu et al., 2010). Previous research has also found that Chinese parents tend to use more than one intervention for their children with autism, which may vary from applied behaviour analysis (ABA) to acupuncture and herbal medicine (Freeth et al., 2013; Ravindran & Myers, 2012).

According to Zuckerman et al. (2014), Latino parents are less likely to seek professional help for their child with autism, because they often feel ignored and dismissed by healthcare providers or that they receive limited information about autism. Furthermore, Gona et al. (2015) reported that African parents use both traditional and biomedical treatment for their children with autism. However, after visiting several professionals at different health facilities without success, parents are more likely to seek help from traditional and spiritual healers in pursuit of a cure for their child's autism (Gona et al., 2015). Other studies have suggested that African American parents rely heavily on the extended family or their church and are less likely to seek professional help (Burkett et al., 2015, 2017) whereas White American parents are more likely to employ both traditional treatments and professional services (Ennis-Cole et al., 2013).

Taken together, cultural influences seem to play an important role in shaping parents, professional, and community understanding of autism and may inform parents' expectations for intervention outcomes for their children with autism (Ravindran & Myers, 2012). Therefore, cultural factors can impact how autism is understood, interpreted, and accepted in different communities, and may influence how the family cares for the child and accesses services; in the current research, sociocultural aspects were considered as related to parental understanding of autism.

2.4.3. Child Factors

Current research suggests that parental understanding of autism may affect help-seeking attitudes and decisions about treatment (Mire et al., 2017). Parents' perceptions about autism may be influenced by child-specific factors, such as the child's behaviour and maladjustments, the presence of co-occurring conditions, as well as the severity of autism symptoms (Dovgan et al., 2019; Zablotsky et al., 2017). Concerning the child's behaviour, several studies have found that parents' primary concerns are related to language and communication impairments, followed by challenging behaviour and difficulties with social interaction (Guinchat et al., 2012; Herlihy et al., 2015; Hess & Landa, 2012; Kozlowski et al., 2011; Moh & Magiati, 2012; Sacrey et al., 2015; Zablotsky et al., 2017). While some challenging behaviours are easily noticed, especially those related to social-communication difficulties such as social withdrawal, others may not specifically relate to a diagnosis of autism, including motor skill deficits, sensory abnormalities, sleep problems, lack of attention, emotion dysregulation, or abnormal levels of activity. Guinchat et al. (2012) suggest that the variety of concerns expressed by parents reflects individual differences in perceptions about autism and expectations towards the child's development. For instance, parents are more likely to raise concerns about social development for 'shy' sons than daughters (Bumiller, 2008; Guinchat et al., 2012; Miller, 2003).

It has been suggested that the gender of the child may influence parents' perceptions about autism. Previous studies have reported that boys with autism tend to exhibit more restricted and repetitive behaviours than girls (Hartley & Sikora, 2009; Hattier et al., 2011; Mandy et al., 2012; Sipes et al., 2011). There is also evidence that girls with autism are diagnosed earlier than boys when they present concurrent intellectual disability (Fombonne, 2003, 2009; Rivet & Matson, 2011) with severe social, communicative, and cognitive functional impairments (Banach et al., 2009; Carter et al., 2007; Crick & Zahn–Waxler, 2003).

However, intellectually able girls with autism tend to be diagnosed later than boys, despite there being no difference in the number of professional visits (Siklos & Kerns, 2007) and the age of the child when the parents expressed their first concerns (Begeer et al., 2013). Nevertheless, the gender of the child may influence parents' perceptions of autism symptoms, given that girls with autism may mask their autism symptoms by imitating and memorising socially appropriate behaviours to appear 'typical' (Holtmann et al., 2007; Wing, 1981).

Parents' perceptions may also be influenced by other factors, such as having an older child with autism or the simultaneous presence of intellectual disability, motor or language delays, and medical problems. It has been reported that parents who have an older child with autism may express earlier concerns about the younger sibling because they are more aware of early signs of autism and deviations from the typical developmental pattern (Herlihy et al., 2015; Hess & Landa, 2012; Ozonoff et al., 2009; Zablotsky et al., 2017). According to Hartley et al. (2013), parents of children with autism and comorbid intellectual disability perceive their child's behaviour problems as more internal and stable and less controllable by the child. Moreover, they report more autism symptoms and a higher level of severity compared to parents of children with autism alone. Hence, parents who believe that more stable and internal characteristics cause their child's challenging behaviour may feel hopeless about their own or their child's ability to control the problem behaviour (Hartley et al., 2013).

Several studies have found more challenging behaviour and greater severity of autism symptoms among children and adolescents with co-occurring conditions (Duerden et al., 2012; Goldman et al., 2011b; Maskey et al., 2013; Matson et al., 2010; Mazurek et al., 2013; Rzepecka et al., 2011; Tseng et al., 2011). For example, it has been reported that younger autistic children with lower language skills and those attending Special School experience more frequent problem behaviours including sensory difficulties, sleep, eating and toileting problems, hyperactivity, and self-injurious behaviour (Maskey et al., 2013). Findings from a study examining the relationship between challenging behaviour and socialization in early childhood revealed that lower levels of adult and peer interaction are associated with a higher frequency of problem behaviours including stereotypical, aggressive/destructive behaviour and self-injury (Matson et al., 2010). Other research has suggested that behaviour problems, and in particular aggression may cooccur with self-injury, and sleep and sensory problems among autistic children and adolescents (Mazurek et al., 2013). Similarly, Duerden et al. (2012) found that self-injurious behaviour is more likely to occur in children and adolescents with autism who also have sensory processing dysfunction, sameness behaviour, impaired social functioning, and non-verbal cognitive ability.

Further findings support the relationship between co-occurring sensory dysfunction and emotional and behavioural problems in children with autism (Tseng et al., 2011). Accordingly, Rzepecka et al. (2011) examined the relationship between sleep problems, anxiety, and challenging behaviour, assessing children with an intellectual disability (ID) and autism and typically developing children. The authors found that children with ID and autism who suffer from sleep problems and anxiety displayed more challenging behaviour than typically developing children. A similar pattern was reported in a study with 1784 children and adolescents with a confirmed diagnosis of autism. In particular, an association was found between poor sleep and behaviour problems from early childhood to adolescence in individuals with autism (Goldman et al., 2011b).

Recent research suggests that the child's specific characteristics may also influence parent ratings of autism severity. In particular, the impact of developmental delays, intellectual disabilities, and co-occurring conditions on the child's overall development and functioning may influence parents' perceptions of the severity of autism symptoms alone (Dovgan et al., 2019). Although such concurrent conditions likely impact the presentation of the core autism symptoms (Maskey et al., 2013), it has also been reported that the severity of the child's disability and problem behaviours are associated with higher levels of stress in parents of children with autism (Hastings, 2003). Therefore, a variety of factors related to the individual characteristics of children with autism appear to influence parental understanding of the nature and course of autism.

2.4.4 Parent Factors

Parenting a child with autism has the potential to be extremely challenging and demanding. Previous studies have shown that compared to parents of children with other disabilities or parents of typically developing children, parents of children with autism experience increased stress and other mental health issues, including anxiety, psychological distress, and depression (Broady et al., 2017; Dabrowska & Pisula, 2010; Davis & Carter, 2008; Duarte et al., 2005; Estes et al., 2009; Gatzoyia et al., 2014; Gray, 2002; Hayes & Watson, 2013). Moreover, a lack of public understanding and awareness can have a significant impact on parents (Glazzard & Overall, 2012; Huws & Jones, 2010; Neely-Barnes et al., 2011). In a recent study, McMahon et al. (2020) found that due to the Dunning-Kruger effect ((Kruger & Dunning, 1999)), a cognitive bias in which individuals with low ability at a task often overestimate their performance), the general public's perceived knowledge of autism may not be related to their actual knowledge of autism. In particular, individuals who have low actual knowledge of autism may not be aware of their ignorance, which may be particularly concerning when such individuals are autism service providers that may both provide lower quality support and be less likely to improve the quality of that support in the future due to high perceived knowledge of autism (McMahon et al., 2020).

Public perceptions of autism may also be influenced by beliefs of exceptional or savant skills promoted by the media; beliefs that people with autism are unable to live independently, as well as beliefs that autism is not a distinct clinical diagnosis, but a type of mental illness, mental retardation or learning disability (Huws & Jones, 2010). These perceptions can have a profound effect on parents of children with autism. Several studies indicated that parents felt judged for poor parenting or blamed for causing their child's autism, which subsequently resulted in stigma and social isolation (Farrugia, 2009; Hutton & Caron, 2005; Neely-Barnes et al., 2011; Woodgate et al., 2008a). These experiences, however, are not limited to the general public with studies revealing that extended family members and friends may also lack understanding of autism (Broady et al., 2017; Papadopoulos et al., 2019). Moreover, Kinnear et al. (2016) highlighted that stigma and the child's autism-related behaviours can play a significant role in how challenging parents perceive the experience of caring for their child with autism. Given the difficulties that many families experience with raising a child with autism, it is understandable how such factors could influence parental understanding of their child's unique traits.

The individual characteristics of the parents of children with autism may also relate to their understanding of the condition. Gender differences may exist in parents' perceptions of their child's symptoms related to autism (Dovgan et al., 2019). For instance, mothers of children with autism may report emotional and social adjustment problems of their children more frequently than fathers, possibly due to the mother's closeness to the child during infancy (Guinchat et al., 2012; Matson, Hess, et al., 2011). Moreover, prior studies have demonstrated that parents of children with autism experience higher rates of depression than parents of children with Down syndrome and those of children with other types of disabilities (Bolton et al., 1998; Micali et al., 2004; Piven & Palmer, 1999). These studies identified that the first parental depressive episode occurred before the birth of the child with autism, suggesting that depression in parents of children with autism may not be solely associated with the stress of the caregiving role (Bolton et al., 1998; Micali et al., 2004; Piven & Palmer, 1999).

Other studies have shown that compared to the general population, parents of children with autism experience particular difficulties in coping in times of stress. For example, Zablotsky et al. (2013) reported that a significant proportion of mothers of adolescents with autism had poor coping skills, possibly due to families' inability to maintain their network of social and professional support for coping. Furthermore, gender differences in mental health problems have been found between mothers and fathers of children with autism. For example, previous studies have found that mothers of children with autism have reported experiencing an increase in mental health problems such as depression (Hastings, Kovshoff, et al., 2005), and stress (Dabrowska & Pisula, 2010; Tehee et al., 2009) compared to fathers.

Some parents of children with autism may also present autism-related traits, referred to as the *Broader Autism Phenotype* (BAP) (Ingersoll & Hambrick, 2011; Sucksmith et al., 2011; Wilson et al., 2010). BAP is a term that describes the milder language and cognitive characteristics of autism that are frequently observed among the relatives of individuals with autism (Rutter, 2000). Parents of children diagnosed with autism may exhibit a variety of social and emotional deficits including impaired emotional recognition, unusual social behaviour, communication difficulties, limited interests, inflexibility, obsessive-compulsive and repetitive behaviour, and a lack of seeking change, compared to parents of children with other developmental disabilities or parents of children with typical development (Gerdts & Bernier, 2011; Sucksmith et al., 2011). Moreover, specific features of parents' personality such as rigidity, aloofness, and pragmatic language deficits have been associated with the BAP (Hurley et al., 2007; Landa et al., 1992; Piven, Palmer, Jacobi, et al., 1997; Piven, Palmer, Landa, et al., 1997).

In a study by Bishop et al. (2004), who used a self-report measure for the assessment of the broad phenotype in parents of individuals with autism, it was found that parents of autistic probands obtained higher scores of autistic-like traits on the social skills and communication scales compared to control parents. Kadak et al. (2014) further suggested that parents of children with autism may experience difficulties in recognising ambiguous or neutral facial expressions as do their children with autism. Moreover, it has been noted that parents of children with autism with the Broader Autism Phenotype (BAP) may lack confidence in coping with their child's autism-related problems (e.g., problems with nonverbal communication or social anxiety) that they also may experience (Losh et al., 2008), and they generally receive less social support, as they are more likely to employ poor coping strategies and less likely to use more adaptive techniques for coping with stress (Ingersoll & Hambrick, 2011). Thus, the expression of the BAP in parents may impact parent interpretation and understanding of their child's autistic symptoms.

Experiences of Parenting a Child with Autism

Many studies have explored the lived experience of parents who have a child with autism. For instance, Woodgate et al. (2008) found that parents defined their experience of raising a child with autism as 'being in their own world', which described both their feelings of social isolation and dissatisfaction with the support system. In line with this view, Nicholas et al. (2016) highlighted that the experiences of mothers who have a child with autism are unique, and one has to 'live it' to understand it.

According to several studies, parents manage to cope with the stresses associated with caring for a child with autism by valuing any accomplishment their child achieved, advocating for their child with autism, and maintaining some type of routine family life (Hoogsteen & Woodgate, 2013; Loukisas & Papoudi, 2016; Woodgate et al., 2008). Although parents report that they were blamed by the community and extended family members for their children's autism, they tend to view their experience of parenting in positive ways (Neely-Barnes et al., 2011). For example, parents tend to focus on the positive learning experiences gained from raising their autistic children, such as personal growth, the recognition of their child’s strengths, meaningful relationships with friends and family, and understanding and acceptance of individuals with disabilities (Altiere & von Kluge, 2009; Neely-Barnes et al., 2011; Nicholas et al., 2016). Other research has revealed that a vital coping strategy of parents of autistic adults was to separate their son or daughter from the disorder, which helped them maintain a positive perspective of their offspring with autism through the years (Hines et al., 2012).

Parent experiences of the impact of autism on their own and their families’ lives could be both positive and negative. Research has shown that parents of children with other disabilities, such as intellectual disability, are likely to report both challenges and positive perceptions of raising their children at the same point in time (Hastings, Beck, et al., 2005). Likewise, Glazzard and Overall (2012) revealed that parents of children with autism experience both negative and positive experiences of raising their autistic offspring. The negative experiences included lack of information and support for themselves and their child and lack of public awareness of autism. The positive experiences were related to parental coping which led to a feeling of optimism about their child’s future. Moreover, Mouzourou et al. (2011) highlighted that the impact of raising a child with autism might be influenced by stressful life changes, such as social and financial constraints, furniture rearrangement, limited time parents spent with siblings, and increased responsibilities for siblings. Nevertheless, the authors noted that family members reported feelings of joy and optimism for the child’s accomplishments, as well as the belief that the presence of a child with autism made the family bond stronger (Mouzourou et al., 2011).

Other studies are focused more specifically on the experiences of mothers who care for a child with autism. For example, Meirsschaut et al. (2010) explored mothers’ perceptions of the impact of autism on family and personal life. They revealed that mothers had to make appropriate adjustments to balance family and job/career responsibilities, while they had limited opportunities for individual activities. Several studies have found that mothers of children with autism struggle to manage their various roles, they spent less time on their own leisure activities, while they often report a lack of understanding of autism from the environment resulting in feelings of social isolation and stigma (Nicholas et al., 2016; Safe et al., 2012; Smith et al., 2010). Also, mothers of adolescents and adults with autism experience a significantly greater number of daily stressors compared to mothers of individuals without autism, resulting in lower levels of positive affect in terms of psychological well-being (Smith et al., 2010).

The experiences of fathers in families with a child with autism are also of interest but have not been assessed consistently. Two studies on fathers' experiences highlighted the need for more research on fathers' experiences of caring for their children with autism. Cheuk & Lashewicz (2016) examined the experiences of fathers of children with autism and those of fathers of typically developing children, and found that while fathers of children with autism shared universal experiences of fathering, they also felt a 'sense of loss'. Fathers of children with autism also mentioned their efforts to come to terms with the unexpected life changes associated with raising a child with autism. Nevertheless, it was noted that parenting a child with autism equipped fathers with a sense of gratitude and sophisticated awareness for the developmental progress and capabilities of their children with autism (Cheuk & Lashewicz, 2016). Accordingly, Frye (2016) reported that fathers' experiences of autism were consistent with previous research on mothers' experiences. In particular, fathers expressed feelings of grief and loss, as well as the need for financial and social support, education about autism, and further information and resources to help them overcome the challenges they face with autism.

Parenting Styles

Parental behaviour seems to play a significant role in the development and functioning of children with autism. However, only a few studies have investigated the influence of parenting styles and parent-child relationship on child and adolescent development. Baumrind's theory of parenting styles has had a powerful impact on the study of parenting. It has been used in cross-cultural research examining the influence of these parenting styles on adolescent development (Baumrind, 1967). Baumrind identified three different types of parenting: 1) authoritative, 2) authoritarian, and 3) permissive. The combination of warmth and demandingness differentiates these three parenting styles. Authoritative parenting is widely used in Western cultures and has been associated with optimum child outcomes, while authoritarian parenting has been associated with positive child outcomes in Asian cultures (Baumrind et al., 2010; Kurasaki et al., 2002; Martínez & García, 2007).

Cultural variations in parenting beliefs and behaviours are thought to shape parents' attitudes and may determine the level of attachment parents and children feel. For example, parents in countries considered to have a collectivist culture, such as China, tend to emphasize the importance of putting the needs of the family before individual needs. In contrast, parents in Western individualist cultures, such as North America and Western Europe, encourage their children to be more independent and self-confident (Gershoff et al., 2010). According to Abubakar et al. (2015), sociocultural factors may determine both the preferred parenting styles and parent-child relationship, as well as their associations with child outcomes. In particular, a study on maternal and paternal parenting styles in Indonesia has shown that mothers of typically developing children were perceived to be more authoritative and permissive, whereas fathers were perceived to be more authoritarian (i.e., less warm), possibly due to cultural influences (Abubakar et al., 2015). A more recent study by Riany et al. (2017) exploring parenting styles and the parent-child relationship of Indonesian parents of children with and without autism indicated that parents of children with autism were more likely to adopt a more authoritarian parenting style (or highly directive) than an authoritative, as compared to parents of children without autism. The authors noted that this preference might be due to the characteristics of children with autism (i.e., challenging behaviours) or parents' characteristics (i.e., higher levels of stress may result in negative parenting) (Riany et al., 2017).

Previous research in China has shown similar associations. For example, Gau et al. (2010) reported that parents of children with autism in the Chinese population adopt less affectionate, more protective, and more controlling parenting (i.e., authoritarian) than parents of children with Down syndrome and typically developing children. This finding may be due to lack of parent-child affectionate interaction because of language and communication impairments in children with autism (Konstantareas & Homatidis, 1992), or increased needs for care and control because of the child's autism-related problem behaviours (Gau et al., 2010). Accordingly, Zhou and Yi, (2014) revealed four patterns of parenting styles in Chinese parents of autistic children, which varied with the balance between the roles of caretaker and coach. In particular, parents who had great expectations for their child's progress experienced significantly high anxiety levels and were more motivated to push their child into intensive training, while parents who were focused on the parent-child relationship relieved such anxiety by adjusting their expectations, and therefore, they had more tolerance for their child's problems. Zhou and Yi noted that parents who adopt a coach-directed approach may be too strict and less warm which could potentially damage the parent-child relationship, resulting in more challenging behaviours in the child. On the contrary, parents who maintain a balance in their caregiving roles seem to have a good parent-child relationship, where the child could experience their unconditional love, and this might help to lessen the effects of autism on the child (Zhou & Yi, 2014).

An investigation by Rutgers et al. (2007) into parenting styles and attachment behaviours among parents of children diagnosed with autism, intellectual disability or language delays, and non-clinical children, has shown that parents of young children diagnosed with autism who displayed a less authoritative parenting style reported parental efficacy to the same degree as parents of children with intellectual disability or language delays, and parents of non-clinical children. It has been noted, however, that coping may reflect positive parenting skills at this early age which is likely to change throughout the child's development (Rutgers et al., 2007). Similarly, Sinha et al. (2016) compared parenting styles and resilience in parents of children with autism, specific learning disorder, and children without psychiatric disorders, and reported that parents of children with autism and/or specific learning disorder who adopted an authoritative parenting style presented higher levels of resilience than those who adopted an authoritarian parenting style, as compared to parents of children with no psychiatric disorders (Sinha et al., 2016).

Research on differential parenting styles supports the hypothesis that parenting behaviour may be influenced by both child and parental characteristics (Jenkins et al., 2003; Schofield et al., 2012). For example, Boonen et al. (2015) reported that mothers of children with autism generally exhibit fewer sensitive behaviours (i.e., the ability to perceive and infer the meaning behind their child's behavioural signals, and to respond to them promptly and appropriately) than mothers of typically developing children, which could be explained both by maternal and child characteristics. In particular, the authors suggest that the child's social interaction and communication impairments may influence maternal sensitive behaviours. Moreover, mothers of children with autism experience various types of stress related to their caregiving roles, work-related stress, or stress related to their own or their partner's mental health (i.e., broader phenotype autism symptoms), which may impact their sensitivity (Boonen et al., 2015). Evidence from research also suggests that there is a link between the degree of stress associated with parenting functioning and the level of parental mental health (i.e., depressive symptoms), parent-child interactions, and how parents balance their multiple roles (Ozturk et al. 2014).

In conclusion, parental cognitions and parenting styles are embedded in the wider sociocultural context and may have a direct impact on child outcomes. Notwithstanding, parenting a child with autism can be highly challenging and may influence parenting experiences and perceived self-efficacy with subsequent effects on child development. Therefore, parent/caregiver variables need to be identified and factored into interventions to improve outcomes for children with autism and their families.

Section 2.5. The Impact of Autism on Parents and Families

Autism is a lifelong disability that affects parents and families at both financial and emotional levels. The latest estimates of the lifetime costs for an individual with autism in the United States were approximately $3.6 million (Cakir et al., 2020). According to Mandell (2012), the lifetime costs of autism, including direct and indirect costs, were about $1.4 million for individuals without intellectual disability, and $2.3 million for those with intellectual disability. Non-medical costs account for the most substantial proportion of expenses, including intervention services, special education, child day-care, and residential placements for adults.

Given the substantial healthcare expenditures associated with autism, the economic impact of caring for a child with autism has affected parents’ employment. It has been reported that mothers who have a child with autism earn an average of 35 per cent less than mothers of children with other types of health problems, and 56 per cent less than mothers of children with no health problems (Cidav et al., 2012). Additionally, mothers of children with autism are 6 per cent more likely to be unemployed and work fewer hours per week (i.e., an average of 7 hours less) than mothers of children with no health problems. Further, families who have a child with autism are 9 per cent more likely to have a parent unemployed than those of children with no health problems. In comparison, parents earn 21 per cent less than parents of children with other types of health problems and 28 per cent less than those of children with no health problems (Cidav et al., 2012).

In the United Kingdom, the aggregate costs for children and young adults with autism were £2.7 billion per annum, and the aggregate costs for adults with autism amount to £25 billion per annum (Knapp et al., 2007, 2009). These estimates were based on 1 per cent autism prevalence across all ages. The largest part of the total cost of supporting children and adults with autism includes health and social care service use, agencies, special education, and housing budgets, voluntary organisation support, as well as lost employment costs of parents and adults with autism, but does not include estimates of costs of benefit payments or informal care. The presence of intellectual disability seems to contribute substantially to these costs, as the estimated lifetime cost for individuals with autism without an intellectual disability was £0.92 million, and for individuals with autism and intellectual impairments was £1.55 million in the United Kingdom (Buescher et al., 2014).

Previous research has documented that approximately 85 per cent of individuals with autism are severely affected and present with significant cognitive and adaptive impairments that limit their ability to live independently. These individuals will require assistance from their parents and families across their lifetime (Volkmar & Pauls, 2003). Parents of children with autism experience lifelong parenting challenges that may impact their perceptions of parenting. Thus, parents may be less optimistic, hopeful, and sure about their own, their autistic child’s, and also the family’s future (Karst & Van Hecke, 2012).

Having a child with autism may also affect other family subsystems (e.g., marital or sibling relationships). It has been found that the rate of divorce for parents of children with autism is nearly twice as high as the rate of families with typically developing children (Hartley et al., 2010). Moreover, parents of children with autism report less marital satisfaction and lower rates of positive affective expression compared with parents of typically developing children (Brobst et al., 2009; Gau et al., 2012). Hartley et al. (2011) noted that marital dissatisfaction had a significant adverse effect on the overall parenting experience of parents of children with autism, especially for fathers whose parenting experiences were more sensitive to child characteristics than the parenting experiences of mothers.

Evidence supports that having a sibling diagnosed with autism in the family can have a profound effect on sibling relationships. For example, Rivers & Stoneman (2003) found that typically developing siblings reported less satisfaction with the sibling relationship when marital stress and family conflict were increased. However, the authors noted that typically developing siblings were more satisfied with the sibling relationship when the autistic sibling was younger, probably because of the less pronounced effects of autism in the early years (Rivers & Stoneman, 2003). Accordingly, a cross-sectional exploratory study reported that siblings of children with autism have more overall adjustment problems, and lower levels of prosocial behaviour compared to the normative sibling group (Hastings, 2003). Therefore, caring for a child with autism can be uniquely challenging for parents and families, and can significantly impact family relationships (Karst & Van Hecke, 2012).

While it is essential to recognise that some people with autism can have highly productive and independent lives, others may require ongoing support from health, education, social care, and their family across the lifespan. Nevertheless, it has been argued that tailored interventions and appropriate support can have a significant positive impact on outcomes for individuals with autism and improve family functioning and quality of life (Howlin & Moss, 2012). The goal of the present research is to provide important information on how parents understand the individual characteristics and unique needs of their children in the context of autism that can be used to individualize the intervention in such a manner that it addresses the specific needs of children with autism and their families.

Section 2.6. Autism Interventions and Parent Involvement

2.6.1. Interventions for Core Features of Autism

Early intervention has been shown to lead to improved outcomes in children with autism and can have positive effects on parents (McConachie & Diggle, 2007; Myers et al., 2007). Parents have an essential role in their child's therapy process, by providing valuable information about the child's health history and development, assisting in educational planning and goal setting, making intervention decisions, and undertaking parent skills training programmes (Campbell & Kozloff, 2007). The findings of several studies indicate that parents who are involved in early intervention gain knowledge and skills to manage their child's behaviour problems, and children make more progress in treatment (Burrell & Borrego, 2012). The primary therapy goals for children diagnosed with autism are to promote cognitive, language, and social development, reduce autism-related symptoms and maladaptive behaviours, maximize functional independence and quality of life, and alleviate family stress and burden. Interventions for autism should ideally target the core symptoms of autism, which include social and communication deficits, and restricted, repetitive behaviours, to help individuals with autism strengthen areas of weakness and build further on areas of strength (Myers et al., 2007).

There are two main types of interventions for autism: 1) educational interventions and 2) medical management. The educational interventions include behavioural approaches and focus mainly to improve communication and social skills, daily living skills, play, and leisure skills, academic achievement, and also provide some advice on the management of challenging behaviours (Myers et al., 2007). Behavioural scientists suggest that the most effective behavioural interventions are Applied Behavioural Analysis (ABA), and Structured Teaching (Lai et al., 2014). However, reviews critically evaluating the empirical evidence relating to the effectiveness of naturalistic and ABA approaches for autism, argue whether the ABA program or the TEACCH intervention demonstrate greater effectiveness. Nevertheless, both interventions share common components and the major users of autism programming (i.e., parents, teachers, and administrators) indicate no clear preference for either model (Callahan et al., 2010; Magiati et al., 2012; Schreibman et al., 2015). Currently, there are no approved medications that target the core deficits of autism; however, behavioural problems that appear to be associated with co-occurring disorders can be improved by the use of pharmacological interventions for autism (Myers et al., 2007). Moreover, it has been reported that the use of complementary and alternative medicine (CAM) approaches is highly prevalent (about 74 per cent) among children with autism (Brondino et al., 2015).

Evidence-based treatments, such as behavioural interventions have been the focus of autism literature. In particular, early childhood interventions, such as Early Intensive Behavioural Intervention (EIBI), should produce favourable outcomes for individuals with autism (Landa, 2007; Scott et al., 2015; Smith & Dillenbeck, 2006). However, parents often use a variety of treatments, including both empirically supported interventions and those without empirical support (Goin-Kochel et al., 2007; Green et al., 2006; Thomas et al., 2007). Parents are more likely to increase the use of treatments for children with more severe autism symptoms (Goin-Kochel et al., 2007; Green et al., 2006), or young children. Nevertheless, it has been reported that younger children with autism receive more educational, behavioural, and alternative treatments than older children, who tend to be offered more medical treatment such as prescription medications and drug therapy (Goin-Kochel et al., 2007).

Early Parent-Mediated Interventions

A growing body of research suggests that early intervention approaches that teach parents how to interact with their children with autism more effectively can have a positive effect on children’s social skills and communication abilities (Weitlauf et al., 2014). These parent training programs can be comprehensive (e.g., the Early Start Denver Model) or targeted (e.g., at shared/joint attention or communication), and focus on building skills to strengthen the parent-child relationships (Weitlauf et al., 2014). This support has the advantage of being adaptable for the clinic or home, can be individual or group-based, and could be used even for very young children at risk for autism. Furthermore, parents can apply the intervention techniques they learned to real-life settings and increase their confidence and efficacy (Dawson & Burner, 2011). However, a comprehensive understanding of the benefits of parent-mediated interventions on child and parent outcomes is still unclear, and further research evaluating parent-mediated interventions for young children with autism will help produce clearer answers (Shalev et al., 2019).

Behavioural Approaches

Behavioural interventions are the most widely accepted and utilised therapy for autism. Various behavioural approaches exist, but the most common are Applied Behaviour Analysis (ABA) also referred to as Early Intensive Behavioural Intervention (EIBI), and structured teaching (Callahan et al., 2010). Early work in the field of Applied Behaviour Analysis (ABA) demonstrated the effectiveness of teaching a variety of skills to children with autism, including language, social skills, self-help, and academic achievement, as well as of reducing challenging behaviours (Schreibman et al., 2015). Based on Lovaas' (2003) pioneering research in children with autism, the Lovaas model formed the basis of ABA interventions in autism (Smith & Eikeseth, 2011). Two commonly used and well-validated behavioural interventions based on the ABA principles, include Discrete Trial Teaching (DTT) and Pivotal Response Training (PRT) (Karst & Van Hecke, 2012).

Discrete Trial Teaching (DTT) methods are incorporated in many intensive behavioural interventions to teach necessary skills such as attention, compliance, and imitation, through the use of positive reinforcement techniques (Ryan & Hemmes, 2005). These interventions are usually intensive (i.e., up to 15–20 h or more per week) and are delivered by trained therapists (Lord et al., 2018). Parent involvement and engagement in their child's early behavioural intervention can lead to improved child outcomes (Burrell & Borrego, 2012).

Pivotal response training (PRT) is an effective ABA-based intervention that focuses on 'pivotal' areas of development, such as motivation, responsivity to multiple cues, self-management, and social initiations (Weisz & Kazdin, 2010). It has been supported that parents could be trained to implement PRT techniques to improve their child's social and communication skills (Coolican et al., 2010; Minjarez et al., 2011). A further development, the Early Start Denver Model (ESDM), is an intensive behavioural intervention that combines ABA and relationship aspects to enable language, social and cognitive skills of children with autism (Vismara & Rogers, 2008). The ESDM therapy can be utilised in different settings, including at home, at a clinic, or in school, while parent involvement is a vital part of the therapy. Parents can be trained by therapists to incorporate ESDM techniques into their daily routines, which can have a significant positive impact on the child's success with the program (Dawson et al., 2010; Vismara & Rogers, 2008). Overall, ABA-based early intervention programs have been found to improve IQ scores, adaptive behaviour skills, receptive and expressive language, communication, and daily living skills, while interfering maladaptive behaviours are also reduced (Reichow et al., 2012).

Other behavioural interventions focus on developing relationships and emotional and social interactions to facilitate emotional and cognitive growth and development. These interventions are family-based and include the development of an emotional bond between parent and child, while parents are trained as the primary therapist in most programs. There are several developmental relationship-based approaches, including the Developmental, Individual Differences based, Relationship-based approach (DIR, or Floortime) and the associated PLAY project, and the Relationship Development Intervention (RDI) (Greenspan & Wieder, 2006; Gutstein et al., 2007; Gutstein, 2009; Solomon et al., 2007). These interventions are typically individualized and based on the child's unique strengths and needs and stage of development. The DIR/Floortime approach is 'child-led', and the parent or therapist applies a set of developmentally appropriate practices to real-life scenarios to improve the child's cognitive, language, and social abilities. The RDI model is parent-led and is designed to help children with autism form reciprocal relationships by building blocks of social connection (such as referencing, emotion sharing, co-regulation, and experience sharing) aiming to systematically build up the motivation and tools for successfully interacting in social relationships. However, neither DIR nor RDI has generated enough scientific evidence to be considered empirically validated treatments for autism (Karst & Van Hecke, 2012).

The interventions that include Structured Teaching, such as the TEACCH approach (Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)) (Mesibov et al., 2005), focus on structuring physical environments through visual schedules, predictable sequence of activities, structured work/activity systems, routines with flexibility, and visually structured activities to increase children's independence, spontaneous communication, and predictability. Parent involvement and engagement in both the assessment and implementation of a TEACCH program is a crucial factor. Improved child outcomes have been documented in several reports, as well as parental satisfaction and improvement in parent teaching skills (Mesibov et al., 2005). Nevertheless, due to the absence of empirical evidence, the effectiveness of TEACCH, as a comprehensive program to address the wide range of behavioural and social difficulties associated with autism, has been argued and more research is needed to evaluate this approach (Virués-Ortega et al., 2017).

Other approaches aim to improve communication skills in children with autism (Myers et al., 2007). Children with autism often have difficulties with social communication, verbal or non-verbal. Speech and Language Therapists (SLT) can help children with autism become more aware of the basics of social interaction by modifying social communication and behaviours so that the individual is better able to build stronger and more meaningful relationships, and function effectively in social settings. Techniques in speech therapy have been shown to increase communication skills and help lessen the symptoms of autism. However, treatment is more effective when the Speech and Language Therapist works closely with parents/caregivers, family members, teachers, special educators, and the child’s peers to enhance social skills and communication competence in natural settings throughout the day (American Speech-Language-Hearing Association, 2006).

Interventions that utilize alternative or augmentative and alternative communication (AAC) methods, including sign language, gestures, and picture point systems, could be particularly useful for children with autism who are non-verbal. The Picture Exchange Communication System (PECS) is based on ABA and developmental pragmatic principles, aiming to enhance the child’s spontaneous and functional communication skills. Using PECS, the child is taught to communicate with another person by giving them a picture of a desired item in exchange for that item. Thus, a non-verbal child or adult with autism can use PECS to initiate communication and to express preferences that are displayed or symbolized on a picture card (Bondy & Frost, 1994, 1998). PECS has been used widely not only with non-verbal children with autism but also with individuals who have other communication disorders.

However, there is little evidence for the long-term effects of this intervention (Maglione et al., 2012). Nevertheless, PECS appears to have the most beneficial outcomes for younger learners, used as an initial intervention to teach requesting, as well as the critical elements of the communication process (Ganz et al., 2012; Ostryn et al., 2008).

Occupational Therapy (OT) helps children with autism to improve everyday living skills, including play skills, academic skills, and self-care (Myers et al., 2007). Sensory Integration (SI) therapy is delivered by occupational therapists and is aiming to remediate sensory processing difficulties by implementing activities to improve the child's adaptation to the environment. Children diagnosed with autism often experience different responses to sensory stimuli than typically-developing children, although sensory abnormalities have also been observed in other developmental conditions. Thus, the efficacy of SI as a therapy for children diagnosed with autism has not been established (Lang et al., 2012).

Social skills interventions have been designed to teach and develop social skills for children with autism. Joint attention skills are impaired in autism; therefore, interventions to increase joint attention in autistic children may be especially beneficial. Social skills interventions are delivered by a therapist or teacher, can be individual or group-based, and target to improve basic conversation skills, perspective-taking, initiating, responding, nonverbal communication skills, social interactions, and emotional regulation (Otero et al., 2015). Types of social skills interventions include social skills groups, peer mentoring, social stories, video modelling, social scripts, and play and leisure curricula, while training usually takes place at school or in clinic settings (Myers et al., 2007). Although there is a growing body of evidence that supports the effectiveness of social skills interventions, the generalizability of skills is still ambiguous, and further research is needed (Whalon et al., 2015). It has also been suggested that interventions which are based on, or which incorporate, the principles of Cognitive Behavioural Therapy (CBT), may be beneficial for children and adolescents with autism and co-occurring anxiety disorders, especially for those diagnosed with high functioning autism (Reaven et al., 2012; Van Steensel & Bögels, 2015).

Medical Approaches

Medications are primarily used to help manage any medical conditions related to autism, as there are no medications that target the core deficits of autism. Associated target symptoms, such as irritability, aggression, repetitive behaviours, self-injurious behaviour, sleep disturbances, anxiety, hyperactivity, impulsivity, inattention, or other maladaptive behaviours, are improved with the use of certain medications (Myers et al., 2007). For example, Risperidone and Aripiprazole are the only antipsychotic medications approved by the Food and Drug Administration (FDA) and are used for treating irritability (including aggressive behaviour, deliberate self-harm, and temper tantrums) in children and adolescents with autism. According to the NICE guidelines, antipsychotic medication for managing challenging behaviours in children and young people with autism should be prescribed and monitored by a specialist (Crowe & Salt, 2015; Howes et al., 2018). Many studies examining the efficacy of antipsychotic medications have shown a reduction of irritability, stereotypic behaviours, hyperactivity, and aggression. However, potential adverse effects include appetite increase, weight gain, and sedation. Therefore, initiation with low doses and gradual slow titration is highly recommended (Doyle & McDougle, 2012; Kent et al., 2013; Marcus et al., 2009; McCracken et al., 2002).

Other medications have been used in the treatment of repetitive behaviours. These include Selective Serotonin Reuptake Inhibitor (SSRI) antidepressants, such as Fluoxetine, Citalopram, Fluvoxamine, and Escitalopram. Some studies have shown that Fluoxetine and Escitalopram can improve repetitive movements and irritability; however, significant adverse effects have also been reported (Hollander et al., 2005; Owley et al., 2005; Speaks, 2009).

Several studies have examined the efficacy of Methylphenidate, Atomoxetine, Guanfacine, and Clonidine (stimulant medications typically used to treat Attention-Deficit/Hyperactivity Disorder (ADHD)) for symptoms of inattention, hyperactivity, and impulsivity among patients with a diagnosis of autism. Initial evidence suggests that Methylphenidate, Atomoxetine, and Guanfacine can improve hyperactivity in children with autism; however, adverse effects may also be caused. Thus, these medications should be administered based on the needs of the individual patient, with due consideration being given to potential benefits as well as risks (Doyle & McDougle, 2012; Handen et al., 2015; Harfterkamp et al., 2012; Mahajan et al., 2012; McPheeters et al., 2011; Scahill et al., 2015; Sturman et al., 2017). Clonidine is at least modestly effective for symptoms of hyperactivity, however, it has been reported to reduce other symptoms, such as sleep initiation latency and night awakening in autism (Doyle & McDougle, 2012).

Complementary and Alternative Medicine (CAM) therapies are widely used for children with autism. A recent review has documented that half of the children with autism have received an alternative or complementary therapy (Höfer et al., 2017). The most frequently used therapies include dietary supplements (e.g., vitamins, omega-3 fatty acids, melatonin, secretin, digestive enzymes), special diets (e.g., gluten-free/ casein-free diet), procedures (e.g., chelation, hyperbaric oxygen therapy, intravenous immunoglobulin therapy), or conventional medicine (e.g., antifungal agents, memantine) (Akins et al., 2010; Anagnostou & Hansen, 2011; Hendren, 2013; Singer & Ravi, 2015). Some CAM therapies are not FDA-approved due to lack of evidence supporting their use, including secretin, chelation therapies, hyperbaric oxygen, intravenous immunoglobulin, and antifungal agents, while others have emerging evidence to support their use, like melatonin (Levy & Hyman, 2015). Moreover, secretin, chelation, and hyperbaric oxygen therapy are strongly disapproved by NICE guidelines (Crowe & Salt, 2015). Nevertheless, most complementary alternative treatments have limited evidence to support their use as treatments for autism (Levy & Hyman, 2015).

2.6.2. Child and Parent Outcomes of Intervention

Research to date suggests that parental involvement in interventions for their children with autism has positive outcomes for both parents and children. There is evidence suggesting that interventions that include parent training (such as the DIR method or the relationship development model), increase parent knowledge of autism, enhance parent understanding of their child's underlying needs and wants, strengthen parent-child relationships, and improve the child's social and communication skills. Moreover, parents have reported decreased mental health concerns, reduced levels of stress and depression, and improved parenting self-efficacy (Karst & Van Hecke, 2012).

Evidence has also shown that when clinicians work closely with parents to develop goals and treatment plans in parent education programs, parents report lower levels of stress, higher levels of parental confidence, and more positive parent-child interactions (Brookman-Frazee & Koegel, 2004). A review by Oono et al. (2013) on the effectiveness of parent-mediated early interventions revealed that children with autism might enhance their language and joint attention skills, and show improvement in their autism symptoms following parent-mediated interventions. Parents may also benefit from being involved in their child's intervention, as gains have been reported in interaction synchronicity between child and caregiver (Oono et al., 2013).

Although there is a growing body of literature focusing on the benefits of intervention on children with autism, there are only a few studies reporting parent outcomes of interventions, in which they are not the primary goal of the program. Karst and Van Hecke

(2012) noted that parent outcomes are often secondary to child outcomes and include parenting self-efficacy, stress, parent mental health, parent-child relationships, and family functioning. However, there is limited research examining what parent or family factors may impact the intervention process or outcome variables (Karst & Van Hecke, 2012).

Parent integration into the intervention process of their child with autism is critical to a positive outcome (Brown et al., 2012; Whittaker & Cowley, 2012). Some studies have suggested that specific parent characteristics, including marital and socioeconomic status, and level of education, may influence intervention outcomes. For example, Clark and Baker (1983) suggested that married parents who have higher SES and higher levels of educational attainment have more experience and skills pre-intervention, and therefore, greater ability to apply knowledge and skills during the program. Moreover, it has been suggested that children from two-parent households make the most gains in intervention; in contrast, children whose parents report higher levels of stress demonstrated fewer gains from the intervention (Robbins et al., 1991).

Parent acceptance and commitment to therapy, as well as parent satisfaction, are also important factors that contribute to the interventional outcome. Koegel et al. (2003) reported that parents who used Pivotal Response Training (PRT) techniques, had more positive experiences with their children, were more committed, and had lower levels of stress, than parents who were trained on individual target behaviours. Other studies have found that parents reported overall satisfaction with a program when parent coaching is incorporated, and when parents feel respected and valued as partners or collaborators in their child's therapy (Buschbacher et al., 2004; Ingersoll & Dvortcsak, 2006). While the effects of parent involvement in their child's treatment are beneficial for both parent and child, with improved social-communicative abilities of the child, increased parental functioning, and positive parent-child interactions, there is a lack of empirical evidence to support this assertion (Grindle et al., 2009; McConachie & Diggle, 2007). Taken together, this review highlights the need for a deeper understanding of parent/caregiver variables and their relationship with child outcomes, which may inform intervention decision-making towards individualised approaches tailored to the unique needs of children with autism and their families.

Section 2.7. The Early Childhood Outcomes (ECO) Conceptual Framework

The literature review highlighted the emerging need for investigating how parents understand their child's unique characteristics in the context of autism to help inform decisions for intervention strategies to optimize child, parent, and family outcomes. The Early Childhood Outcomes (ECO) framework (Wainer et al., 2017) provides a theoretical and contextual setting for the research presented in the following chapters.

The ECO framework is a theoretical model that can help researchers and healthcare professionals improve long-term outcomes for children with autism and their families. The framework focuses on identifying appropriate child and family level outcomes to increase the efficacy of early interventions in autism. The five immediate family-level benefits the ECO framework proposes include: 1) 'families know their rights and advocate effectively for their child,' 2) 'families understand their child's strengths, abilities and special needs,' 3) 'families help their child develop and learn,' 4) 'families have support systems,' and 5) 'families can gain access to desired services and activities in their communities' (Bailey et al., 2006). These immediate family-level benefits are considered to contribute to the ultimate goal of early intervention, which is to enhance the family quality of life through improving family interaction, parenting attitudes, and physical, emotional, and material well-being (Dunst & Bruder, 2002; Epley et al., 2011; McWilliam, 2010; Summers et al., 2007).

The focus of the present research is on the ECO framework's family-level outcome '*families understand their child's strengths, abilities, and special needs*.' The framework prompts researchers to explore the ECO-recommended family outcomes and their relationship with early intervention services (i.e., EI/Part C and preschool/Part B programs). According to the Individuals with Disabilities Education Act (IDEA) guidelines (Katsiyannis et al., 2001; US Department of Education, 2010; Yell & Shriner, 1997), Part C programs apply specifically to infants and toddlers (birth to 2 years of age), while Part B programs apply to children ages three through 21 years.

The ECO framework proposes that immediate family-level benefits could align with both Part C and Part B programs. Thus, it is suggested that examining areas of importance to families allows determination of key family outcomes (e.g., immediate outcomes such as understanding of the child's strengths, abilities, and special needs, as well as more distal outcomes such as well-being) that are thought to contribute to enhanced family quality of life. Moreover, the ECO framework prompts researchers to engage stakeholders in all aspects of the research process, which provides a unique opportunity to identify key areas of emphasis that will improve effective real-world implementation. Thus, stakeholder consultation at all the stages of this research was deemed essential.

Section 2.8. Discussion

The review and critique of the literature given in Chapter 2 demonstrated that the medical and theoretical models of autism have contributed to a deeper understanding of the complex nature of autism and the challenges autistic individuals face due to the condition. However, integrated research frameworks invariably overlook parent-related factors that may impede the development and functioning of children with autism. Research into the way parents understand the unique characteristics of their autistic children could bridge the gap between theory and practice, and inform decisions for intervention strategies that are tailored to the specific needs of the child with autism and their caregivers.

In investigating the views and experiences of parents of autistic children, it was necessary to explore the underlying factors that contributed to their conceptualisation of the condition. The critical review of the literature highlighted that several factors may influence the way parents perceive their child’s behaviour in the context of autism, including socioeconomic differences, sociocultural influences, child-specific factors, as well as parents’ individual characteristics and experiences.

Socioeconomic Differences

Concerning socioeconomic differences, the review has highlighted that socioeconomic factors such as family SES and the education level of a parent may affect timely diagnosis. For example, children from families with higher SES levels, as well as children whose parents are more educated are more likely to receive a diagnosis of autism at a younger age (Kelly et al., 2019; Thomas et al., 2012). Thus, different levels of educational and financial resources, as well as different opportunities to access health services, may play a significant role in how parents of children with autism understand and interpret their child’s behaviour (Fountain et al., 2011; Fujiwara, 2014).

Sociocultural Influences

Sociocultural factors may also influence parental understanding of autism. The review indicated that parents from diverse sociocultural backgrounds interpret child behaviour problems within their cultural context (Tek & Landa, 2012). Within the cultural context, religion and spirituality, as well as communities' representations of health and illness, seem to play an essential role in how parents view their child's condition (Jegatheesan et al., 2010 and Ha et al., 2014).

Child Factors

The individual characteristics of children with autism also appear to influence parental understanding of the nature and development of autism. Specifically, a child's behaviour and maladjustments, gender, the presence of co-occurring conditions, as well as the severity of autism symptoms may impact parents' perceptions about autism (Dovgan et al., 2019; Zablotsky et al., 2017).

Parent Factors

Lastly, the literature review highlighted that parenting experiences of caring for a child with autism (Woodgate et al., 2008), as well as parents' individual characteristics, including parent mental health (Ingersoll & Hambrick, 2011) and styles of parenting (Riany et al., 2017) may influence parental understanding of, and acceptance of, their child's difficulties.

The literature review findings underscore the need for a deeper understanding of parent/caregiver variables and their relationship with child outcomes. To date, no previous research has investigated the particular pattern of parental understanding of autism as related to the strengths and unique differences of their children with autism. Identifying how parents understand their child's strengths, abilities and special needs in the context of autism is critical to help inform decisions for intervention strategies that can meet the needs of the child with autism and their caregivers.

This thesis focuses on the investigation of the basic elements comprising parental understanding of their child’s presentation of autism and their pre-existing knowledge about the condition, and the extent to which parent knowledge reflects current evidence on the definition, diagnosis, and causal theories of autism. In exploring this, a tool was developed in conjunction with key stakeholders and specialists in the field of autism, to help identify distinct parent profiles based on their child’s individual characteristics and unique needs.

The following objectives are more directly explored in this thesis: firstly, it was examined whether there are differences between parents’ understanding of the general nature and characteristics of autism and the characteristics of their child with autism. Secondly, it was examined whether there are distinct profiles of parental understanding of autism based on their child’s individual characteristics and unique needs. The first research objective addressed by the development and evaluation of an initial questionnaire for the evaluation of parental understanding of autism is presented in separate phases in Chapter 3 and Chapter 4. The second research objective addressed by the development of an Individualised Autism Profiling (IAP) tool is presented in Chapter 5 using a latent profile analysis to identify different profiles of parental understanding of autism within the data. The last chapter, Chapter 6, provides an overall discussion of the studies presented in the respective chapters of this thesis, as well as limitations, future directions, and conclusions.

CHAPTER 3

DEVELOPMENT OF AN INITIAL QUESTIONNAIRE

Chapter Overview

This chapter aims to describe the rationale behind the development of an initial questionnaire to evaluate parental understanding of the nature and characteristics of children with autism. This chapter discusses the item selection process of an initial item pool of 229 items, that was generated based on a literature review of the factors that should be considered when framing parental understanding of autism. The item selection process involved two steps, an evaluation by the academic research team, and stakeholder consultation with six parents of children diagnosed with autism. A total of one hundred and thirty items were eliminated during this process. The revised version of the questionnaire contained 99 items that map into several domains. Each item was scored on a 7-point Likert scale ranging from (1) strongly disagree to (7) strongly agree. The item selection process is described in detail below.

Section 3.1. Introduction

This study aimed to design a questionnaire for the evaluation of parental understanding of autism in relation to the nature and characteristics of children with autism. The review of the literature in Chapter 2 highlighted the need for research to incorporate practices that will help parents better understand their child in the context of autism and individual differences, intending to inform decisions for intervention strategies for children with autism and their caregivers (Karst & Van Hecke, 2012; Wainer et al., 2017). To date, no questionnaires have been developed for the evaluation of parental understanding of autism.

During the preliminary questionnaire development, an initial item pool of 229 items was generated from the critical literature review. In the absence of a comparative tool, the understanding of autism was explored based on the clinical description and characteristics of autism (American Psychiatric Association, 2013; World Health Organization, 1992). Additionally, parent factors, such as parenting experiences and views about autism were considered.

The item selection process involved two steps. Firstly, the academic research team independently reviewed the pool of potential items for their suitability and appropriateness, the clarity of the questions, and their importance; two hundred and fifteen items were selected in this step and fourteen items that were ambiguous or irrelevant were omitted. In the second step, six parents of children with autism were interviewed regarding the proposed 215 items. Parents of children diagnosed with autism were asked about the suitability, appropriateness of the wording, and ambiguity for each item. After the consultation with parents, the revised version of the first questionnaire on parental understanding of autism contained 99 items that were scored on a 7-point Likert scale ranging from (1) strongly disagree to (7) strongly agree (Chapter 4).

Section 3.2. Materials and Methods

3.2.1. Item Generation

The content of the questionnaire was developed from December 2017 to June 2018 from a literature review and stakeholder (i.e., parents of children with autism) consultation. The literature review included a search of the Medline, PubMed, PsycINFO, and Scopus databases (2009–2018) using search terms, such as “autism”, “understanding autism”, “parent understanding”, “parent experiences”, “questionnaire” and “parent needs”. Moreover, a manual search for citations from the located articles was conducted to identify additional relevant studies. The literature review identified major themes that were considered potentially relevant to the study. Identified areas of understanding of autism were mainly focused on the clinical features and causes of autism, the signs and developmental course, challenging behaviours, parenting experiences, and societal influences.

An initial pool of 229 items was generated with input from the literature review to capture different aspects of understanding of autism, based on the clinical description and characteristics of autism (American Psychiatric Association, 2013; World Health Organization, 1992), as well as parent-specific factors (e.g., parenting experiences and views about autism). To date, no previous research has investigated the particular pattern of parental understanding of autism. The questionnaire aims to explore parental understanding of the nature and characteristics of children with autism, as well as parent sources of information and social support, and their views about autism.

3.2.2. Item Selection

Study Design and Participants

A two-step approach, including an evaluation of the initial item pool of 229 items by the academic research team and individual interviews with six parents of children diagnosed with autism, was used to develop a questionnaire that considered parental understanding of autism in relation to the nature and characteristics of children with autism. In the first step of the item selection process, the academic research team consisted of three members of the University's academic staff, independently reviewed the initial item pool to identify whether potential items derived from the review of the literature were relevant and applicable to parents of children with autism. The academic research team used the traffic light coding system for each of the questionnaire items. An item highlighted with red indicated that it required attention regarding its suitability and appropriateness; these items were followed by additional comments to provide context. An item highlighted with amber indicated that the item was acceptable but further clarification should be sought from the primary investigator. A green light coding indicated the item demonstrated evidence of meeting the questionnaire's objective and there was no cause for concern. During this process, two hundred and fifteen items were selected and fourteen items that were ambiguous or irrelevant to the questionnaire's objective were omitted. The selected 215 items map into several domains across four separate questionnaire parts (Appendix 1).

Questionnaire Part 1. The General Nature of Autism. This part consists of five domains reflecting the general nature of autism. In particular, the domains include items about: the clinical features (1), the causes (2), the developmental course (3), the effects of an intervention (4), and the signs and symptoms of autism (5).

Questionnaire Part* 2*. Characteristics of All Children with Autism. This part consists of seven domains reflecting the characteristics of children with autism in core areas of development and learning. These include: social (1), communication (2), behaviour (3), self-care (4), self-occupation (5), sensory (6), and education (7) characteristics of children with autism.

Questionnaire Part* 3*. Characteristics of the Individual Child with Autism. This part consists of seven domains asking parents about the characteristics of their child with autism, in core areas of development and learning, including social (1), communication (2), behaviour (3), self-care (4), self-occupation (5), sensory (6) and education (7) characteristics of their child. The items included in this part were identical to the items in Part 2 except that they referred to the characteristics of the individual child with autism rather than to all children with autism.

Questionnaire* Part 4. *About the Parents. This last part consists of three domains asking parents about the sources of information they use (1), the social support they receive (3), as well as their views about autism.

In the second step of the item selection process, six parents of children with an autism diagnosis were interviewed individually regarding the proposed 215 items to ensure that the questionnaire fully reflects their perspective and that items are acceptable, comprehensive, and relevant to parents of autistic children, which was developed based on the findings of the consultation with parents. All parents provided their informed consent to participate in the study (Appendix 2). Participants were recruited for an interview by email from the first supervisor's local network. Parents were included in the study if they: 1) were 18 years or older, and 2) had a child who has been formally diagnosed with autism using the DSM-IV or DSM-5 (American Psychiatric Association, 2013) or ICD-10 (World Health Organization, 1992) criteria for 'Childhood Autism', 'Autistic Disorder' or 'Autism Spectrum Disorder' by a qualified healthcare professional. The study was conducted according to the Declaration of Helsinki and was approved by the Ethics Committee of the University of Derby.

Parents were interviewed face-to-face and by telephone, using a brief semi-structured interview schedule. The schedule acted as a guide in the interview to ensure the aims of the study were met. All parents included in this phase of the study were asked to rate each item on a five-point Likert scale ranging from (1) very unsuitable, (2) somewhat unsuitable, (3) neutral, (4) somewhat suitable to (5) very suitable. The interview schedule included questions such as: 'How suitable do you think the statement is?', 'Would this statement be acceptable to most parents?', 'How do you find the questionnaire's overall structure?' (Appendix 2). The interviews were audio-taped and transcribed verbatim. As highlighted in the objectives of this research (Section 1.1.), the consultation with parents was a key component in the development of an instrument for the evaluation of parental understanding of autism.

In the present study, the stakeholder consultation was an important step in the item selection process because it offered the opportunity to adjust questionnaire design issues (e.g., appropriate wording, context-dependent item set, and phrasing, etc.) and ensured relevance, comprehensiveness, and content validity of the questionnaire by incorporating parent rating and feedback into the revised version of the first questionnaire on parental understanding of autism. The criteria used for the inclusion of items in the revised version of the questionnaire included: a) qualitative criteria (i.e., parent feedback) and parent rating neutral (3) and above on the five-point Likert scale, b) item’s significance determined by the high recall rate of references in the research databases, and c) questionnaire length. The information obtained from the consultation with parents were used in combination with the input from the literature review to revise items to reflect both the literature and the opinions of the target audience.

Section 3.3. Results

Questionnaire Part 1. *The General Nature of Autism.*

In the first part of the questionnaire, the items were divided into five groups: *Group 1* the clinical features of autism; *Group 2* the causes of autism; *Group 3* the developmental course of autism; *Group 4* the effects of an intervention, and *Group 5* the signs and symptoms of autism.

Table 1. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 1 The Clinical Features of Autism (N=6)

Items	**M**	**SD**
1. Autism is characterized by difficulties in social interaction and communication, and by a preference for repetitive, stereotyped behaviours	3.67	1.03
2. The brain of the autistic child functions in a different way	3.17	0.98
3. Autism is associated with learning and attention issues	2.83	0.41
4. Autism is more of an intellectual disability	2.83	1.17
5. Autism is more of an emotional disorder	2.50	0.55
6. Autism is more of a communication disorder	3.17	0.98
7. Autism is more of a developmental disorder	3.50	1.22

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 2. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 2 The Causes of Autism (N=6)

	Items	M	SD
1.	The causes of autism are still unknown	3.00	0.63
2.	Autism can affect any child	3.00	0.00
3.	Autism affects boys much more often than girls	2.67	0.52
4.	Autism may occur from more than one cause	3.00	0.00
5.	Autism is more likely to occur when there is a history of 'autistic traits' in the family	3.00	1.26
6.	Genetic factors may cause autism	3.50	1.23
7.	Factors associated with mothers during pregnancy may cause autism	2.83	0.75
8.	Environmental factors (air pollution, chemicals, etc.) may cause autism	2.67	0.52
9.	Medication during pregnancy may cause autism	2.50	1.38
10.	Toxins in vaccines may cause autism	1.50	0.55
11.	Traumatic experiences in very early years may cause autism (e.g., psychological trauma caused by early separation with parents or frequent change of caregivers)	1.83	0.98
12.	Autism may be caused by poor parenting	1.83	0.98

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 3. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 3 The Developmental Course of Autism (N=6)

	Items	M	SD
1.	Autism is a lifelong condition	3.00	0.00
2.	Autism exists only in childhood	2.67	0.52
3.	The signs of autism are present in the early years of life	3.00	0.00
4.	Some children may begin to develop typically but then they lose skills and develop autism	3.33	0.75
5.	Children with autism develop differently from their peers	3.83	0.98
6.	The symptoms of autism change a great deal from day to day	2.83	0.75
7.	The course of autism depends on the parents	2.00	0.89
8.	Autism symptoms may be improved from early childhood to adulthood	2.83	0.41
9.	The role of parents is important in helping the autistic child's transition to adulthood	4.00	0.89
10.	The role of parents is important for the mental and physical health of the child throughout the lifespan	4.00	0.89

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 4. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 4 the Effects of an Intervention (N=6)

Items	M	SD
1. Early intervention – such as behavioural and speech therapy – can help improve the learning skills of the autistic child and increase communication	3.00	0.00
2. With proper intervention and training the child with autism will show substantial improvement	3.33	0.52
3. With proper intervention and training the severity of autism symptoms can be reduced	3.33	0.52
4. With proper intervention and training children eventually ‘outgrow’ autism	1.83	0.75
5. The negative effects of autism can be prevented with the proper treatment	2.33	0.52
6. The role of parents is important in deciding the most appropriate treatment for their child with autism	3.50	0.55
7. Parents’ involvement in their child’s intervention program is important	4.00	0.89

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 5. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 5 the Signs and Symptoms of Autism (N=6)

Items	M	SD
1. All children with autism have some symptoms in common	2.83	0.41
2. Asperger’s Syndrome and High Functioning Autism is the same diagnosis	2.67	0.52
3. Autism affects each child differently	3.67	1.03
4. Some signs of autism are similar to or the same as those of other conditions	2.83	0.41
5. The word spectrum means there is a range of how the symptoms affect each child	3.33	0.82

Values are expressed: Mean (M) and Standard Deviation (SD).

Questionnaire Part 2. *Characteristics of Children with Autism.*

In this part of the questionnaire, the items were divided into seven-item groups. These include *Group 6* social characteristics; *Group 7* communication characteristics; *Group 8* behaviour characteristics; *Group 9* self-care characteristics; *Group 10* self-occupation characteristics; *Group 11* sensory characteristics; and *Group 12* education characteristics of children with autism.

Table 6. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 6 Social Characteristics of Children with Autism (N=6)

	Items	**M**	**SD**
1.	Children with autism have social difficulties (e.g., find it hard to understand facial and voice expressions and gestures, lack of awareness of others feelings, etc.)	2.83	0.41
2.	Children with autism most of the time live in a world of their own	2.50	0.55
3.	Children with autism avoid eye contact when talking	3.00	0.00
4.	Children with autism are affectionate to family members	3.00	0.00
5.	Children with autism have poor relationships in peer group situations	3.00	0.00
6.	Children with autism prefer to play by themselves	3.00	0.00
7.	Children with autism prefer to play with their parents	3.00	0.00
8.	Children with autism prefer to play with their siblings	3.00	0.00
9.	Children with autism prefer to play with other children at the same age	3.00	0.00
10.	Children with autism find it hard to understand instructions	3.00	0.00
11.	Children with autism are able to understand instructions only with guidance	2.83	0.41
12.	Children with autism expect others to see things only from their own point of view	2.67	0.52
13.	Family activities have to be very structured and planned	3.00	0.00
14.	Parents are not able to attend social events with their child with autism	2.67	0.52
15.	Parents are not able to control their children when they have meltdowns in public (e.g., when they get overwhelmed by everything around them and may begin to shout, scream, cry or lose control)	2.67	0.82
16.	People in public are not usually receptive to the meltdowns of children with autism	3.33	1.03

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 7. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 7 Communication Characteristics of Children with Autism (N=6)

Items		M	SD
1.	Children with autism have language and speech difficulties	3.00	0.00
2.	Children with autism are unable to talk	2.50	0.84
3.	Children with autism are unable to share their thoughts	3.00	0.00
4.	Children with autism respond poorly to others (e.g., appear withdrawn and indifferent to other people)	2.83	0.41
5.	Children with autism ignore verbal comments as if deaf	3.00	1.09
6.	Children with autism use gestures to get what they want	3.33	0.82
7.	Children with autism are unable to communicate their needs and wants	3.00	1.09

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 8. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 8 Behaviour Characteristics of Children with Autism (N=6)

Items		M	SD
1.	Children with autism have behaviours similar to children with a severe learning disability	2.67	0.52
2.	Children with autism are usually clumsy	2.83	0.41
3.	Children with autism are usually restless and hyperactive	2.83	0.41
4.	Children with autism have self-injurious behaviour	3.17	0.98
5.	Children with autism show violent and aggressive tendencies	3.00	0.63
6.	Children with autism have sleep disturbances	3.33	0.82
7.	Children with autism are excessively sleepy during daytime	2.67	0.52
8.	Children with autism have abnormal food preferences and/or refuse to eat	3.00	0.00
9.	Children with autism do not adapt easily to changes and unforeseen circumstances	3.00	0.00
10.	Children with autism show excessive separation anxiety from significant others (parents, siblings, etc.)	2.67	0.52
11.	Children with autism are reluctant to attend school/kindergarten	2.67	0.52
12.	Children with autism are usually cold and distant	2.17	0.98
13.	Children with autism show an inappropriate response to embraces (e.g., push away the person who gives them a hug)	3.00	0.00
14.	Children with autism show affection and are receptive to hugs	3.00	0.00
15.	Children with autism are affectionate only with their parents	2.50	0.55

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 9. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 9 Self-Care Characteristics of Children with Autism (N=6)

Items	M	SD
1. Children with autism are unable to serve themselves at mealtimes	3.00	0.00
2. Children with autism are unable to use cutlery properly	3.00	0.00
3. Children with autism are unable to feed themselves independently	3.00	0.00
4. Children with autism require more help than typically developing children of their age to get dressed or undressed	3.33	0.82
5. Children with autism find it difficult to tolerate wearing certain types of clothes	3.33	0.82
6. Children with autism have problems with personal hygiene (e.g., brush teeth, wash hands, use the shower, etc.)	2.83	0.41
7. Children with autism require extensive help to fall asleep	2.83	0.41
8. Children with autism are not toilet-trained	2.67	0.52

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 10. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 10 Self-Occupation Characteristics of Children with Autism (N=6)

Items	M	SD
1. Children with autism insist on the same routine	3.00	0.00
2. Children with autism favour specific routines and rituals	3.00	0.00
3. Children with autism often rock their head or body repeatedly	3.00	0.00
4. Children with autism have a lot of physical and verbal tics	2.83	0.41
5. Children with autism prefer to arrange things in a certain way	3.00	0.00
6. Children with autism are unable to engage in pretend play	3.17	0.98
7. Children with autism have poor balance and fall a lot	2.83	0.41

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 11. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 11 Sensory Characteristics of Children with Autism (N=6)

Items	M	SD
1. A quiet and organized environment has a positive impact on the autistic child's behaviour	2.83	0.41
2. An environment with multiple distractions has a negative impact on the autistic child's behaviour	3.17	0.41
3. Children with autism are distressed by minor changes in their environment (e.g., rearranged furniture, new cutlery, etc.)	3.00	0.00
4. Children with autism behave best when surrounded by familiar faces	3.33	0.82
5. Crowded places have a negative impact on the autistic child's behaviour	3.67	1.03
6. Bright lights, loud sounds, and intense smells cause discomfort to the autistic child	2.83	0.41
7. Children with autism are bothered by bright lights or certain kind of lights	3.00	0.00
8. Children with autism are distressed by certain smells or avoid certain tastes	3.33	0.82
9. Children with autism have a limited range of food preferences based on colour, texture, and/or presentation	3.00	0.00
10. Children with autism express distress when they are touched (e.g., someone touches their hair)	3.17	0.98
11. Children with autism are easily distracted and cannot focus their attention if there is a lot of noise around	3.00	0.00

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 12. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 12 Education Characteristics of Children with Autism (N=6)

	Items	M	SD
1.	Children with autism should be educated in a mainstream school	3.00	0.00
2.	Children with autism should be educated in a Special Educational Needs school	3.00	1.23
3.	Children with autism should be home-schooled	2.67	1.03
4.	Children with autism need an individual teaching program	3.17	0.41
5.	Children with autism need a Teaching Assistant in a mainstream school	3.17	0.41
6.	Children with autism are very creative	2.83	0.41
7.	Children with autism have great attention to detail	2.83	0.41
8.	Children with autism have great problem-solving skills	2.83	0.41
9.	Children with autism are able to do quick mathematical calculations	2.67	0.82
10.	Children with autism are unable to get along with typical developing classmates	2.50	0.55
11.	Children with autism are unable to do their homework alone	3.00	0.00
12.	Children with autism cannot hold a pen/pencil right	2.83	0.41
13.	Children with autism cannot write their name	2.67	0.52

Values are expressed: Mean (M) and Standard Deviation (SD).

Questionnaire Part 3. *Characteristics of the Individual Child with Autism.*

In this part of the questionnaire, the items were divided into seven-item groups including *Group 13* social characteristics; *Group 14* communication characteristics; *Group 15* behaviour characteristics; *Group 16* self-care characteristics; *Group 17* self-occupation characteristics; *Group 18* sensory characteristics; and *Group 19* education characteristics of the individual child with autism.

Table 13. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 13 Social Characteristics of the Individual Child with Autism (N=6)

	Items	**M**	**SD**
1.	My child has social difficulties	3.00	0.00
2.	My child most of the time lives in a world of his/her own	2.67	0.52
3.	My child avoids eye contact when talking	3.00	0.00
4.	My child is affectionate to family members	3.00	0.00
5.	My child has poor relationships in peer group situations	3.00	0.00
6.	My child prefers to play by himself/herself	3.00	0.00
7.	My child prefers to play with his/her parents	3.00	0.00
8.	My child prefers to play with his/her siblings	3.00	0.00
9.	My child prefers to play with his/her friends	3.00	0.00
10.	My child finds it hard to understand instructions	3.00	0.00
11.	My child is able to follow instructions only with guidance	3.00	0.00
12.	My child expects others to see things only from his/her own point of view	2.83	0.41
13.	Family activities have to be very structured and planned	3.00	0.00
14.	I am able to attend social events with my child	3.00	0.00
15.	I am able to control my child’s meltdowns in public (e.g., when my child gets overwhelmed by everything around him/her and may begin to shout, scream, cry or lose control)	3.00	0.00
16.	People in public are not usually receptive to my child’s meltdowns	3.33	1.03

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 14. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 14 Communication Characteristics of the Individual Child with Autism (N=6)

Items	M	SD
1. My child has language and speech difficulties	3.00	0.00
2. My child is unable to talk	2.83	0.41
3. My child is unable to share his/her thoughts	3.00	0.00
4. My child responds poorly to others (e.g., appears withdrawn and indifferent to other people)	3.00	0.00
5. My child ignores verbal comments as if deaf	2.67	0.52
6. My child uses gestures to get what he/she wants	3.00	0.00
7. My child is able to communicate his/her needs and wants	3.00	0.00

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 15. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 15 Behaviour Characteristics of the Individual Child with Autism (N=6)

Items	M	SD
1. My child has a severe learning disability	3.00	0.00
2. My child is clumsy most of the times	3.00	0.00
3. My child is usually restless and hyperactive	2.83	0.41
4. My child has self-injurious behaviour	3.00	0.00
5. My child shows violent and aggressive tendencies	3.00	0.00
6. My child has sleep disturbances	3.00	0.00
7. My child is excessively sleepy during daytime	3.00	0.00
8. My child has abnormal food preferences and/or refuses to eat	3.00	0.00
9. My child does not adapt easily to changes and unforeseen circumstances	3.00	0.00
10. My child shows excessive separation anxiety from significant others (parents, siblings, etc.)	2.83	0.41
11. My child is reluctant to attend school/kindergarten	3.00	0.00
12. My child is usually cold and distant	2.33	0.82
13. My child shows an inappropriate response to embraces (e.g., pushes away the person who gives him/her a hug)	3.00	0.00
14. My child shows affection and is receptive to hugs	3.00	0.00
15. My child is affectionate only with his/her parents	2.83	0.41

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 16. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 16 Self-Care Characteristics of the Individual Child with Autism (N=6)

Items	**M**	**SD**
1. My child is able to serve himself/herself at mealtimes	3.00	0.00
2. My child is able to use cutlery properly	3.00	0.00
3. My child is able to feed himself/herself independently	3.00	0.00
4. My child requires more help than other children of his/her age to get dressed or undressed	3.00	0.00
5. My child finds it difficult to tolerate wearing certain types of clothes	3.00	0.00
6. My child has problems with personal hygiene (e.g., brushing teeth, washing hands, using the shower, etc.)	2.83	0.41
7. My child requires extensive help to fall asleep	2.83	0.41
8. My child is not toilet-trained	2.67	0.52

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 17. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 17 Self-Occupation Characteristics of the Individual Child with Autism (N=6)

Items	**M**	**SD**
1. My child insists on the same routine	3.00	0.00
2. My child favours specific routines and rituals	3.00	0.00
3. My child often rocks his/her head or body repeatedly	3.00	0.00
4. My child has a lot of physical and verbal tics	2.83	0.41
5. My child enjoys arranging things in a certain way	3.00	0.00
6. My child enjoys pretend-play	3.00	0.00
7. My child has poor balance and falls a lot	2.83	0.41

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 18. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 18 Sensory Characteristics of the Individual Child with Autism (N=6)

Items	M	SD
1. A quiet and organised environment has a positive impact on my child's behaviour	2.83	0.41
2. An environment with multiple distractions has a negative impact on my child's behaviour	3.17	0.41
3. My child is distressed by minor changes in his/her environment (e.g., rearranged furniture, new cutlery, etc.)	3.00	0.00
4. My child behaves best when surrounded by familiar faces	3.33	0.82
5. Crowded places have a negative impact on my child's behaviour	3.33	0.82
6. Bright lights, loud sounds, and intense smells cause discomfort to my child	3.00	0.00
7. My child is bothered by bright lights or certain kind of lights	3.00	0.00
8. My child is distressed by certain smells or avoids certain tastes	3.00	0.00
9. My child has a limited range of food preferences relevant to colour, texture, and/or presentation	3.00	0.00
10. My child expresses distress when he/she is touched (e.g., someone touches his/her hair)	3.00	0.00
11. My child is easily distracted and cannot focus his/her attention if there is a lot of noise around	3.00	0.00

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 19. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 19 Education Characteristics of the Individual Child with Autism (N=6)

Items	**M**	**SD**
1. My child should be educated in a mainstream school	3.00	0.00
2. My child should be educated in a Special Educational Needs school	3.00	0.00
3. My child should be home-schooled	2.67	1.03
4. My child needs an individual teaching program	3.17	0.41
5. My child needs a Teaching Assistant in a mainstream school	3.17	0.41
6. My child is very creative	3.00	0.00
7. My child has great attention to detail	2.83	0.41
8. My child has great problem-solving skills	2.83	0.41
9. My child is able to do quick mathematical calculations	3.00	0.00
10. My child is able to get along with typical developing classmates	2.67	0.52
11. My child is able to do his/her homework alone	3.00	0.00
12. My child is able to hold a pen/pencil right	3.00	0.00
13. My child is able to write his/her name	3.00	0.00

Values are expressed: Mean (M) and Standard Deviation (SD).

Questionnaire Part 4. ***About the Parents.***

In the last part of the questionnaire, the items were divided into three groups: *Group 20* sources of information about autism; *Group 21* sources of social support; and *Group 22* parents' own views and experiences of raising a child with autism.

Table 20. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 20 Sources of Information (N=6)

	Items	**M**	**SD**
1.	Healthcare professionals inform me sufficiently about autism	3.00	0.00
2.	Other parents of children with autism inform me sufficiently about autism	2.83	0.41
3.	The Internet (social media, autism-related websites, online forums, etc.) informs me sufficiently about autism	3.00	0.00
4.	The Media (TV, radio) inform me sufficiently about autism	3.00	0.00
5.	Scientific journals and books inform me sufficiently about autism	3.00	0.00
6.	Autism support and advocacy groups inform me sufficiently about autism	3.00	0.00

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 21. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 21 Sources of Social Support (N=6)

	Items	**M**	**SD**
1.	My partner supports me with my child's autism	3.33	0.82
2.	My family and friends support me with my child's autism	3.00	0.00
3.	Healthcare professionals support me with my child's autism	3.00	0.00
4.	Other parents of children with autism support me with my child's autism	3.00	0.00
5.	Autism support and advocacy groups support me with my child's autism	3.00	0.00

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 22. Descriptive Statistics: Means and Standard Deviations of Suitability Ratings for Group 22 Parents' Own Views about Autism (N=6)

Items	M	SD
1. Autism is not a disability but a different way of interpreting and interacting with the world	2.50	0.84
2. Children with autism have special talents and abilities	2.33	0.82
3. Parenting a child with autism makes the family bond stronger	3.00	0.00
4. Society has negative attitudes towards autistic people	3.33	0.82
5. The autistic child's behaviour causes negative attitudes against him/her	3.33	0.82
6. Autism strongly affects the way others see the child	3.33	0.82
7. People in public see autism as a result of bad parenting	3.00	0.00
8. Having a child with autism is a social stigma	2.67	0.82
9. Autism affects people from all backgrounds and nationalities	3.33	0.82

Values are expressed: Mean (M) and Standard Deviation (SD).

Section 3.4. Discussion

Following the consultation with parents, the 215 items were revised to ensure there were no duplicates, unclear items, or items that would not relate to the majority of parents of children with autism. Additionally, the wording and phrasing of the items were corrected wherever possible, based on the obtained feedback. None of the participants found any of the items to be inappropriate or uncomfortable however, consideration was given to the overall length of the questionnaire. The items that were rated by parents neutral (3) and above on the five-point Likert scale were considered for inclusion in the questionnaire. Administration time, length of the questionnaire, and the aims of this research were also taken into account. The decision regarding the inclusion of items in the revised version of the questionnaire was widely discussed and taken by the academic research team consisting of three members of the University's academic staff and the author based on a) parent rating and feedback, b) item's significance based on the literature, and c) questionnaire length to develop suitability, appropriateness, and comprehensibility of the questionnaire. Details are shown below.

Questionnaire Part 1. *The General Nature of Autism.*

A total of 20 items were included in the first part of the questionnaire, and 16 items were eliminated. Five items were included in *Group 1* the clinical features of autism (Table 1). Items *1.1, 1.2, 1.6,* and *1.7* were included due to high parent rating. Item *1.3* was included due to the item's significance based on the literature. Item *1.5* was eliminated due to low parent rating, and item *1.4* was eliminated due to ambiguity of wording. Four items were included in *Group 2* the causes of autism (Table 2). Items *2.1, 2.2, 2.4,* and *2.6* were included due to high parent rating, significance, and relevance. Eight items were eliminated due to qualitative criteria (i.e., parent feedback) and ambiguity of content. Five items were included in *Group 3* the developmental course of autism (Table 3). These were items *3.1, 3.3, 3.5, 3.6,* and *3.10*. Items *3.1, 3.3, 3.5,* and *3.10* were included due to high parent rating. Item *3.6* was included due to the item's significance based on the literature. Five items were eliminated due to parent feedback and item duplication. Three items were included in *Group 4* the effects of an intervention (Table 4). Items *4.1, 4.2,* and *4.6* were included due to high parent rating. Items *4.4* and *4.5* were eliminated due to low parent rating, and items *4.3* and *4.7* were eliminated due to similar content. Three items were included in *Group 5* the signs and symptoms of autism (Table 5). These were items *5.1, 5.3,* and *5.5*. Items *5.3* and *5.5* were included due to high parent rating. Item *5.1* was included due to the item's significance based on the literature. Two items were eliminated due to low parent rating and ambiguity of wording.

Questionnaire Part 2. *Characteristics of Children with Autism.*

A total of 31 items were included in the second part of the questionnaire, and 46 items were eliminated. Five items were included in *Group 6* social characteristics of children with autism (Table 6). Items *6.3, 6.5, 6.6, 6.7,* and *6.10* were included due to high parent rating, significance, and relevance. Items *6.1, 6.2, 6.11, 6.12, 6.14,* and *6.15* were eliminated due to low parent rating, and items *6.4, 6.13,* and *6.16* were eliminated due to content irrelevance. Items *6.8* and *6.9* were eliminated due to similar content. Five items were included in *Group 7* communication characteristics of children with autism (Table 7). Items *7.1, 7.3, 7.6,* and *7.7* were included due to high parent rating. Item *7.4* was included due to the item's significance based on the literature and relevance. Two items were eliminated due to the ambiguity of content and wording. Five items were included in *Group 8* behaviour characteristics of children with autism (Table 8). Items *8.4, 8.6, 8.8, 8.9,* and *8.13* were included due to high parent rating, significance, and relevance. Ten items were eliminated due to low parent rating, the ambiguity of wording, and similar content. Three items were included in *Group 9* self-care characteristics of children with autism (Table 9). Items *9.4, 9.5,* and *9.6* were included due to high parent rating, and relevance. Items *9.1, 9.3,* and *9.5* were eliminated due to similar content, and items *9.7* and *9.8* were eliminated due to low parent rating. Four items were included in *Group 10* self-occupation characteristics of children with autism (Table 10). Items *10.1, 10.3, 10.5,* and *10.6* were included due to high parent rating and significance based on the literature. Item *10.2* was eliminated due to similar content, and items *10.4* and *10.7* were eliminated due to low parent rating and ambiguity of wording. Five items were included in *Group 11* sensory characteristics of children with autism (Table 11). Items *11.2, 11.3, 11.6, 11.9,* and *11.10* were included due to high parent rating, significance, and relevance. Six items were eliminated due to similar content and item irrelevance. Four items were included in *Group 12* education characteristics of children with autism (Table 12). Items *12.2, 12.5, 12.6,* and *12.11* were included due to high parent rating, significance, and relevance. Nine items were eliminated due to low parent rating and content ambiguity.

Questionnaire Part 3. *Characteristics of the Individual Child with Autism.*

A total of 17 items were included in the third part of the questionnaire, and 46 items were eliminated due to questionnaire structure and consistency. Five items were included in

Group 13 social characteristics of the individual child with autism (Table 13). Items *13.3, 13.5, 13.6, 13.7*, and *13.10* were included due to high parent rating, significance, and relevance with the akin *Group 6*. Five items were included in *Group 14* communication characteristics of the individual child with autism (Table 14). Items *14.1, 14.3, 14.6,* and *14.7* were included due to high parent rating, significance, and relevance with the akin *Group 7*. Five items were included in *Group 15* behaviour characteristics of the individual child with autism (Table 15). Items *15.4, 15.6, 15.8, 15.9,* and *15.13* were included due to high parent rating, significance, and relevance with the akin *Group 8*. Three items were included in *Group 16* self-care characteristics of the individual child with autism (Table 16). Items *16.4, 16.5,* and *16.6* were included due to high parent rating, significance, and relevance with the akin *Group 9.* Four items were included in *Group 17* self-occupation characteristics of the individual child with autism (Table 17). Items *17.1, 17.3, 17.5,* and *17.6* were included due to high parent rating, significance, and relevance with the akin *Group 10.* Five items were included in *Group 18* sensory characteristics of the individual child with autism (Table 18). Items *18.2, 18.3, 18.6, 18.9,* and *18.10* were included due to high parent rating, significance, and relevance with the akin *Group 11*. Four items were included in *Group 19* education characteristics of the individual child with autism (Table 19). Items *19.2, 19.5, 19.6,* and *19.11* were included due to high parent rating, significance, and relevance with the akin *Group 12.*

Questionnaire Part 4. *About the Parents.*

A total of 17 items were included in the last part of the questionnaire, and 3 items were eliminated. According to parent feedback all items of *Group 20* sources of information (Table 20) and *Group 21* sources of social support (Table 21) were considered suitable and appropriate, and no items were eliminated. Four items were included in *Group 22* parents' own views (Table 22). Items *22.1, 22.3, 22.6, 22.7, 22.8,* and *22.9* were included due to parent feedback and relevance based on the literature. Three items were eliminated due to qualitative criteria, the ambiguity of content, and negative wording.

A total of one hundred and sixteen items were eliminated resulting in the revised version of the first questionnaire on parental understanding of autism with 99 items (Appendix 3). The items were introduced in four separate parts including, **Part 1.** *The General Nature of Autism* containing a total of 20 items; **Part 2.** *Characteristics of Children with Autism* containing a total of 31 items; **Part 3.** *Characteristics of the Individual Child with Autism* containing a total of 31 items; and **Part 4.** *About the Parents* containing a total of 17 items. All items were scored on a 7-point Likert scale, where (1) means strongly disagree and (7) means strongly agree. The evaluation of the questionnaire by conducting an online survey among parents of children with autism and a series of interviews with stakeholders and specialists in the field of autism is presented in Chapter 4.

CHAPTER 4

QUESTIONNAIRE EVALUATION

Chapter Overview

This chapter describes the rationale for the first evaluation study of a 99-item questionnaire for assessing parental understanding of the nature and characteristics of children with autism. The aim of the present study was two-fold. Firstly, it attempted to determine whether there are differences between parents' understanding of the general nature and characteristics of autism and the characteristics of their child with autism. Secondly, it aimed to describe the rationale behind the development of a new profiling tool. An online survey was conducted among 300 parents of children diagnosed with autism, followed by a series of interviews with stakeholders and specialists in the field of the study. This chapter presents the results of research carried out to test the first research objective, as well as a preliminary assessment of internal reliability, factor structure, and construct validity of a new profiling tool for parental understanding of autism.

Section 4.1. Introduction

The aim of this study was two-fold; firstly, it aimed to address the first research objective, which was to determine whether there are differences between the understanding of autism in general and in relation to the individual child with autism, and in particular to examine how parents understand the general nature and characteristics of all children with autism as related to the characteristics of their autistic child. The second objective of this study was to describe the rationale behind the development of a new profiling tool.

To date, no questionnaires have been developed to assess parental understanding of autism. To the best of the author's knowledge, this is the first study to examine how parents understand autism and the characteristics of children with autism. An online survey was conducted, followed by a series of interviews with stakeholders and specialists in the field of autism to 1) determine whether there are differences between general and specific understanding of autism, and 2) test the internal reliability and construct validity (factor analysis by means of maximum likelihood analysis) of the questionnaire and estimate the number of appropriate items for use in a new profiling tool for parental understanding of autism. The final revisions being made to the questionnaire were based on both the results of the statistical analysis and input by stakeholder and expert consultation resulting in a provisional instrument with 20 items, called the Individualised Autism Profiling (IAP) tool (Chapter 5).

Section 4.2. Methods

Participants

Following written informed consent four hundred and seventy (n=470) parents, all having children with an autism diagnosis, volunteered to participate in this study. Participants were recruited via an announcement on social media (e.g., Facebook and Twitter) and the National Autistic Society (NAS) website. An invitation email was also sent to the Headteachers of selected Special Schools across the UK. Participants were included in the study if they 1) were 18 years or older, 2) had a child who has been formally diagnosed with autism using the DSM-IV or DSM-5 (American Psychiatric Association, 2013b) or ICD-10 (World Health Organization, 1992) criteria for 'Childhood Autism', 'Autistic Disorder' or 'Autism Spectrum Disorder' by a qualified healthcare professional, 3) the child lived in the family home. The study was conducted according to the Declaration of Helsinki and was approved by the Ethics Committee of the University of Derby.

Procedure and Materials

The study took place between February 2019 and June 2019. The survey was created and administered using the Qualtrics system. Through a hyperlink, parents were provided with participant information and were then asked to provide informed consent before accessing the survey. If parents had more than one child who had received a diagnosis of autism, they were asked to provide information only for their older child with autism.

The questionnaire consisted of four separate parts; each part was divided into several domains consisting of up to six items. The demographic information included data from the parent (e.g., age, gender, ethnicity, marital status, employment status, highest level of education achieved), and diagnostic information about the child (e.g., type of diagnosis, medication, participation in intervention programs for autism). All items except the demographics were scored on a seven-point Likert scale ranging from (1) strongly disagree, (2) disagree, (3) somewhat disagree, (4) neither agree or disagree, (5) somewhat agree, (6) agree to (7) strongly agree (Appendix 3).

Questionnaire Part 1. *The General Nature of Autism.* In the first part of the questionnaire, participants were asked to rate their agreement or not with statements about the general nature of autism, divided into five domains: (1) the clinical features of autism (five items), (2) the causes of autism (four items), (3) the developmental course of autism (five items), (4) the effects of an intervention (three items), and (5) the signs and symptoms of autism (three items).

Questionnaire Part 2. *Characteristics of Children with Autism.* In the second part of the questionnaire, parents were asked to rate their agreement or not with statements about the characteristics of all children with autism in core areas of development and learning, divided into seven domains: (1) social characteristics (five items), (2) communication characteristics (five items), (3) behaviour characteristics (five items), (4) self-care characteristics (three items), (5) self-occupation characteristics (three items), (6) sensory characteristics (five items), and (7) education characteristics (five items).

Questionnaire Part 3. ***Characteristics of the Individual Child with Autism.*** In this part, participants were asked to rate their agreement or not with statements about the characteristics of their child with autism, including seven domains: their child's (1) social characteristics (five items), (2) communication characteristics (five items), (3) behaviour characteristics (five items), (4) self-care characteristics (three items), (5) self-occupation characteristics (three items), (6) sensory characteristics (five items), and (7) education characteristics (five items). The items included in this part were identical to the items in Part 2 except that they referred to the characteristics of the individual child with autism rather than to all children with autism.

Questionnaire Part 4. ***About the Parents.*** In the last part, parents were asked to provide information about how they acquire information about autism (six items), support about themselves and their child (five items), and their own views about autism (six items).

The questionnaire took approximately 20 minutes to complete. At the end of the survey participants were asked to indicate whether they would like to take part in follow-up interviews to inform revisions to the questionnaire.

Stakeholder and Expert Consultation

A series of semi-structured interviews with stakeholders and specialists in the field of autism was conducted to ensure whether any essential items were missing and to define the number of appropriate items for use in the new profiling tool for parental understanding of autism. It is important to note here that in this phase of preliminary tool development, stakeholder and expert consultation was deemed essential to ensure that all the underlying aspects of parental understanding of their child's potential and unique needs had been considered and that no important aspect was omitted.

A sample of ten survey respondents (parents of children with autism) and six specialists (one Educational Psychologist, one Special School Headteacher, two CEOs of UK charities for autism, and two researchers in the field of autism) were interviewed using a brief semi-structured interview schedule. The schedule acted as a guide in the interview to ensure the aims of the study were met. Participants were asked to comment on the thirty-one items of Part 3 *Characteristics of the Individual Child with Autism* of the questionnaire, whether they were perceived to be relevant and appropriate, and whether any particular aspect had been missed (Appendix 4). All the interviews were conducted by the author at the University setting, and via Skype, were audio-taped and transcribed verbatim. The study was conducted according to the Declaration of Helsinki and was approved by the Ethics Committee of the University of Derby. All participants gave written informed consent to take part (Appendix 4). The interviews helped to refine the layout and ease of use of the questionnaire and to gain insight into the appropriateness of the items for different groups. To ensure content validity, the final revisions being made to the questionnaire were based on both the results of the statistical analysis and input by stakeholder and expert consultation.

Statistical Analysis

Reliability analysis was conducted to test the internal consistency of the questionnaire using Cronbach's alpha coefficient. The alpha value was set at 0.7 and above to be an acceptable internal consistency (Blunch, 2008).

Paired sample *t*-tests were conducted for each item to determine whether there were significant differences between parents' views of autism in all children (Part 2) and their perceptions of their child (Part 3) in relation to autism characteristics. Also, paired sample *t*-tests were conducted for each domain between the two questionnaire parts to assess whether any differences could be explained by domain rather than individual items.

An exploratory factor analysis using the maximum likelihood extraction method and oblique rotation was conducted on Part 1 *The General Nature of Autism* and Part 3 *Characteristics of the Individual Child with Autism* of the questionnaire, following the exclusion of Part 2 *Characteristics of Children with Autism* from further analysis based on the interpretation of the results of the pairwise comparisons. Part 4 *About the Parents* was excluded from further analyses based on the alpha value criterion set at 0.7 and above to be an acceptable internal consistency. Before performing the exploratory factor analysis, the normality in distribution was tested by examining skewness and kurtosis. Items with loadings below 0.4 were removed.

Independent *t*-tests were used to investigate differences within study variables (e.g., gender, comorbid diagnoses, medication) for each of the factors elucidated by the exploratory factor analysis. A multivariate analysis of variance (MANOVA) was applied to examine between-subject effects of the independent variables of age (parent's and child's), level of education, and employment on each of the EFA factors. Also, one-way or two-way analyses of variance (ANOVA) were applied to examine specific group differences in case any significant differences or variances were found. Data analyses were conducted using SPSS version 25, and all tests were 2-tailed with a significance level set at $p < 0.05$, missing data were treated pairwise.

Section 4.3. Results

Descriptive Statistics

A total of three hundred (N=300) parents completed this stage of the research, corresponding to 64 per cent of the total number of participants who volunteered to participate in this study (N=470). A hundred and seventy (N=170) participants had been excluded due to incomplete responses. Participants were mostly mothers [286 (95.3%); 14 (4.7%) fathers], with a mean age of 41.3 (range 23–66 years). Demographic information for parents can be found in Table 23.

Table 23. Demographic Characteristics of Studied Parents [a] (N=300)

		Parents	
		M	**SD**
Age (y) [b]		41.36	7.68
No. of children [c]		2.16	1.04
No. of children with autism [d]		1.17	0.44
		N	**%**
Education level	A-level	80	26.7
	Undergraduate (BSc, BA) or work qualifications	160	53.3
	Postgraduate (MSc, PhD)	43	14.3
	No qualifications	17	5.7
Gender [e]		14/286	

[a] Parents of children with autism (N=300), [b] y= years, [c, d] No.=number, [e] Male/Female; Values are expressed: Mean (M) and Standard Deviation (SD).

Reliability Analysis

Reliability analysis was conducted to test the internal consistency reliability of the questionnaire set. The 99-item questionnaire had excellent internal consistency with a Cronbach's alpha of 0.93 overall. Internal consistency reliability of the four questionnaire parts ranged from moderate to high (Cronbach's alpha = 0.67 – 0.94). The alpha values for each part were 0.72 for Part 1, 0.94 for Part 2, 0.88 for Part 3, and 0.67 for Part 4. Based on the alpha value criterion set at 0.7 and above to be an acceptable internal consistency, Part 4 (i.e., About the Parents) was excluded from further analyses. Examination of the alpha levels if items were deleted revealed that the alpha coefficient values decreased with deletion of any of the items in the rest of the parts, indicating that all items were important to the scale at this stage of development and so were retained.

Paired Samples T-tests

A paired-samples t-test was conducted for each item in Part 2 *Characteristics of All Children with Autism* and Part 3 *Characteristics of the Individual Child with Autism* to determine whether there were significant differences in parental understanding of autism between the parts. As shown in Table 24, the results indicated that there were significant differences in sixteen pairwise comparisons.

Table 24. Differences between Items for All Children and the Individual Child with Autism (N=300)

		All Children		**Individual Child**		**Statistics**		
Items		**M**	**SD**	**M**	**SD**	**t-value**	**p-value**	**Cohen's d**
1.	Avoid eye contact when talking	4.77	1.44	4.54	1.78	2.65	<0.01	0.14
2.	Have poor relationships in peer group situations	5.07	1.39	5.28	1.57	-2.49	<0.05	-0.10
3.	Are not able to share their thoughts	4.31	1.61	4.76	2.03	-4.14	<0.001	-0.14
4.	Use gestures to get what they want	3.95	1.57	3.58	2.01	4.27	<0.001	0.12
5.	Have sleep disturbances	5.01	1.51	5.28	1.85	-3.41	0.001	-0.10
6.	Do not adapt easily to changes and unforeseen circumstances	5.88	1.11	5.54	1.46	4.95	<0.001	0.09
7.	Have problems with personal hygiene (e.g., brush teeth, wash hands, use the shower)	4.93	1.59	5.13	1.84	-2.46	<0.05	-0.10
8.	Insist on the same routine	5.34	1.27	4.93	1.62	5.76	<0.001	0.10
9.	Often rock their head or body repeatedly	3.95	1.57	3.06	1.87	10.43	<0.001	0.12
10.	Prefer to arrange things in a certain way	5.03	1.36	4.78	1.76	3.15	<0.01	0.10
11.	Find it hard to engage to pretend play	4.66	1.63	4.47	2.01	2.15	<0.05	0.10
12.	An environment with multiple distractions has a negative impact on the autistic child's behaviour	5.63	1.19	5.85	1.40	-3.03	<0.01	-0.10
13.	Are distressed by minor changes in their environment (e.g., rearranged furniture, new cutlery)	4.97	1.29	4.66	1.78	3.68	<0.001	0.11
14.	Have a limited range of food preferences based on colour, texture and/or presentation	5.09	1.57	4.80	2.12	3.00	<0.01	0.12
15.	Are best educated in a Special Educational Needs school setting	3.61	1.82	3.99	2.36	-3.58	<0.001	-0.13
16.	Find it hard to do their homework alone	5.01	1.57	5.41	1.75	-4.69	<0.001	-0.11

Note. Table 24 shows only the statistically significant pairwise comparisons between items for Part 2 and Part 3. Values are expressed: Mean (M) and Standard Deviation (SD).

A paired-samples t-test was conducted for each domain in Part 2 *Characteristics of All Children with Autism* and Part 3 *Characteristics of the Individual Child with Autism* to assess whether any differences could be explained by domain rather than individual items. The results indicated that there were significant differences in two out of seven domains. Analytic statistics are presented in Table 25.

Table 25. Differences between Domains for All Children and the Individual Child with Autism (N=300)

	All Children		**Individual Child**		**Statistics**		
Domains	**M**	**SD**	**M**	**SD**	**t-value**	**p-value**	**Cohen's d**
1. Social	23.43	5.25	23.59	5.57	-0.67	N.S.	-0.03
2. Communication	21.10	6.35	21.16	7.65	-0.17	N.S.	-0.01
3. Behaviour	24.32	5.51	23.98	5.89	1.26	N.S.	0.06
4. Self-care	13.80	4.03	14.12	4.74	-1.48	N.S.	-0.07
5. Self-occupation	18.98	4.32	17.24	5.05	8.24	<0.001	0.37
6. Sensory	25.91	5.00	25.37	6.00	1.92	N.S.	0.10
7. Education	17.45	3.88	18.21	3.70	-3.78	<0.001	-0.20

N.S.= Not Significant. Values are expressed: Mean (M) and Standard Deviation (SD).

Exploratory Factor Analysis

Maximum likelihood analysis with an oblique rotation was conducted on Part 1 *The General Nature of Autism* consisting of 20 items and Part 3 *Characteristics of the Individual Child with Autism* consisting of 31 items (see Section 4.2. Methods). The Kaiser–Meyer–Olkin measure of sampling adequacy was high at 0.84 and Bartlett's test of sphericity was significant (3373.48, df = 465, $p < 0.001$), which confirms that it was appropriate to use the factor analytic model for this set of data. Three factors with eigenvalues over 1, explaining a total of 44.8 per cent of the variance in the scores, were identified. The first factor explained 25.5 per cent of the variance, the second 9.9 per cent, and the third 9.4 per cent of the variance. The obtained pattern matrix is displayed in Table 26. Only items with factor loadings of above 0.4 are shown and there are no cross-loadings. The factors were labelled: eating habits, adaptive skills, and social interaction skills according to the common theme presented by the items loaded on each factor.

Table 26. Summary of Exploratory Factor Analysis Results using a Maximum Likelihood Estimation with Oblique Rotation (N=300)

Item	**Factor Loadings**		
	1	**2**	**3**
My child prefers to play by himself/herself.			0.43
My child has language and speech difficulties.			0.72
My child is not able to share his/her thoughts.			0.80
My child responds poorly to others (e.g., appears withdrawn and indifferent to other people).			0.52
My child uses gestures to get what he/she wants.			0.71
My child is not able to communicate his/her needs and wants.			0.72
My child has unusual eating patterns and food selectivity.	0.83		
My child does not adapt easily to changes and unforeseen circumstances.		0.80	
My child requires more help than other children of his/her age to get dressed or undressed.			0.42
My child insists on the same routine.		0.77	
An environment with multiple distractions has a negative impact on my child’s behaviour.		0.66	
My child is distressed by minor changes in his/her environment (e.g., rearranged furniture, new cutlery).		0.78	
Bright lights, loud sounds, and intense smells cause discomfort to my child.		0.58	
My child has a limited range of food preferences relevant to colour, texture, and/or presentation.	1.01		
My child expresses distress when he/she is touched (e.g., someone touches his/her hair).		0.46	

Note. Table 26 shows the factor loadings after rotation using a significant factor criterion of 0.4.

Factor Interpretation

As can be seen from Table 26, **Factor 1** is comprised of two items. Conceptually these items were related to parental understanding of their child's eating habits. Therefore, it was decided to describe or label this factor as **Eating Habits**.

Factor 2 is comprised of six items that focus on the characteristics related to the adaptive behaviour of their child with autism. Therefore, the factor was labelled as **Adaptive Skills**.

Factor 3 is comprised of seven items. Conceptually these items were related to parental understanding of their child's social interaction skills and accordingly the factor was labelled as **Social Interaction Skills**.

Internal consistency for each of the factors was examined using Cronbach's alpha (Table 27). Correlations between factors were statistically significant. These results suggest the existence of three unique factors for the data set (Table 28). In summary, a total of 36 items were removed, and 15 items remained in the final analysis because their correlations and loadings were at an acceptable level (of above 0.4).

Table 27. Descriptive Statistics for the three EFA Factors (N=300)

Factor	No. of Items	M (SD)	Skewness	Kurtosis	Alpha
1. Eating habits	2	9.87 (3.94)	-0.71	-0.78	0.90
2. Adaptive skills	6	31.05 (7.17)	-0.92	0.73	0.83
3. Social interaction skills	7	30.86 (9.66)	-0.09	-0.70	0.82

Values are expressed: Mean (M) and Standard Deviation (SD).

Table 28. Pearson Correlations among the three EFA Factors (N=300)

Factor	1	2	3
1. Eating habits	—		
2. Adaptive skills	0.35**	—	
3. Social interaction skills	0.33**	0.22**	—

**Bivariate correlations are significantly different from zero at p < 0.01 (two-tailed).

Independent Samples T-tests

An independent-samples t-test was conducted to investigate whether there were differences between mothers and fathers of children with autism, separately for each of the EFA factors. A significant difference was found for **Factor 3** *Social Interaction Skills* between the two groups. The results are presented in Table 29.

Table 29. Differences between Mothers and Fathers of Children with Autism for each of the EFA Factors (N=300)

	Male (n=14)		**Female (n=286)**		**Statistics**		
Factors	**M**	**SD**	**M**	**SD**	**t-value**	**p-value**	**Cohen's d**
1. Eating habits	10.29	4.23	9.85	3.93	0.40	N.S.	0.11
2. Adaptive skills	26.14	11.19	31.29	6.85	-1.70	N.S.	-0.73
3. Social interaction skills	37.86	6.90	30.51	9.66	2.81	<0.01	0.77

N.S.= Not Significant. Values are expressed: Mean (M) and Standard Deviation (SD).

An independent-samples t-test was conducted to investigate whether there were differences between parents of male children with autism and those of female children with autism, separately for each of the EFA factors. A significant difference was found for **Factor 2** *Adaptive Skills* between the two groups. The results are presented in Table 30.

Table 30. Differences between Male and Female Children with Autism for each of the EFA Factors (N=300)

	Male (n=221)		Female (n=79)		Statistics		
Factors	**M**	**SD**	**M**	**SD**	**t-value**	**p-value**	**Cohen's d**
1. Eating habits	9.88	3.98	9.85	3.84	0.07	N.S.	0.01
2. Adaptive skills	30.45	7.46	32.72	6.00	-2.70	<0.01	-0.32
3. Social interaction skills	31.23	9.87	29.82	9.05	1.11	N.S.	0.15

N.S.= Not Significant. Values are expressed: Mean (M) and Standard Deviation (SD).

An independent-samples t-test was conducted to investigate whether there were differences between parents of children with comorbid diagnoses and those of children without comorbid diagnoses. A significant difference was found for **Factor 2** *Adaptive Skills* between the two groups. The results are presented in Table 31.

Table 31. Differences between Children with and without Comorbid Diagnoses for each of the EFA factors (N=300)

	Comorbid Diagnoses (n=155)		Without Comorbid Diagnoses (n=145)		Statistics		
Factors	**M**	**SD**	**M**	**SD**	**t-value**	**p-value**	**Cohen's d**
1. Eating habits	9.73	4.12	10.03	3.74	-0.66	N.S.	-0.08
2. Adaptive skills	32.10	6.92	29.93	7.28	2.64	<0.01	0.31
3. Social interaction skills	31.13	9.60	30.57	9.75	0.50	N.S.	0.06

N.S.= Not Significant. Values are expressed: Mean (M) and Standard Deviation (SD).

An independent-samples t-test was conducted to investigate whether there were differences between parents of children with autism under medication and those of children not receiving medication. A significant difference was found for **Factor 2** *Adaptive Skills* between the two groups. The results are illustrated in Table 32.

Table 32. Differences between Children Under Medication and those Not Receiving Medication for each of the EFA Factors (N=300)

	Under Medication (n=106)		**Not Receiving Medication (n=194)**		**Statistics**		
Factors	**M**	**SD**	**M**	**SD**	**t-value**	**p-value**	**Cohen's d**
1. Eating habits	10.02	3.83	9.79	4.01	0.47	N.S.	0.06
2. Adaptive skills	32.82	6.13	30.08	7.51	3.41	0.001	0.39
3. Social interaction skills	31.58	9.70	30.46	9.65	0.95	N.S.	0.12

N.S.= Not Significant. Values are expressed: Mean (M) and Standard Deviation (SD).

Multivariate Analysis of Variance

A multivariate analysis of variance (MANOVA) was performed with the three EFA factors as dependent variables and parent's age, child's age, level of education, and employment status as independent variables. In Table 33 it can be observed that the overall effect of age (parent's and child's), level of education, and employment status on the three EFA factors was not significant. However, a significant main effect was found for child's age with F (9,545) = $p < 0.05$, $\eta^2 p = 0.03$.

Table 33. MANOVA Results Showing the Effects of Parent's Age, Child's Age, Level of Education and Employment Status on each of the EFA factors[a] (N=300)

	Wilk's Λ	**F-value**	**Degrees of freedom**	**p-value**	**$\eta^2 p^b$**	**Power [c]**
Parents' age	0.99	0.32	6, 448	N.S.	<0.01	0.14
Child's age	0.91	2.54	9, 545	<0.05	0.03	0.87
Education	0.90	1.61	15, 619	N.S.	0.04	0.87
Employment	0.95	1.24	9, 545	N.S.	0.02	0.50
Education*Employment* Parent's age*Child's age	0.99	0.09	3, 224	N.S.	0.001	0.07

[a]Factor 1= Eating Habits, Factor 2=Adaptive Skills, Factor 3=Social Interaction Skills; [b] = partial eta-squared; [c]= when the significance level is alpha=0.05; N.S.= Not Significant. Values are expressed: Mean (M) and Standard Deviation (SD).

One-way Analysis of Variance

A one-way analysis of variance (ANOVA) showed a statistically significant effect of child's age on **Factor 2** *Adaptive Skills* (F (3, 296) = 3.69, $p < 0.05$; $\eta^2p = 0.04$) and **Factor 3** *Social Interaction Skills* (F (3, 296) = 15.90, $p < 0.001$; $\eta^2p = 0.14$). Post hoc analysis using the Tukey HSD test indicated that for mean scores for **Factor 2** *Adaptive Skills* there was a statistically significant difference between children under 5 years and those over 18 years ($p < 0.05$). For **Factor 3** *Social Interaction Skills* there were statistically significant differences between children under 5 years and those between 6-11 years ($p < 0.001$), children under 5 years and those between 12-17 years ($p < 0.001$), and children under 5 years and those over 18 years ($p < 0.05$). The results are illustrated in Table 34.

Table 34. ANOVA Results for Child's Age Groups (N=300)

Factors	Group 1[a] (n=70) M(SD)	Group 2[b] (n=129) M(SD)	Group 3[c] (n=81) M(SD)	Group 4[d] (n=20) M(SD)	F-value	Degrees of freedom	p-value	η^2p[e]	Post-hoc tests statistics[f]
Eating habits	10.74(3.81)	9.73(4.10)	9.23(3.79)	10.35(3.65)	2.02	3, 296	N.S.	0.02	a/b, a/c, a/d, b/c, b/d, c/d= N.S.
Adaptive skills	28.97(8.56)	31.15(6.59)	31.94(6.84)	34.10(4.80)	3.69	3, 296	<0.05	0.04	a/b. a/c= N.S.; a/d= p<0.05; b/c, b/d, c/d= N.S.
Social interaction skills	37.36(8.29)	28.83(9.58)	28.74(8.72)	29.75(8.81)	15.90	3, 296	<0.001	0.14	a/b= p<0.001; a/c= p<0.001; a/d= p<0.05; b/c, b/d, c/d= N.S.

[a]= age group under 5 years; [b] =age group 6-11 years; [c]=age group 12-17 years; [d]=age group over 18; [e] = partial eta-squared;

[f] = Tukey HSD test. N.S.= Not Significant. Values are expressed: Mean (M) and Standard Deviation (SD).

Stakeholder and Expert Consultation

In this phase of preliminary tool development, the decision was taken to consult stakeholders and specialists in the field of autism to ensure the tool fully reflects their perspective and that items are acceptable, comprehensive, and relevant to parents of autistic children. Participants were asked to comment on the thirty-one items of Part 3 *Characteristics of the Individual Child with Autism* of the questionnaire, whether they were perceived to be relevant and appropriate, and whether any essential items were missing. Both parents of children with autism and specialists indicated that five items from the scale were of particular concern, so item revisions were made accordingly. These items had good Cronbach's alpha but factor loading below the cutoff value of 0.4. The wording and setting of each item were revised based on parent and expert feedback.

The items were: **1)** my child often rocks his/her body repeatedly, which changed to *my child has frequent tantrums and/or meltdowns*, **2)** my child finds it difficult to understand instructions, that changed to *my child finds it difficult to understand other people's emotions*, **3)** my child has poor relationships in peer group situations, that changed to *my child covers his/her social and communication difficulties*, **4)** my child has self-injurious behaviour, which changed to *my child is unaware of the risks around him/her*, and **5)** my child prefers to arrange things in a certain way, that changed to *my child shows a strong attachment to certain objects*. Taken together, most respondents were concerned with items relevant to temper tantrums, the ability to understand other people's emotions, camouflaging behaviours, self-injurious behaviour, and restricted, fixated interests. These items were considered important for the development of an autism profiling tool, as they reflect core autistic features that are common in children with autism and which could be key indicators for assessing parental perceptions of their child's behaviour in the context of autism and individual differences.

Section 4.4. Discussion

The aim of the present study was two-fold. Firstly, it attempted to determine whether there are differences between parental understanding of autism in general and in relation to the individual child with autism, and in particular to examine how parents understand the general nature and characteristics of all children with autism as related to the characteristics of their autistic child, which was also the first research objective. Secondly, it aimed to describe the rationale behind the development of a new profiling tool for parental understanding of autism. To date, no questionnaires have been developed to assess parental understanding of autism. This is the first study to examine, using a representative data set, how parents understand autism and the characteristics of children with autism.

Regarding the first aim, the results of the present study demonstrated that there were no statistically significant differences in five out of seven domains of function, including *Social*, *Communication*, *Behaviour*, *Self-care,* and *Sensory* domains, while statistically significant differences were found in the Self-occupation and Education domains. These results are consistent with relevant research in the area. McMahon et al. (2020) suggested that due to the Dunning-Kruger effect (Kruger & Dunning, 1999), the general public's perceived knowledge of autism may not be related to their actual knowledge of autism. In particular, individuals who are least knowledgeable about autism may overestimate their knowledge, and more knowledgeable individuals, such as parents of children with autism, may underestimate their knowledge about autism (McMahon et al., 2020). The results in this study suggest that parents may underestimate their knowledge of the differences in the characteristics of all children and those of their autistic child. Moreover, the complex nature of autism itself and the wide variation in the type and severity of symptoms children experience may result in the perception of the characteristics of autism as a whole rather than separate entities. For example, no statistically significant differences were found between questions about all children with autism and the individual child in both *Social* and *Communication* domains, which may indicate that parents perceive the social interaction and communication impairments in autism as one entity. Previous research supports the notion that the social and communication impairments in autism reflect the same underlying cognitive deficit, known as the 'theory of mind' hypothesis of autism (Tager-Flusberg, 1999).

In the present study, there were no statistically significant differences in the *Behaviour*, *Self-care*, and *Sensory* domains, which suggests that parents of children with autism may recognize as typical the challenging behaviours of their autistic child as related to all children with autism. This is not surprising; several studies have shown that parents of children diagnosed with autism often report functional and behavioural problems, such as problems in sleeping, toileting, eating, and self-injury (Chandler et al., 2016; Maskey et al., 2013). The frequency of parent-reported emotional and behaviour problems points to a universality of cooccurring challenging behaviours in autism, which may explain why there were no differences between parents' perceptions of the behaviour, self-care, and sensory characteristics of all children with autism and those of their autistic child.

A variety of factors may influence how parents perceive autism and could potentially affect parental understanding of the potential and unique needs of their autistic children. It is well-documented that parents of children with autism experience increased stress and other mental health issues, including anxiety, psychological distress, and depression, compared to parents of children with other disabilities or parents of typically developing children (Broady et al., 2017; Gatzoyia et al., 2014; Hayes & Watson, 2013). Moreover, research suggests that parents of children diagnosed with autism show low levels of parenting self-efficacy (Meirsschaut et al., 2010), and experience particular difficulties in coping in times of stress (Zablotsky et al., 2013). In this study, the results demonstrated that there were no differences between parents' perceptions of their autistic child and their views of autism in all children.

A statistically significant difference was found between parents' perceptions of their child with autism and their views of autism in all children, in the *Self-occupation* and *Education* domains. To interpret these differences, it was important to examine them at the level of individual items. Sixteen out of thirty-one statistically significant pairwise comparisons were observed, however, a closer examination of these comparisons showed that parent ratings for items 1, 2, 3, 5, 6, 7, 8, 10, 11, 12, 13, 14, and 16 all indicated an agreement with the statements ranging from (4) neither agree or disagree to (5) somewhat agree, but to a slightly different level for their child (e.g., *Children with autism have sleep disturbances* M=5.01 versus *My child has sleep disturbances* M=5.28). It is likely that because parents are more aware of their child's behaviour, are more confident to rate the statements that reflect their child's characteristics compared to the characteristics of all children with autism. Likewise, parent ratings for items 4, 9, and 15 all indicated a disagreement with the statements ranging from (3) somewhat disagree to (4) neither agree or disagree, but to a slightly different level for their child (e.g., *Children with autism often rock their head or body repeatedly* M=3.95 versus *My child often rocks his/her head or body repeatedly* M=3.06) (see Table 24). This result could be explained by society's attitudes towards people with disabilities and the subsequent experiences of stigma for parenting a child with Special Educational Needs (SEN) (Loukisas & Papoudi, 2016; Papadopoulos et al., 2019). Parents in the present study have likely disagreed with these statements to prevent being stigmatized. Taken together, these results further support the notion that parents perceive the characteristics of autism as one entity, therefore, parental understanding of autism in general and in relation to their child with autism might not be theoretically distinct constructs.

Concerning the psychometrics of the 99-item questionnaire, an examination of internal consistency indicated that the questionnaire had excellent internal consistency (Cronbach's a = 0.93) overall; however, internal consistency was considerably lower for Part 4 *About the* *parents*, including seventeen items that did not correlate with the total score of the questionnaire (Cronbach's a = 0.67). This is not surprising, given that these items were related to information and support needs of parents, as well as their views about autism, and were not related to the nature and characteristics of autism. Thus, Part 4 *About the parents* was excluded from further analyses according to the a priori criteria outlined in the Methods section (see Section 4.2.).

Following the exclusion of Part 2 *Characteristics of Children with Autism* based on the interpretation of the results of the pairwise comparisons, exploratory factor analysis using the maximum likelihood extraction method and oblique rotation was conducted on 51 items of the questionnaire (i.e., Part 1 *The General Nature of Autism* consisting of 20 items and Part 3 *The Individual Child's Characteristics* consisting of 31 items) to uncover the underlying structure of the data. The analysis revealed three underlying dimensions, or factors, for the questionnaire, namely, **Factor 1** *Eating Habits* comprised of two items related to parental understanding of their child's eating habits; **Factor 2** *Adaptive Skills* comprised of six items that focus on the characteristics related to the adaptive behaviour of their child with autism, and **Factor 3** *Social Interaction Skills* comprised of seven items related to parental understanding of their child's social interaction skills. The labelling of the three factors was based on the constructs that made the most theoretical sense to the author in light of the available literature.

This study examined whether there were differences between mothers' and fathers' cognitions for the eating habits, adaptive skills, and social interaction skills of their children with autism. The results indicated that there was a statistically significant difference between the two groups for social interaction skills. These results are consistent with previous studies that found that mothers perceive specific child's behaviours differently than fathers, and in particular, mothers engage more with their child's social interactions in the early stages of development compared to fathers, due to the mothers' closeness to the child during infancy (Dovgan et al., 2019; Guinchat et al., 2012).

This study further examined whether there were differences between parents of male and those of female children with autism for the eating habits, adaptive skills, and social interaction skills of their children with autism. A statistically significant difference was found between the two groups for adaptive skills. Adaptive behaviours are defined as daily living skills that are required to function and meet the demands of the environment (Luckasson et al., 2002). Several studies have reported that boys tend to exhibit more restricted and repetitive behaviours than girls (Hartley & Sikora, 2009; Hattier et al., 2011; Mandy et al., 2012; Sipes et al., 2011). Moreover, girls with autism may camouflage their autism symptoms by imitating and memorising socially appropriate behaviours to appear 'typical' (Carpenter et al., 2019). Therefore, it is likely that parents of autistic sons interpret the adaptive skills of their children differently compared to parents of autistic daughters.

The findings of this study also revealed that parents of children with comorbid diagnoses perceived differently their child's adaptive skills compared to parents of children without comorbid diagnoses. Previous research supports that the simultaneous presence of other conditions, such as intellectual disability, motor or language delays, and medical problems may influence the level of adaptive functioning in children with autism (Duerden et al., 2012; Mazurek et al., 2013; Rzepecka et al., 2011). Children diagnosed with concurrent conditions alongside autism are likely to present more challenging behaviours that could affect adaptive functioning compared to children with an autism spectrum diagnosis, which could influence parents' perceptions of adaptive skills.

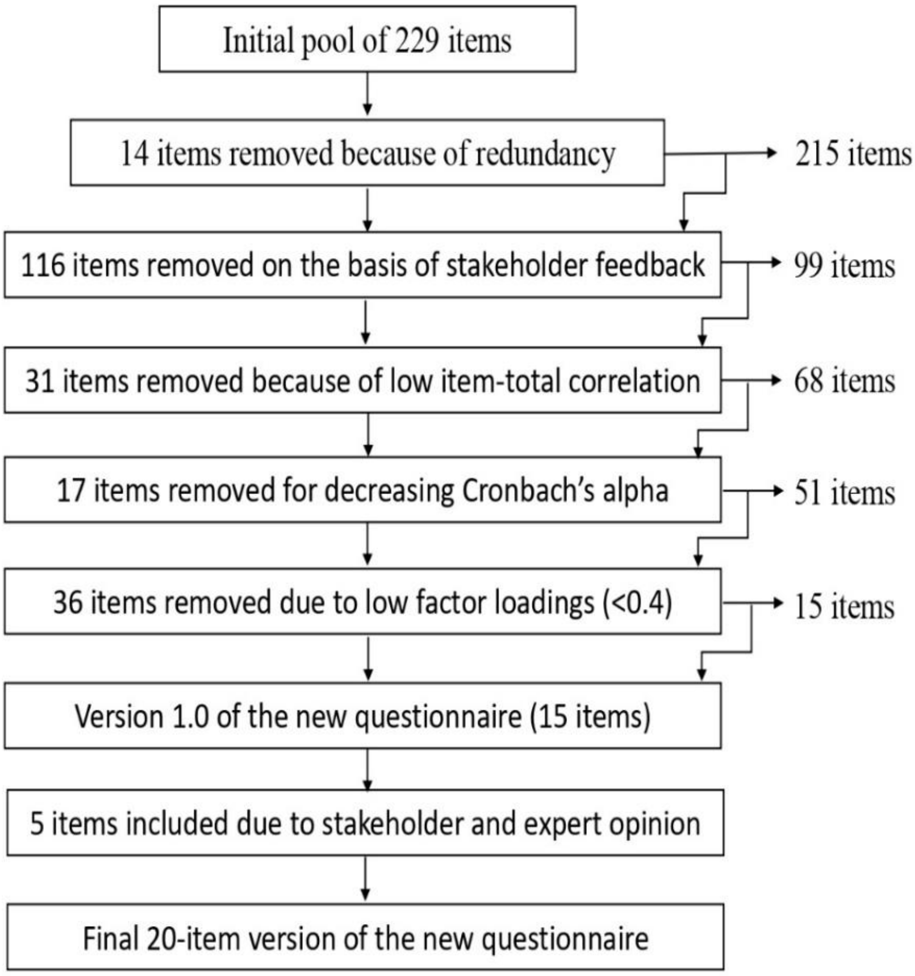
The present study found a statistically significant difference in adaptive skills between parents of children with autism under medication and parents of children not receiving medication. Prescription medication is primarily used to help manage target symptoms, such as irritability, aggression, repetitive behaviours, self-injurious behaviour, sleep disturbances, anxiety, hyperactivity, impulsivity, inattention, or other maladaptive behaviours, and not for the management of core symptoms of autism (Myers et al., 2007). Research suggests that problem behaviour can negatively impact early intervention outcomes if it is not treated as a separate target, and subsequently affect the level of cognitive and adaptive functioning in children with autism (Fulton et al., 2014); this may indicate that children with autism who receive targeted medication may show improvement in their adaptive skills, which could explain the difference found between the two groups.

The MANOVA indicated that there were significant group differences in adaptive and social interaction skills between younger and older children with autism. In particular, a significant difference was found in adaptive skills between children who were under the age of five and those who were over 18 years of age. Also, a significant difference was found in social interaction skills between children who were under five years of age and children of all the other age groups (i.e., 6-11 years, 12-17 years, and over 18 years). This difference is not surprising, given that younger children who have received an early diagnosis of autism (Charman & Baird, 2002), may have not yet received an intervention to improve their functioning and social interactions compared to older children with autism who may have learned how to cope with the everyday environment and may have developed their social interaction skills (Myers et al., 2007). Interestingly, parents' age, level of education, and employment status did not have any significant effect on parents' cognitions of the eating habits, adaptive skills, and social interaction skills of their children with autism. However, the inclusion of parent's age might have accounted for the non-significance observed, as in relation to understanding of their child's autism traits the age of the parent is likely related to parent experience and expectations rather than actual age differences in the sample.

The secondary aim of this study was to determine the underlying structure of a new tool for measuring parental understanding of autism. For this reason, follow-up interviews with stakeholders and specialists in the field of autism were conducted. Both parents of children with autism and specialists highlighted that five items were important for inclusion, with the appropriate re-wording and adjustment. The decision regarding the inclusion of each of the five items was widely discussed and taken by general consent by the author and her academic supervisory team based on both the results of the statistical analysis and input from the stakeholder and expert consultation. The mixed method of incorporating parent and specialist input along with the results of the statistical analysis into the development of a new profiling tool for parental understanding of autism enhanced the validity of the tool. Taking account of all the above information, a consensus view was achieved on twenty items to be included in the new tool, resulting in a provisional instrument with 20 items, called the Individualised Autism Profiling (IAP) tool (Appendix 5).

This study has shown that the questionnaire used to evaluate whether parents' perceptions of their autistic child differed from their views of all children with autism, was an acceptable instrument to measure parental understanding of autism content. Additionally, the present study established the content validity of a new tool based on both the results of the statistical analysis and input by stakeholder and expert consultation, thus ensuring good content and face validity. The process of questionnaire development and the number of items eliminated described in Chapter 3 and Chapter 4 is shown in Figure 1. The IAP tool was evaluated in an online survey among parents of children with autism discussed in Chapter 5.

Figure 1. Items Eliminated at Different Stages of the Questionnaire Development Process



CHAPTER 5

AN INDIVIDUALISED AUTISM PROFILING TOOL

Chapter Overview

This chapter aims to describe the rationale behind the second evaluation study aiming to identify distinct parent profiles based on their child's individual characteristics and unique needs. An online survey was conducted among 563 parents of children with autism using the 20-item Individualised Autism Profiling (IAP) tool, followed by a latent profile analysis to identify different profiles of parental understanding of autism within the data. In addition, it was examined whether the profiles identified in the latent profile analysis differed in their levels of parenting self-efficacy, well-being, and severity of autism symptoms to better understand the nature of the profiles. Finally, an assessment of internal consistency and construct validity of the new IAP tool was performed.

Section 5.1. Introduction

This study aimed to address the second research objective, which was to determine whether there are distinct profiles of parental understanding of autism based on their child's individual characteristics and unique needs. Latent class analysis (LCA) (McLachlan et al., 2019) is a statistical method developed in the social sciences, which is used to identify distinct subsets (classes) underlying the observed heterogeneity in a population. Such classes are not directly observable and must be determined from the observed data. Thus, this study aims to apply LCA to a multivariate data set, to identify and describe profiles of parental understanding of autism as related to the unique characteristics of their autistic children. The emphasis of the present study is on the potential of this approach to identify profiles of parental understanding of autism that could be useful for developing intervention strategies targeting the specific needs and requirements of children with autism and their caregivers. To date, no studies have been performed to evaluate profiles of parents in relation to parental perceptions of their child's behaviour in the context of autism and individual differences by means of LCA. Therefore, this study investigated the latent profiles of parental understanding of autism among a sample of 563 parents in the UK to provide primary evidence for future potential intervention strategies.

Section 5.2. Methods

Participants

Following written informed consent nine hundred and eleven (n=911) parents, all having children with an autism diagnosis, volunteered to participate in this study. Participants were recruited via an announcement on social media (e.g., Facebook and Twitter) and the National Autistic Society (NAS) website, the Derbyshire Autism Services, and the ADHD Foundation. An email invitation was also sent out to people who had registered on a Massive Open Online Course (MOOC) that focussed on autism and ADHD by the University of Derby, and the Headteachers of selected Special Schools across the UK. Participants were included in the study if they 1) were 18 years or older, 2) had a child who has been formally diagnosed with autism using the DSM-IV or DSM-5 (American Psychiatric Association, 2013) or ICD-10 (World Health Organization, 1992) criteria for 'Childhood Autism', 'Autistic Disorder' or 'Autism Spectrum Disorder' by a qualified healthcare professional, and 3) the child lived in the family home. The study was conducted according to the Declaration of Helsinki and was approved by the Ethics Committee of the University of Derby.

Procedure and Materials

An online survey was conducted among parents of children with autism using the 20-item Individualised Autism Profiling (IAP) tool. The study took place between February 2020 and August 2020. The survey was created and administered using the Qualtrics system. Through a hyperlink, parents were provided with participant information and were then asked to provide informed consent before accessing the survey. If parents had more than one child who had received a diagnosis of autism, they were asked to provide information only for their older child with autism. Also, parents were asked to indicate whether they had participated in previous research conducted by the University of Derby (Chapter 4). The participants who had contributed to the previous study were not included in the data analysis.

The demographic information included data from the parent (e.g., age, gender, ethnicity, marital status, employment status, highest level of education achieved), and diagnostic information about the child (e.g., type of diagnosis, medication, participation in intervention programs for autism). Parents were asked to rate their agreement or disagreement with statements about the characteristics of their child with autism. All items except the demographics were scored on a seven-point Likert scale ranging from (1) strongly disagree, (2) disagree, (3) somewhat disagree, (4) neither agree or disagree, (5) somewhat agree, (6) agree to (7) strongly agree (Appendix 5).

In addition to completing the 20-item IAP tool, participants also completed three validated scales to assess construct validity.

1. **The Child Adjustment and Parent Efficacy Scale – Developmental Disability (CAPES-DD)** is a 24-item scale assessing emotional, behavioural problems, and prosocial skills of children with developmental disabilities and caregiver's confidence. Responses are made on a 4-point scale from 0 (not true of my child at

all) to 3 (true of my child very much, or most of the time) taking into account the child's behaviour over the past four weeks. For the Parent Self-Efficacy scale, responses are made on a 10-point scale from 1 (certain I can't manage it) to 10 (certain I can manage it). An example item for the child's emotional and behavioural problems is '*My child yells, shouts, or screams'*. Items are summed with higher scores indicating greater levels of parent self-efficacy. Internal consistency of the Self-Efficacy scale has been reported as high in an Australian sample (Cronbach's alpha = 0.94) (Emser et al., 2016).

2. **The World Health Organisation – Five Well-Being Index (WHO-5)** (Topp et al., 2015) is a short 5-item scale of current mental well-being that asks individuals to state how they have felt over the last 14 days. An example question is '*I woke up feeling fresh and rested*'. It uses a 6-point Likert scale from none of the time (scored 0) to all of the time (scored 5). Scores have a range from 0 to 25 and are multiplied by 4 to give the final score, with 0 representing the absence of well-being and 100 representing maximal well-being. The scale can be applied in both clinical practice (e.g., as a screening tool for depression) as well as in research studies to assess well-being over time or to compare well-being between groups (Topp et al., 2015). Internal consistency of the WHO-5 has been reported as high in a sample of Iranian participants (Cronbach's alpha > 0.85) (Omani-Samani et al., 2019).
3. **The Autism Spectrum Quotient - 10 (AQ-10) – Child and Adolescent Version: Parent/Caregiver** (Allison et al., 2012) that is the short version of the AQ (child and adolescent versions) has 10 items and uses a 4-point scale ranging from Definitely Agree to Definitely Disagree. Only 1 point can be scored for each question. The AQ is a quick reference guide for parents to complete about a child or adolescent with suspected autism who does not have a learning disability. If

scores are 6 or above, the individual should be referred for a specialist diagnostic assessment. Internal consistency has been reported as high in a UK sample (Cronbach’s alpha > 0.85) (Allison et al., 2012).

Statistical Analysis

Latent class analysis (LCA) was used in this study to define otherwise unobserved groups of parents relative to their understanding of the child’s individual characteristics and unique needs. LCA is a method that can classify respondents to multiple profiles based on their responses to items in the questionnaire (Collins & Lanza, 2009). This kind of approach is therefore suitable for investigating the research objectives set out in this thesis, aimed at categorizing a heterogeneous population into profiles of autism understanding. Identifying subgroups could be useful for developing interventions targeting the specific needs and requirements of children with autism and their caregivers.

The LCA method provides a classification of cases with categorical indicators that is similar to factor analysis with continuous variables. LCA, however, provides the probability of belonging to a particular profile given the observed features of a response. As a result, each profile contains individuals who are similar to each other and different from individuals in other profiles (Clogg, 1995; Muthén & Muthén, 2000). As is common practice in LCA (McLachlan et al., 2019), each parent in the sample was assigned to the profile for which they had the highest membership probability. LCA was computed using the R poLCA package (Linzer & Lewis, 2011). The LCA approach estimates the response probabilities for all items rather than the manifest response patterns, to best predict the distribution of response patterns within the study sample. This approach avoids the flawed assumption of error-free observations. The optimal number of classes was determined by using the Bayesian information criterion (BIC). The BIC is a global measure that weights the fit and parsimony of the model simultaneously. The lower the BIC, the better the data distribution is fitted by the model given the number of fit parameters (Hagenaars & McCutcheon, 2002; McCutcheon, 1987).

Further Statistical Analyses

To assess the association between classes' membership and demographic variables, multinomial logistic regression was conducted in Mplus version 8.4 (Muthén & Muthén, 2017) by regressing the unordered categorical latent variable (i.e., class) on a set of covariates including parent's age, education level, employment status, age of the autistic child, and the number of children with autism in the family. Class membership was assigned to each individual using the maximum-probability assignment rule in which individuals are assigned to the latent class that corresponds to their maximum posterior probability (Nagin, 2005). In the present case, the class assignment was used as the dependent variable in the multinomial logistic regression analysis. One-way analysis of variance (ANOVA) was used to investigate differences among the latent classes in parenting self-efficacy, well-being, and parent-reported autistic traits.

Reliability analysis was conducted to calculate the internal consistency of the IAP tool using Cronbach's alpha coefficient. The alpha value was set at 0.7 and above to be an acceptable internal consistency (Blunch, 2008). Pearson's correlations were performed to assess the construct validity of the tool compared with other psychometric scales, including parent efficacy (CAPES-DD) scale, well-being (WHO-5) scale, and the parent-reported autism spectrum quotient (AQ-10) child and adolescent version for autism symptom severity. Multiple linear regression was conducted to examine the degree to which the relationship among IAP tool scoring, parenting self-efficacy (CAPES-DD), and parent-reported severity of autism symptoms (AQ-10) could predict parenting well-being (WHO-5). All independent variables were entered into the equation simultaneously (Field, 2013). Data analyses were conducted using SPSS version 25, and all tests were 2-tailed with a significance level set at $p < 0.05$, missing data were treated pairwise.

Section 5.3. Results

Descriptive Statistics

A total of five hundred and sixty-three (N=563) parents completed this stage of the research, corresponding to 62 per cent of the total number of participants who volunteered to participate in this study (N=911). Two hundred and eighty-two (N=282) participants had been excluded due to incomplete responses and sixty-two (N=62) participants had been excluded due to participation in the previous study. Participants were mostly mothers [528 (94%); 30 (5.3 %) fathers], with a mean age of 42.2 (range 18-73 years). Demographic information for parents can be found in Table 35.

Table 35. Demographic Characteristics of Studied Parents [a] *(N=563)*

		Parents	
		M	**SD**
Age (y) [b]		42.25	8.97
No. of children [c]		2.82	13.71
No. of children with autism [d]		1.11	0.50
		N	**%**
Education level	A-level	113	20.1
	Undergraduate (BSc, BA) or work qualifications	318	56.5
	Postgraduate (MSc, PhD)	107	19.0
	No qualifications	25	4.4
Gender [e]		30/528	

[a] Parents of children with autism (N=563), [b] y= years, [c, d] No.=number, [e] Male/Female; Values are expressed: Mean (M) and Standard Deviation (SD).

Latent Class Analysis (LCA)

LCA identified a three-class model as providing the best fit to the data according to the BIC. Specifically, the three-class solution had the lowest BIC (three-class model: BIC = 38461.99, L2 = 29047.43, df = 201; two-class model: BIC = 38506.07, L2 = 29857.84, df = 222; four-class model: BIC = 38586.36, L2 = 28405.47, df = 80). The fit statistics for each model are presented in Table 36. In addition to empirical measures for class determination, the three-class solution was chosen as the final model for reasons of ease of class interpretability and theoretical considerations.

Table 36. Fit Statistics for All Class Solutions Using Latent Class Analysis

	G^2	**BIC**	**AIC**
Two Latent Classes	29857.84	38506.07	37461.75
Three Latent Classes	29077.39	38491.95	36923.3
Four Latent Classes	28405.47	38586.36	36493.38

Note. G2= Likelihood-ratio chi-squared test; BIC= Bayesian Information Criterion; AIC= Akaike's Information Criterion.

The class-specific response probabilities for each of the twenty items derived from the three-class model can be found in Appendix 6. Each class was assigned a summary label: **Class 1** (49.3 per cent of the sample) was composed mainly of respondents who scored high in the agreement range – *High Level of Autism Understanding*, **Class 2** (6.2 per cent) was comprised of respondents who reported a low rate in the agreement range on over half of the statements – *Poor Level of Autism Understanding*, and **Class 3** (44.5 per cent) was comprised of respondents whose answers on over half of the statements were moderate to high in the agreement range – *Moderate Level of Autism Understanding*. The 3-class solution yielded a high-class membership probability for the majority of participants. The demographic characteristics of the three classes can be seen in Table 37.

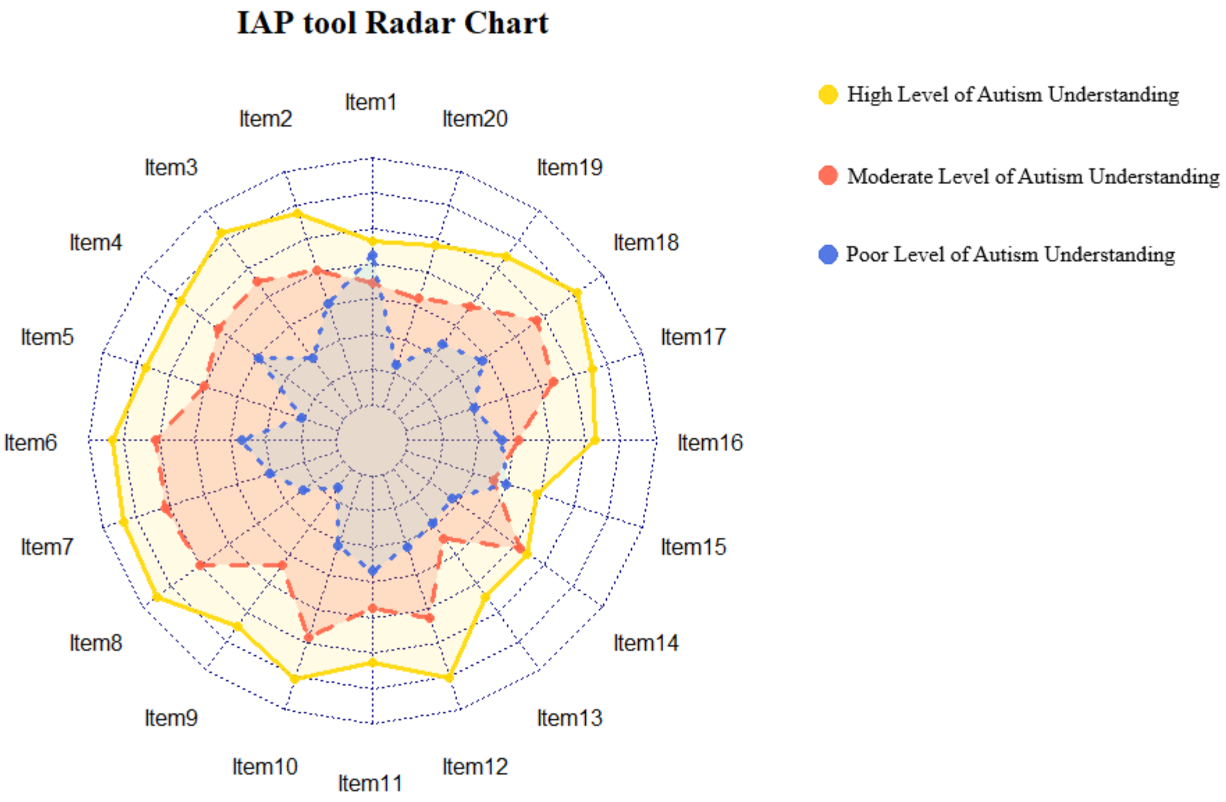
Table 37. Demographic Characteristics of the Three Latent Classes (N=563)

Characteristic	**Class 1[a]** **49.3%** **(n=277)** **M(SD)**	**Class 2[b]** **6.2%** **(n=36)** **M(SD)**	**Class 3[c]** **44.5%** **(n=250)** **M(SD)**
Age (y)[1]	40.78 (8.60)	43.06 (8.76)	43.64 (9.11)
	% (N)	**% (N)**	**% (N)**
Education level			
A-level	23.10 (64)	19.44 (7)	16.00 (40)
Undergraduate (BSc, BA) or work qualifications	52.71 (146)	47.22 (17)	55.20 (138)
Postgraduate (MSc, PhD)	15.16 (42)	30.56 (11)	21.20 (53)
No qualifications	9.03 (25)	2.78 (1)	7.60 (19)
Employment			
Employed	78.00 (216)	61.11 (22)	76.80 (192)
Unemployed	16.60 (46)	33.33 (12)	13.60 (34)
Other	5.42 (15)	5.56 (2)	9.60 (24)

[a] Class 1 = High Level of Autism Understanding; [b] Class 2 = Poor Level of Autism Understanding; [c] Class 3 = Moderate Level of Autism Understanding; [1] y= years; Values are expressed: Mean (M) and Standard Deviation (SD).

Conditional probabilities allowed to depict the precise meaning of the latent classes. The sizes of the different classes for each item are presented as percentages in Appendix 6. The radar chart comparing **Class 1** – *High Level of Autism Understanding*, **Class 2** – *Poor Level of Autism Understanding*, and **Class 3** – *Moderate Level of Autism Understanding* responses to the IAP tool is presented in Figure 2.

Figure 2. Radar Chart of Latent Class Analysis Results



Note. Radar chart comparing latent class responses to the 20-item IAP tool. Class 1 = High Level of Autism Understanding [Yellow]; Class 2 = Poor Level of Autism Understanding [Blue]; Class 3 = Moderate Level of Autism Understanding [Red]. Values are expressed as mean.

Multinomial Logistic Regression

To assess the association between classes' membership and demographic variables, multinomial logistic regression was conducted on a set of covariates including parent's age, education level, employment status, age of the autistic child, and the number of children with autism in the family. Results from multinomial logistic regression indicated that the age of the parent and the age of the child with autism predicted membership in latent classes. The factors for parents' employment, level of education, and the number of children with autism in the family did not significantly predict class membership in the model. The results are presented in Table 38.

Table 38. Association among Latent Classes in relation to Sociodemographic Variables Serving Class 1 as Reference Group (N=563)

Comparison with Class 1 High Level of Autism Understanding	**Class 2 Poor Level of Autism Understanding**			**Class 3 Moderate Level of Autism Understanding**			**Likelihood ratio**	
	OR	**Wald** [a]	**p-value**	**OR**	**Wald** [a]	**p-value**	**Chi-square** [b]	**p-value**
Constant		5.07	<0.05		7.11	<0.01	10.12	<0.01
Parent's Age	1.07	8.17	<0.01	1.03	4.85	<0.05	10.64	<0.01
Education	0.93	0.43	N.S.	1.10	3.75	N.S.	5.06	N.S.
Employment	0.97	0.13	N.S.	1.94	1.89	N.S.	1.90	N.S.
Child's age	0.88	8.52	<0.01	1.03	1.87	N.S.	14.77	0.001
No. of children with autism	0.50	1.98	N.S.	1.77	1.92	N.S.	3.76	N.S.

[a] df=1; [b] df=2; OR = odds ratio; N.S.= Not Significant.

Age of Parent

The age of the parent was a significant predictor of membership comparing **Class 1** *High Level of Autism Understanding* to **Class 2** *Poor Level of Autism Understanding*, suggesting that it is more likely for older parents to score higher on the IAP tool than lower compared to younger parents. Also, the comparison between **Class 1** *High Level of Autism Understanding* and **Class 3** *Moderate Level of Autism Understanding* indicated that older parents are more likely to score higher on the IAP tool than moderate compared to younger parents.

Age of the Child with Autism

The age of the child with autism was a significant predictor of membership comparing **Class 1** *High Level of Autism Understanding* to **Class 2** *Poor Level of Autism Understanding*, suggesting that it is more likely for parents who have older children with autism to score higher on the IAP tool than lower compared to parents of younger children with autism. The comparison between **Class 1** *High Level of Autism Understanding* and **Class 3** *Moderate Level of Autism Understanding* was not significant.

One-way Analysis of Variance

One-way analysis of variance (ANOVA) was conducted to investigate whether differences among latent classes in parenting self-efficacy, well-being, and parent-reported autistic traits were differentially associated with latent class membership. Among the three classes, a significant difference was found in all measures. The results are illustrated in Table 39.

Table 39. ANOVA Results for CAPES-DD, WHO-5, and AQ-10 among Latent Classes

Measures	**Class 1[a] M(SD)**	**Class 2[b] M(SD)**	**Class 3[c] M(SD)**	**F-value**	**Degrees of freedom**	**p-value**	**Post-hoc tests statistics[d]**
CAPES-DD [1]	102.57 (35.56)	119.44 (47.27)	117.61 (33.07)	11.72	2, 498	<0.001	a/b = $p<0.05$; a/c = $p<0.001$; b/c = N.S.
WHO-5 [2]	20.91 (5.31)	14.07 (6.98)	17.71 (5.12)	33.51	2, 473	<0.001	a/b, a/c = $p<0.001$; b/c = $p<0.05$
AQ-10 [3]	26.88 (3.62)	24.80 (3.86)	26.40 (3.40)	3.48	2, 395	<0.05	a/b = $p<0.05$; a/c, b/c = N.S.

[1]= Parent Self-Efficacy scale (n=501); [2]= Well-Being scale (n=476); [3]= Self-reported Severity of Autism Symptoms scale (n=398); [a] = High Level of Autism Understanding class; [b] = Poor Level of Autism Understanding class; [c] = Moderate Level of Autism Understanding class; [d] = Tukey HSD test. N.S.= Not Significant. Values are expressed: Mean (M) and Standard Deviation (SD). The mean difference is significant at the 0.05 level.

Reliability Analysis

The IAP tool had excellent internal consistency with a Cronbach's alpha of 0.88 overall. Examination of the alpha levels if items were deleted revealed that the alpha coefficient values decreased with the deletion of any of the twenty items, indicating that all items were important to the scale and so were retained. Alphas can be seen in Appendix 6.

Correlations with Other Scales

Pearson’s correlations were conducted to assess the construct validity of the tool compared with other psychometric scales, including parent efficacy (CAPES-DD) scale, well-being (WHO-5) scale, and the parent-reported autism spectrum quotient (AQ-10) child and adolescent version for autism symptom severity. The results are illustrated in Table 40.

Table 40. Pearson Correlations among CAPES-DD[1], WHO-5[2], AQ-10[3] and the IAP tool[4]

Measures	IAP tool	Sig (2-tailed)
CAPES-DD	-0.21**	<0.001
WHO-5	0.36**	<0.001
AQ-10	0.13**	<0.01

[1]CAPES-DD (n=501); [2]= WHO-5 (n=476); [3]= AQ-10 (n=398); [4]= Individualised Autism Profiling (IAP) tool (n=563).
**Bivariate correlations are significantly different from zero at $p < 0.01$ (two-tailed).

Multiple Regression

Multiple linear regression was conducted to investigate the degree to which the relationship among IAP tool scoring, parenting self-efficacy (CAPES-DD), and parent-reported autistic traits (AQ-10) could predict parenting well-being (WHO-5). The results indicated that 20.0 per cent of the variance was explained by the model and was a significant predictor of the WHO-5 score. All three variables added statistically significantly to the prediction, $p < 0.05$. The results are presented in Table 41.

Table 41. Multiple Regression Results between IAP, CAPES-DD and AQ-10 Variables and Parenting Well-Being (WHO-5) (N=343)

	Model fit					Coefficients				
Variable	**Adjusted R2**	**Durbin-Watson**	**Degrees of freedom**	**F-value**	**p-value**	**β**	**t-value**	**p-value**	**Tolerance**	**VIF[a]**
Model	0.20	2.00	3, 339	28.86	<0.001					
IAP[1]						0.05	3.48	0.001	1.00	1.11
CAPES-DD[2]						-0.05	-6.31	<0.001	1.00	1.10
AQ-10[3]						0.25	3.10	<0.05	1.00	1.01

[1]= Individualised Autism Profiling tool; [2]=Parent Self-Efficacy scale; [3]= Self-reported Severity of Autism Symptoms scale; [a]= Variance Inflation Factor. The mean difference is significant at the 0.05 level.

Section 5.4. Discussion

The present study was conducted among a sample of parents of children with autism using the 20-item Individualised Autism Profiling (IAP) tool, aiming to identify different profiles of parental understanding of autism within the data. This is the first study to evaluate profiles of parents in relation to parental perceptions of their child's behaviour in the context of autism and individual differences by means of LCA.

The results revealed that there are classes or 'profiles' of parents that demonstrate distinct patterns of understanding of their child's individual characteristics in the context of autism. Specifically, the findings suggest that there are three profiles: a *High Level of Autism Understanding,* a *Moderate Level of Autism Understanding,* and a *Poor Level of Autism Understanding* profile. In the *High Level of Autism Understanding* profile, consisting of 49.3 per cent of the parents of the sample, participants scored highly on all the items of the IAP tool. The rates in this profile were higher than the other two profiles for all items. In the *Moderate Level of Autism Understanding* profile, composed of 44.5 per cent of the sample, participants scored moderate to high in fourteen out of twenty items of the IAP tool, while there was a spread of responses in six items ranging from very low to very high. In the *Poor Level of Autism Understanding* profile, comprised of 6.2 per cent of the sample, participants scored low in seventeen out of twenty items of the IAP tool, while there was a spread of responses in three items ranging from very low to very high. The three profiles are elaborated on below.

The main finding of this study is that three distinct profiles of parental understanding of autism could be identified by applying an LCA approach, **(1)** a *High Level of Autism Understanding* profile, which has a high understanding of the characteristics of their child in all domains of function; **(2)** a *Moderate Level of Autism Understanding* profile which has a moderate to high understanding of the social, behaviour, and self-occupation characteristics of their child, while the understanding of the communication, self-care, and sensory characteristics is unclear; and **(3)** a *Poor Level of Autism Understanding* profile, which exhibits a poor understanding of their child's characteristics in almost all domains of function, including social, self-care, self-occupation, and sensory characteristics, while the understanding of the communication and behaviour characteristics is unclear.

The use of LCA in this study has helped to identify three unique empirically derived profiles of parental understanding of autism. The findings suggest that there may be a relationship between the level of parental understanding of their child's autism (i.e., high, poor, moderate) and child and parent outcomes. For example, parents who fall into the *Poor* scoring profile may experience more difficulties interpreting challenging behaviours associated with autism compared to parents of the other two profiles, and therefore, they may not recognize early signs of autism in their children. This, in turn, may cause delays in early diagnosis and influence intervention decision-making. The results of the present study correspond to the 'Early Childhood Outcomes (ECO) conceptual framework' and its suggestions on family outcomes (Wainer et al., 2017), assuming that the identification of distinct profiles of parental understanding of autism can help inform intervention decision-making and improve child, parent and family outcomes.

As was highlighted from the review of the literature in Chapter 2, a variety of factors may be associated with the presence of different profiles of parental understanding of autism. Previous research has demonstrated that socioeconomic characteristics (i.e., family income, parent education level) may have a significant impact on how parents view autism (Durkin et al., 2010; Fountain et al., 2011), as well as on equal opportunities for access to healthcare and support for the child with autism (Fujiwara, 2014; Mazurek et al., 2014). For example, parents who have higher levels of education and/or higher income are more likely to seek professional support for their child from an early age (Kelly et al., 2019; Thomas et al., 2012). In reverse, parents of low income and educational background are less likely to interpret behaviours within the context of autism (Zuckerman et al., 2015). This study examined whether parents' employment and level of education could predict profile assignment. The results suggested that none of these factors was significantly predictive of class membership, however, further research is needed to confirm the present findings.

Another factor that may contribute to a different level of understanding is the experiences parents have with caring for a child with autism. The present study examined whether the age of the parent, the age of the child with autism and the presence of other children with autism in the family could predict profile assignment. The results revealed that the age of the parent and the age of the child were significant predictors of class membership. Specifically, older parents of children with autism are more likely to score higher on the IAP tool than lower compared to younger parents. The differing level of understanding in this study, however, is likely related to parent experience and expectations rather than actual age differences in the sample. According to Fountain et al. (2011), first-time parents are less experienced and therefore it may be particularly challenging for them to recognize problem behaviours specific to autism or abnormal patterns of development in their children.

The present study also revealed that parents of older children with autism are more likely to fall into the *High Level of Autism Understanding* profile rather than the *Poor Level of Autism Understanding* profile compared to parents of younger children with autism. This finding is consistent with previous research suggesting that parents of older children with autism have gained more experiences through the years (including communication with healthcare providers, involvement in the child's intervention, etc.) and have become more aware of the needs of their child and their family, compared with parents who have a younger child with autism (Altiere & von Kluge, 2009; Neely-Barnes et al., 2011; Woodgate et al., 2008). It would be expected that parents who have more than one child with autism to have differing levels of autism understanding, however, the number of children with autism in the family was not shown to be significantly predictive of class membership in the present study.

Concerning the psychometrics of the IAP tool, the tool has excellent internal reliability and good construct validity as demonstrated by correlations with measures of parent efficacy (CAPES-DD) scale, the psychological well-being (WHO-5) scale, and the parent-reported Autism Spectrum Quotient (AQ-10) for autism symptom severity. Correlations were significant and the magnitude of the correlation coefficients was low to moderate between 0.1 to 0.4, indicating that the IAP tool has good discriminant validity (Field, 2013). An important finding of this study is that the IAP tool has a positive predictive ability for psychological well-being, which suggests that parental understanding of autism could have a positive effect on parent well-being.

Notably, the findings of the present study demonstrated that there was a statistically significant inverse relationship between the IAP tool and parent self-efficacy. According to Bandura's theory, an individual's belief in their ability to successfully perform a given task, namely 'self-efficacy', draws on their interpretations of their own performance, their abilities by watching others perform a task, their response to social persuasion, and their psychological state (Bandura, 2004; Bandura et al., 1999). Parenting self-efficacy is determined as parent's belief about their ability to successfully raise their children. However, the construct of parenting self-efficacy may be significantly affected by having a child on the autism spectrum (Jones & Prinz, 2005). The findings of the present study suggest that a greater understanding of autism may lead parents to feel more overwhelmed and less efficacious. This may be explained by various factors, including parental mental health, parenting styles, and child's challenging behaviours. Previous research has demonstrated that parents of children with autism experience increased levels of stress and other mental health issues, that may affect parents' sense of self-efficacy (Dabrowska & Pisula, 2010; Estes et al., 2009; Giallo et al., 2013; Hayes & Watson, 2013). Accordingly, parents with the Broader Autism Phenotype (BAP) may lack confidence in coping with their child's autism-related problems that they also may experience (Losh et al., 2008). Prior literature also suggests that parents of children with autism tend to adopt highly directive parenting strategies due to the child's challenging behaviour or due to the higher levels of stress that they experience, which may impact their ability to become effective parents to their children (Gau et al., 2010; Riany et al., 2017).

The IAP tool was significantly correlated with the psychological well-being scale, demonstrating a positive relationship between parental understanding of autism and well-being. Shyu et al. (2010) noted that the way parents understand their child's difficulties and their explanations about autism may have a significant effect on parent well-being, the functioning of the child, and the interventions selected by the family. The findings of the present study are also in agreement with the ECO theoretical framework (Wainer et al., 2017) which suggests that assessing how families understand their child's strengths, abilities, and special needs may have a positive effect on well-being and enhance the overall family quality of life, and thus, should be considered before intervention decision-making.

The results further indicated that the IAP tool was positively correlated with the parent-reported Autism Spectrum Quotient (AQ-10) for autism symptom severity, although correlations were very low. The parent-report questionnaire AQ-10 is designed as a screening instrument to record a child's behaviour on a range of autistic traits (Baron-Cohen, Wheelwright, Skinner, et al., 2001). Although the AQ-10 was positively correlated with the IAP tool, the self-report nature of the AQ-10, the presence of co-occurring conditions in autism, and the effect of these conditions on the presentation of autism may have resulted in this outcome.

The present study further examined whether there were significant differences in the parent profiles for parenting self-efficacy, well-being, and parent-reported severity of autism symptoms. Statistically significant differences emerged in parenting self-efficacy between parents who were assigned to the *High Level of Autism Understanding* profile and those who were assigned to the *Moderate Level of Autism Understanding* profile, as well as between parents who were assigned to the *High Level of Autism Understanding* profile and those who were assigned to the *Poor Level of Autism Understanding* profile. Additionally, significant differences were found in well-being across all parent profiles.

According to Bandura (2010), one of the important factors that can affect well-being, and appropriate response to stressors is high self-efficacy. Specifically, for the CAPES-DD measure of self-efficacy used in this study, clinical cut-off scores are 1 ± SD the mean of the normative group (Emser et al., 2016). The lowest score of the sample was 74 (110±36), which is above the clinical cut-off. Therefore, although it was found that the *High Level of Autism Understanding* profile had a lower score in parenting self-efficacy (M=102.57) compared to both *Moderate* (M=117.61) and *Poor Level of Autism Understanding* (M=119.44) profiles, this score is considered ‘normal’ as it is above the cut-off value.

For the WHO-5 measure of psychological well-being, the raw score ranges from 0 (absence of well-being) to 25 (maximal well-being), however, because scales measuring health-related quality of life are conventionally translated to a percentage scale from 0 (absent) to 100 (maximal), it is recommended to multiply the raw score by 4 (Topp et al., 2015). In the present study, participants who were assigned to the *High Level of Autism Understanding* profile reported higher well-being (i.e., 83.64), compared to parents who were assigned to both *Moderate* (70.84) and *Poor Level of Autism Understanding* (56.28) profiles, confirming the findings that a greater understanding of autism could have a positive effect on parent well-being (Wainer et al., 2017).

Lastly, this study revealed statistically significant differences in parent-reported severity of autism symptoms between the *High* and *Poor Level of Autism Understanding* profiles, suggesting that a lower level of understanding of autism could have a significant negative impact on parent perceptions of their child's autistic traits. A significant finding of this study is that no differences were found in parent-reported severity of autism between the *Moderate Level of Autism Understanding* profile and both *High* and *Poor Level of Autism Understanding* profiles, which may suggest that parents who were assigned in the *Moderate Level of Autism Understanding* profile may lack understanding of specific aspects of their child's development and functioning, that may require particular attention before intervention decision-making. Current findings underscore the importance of integrating into research and practice parental understanding of the unique strengths, abilities, and special needs of their children with autism to inform intervention decision-making and help promote child, parent, and family outcomes.

CHAPTER 6

DISCUSSION AND CONCLUSIONS

Chapter Overview

The preceding chapters presented the studies that explored parental perceptions of the individual characteristics and unique needs of their children in the context of autism via the development and evaluation of an Individualised Autism Profiling tool (IAP). In this final chapter, the findings from this research are considered together and a theoretical model for parental understanding of autism is proposed. The chapter offers a general discussion, research implications, strengths, limitations, directions for future research, and conclusions.

Section 6.1. Summary of Findings

The main aim of this research was to provide an investigation of the basic elements comprising parental understanding of their child's presentation of autism and their pre-existing knowledge about the condition. Specifically, this thesis examined (1) whether there are differences between parents' understanding of the general nature and characteristics of autism and the characteristics of their autistic child, and (2) whether there are distinct profiles of parental understanding of autism based on their child's individual characteristics and unique needs. The comprehensive critical review of the literature and the use of the Early Childhood Outcomes (ECO) framework allowed the design of a new systematic empirical approach for establishing parental understanding of autism.

The findings of the present research support the notion that parental understanding of autism in general and in relation to their child with autism might not be theoretically distinct constructs, and that parents of children with autism may recognize as common the characteristics of their child as related to all children with autism. The results of this research also suggest that three parent profiles demonstrate distinct patterns of understanding of the child's potential and unique needs related to autism. The results will be interpreted and discussed in the context of relevant research, and the theoretical implications of the findings will be highlighted. This will be followed by a discussion of the strengths and limitations of this research, and directions for future research. The chapter concludes with the implications the current project has for informing parents' decisions regarding intervention strategies that are specific to the needs and requirements of the child with autism and their family.

Section 6.2. A Framework for Parental Understanding of Autism

Research Objective 1: To investigate whether there are differences between parents' understanding of the general nature and characteristics of autism and the characteristics of their child with autism.

The current research is unique as it is the first of its kind to examine parental perceptions of the individual characteristics and unique needs of their children with autism. For this study, an initial questionnaire was developed in conjunction with parents of children with autism to evaluate parental understanding of the general nature and characteristics of all children with autism and the characteristics of their autistic child. The questionnaire contained 99 items grouped into four separate parts including **(1)** the general nature of autism, **(2)** the characteristics of all children with autism, **(3)** the characteristics of the individual child with autism, and **(4)** parents' sources of information and support, and their views about autism, and was evaluated in an online survey among 300 parents of autistic children.

The results demonstrated that there were no differences between parents' perceptions of their autistic child and their views of autism in all children. Specifically, no statistically significant differences were found in five out of seven core areas of development and function, including social, communication, behaviour, self-care, and sensory characteristics. Moreover, a closer examination of the differences found in the self-occupation and education characteristics between all children with autism and the individual child further supported the notion that general and specific understanding of autism might not be theoretically distinct constructs, as parents rated the statements between all children with autism and their autistic child in the same direction (i.e., agreement/disagreement) in both domains.

These results are in line with previous research in the area. McMahon et al. (2020) suggested that perceived knowledge of autism is not related to actual autism knowledge and in particular, individuals who are least knowledgeable about autism may overestimate their knowledge, and more knowledgeable individuals, such as parents of children with autism, may underestimate their knowledge about autism. The results of this study suggest that parents may underestimate their knowledge of the differences in the characteristics of all children and those of their autistic child.

Autism Spectrum Disorder (ASD) encompasses a wide range of symptoms, skills, and levels of functioning individuals experience which may result in the perception of the characteristics of autism as a whole rather than separate entities. In the current research, there were no statistically significant differences between all children with autism and the individual child in both *Social* and *Communication* domains, which may indicate that parents perceive the social interaction and communication impairments in autism as one entity. These findings are consistent with previous research suggesting that impairments in social communication and social interaction in individuals with autism reflect the same underlying cognitive deficit, known as the 'theory of mind' hypothesis in autism (Tager-Flusberg, 1999). Moreover, several studies have found a universality of parent-reported challenging behaviours in autism (Chandler et al., 2016; Maskey et al., 2013) which may explain why there were no significant differences in the *Behaviour*, *Self-care,* and *Sensory* domains of function. These findings, together with the results observed in the present study, support the notion that parents of children with autism may recognize as common the characteristics of their autistic child as related to all children with autism.

Parenting a child with autism can be extremely challenging and demanding, and may affect how parents understand their child's unique traits and potential. It is well-established that parents of children with autism experience increased stress and other mental health issues, compared to parents of typically developing children or parents of children with other disabilities (Gatzoyia et al., 2014; Hayes & Watson, 2013). Research indicates that parents of children with autism experience particular difficulties in coping and they also tend to have a decreased sense of parenting self-efficacy, which may have serious implications for their mental health (Meirsschaut et al., 2010; Zablotsky et al., 2013). Taken together, these factors may influence parental understanding of their child's individual characteristics and unique needs related to autism. The tentative nature of this finding is due to the lack of literature in the field; however, it indicates that 'understanding' is not a singular concept, and that parents may 'understand' their child's autistic traits in the wider sense, and not separately of characteristics common to all children with autism.

This set of results seems to confirm the notion that general and specific understanding of autism might not be theoretically distinct constructs, and that parents of children with autism may perceive the individual characteristics of their child as a whole, and not separately of common characteristics of all children with autism. This finding is important, not only in consolidating the findings of previous research but in widening the scope of a specific instrument that could identify how parents understand their child's specific type of autism and serve the growing need to provide evidence-based practice and decision-making, as well as increased parental participation in the care of children with autism.

Research Objective 2: To identify distinct profiles of parental understanding of autism based on their child's individual characteristics and unique needs.

Although there is a great volume of research on autism (see Chapter 2 – Literature Review), there is a distinct lack of studies investigating the understanding of autism in parents of autistic children. For this reason, the development and evaluation of an instrument that could identify distinct profiles of parental understanding of autism were deemed essential. Based on the 'Early Childhood Outcomes (ECO) conceptual framework' and its suggestions of family outcomes (Wainer et al., 2017), this work is in agreement with the framework's immediate family-level outcome of parents understanding their child's strengths, abilities, and special needs, with the ultimate goal to enhance the overall family quality of life.

This study is the first to identify and describe distinct patterns of parental understanding of their child's individual characteristics and unique needs related to autism using a new, carefully designed instrument with 20 items, called the Individualised Autism Profiling (IAP) tool. The data established that there are three unique profiles of autism understanding: a *High Level of Autism Understanding*, a *Moderate Level of Autism Understanding*, and a *Poor Level of Autism Understanding* profile. The results of the current study suggest that parents who fall into the *High Level of Autism Understanding* profile (49.3 per cent of the sample) show a high understanding of their child's autism across all areas of development and function, including social, communication, behaviour, self-care, self-occupation and sensory sensitivities. Parents who fall into the *Moderate Level of Autism Understanding* profile (44.5 per cent of the sample) show a moderate to high understanding of their child's social, behaviour, and self-occupation characteristics related to autism, while the understanding of the communication, self-care, and sensory characteristics is unclear. Parents who fall into the *Poor Level of Autism Understanding* profile (6.2 per cent of the sample) show a poor understanding of their child's autistic traits across several areas, including social, self-care, self-occupation, and sensory sensitivities, while the understanding of the communication and behaviour characteristics is unclear (See Chapter 5 – Figure 2).

These findings have broad implications for the understanding of autism in parents of children diagnosed with autism as they provide important information about the specific areas of the child's development and function parents understand to a greater or smaller extent, which may help inform decisions for individualised intervention strategies that are tailored to the needs of the child with autism and their caregivers. This also corresponds to the ECO conceptual framework (Wainer et al., 2017), assuming that an instrument that could identify distinct profiles of parental understanding of autism can help inform intervention decision-making and improve family outcomes.

A significant finding of this study is that the IAP tool demonstrates a positive relationship between parental understanding of autism and well-being. Specifically, statistically significant differences were found in well-being between parents who belong to the *High Level of Autism Understanding* profile compared to parents who belong to the other two profiles. This finding further supports ECO's family recommended 'well-being' outcomes, providing preliminary evidence that a greater understanding of autism could have a positive effect on parent well-being. This finding may also have broader implications for parental mental health and experiences of caring for a child with autism. A better parental understanding of their child's strengths, abilities and special needs in the context of autism could help to equip parents with the knowledge and strategies to cope with some of the challenges of daily living, and in turn, increase autism awareness to prevent stigma and social exclusion. However, potential confounding factors that have not been adequately addressed in this research, such as family income and regional variations, might have contributed to the present result. Therefore, future research is needed to investigate the association of these factors with parental understanding of autism and parent well-being.

Section 6.3. Research Implications

The Importance of Parental Understanding of Autism

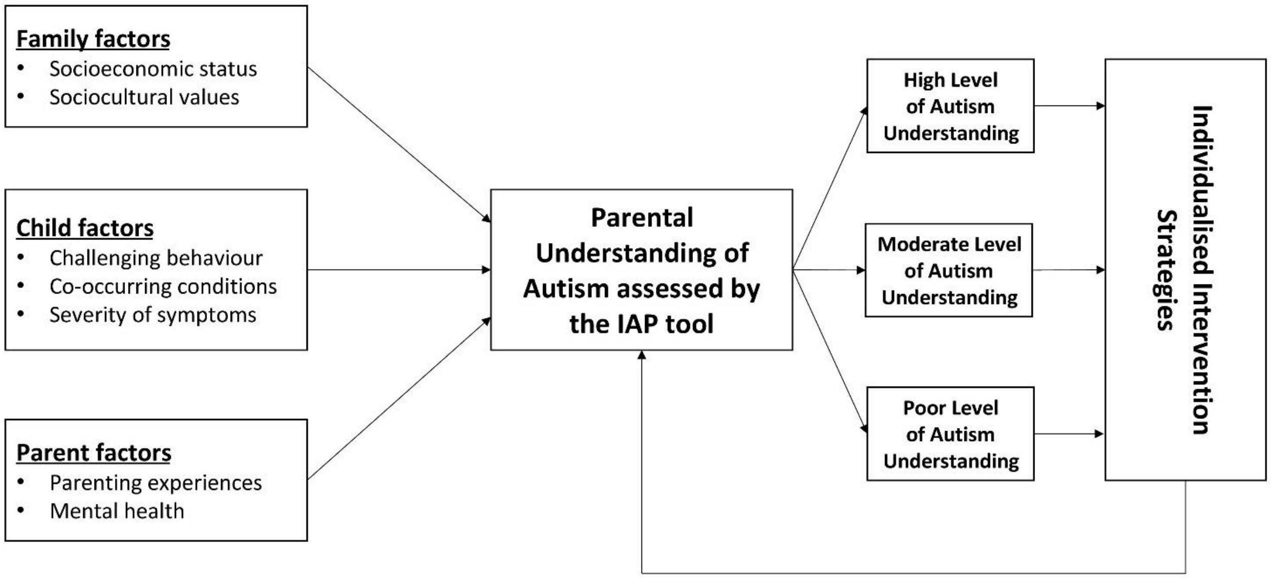
Despite a developing literature base on some aspects of parenting a child with autism, no published studies to date have examined how parents understand their child's unique characteristics related to autism. The data presented here provide a first insight into parental understanding of autism which could have important implications for parents, health service providers, and support agencies. While every parent's journey is personal and unique, raising a child with autism places some extraordinary demands on parents which may negatively affect their sense of parenting efficacy and competence, and impact their mental health and well-being (e.g., Gatzoyia et al., 2014).

Parents should feel confident and supported to understand their children with autism better and be assisted to manage the unique challenges that come with trying to meet their child's needs. Solomon and Chung (2012) highlighted the need for family therapists to understand parents' beliefs about their child's autism and how those beliefs impact their coping. A tool like the IAP could be particularly useful, especially for parents who may not fully understand the disorder and their child's specific needs; they may be distressed and have to face multiple demands and roles (e.g., other children, work commitments, marital issues). Thus, understanding how parents perceive the individual characteristics and unique needs of their autistic children could inform service providers about how best to improve their provision both in terms of appropriate and timely information that can help parents better understand their child and their personal needs and in terms of effective parental involvement in autism interventions.

As discussed in Chapter 2, previous research has shown that parent involvement in early intervention for their children with autism has positive outcomes for both parents and children. In particular, it is documented that interventions that include parent training increase parent knowledge of autism, enhance parent understanding of their child's needs and wants, strengthen parent-child relationships, improve child's social and communication skills, and have a positive effect on parents' mental health (Karst & Van Hecke, 2012; Oono et al., 2013). Moreover, parent-mediated early interventions have been shown to improve parents' knowledge and skills, increase their confidence and efficacy to manage their child's behaviour problems and lead to children making more progress in treatment (Burrell & Borrego, 2012; Dawson & Burner, 2011). Perhaps one of the most important implications of this research is to match support to each child's individual needs, which may be determined to a large extent by the understanding of the child's strengths and potential by the parent.

In consideration of the research presented in this thesis, a model for parental understanding of autism is proposed (Figure 3). This model follows the Early Childhood Outcomes (ECO) conceptual framework proposed by Wainer et al. (2017) for family outcomes, which suggests that while the effects of parent involvement in their child's treatment are beneficial for both parent and child with autism, the question of whether or not an intervention has helped a family understand their child's strengths, abilities, and special needs is not currently represented in the published literature. The proposed model for parental understanding of autism provides important information that could be used to individualise the intervention in such a manner that it addresses the unique needs of the child with autism and their caregivers.

Figure 3. A Model for Parental Understanding of Autism



The proposed model is intended to give a first insight into the way parents understand their child's individual characteristics and unique needs related to autism, to help inform intervention decision-making. The two main domains included in the proposed model, **(1)** *Parental Understanding of Autism* and **(2)** *Individualised Intervention Strategies*, have been demonstrated by the present research to be interrelated. The first domain includes several factors that should be considered when framing understanding of autism for parents of autistic children. The factors included in this domain were identified as important based on an extensive review of the current literature which highlighted that family factors (such as socioeconomic differences and sociocultural values), child factors (including challenging behaviour, the presence of co-occurring conditions, and symptom severity), and parent factors (especially parenting experiences and mental health) can influence the understanding of autism (see Chapter 2). The complex dynamic interactions among these factors could lead to a distinct profile of parental understanding of autism.

The proposed model includes an evidence-based profiling tool, the Individualised Autism Profiling (IAP) tool, that was designed to identify profiles of parental understanding based on their child's individual characteristics and unique needs. The model suggests that there is a pathway to better understanding of autism following assessment using the IAP tool. Specifically, it is suggested that the IAP tool could inform professionals' decisions for intervention strategies, which could lead to more individualised and effective therapeutic approaches to cater to the specific needs of the child with autism and their caregivers. The following recommendations for practice are proposed based on the major findings of this research.

Recommendations for Practice

High Level of Autism Understanding profile

As demonstrated above, early intervention is important for the child's later development, and parental involvement in the intervention process could lead to improved outcomes (e.g., Burrell & Borrego, 2012). The findings of the current research suggest that parents with a *greater* level of autism understanding may benefit from engaging at the earliest stages of intervention planning and implementation, due to their increased awareness and acceptance of autism as an entity and also due to their commitment to the intervention process to maintain long-term outcomes for their children with autism. Additionally, consideration should be given to the social support provided to parents, given that parents of autistic children may experience burnout and psychological distress (Ardic, 2020). Social support is associated with the psychological well-being of parents (Hsiao, 2016), therefore, parents of children with autism should also be provided with financial advice and emotional support.

Moderate Level of Autism Understanding profile

The findings of the current research suggest that parents with a *moderate* level of autism understanding may face difficulties understanding the wide range of symptoms and behaviours associated with autism which in turn may affect intervention decision-making. Parents with this profile may benefit from a range of psychosocial support, including parent training and psychoeducation programs, as well as support to access appropriate healthcare services and resources related to their child's specific type of autism. Additionally, social support in terms of access to financial advice, parent support groups, and psychological interventions aiming at emotional regulation could help parents cope with the stresses associated with parenting a child with autism.

Poor Level of Autism Understanding profile

In addition to the aforementioned recommendations, parents with a *poorer* level of autism understanding may benefit from multi-component intervention strategies that focus on various aspects of everyday life to promote optimal outcomes for both parents and children. The approaches should aim not only to promote knowledge about autism but also to increase awareness about the specific needs and requirements of their child with autism. In particular, parents with this profile may benefit from targeted psychoeducational programmes to increase knowledge and awareness about the nature of autism. Additionally, parents should be provided with financial advice and support for their child's special educational needs, as well as social support to prevent stigma and discrimination that they might experience.

It is important to remember that each parent is different and may cope with the everyday challenges of raising a child with autism differently. Following guidance from the National Institute for Health and Clinical Excellence (NICE) for the management and support of children and young people on the autism spectrum, all parents should be offered an assessment of their own needs, including whether they have personal, social and emotional support; practical support in their caregiving role; and a plan for future care for their child or young adult with autism (Crowe & Salt, 2015). The new IAP tool may play an important role in facilitating practice in line with this guidance.

The critical review of the literature presented in Chapter 2, highlighted the need to integrate into research and practice parent-related factors that may influence children's intervention outcomes. Promoting knowledge about how parents understand the strengths, abilities, and special needs of their children with autism will likely provide clinicians with the necessary information to select the most appropriate interventions. One role of the IAP tool is to inform the other sources of information that clinicians have at their disposal which could contribute to multi-agency teams' appraisals of the family context and wider circumstances and resources available to the child. Also, the IAP tool could be used to inform the possible efficacy of certain interventions and outcomes for both children and parents.

A key role of this tool is not to act in isolation but to be used in conjunction with other sources of information to build up a wider understanding of the parent and child. Most assessments focus on the autistic child, but the role of the parent is critical, yet rarely is this fully appraised. An evidence-based tool, such as the IAP, that is specifically designed to capture parental understanding of their child's presentation of autism could add another dimension to what information can be captured to assist with professionals' decisions about assessment, diagnosis, and support services. Moreover, an adapted form of the IAP tool may also serve as an important tool for parents to self-reflect on their understanding of autism and their child. The IAP tool may also play a role in Educational Psychology in informing Education and Health Care Plans and assessments, and to contribute to paediatric diagnostic services.

It should be noted that the proposed implications and applications of the findings are suggestive in nature; further research is needed to elucidate whether the IAP tool could help inform intervention decision-making by taking into account parental understanding of their child's individual characteristics and unique needs.

Section 6.4. Strengths, Limitations and Future Directions

In the development of the IAP tool, the ECO framework (Wainer et al., 2017) was used to inform the consideration of family-level outcomes of early intervention, and the contribution of these outcomes to the ultimate goal of early intervention, which is to enhance the family quality of life through improving family interaction, parenting practices, and overall well-being. Using this conceptual framework, the gap in the literature on how parents understand their child's strengths, abilities, and special needs was highlighted, as well as the need to develop a tool that could help identify distinct patterns of parental understanding of autism. This framework informed the conceptualisation of the categories that were included in the development work of the IAP tool.

One of the biggest strengths of the present research is that it was embedded within a theoretical framework and reported new findings that were used to elaborate and extend this framework. Another strength of this research is the systematic, evidence-based development process of the IAP tool, including stakeholder and expert consultation and advanced statistical techniques, such as Latent Class Analysis (LCA) to identify and describe profiles of parental understanding of autism as related to the unique characteristics of their children with autism.

This research was carried out with a generally sufficient sample of parents of autistic children, however, cross-validation within a larger study sample would be helpful to further investigate the generalisability of the findings. Nevertheless, the sample size used in this research allowed an accurate evaluation of the solutions producing reliable latent classes in line with previous studies conducted with similar methods on mixed clinical and general population samples (e.g., Chng et al., 2018). Further research is needed to test if parent profiles remain distinct and stable over time and if class membership is associated with a more varied range of child and family outcomes in the long run.

One of the limitations of this research is that there is no other tool designed to capture parental understanding of autism to use as a ‘gold standard’ with which to compare the results, and this introduces considerable challenges in terms of validation. However, extensive stakeholder and expert consultation was conducted to ensure that the instrument had face validity. Given that parental understanding of autism is a subject area related to a wide range of factors that might contribute to the conceptualisation of autism by parents (See Chapter 2), the exhaustive inclusion of all the factors related to parental understanding of autism, despite the considerable effort, was not possible. Therefore, a key consideration of this initial and original research is the abovementioned aspect of construct validity of the IAP tool; future research is needed to confirm these novel findings. Furthermore, the items of the IAP tool reflect parental perceptions of their child’s individual characteristics, including abilities and special needs, however, more research is needed on the range of strengths and skills of autistic children.

Another limitation is that the majority of respondents were mothers; therefore, these findings may not be generalisable to fathers. In fact, fathers of autistic children are generally underrepresented in research studies (Flippin & Crais, 2011), and on that account future research would benefit from the examination of any differences in profiles of autism understanding between genders. Also, a robust understanding of the factors that influence parental understanding over time is needed to ensure the needs of parents are met when appropriate.

It should also be noted that the sample of parents of autistic children across the UK who took part in this research does not necessarily reflect the perceptions of parents of autistic children from diverse backgrounds. It would thus be simplistic to suggest that the present findings would be applicable to all diverse groups. As discussed in Chapter 2, socioeconomic disparities in healthcare access and quality of services could have a significant impact on early detection, diagnosis, and intervention for children with autism (e.g., Kelly et al., 2019). Additionally, sociocultural factors may influence parental perceptions of autism diagnosis, acceptance, and treatment (e.g., Tek & Landa, 2012). Hence, future studies could probe into socioeconomically and culturally diverse populations using bigger samples to address the existing gap. On this basis, it will be important that future studies investigate the association between the level of parental understanding of their child's autism and socioeconomic factors. Such knowledge would facilitate a greater understanding of how parents with different socioeconomic backgrounds perceive their child's autistic traits. Furthermore, with this type of knowledge, the foundation could be laid to develop support services for autistic individuals and their families that are to be more reflective and inclusive of all socioeconomic backgrounds. Future research across different cultures is also needed to better understand the cross-cultural nature of parental understanding of autism.

Finally, a limitation of the present research that should be considered is the coronavirus (Covid-19) outbreak. This research was conducted under a major international pandemic lockdown, resulting in significant challenges with participant recruitment and retention. Moreover, the Covid-19 pandemic imposed a psychological burden on people worldwide, including uncertainty, fear, and anxiety, which might have influenced the responses of the participants in the present research. Even given these limitations, there are important implications related to the current findings. The IAP tool is a relatively short and reliable tool, which may play a useful part in guiding the planning of tailored and targeted intervention strategies based on the diverse profiles of parental understanding of autism. Further work to include the IAP tool within intervention evaluation research or qualitative research could help establish how parent-level moderators (i.e., different levels of autism understanding) may affect intervention processes and outcomes for both the child and the parent.

Section 6.5. Conclusions

The presented series of studies and development expands the field of parental understanding of autism that has not been previously explored in depth. Findings from this research support the notion that general and specific understanding of autism might not be theoretically distinct constructs, and that parents of children with autism may recognize as common the characteristics of their child as related to all children with autism. The present research has provided evidence for the proposal of three distinct profiles of parental understanding of autism: a high, a moderate, and a poor level of autism understanding profile. These findings may have important implications for the development of appropriate interventions to support parents in better understanding their child's potential and unique needs, and help improve child, parent, and family outcomes.

The IAP tool is the first tool designed to provide evidence of distinct patterns of parental understanding of their child's autistic traits, thus, its' incorporation into practice could serve as a marker of the current level of autism understanding, parent-specific needs, and expectations for intervention outcomes. In this way, service providers could assess parental understanding of autism, identify support needs, apply effective interventions for the child, and make appropriate changes according to the specific needs of the family. Further research to confirm the current findings and in different samples may assist in theoretical framework development, which will ultimately enhance our understanding of the interventions that can best support the individual needs and requirements of children with autism and their families. In conclusion, a new valid and reliable tool, called the IAP tool, has been successfully developed and could be incorporated into practice to help parents better understand their child’s potential and unique needs, and health service providers to deliver more attuned interventions to cater to the varying needs of families of children and young adults with autism.

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Appendices

Appendix 1: Chapter 3. Initial Questionnaire

Appendix 2: Chapter 3. Consent Form and Interview Schedule

Appendix 3: Chapter 4. Revised Questionnaire for Use in Online Survey

Appendix 4: Chapter 4. Consent Forms and Interview Schedule

Appendix 5: Chapter 5. The Individualised Autism Profiling tool

Appendix 6: Chapter 5. Tables and Figures

Appendix 1: Chapter 3. Initial Questionnaire Including 215 Items for Use in Stakeholder Consultation

Questionnaire on Parental Understanding of Autism

Part 1. The General Nature of Autism

1) The Clinical Features of Autism

1. Autism is characterised by difficulties in social interaction and communication, and by a preference for repetitive, stereotyped behaviours.
2. The brain of the autistic child functions in a different way.
3. Autism is associated with learning and attention issues.
4. Autism is more of an intellectual disability.
5. Autism is more of an emotional disorder.
6. Autism is more of a communication disorder.
7. Autism is more of a developmental disorder.

2) The Causes of Autism

8. The causes of autism are still unknown.
9. Autism can affect any child.
10. Autism affects boys much more often than girls.
11. Autism may occur from more than one cause.
12. Autism is more likely to occur when there is a history of ‘autistic traits’ in the family.
13. Genetic factors may cause autism.
14. Factors associated with mothers during pregnancy may cause autism.
15. Environmental factors (air pollution, chemicals, etc.) may cause autism.
16. Medication during pregnancy may cause autism.
17. Toxins in vaccines may cause autism.
18. Traumatic experiences in very early years may cause autism (e.g., psychological trauma caused by early separation with parents or frequent change of caregivers).
19. Autism may be caused by poor parenting.

3) The Developmental Course of Autism

20. Autism is a lifelong condition.
21. Autism exists only in childhood.
22. The signs of autism are present in the early years of life.
23. Some children may begin to develop typically but then they lose skills and develop autism.
24. Children with autism develop differently from their peers.
25. The symptoms of autism change a great deal from day to day.
26. The course of autism depends on the parents.
27. Autism symptoms may be improved from early childhood to adulthood.
28. The role of parents is important in helping the autistic child’s transition to adulthood.

29. The role of parents is important for the mental and physical health of the child throughout the lifespan.

4) The Effects of an Intervention

30. Early intervention — such as behavioural and speech therapy — can help improve the learning skills of the autistic child and increase communication.
31. With proper intervention and training the child with autism will show substantial improvement.
32. With proper intervention and training the severity of autism symptoms can be reduced.
33. With proper intervention and training children eventually “outgrow” autism.
34. The negative effects of autism can be prevented with proper treatment.
35. The role of parents is important in deciding the most appropriate treatment for their child with autism.
36. Parents’ involvement in their child’s intervention program is important.

5) The Spectrum of Symptoms

37. All children with autism have some symptoms in common.
38. Asperger’s Syndrome and High Functioning Autism is the same diagnosis.
39. Autism affects each child differently.
40. Some signs of autism are similar to or the same as those to other conditions.
41. The word spectrum means there is a range of how the symptoms affect each child.

Part 2. The Characteristics of All Children with Autism

1) Social Characteristics

42. Children with autism have social difficulties (e.g., find it hard to understand facial and voice expressions and gestures, lack of awareness of others feelings etc.)
43. Children with autism most of the time live in a world of their own.
44. Children with autism avoid eye contact when talking.
45. Children with autism are affectionate to family members.
46. Children with autism have poor relationships in peer group situations.
47. Children with autism prefer to play by themselves.
48. Children with autism prefer to play with their parents.
49. Children with autism prefer to play with their siblings.
50. Children with autism prefer to play with other children at the same age.
51. Children with autism find it hard to understand instructions.
52. Children with autism are able to understand instructions only with guidance.
53. Children with autism expect others to see things only from their own point of view.
54. Family activities have to be very structured and planned.
55. Parents are not able to attend social events with their child with autism.

56. Parents are not able to control their children when they have meltdowns in public (e.g., when they get overwhelmed by everything around them and may begin to shout, scream, cry, or lose control).
57. People in public are not usually receptive to the meltdowns of children with autism.

2) Communication Characteristics

58. Children with autism have language and speech difficulties.
59. Children with autism are unable to talk.
60. Children with autism are unable to share their thoughts.
61. Children with autism respond poorly to others (e.g., appear withdrawn and indifferent to other people).
62. Children with autism ignore verbal comments as if deaf.
63. Children with autism use gestures to get what they want.
64. Children with autism are unable to communicate their needs and wants.

3) Behaviour Characteristics

65. Children with autism have behaviours similar to children with a severe learning disability.
66. Children with autism are usually clumsy.
67. Children with autism are usually restless and hyperactive.
68. Children with autism have self-injurious behaviour.
69. Children with autism show violent and aggressive tendencies.
70. Children with autism have sleep disturbances.
71. Children with autism are excessively sleepy during daytime.
72. Children with autism have abnormal food preferences and/or refuse to eat.
73. Children with autism do not adapt easily to changes and unforeseen circumstances.
74. Children with autism show excessive separation anxiety from significant others (parents, siblings etc.)
75. Children with autism are reluctant to attend school/kindergarten.
76. Children with autism are usually cold and distant.
77. Children with autism show an inappropriate response to embraces (e.g., push away the person who gives them a hug).
78. Children with autism show affection and are receptive to hugs.
79. Children with autism are affectionate only with their parents.

4) Self-care Characteristics

80. Children with autism are unable to serve themselves at mealtimes.
81. Children with autism are unable to use cutlery properly.
82. Children with autism are unable to feed themselves independently.
83. Children with autism require more help than typically developing children of their age to get dressed or undressed.
84. Children with autism find it difficult to tolerate wearing certain types of clothes.
85. Children with autism have problems with personal hygiene (e.g., brush teeth, wash hands, use the shower etc.)

86. Children with autism require extensive help to fall asleep.
87. Children with autism are not toilet-trained.

5) Self-occupation Characteristics

88. Children with autism insist on the same routine.
89. Children with autism favour specific routines and rituals.
90. Children with autism often rock their head or body repeatedly.
91. Children with autism have a lot of physical and verbal tics.
92. Children with autism prefer to arrange things in a certain way.
93. Children with autism are unable to engage in pretend play.
94. Children with autism have poor balance and fall a lot.

6) Sensory Characteristics

95. A quiet and organised environment has a positive impact on the autistic child's behaviour.
96. An environment with multiple distractions has a negative impact on the autistic child's behaviour.
97. Children with autism are distressed by minor changes in their environment (e.g., rearranged furniture, new cutlery etc.)
98. Children with autism behave best when surrounded by familiar faces.
99. Crowded places have a negative impact on the autistic child's behaviour.
100. Bright lights, loud sounds, and intense smells cause discomfort to the autistic child.
101. Children with autism are bothered by bright lights or certain kind of lights.
102. Children with autism are distressed by certain smells or avoid certain tastes.
103. Children with autism have a limited range of food preferences based on colour, texture, and/or presentation.
104. Children with autism express distress when they are touched (e.g., someone touches their hair).
105. Children with autism are easily distracted and cannot focus their attention if there is a lot of noise around.

7) Education Characteristics

106. Children with autism should be educated in a mainstream school.
107. Children with autism should be educated in a Special Educational Needs school.
108. Children with autism should be home-schooled.
109. Children with autism need an individual teaching program.
110. Children with autism need a Teaching Assistant in a mainstream school.
111. Children with autism are very creative.
112. Children with autism have great attention to detail.
113. Children with autism have great problem-solving skills.
114. Children with autism are able to do quick mathematical calculations.

115. Children with autism are unable to get along with typical developing classmates.
116. Children with autism are unable to do their homework alone.
117. Children with autism cannot hold a pen/pencil right.
118. Children with autism cannot write their name.

Part 3: The Individual Child's Characteristics

1) Social Characteristics

119. My child has social difficulties.
120. My child most of the time lives in a world of his/her own.
121. My child avoids eye contact when talking.
122. My child is affectionate to family members.
123. My child has poor relationships in peer group situations.
124. My child prefers to play by himself/herself.
125. My child prefers to play with his/her parents.
126. My child prefers to play with his/her siblings.
127. My child prefers to play with his/her friends.
128. My child finds it hard to understand instructions.
129. My child is able to follow instructions only with guidance.
130. My child expects others to see things only from his/her own point of view.
131. Family activities have to be very structured and planned.
132. I am able to attend social events with my child.
133. I am able to control my child's meltdowns in public (e.g., when my child gets overwhelmed by everything around him/her and may begin to shout, scream, cry, or lose control).
134. People in public are not usually receptive to my child's meltdowns.

2) Communication Characteristics

135. My child has language and speech difficulties.
136. My child is unable to talk.
137. My child is unable to share his/her thoughts.
138. My child responds poorly to others (e.g., appears withdrawn and indifferent to other people).
139. My child ignores verbal comments as if deaf.
140. My child uses gestures to get what he/she wants.
141. My child is able to communicate his/her needs and wants.

3) Behaviour Characteristics

142. My child has a severe learning disability.
143. My child is clumsy most of the time.
144. My child is usually restless and hyperactive.

145. My child has self-injurious behaviour.
146. My child shows violent and aggressive tendencies.
147. My child has sleep disturbances.
148. My child is excessively sleepy during daytime.
149. My child has abnormal food preferences and/or refuses to eat.
150. My child does not adapt easily to changes and unforeseen circumstances.
151. My child shows excessive separation anxiety from significant others (parents, siblings etc.)
152. My child is reluctant to attend school/kindergarten.
153. My child is usually cold and distant.
154. My child shows an inappropriate response to embraces (e.g., pushes away the person who gives him/her a hug).
155. My child shows affection and is receptive to hugs.
156. My child is affectionate only with his/her parents.

4) Self-care Characteristics

157. My child is able to serve himself/herself at mealtimes.
158. My child is able to use cutlery properly.
159. My child is able to feed himself/herself independently.
160. My child requires more help than other children of his/her age to get dressed or undressed.
161. My child finds it difficult to tolerate wearing certain types of clothes.
162. My child has problems with personal hygiene (e.g., brushing teeth, washing hands, using the shower etc.)
163. My child requires extensive help to fall asleep.
164. My child is not toilet-trained.

4) Self-occupation Characteristics

165. My child insists on the same routine.
166. My child favours specific routines and rituals.
167. My child rocks his/her head or body repeatedly.
168. My child has a lot of physical and verbal tics.
169. My child enjoys arranging things in a certain way.
170. My child enjoys pretend-play.
171. My child has poor balance and falls a lot.

5) Sensory Characteristics

172. A quiet and organised environment has a positive impact on my child’s behaviour.
173. An environment with multiple distractions has a negative impact on my child’s behaviour.
174. My child is distressed by minor changes in his/her environment (e.g., rearranged furniture, new cutlery etc.)

175. My child behaves best when surrounded by familiar faces.
176. Crowded places have a negative impact on my child's behaviour.
177. Bright lights, loud sounds, and intense smells cause discomfort to my child.
178. My child is bothered by bright lights or certain kind of lights.
179. My child is distressed by certain smells or avoids certain tastes.
180. My child has a limited range of food preferences relevant to colour, texture, and/or presentation.
181. My child expresses distress when he/she is touched (e.g., someone touches his/her hair).
182. My child is easily distracted and cannot focus his/her attention if there is a lot of noise around.

6) Education Characteristics

183. My child should be educated in a mainstream school.
184. My child should be educated in a Special Educational Needs school.
185. My child should be home-schooled.
186. My child needs an individual teaching program.
187. My child needs a Teaching Assistant in a mainstream school.
188. My child is very creative.
189. My child has great attention to detail.
190. My child has great problem-solving skills.
191. My child is able to do quick mathematical calculations.
192. My child is able to get along with typical developing classmates.
193. My child is able to do his/her homework alone.
194. My child is able to hold a pen/pencil right.
195. My child is able to write his/her name.

Part 4: About the Parents.

1) Sources of information

196. Healthcare professionals inform me sufficiently about autism.
197. Other parents of children with autism inform me sufficiently about autism.
198. The Internet (social media, autism-related websites, online forums etc.) informs me sufficiently about autism.
199. The Media (TV, radio) inform me sufficiently about autism.
200. Scientific journals and books inform me sufficiently about autism.
201. Autism support and advocacy groups inform me sufficiently about autism.

2) Social support

202. My partner supports me with my child's autism.
203. My family and friends support me with my child's autism.
204. Healthcare professionals support me with my child's autism.

205. Other parents of children with autism support me with my child’s autism.
206. Autism support and advocacy groups support me with my child’s autism.

3) Beliefs about Autism

207. Autism is not a disability but a different way of interpreting and interacting with the world.
208. Children with autism have special talents and abilities.
209. Parenting a child with autism makes the family bond stronger.
210. Society has negative attitudes towards autistic people.
211. The autistic child’s behaviour causes negative attitudes against him/her.
212. Autism strongly affects the way others see the child.
213. People in public see autism as a result of bad parenting.
214. Having a child with autism is a social stigma.
215. Autism affects people from all backgrounds and nationalities.

Appendix 2: Chapter 3. Consent Form for Stakeholder Consultation

Asking you about the suitability of a bank of questions for use in a study about parental understanding of autism

Human Sciences Research Centre University of Derby

STATEMENT OF INFORMED CONSENT

Thank you for reading the information sheet. If you are happy to participate then please complete and sign the form below. Please tick the boxes below to confirm that you agree with each statement:

Please tick each box to indicate you have read the statement:

I confirm that I have read and understood the information sheet provided to me and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and will not be identified or identifiable in the report or reports that result from the research. ☐

The interview will last approximately 20 minutes. I agree for this interview to be audio-recorded. I understand that the audio recording made of this interview will be used only for analysis and that extracts from the interview, from which I would not be personally identified, may be used in any conference presentation, report, or journal article developed as a result of the research. I understand that no other use will be made of the recording without my written permission and that no one outside the research team will be allowed access to the original recording. ☐

I agree that my anonymised data will be kept for future research purposes such as publications related to this study after the completion of the study. ☐

I understand that this research study has been reviewed and approved by the College Research Ethics Committee (CREC) of the University of Derby. ☐

Please provide a unique participant identification code in the box below. By providing this you are signing your consent to all of the statements that you have ticked above.

The purpose of this code is so that we can keep your data completely anonymous. This code is made up of the first two letters of your first name, and month and year of birth, e.g., if your first name is Anna and you were born in April 1987, your code would be An-04-87. Should you wish to withdraw your responses please contact the researcher and quote this reference.

Unique participant Code: _______-_______-_______

Appendix 2: Chapter 3. Interview Schedule for Stakeholder Consultation

Asking you about the suitability of a bank of questions for use in a study about parental understanding of autism

Human Sciences Research Centre University of Derby

INTERVIEW SCHEDULE

Participants were asked to rate each item on a five-point Likert scale ranging from (1) very unsuitable, (2) somewhat unsuitable, (3) neutral, (4) somewhat suitable to (5) very suitable.

1. How suitable do you think this statement is?

2. Would this statement be acceptable to most parents or would it stand out?

3. How is the wording here? Is the statement clear enough?

4. Is there any statement that doesn’t fit well?

5. How do you find the questionnaire’s overall structure?

6. Do you need to add anything at all or ask me any questions?

Appendix 3: Chapter 4. Revised Questionnaire Including 99 Items for Use in Online Survey

Questionnaire on Parental Understanding of Autism

Demographic information about the Parent and Diagnostic Information about the Child.

1. What is your country of origin?
2. What is your gender? [Male, Female, Other, Do not wish to declare].
3. What is your year of birth?
4. Which of the following best describes your cultural background? Please select one only. [White, Mixed/Multiple Ethnic Groups, Asian/Asian British, Black/African/Caribbean/Black British, Other (please specify), Do not wish to declare].
5. What is the highest educational qualification you have completed (including foreign equivalents)? Please select one only. [CSE/GCSE/O-Level, A-level/AS-level/S-Levels, Higher Diploma, Undergraduate Degree or equivalent (e.g., BSc, BA), Post-graduate (e.g., MSc, MA), Doctorate level (e.g., PhD), Vocational/work-related qualifications, no qualifications, Other (please specify), Do not wish to declare].
6. What is your current employment status? [Full-time employed, part-time employed, not currently employed, Caregiver (e.g., children, elderly), Homemaker, retired, disabled (not working because of disability), Other (please specify), Do not wish to declare].
7. What is your legal marital status or civil partnership status? [Never Married and never registered a Civil Partnership, Married, formerly in a registered Civil Partnership which is now dissolved, in a registered Civil Partnership, Separated, but still in a registered Civil Partnership, Separated, but still legally Married, Divorced, surviving partner from a registered Civil Partnership, Widowed, Other (please specify), Do not wish to declare].
8. How many children do you have that live at home with you or who you have regular responsibility for? [number].
9. How many children do you have with an autism diagnosis? [number].

*If you have more than one child with an autism diagnosis, we kindly ask you to provide us with information only for your **older child**. Please answer all the questions by ticking the box or typing additional information.

10. What is your relationship to your child with autism? [Mother, Father, Legal Guardian, Other (please specify)].
11. What is the gender of your child? [Male, Female].
12. Has your child been given any other than autism diagnoses? If yes, please provide details. [yes/no].
13. Does your child take any long-term prescription medications? If yes, please state the name and dosage (if known) of the medication and what it has been prescribed for. [yes/no].
14. Has your child been involved in any of the following intervention programmes/strategies of support for autism? Please tick all the options listed below that apply. [ABA (Applied Behavioural Analysis), TEACCH (Treatment of Autistic and Communication Handicapped Children), PECS (Picture Exchange Communication System), Sensory Integration Therapy, Speech, and Language Therapy, Special Unit or Special School provision, Support by a Teaching Assistant at mainstream school, Occupational Therapy, Change in the diet (please state what adaptations to your child's diet have been made), another intervention/s (Please state the name of the intervention/s if possible)].
15. Do you know people with autism other than your child/children? [Myself, My partner, A member of my extended family, A friend (not related to you), A colleague, I work closely with people on the autism spectrum, Other (please specify), I do not know people with autism other than my child/children, Do not wish to declare].

(Survey – Part 1) The General Nature of Autism.

In this part, there are some questions about the general nature of autism. The term 'autism' will be used in this survey to encompass all Autism Spectrum Disorders (ASDs), including Asperger's Syndrome. If you are unsure of your answer, please answer to the best of your knowledge.

For each of the questions below, please circle the response which indicates how much the statement applies to you, where: 1 = Strongly Disagree and 7 = Strongly Agree.

Q1) If you were asked to ***describe autism*** to what extent do you agree or disagree with the following statements?

1. Autism is characterised by difficulties in social interaction and communication, and by a preference for repetitive, stereotyped behaviours.
2. Autism is characterised by individual differences in the child's brain.
3. Autism is associated with learning and attention issues.
4. Autism is more of a communication disorder.
5. Autism is more of a developmental disorder.

Q2) To what extent do you agree or disagree with the following statements about ***the causes*** of autism?

6. The causes of autism are still unknown.
7. Autism can affect any child.
8. Autism may occur from more than one cause.
9. Genetic factors may cause autism.

Q3) To what extent do you agree or disagree with the following statements about ***the course of development*** of autism?

10. Autism is a lifelong condition.
11. The signs of autism are present in the early years of life.
12. Children with autism develop differently from their peers.
13. The symptoms of autism change a great deal from day to day.
14. The role of parents is important for the mental and physical health of the child throughout the lifespan.

Q4) To what extent do you agree or disagree with the following statements about ***the effects of an intervention*** on the development of autism?

15. Early intervention — such as behavioural and speech therapy — can help improve the learning skills of the autistic child and increase communication.
16. With proper intervention and training the child with autism will show substantial improvement.
17. The role of parents is important in deciding the most appropriate treatment for their child with autism.

Q5) To what extent do you agree or disagree with the following statements about ***the spectrum of autism symptoms***?

18. All children with autism have some symptoms in common.
19. Autism affects each child differently.

20. The word ‘*spectrum’* means there is a range of how the symptoms affect each child.

(Survey – Part 2) The Characteristics of All Children with Autism.

In this part, there are some statements about the characteristics of autism in relation to all children on the autism spectrum. These questions are general and not specifically related to your child. If you are unsure of your answer, please answer to the best of your knowledge.

For each of the questions below, please circle the response which indicates how much the statement applies to you, where: 1 = Strongly Disagree and 7 = Strongly Agree.

Q6) If you think about the ***social characteristics*** of children with autism, to what extent do you agree or disagree with the following statements?

Generally, children with autism

21. Avoid eye contact when talking.
22. Have poor relationships in peer group situations.
23. Prefer to play by themselves.
24. Prefer to play with their parents.
25. Find it hard to understand instructions.

Q7) To what extent do you agree or disagree with the following statements about the ***communication characteristics*** of children with autism?

Generally, children with autism

26. Have language and speech difficulties.
27. Are not able to share their thoughts.
28. Respond poorly to others (e.g., appear withdrawn and indifferent to other people).
29. Use gestures to get what they want.
30. Are not able to communicate their needs and wants.

Q8) To what extent do you agree or disagree with the following statements about the ***behavioural characteristics*** of children with autism?

Generally, children with autism

31. Have self-injurious behaviour.

32. Have sleep disturbances.
33. Have unusual eating patterns and food selectivity.
34. Do not adapt easily to changes and unforeseen circumstances.
35. Show an inappropriate response to embraces (e.g., push away the person who gives them a hug).

Q9) To what extent do you agree or disagree with the following statements about ***the self-care skills*** of children with autism?

Generally, children with autism

36. Are not able to use cutlery properly.
37. Require more help than other children of their age to get dressed or undressed.
38. Have problems with personal hygiene (e.g., brush teeth, wash hands, use the shower etc.)

Q10) To what extent do you agree or disagree with the following statements about ***the self-occupation skills*** of children with autism?

Generally, children with autism

39. insist on the same routine.
40. often rock their head or body repeatedly.
41. prefer to arrange things in a certain way.
42. Find it hard to engage in pretend play.

Q11) Thinking about ***the sensory sensitivities*** of children with autism to what extent do you agree or disagree with the following statements?

43. An environment with multiple distractions has a negative impact on the autistic child's behaviour.
44. Generally, children with autism are distressed by minor changes in their environment (e.g., rearranged furniture, new cutlery etc.)
45. Bright lights, loud sounds, and intense smells cause discomfort to the autistic child.
46. Generally, children with autism have a limited range of food preferences based on colour, texture, and/or presentation.
47. Generally, children with autism express distress when they are touched (e.g., someone touches their hair).

Q12) To what extent do you agree or disagree with the following statements about ***the educational characteristics*** of children with autism?

Generally, children with autism

48. Are best educated in a Special Educational Needs school setting.
49. Are best educated with a Teaching Assistant in a mainstream school setting.
50. Find it hard to do their homework alone.
51. Are very creative.

(Survey – Part 3) The Characteristics of the Individual Child.

The next part is about the individual characteristics of your own child. The following statements are specifically related to your child. Thinking about the unique strengths and abilities of your child, please select the answer that best applies to you.

For each of the questions below, please circle the response which indicates how much the statement applies to you, where: 1 = Strongly Disagree and 7 = Strongly Agree.

Q13) To what extent do you agree or disagree with the following statements about ***the social characteristics*** of your child?

My child,

52. Avoids eye contact when talking.
53. Has poor relationships in peer group situations.
54. Prefers to play by himself/herself.
55. Prefers to play with his/her parents.
56. Finds it hard to understand instructions.

Q14) To what extent do you agree or disagree with the following statements about ***the communication characteristics*** of your child?

My child,

57. Has language and speech difficulties.
58. Is not able to share his/her thoughts.
59. Responds poorly to others (e.g., appears withdrawn and indifferent to other people).
60. Uses gestures to get what he/she wants.
61. Is not able to communicate his/her needs and wants.

Q15) To what extent do you agree or disagree with the following statements about ***the behavioural characteristics*** of your child?

My child,

62. Has self-injurious behaviour.
63. Has sleep disturbances.
64. Has unusual eating patterns and food selectivity.
65. Does not adapt easily to changes and unforeseen circumstances.
66. Shows an inappropriate response to embraces (e.g., pushes away the person who gives him/her a hug).

Q16) To what extent do you agree or disagree with the following statements about ***the self-care skills*** of your child?

My child,

67. Is not able to use cutlery properly.
68. Requires more help than other children of his/her age to get dressed or undressed.
69. Has problems with personal hygiene (e.g., brushing teeth, washing hands, using the shower etc.)

Q17) To what extent do you agree or disagree with the following statements about ***the self-occupation skills*** of your child?

My child,

70. Insists on the same routine.
71. Often rocks his/her head or body repeatedly.
72. Prefers to arrange things in a certain way.
73. Finds it hard to engage in pretend play.

Q18) To what extent do you agree or disagree with the following statements about ***the sensory sensitivities*** of your child?

74. An environment with multiple distractions has a negative impact on my child’s behaviour.
75. My child is distressed by minor changes in his/her environment (e.g., rearranged furniture, new cutlery etc.)
76. Bright lights, loud sounds, and intense smells cause discomfort to my child.
77. My child has a limited range of food preferences relevant to colour, texture, and/or presentation.
78. My child expresses distress when he/she is touched (e.g., someone touches his/her hair).

Q19) To what extent do you agree or disagree with the following statements about ***the educational characteristics*** of your child?

My child,

79. Is best educated in a Special Educational Needs school setting.
80. Is best educated with a Teaching Assistant in a mainstream school setting.
81. Finds it hard to do his/her homework alone.
82. Is very creative.

(Survey – Part 4) About the Parents.

In this last part, we would like to ask how you access information and support about you and your child, as well as your own thoughts about autism.

For each of the questions below, please circle the response which indicates how much the statement applies to you, where: 1 = Strongly Disagree and 7 = Strongly Agree.

Q20) To what extent do you agree or disagree with the following statements about ***the sources of information*** you use about autism?

83. Healthcare professionals inform me sufficiently about autism.
84. Other parents of children with autism inform me sufficiently about autism.
85. The Internet (social media, autism-related websites, online forums etc.) informs me sufficiently about autism.
86. The Media (TV, radio) inform me sufficiently about autism.
87. Scientific journals and books inform me sufficiently about autism.
88. Autism support and advocacy groups inform me sufficiently about autism.

Q21) To what extent do you agree or disagree with the following statements about ***the social support*** you receive about you and your child?

89. My partner supports me sufficiently with my child’s autism.
90. My family and friends support me sufficiently with my child’s autism.
91. Healthcare professionals support me sufficiently with my child’s autism.
92. Other parents of children with autism support me sufficiently with my child’s autism.
93. Autism support and advocacy groups support me sufficiently with my child’s autism.

Q22) To what extent do you agree or disagree with the following statements ***about autism***?

94. Autism is not a disability but a different way of interpreting and interacting with the world.
95. Parenting a child with autism makes the family bond stronger.
96. Autism strongly affects the way others see the child.
97. People in public see autism as a result of bad parenting.
98. Having a child with autism is a social stigma.
99. Autism affects people from all backgrounds and nationalities.

Appendix 4: Chapter 4. Consent Form for Parent Consultation

PARENTAL UNDERSTANDING OF AUTISM IN RELATION TO YOUR CHILD'S INDIVIDUAL CHARACTERISTICS

Human Sciences Research Centre University of Derby

STATEMENT OF INFORMED CONSENT

(Parent)

If you are happy to participate please complete and sign the form below. Please tick the boxes below to confirm that you agree with each statement:

	Please tick each box to indicate you have read the statement:
I confirm that I have read and understood the information sheet dated **[date]** and have had the opportunity to ask questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.	☐
I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and will not be identified or identifiable in the report or reports that result from the research.	☐
I agree for this interview to be audio-recorded. I understand that the audio recording made of this interview will be used only for analysis and that extracts from the interview, from which I would not be personally identified, may be used in any conference presentation, report, or journal article developed as a result of the research. I understand that no other use will be made of the recording without my written permission and that no one outside the research team will be allowed access to the original recording.	☐
I agree that my anonymised data will be kept for future research purposes such as publications related to this study after the completion of the study.	☐

Please provide a unique participant identification code in the box below. By providing this you are signing your consent to all of the statements that you have ticked above.

The purpose of this code is so that we can keep your data completely anonymous. This code is made up of the first two letters of your first name, and month and year of birth, e.g., if your first name is Anna and you were born in April 1987, your code would be An-04-87.

Unique participant Code: _______-_______-_______

Appendix 4: Chapter 4. Consent Form for Professional Consultation

PARENTAL UNDERSTANDING OF AUTISM IN RELATION TO THE CHILD'S INDIVIDUAL CHARACTERISTICS

Human Sciences Research Centre University of Derby

STATEMENT OF INFORMED CONSENT

(Professional)

Please tick the boxes below to confirm that you agree with each statement:

	Please tick each box to indicate you have read the statement:
I confirm that I have read and understood the information sheet dated **[date]** and have had the opportunity to ask questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline	☐
I understand that I can withdraw my interview data from the study for a period of up to **four weeks** following completion of it. After this period, I understand that my data will form part of the study data set.	☐
I understand that all data I provide will only be available to the researcher and her academic supervisors. All data will be stored securely on a password protected computer for a period of up to 6 years. Any hard copies of data will be stored in a locked filing cabinet. Only the primary researchers will have access to this.	☐
I agree for this interview to be audio-recorded. I understand that the audio recording made of this interview will be used only for analysis and that extracts from the interview, from which I would not be personally identified, may be used in any conference presentation, report, or journal article developed as a result of the research. I understand that no other use will be made of the recording without my written permission and that no one outside the research team will be allowed access to the original recording.	☐
I agree that my anonymised data will be kept for future research purposes such as publications related to this study after the completion of the study.	☐

Name of Professional____

Signature of Professional_____________________________________

Date____

Name of Researcher____

Signature of Researcher______________________________________

Date____

Appendix 4: Chapter 4. Interview Schedule for Parent and Professional Consultation

Asking you about the Suitability of the Items for Use in the Development of an Individualised Autism Profiling tool

Human Sciences Research Centre University of Derby

INTERVIEW SCHEDULE

(Parent and Professional)

Participants were asked to comment on the items, whether they were perceived to be relevant and appropriate, and whether any particular aspect had been missed.

1. In your opinion is the questionnaire broad enough to cover all the different aspects of the individual child's characteristics?
2. Is there anything you would change/add/remove to make this better for you?
3. Is there anything missing?
4. What are your suggestions for making the questionnaire more user-friendly?
5. How could we present the information in a more meaningful way?
6. Is there anything specific you would like to see in the revised version of the questionnaire?

Appendix 5: The Individualised Autism Profiling tool

The Individualised Autism Profiling tool

Please indicate how much you agree or disagree with each of the following statements about your child.

For each of the questions below, please circle the response which indicates how much the statement applies to you, where: 1 = Strongly Disagree and 7 = Strongly Agree.

My child,

1. Has speech and language difficulties.
2. Has unusual eating patterns and food selectivity.
3. Gets upset in a place full of distractions.
4. Is unaware of the risks around him/her.
5. Has frequent tantrums and/or meltdowns.
6. Struggles to express his/her thoughts and feelings.
7. Prefers the same routines and rituals.
8. Has trouble adapting to change and unforeseen events.
9. Is distressed by minor changes around him/her (e.g., rearranged furniture, new cutlery).
10. Finds it difficult to understand other people's emotions.
11. Responds poorly to others (e.g., appears withdrawn and indifferent to other people).
12. Is overwhelmed by bright lights, certain sounds, and/or certain smells.
13. Requires a lot of help to get dressed and undressed.
14. Covers his/her social and communication difficulties.
15. Uses gestures to get what he/she wants.
16. Has a limited range of food preferences based on colour, texture, and/or presentation.
17. Prefers to spend time alone.
18. Shows a strong attachment to certain objects.
19. Struggles to communicate his/her needs and wants.
20. Is distressed when he/she is touched (e.g., someone touches his/her hair).

Appendix 6: Chapter 5. Tables and Figures

Table 42. Conditional Probabilities of Responses to the Three Latent Classes

Items	**Response scales**	**Distribution of the three latent classes**		
		Class 1[a]	**Class 2**[b]	**Class 3**[c]
1. My child has speech and language difficulties	1. Strongly disagree	11.4%	23.0%	22.6%
	2. Disagree	8.0%	3.0%	13.2%
	3. Somewhat disagree	6.5%	8.6%	6.0%
	4. Neither agree or disagree	4.0%	0.0%	8.0%
	5. Somewhat agree	17.6%	14.3%	**23.0%**
	6. Agree	17.6%	**31.5%**	13.2%
	7. Strongly agree	**35.3%**	20.0%	15.0%
2. My child has unusual eating patterns and food selectivity	1. Strongly disagree	2.1%	**43.0%**	9.6%
	2. Disagree	2.5%	5.7%	13.9%
	3. Somewhat disagree	4.03%	8.5%	6.3%
	4. Neither agree or disagree	3.3%	5.7%	4.7%
	5. Somewhat agree	12.2%	11.5%	**30.3%**
	6. Agree	28.3%	5.7%	23.0%
	7. Strongly agree	**47.5%**	20.0%	12.1%
3. My child gets upset in a place full of distractions	1. Strongly disagree	0.0%	**45.8%**	2.0%
	2. Disagree	2.0%	20.0%	9.2%
	3. Somewhat disagree	7.0%	5.7%	6.0%
	4. Neither agree or disagree	1.7%	5.7%	7.3%
	5. Somewhat agree	11.2%	11.5%	34.0%
	6. Agree	28.3%	8.5%	**34.1%**
	7. Strongly agree	**56.3%**	2.7%	7.5%

4. My child is unaware of the risks around him/her	1.	Strongly disagree	1.7%	**28.7%**	2.5%
	2.	Disagree	4.0%	11.5%	11.0%
	3.	Somewhat disagree	4.7%	8.6%	12.3%
	4.	Neither agree or disagree	4.0%	20.0%	9.2%
	5.	Somewhat agree	12.3%	20.0%	**31.1%**
	6.	Agree	24.6%	5.7%	17.8%
	7.	Strongly agree	**48.7%**	5.7%	16.3%
5. My child has frequent tantrums and/or meltdowns	1.	Strongly disagree	1.0%	**54.4%**	3.3%
	2.	Disagree	3.6%	28.4%	13.3%
	3.	Somewhat disagree	1.0%	0.0%	15.1%
	4.	Neither agree or disagree	4.7%	5.7%	11.2%
	5.	Somewhat agree	21.6%	5.7%	**31.1%**
	6.	Agree	29.1%	3.0%	17.6%
	7.	Strongly agree	**39.2%**	3.0%	8.5%
6. My child struggles to express his/her thoughts and feelings	1.	Strongly disagree	1.0%	**34.3%**	1.3%
	2.	Disagree	0.0%	17.2%	5.6%
	3.	Somewhat disagree	2.0%	5.7%	6.0%
	4.	Neither agree or disagree	0.4%	3.0%	6.4%
	5.	Somewhat agree	9.3%	22.7%	23.3%
	6.	Agree	23.0%	11.4%	**37.6%**
	7.	Strongly agree	**64.4%**	5.7%	20.1%

7. My child prefers the same routines and rituals	1. Strongly disagree	0.0%	**43.0%**	1.0%
	2. Disagree	0.5%	23.0%	4.6%
	3. Somewhat disagree	0.4%	3.0%	3.0%
	4. Neither agree or disagree	1.3%	11.5%	9.0%
	5. Somewhat agree	7.0%	5.7%	26.1%
	6. Agree	30.2%	8.6%	**39.6%**
	7. Strongly agree	**61.0%**	5.7%	17.1%
8. My child has trouble adapting to change and unforeseen events	1. Strongly disagree	0.0%	**54.4%**	0.0%
	2. Disagree	1.1%	14.3%	5.0%
	3. Somewhat disagree	0.4%	5.7%	5.0%
	4. Neither agree or disagree	1.1%	17.2%	8.6%
	5. Somewhat agree	8.1%	0.0%	30.1%
	6. Agree	23.2%	3.0%	**37.4%**
	7. Strongly agree	**66.2%**	5.6%	14.2%
9. My child is distressed by minor changes around him/her (e.g., rearranged furniture, new cutlery)	1. Strongly disagree	2.4%	**62.3%**	4.5%
	2. Disagree	3.2%	28.4%	22.4%
	3. Somewhat disagree	3.2%	0.0%	14.4%
	4. Neither agree or disagree	6.2%	3.0%	16.3%
	5. Somewhat agree	19.3%	5.7%	**25.3%**
	6. Agree	**34.3%**	0.0%	15.1%
	7. Strongly agree	31.4%	0.0%	2.0%

10. My child finds it difficult to understand other people's emotions	1. Strongly disagree	0.3%	**48.5%**	1.6%
	2. Disagree	2.0%	11.4%	4.7%
	3. Somewhat disagree	1.4%	5.7%	7.0%
	4. Neither agree or disagree	3.5%	5.7%	11.2%
	5. Somewhat agree	11.0%	17.2%	28.5%
	6. Agree	28.0%	3.0%	**32.2%**
	7. Strongly agree	**54.0%**	8.6%	15.0%
11. My child responds poorly to others (e.g., appears withdrawn and indifferent to other people).	1. Strongly disagree	2.2%	**37.2%**	2.4%
	2. Disagree	5.7%	17.1%	15.0%
	3. Somewhat disagree	3.6%	8.6%	13.6%
	4. Neither agree or disagree	3.0%	5.7%	18.2%
	5. Somewhat agree	27.3%	11.3%	**31.7%**
	6. Agree	**30.0%**	20.0%	16.0%
	7. Strongly agree	28.2%	0.0%	3.5%
12. My child is overwhelmed by bright lights, certain sounds, and/or certain smells.	1. Strongly disagree	1.4%	**54.4%**	2.0%
	2. Disagree	1.0%	11.4%	13.6%
	3. Somewhat disagree	2.2%	5.7%	8.0%
	4. Neither agree or disagree	3.0%	5.7%	11.3%
	5. Somewhat agree	11.1%	5.7%	**31.0%**
	6. Agree	34.0%	8.6%	24.3%
	7. Strongly agree	**47.5%**	8.5%	10.1%

13. My child requires a lot of help to get dressed and undressed.	1. Strongly disagree	9.0%	**51.5%**	26.1%
	2. Disagree	11.2%	17.2%	**26.3%**
	3. Somewhat disagree	5.6%	5.6%	9.3%
	4. Neither agree or disagree	6.7%	14.3%	7.3%
	5. Somewhat agree	22.1%	8.6%	17.5%
	6. Agree	20.7%	0.0%	8.2%
	7. Strongly agree	**24.7%**	3.0%	5.4%
14. My child covers his/her social and communication difficulties.	1. Strongly disagree	9.7%	**31.5%**	3.2%
	2. Disagree	8.0%	23.0%	13.7%
	3. Somewhat disagree	4.3%	23.0%	9.3%
	4. Neither agree or disagree	14.1%	8.6%	15.1%
	5. Somewhat agree	20.5%	5.7%	**26.0%**
	6. Agree	**23.0%**	3.0%	22.0%
	7. Strongly agree	20.6%	5.6%	10.7%
15. My child uses gestures to get what he/she wants.	1. Strongly disagree	9.1%	**43.0%**	18.0%
	2. Disagree	17.6%	8.6%	**31.0%**
	3. Somewhat disagree	7.2%	5.7%	7.6%
	4. Neither agree or disagree	11.1%	3.0%	12.0%
	5. Somewhat agree	20.0%	5.7%	20.0%
	6. Agree	**21.2%**	23.0%	9.2%
	7. Strongly agree	14.0%	11.5%	2.5%

16. My child has a limited range of food preferences based on colour, texture, and/or presentation.	1. Strongly disagree	3.0%	**46.0%**	16.0%
	2. Disagree	9.3%	11.4%	**26.0%**
	3. Somewhat disagree	3.3%	8.5%	6.7%
	4. Neither agree or disagree	5.0%	5.7%	9.3%
	5. Somewhat agree	16.0%	8.6%	15.0%
	6. Agree	20.1%	8.6%	16.0%
	7. Strongly agree	**43.4%**	11.3%	11.1%
17. My child prefers to spend time alone.	1. Strongly disagree	4.0%	**51.5%**	4.1%
	2. Disagree	2.5%	14.3%	12.4%
	3. Somewhat disagree	2.3%	2.7%	9.1%
	4. Neither agree or disagree	5.6%	8.6%	12.1%
	5. Somewhat agree	18.7%	14.3%	19.5%
	6. Agree	23.7%	8.6%	**27.0%**
	7. Strongly agree	**43.2%**	0.0%	16.0%
18. My child shows a strong attachment to certain objects.	1. Strongly disagree	1.6%	**34.4%**	2.0%
	2. Disagree	1.5%	23.0%	9.1%
	3. Somewhat disagree	0.4%	5.7%	7.6%
	4. Neither agree or disagree	4.1%	5.7%	9.5%
	5. Somewhat agree	8.6%	11.5%	20.0%
	6. Agree	24.0%	8.6%	**34.2%**
	7. Strongly agree	**60.0%**	11.3%	18.0%

19. My child struggles to communicate his/her needs and wants.	1. Strongly disagree	3.0%	**37.2%**	6.7%
	2. Disagree	3.0%	23.0%	16.2%
	3. Somewhat disagree	3.0%	11.3%	11.2%
	4. Neither agree or disagree	4.0%	5.7%	14.3%
	5. Somewhat agree	23.4%	8.6%	**30.0%**
	6. Agree	**32.4%**	5.7%	15.0%
	7. Strongly agree	31.4%	8.6%	7.1%
20. My child is distressed when he/she is touched (e.g., someone touches his/her hair).	1. Strongly disagree	4.3%	**54.4%**	8.4%
	2. Disagree	7.6%	25.7%	24.3%
	3. Somewhat disagree	7.1%	5.7%	9.7%
	4. Neither agree or disagree	9.5%	3.0%	15.1%
	5. Somewhat agree	**24.6%**	0.0%	**26.0%**
	6. Agree	23.3%	3.0%	14.5%
	7. Strongly agree	23.6%	8.5%	2.2%

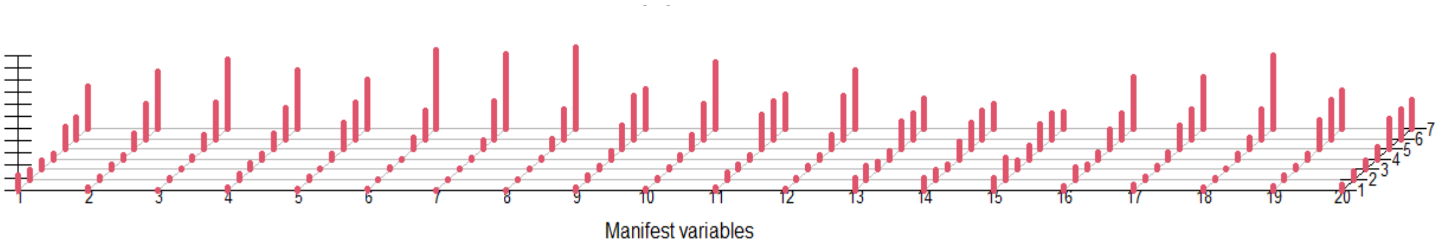
[a]*Class 1 = High Level of Autism Understanding;* [b]*Class 2 = Poor Level of Autism Understanding;* [c]*Class 3 = Moderate Level of Autism Understanding.*

Table 43. Cronbach's Alpha Coefficients for the IAP tool's Items (N=563)

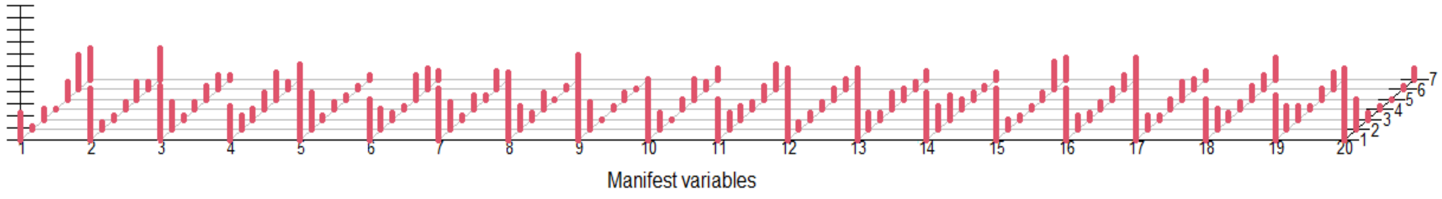
Items	**Alpha**
1. My child has speech and language difficulties	0.88
2. My child has unusual eating patterns and food selectivity	0.87
3. My child gets upset in a place full of distractions	0.87
4. My child is unaware of the risks around him/her	0.87
5. My child has frequent tantrums and/or meltdowns	0.87
6. My child struggles to express his/her thoughts and feelings	0.87
7. My child prefers the same routines and rituals	0.87
8. My child has trouble adapting to change and unforeseen events	0.87
9. My child is distressed by minor changes around him/her (e.g., rearranged furniture, new cutlery)	0.87
10. My child finds it difficult to understand other people's emotions	0.87
11. My child responds poorly to others (e.g., appears withdrawn and indifferent to other people).	0.87
12. My child is overwhelmed by bright lights, certain sounds, and/or certain smells.	0.87
13. My child requires a lot of help to get dressed and undressed.	0.87
14. My child covers his/her social and communication difficulties.	0.88
15. My child uses gestures to get what he/she wants.	0.88
16. My child has a limited range of food preferences based on colour, texture, and/or presentation.	0.87

17. My child prefers to spend time alone.	0.87
18. My child shows a strong attachment to certain objects.	0.87
19. My child struggles to communicate his/her needs and wants.	0.87
20. My child is distressed when he/she is touched (e.g., someone touches his/her hair).	0.87

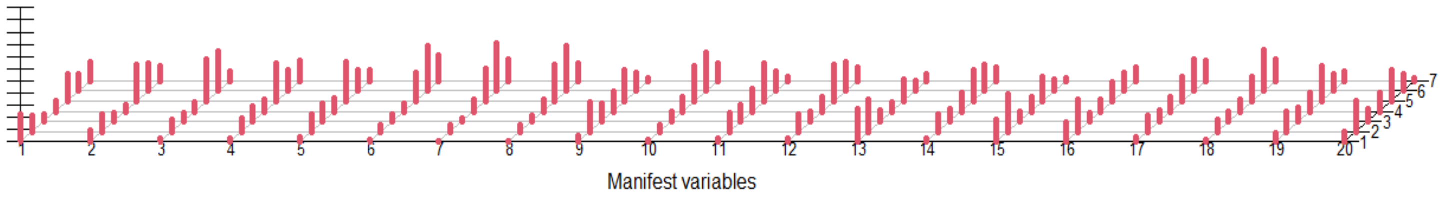
Figure 4. Class-Conditional Item Response Probabilities and Class Population Shares



Class 2: population share = 0.062



Class 3: population share = 0.445



Note. The red bars show the distribution of item response probabilities for frequency (strongly disagree [nearer], disagree, somewhat disagree, either agree or disagree, somewhat agree, agree, strongly agree [further]) for all classes. Manifest variables=20-item IAP tool.