Development and Validation of Public Education Pamphlets on Autism Spectrum Disorder for Parents and Caregivers in the Indian Context

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June- 2026

CERTIFICATE

This is to certify that this dissertation entitled **"Development and Validation of Public Education Pamphlets on Autism Spectrum Disorder for Parents and Caregivers in the Indian Context"** is a Bonafide work submitted as part of fulfilment of the degree of Master of Science (Speech-Language Pathology) of the student with Registration Number P01II24S123033. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other university for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled **"Development and Validation of Public Education Pamphlets on Autism Spectrum Disorder for Parents and Caregivers in the Indian Context"** is the result of my own study under the guidance of Dr. Jayashree C. Shanbal, Professor of Language Pathology, Head-Department of Special Education, All India Institute of Speech and Hearing, Mysuru and has not been submitted earlier to any other university for the award of any other Diploma or Degree.

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Dedicated to my Mummy, Papa & Bhaiya!

Whose sacrifices spoke louder than words,

The strength behind my struggles,

And the reason this dissertation exists today.

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'परस्परोपग्रहो जीवानाम्'

"Institutions shape identities, and AIISH has become a part of mine."

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"The best teachers are those who show you where to look, but do not tell you what to see."

— Alexandra K. Trenfor

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"From humble beginnings come great things."

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LIST OF FREQUENTLY USED ABBREVIATIONS

AIISH – All India Institute of Speech and Hearing

ASD – Autism Spectrum Disorder

CVI – Content Validity Index

CVQ – Content Validation Questionnaire

CVR – Content Validity Ratio

FVQ – Face Validation Questionnaire

PEP – Public Education Pamphlet

SLP – Speech-Language Pathologist

Abstract

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition characterised by persistent difficulties in social communication and interaction along with restricted behaviours and sensory processing differences (American Psychiatric Association [APA], 2022). Parents and caregivers of children with ASD require accessible educational resources to understand the condition, access services and support intervention within everyday routines. However, culturally relevant and validated parent-oriented educational materials remain limited in the Indian context. The present study aimed to develop and validate Public Education Pamphlets (PEPs) on ASD for parents and caregivers and to evaluate their effectiveness in improving parental knowledge and confidence. A descriptive developmental research design with a preliminary evaluation component was adopted. Five culturally adapted PEPs were developed and validated by a multidisciplinary panel of 11 experts using Lawshe's Content Validity Ratio (CVR) and qualitative feedback analysis. Face validity was established quantitatively using a 3-point Likert-type rating scale and qualitatively through feedback obtained from five parents/caregivers of children with ASD. Pilot testing was conducted to evaluate the feasibility, clarity and practicality of the PEPs and associated procedures prior to field testing. Subsequently, field testing was conducted among 10 parents/caregivers using a pre-test and post-test design. Strong content validity was observed across all five PEPs, as all items exceeded the critical CVR value of 0.59 and were retained. The findings further demonstrated statistically significant improvement in total parental knowledge and confidence scores following exposure to the PEPs ($p < .05$). The developed PEPs were also found to be feasible, parent-friendly, culturally relevant and practically useful for supporting caregiver understanding and participation in ASD management. Overall, the findings support the effectiveness of the developed PEPs in improving caregiver knowledge and confidence in applying ASD-related information within everyday caregiving situations in the Indian context.

Keywords: Autism Spectrum Disorder, Public Education Pamphlets, Parent Education, Caregiver Awareness, Content Validation, Indian Context.

CHAPTER I

INTRODUCTION

"We are all different, not less."

– Temple Grandin

Autism spectrum disorder (ASD) is recognised as a lifelong neurodevelopmental condition characterised by persistent difficulties in social communication and social interaction, alongside restricted and repetitive patterns of behaviour and atypical sensory processing, with or without intellectual disability (American Psychiatric Association [APA], 2022). The term spectrum is used because presentations vary widely in language level, cognitive ability, adaptive functioning, and support needs, and because strengths and challenges often co-exist within the same individual (Lai et al., 2014; Happé & Frith, 2020). Clinical and developmental research shows that two autistic children may both meet diagnostic criteria while displaying very different patterns of abilities and difficulties in everyday life (Lai et al., 2014; Lord et al., 2020). Sensory differences such as hyper- or hypo-reactivity to sound, touch, or movement, and sensory-seeking behaviours, are now recognised as integral to the ASD profile alongside restricted and repetitive behaviours, routines, and interests (Ben-Sasson et al., 2009; Cascio et al., 2016; Kirby et al., 2022; Leekam et al., 2011; Chaxiong et al., 2022).

Globally, ASD is now recognised as a common neurodevelopmental condition rather than a rare disorder, with recent meta-analyses and burden-of-disease models indicating that roughly 1 in 100 children may be on the spectrum and that tens of millions of people are affected worldwide (GBD 2021 Autism Spectrum Collaborators, 2025; Zeidan et al., 2022). Surveillance data from the Autism and Developmental Disabilities

Monitoring Network show a sustained rise in identified prevalence from approximately 1 in 150 in 2000 to about 1 in 31 in 2022, reflecting both improved detection and ongoing challenges in service planning (Centers for Disease Control and Prevention, 2023).

In India, available estimates and narrative reviews suggest that ASD is an important public health concern, with population-based studies indicating that approximately 1 in 60–70 children may meet criteria for autism and that detection gaps are likely in communities where awareness is low and specialist diagnostic services are limited (Chattopadhyay, 2024; Panda, 2019; Srivastava et al., 2023). Indian Academy of Pediatrics (IPA) guidelines similarly emphasise that ASD is a relatively frequent developmental condition that requires systematic screening and coordinated services (Indian Academy of Pediatrics Childhood Disability Group, 2017). Despite this growing recognition, awareness of autism in the general population remains uneven, and many families encounter misconceptions, stigma, and limited access to reliable information, particularly outside major urban centres (Chattopadhyay, 2024; Srivastava et al., 2023). These factors contribute to delays in diagnosis and restrict timely access to appropriate services and interventions (Dey et al., 2024; Mukherjee et al., 2024).

Over the past two decades, India has developed an evolving policy framework to address the needs of persons with autism and other developmental disabilities. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, created a statutory body to support individuals with autism and related conditions through legal guardianship mechanisms and welfare schemes that include early intervention, day care, residential care, and health insurance (The National Trust, 1999). The Rights of Persons with Disabilities (RPwD) Act, 2016, subsequently recognised autism as a specified disability and strengthened rights to inclusive education, non-discrimination, accessibility, and social participation, linking

disability recognition to certification and access to schemes, and affirming a rights-based rather than a purely medical approach to disability (RPwD Act, 2016; Department of Empowerment of Persons with Disabilities, n.d.). Complementary measures, including the Unique Disability ID (UDID) system and related digital portals, seek to standardise certification and facilitate access to services and entitlements across states (Swavlamban Card/UDID Portal, n.d.). Agencies such as the National Trust and the Rehabilitation Council of India contribute by providing scheme portfolios and regulating training frameworks to support early intervention, education, and livelihood for persons with ASD and their families (Rehabilitation Council of India Act, 1992; Rehabilitation Council of India, n.d.; The National Trust, 1999). Nevertheless, service delivery remains fragmented, with specialist resources often concentrated in urban areas and many families in rural and semi-urban regions facing barriers in reaching diagnostic, therapeutic, and educational supports despite the presence of legal and policy provisions (Chattopadhyay, 2024; Srivastava et al., 2023).

Research consistently shows that early detection and timely intervention can improve developmental and behavioural outcomes for children with ASD, particularly when evidence-based approaches such as early behavioural programmes, parent-mediated strategies, speech-language therapy, occupational therapy, and structured educational support are introduced during the preschool years (Hyman et al., 2020; National Autism Center, 2015; Steinbrenner et al., 2020; Wong et al., 2015). Converging findings from retrospective and prospective studies indicate that early signs of ASD can often be detected in the first two years of life, including differences in social attention, joint attention, gesture use, and language development, and that systematic developmental surveillance and screening can shorten the delay between first concern and formal diagnosis (Ozonoff et al., 2009, 2010, 2023; Zwaigenbaum et al., 2015, 2019). Research

studies emphasise that screening alone is insufficient unless it is linked to timely referral, multidisciplinary assessment, and sustained intervention, because intervention effectiveness is closely tied to starting support during periods of greatest developmental plasticity (Hyman et al., 2020; Sheldrick et al., 2022). Studies on screening pathways also show that delays can occur between a positive screen and diagnosis, sometimes exceeding one to two years, highlighting the need for efficient referral systems and parent awareness (Chen et al., 2023; King et al., 2023).

In the Indian context, tools such as the M-CHAT-R/F have been adapted and validated, yet authors note that widespread use is limited and that screening remains uneven across settings (Mukherjee et al., 2024). These opportunities can only be realised when autism is recognised early, families are aware of available supports, and information is presented in forms that parents can understand and apply within their everyday routines and community settings, including in low-resource and linguistically diverse environments (Chattopadhyay, 2024; Srivastava et al., 2023).

For families, raising a child with ASD involves not only managing the child's developmental profile but also navigating structural, social, and emotional challenges. Qualitative and quantitative studies from different countries, including India, report high levels of caregiver burden, emotional strain, financial difficulties, time demands, and social isolation, particularly among mothers who are frequently the primary caregivers (DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Patel et al., 2022; Barik et al., 2025). Parents often experience stress, anxiety, and depressive symptoms, and family functioning may be affected by the cumulative demands of caregiving, uncertainty about the future, and limited access to coordinated services and respite (Karst & Van Hecke, 2012; Srivastava et al., 2023). Research suggests that caregiver burden is influenced by symptom severity, socioeconomic status, and family structure, with families from

lower-income or nuclear households often reporting higher strain (Barik et al., 2025; Patel et al., 2022). Stigma and misunderstanding about autism and developmental disabilities can further intensify these challenges, as atypical communication and behaviour may be misinterpreted as poor parenting, disobedience, or general mental health problems rather than as manifestations of a neurodevelopmental condition (Chattopadhyay, 2024; Desai et al., 2012). Sensory sensitivities and anxiety can also contribute to behavioural difficulties, making everyday environments such as schools, markets, or public transport particularly stressful for autistic children and their families (Ben-Sasson et al., 2009; Kirby et al., 2022; South & Rodgers, 2017).

In the Indian context, cultural expectations around child behaviour, limited awareness of neurodevelopmental disorders, and the concentration of specialised services in cities can delay help-seeking, discourage disclosure, and contribute to social isolation and blame (Chattopadhyay, 2024; Srivastava et al., 2023). At the same time, families must navigate complex procedures for disability certification, educational placements, and welfare schemes under frameworks such as the RPwD Act and the National Trust, which can be difficult to access and understand without clear guidance (Department of Empowerment of Persons with Disabilities, n.d.; The National Trust, 1999).

Parent education and public education materials have therefore been identified as key components of comprehensive autism support. International evidence demonstrates that parent education programmes, caregiver training, and parent-mediated interventions can improve parental understanding of ASD, enhance the use of communication and behaviour-support strategies at home, and strengthen parent–professional collaboration by turning clinical recommendations into everyday practices (Burrell & Borrego, 2012; Oono et al., 2013; Schreibman et al., 2015; Wainer & Ingersoll, 2013). Meta-analyses and systematic reviews indicate that when parents are coached to use developmentally

appropriate interaction strategies, children's communication, social engagement, and adaptive skills can improve, and parental stress may decrease (Sandbank et al., 2020; Oono et al., 2013; Kalorath et al., 2022; Koly et al., 2021). Behavioural and sensory frameworks further show that everyday behaviours can be understood as communication, and that structured supports such as the ABC model, visual schedules, and task analysis can reduce distress and promote independence in daily living skills (Carr & Durand, 1985; Cooper et al., 2022; Hanley et al., 2003; Hume et al., 2021; National Autism Center, 2015; Wong et al., 2015).

Public education materials such as booklets, toolkits, visual guides, and web-based resources also play an important role in increasing awareness, reducing stigma, and helping teachers, extended family members, and the wider community understand autism and appropriate ways to support autistic children in home, school, and community settings (Autism Society, 2024; Autism Speaks, 2018, 2022; Centers for Disease Control and Prevention, 2025). These materials are most effective when they use simple language, visual supports, and practical examples, and when they are aligned with local service systems and cultural norms (Aspect, 2022; Hosie et al., 2024; VKC TRIAD, 2015). In India, several resources exist, including AIIMS-developed hospital information booklets, teacher handbooks on including children with autism in classrooms, disability guides, and online information portals from government institutions and non-governmental organisations (AIIMS New Delhi, 2015; AIIMS Guwahati, n.d.; Gulati et al., 2014; NCERT, 2019; Nayi Disha Resource Centre, 2023; Mobility India, 2023; National Institute for Empowerment of Persons with Multiple Disabilities, 2024). However, their depth, accessibility, language, and cultural fit vary widely, and many materials are lengthy, highly technical, or not designed specifically for parents with diverse literacy levels. Existing resources often focus on single domains or general

disability rather than providing integrated guidance across communication, behaviour, sensory needs, daily living skills, and school participation, and relatively few explicitly explain Indian legal rights, certification pathways, and scheme access in a parent-friendly format. Internationally, there are examples of autism information booklets and caregiver guides that have been systematically developed and validated, including studies that created and psychometrically evaluated educational booklets for caregivers, but in the Indian context there is limited documentation of materials that have been developed using health-literacy tools and then subjected to expert content validation, parent face validation, and field testing with outcome measures (Fernandes Moll et al., 2024; Scottish Intercollegiate Guidelines Network, 2017; Huang-Storms, n.d.). Against this background of increasing prevalence, evolving policy frameworks, and persistent gaps in awareness and service access, the present study focuses on public education pamphlets as a practical and scalable way to support families of children with ASD in the Indian context.

Need for the study

The need for this study arises from the complex challenges faced by Indian families of children with ASD and the current limitations of existing educational resources. Research indicates that parents frequently encounter delays in obtaining a diagnosis and accessing services because of low awareness, cultural stigma, and fear of discrimination, particularly in regions where specialist services are scarce and autism is poorly understood (Chattopadhyay, 2024; Divan et al., 2012; Mahapatra et al., 2019). Caregivers often lack simple, culturally sensitive, and visually engaging information that explains autism, early signs, intervention options, legal rights, and practical day-to-day strategies in language they can readily understand and use, which limits their ability to become effective partners in their child's care (Divan et al., 2012; Srivastava et al., 2023). Available materials are not always tailored to the diverse linguistic and socioeconomic

backgrounds of Indian families and may not adequately address key caregiving domains such as communication support, behaviour management, sensory regulation, daily living skills, and school participation in an integrated and actionable manner (Gulati et al., 2014; NCERT, 2019). Evidence from Indian and international studies also highlights that parents experience substantial emotional burden, including grief, helplessness, and ongoing stress, and many report a need for clear guidance on how to support their child at home, prepare for school, and advocate effectively in health, education, and social care systems (DePape & Lindsay, 2015; Karst & Van Hecke, 2012; Mahapatra et al., 2019).

Although non-governmental organisations and some public institutions have made important contributions to autism awareness and parent support, government-led materials and programmes are unevenly distributed and not always easy for families to locate or use, particularly for those who are new to the diagnosis or living outside major cities (Chattopadhyay, 2024; Srivastava et al., 2023). There is limited availability of brief, structured, family-friendly pamphlets that integrate current evidence with Indian legal and service frameworks, and that are explicitly designed to be used both by caregivers and by clinicians for parent counselling in routine practice.

Furthermore, to the best of our knowledge no existing resources have been rigorously developed using health literacy tool/frameworks such as the Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) and the Suitability Assessment of Materials (SAM), which assess understandability, actionability, readability, layout, and cultural suitability (Shoemaker et al., 2014; Doak et al., 1996) or have undergone formal expert content validation, parent face validation, and field testing to examine their practical impact on caregiver knowledge and confidence.

Taken together, these gaps highlight a clear need for validated, accessible, and visually engaging public education pamphlets that provide culturally and linguistically

appropriate information for Indian caregivers and can also serve as structured aids for professionals involved in autism counselling and guidance (Burrell & Borrego, 2012; Oono et al., 2013; Schreibman et al., 2015). The present study was therefore planned to develop and validate set of five Public Education Pamphlets (PEPs) on autism spectrum disorder for parents and caregivers in the Indian context and to evaluate their effectiveness in improving caregiver knowledge and confidence in caregiving situations.

Aim and objectives of the study

The primary aim of the present study was to develop and validate a set of five Public Education Pamphlets (PEPs) on autism spectrum disorder (ASD) for parents and caregivers in the Indian context and to evaluate their effectiveness in improving caregiver knowledge of ASD and confidence in applying this information in caregiving situations.

The specific objectives of the study were:

1. To compile contextually relevant, accessible, evidence-based information and practical strategies on Autism Spectrum Disorder (ASD) for parents/caregivers, covering key areas including namely ‘Understanding Autism and Rights’, ‘Diagnosis, Evaluation, and Intervention Planning’, ‘Communication and Language Development’, ‘Behaviour, Sensory Skills, and Social Development’ and ‘Daily Living Skills, Home Routines, and Schooling’.
2. To develop a set of five culturally adapted PEPs for parents and caregivers of children with ASD in the Indian context.
3. To establish the content validity and face validity of the developed PEPs through quantitative and qualitative evaluation by a multidisciplinary panel of experts and by parents/caregivers of children diagnosed with ASD, respectively.

4. To conduct a pilot testing to evaluate the feasibility, design, and methodological framework of the developed PEPs. And to conduct a field testing to evaluate their effectiveness in improving the caregiver knowledge of Autism spectrum disorder, and confidence in applying this information in the caregiving situations by pre-test and post-test comparison. Followed by refinement of the PEPs based on feedback, prior to dissemination in public and clinical settings.

CHAPTER 2

Review of Literature

"If you have met one person with autism, you have meet one person with autism."

~Dr. Stephen Shore

Existing literature highlights the significant role of parent and caregiver education in supporting children with Autism Spectrum Disorder (ASD). Better access to clear, evidence-based and practically oriented information has been associated with improved parental understanding, greater confidence in caregiving and more effective participation in intervention and daily management. At the same time, several studies have noted the need for educational resources that are not only scientifically accurate, but also culturally relevant and easy for families to apply in real-life situations. The literature related to parent education and public educational resources in ASD is reviewed below under the following headings:

2.1 Autism Spectrum Disorder

2.2 Epidemiology of ASD

2.3 Early Signs and Early Identification

2.4 Communication and Language Challenges in ASD

2.5 Behaviour, Sensory Issues, and Social Development

2.6 Daily Living Skills, Home Routines, and School Readiness

2.7 Role of Professionals in ASD Management

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2.1 Autism Spectrum Disorder

2.1.1 Definition of ASD

As defined by American Psychiatric Association (2022), "Autism spectrum disorder (ASD) is recognised as a lifelong neurodevelopmental condition characterised by persistent difficulties in social communication and social interaction, alongside restricted and repetitive patterns of behaviour and atypical sensory processing, with or without intellectual disability." These challenges are present from the early developmental period and most of the time interfere with everyday functioning, although they may become more noticeable when social and academic demands increase during later period (Lord et al., 2020).

The term "spectrum" is very important to understand because autism does not present in one fixed way. Most the times it includes wide variation in communication, behaviour, learning and support needs (Happé & Frith, 2020; Lord et al., 2020). This variability means that two children with ASD may both meet same diagnostic criteria but show very different patterns of strengths and difficulties (Lord et al., 2020; Zwaigenbaum et al., 2015). That's why ASD is best understood as a heterogeneous developmental condition, not a single uniform profile (Happé & Frith, 2020; Lord et al., 2020).

The spectrum nature of ASD also reflects differences in intellectual ability and adaptive functioning (Lai et al., 2014; Lord et al., 2020). Some individuals with ASD may have significant learning difficulties and require substantial support, while others may have average or above-average intelligence but still experience marked difficulties in social communication, pragmatic language, flexibility and sensory regulation in day to

day activities (Lai et al., 2014; Zwaigenbaum et al., 2015). Because of this, a mere diagnosis of autism does not tell us everything about a person's abilities or needs (Lai et al., 2014; Lord et al., 2020).

Another important aspect of the spectrum nature of ASD is that support needs can change across time and settings (Happé & Frith, 2020; Lord et al., 2020). A child with ASD may cope well in a structured classroom but struggle when routines change or when social and sensory demand increases (Lord et al., 2020; Zwaigenbaum et al., 2015). Therefore, individualised assessment is essential and intervention should be based on the person's individual profile of strengths, challenges and environmental demands not only on the diagnostic label alone (Lai et al., 2014; Lord et al., 2020).

The spectrum idea also reminds us that strengths and challenges often co-exist (Happé& Frith, 2020; Mottron et al., 2006). Many persons with ASD show qualities such as attention to detail, persistence, strong memory or deep interest in particular topics. Even when they also experience difficulty with social interaction or change (Happé& Frith, 2020; Mottron et al., 2006). Thus, autism should be understood in a way that recognises both support needs and abilities (Lai et al., 2014; Lord et al., 2020).

2.1.2 Core characteristics of ASD

The core characteristics of ASD are organised into two major domains, first; persistent difficulties in social communication and social interaction, and second; restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association [APA], 2022; Lord et al., 2020). This two-domain model shows that the current diagnostic understanding of autism and is applicable in both research and clinical practice (Lai et al., 2014). Although these features are considered core to ASD, their expression differs according to age, language level, cognitive ability, and environmental

context i.e., a person with ASD will not show same characteristics with respect to another person across all the domains (Lord et al., 2020; Hyman et al., 2020).

The first core domain i.e., difficulties in social communication and social interaction may include reduced social-emotional reciprocity, limited or no use/understanding of nonverbal communication and difficulty in developing, maintaining and understanding relationships (American Psychiatric Association, 2022; Hyman et al., 2020). Children with ASD usually find it difficult to initiate interaction, respond appropriately to others, share interests or emotions with other, interpret facial expressions and gestures or adjust communication with respect to the social context (Lai et al., 2014; Lord et al., 2020). These difficulties do not primarily indicate lack of interest in other persons but rather, it reflects differences in social understanding, communication style and reciprocal engagement (Happé& Frith, 2020; Lord et al., 2020).

The second core domain i.e., restricted and repetitive patterns of behaviour, interests, or activities mainly appear as repetitive motor movements, repetitive use of objects or speech, insistence on sameness, distress at change, highly restricted interests or unusual responses to sensory input most of the times (American Psychiatric Association [APA], 2022; Hyman et al., 2020). Sensory differences are also now recognised as an important part of the autism profile and can include either hyper-reactivity or hypo-reactivity to sound, light, touch, pain or other environmental stimuli (American Psychiatric Association, 2022; Lai et al., 2014). They can significantly affect participation in home, school and community settings, primarily when routines are disrupted or sensory demands are very high (Lord et al., 2020; Hyman et al., 2020).

In addition to the core domains, ASD is often associated with broader developmental and functional differences with includes, having uneven cognitive profiles,

executive functioning difficulties, and co-occurring emotional or behavioural conditions (Lai et al., 2014; Lord et al., 2020). However, these associated features should be distinguished from the core diagnostic characteristics themselves, which primarily remain focused on social communication differences and restricted or repetitive patterns of behaviour (Lord et al., 2020). A good understanding of these core characteristics is essential because it supports accurate identification, informed parent education and the development of interventions that are responsive to the child's specific profile (Hyman et al., 2020; Zwaigenbaum et al., 2015).

2.1.3 Strengths and challenges across the spectrum

ASD should not be understood only in terms of deficits, because research increasingly shows that autistic individuals often demonstrate meaningful strengths alongside areas of difficulty (Woods & Estes, 2023; Taylor et al., 2023). A strengths-based perspective does not deny the challenges associated with autism; rather, it provides a more balanced and accurate understanding of autistic development and functioning (Happé& Frith, 2020; Taylor et al., 2023). This approach is particularly important because autistic characteristics may contribute both to competence in some domains and to difficulty in others, depending on context and support (Mottron et al., 2006; Taylor et al., 2023).

Among the strengths commonly reported in the literature are attention to detail, focused interests, persistence, pattern recognition, memory, and deep knowledge in specific subject areas (Woods & Estes, 2023; Mottron et al., 2006). Focused interests, often described in diagnostic systems as restricted interests, can also support learning, expertise, emotional well-being, and vocational development when they are recognised and constructively nurtured (Woods & Estes, 2023; Taylor et al., 2023). Emerging evidence further suggests that the use of personal strengths is associated with better

quality of life, greater subjective well-being, and lower levels of anxiety, depression, and stress among autistic individuals (Taylor et al., 2023; Chow & Cooper, 2026). These findings primarily show the importance of interventions that identify and build on strengths rather than concentrating mainly on deficits (Taylor et al., 2023; Chow & Cooper, 2026).

At the same time, children with ASD may experience substantial challenges in social communication, social reciprocity, flexibility, sensory processing and adaptation to change (APA, 2022; Lord et al., 2020). Difficulties in interpreting nonverbal cues, managing transitions, tolerating sensory input or coping with unpredictable environments may significantly affect participation in school, family and community settings (Lai et al., 2014). These challenges can also contribute to emotional distress, behavioural difficulties, social exclusion and reduced opportunities as most of the time they are misunderstood or unsupported by public (Happé& Frith, 2020; Lord et al., 2020). Hence, a realistic profiling of autism must also include the barriers autistic people face and the capacities they have.

It is also important to note that, strengths and challenges in ASD often interact across development and everyday life rather than existing as completely isolated ares (Mottron et al., 2006; Taylor et al., 2023). For example, an intense interest in a particular activity may support learning and motivation in one context but at the same time it creates difficulty with flexibility or adaptation in another one (Woods & Estes, 2023; Taylor et al., 2023). This wide variation in abilities, challenges, and support needs highlights the importance of understanding that how complex ASD is and how it affects families, services and society. Since recent studies shows increasing incidence and prevalence of ASD around the world, a review of the epidemiology of ASD is important to understand

prevalence trends, service burden and the growing need for awareness, early identification and intervention, primarily in the Indian context.

2.2 Epidemiology of ASD

ASD is now recognised as a common neurodevelopmental condition worldwide, with prevalence estimates that have risen across time and vary by method, age group, and case definition (Zeidan et al., 2022). The burden of ASD extends beyond prevalence because the condition affects multiple domains of functioning across the life course (Global Burden of Disease Study 2021 Autism Spectrum Collaborators, 2025).

2.2.1 Global prevalence

Global prevalence estimates indicate that autism is a common neurodevelopmental condition worldwide, although reported rates vary widely across regions, study designs, and diagnostic methods (Zeidan et al., 2022; GBD 2021 Autism Collaborators, 2025). A systematic review update published in 2022 found a median global prevalence of 100 per 10,000, or about 1 in 100 children, across 71 studies published since 2012 (Zeidan et al., 2022).

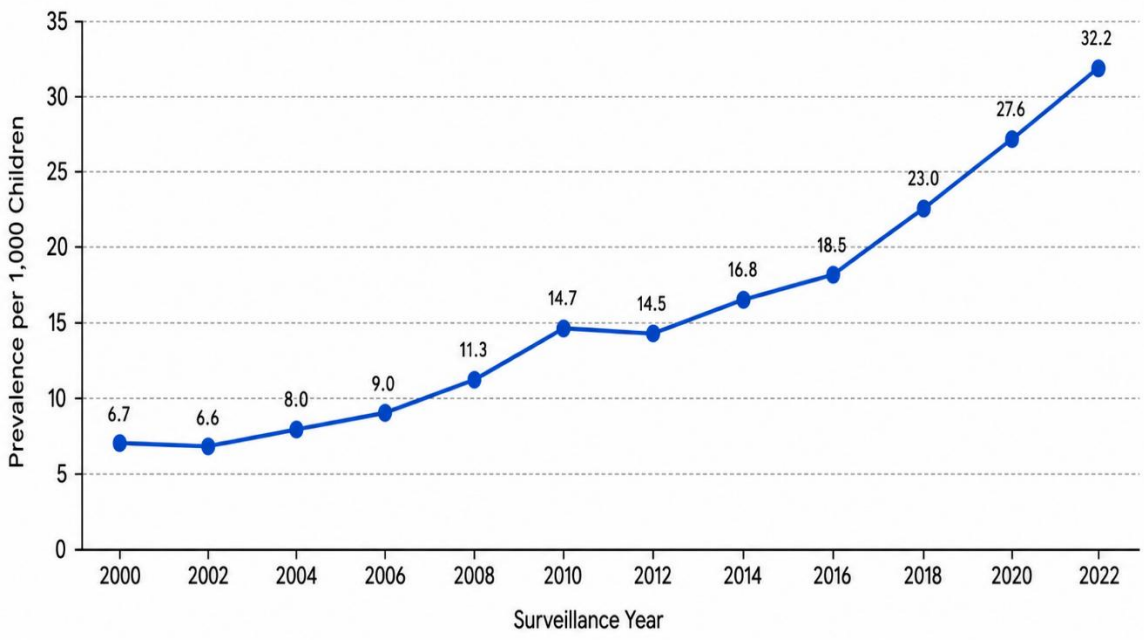
More recent burden-of-disease modelling published in *The Lancet Psychiatry* estimated that 61.8 million people worldwide were on the autism spectrum in 2021, equivalent to 1 in every 127 individuals, this study also showed marked sex differences in prevalence, with substantially higher estimated prevalence 4.2 times more often in males than female, and it concluded that autism contributes a major non-fatal health burden globally (GBD 2021 Autism Collaborators, 2025).

According to the Centers for Disease Control and Prevention, ASD was identified in about 1 in 31 children aged 8 years, or 3.2%, in the most recent ADDM Network estimates (CDC, 2023). The CDC also reports that autism occurs across all racial, ethnic,

and socioeconomic groups, showing that it is a condition found in every part of the population rather than limited to any one community (CDC, 2023). In addition, ASD is more than three times more common among boys than among girls, which highlights a clear sex difference in reported prevalence (CDC, 2023).

Figure 2.1

Longitudinal Trends in ASD Prevalence (2000–2022)



Legend. The line graph illustrates the identified prevalence of Autism Spectrum Disorder (ASD) per 1,000 children reported by the Autism and Developmental Disabilities Monitoring (ADDM) Network across surveillance years from 2000 to 2022.

Note. The identified prevalence of ASD within the ADDM Network demonstrated a significant and sustained upward trend between 2000 and 2022. Prevalence estimates are presented as the number of identified cases per 1,000 children. ASD = Autism Spectrum Disorder; ADDM = Autism and Developmental Disabilities Monitoring Network. Graph created by the author using prevalence data reported in the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network surveillance reports (CDC, 2023).

As presented in the Figure 2.1 the identified prevalence of ASD within the ADDM Network has demonstrated a significant and sustained upward trend from 2000 to

2022(Centers for Disease Control and Prevention, Autism and Developmental Disabilities Monitoring [ADDM] Network, 2023). Over this 22-year period, the combined prevalence rose from 6.7 per 1,000 children (approximately 1 in 150) in 2000 to a peak of 32.2 per 1,000 children (approximately 1 in 31) in 2022, representing an increase of approximately 380%. Given data shows some minor fluctuations, such as a slight decrease from 14.7 to 14.5 per 1,000 between the 2010 and 2012 surveillance years, still the overall trajectory remains sharply positive. This growth in identification primarily corresponds with expansion of the network's reach, with the number of reporting sites increasing from merely 6 in the initial year to 16 in the recent report. Moreover, the data published in 2022, highlights the substantial regional variability, with prevalence ranges across different ADDM sites ranging from 9.7 to 53.1 per 1,000 children (ADDM Network, 2023)

2.2.2 Indian prevalence and reported trends

Indian studies suggests that at present ASD has become is a significant public health concern, with one influential estimate placing prevalence at 1.12 per 100 children aged between 2–9 years or approximately 1 in 68 children (Chattopadhyay, 2024; Panda, 2019). India is having a very large child population, a prevalence around 1 in 68 translates into the enormous absolute number of children requiring identification, long-term support and services (Srivastava et al., 2023).

The Indian studies also shows that reported prevalence is primarily affected by methodology, region, age group and easy to access the diagnostic services (Chattopadhyay, 2024). School based and clinical based studies may miss children who are not enrolled in school or who remain undiagnosed because of limited awareness, language barriers or scarcity of trained the professionals (Srivastava et al., 2023; Panda, 2019). As a result, the prevalence figures reported in India are likely to reflect both true

cases as well as a detection gap, rather than a single stable national rate (Chattopadhyay, 2024).

Reported trends have pointed toward an increasing identification rate rather than a mere increase in disease occurrence (Panda, 2019). Greater professional awareness, improved screening efforts and increased parent recognition of early signs have contributed to more diagnoses over a period of time, but still many children are identified late or not at all (Chattopadhyay, 2024; Srivastava et al., 2023). The detection gap becomes especially important in rural areas where screening tools, trained personnel and referral systems are usually limited (Chattopadhyay, 2024; Srivastava et al., 2023). These findings have practical implications for India's fragile health and education systems. They support the need for universal early screening program for ASD, stronger referral pathways, trained frontline workers and culturally appropriate diagnostic tools that can be used at scale (Chattopadhyay, 2024; Indian Academy of Pediatrics Childhood Disability Group & Committee on Child Development and Neurodevelopmental Disorders [IAP], 2017). They also highlight why ASD should be treated as a priority neurodevelopmental condition in India, because prevalence is high enough to demand system level planning rather than isolated clinic based approach (Chattopadhyay, 2024; IAP, 2017).

2.2.3 Family, social, and service burden

ASD imposes significant burden not only on this child with ASD but equally on families, community and service systems as support needs are often long term and multidimensional (Hyman et al., 2020; Lord et al., 2020). The burden extends across emotional, social, educational, occupational and financial domains, mainly when access to early diagnosis services and intervention is delayed. In the Indian context, these pressures are further amplified by large service gaps, variable awareness and the

concentration of specialised care in urban settings than rural ones (Chattopadhyay, 2024; Srivastava et al., 2023).

Family burden is especially high in caregivers, they frequently report elevated stress, fatigue and reduced quality of life while managing the child's communication difficulties, behavioural challenges and long-term developmental needs (DePape & Lindsay, 2015; Patel et al., 2022). A study from north India reported a high burden of care among caregivers of children and adolescents with ASD and reported that burden was greater in low-income families and it increased with symptom severity (Patel et al., 2022). Similarly, a recent Indian cross-sectional study from Odisha reported that caregiver strain was significantly higher among families with lower education, lower middle socioeconomic status and nuclear family structures, indicating that the burden of autism is shaped by social and family resources not only on the child's condition (Barik et al., 2025).

The social burden of ASD primarily includes stigma, isolation, and reduced participation in everyday community life (Chattopadhyay, 2024; Srivastava et al., 2023). Parents may experience blame, social judgment, or lack of understanding from relatives, schools, and the wider public, while autistic children may be excluded or misunderstood in educational and social environments (DePape & Lindsay, 2015; Srivastava et al., 2023). These experiences usually delay help-seeking and intensify parental distress, mainly in settings where ASD related awareness remains limited and cultural expectations of child behaviour are very rigid (Chattopadhyay, 2024; Srivastava et al., 2023).

Service burden becomes very important because effective ASD management often requires multidisciplinary and long term intervention, including services like developmental paediatrics, speech-language therapy, occupational therapy, psychology

and special education (Hyman et al., 2020; Lord et al., 2020). The economic consequences are direct as well as indirect, it includes direct expenses for treatment and training as well as indirect costs such as transportation, lost work time and informal care demands (Chaudhary et al., 2022; Barik et al., 2025). A South Asian cost of illness study reported that autism-related costs include healthcare, education, productivity losses, informal care and respite care, which shows that the service burden is very high even before long-term adult support needs are considered (Chaudhary et al., 2022). In India, where specialised services are often fragmented or inaccessible outside urban cities, these demands place extra strain on both families and fragile the health system of the country (Chattopadhyay, 2024; Srivastava et al., 2023).

Overall, the existing evidences shows that ASD in India should be understood not only as a developmental disorder but also as a family, social and service challenge requiring coordinated policy and public health response (Hyman et al., 2020; Chattopadhyay, 2024). Reducing burden will require earlier screening, stronger referral systems, affordable intervention services, family education and counselling, broader efforts to reduce stigma and improve inclusion in the society (Chattopadhyay, 2024; Srivastava et al., 2023). Without these measures, the impact of ASD extends beyond the individual child and affects caregiver wellbeing, social participation, quality of life and service capacity on a large scale (Lord et al., 2020; Chaudhary et al., 2022).

2.2.4 Importance of awareness in the Indian context

Awareness of ASD is especially important in the Indian context, because low recognition of early signs contributes to delayed screening, delayed diagnosis and ultimately delayed intervention (Chakrabarti, 2023; Chattopadhyay, 2024). In India, many parents, teachers and even health workers may not be adequately familiar with the early manifestations of autism, which postpone referral to specialist services during the critical

developmental period (Chattopadhyay, 2024; Srivastava et al., 2023). Since early intervention is associated with better developmental and behavioural outcomes, awareness is not merely an educational issue but a central component of effective autism management (Hyman et al., 2020; Chakrabarti, 2023).

Awareness is very important and necessary to reduce the existing stigma and social misunderstanding surrounding autism (Tonge & Brereton, 2022; Srivastava et al., 2023). In many Indian communities, atypical communication, behaviour or developmental delay are misinterpreted as poor parenting, disobedience or a general mental health problem, which usually discourage families from seeking support (Tonge & Brereton, 2022; Chattopadhyay, 2024). Therefore, better awareness can help to create a social environment in which children with ASD and their families are treated with understanding rather than blame or exclusion (Tonge & Brereton, 2022; Srivastava et al., 2023).

From a systems perspective, awareness is necessary for building equal access to services across the country (Chakrabarti, 2023; Chattopadhyay, 2024). Public awareness can increase community demand for early screening and timely intervention, while professional awareness can improve identification by paediatricians, teachers, frontline workers and the significant others (Chattopadhyay, 2024; Hyman et al., 2020). In India, where specialist services are limited and unevenly distributed, awareness among community workers such as ASHA and Anganwadi members is particularly important for early recognition and referral (Chakrabarti, 2023; Chattopadhyay, 2024).

Awareness has long-term policy relevance as it influences how ASD is prioritised within health, education and disability systems (Chakrabarti, 2023; Srivastava et al., 2023). The Indian literature increasingly argues that ASD should be addressed through

coordinated national planning, supported by stronger public understanding, advocacy and broader acceptance of autism as a neurodevelopmental and rights based issue (Chakrabarti, 2023; Tonge & Brereton, 2022). As the awareness and recognition improve, the need for timely detection and early support also becomes more significant, because delayed identification can postpone access to intervention during critical developmental period (Chattopadhyay, 2024; Hyman et al., 2020). Therefore, understanding the early signs of ASD and the importance of early identification is essential for improving referral, intervention planning and long-term developmental outcomes.

2.3 Early Signs and Early Identification

Early identification of autism ASD is important because autistic features usually often emerge in the first two years of life and earlier diagnosis allows children to access intervention when developmental plasticity is greatest in the critical period (Zwaigenbaum et al., 2015; Ozonoff et al., 2023). Evidences from the retrospective and prospective studies have shown that early signs can be detected before the age of 24 months, especially in social communication, attention, emotion regulation and repetitive behaviour (Zwaigenbaum et al., 2015; Ozonoff et al., 2023). The literature therefore supports a developmental view in which autism can often be recognised well before a formal diagnosis is made (Zwaigenbaum et al., 2015; Ozonoff et al., 2023).

The earliest signs commonly include poor response to name, limited eye contact, limited use/understanding of gestures, reduced joint attention, absent social smiling, and delayed or atypical language development (Zwaigenbaum et al., 2015; Ozonoff et al., 2023). Other early markers can include unusual sensory responses, repetitive motor behaviours, limited pretend play, and atypical interest in objects rather than people (Ozonoff et al., 2023; Salgado-Cacho et al., 2021). These features are not diagnostic by

themselves alone, but they can alert parents and clinicians to the need for detailed evaluation for ASD (Zwaigenbaum et al., 2015; Ozonoff et al., 2023).

Early identification is clinically valuable because it reduces the time delay between parental concern and formal assessment, usually described as the "diagnostic odyssey" (Zwaigenbaum et al., 2015; Hyman et al., 2020). Earlier recognition also makes it more likely that children will receive evidence-based intervention during the critical period when language, social learning and adaptive skills are developing most rapidly (Hyman et al., 2020; Zwaigenbaum et al., 2015). For this reason, screening and surveillance in infancy and toddlerhood are strongly emphasised in paediatric practice (Hyman et al., 2020; Zwaigenbaum et al., 2015).

In the Indian context, early identification becomes important because diagnostic delays are common and awareness is uneven across communities and health systems (Chattopadhyay, 2024; Chakrabarti, 2023). Families may first notice differences, but referral is often delayed by the lack of awareness, limited access to qualified professionals and uncertainty about early neurodevelopmental variation (Chattopadhyay, 2024; Srivastava et al., 2023). Improving early identification therefore requires both community level awareness and routine neurodevelopmental screening for ASD within primary care and child health services (Chattopadhyay, 2024; Chakrabarti, 2023).

2.3.1 Early developmental red flags

Early developmental red flags for ASD typically involve differences in social attention, communication, and reciprocal interaction during the first year of life (Zwaigenbaum et al., 2015; Zwaigenbaum et al., 2019). The literature on early detection shows that infants later diagnosed with ASD may display reduced response to name, limited eye contact, limited use of gestures, poor joint attention, and limited social

smiling than typically developing peers (Zwaigenbaum et al., 2015; Ozonoff et al., 2010). These signs are not diagnostic on their own, but they are important indicators that should prompt careful detailed ASD evaluation by qualified professionals (Hyman et al., 2020; Zwaigenbaum et al., 2015).

Other early red flags include limited back and forth babbling, reduced imitation, delayed or absent pointing to share interest and limited interest in people, atypical interest in objects (Zwaigenbaum et al., 2015; Ozonoff et al., 2024). Repetitive movements, unusual sensory responses and atypical play patterns may also appear early, although these signs are sometimes more variable than the social-communication markers (Ozonoff et al., 2024; Zwaigenbaum et al., 2015). When such behaviours occur together, alongside language delay, the likelihood of ASD increases and detailed diagnostic assessment becomes mandatory (Hyman et al., 2020; Zwaigenbaum et al., 2015).

Recognition of these red flags matters because parents can notice differences before formal professionals do and earlier concern can shorten the delay to diagnosis and intervention (Hyman et al., 2020; Chattopadhyay, 2024). In India, where awareness and screening are uneven, these early signs may be missed or attributed to “late talking” or temporary developmental variation, which can further delay the referral (Chakrabarti, 2023; Chattopadhyay, 2024). For that reason, any persistent combination of social, communicative and behavioural red flags in infancy or toddlerhood should be treated as a need for detailed ASD evaluation rather than reassurance alone (Hyman et al., 2020; Chakrabarti, 2023).

2.3.2 Age-wise signs of concern

The signs of concern in ASD can vary with age and developmental stage. Early concerns are commonly related to social communication, language development,

interaction with others, play skills, and behavioural flexibility. Some signs may appear during infancy or toddlerhood, while others become more noticeable when social and school demands increase. Table 2.1 presents the major age-wise signs of concern associated with ASD across different developmental periods.

Table 2.1

Age-wise Signs of Concern in Autism Spectrum Disorder

Age	Domains	Signs	Implications	Key References
Infancy (Birth to 12 months)	• Early social communication • Joint attention •Reciprocity	• Reduced response to name • Limited eye contact • Lack of social smiling • Poor sharing of attention • Fewer gestures such as pointing, waving, or showing objects	• Signs may appear before formal diagnosis • Parents often notice concerns early • Early identification supports timely intervention	Zwaigenbaum et al. (2015); Hyman et al. (2020); Ozonoff et al. (2010)
Toddlerhood (1 to 3 years)	• Language development • Imitation • Play skills • Early social interaction	• Language delay • Limited imitation • Weak pretend play • Reduced interest in peers • Repetitive use of objects or words • Distress with changes in routine • Regression such as loss of words or reduced social engagement	• Developmental regression often prompts earlier referral • Mild or gradual differences may otherwise be overlooked	Hyman et al. (2020); Zwaigenbaum et al. (2015); Ozonoff et al. (2010)
Pre-school years (3 to 5 years)	• Social communication • Peer interaction • Flexible play • Group adaptation	• Difficulty with back-and-forth conversation • Problems with peer interaction • Reduced flexible play • Emotional regulation difficulties • Difficulty adapting to group routines • Repetitive interests • Literal interpretation of language	• Classroom demands may make concerns more visible • Some children remain undiagnosed until school age due to subtle symptoms	American Psychiatric Association (2022); Hyman et al. (2020); Lord et al. (2020); Volkmar & McPartland (2012)

Age	Domains	Signs	Implications	Key References
		• Insistence on sameness • Sensory sensitivities affecting school participation		
School Age (5 to 12 years)	• Peer relationships • Social understanding • Pragmatic language • Flexibility	• Persistent social difficulties • Problems making or keeping friends • Emotional exhaustion • Rigidity • Difficulty understanding social rules or nonverbal cues • Pragmatic language difficulties despite adequate vocabulary	• Autism may be missed when academic or language skills appear adequate • Ongoing screening remains important	Lord et al. (2020); Lai et al. (2014); Crowe & Salt (2015); Hyman et al. (2020)
Indian context	• Recognition patterns • Developmental surveillance • Screening	• Early differences may be interpreted as "late talking" or temperament • Delayed recognition of developmental concerns is common	• Routine developmental surveillance is essential • Screening is important during periods of rapid language, play, and social development • Structured age-wise monitoring may reduce diagnostic delay and support timely referral	Chattopadhyay (2024); Chakrabarti (2023)

Overall, age-wise developmental monitoring and screening are important because the signs of autism can change across different stages of development and may not always be identified early. A structured age-wise approach can help in earlier identification, reduce delay in diagnosis, and support timely referral for assessment and intervention.

2.3.4 Role of parents in early identification

Parents are central to early identification because they are usually the first to notice developmental differences in social communication, language, behaviour, and responsiveness (Zwaigenbaum et al., 2015; Ozonoff et al., 2010). Research shows that parental concern often appears long before formal diagnosis, and that the age of first concern is an important predictor of the age of diagnosis and entry into services (Ozonoff et al., 2009; Leach et al., 2025). Since daily routines give parents repeated opportunities to observe the child across different settings, their reports become the most informative early source of developmental information (Ozonoff et al., 2009; Zwaigenbaum et al., 2015).

Parents are especially well placed to notice early red flags, for e.g. reduced response to name, poor eye contact, limited gesture use, delayed babbling or speech and loss of previously acquired skills (Ozonoff et al., 2010; Leach et al., 2025). Studies comparing parental first concerns with later diagnosis show that concerns about speech, gestures, eye contact and regression are associated with earlier recognition of ASD (Leach et al., 2025; Ozonoff et al., 2009). This means that parent reports are not simply subjective impressions, they provide clinically meaningful early evidence that supports referral and early identification (Zwaigenbaum et al., 2015; Hyman et al., 2020).

The role of parents becomes even more important in India where access to formal evaluations is uneven, and families can be the first and only observers of subtle early

differences (Chattopadhyay, 2024; Chakrabarti, 2023). In India, where diagnostic delay remains common, parent concern can help compensate for gaps in early screening and limited access to specialist services (Chattopadhyay, 2024; Srivastava et al., 2023). However, parental concern should also be taken seriously by health care professionals, otherwise the opportunity for early referral may be lost (Hyman et al., 2020; Chakrabarti, 2023).

An effective early identification system therefore depends on strong understanding and partnership between parents and professionals (Zwaigenbaum et al., 2015; Hyman et al., 2020). Parents need information about developmental milestones and warning signs, whereas clinicians need to listen carefully to parental observations and respond to them promptly (Chattopadhyay, 2024; Zwaigenbaum et al., 2015). When parents are supported and involved, early identification is more likely to occur and children with ASD are more likely to receive timely intervention (Leach et al., 2025; Hyman et al., 2020). Since communication difficulties are often among the earliest and most noticeable concerns reported by parents, understanding the nature of language and communication challenges in ASD is essential for early identification and timely intervention. Therefore, a review of communication and language challenges in ASD is important to understand how these difficulties affect everyday interaction, learning, and participation across home and school settings.

2.4 Communication and Language Challenges in ASD

2.4.1 Overview of Communication and Language Difficulties

Communication and language difficulties are among the most frequently described clinical characteristics of Autism Spectrum Disorder (ASD), although their presentation differs considerably across individuals. Some children present with delayed speech and language development whereas others demonstrate relatively intact structural

language alongside marked difficulties in social communication and reciprocal interaction. Echolalia, repetitive or scripted language use, pragmatic language difficulties, and reduced flexibility in communication are also commonly reported within the spectrum. The impact often extends beyond communication alone, influencing classroom participation, peer relationships, social learning, and everyday functional interactions in different environments. Table 2.2 summarises the major communication and language difficulties commonly associated with ASD

Table 2.2

Communication and Language Difficulties in Autism Spectrum Disorder

Area of Concern	Features	Functional impact	Clinical Significance	References
Speech and language delay	Delayed babbling, first words, phrase speech, or difficulty understanding and using language	Affects communication, learning, and interaction	Often one of the earliest parental concerns and may support early identification of ASD	Tager-Flusberg (2016); Tager-Flusberg & Kasari (2013); Mayo et al. (2013); Kover et al. (2016)
Pragmatic language difficulties	Difficulty with turn-taking, topic maintenance, listener awareness, figurative language, sarcasm, and conversational reciprocity	Impacts peer relationships, classroom participation, and social interaction	May be overlooked in verbally fluent children despite significant social communication difficulty	Thurm et al. (2015); Tager-Flusberg (2016); Vogindroukas et al. (2022); Dolata et al. (2022)
Echolalia	Immediate or delayed repetition of words or phrases spoken by others	May support requesting, self-regulation, turn-taking, or maintaining interaction	Should be interpreted in context rather than viewed as meaningless repetition	Xie et al. (2023); Blackburn et al. (2023); Stiegler (2015)
Repetitive or scripted language	Repeated phrases, verbal routines, or context-dependent scripted speech	Can affect flexibility in communication and interaction	May represent an attempt at communication rather than absence of communicative intent	Xie et al. (2023); Blackburn et al. (2023); Stiegler (2015)
Literal interpretation of language	Difficulty understanding indirect language, idioms, metaphor, or implied meaning	Can lead to misunderstanding in social and academic settings	Affects comprehension of everyday communication and classroom interaction	Tager-Flusberg (2016); Vogindroukas et al. (2022)

Area of Concern	Features	Functional impact	Clinical Significance	References
Joint attention and gesture difficulties	Reduced pointing, showing, eye gaze, imitation, and shared attention behaviours	Limits opportunities for social learning and language development	Strongly associated with early communication development in ASD	Tager-Flusberg & Kasari (2013); Zwaigenbaum et al. (2015)
Uneven receptive and expressive language profile	Some children understand more than they express, while others speak fluently but struggle with organization and flexibility	Creates variability in communication abilities across situations	Highlights the heterogeneity of communication profiles in ASD	Tager-Flusberg (2016); Vogindroukas et al. (2022)
Social communication difficulties	Difficulty initiating interaction, sharing interests, maintaining reciprocal conversation, and adapting communication to context	Affects relationships, participation, and adaptive functioning	Communication difficulties in ASD are closely linked to social interaction rather than speech alone	Tager-Flusberg & Kasari (2013); Thurm et al. (2015); Hyman et al. (2020)
Indian context-related concerns	Language delay may be interpreted as “late talking” or temporary variation	Delayed referral and reduced access to intervention services	Highlights the importance of awareness, developmental surveillance, and timely referral	Chattopadhyay (2024); Chakrabarti (2023); Srivastava et al. (2023)

Note. *Communication and language difficulties in ASD are highly variable and may affect speech, social communication, pragmatic language, and interaction skills differently across individuals.*

Communication profiles in ASD are rarely uniform. Difficulties may involve both structural components of language and the social use of communication, with considerable variation in severity and functional impact across developmental stages and contexts. Identification of these patterns at an early stage remains clinically significant because intervention planning, educational support, and participation outcomes are closely linked to the nature of the individual's communication profile.

2.4.2 Role of communication support in daily life

Communication support is essential in daily life for autistic individuals because communication differences affect participation at home, school, work, and in the community (Tager-Flusberg, 2016; Schlosser & Wendt, 2008). Support may include simplified language, visual schedules, communication boards, social stories, speech-language therapy, and augmentative and alternative communication (AAC) systems (Schlosser & Wendt, 2008; Iacono et al., 2016). These supports do not replace language development; rather, they help the person communicate needs, understand routines, and participate more independently in everyday activities (Iacono et al., 2016; Tager-Flusberg, 2016).

AAC is particularly important for autistic individuals who are minimally verbal or who need additional support for functional communication (Schlosser & Wendt, 2008; Iacono et al., 2016). Research shows that AAC can support requesting, social interaction, participation in routines, and broader communication functions when it is introduced early and used consistently across settings (Iacono et al., 2016; Tager-Flusberg & Kasari, 2013). Evidence-based reviews also indicate that AAC interventions can improve social-communication outcomes, especially when families, teachers, and therapists use them collaboratively (Schlosser & Wendt, 2008; Iacono et al., 2016).

In daily life, communication support reduces frustration and behavioural distress by giving the child a reliable way to express wants, needs, discomfort, and choices (Hyman et al., 2020; Iacono et al., 2016). It also supports understanding by making expectations more predictable through visual cues, structured routines, and direct language (Hyman et al., 2020; Tager-Flusberg, 2016). These supports are important not only for children with limited speech but also for verbally fluent autistic individuals who struggle with pragmatic language, transitions, or complex social situations (Tager-Flusberg, 2016; Tager-Flusberg & Kasari, 2013).

In the Indian context, communication support is especially important because many children are identified late and may enter school without the language supports they need (Chattopadhyay, 2024; Srivastava et al., 2023). Schools and families often need practical, low-cost communication strategies that can be used consistently in everyday settings, not only in therapy rooms (Chattopadhyay, 2024; Chakrabarti, 2023). For this reason, communication support should be understood as part of daily care and education, not as an optional specialist add-on (Hyman et al., 2020; Srivastava et al., 2023)

2.4.3 Need for parent-mediated communication strategies

Parent-mediated communication strategies are important because they extend intervention into the child's everyday routines, where communication is most naturally learned and practised (Oono et al., 2013; Yang, 2019). These approaches train parents to use responsive, language-rich interaction strategies so that communication goals are supported not only in therapy sessions but also at home and in community settings (Yang, 2019; Vivanti et al., 2018). The evidence base suggests that parent-mediated intervention can improve child social communication, language, and engagement while also strengthening parental confidence and interaction skills (Oono et al., 2013; Vivanti et al., 2018). A key reason for using parent-mediated strategies is that autism affects

communication across daily life rather than only in clinic-based tasks (Tager-Flusberg, 2016; Hyman et al., 2020). Parents spend the most time with the child and can create repeated opportunities for requesting, turn-taking, shared attention, and functional language practice throughout ordinary activities such as meals, play, and dressing (Yang, 2019; Oono et al., 2013). This makes parent involvement especially valuable for children who need intensive early support or who live in settings where specialist therapy time is limited (Chattopadhyay, 2024; Chakrabarti, 2023).

Parent-mediated strategies are also important because they can be adapted for families with different resources and service access levels (Vivanti et al., 2018; Hyman et al., 2020). In India, where professional services are unevenly distributed, training parents in communication support can help bridge gaps between diagnosis and continuous intervention (Chakrabarti, 2023; Chattopadhyay, 2024). The literature therefore supports parent-mediated intervention as a practical and scalable way to improve communication outcomes while reducing dependence on scarce specialist services (Yang, 2019; Srivastava et al., 2023).

These strategies are not intended to replace professional therapy, but to complement it by making communication practice more consistent and ecologically valid (Oono et al., 2013; Vivanti et al., 2018). When parents are coached to respond to the child's communicative attempts, expand utterances, and use visual or contextual supports, children are more likely to generalise skills across people and settings (Yang, 2019; Tager-Flusberg, 2016). For this reason, parent-mediated communication should be treated as a core component of early autism support rather than an optional extra (Hyman et al., 2020; Vivanti et al., 2018).

Overall, the literature shows that communication and language difficulties in ASD are closely connected with behaviour, sensory processing, and social interaction in everyday life. Difficulties in expressing needs, understanding social situations, or coping with sensory input can influence emotional regulation, repetitive behaviours, peer relationships, and participation across settings. Therefore, understanding behaviour, sensory issues, and social development is important for developing supportive strategies that improve communication, adjustment, and functional participation at home and school.

2.5 Behaviour, Sensory Issues, and Social Development

2.5.1 Overview of Behavioural, Sensory, and Social Characteristics in ASD

Behavioural, sensory, and social difficulties are very commonly reported in individuals with Autism Spectrum Disorder (ASD). These characteristics often overlap and may influence participation, communication, emotional regulation, classroom engagement, peer interaction, and adaptation across daily environments. Table 2.3 summarises major behavioural, sensory, and social characteristics associated with ASD along with their functional impact and clinical significance.

Table 2.3

Behavioural, Sensory, and Social Characteristics Associated with Autism Spectrum Disorder

Domain	Description / Characteristics	Impact on Functioning	Clinical Significance	Key references
Restricted and repetitive behaviours	Includes repetitive movements, insistence on sameness, restricted interests, and distress with routine changes	May interfere with participation, flexibility, and adaptation to daily activities	Often serves a regulatory or coping function rather than intentional misbehavior	American Psychiatric Association (2022); Chaxiong et al. (2022); Hyman et al. (2020)
Rigidity and transition difficulties	Difficulty managing changes in routines, activities, or environments	May lead to distress, refusal, shutdowns, or repetitive behaviours during transitions	Predictability and structured routines can reduce stress and improve participation	Leekam et al. (2011); Poljac et al. (2017); South & Rodgers (2017)
Sensory hyper responsivity	Exaggerated responses to sensory input such as loud sounds, bright lights, or touch	Can cause sensory overload, anxiety, avoidance, irritability, or withdrawal	Requires sensory accommodations and environmental modifications	Robertson & Baron-Cohen (2017); Cascio et al. (2016); Marco et al. (2011)
Sensory hypo responsivity	Reduced or delayed response to sensory input, including pain, sound, or social cues	May appear as inattention, passivity, or reduced awareness of surroundings	Can affect engagement, learning, and safety awareness	Marco et al. (2011); Ben Sasson et al. (2009); Robertson & Baron-Cohen (2017)
Sensory seeking behaviours	Atypical interest in movement, touch, visual stimulation, or sensory experiences	Can affect classroom participation and activities of daily living	Reflects attempts to regulate sensory system	Cascio et al. (2016); Rogers & Ozonoff (2005)

Domain	Description / Characteristics	Impact on Functioning	Clinical Significance	Key references
Behaviour as communication	Behaviours may be used to express discomfort, avoidance, sensory overload, requests or unmet needs	Misinterpretation can lead to ineffective or punitive responses	Behavioural understanding improves supportive intervention planning	Carr & Durand (1985); Hanley et al. (2003); Cooper et al. (2022)
Social interaction difficulties	Difficulty initiating interaction, processing social cues, maintaining reciprocal communication, and poor peer relationships	Affects peer bonding, classroom participation and inclusion	Social skills improve with structured support and supportive environments	Lord et al. (2020); Calder et al. (2013); Weinger (2014)
Peer Relationship	Atypical play patterns, difficulty in maintaining interaction, and responding to peer expectations	May increase social isolation, frustration, or withdrawal	Peer-mediated and inclusive approaches can improve participation	Kasari et al. (2012); Chang & Locke (2016)
Concerns related to Indian context	Behavioural and sensory differences can be misinterpreted as stubbornness, poor discipline/ disobedience	Can delay in timely referral and support	Highlights the need for awareness, structured support and inclusive environments	Chattopadhyay (2024); Chakrabarti (2023); Srivastava et al. (2023)

Note. Behavioural, sensory and social characteristics in ASD are closely interconnected and primarily influences the participation, communication, learning and daily functioning across different settings.

Behavioural, sensory, and social characteristics in ASD are highly variable across different individuals and contexts. Understanding these patterns becomes very important for early recognition, appropriate support planning and development of structured, sensory sensitive and participation focused intervention approaches and inclusive environment.

2.5.2 Behaviour support at home and school

Behaviour support becomes effective when it is consistent across home and school, because children with ASD rely heavily on predictable routines and clear expectations to regulate behaviour and participation (Hyman et al., 2020; Odom et al., 2021). At home, support may include structured routines, visual schedules, positive reinforcement and teaching alternative and augmentative mode of communication (AAC) so that the child can express needs without escalating distress (Cooper et al., 2022; Odom et al., 2021). At school, the same principles are often implemented through classroom structure, antecedent supports, visual cues and reinforcement systems that reduce uncertainty and increase successful participation and provides an inclusive environment (Steinbrenner et al., 2020; Odom et al., 2021).

An important principle in home and classroom settings is that challenging behaviour should be addressed through functional behavioural understanding rather than punishment alone (Carr & Durand, 1985; Cooper et al., 2022). When adults identify the function or antecedent of a behaviour, they can change the environment, teach replacement skills and reinforce appropriate responses in ways that are more sustainable rather than mere reactive discipline (Hanley et al., 2003; Odom et al., 2021). This approach becomes very useful for transitions, task demands, sensory distress and communication breakdowns, all of which commonly trigger behavioural escalation (Hyman et al., 2020; Lord et al., 2020).

School-based behaviour support also benefits from EBP such as visual supports, peer mediated instruction, antecedent interventions and functional communication training (Steinbrenner et al., 2020; Odom et al., 2021). These strategies help children with ASD to participate in lessons, move between activities and interact effectively with peers and teachers (Chang & Locke, 2016; Steinbrenner et al., 2020). In home settings also, parents can use similar simple techniques to maintain consistency, which improves generalisation of skills across the environments (Oono et al., 2013; Hyman et al., 2020).

In the Indian context, behaviour support at home and school becomes very important because families may receive uneven guidance and schools may have limited ASD specific training or resources (Chakrabarti, 2023; Chattopadhyay, 2024). Practical, low-cost strategies, for e.g., visual schedules, parent and teacher coaching can make support more feasible across diverse settings (Srivastava et al., 2023; Chattopadhyay, 2024). Since behavioural regulation, sensory processing and social participation directly influence how children with ASD manage everyday activities and adapt to structured environments, these difficulties affect independence at home as well as readiness for school participation (Hyman et al., 2020; Chakrabarti, 2023). Therefore, understanding of daily living skills, home routines and school readiness becomes very important because these areas form the foundation for functional independence, better participation and long-term adjustment in children with ASD.

2.6 Daily Living Skills, Home Routines, and School Readiness

Daily living skills, home routines, and school readiness are very closely connected in ASD because independence in these everyday activities supports the participation, regulation, and learning across different settings (Hyman et al., 2020; Odom et al., 2021). Daily living skills include self-care tasks such as dressing, eating, toileting, hygiene and following simple daily routines, all of which affect a child's ability to function at home

and in school if altered (Klin et al., 2007; Kenworthy et al., 2010). School readiness in ASD is not only about academic skills, it also depends on communication skills, behavioural regulation, flexibility and the ability to follow classroom instructions and routines (Hyman et al., 2020; Odom et al., 2021).

Children with ASD commonly show uneven development in adaptive functioning which means that practical life skills may be poor than child's cognitive or language abilities (Klin et al., 2007; Kenworthy et al., 2010). This gap can become ecident in daily routines, where the child might need extra support for transitions, task sequencing and responding to simple verbal instructions (Hyman et al., 2020; Lord et al., 2020). Home routines become very important because repeated practice in natural settings helps children learn functional skills through consistency, modelling adequate support (Odom et al., 2021; Oono et al., 2013).

School readiness in ASD becomes strong when children have already developed basic self-help, communication and behavioural routines before entry into formal schooling (Hyman et al., 2020; Odom et al., 2021). Teachers usually expect children to manage waiting, sitting, packing materials, following group instructions and coping with transitions. Children with ASD who lack these daily living foundations may struggle even when they have academic potential (Lord et al., 2020; Steinbrenner et al., 2020). For this reason, school readiness should be understood broadly as participation readiness, not only pre academic knowledge (Hyman et al., 2020; Odom et al., 2021).

In the Indian context, the development of daily living skills and home routines becomes very important because families might need to prepare children for school with limited access to required support and varied classroom resources (Chakrabarti, 2023; Chattopadhyay, 2024). Parent guided routines and practical home based teaching can help

bridge the gap between developmental needs, school expectations and unavailability of professional services (Srivastava et al., 2023; Hyman et al., 2020). Strengthening these skills early therefore improves both independence and inclusion and ultimately improves quality of life in the long run (Oono et al., 2013; Odom et al., 2021).

2.6.1 Toilet training and feeding difficulties

Toilet training and feeding difficulties are very common in children with ASD and primarily reflects differences in communication, sensory processing and behavioural regulation rather than stubbornness, simple refusal or poor parenting (Hyman et al., 2020; Cocchiola et al., 2012). Toilet training may take longer in children with ASD than typical peers because readiness, routine changes, sensory discomfort and communication about bodily needs are affected and not same (Cicero & Pfadt, 2002; Kroeger &Sorensen-Burnworth, 2009). Feeding difficulties are also very common, with many children with ASD showing food selectivity, strong preference for sameness, texture sensitivity or refusal of unfamiliar foods secondary due to sensory issues (Cermak et al., 2010; Sharp et al., 2013).

In daily life, toilet training challenges may include reluctance to sit on the toilet, fear of flushing sounds, accidents, constipation or difficulty in recognising and communicating the need to use the toilet (Cicero & Pfadt, 2002; Cocchiola et al., 2012). Feeding problems might include rigid food preferences, distress around new foods and limited diets that can also affect nutrition and family routines (Cermak et al., 2010; Sharp et al., 2013). These difficulties are important because they influence comfort, independence, school participation and caregiver stress and ultimately quality of life of the individual with ASD (Hyman et al., 2020; Sharp et al., 2013).

Research studies reported that behavioural and environmental supports are usually more effective than punishment based responses. Use of stepwise toilet training methods, visual schedules, consistent routines and reinforcement can help children learn toileting skills. Whereas structured exposure, predictable mealtime routines and gradual food introduction can improve feeding skills and participation (Cicero & Pfadt, 2002; Sharp et al., 2013). The most effective approach is typically individualised and function-based, with due attention to both sensory and communication needs (Hyman et al., 2020; Cocchiola et al., 2012).

In the Indian context, these issues can be very challenging because families may have a limited access to specialised toilet-training or feeding support/intervention and problems may be delayed until school entry or later (Chattopadhyay, 2024; Srivastava et al., 2023). Parent education matters because home routines strongly support skill development, and early support can reduce stress for both the child and family (Chakrabarti, 2023; Hyman et al., 2020). For school readiness, improving toileting and feeding independence is therefore a practical developmental goal, not only a basic care issue (Odom et al., 2021; Hyman et al., 2020).

2.6.2 Dressing and self-care skills

Dressing and other self-care skills are important daily living abilities in autism because they support independence, participation in school, and readiness for community life (Hyman et al., 2020; Odom et al., 2021). Autistic children may need extra support for dressing because the task requires motor planning, sequencing, attention, tolerance of clothing textures, and the ability to follow multi-step routines (Klin et al., 2007; Neitzel & Wolery, 2009). When these skills are weak, a child may appear less independent than their cognitive abilities would suggest, which can affect family routines and school preparation (Klin et al., 2007; Kenworthy et al., 2010).

Dressing difficulties may involve problems with putting on and removing clothing, fastening buttons or zips, selecting appropriate clothing for the context, or tolerating certain fabrics and seams (Neitzel & Wolery, 2009; Sensory Processing in Autism, 2011). These difficulties reflect a mix of sensory sensitivity, fine-motor coordination and executive functioning challenges than a mere lack of willingness to cooperate or stubbornness (Marco et al., 2011; Robertson & Baron-Cohen, 2017). Since dressing occurs repeatedly every day, even small difficulties can have a large effect on the child's independence and required caregiver support (Hyman et al., 2020; Odom et al., 2021).

Self-care teaching becomes effective when tasks are broken into small steps and taught systematically by using prompting, reinforcement and repeated practice in real routines (Neitzel & Wolery, 2009; Odom et al., 2021). Visual schedules, modelling, task analysis, and gradual fading of assistance can help children learn dressing skills more successfully than general instruction alone (Steinbrenner et al., 2020; Neitzel & Wolery, 2009). When the child's sensory needs are also considered, such as by using comfortable clothing or reducing environmental stress, learning is often smoother and distress is reduced (Marco et al., 2011; Robertson & Baron-Cohen, 2017).

In the Indian context, dressing and self-care skills are important because school readiness and independence are often expected early, but access to therapy support and parent coaching may vary widely (Chattopadhyay, 2024; Srivastava et al., 2023). Parent-guided routines at home can strengthen these skills and reduce dependence on adults during school mornings and transitions (Hyman et al., 2020; Odom et al., 2021). For this reason, dressing should be treated as a functional skill that supports overall developmental participation rather than as a minor daily task (Klin et al., 2007; Hyman et al., 2020).

2.6.3 Use of visual schedules and routines

Visual schedules and routines are widely used in autism because they make daily events more predictable, support transitions, and reduce confusion about what comes next (visual schedules can be considered an evidence-based practice for ASD, especially when paired with systematic instruction) (Knight et al., 2015; Wong et al., 2015). They are especially helpful in home and school settings because many autistic children respond better to concrete, visual information than to verbal instructions alone (Knight et al., 2015; Spriggs et al., 2017). When used consistently, visual supports improve independence, compliance and routine completion (Knight et al., 2015; Wong et al., 2015).

Routines matter most because they give structure to repeated activities such as waking up, dressing, eating, packing a bag and daily tasks (Spriggs et al., 2017; Hyman et al., 2020). Visual schedules often work by reducing demands, uncertainty and ultimately helping the child sequence steps in a predictable order, which can lower anxiety during transitions (Knight et al., 2015; Spriggs et al., 2017). For many children, the visual schedule itself becomes a support for self-regulation as well as task completion (Wong et al., 2015; Hyman et al., 2020).

In school, visual schedules can help children follow classroom routines, instructions and understand the order of activities and move between tasks with less prompting (Spriggs et al., 2017; Wong et al., 2015). In the home, they can support morning and bedtime routines, homework time and ease preparation for school, provided caregivers use the same visual format every day (Knight et al., 2015; Odom et al., 2021). The benefit is strongest when visual schedules are accompanied with positive reinforcement, prompting and clear expectations rather than used as a standalone tool (Knight et al., 2015; Wong et al., 2015).

In the Indian context, visual schedules are useful because they are practical, low-cost, and adaptable across home and school settings even where specialist services are limited (Chattopadhyay, 2024; Srivastava et al., 2023). They can also help parents and teachers work in a more consistent way, which is important for school readiness and daily functioning (Chakrabarti, 2023; Hyman et al., 2020). For this reason, routines and visual schedules should be viewed as part of everyday autism support rather than as an optional classroom extra (Odom et al., 2021; Wong et al., 2015).

2.6.4 Developing attention and sitting tolerance

Developing attention and sitting tolerance is important in autism because many learning tasks require a child to remain engaged long enough to respond, follow instructions, and complete activities (Rogers & Pennington, 1991; Tager-Flusberg, 2007). Children with ASD may find sustained sitting difficult because of differences in attention spam, poor regulation, sensory processing issue, and limited joint engagement, which can make classroom participation harder (Marco et al., 2011). These challenges are often most visible during structured demanding activities such as circle time, desk work or therapy sessions (Wong et al., 2015; National Research Council, 2001).

Attention span can be improved through structured, predictable teaching, shorter activities and gradual increas in time spent seated and engaged (National Research Council, 2001; Wong et al., 2015). Tools such as visual cues, timers, clear beginning and end markers and positive reinforcement can help children with ASD understand expectations and tolerate transitions successfully (Hume et al., 2021; Wong et al., 2015). In practice the goal is not simply to make a child sit still for long period of time, but it is to support meaningful participation and improved regulation during learning activities (Hume et al., 2021; Rogers & Pennington, 1991).

Sitting tolerance is usually built best when the task is motivating as well as developmentally appropriate and includes movement breaks, sensory supports when needed (Marco et al., 2011; Hume et al., 2021). For some children with ASD, multiples short bursts of seated work combined with positive reinforcement are more effective than expecting long periods of passive sitting (National Research Council, 2001; Wong et al., 2015). This approach can improve attention span without increasing distress or behavioural escalation (Hume et al., 2021).

In the Indian context attention-building strategies becomes very useful because many children receive support in inclusive classrooms where individualised attention is usually be limited (Chattopadhyay, 2024; Srivastava et al., 2023). Low-cost supporting tools such as visual schedules, routine-based teaching by parents or caregiver can make a practical difference at home and school (Chakrabarti, 2023; Hume et al., 2021). For this reason, attention and sitting tolerance need to be understood as teachable functional skills rather than acquired developmental traits of the children (Wong et al., 2015; Hume et al., 2021).

2.6.5 Preparing the child for school participation

Preparing a child with autism for school participation means to build the practical skills that are required to take part in classroom routines, transitions, group activities and peer group interactions (Hyman et al., 2020; Odom et al., 2021). School participation becomes easy with predictability i.e., when children understand what will happen, what is expected and how to move between activities with less uncertainty (National Research Council, 2001; Wong et al., 2015). Visual supports, predictable routines and explicit teaching become helpful to bring predictability, reducing anxiety and make school demands more understandable (Knight et al., 2015; Spriggs et al., 2017). A child may need support different types of support for example, entering the classroom, following

instructions, sitting for short periods, asking for help and coping with changes such as assemblies, trips, or substitute teachers (Hyman et al., 2020; National Research Council, 2001).Planning for transitions also matters a lot because children with ASD often find shifting between home, school and different setting very difficult, especially when routines changes suddenly (Odom et al., 2021; Wong et al., 2015). When families, therapist as well as teachers share the same strategies, children usually adapt more quickly and with less distress (Hyman et al., 2020; Spriggs et al., 2017).

School preparation is strongest when provided supports are practical and individualized for need and strengths of the children. It may include supports such as visual schedules, social stories, task breakdowns and rehearsal of daily routines even before the child is expected to do them independently (Knight et al., 2015; Odom et al., 2021). Peer mediated support strategies like peer buddy and structured opportunities for participation can improve inclusion and reduce isolation in school settings (Wong et al., 2015; Odom et al., 2021). The aim is not just attendance in classroom, it included meaningful participation in learning and social life (National Research Council, 2001; Hyman et al., 2020). In India, preparing children for school participation becomes very important because access to professional support may vary, so following same strategies at home and school becomes a major source of support (Chakrabarti, 2023; Chattopadhyay, 2024). Low cost and easily available tools such as visual timetables and routine based teaching can be used in both mainstream and special education settings (Srivastava et al., 2023; Wong et al., 2015). For this reason, school preparation should be primarily framed as a developmental and educational support. Not only need based and behavioural issue (Hyman et al., 2020; Odom et al., 2021).

2.6.6 Promoting independence in daily activities

Promoting independence in daily activities includes teaching children with ASD to do everyday tasks with less caregiver support over time. Including self-care, dressing, eating, hygiene and following basic home routines more independently (Hyman et al., 2020; Odom et al., 2021). Daily living skills are very important because they support participation at home, school and later adult life, and difficulties in these skills can limit long-term independence and alter quality of life (Kanne et al., 2011; National Autism Center, 2015). The most effective support usually starts early and is practised regularly in natural routines, not only in therapy sessions (Odom et al., 2021; Wong et al., 2015).

These skills are often taught best through task analysis, prompting, visual supports, modelling, and repeated practice with reinforcement (Wong et al., 2015; Hume et al., 2021). Breaking a task into small steps helps children succeed with activities that may otherwise feel overwhelming, such as washing hands, packing a school bag, or preparing simple food (Odom et al., 2021; National Autism Center, 2015). Gradual fading of support is important so the child does not become dependent on adult prompting (Wong et al., 2015; Hume et al., 2021).

Independence should be seen as a developmental process rather than an all-or-nothing outcome, because many autistic children can do some parts of a task independently and need help with others (Kanne et al., 2011; National Autism Center, 2015). Families and teachers can encourage progress by using the same routine, the same words, and the same visual cues across settings (Hyman et al., 2020; Odom et al., 2021). When support is consistent, children are more likely to generalise a skill from one setting to another, such as from home to school (Wong et al., 2015; Hume et al., 2021).

In India, promoting daily independence is especially relevant because family routines and school expectations often place pressure on children to manage self-care early (Chakrabarti, 2023; Srivastava et al., 2023). Practical and low-cost tools such as checklists, picture cues and structured home routines can make a meaningful difference even where professional services are limited (Chattopadhyay, 2024; Hyman et al., 2020). Therefore, it is important that daily activity training should be treated as a core part of autism support rather than an optional one (Odom et al., 2021; Wong et al., 2015).

Overall, the literature shows that supporting children with ASD requires attention not only to daily functioning and school participation but it also include the coordinated management of communication, behaviour, sensory needs and developmental challenges across different settings. Because autism affects multiple areas of functioning, effective intervention usually depends on collaboration among different professionals who contribute specialised knowledge and support. Therefore, understanding the role of professionals in ASD management is important for ensuring comprehensive assessment, intervention planning, family guidance, and long-term developmental support.

2.7 Role of Professionals in ASD Management

2.7.1 Overview of Role of Professionals in ASD Management

Management of ASD is usually multidisciplinary, because the child's needs can involve communication, behaviour, learning, sensory regulation, daily living, and medical concerns at the same time (Hyman et al., 2020; National Institute for Health and Care Excellence [NICE], 2012). A coordinated team approach improves the chance that assessment findings are turned into practical support rather than isolated reports (NICE, 2012; National Autistic Society, 2026). In practice, each professional contributes a different part of the child's profile and intervention plan (Hyman et al., 2020; National

Autistic Society, 2026). Table 2.4 presents the roles of multidisciplinary professionals involved in the management of ASD along with their major responsibilities and clinical significance.

Table 2.4

Roles of Multidisciplinary Professionals in the Management of Autism Spectrum Disorder

Professional	Key Role	Responsibilities	Importance	Key references
Pediatrician / Child psychiatrist	Diagnosis, medical evaluation, treatment planning	Identifies ASD and co-occurring conditions such as ADHD, anxiety, sleep problems, epilepsy, and gastrointestinal concerns	Supports early diagnosis, medical management, and referral to intervention services	Hyman et al. (2020); NICE (2012)
Speech-language pathologist (SLP)	Communication and social communication support	Assesses speech, language, pragmatics, AAC needs, feeding, and swallowing; provides communication intervention and parent guidance	Supports communication, participation, classroom interaction, and functional daily communication	ASHA (2006); Lindblad (2011); Sandbank et al. (2020); Wong et al. (2015)
Occupational therapist (OT)	Sensory processing, motor skills, daily living skills	Works on sensory regulation, self-care, fine motor skills, play, transitions, handwriting, and environmental adaptations	Improves participation, independence, emotional regulation, and daily functioning	Case-Smith & Arbesman (2008); Tomchek & Koenig (2016); Crasta et al. (2024)
Clinical psychologist	Cognitive, behavioural, and emotional assessment	Assesses cognition, adaptive functioning, emotional regulation, and behaviour; guides behavioural intervention and parent support	Helps identify strengths and challenges and supports behavioural planning	Gulati et al. (2014); Volkmar et al. (2012); Hyman et al. (2020)

Professional	Key Role	Responsibilities	Importance	Key references
Psychiatrist	Mental health and medical management	Evaluates co-occurring psychiatric and behavioural conditions; may prescribe medication when needed	Important for management of anxiety, aggression, mood difficulties, ADHD, and sleep concerns	NICE (2012); Gulati et al. (2014); Lever & Geurts (2016)
Special educator	Educational support and classroom adaptation	Uses structured teaching, visual schedules, prompting, reinforcement, and individualized education plans	Supports academic participation, behaviour management, and skill generalization in school settings	NCERT (2019); Odom et al. (2021); McLeskey et al. (2021)
Teachers and school staff	Inclusive classroom participation	Supports classroom routines, peer interaction, and implementation of accommodations	Promotes inclusion, consistency, and participation in school activities	Odom et al. (2021); Knight et al. (2015)
Social worker / counsellor	Family and community support	Assists with services, entitlements, counselling, stress management, and access to resources	Helps families navigate support systems and community services	NICE (2012); IAP Guidelines on Neuro Developmental Disorders et al. (2017)
Parents and caregivers	Home-based support and carryover	Implements routines, communication strategies, behaviour support, and therapy recommendations at home	Consistency across home and school improves outcomes and generalization	Lindblad (2011); Sandbank et al. (2020); Hyman et al. (2020)

Note. Management of ASD is multidisciplinary because communication, behaviour, learning, sensory regulation, adaptive functioning, and medical needs often overlap and require coordinated support across home, school, and clinical settings.

Multidisciplinary management helps address the diverse and interconnected needs associated with ASD across home, school, and clinical settings. Coordinated support between professionals, teachers, and caregivers can improve participation, communication, learning, and overall functional outcomes. Overall, the literature shows that effective ASD management depends not only on professional intervention but also on access to appropriate educational, health, and social support systems. Families often require guidance regarding disability rights, certification procedures, inclusive education, and available government services in order to access timely support for their child. Therefore, understanding the legal rights, certification process, and support services available in India is important for improving service access, educational inclusion, and long-term support for individuals with ASD and their families.

2.8 Legal Rights, Certification, and Support Services in India

India's ASD support framework is shifting from a medical model to a social model, now it combines legal rights, disability certification, welfare schemes, guardianship provisions and service supports that are especially important for families navigating long-term care needs (The Rights of Persons with Disabilities Act, [RPwD] 2016; The National Trust, 1999). The RPwD Act, 2016 is the main legal framework for recognising disability rights in India, while the National Trust Act, 1999 establishes a statutory body to support persons with autism, cerebral palsy, intellectual disability and multiple disabilities. Together, these measures link autism to a rights-based system rather than treating it only as a medical condition.

Disability certification is the gateway to most public benefits and schemes, so it is a key step for families those who seek support (Department of Empowerment of Persons with Disabilities [DEPwD], n.d.; The RPwD Act, 2016). The government's certification framework is used to determine eligibility for all the available welfare benefits,

concessions, access to available schemes, reservations benefits. Dyability certification with benchmark disability is required to avail all of these services (The RPwD Act, 2016). Therefore, it makes certification central to access rather than only limited to the administrative paperwork.

The National Trust is the main welfare institution for ASD support in India (The National Trust, 1999). Its official description states that it discharges legal duties through the local level committees and welfare duties through various schemes, including early intervention and school readiness, day care, residential care and health insurance (The National Trust, 1999). The Trust also identifies its role in legal guardianship, which is especially important for families concerned about future care of their children when parents are no longer able to provide the require support.

Under The National Trust Act (1999), the most popular National Trust schemes are Samarth, Gharaunda, Niramaya, Gyan Prabha, and Uddyam Prabha. Samarth scheme provides residential and respite-based services, Gharaunda scheme supports lifelong shelter and care, whereas Niramaya offers health insurance, Gyan Prabha supports the education and vocational preparation, and Uddyam Prabha provides incentives for the self-employment. These schemes show that ASD related support in India is intended to extend beyond diagnosis and therapy to include education, livelihood, and long-term living arrangements.

Other support systems also contribute to the ASD support system. The Rehabilitation Council of India (RCI) regulates training and standards in rehabilitation and special education, helping shape the professional workforce that serves individuals with ASD and their families. Its Punarbhava portal provides public information on disability definitions, certification procedures, benefits, schemes and training institutions,

which can help families navigate the support system more effectively (Rehabilitation Council of India, n.d.). It also maintains a Central Rehabilitation Register (CRR) for rehab and mental health professionals, in order to promote patients by ensuring that all the professionals meet standardized education and ethical guidelines. Other types of services are also provided by the government including benefits such as railway concessions and selected hospitality discounts, provided the individual shows the proof of disability certification (India Tourism Development Corporation, n.d.).

Non-Government Organisations (NGO) also plays and important role in awareness, advocacy and service navigation. National groups such as Action for Autism and Autism Society of India, along with local organisations, often help families understand scheme eligibility, connect with professionals, and find support groups (Action for Autism, n.d.). This is important because legal rights and welfare schemes are most useful when families know how to access them and have help completing the required processes (The RPwD Act, 2016; The National Trust, 1999).

2.8.1 Rights of Persons with Disabilities Act, 2016

The Rights of Persons with Disabilities Act, 2016 is the principal law governing disability rights in India and is the legal foundation for many autism-related entitlements and protections (RPwD Act, 2016). The Act defines “person with disability” broadly and includes autism among the specified disabilities, which places autism within a rights-based legal framework rather than a purely medical one (RPwD Act, 2016). It also sets out general rights and entitlements relating to equality, non-discrimination, accessibility, and participation in society (RPwD Act, 2016).

A major significance of the Act is that it supports access to certification, benefits, and protection mechanisms through the formal disability system (RPwD Act, 2016;

Department of Empowerment of Persons with Disabilities, n.d.). Certification is important because many government schemes and concessions depend on official recognition of disability status, and the Act provides the legal basis for that recognition (RPwD Act, 2016). For individuals with ASD, it means that the law is not only limited to the diagnosis but it is also about enabling practical access to support services and welfare schemes (RPwD Act, 2016).

The RPwD Act also becomes important because it creates a stronger framework for inclusion in education, employment, and community life. By recognising disability rights, it supports a shift away from charity based or purely welfare based thinking toward a rights based model that emphasises dignity, equal opportunity, and accessibility (RPwD Act, 2016). For families of children with ASD individuals, it further strengthens the basis for requesting accommodations, support, and protection in public systems .

In addition, the RPwD Act works together with institutions dedicated to disabilities and scheme owners, including the National Trust and the Rehabilitation Council of India, to create a broader support system for persons with ASD (The Rehabilitation Council of India Act, 1992). The legal value of this Act shapes how certification, access, and service delivery are organised in practice. This makes it a central reference point in any discussion for disabilities including ASD in India (RPwD Act, 2016).

2.8.2 Disability certification and UDID Card

Disability certification is the standardised evaluation process by which a person's disability status is medically assessed and recorded for legal and service access purposes in India (RPwD Act, 2016; Department of Empowerment of Persons with Disabilities, n.d.). For ASD, this certification is important as it is used to determine eligibility for

government benefits, concessions and welfare schemes, including those linked to the National Trust (The National Trust, 1999; RPwD Act, 2016). In practical terms, certification is the key that connects diagnosis with the entitlements (RPwD Act, 2016).

The UDID i.e., Unique Disability ID, was created to standardise disability documentation and make access to benefits easier across the country. The official UDID portal provides the online application and management system for disability certificate registration and related processes, and it allows individual to apply through a government digital platform rather than relying only on paper based procedures. It becomes important for families because it simplifies record keeping and help to link the disability certificate to future applications for services and schemes (Swavlamban Card/UDID Portal, n.d.).

For ASD related benefits, the UDID number or valid benchmark disability certificate is often required by scheme providers. The National Trust's Niramaya health insurance page states that persons covered under the National Trust Act with a valid benchmark disability certificate and UDID card or UDID enrolment number are eligible for the scheme. This shows that certification is not just an identification document but also a practical eligibility document for the welfare access.

The National Trust also uses the same UDID framework in its own service delivery systems, including online registration and scheme enrolment processes. Families seeking support require to complete disability certification first, then use that documentation to access services such as health insurance, care support, and other entitlements (The National Trust, 1999). Because of this, awareness about how to apply for a disability certificate and UDID card becomes very important for parents and caregivers of children with ASD (Department of Empowerment of Persons with Disabilities, n.d.)

Overall, disability certification and UDID form the administrative backbone of autism-related support services in India (RPwD Act, 2016; Swavlamban Card/UDID Portal, n.d.). They help ensure that legal recognition is translated into practical access to welfare schemes, insurance, and other entitlements (The National Trust,1999).

2.8.3 Available schemes and support systems

Table 2.5 presents major national schemes and support systems available in India for individuals with autism spectrum disorder and their families, with a focus on early intervention, education, health, and long-term care supports (The National Trust, 1999; RPwD Act, 2016; Rehabilitation Council of India, 1992).

Table 2.5

Major National Trust Schemes and Support Services Relevant to Autism Spectrum Disorder in India

Scheme / Support service	Implementing / Governing body	Purpose	Key Features	Relevance for individuals with ASD and families
DISHA	The National Trust	Early intervention and school readiness	Provides early intervention, therapy support, and developmental readiness activities for young children	Supports early developmental needs and school readiness
VIKAAS	The National Trust	Day care services	Provides day care, structured activities, and skill development support	Helps improve daily functioning, participation, and caregiver support
SAMARTH	The National Trust	Respite and residential care	Provides short-term and long-term residential care, including group home support	Supports families requiring respite care and continuing support
GHARAUNDA	The National Trust	Lifelong shelter and care	Provides long-term residential and supported living arrangements	Important for long-term care planning and future support needs
Niramaya	The National Trust	Health insurance support	Provides health insurance coverage for eligible beneficiaries with disability certification and UDID registration	Helps reduce financial burden related to therapy, hospitalization, and medical care

Scheme / Support service	Implementing / Governing body	Purpose	Key Features	Relevance for individuals with ASD and families
Gyan Prabha	The National Trust	Educational and vocational support	Encourages vocational, professional, and post-school training opportunities	Promotes educational advancement and skill development
Uddyam Prabha	The National Trust	Self-employment and livelihood support	Provides incentives and support for self-employment and income-generating activities	Supports independence and economic participation
Local Level Committees (LLCs)	The National Trust	Legal guardianship support	Handles guardianship-related legal responsibilities under the National Trust framework	Assists families with legal care planning and decision-making support
Punarbhava Portal	Rehabilitation Council of India (RCI)	Information and resource support	Provides information related to disability services, institutions, and rehabilitation resources	Helps families access services, institutions, and support systems
Rehabilitation Council of India (RCI)	Government of India	Regulation and professional training	Regulates rehabilitation training programmes and approved institutions	Supports access to qualified rehabilitation professionals and services

Note. The National Trust is the central statutory body responsible for welfare and legal support services for persons with autism, cerebral palsy, intellectual disability, and multiple disabilities in India. Relevant sources include The National Trust (1999), RPwD Act (2016), and Rehabilitation Council of India (1992).

As represented in Table 2.5, These schemes indicate that a structured network of statutory supports that already exists for early intervention, education, health coverage, livelihood, and long-term care for persons with autism in India (The National Trust, 1999; RPwD Act, 2016; Rehabilitation Council of India, 1992). However, their actual impact on children with ASD depends on families, professionals, and local systems being aware of these provisions and their ability in navigating the eligibility, registration, and implementation processes (The National Trust, 1999; RPwD Act, 2016; Rehabilitation Council of India, 1992

2.8.4 School-related rights and inclusive education

The Rights of Persons with Disabilities Act, 2016 gives children with disabilities the legal right to inclusive education and requires educational institutions funded or recognised by government to admit children without discrimination, provide reasonable accommodation, and make the campus accessible (RPwD Act, 2016). The Act also states that children with benchmark disability between the ages of 6 and 18 have the right to free education in a neighbourhood school or a special school of their choice (RPwD Act, 2016). For children with ASD, it means schooling is now seen as a right, supported by legal duties on schools and governments, not as a discretionary or charity service (RPwD Act, 2016).

The law also requires supportive educational measures that are directly relevant to children with ASD. It guides governments to provide necessary support in environments that maximise academic and social development and it also calls for teacher training, resource centres and standardised professional support for inclusive education. These provisions become important as many children with ASD need structured support, communication accommodations and behavioural understanding in school settings. The

policy emphasis is therefore not only limited to placement in a classroom but also on the quality of support provided after the admission (RPwD Act, 2016).

The National Trust also extends its welfare role to school readiness and inclusive participation. Its official home page states that the NTA's activities include schemes for early intervention and school readiness, day care, residential care and health insurance. It also highlights that legal duties are provided by the Local Level Committees while welfare duties are carried out through schemes. It becomes relevant because school inclusion often begins with early intervention and family support, especially when children have to shift from home based services to school settings. Overall, the school-related rights framework is connected to broader developmental and welfare support systems rather than isolated one (The National Trust, 1999).

Inclusive education in India also has a rights based policy meaning beyond mere integration. The website page on the RPwD Act states that the Act strengthens inclusive education, employment and community living by mandating accessibility, non-discrimination and full participation for persons with disabilities, including children with ASD. This also implies that schools should not only allow attendance to children with ASD but also provide reasonable accommodations, adapted communication and inclusive learning conditions. The combination of legal protection and service support is what makes the school rights framework meaningful in practice (RPwD Act, 2016; The National Trust, 1999).

Taken together, the literature shows that school-related rights for autism in India are built on three linked ideas, first access, second accommodation and third support. Where access ensures admission and free education within the legal age range, accommodation ensures that teaching and school environments can meet different needs

and support connects families to early intervention and welfare schemes that help children remain in school (RPwD Act, 2016; The National Trust, 1999). This makes inclusive education an essential part of autism support services in India rather than only an optional addon.

2.8.5 Awareness of services among parents

Awareness of disability related services among parents of children with ASD is often limited, and it directly affects whether these families can actually use available supports. A parent focused handbook on disability services notes that lack of information is one of the main reasons many parents do not access the available benefits, and it reports that only a small proportion of children with ASD were benefiting from government programmes at the time when it was written (Planning Commission, Government of India, 2002). This becomes important because service systems only work when families know how to enter them, including how to obtain disability certification and where to apply for scheme benefits.

Recent service oriented resources have shown that increased awareness improves the number of individuals availing disability related services. A parent support platform explains that families often need simple, clear and practical information about therapies, schooling and future planning and the access to evidence-based information in this form helps them identify appropriate services earlier (Nayi Disha Resource Centre, 2023). It also states that parents who participated in rights focused sessions gained information about government support such as the UDID card and the Niramaya health insurance scheme (Nayi Disha Resource Centre, 2023). This suggests that awareness is not just about general knowledge, but about knowing which schemes exist and how to make best use of them (Nayi Disha Resource Centre, 2023).

This same pattern also appears in community based parent sensitisation programme specifically designed to help parents understand home management and available opportunities for children with intellectual disabilities. reported that parents after gaining information on disability classification, daily living support, behaviour management and livelihood opportunities, showed better decision making (Mobility India, 2023). For an ASD related view, it highlights that structured awareness efforts can improve both confidence and service access.

Overall, the literature suggests that parental awareness is a key factor in the effective use of ASD related services, rights and support systems. Without clear information, families may not know which benefits exist, how to access them or how to navigate certification and intervention pathways, which ultimately reduces the practical impact of available policies and programmes (Planning Commission, Government of India, 2002; Nayi Disha Resource Centre, 2023). Since parents are usually responsible for recognising developmental concerns, seeking services and supporting intervention at home, their knowledge and attitudes play very important role in the child's developmental outcomes. Therefore, parental awareness, knowledge and education in ASD is important because informed parents are in a better position to seek timely intervention, access support services and participate actively in their child's care and development.

2.9 Parental Awareness, Knowledge and Education ASD

Parental awareness, knowledge, and attitudes are central to autism identification because parents are usually the first to notice developmental differences and the first one to seek help (Ozonoff et al., 2009; Zwaigenbaum et al., 2015). In the Indian context, this issue is especially important because delayed recognition remains very common and early concerns are not always translated into timely referral (Chattopadhyay, 2024; Chakrabarti, 2023). A parent who understands early red flags is more likely to undergo assessment, ask

for screening and strictly follow the referral pathway even when services are difficult to access (Hyman et al., 2020; Chattopadhyay, 2024). Knowledge about autism is not only theoretical since it shapes how parents interpret early behaviours such as delayed speech, limited eye contact, reduced pointing or poor response to name (Ozonoff et al., 2010; Zwaigenbaum et al., 2015). When parents have better awareness, they are more likely to identify concerns early and describe them clearly to professionals, which can accelerate early identification, diagnosis and intervention (Ozonoff et al., 2009; Leach et al., 2025). In contrast, limited or incorrect knowledge about ASD can lead families to attribute ASD to temperament, developmental delay or temporary variation, which can ultimately delay help-seeking (Chattopadhyay, 2024; Srivastava et al., 2023).

Parental attitudes also become important because they influence acceptance of the diagnosis, willingness to seek support and engagement with intervention (Ozonoff et al., 2009; Hyman et al., 2020). Positive attitudes of parents toward screening and early intervention make it more likely that families will respond to professional advice and will continue to follow-up, in contrast the stigma, fear, or denial can delay identification and care (Chakrabarti, 2023; Srivastava et al., 2023). In India, where social judgment are most of the time strong, parental attitude is not a minor issue but a key factor in whether children are connected to services on time or not (Chattopadhyay, 2024; Chakrabarti, 2023). The literature also suggests that parental knowledge is linked to social and educational background, previous exposure to ASD and access to reliable information. This means awareness campaigns should not assume a uniform level of understanding across families, instead campaigns should be culturally sensitive, simple and aligned with the local languages and service realities (Chattopadhyay, 2024; Hyman et al., 2020). Increasing parental awareness about ASD is therefore a practical strategy for improving

early identification, reducing delay and promoting more informed decision-making in Indian families (Chakrabarti, 2023; Zwaigenbaum et al., 2015).

Within this context, parent education programmes become an important part of autism support because they help families understand ASD, respond to behaviour effectively, and use every day routines as learning opportunities (Oono et al., 2013; Schreibman et al., 2015). These programmes can include psychoeducation, coaching, caregiver skills training or structured parent-mediated intervention, depending on the child's age and needs and the ease to access professional services (Burrell & Borrego, 2012; Hyman et al., 2020). When parents are well informed and supported, they are more likely to carry strategies into daily routine and maintain intervention gains over time (Oono et al., 2013; Musetti et al., 2021). Public education materials also play a major role because they increase awareness, reduce stigma and help schools and communities respond more appropriately to children with ASD (Autism Society, 2024; Centers for Disease Control and Prevention [CDC], 2025). Materials such as toolkits, guides, brochures, pamphlets and web-based resources can help teachers, relatives and the general public to understand ASD in laymen language and ultimately promotes inclusion in the society, provided the materials are clear, family-friendly, and adapted to local service systems (NHS England, n.d.; Autism Society, 2024).

In India, public education materials are particularly helpful because many families first learn about ASD from non-specialist sources and good-quality information in simple terms can improve early recognition and referral (Gulati et al., 2014; Chakrabarti, 2023). Parent education and public awareness should therefore be seen as complementary one that can support the family directly and creates a more inclusive environment around the child (Gulati et al., 2014; Oono et al., 2013). Together, they strengthen both intervention outcomes and social acceptance (Schreibman et al., 2015; Autism Society, 2024).

2.9.1 Parental understanding of child development

Parental understanding of child development is fundamental to early autism identification because parents are usually the first to compare their child's milestones with expected progress, and studies consistently link better developmental knowledge with earlier recognition of social, communication, and play-related concerns (Ozonoff et al., 2009; Ozonoff et al., 2010; Zwaigenbaum et al., 2015; Hyman et al., 2020). When parents know what typical trajectories for language, gesture use, joint attention, and social engagement look like in the first two years of life, they are more likely to notice signs such as reduced response to name, fewer gestures, limited joint attention, delayed babbling, or less social interest and to seek advice earlier, whereas limited knowledge can make early differences appear normal or temporary and contribute to delayed referral (Ozonoff et al., 2009; Ozonoff et al., 2010; Zwaigenbaum et al., 2015; Hyman et al., 2020; Chattopadhyay, 2024; Srivastava et al., 2023).

In India, uneven awareness, limited access to screening and frequent diagnostic delay mean that developmental understanding plays an very important role, as families may interpret delayed speech or atypical behaviour as "late development" rather than as a reason for assessment, especially when they are not given clear guidance about milestones and warning signs (Chakrabarti, 2023; Chattopadhyay, 2024; Srivastava et al., 2023; Hyman et al., 2020). Better parental understanding help in bridging the gap between first concern and professional evaluation particularly where specialist services are scarce. It also shapes how families respond after the concern is raised. With the informed parents who are more likely to accept screening, follow referral pathways and engage in early intervention, developmental education should be considered as an integral component of early ASD care rather than an only an optional addon (Ozonoff et al., 2009; Zwaigenbaum et al., 2015; Hyman et al., 2020; Chattopadhyay, 2024; Chakrabarti, 2023).

2.9.2 Common myths and misconceptions about autism

Common myths about ASD can delay identification, reinforce stigma and affect parental decision making, so irradiating them is essential for early detection and support (John et al., 2018; Bölte et al., 2019). One persistent misconception in the society is that autism is caused by vaccines, but high-quality epidemiological evidence does not support any causal link between vaccination and autism (Hviid et al., 2019). Another misconception is that autism results from poor parenting, this claim has been rejected by decades of research and remains harmful because it blames families rather than supporting them (Bölte et al., 2018; Chakrabarti, 2023).

It is also a myth that all person with ASD have intellectual disability or, conversely, that all autistic people are "savant-like" and gifted in an exceptional way (Bölte et al., 2019; "Autistic Spectrum Disorder," 2007). In reality, ASD occurs across a wide range of intellectual and adaptive functioning, and strengths in one area may coexist with difficulties in another (Lord et al., 2020; Happé & Frith, 2020). Similarly, the belief that person with ASD do not want relationships or lack emotion is inaccurate, but in reality, they value social connection but experience difficulty with social communication, reciprocity and interpreting social cues (Bölte et al., 2019; Lai et al., 2014).

Another misconception is that ASD only affects childhood or is always obvious in the early years (Hyman et al., 2020; Zwaigenbaum et al., 2015). But in reality, many people receive late diagnoses, especially when language skills, intelligence, or supportive environments mask difficulties in social communication or flexibility (Lai et al., 2014; Lord et al., 2020). This becomes very important in India context, where limited awareness may cause families and professionals to misinterpret early signs as harmless variation or temporary delay, thereby postponing referral, early screening and diagnosis (Chattopadhyay, 2024; Srivastava et al., 2023).

Myths about autism are not only the harmless misunderstandings, but actually they influence stigma, family stress, and access to services (Bölte et al., 2019; Cleary et al., 2023). Public education, parent education, and professional awareness are therefore necessary to replace unsupported beliefs with evidence-based understanding (Chakrabarti, 2023; Chattopadhyay, 2024). In the Indian context, correcting myths is especially important because early identification depends on whether families and frontline professionals recognise autism as a developmental condition that requires timely assessment and support (Chakrabarti, 2023; Hyman et al., 2020).

2.9.3 Parental attitudes and beliefs about ASD

Parental attitudes and beliefs strongly influence how autism is recognised, interpreted, and managed, especially in the early years when families are deciding whether a child's behaviour is part of normal variation or a sign of developmental concern (Ozonoff et al., 2009; Zwaigenbaum et al., 2015). In India, beliefs about autism are shaped not only by knowledge of child development but also by stigma, cultural explanations, and the availability of trusted professional guidance (Desai et al., 2012; Srivastava et al., 2023). Because of this, parental beliefs can either accelerate help-seeking or contribute to denial, delay, and incomplete follow-through with referral (Chattopadhyay, 2024; Chakrabarti, 2023).

Research from Indian families suggests that parents often begin with uncertainty, then move through a process of reinterpretation as they learn more about autism and begin to compare their child's development with that of peers (Desai et al., 2012). In the early phase, some parents initially view delays or social differences as temporary or manageable without specialist help, which can reduce urgency around assessment (Desai et al., 2012; Chattopadhyay, 2024). As understanding increases, parents may become more accepting of the diagnosis and more willing to pursue therapy, but that shift usually

depends on access to reliable information and supportive professionals (Desai et al., 2012; Hyman et al., 2020).

Beliefs about cause of ASD are also important because they shape where parents seek help and how they respond to the professional advice (Taylor et al., 2002; Tulgar, 2022). Literature shows that harmful myths, such as the false belief that autism is caused by vaccines or poor parenting, can increase confusion and blame, ultimately weakening trust in formal healthcare systems (Taylor et al., 2002; Tulgar,2022). In India context, cultural beliefs such as fate, karma, or family fault may also influence how ASD is understood, which makes culturally sensitive counselling very important (Desai et al., 2012; Srivastava et al., 2023).

Parental attitudes toward the intervention services are similarly consequential. Families who believe that autism is a developmental condition with meaningful support options are more likely to pursue screening, accept referral and remain engaged with therapy for a longer duration (Hyman et al., 2020; Zwaigenbaum et al., 2015). Whereas in contrast, negative attitudes shaped by stigma, denial or fear of labelling can delay intervention and reduce acceptance for care (Chattopadhyay, 2024; Srivastava et al., 2023). For this reason, parental beliefs should be addressed directly during counselling considering their cultural, rather than assumed to change on their own (Hyman et al., 2020; Chakrabarti, 2023).

2.9.4 Influence of knowledge on help-seeking and intervention

Parental knowledge about ASD influences whether their concerns are translated into help-seeking, screening and intervention (Ozonoff et al., 2009; Hyman et al., 2020). When parents understand the clinical significance of reduced eye contact, delayed language, limited gesture use or poor social reciprocity, they are more likely to seek

professional advice earlier and accept referral for assessment (Zwaigenbaum et al., 2015; Ozonoff et al., 2009). Whereas in contrast, the limited knowledge can lead families to minimise concerns, wait for spontaneous improvement or consult services only after the child's difficulties become more obvious and disruptive (Chattopadhyay, 2024; Srivastava et al., 2023).

Knowledge also influences how parents engage with intervention after diagnosis. Studies have reported in parent mediated and family centred autism programmes, parents who understand the importance of early intervention are more likely to participate consistently, practice strategies at home and maintain follow up with the professionals (Bearss et al., 2015; Oono et al., 2013). Parent engagement is not only supportive, but it is an important part of the intervention itself, especially in early developmental programmes which primarily depend on parent practice in everyday routines (Bearss et al., 2015; Oono et al., 2013). For that reason, parental knowledge can influence both the speed of access to services and the quality of intervention implementation in home practise (Hyman et al., 2020; Bearss et al., 2015).

In the Indian context, knowledge has an additional role because service access is mostly uneven and families often need to navigate the health system with limited specialist support. Parents with better knowledge are believed to be in a good position to ask for screening, take referral and continue services, whereas parents with inadequate knowledge and information may feel uncertain about where to go or what to expect from therapy (Srivastava et al., 2023; Chattopadhyay, 2024). This makes parent education a practical intervention, because informed families are more likely to enter the care pathway early and remain engaged over a longer period of time as well (Hyman et al., 2020).

Knowledge also shapes the family confidence and emotional readiness. When parents understand ASD as a neurodevelopmental condition with availability of evidence based supports, they are more likely to view intervention as useful and to cooperate well with recommended strategies (Hyman et al., 2020; Oono et al., 2013). When knowledge is poor, parents may be more vulnerable to confusion, stigma and unrealistic expectations all of which ultimately hampers adherence to intervention services and reduce benefit (Srivastava et al., 2023; Chattopadhyay, 2024). Therefore, improving parental knowledge is not simply about information transfer, but it is a mechanism for increasing timely help seeking and strengthening intervention outcomes (Bearss et al., 2015; Hyman et al., 2020).

2.9.5 Role of the parent as a partner in intervention

Parents are essential partners in autism intervention because they know their child the best, they only spend the most time with the child and therefore can help make therapy strategies part of day to day routines (Burrell & Borrego, 2012; Musetti et al., 2021). When parents are actively involved, children are more likely to practice skills more often and across different settings, which ultimately improves generalisation and maintenance of learning (Brookman-Frazee & Koegel, 2004; Oono et al., 2013). Parent involvement also helps professionals understand the child's behaviour, strengths and difficulties in a natural context rather than only in clinic settings (Burrell & Borrego, 2012; Oono et al., 2013).

The parent's role may include learning communication strategies, reinforcing desired behaviours, supporting daily living skills and following the home training recommended by therapists (Schreibman et al., 2015; Wainer & Ingersoll, 2013). Parents also help with shared goal setting, progress monitoring and carrying over interventions into home and community settings, which makes treatment more consistent and practical

(Oono et al., 2013; Schreibman et al., 2015). This partnership is especially important because many autistic children benefit from repeated teaching in familiar environments rather than isolated therapy sessions alone (Brookman-Frazee & Koegel, 2004; Wainer & Ingersoll, 2013).

A strong parent-professional partnership also reduces stress when families receive clear explanations, realistic expectations, and practical support they can actually use (Karst & Van Hecke, 2012; Musetti et al., 2021). For intervention to work well, parents should be respected as collaborators, not treated only as observers or assistants (Burrell & Borrego, 2012; Karst & Van Hecke, 2012). In this way, parent participation becomes a core part of intervention rather than an optional addition (Schreibman et al., 2015; Oono et al., 2013).

2.9.6 Need for parent education in ASD

Parent education is needed in ASD because families are the people who spend the most time with the child, and they are the ones who can turn therapy advice into everyday practice (Burrell & Borrego, 2012; Oono et al., 2013). When parents understand ASD better, they are more likely to use consistent routines, communication supports, and behaviour strategies at home, which improves the chance that gains will carry over into daily life (Schreibman et al., 2015; Wainer & Ingersoll, 2013). Parent education also gives families clearer expectations, which can reduce confusion and stress after diagnosis (Karst & Van Hecke, 2012; Musetti et al., 2021).

Education is especially important because many children with ASD need support in communication, self-help, social behaviour and emotional regulation and these needs do not usually end when the end of therapy session (Oono et al., 2013; Schreibman et al., 2015). Parents can reinforce the same strategies across home, school, and community

settings, making intervention more effective and more consistent (Brookman-Frazee & Koegel, 2004; Burrell & Borrego, 2012). For this reason, parent education is not separate from intervention, but it is an important part of intervention itself (Schreibman et al., 2015; Wainer & Ingersoll, 2013).

In addition, parent education can improve parental confidence and reduce the sense of helplessness that often follows an autism diagnosis (Karst & Van Hecke, 2012; Musetti et al., 2021). Families who receive accurate, practical information are better able to advocate for services and support their child's development over time (Oono et al., 2013; Burrell & Borrego, 2012). Therefore, parent education should be treated as a core need in ASD management rather than a just an addon (Schreibman et al., 2015; Karst & Van Hecke, 2012).

2.9.7 Benefits of simplified educational materials

Simple educational materials are helpful in because parents understand information better when it is concrete, visual, and broken into short, clear steps (Gulati et al., 2014). If parents can follow the instruction and strategies provided in these materials, it reduces the amount of load that the child have, it can lower confusion and make learning more predictable (Hosie et al., 2024; Vanderbilt Kennedy Center Treatment and Research Institute for ASD [TRIAD], 2015). They simple strategies become useful when teaching routines, communication and classroom expectations (Gulati et al., 2014).

Simple visual supports such as pictures, symbols, schedules and short written cues can improve comprehension, support transitions, and reduce anxiety around change (Aspect, 2022; Hosie et al., 2024). For this reason, they are often recommended in both home and school settings (Autism Speaks, 2022; Aspect, 2022).

Another advantage is that simplified materials support parents and teachers by making instruction more consistent across different settings (Gulati et al., 2014; CDC, 2025). When the same visual cues or simplified explanations are used repeatedly, the child is more likely to understand expectations and generalise skills (VKC TRIAD, 2015; Autism Speaks, 2018). In this way, simplified educational materials are easier for caregivers to use in everyday life (Hosie et al., 2024; Gulati et al., 2014).

Overall, the literature shows that parental awareness and education play a major role in early identification, help-seeking, intervention participation and long-term support for children with ASD. As a result, many educational materials, parent guides, awareness resources and support tools have been developed to improve autism understanding and provide practical guidance for families, teachers and caregivers. Therefore, reviewing existing educational resources and materials is important to understand the type of information currently available, their usefulness for families, and the need for culturally relevant and parent-friendly resources in the Indian context.

2.10 Existing Educational Resources and Review of Materials

2.10.1 Review of Existing Autism Awareness, Educational, and Support Resources

A variety of national and international educational, awareness, and parent-guidance resources related to Autism Spectrum Disorder (ASD) are currently available through government platforms, healthcare institutions, rehabilitation and organisations working for PwD, and public awareness materials. These resources include digital educational supports, parent guidance booklets, psychoeducational materials, and practical home-based resources for families and caregivers. Table 2.6 summarises some of the major existing educational and parent-support resources relevant to ASD.

Table 2.6

Existing Educational, Awareness, and Parent Guidance Resources Relevant to Autism Spectrum Disorder

Resource / Programme	Developed by / Source	Type of Resource	Features	Relevance for ASD
PM e-Vidya	Ministry of Education	Digital educational platform	Provides digital books, exemplar materials, and digital learning support for children with special needs through the CWSN framework	Supports accessible, inclusive, and home-based learning
DIKSHA	Ministry of Education	Digital learning platform	Includes audiobooks and Indian Sign Language (ISL) dictionary support for learners with disabilities	Useful for alternative and multimodal learning
NIOS Accessible Resources	National Institute of Open Schooling (NIOS)	Accessible educational support	Provides accessible website features and inclusive educational materials	Improves educational accessibility
Digital Promise Resources	Digital Promise	Accessibility and assistive learning resources	Supports adapted digital learning and assistive educational approaches	Promotes accessible learning formats
Theirworld Resources	Theirworld	Disability-inclusive education resources	Focuses on inclusive classroom adaptation and educational accessibility	Highlights the need for individualized and structured learning
Autism: A Booklet for Parents, Carers and Families of Children and	Scottish Intercollegiate Guidelines	Parent awareness and psychoeducational booklet	Explains diagnosis, assessment, intervention approaches, available services, support options, and parent guidance	Helps parents understand autism and access available supports

Resource / Programme	Developed by / Source	Type of Resource	Features	Relevance for ASD
Young People with Autism	Network (SIGN, 2017)			
Autism Information Sheet	National Institute of Mental Health (NIMH, 2022/2024)	Public awareness material	Provides information on symptoms, diagnosis, treatment options, and service access	Supports early awareness and help-seeking
Autism Awareness: Bringing Them in the Mainstream	All India Institute of Medical Sciences, New Delhi (2015)	Parent guidance and awareness booklet	Covers behavioural interventions, evidence-based practices, home-based strategies, complementary approaches, and government schemes	Provides practical family guidance and autism awareness
Patient Information Booklet on Autism	All India Institute of Medical Sciences, Guwahati	Parent guidance and psychoeducational booklet	Includes communication, behaviour management, home routines, reinforcement, visual supports, special education, and caregiving strategies	Supports home-based management and parent involvement
OHSU ASD Handbook	Huang-Storms	Family guidance handbook	Covers emotional adjustment, service navigation, education, advocacy, treatment options, and family planning	Helps families navigate support systems and educational services
Parent-Mediated Intervention Programmes	Bearss et al. (2015); Schultz et al. (2011)	Formal intervention programmes	Structured parent-training and skill-teaching interventions targeting communication, behaviour, and developmental outcomes	Supports parent involvement in evidence-based intervention

Resource / Programme	Developed by / Source	Type of Resource	Features	Relevance for ASD
Autistic Spectrum Disorder: A Guide for Paediatricians in India	Autism Society of India (Barua & Daley, 2008)	Professional and family guidance resource	Explains autism characteristics, early identification, referral pathways, educational supports, and family guidance; also lists autism organisations, schools, and services in India	Links diagnosis, parent guidance, and transition to educational and support services
Handbook for Parents of Children with Disabilities	Planning Commission, Government of India (2002)	General disability parent handbook	Provides guidance for families regarding disability support, services, and caregiving	Represents early parent-facing disability support material in India
Understanding My Child with ASD: Answers to the Commonly Asked Questions of Parents	National Institute for Empowerment of Persons with Multiple Disabilities (2024)	Parent handbook and awareness resource	Addresses common parent concerns regarding diagnosis, support, daily management, and caregiving	Improves parental understanding and practical management skills
Parent Child Training Programme	Action for Autism	Structured parent-training programme	Provides guided parent training on communication, learning, behaviour management, and school readiness with active child participation	Combines parent education with practical skill-based intervention
CWSN Resource Materials and E-content Accessibility Guidelines	Ministry of Education (2021)	Inclusive educational and accessibility resources	Provides digital books, audiobooks, accessible learning materials, adapted teaching methods, and structured learning support	Supports inclusive and autism-sensitive educational practices

Resource / Programme	Developed by / Source	Type of Resource	Features	Relevance for ASD
Inclusive Classroom and School Adaptation Guides	Ministry of Education (2021); Autism Society of India (2007)	School-based inclusion and classroom support resources	Includes classroom adaptation strategies, visual supports, inclusive practices, and structured learning approaches	Assists teachers in supporting autistic learners within mainstream classrooms
Indian School-Based Autism Guidance Materials	Autism Society of India (2007); Ministry of Education (n.d.)	School inclusion and educational guidance resources	Combines classroom strategies, parent guidance, accessibility support, and service-related information	Supports usability and relevance of autism resources in Indian school settings
Autism Society of India Resource Materials	Autism Society of India (n.d.)	Autism support and service resource materials	Provides practical autism-related information, therapy and school links, service directories, and intervention guidance	Helps families access autism-related services and support systems
Sensory Processing Resources	Autism Research Institute (n.d.)	Sensory regulation and caregiver education resources	Includes sensory-processing articles, webinars, and regulation strategies for understanding behaviour and environmental responses	Supports caregiver understanding of sensory needs and behavioural regulation
AAC and Communication Support Materials	Hussman Autism Foundation (n.d.); India Autism Center (2025)	Communication and AAC resources	Includes picture symbols, communication boards, visual schedules, aided communication systems, and structured prompts	Supports communication for minimally verbal and non-speaking autistic children

Resource / Programme	Developed by / Source	Type of Resource	Features	Relevance for ASD
Sensory Kits and Multisensory Teaching Materials	The Autism Clinic (n.d.)	Sensory and classroom-readiness resources	Provides sensory kits and multisensory materials targeting attention, movement, touch, emotional regulation, and learning support	Assists regulation, classroom participation, communication, and daily functioning
Samagra Shiksha Inclusive Education Framework	Samagra Shiksha (2018)	National inclusive education framework	Includes identification and assessment, assistive devices, therapeutic services, teaching-learning materials, and accessible educational formats for children with special needs	Supports inclusive school participation and continuity of educational support
Block Resource Centre ASD Support Services	*Samagra Shiksha* Scheme [Press Information Bureau (2025)]	School-based public support initiative	Provides therapy services, specialized interventions, learning support, screening camps, parent counselling, teacher orientation, and teaching-learning materials linked to Samagra Shiksha and NEP 2020	Strengthens school participation, support access, and inclusive education for autistic children

Note. Existing autism-related resources may broadly be grouped into digital accessibility resources, school-based inclusion guides, public education materials, psychoeducational resources, sensory and communication supports, practical home-guidance materials, family guidance handbooks, and formal parent-mediated intervention programmes.

Overall, the available resources presented in Table 2.6 show that support for children with ASD and their families extends beyond formal therapy and it also includes educational access, parent awareness, home guidance, and service-related information. However, the usefulness of these materials depends on whether they are accessible, practical, easy to understand and suitable for the needs of children and families

2.10.2 Need for culturally appropriate and usable materials in India

Indian literature shows that autism-related guidance cannot be assumed to transfer neatly from Western settings to Indian families because parent experiences, beliefs and help-seeking are shaped by local cultural and social contexts. In Goa, parents described a process of learning to interpret their child's behaviour within everyday family and community life, which indicates that ASD related information needs to be understandable within Indian cultural realities rather than only medically accurate (Desai et al., 2012). In Kerala, parent-professional relationships were found to be influenced by collectivist norms, and the authors noted that parent mediated interventions in low and middle income settings must address cultural barriers if parents are expected to work as equal partners with professionals (Ramachandran, 2020).

This is why culturally appropriate materials are important in India. Parent-facing resources need to do more than define autism, they need to support parents in understanding diagnosis, communicating with professionals, and using feasible strategies at home and in school (Desai et al., 2012; Ramachandran, 2020). The literature suggest that Indian families need information that fits local family structures, social expectations and service access, because these factors affect whether guidance is accepted and applied (Desai et al., 2012; Ramachandran, 2020).

The distinction between parent education, psychoeducation and parent training becomes very important when designing materials for India. Bearss et al. (2015) noted that the term *parent training* has been used for several different kinds of interventions, including psychoeducation and parent-mediated approaches, so parent resources should be matched to their intended purpose and not treated as interchangeable. This matters in India because many families first need accessible awareness materials and only later require more structured intervention guidance (Desai et al., 2012; Ramachandran, 2020).

Institutional materials from India already reflect this need for local adaptation. The AIIMS New Delhi booklet *Autism awareness: Bringing them in the mainstream* offers family guidance on evidence-based practices, behavioural interventions, home-based intervention and government schemes. Showing an effort to make autism information practical for Indian parents (All India Institute of Medical Sciences New Delhi, 2015). The AIIMS Guwahati *Patient information booklet on autism* similarly aims to empower parents with practical, evidence-based strategies and includes chapters on home routines, communication, behaviour, and collaborative caregiving (All India Institute of Medical Sciences Guwahati, n.d.). These examples show that culturally and contextually appropriate materials are not only desirable but already being developed in the premier Indian institutions (All India Institute of Medical Sciences New Delhi, 2015; All India Institute of Medical Sciences Guwahati, n.d.).

Overall, the literature supports the view that ASD related materials in India should be culturally sensitive, practically usable, and aligned with local caregiving realities (Desai et al., 2012; Ramachandran, 2020; Bearss et al., 2015). Such materials are more likely to help parents understand autism, engage with professionals, and use intervention strategies in ways that fit Indian family life.

2.10.3 Gaps in existing resources

The main gap in existing ASD related educational resources in India is that availability does not always translate into usability. A recent study on autism community priorities in low-resource settings notes major barriers such as limited government commitment, over-centralised systems, inadequate professional training and limited local expertise, ultimately all of which affect access to services and materials. The same source also highlights stigma, delayed diagnosis and weak integration of mental health and developmental services, which means families often struggle to find and use the resources that do exist (Dey et al., 2024).

A second gap is the lack of autism-specific depth in many public education materials. Government resources such as Samagra Shiksha and PM e-Vidya provide broad inclusive education support, but much of the content is general and not tailored to communication, sensory regulation, or learning profiles typical of autism (Ministry of Education, n.d.; Samagra Shiksha, 2018). That means families and teachers still need to adapt general materials themselves, which can be difficult without specialist training. In practice, a resource may exist but still be too generic to solve the day-to-day needs of an autistic learner.

A third gap is uneven accessibility across formats and locations. Public systems may offer digital learning tools, assistive devices, and therapy-linked support, but these resources are not always easy to reach in rural or under-resourced areas, and they may depend on internet access, school capacity, or local implementation quality (Press Information Bureau, 2025; Dey et al., 2024). This creates a weak support system where some families can use services easily while others cannot. The result is a gap between policy intent and practical delivery.

Overall, the literature suggests that existing resources are fragmented, unevenly implemented, and often too general for ASD specific needs (Dey et al., 2024; Ministry of Education, n.d.). The strongest conclusion from the review is that India needs more locally usable, autism-specific and family-friendly resources that are integrated with school support and service pathways (Press Information Bureau, 2025; Samagra Shiksha, 2018). Without that, resources remain present in theory but inconsistent in real use. Therefore, these identified gaps provide the basis for the present study, which aims to develop culturally relevant and practically usable parent educational pamphlets for children with ASD.

2.11 Need and Rationale for the Present Study

The present study is needed because autism support in India still shows a clear gap between policy intent, available resources, and everyday use by families and schools. Research indicates that autism education in India continues to face inequities in resources, training, and service access, while school-based support often depends on local capacity rather than consistent implementation (V. S. et al., 2025; Dey et al., 2024). This makes it important to examine what resources actually exist, how they are being used, and whether they are genuinely practical for Indian families and schools.

A further reason for the study is that many existing materials are broad rather than autism-specific. Government platforms such as Samagra Shiksha and PM e-Vidya provide inclusive education support, but these resources often remain general and do not fully address autism-related needs such as communication, sensory regulation, or individualized classroom adaptation (Ministry of Education, n.d.; Samagra Shiksha, 2018). As a result, families and teachers may still need to improvise, which reduces the effectiveness of otherwise useful public resources.

The study is also necessary because parent guidance and service awareness remain uneven. Existing Indian autism resources show that families often rely on organisational websites, handbooks, and parent-training models to understand diagnosis, services, and educational options (Action for Autism, n.d.; National Institute for Empowerment of Persons with Multiple Disabilities, 2024). However, the literature also suggests that many parents still struggle to find usable, locally relevant information, which limits their ability to support their child effectively (Sobti, 2002; Nayi Disha Resource Centre, 2020). This makes a focused review of current resources especially important.

Another important reason for the study is that a large number of families still do not have access to validated, parent-friendly, and culturally relevant educational materials. The emotional burden on caregivers, including grief and helplessness, further shows the need for resources that do more than just providing the information; they must also offer practical guidance, reassurance and support (Mahapatra et al., 2019). In this context, educational materials can play a meaningful role in helping parents understand autism, navigate services, and engage more confidently with professionals.

Overall, the present study is needed because it can identify what is available, what is missing and where the biggest usability gaps remain. By reviewing all the existing educational resources, parent materials, sensory supports and public education tools together, the study can provide a clearer picture of how autism support is organized in India and where improvement is most needed. This makes the study useful not only for documentation but also for practical planning in schools, families, and service settings.

2.11.1 Link between literature gap and present study

The literature shows several clear gaps, including limited systematic mapping of autism priorities in India, uneven public awareness and a shortage of ASD specific educational resource that are both practical and locally usable (Dey et al., 2024; Srivastava et al., 2023). There is also evidence that even professionals, like special educators in India need stronger training in ASD related educational programming, which reinforces the need for better materials and clearer guidance (Tiwari & John, 2017). These gaps justify a focused review of current educational resources and parent facing materials.

The present study is directly linked to these gaps because it examines existing school-based guides, parent handbooks, sensory and communication tools and public education materials to identify what is available, what is missing and what is not sufficiently adapted for Indian families and classrooms (V. S. et al., 2025; Paul, 2018). This is important because a resource can exist on paper but still fail to help if it is not understandable, accessible, or contextually relevant.

The study also responds to the need for better implementation support. Evidence from India suggests that many interventions and materials remain fragmented, with few outcomes based or well evaluated programmes available to families and schools (Bharat et al., 2022; Dey et al., 2024). Reviewing the literature alongside existing materials can therefore help build a stronger foundation for future parent education programmes and school support tools.

Overall, the gap in the literature is not just a research problem, it is a practical one. If families, teachers and service providers do not have validated, culturally relevant and parent-friendly materials, then even good policies may have limited impact (Srivastava et al., 2023; Tiwari & John, 2017). The present study is designed to address that gap by

systematically examining the current resource landscape and identifying priorities for improvement.

2.11.2 Need for culturally relevant PEPs

Culturally relevant parent education programmes are needed because ASD related education material does not work well when the examples, language, routines and expectations do not fit family life. Research on culturally adapted interventions in India shows that caregivers and therapists value approaches that reflect Indian values and daily practices rather than simply importing Western models unchanged (Singh, 2023). This matters because parent education is most effective when families can actually apply it in their own home and community settings.

Indian autism resources also show that parent guidance often works best when it is locally grounded. Autism India's inclusive education materials describe school inclusion, teacher training and practical support for mainstream classrooms, including collaboration with families and government programmes (Autism India, 2007). That kind of locally oriented support suggests that parent education should reflect Indian school realities, family structures and service pathways rather than assuming a uniform model of intervention.

The need for culturally relevant PEPs is also supported by broader evidence on autism education in India. Recent reviews note that inclusive practices, teacher training and access to structured support remain uneven, which means parents often become the main bridge between school, therapy, and home support (V. S. et al., 2025; Srivastava & Singh, 2026). If parent programmes are not culturally relevant, families may understand the information but still find it hard to use in practice.

Overall, culturally relevant PEPs are needed to improve acceptability consistency, and usefulness. A good parent education material should use familiar language, respect family routines and connect with Indian school and service systems (Singh, 2023; Autism India, 2007). That makes cultural adaptation not an extra feature, but a core requirement for meaningful parent support.

2.11.3 Need for parent-friendly ASD information

Parent-friendly ASD information is needed because many families cannot use technical or clinically written material effectively in daily life. Indian parent-training resources show that families benefit most when information is given in simple language, linked to school readiness, communication, and independent living skills and reinforced through discussion and feedback rather than through abstract instruction alone (Action for Autism, n.d.; Rajaraman & Mundkur, 2021). This is especially important in ASD because parents often become the main coordinators of home-based support. The need is also supported by evidence that parent mediated programmes work better when families can understand and apply them in their own context. A systematic review of parent-mediated intervention programmes in India found that these approaches can improve parent and child skills, but the success of the model depends on parents being able to engage with the information and carry out the strategies at home (Kalorath et al., 2022; Koly et al., 2021). That means information must be not only accurate but also easy to follow and relevant to everyday caregiving.

Indian autism organisations also show why parent-friendly formats matter. Action for Autism's Parent Child Training Programme combines structured teaching with parent discussion, feedback and practical skill-building, which shows that parents need information packaged in a usable form rather than as a one-time leaflet or technical report (Action for Autism, n.d.). Similarly, Nayi Disha and related family support platforms focus

on accessible explanations, service navigation and caregiver guidance, which suggests that families need information that helps them act, not just understand (Nayi Disha Resource Centre, 2020). This is particularly useful when parents are trying to connect diagnosis, school support and therapy.

Overall, parent-friendly ASD information is needed because it improves comprehension, confidence and follow-through. When information is written in simple language and well connected to local services, parents are more likely to use it in real life and sustain support for the child (Action for Autism, n.d.; Nayi Disha Resource Centre, 2020). For that reason, parent education materials should be clear, culturally familiar, and focused on practical steps.

Educational materials for autism should also be validated because helpful-sounding content is not automatically accurate, usable, or appropriate for families. Studies on autism related educational tools show that materials need expert review and user feedback to ensure that the content is clear, relevant and suitable for the intended audience (Fernandes Moll et al., 2024). Without validation, a booklet or guide may contain technically correct information but still fail to meet the practical needs of parents or teachers. Validation is especially important in the Indian context because educational materials are often adapted from general or international sources. The Ministry of Education's e-content guidelines state that accessible content should be tested and validated for suitability, which reflects the need for quality control before materials are used widely in schools (Ministry of Education, 2021). This is relevant to autism because learners may need visual supports, simplified language, and predictable formatting, all of which should be checked rather than assumed to work. Validation therefore helps ensure that resources are not only available but also functional.

Research in India also shows that autism related tools can achieve stronger usefulness when they are psychometrically or professionally validated. For example, Hindi versions of autism-specific screening tools were validated to confirm reliability and acceptable measurement properties in Indian children, showing that local validation is possible and important (Mukherjee et al., 2024). Although screening tools are not the same as educational materials, the same principle applies. Tools must be adapted and tested in the context in which they will be used. That is especially true for parent-friendly educational materials, which must be understandable across different literacy levels and family settings.

Overall, the need for validation comes from the gap between intention and practical impact. A resource may be well designed in theory, but if parents cannot understand it, teachers cannot apply it or the examples do not fit Indian settings, its usefulness is very limited (Ministry of Education, 2021; Fernandes Moll et al., 2024). Validating materials through expert review, parent feedback and field testing improves credibility and makes the final product more likely to support real learning and care.

Therefore, this study is a timely and necessary response to the persistent gap between autism-related policy, available educational resources and the actual needs of Indian families, caregivers, and clinicians. By developing and validating culturally and linguistically appropriate public education pamphlets on ASD, the study aims to provide practical, accessible and visually engaging materials that can improve early recognition, support informed caregiving, strengthen parent-professional collaboration and promote consistent guidance across clinical, educational and various community settings. Ultimately, the study is expected to contribute not only to better awareness and usability of autism information but also to more meaningful support for families and improved developmental outcomes for children with ASD in the Indian context.

CHAPTER III

METHOD

The present study aimed to develop and validate a set of five Public Education Pamphlets (PEPs) for the parents and caregivers of children with Autism Spectrum Disorder (ASD), in the Indian context. The study further aimed to evaluate the effectiveness of the developed PEPs in improving parent/caregiver knowledge of Autism Spectrum Disorder and their confidence in applying the information in caregiving situations.

3.1 Research design

The present study adopted a descriptive developmental research design with a preliminary evaluation component to develop, validate, and field-test five Public Education Pamphlets for parents and caregivers of children with ASD in the Indian context.

Ethical considerations: The study was conducted in accordance with the AIISH ethical committee guidelines for the Bio-Behavioural Sciences for Human Subjects (AEC, 2009). Prior to the content validation and field-testing phases, all the participants including, the experts and parents/caregivers were informed about the purpose of the study, the nature of their participation, and the use of the PEPs, questionnaires and feedback forms. Informed consent was obtained from all participants before their inclusion in the study.

3.2 Participants

The participants of the study varied according to the phase of the study. In Phase 2, eleven experts including five Speech-Language Pathologists and one each of a Clinical Psychologist, Psychiatrist, Paediatrician, Occupational Therapist, Special Educator and

Medical Social Worker and five parents/caregivers of children with ASD participated in the content validation process.

Table 3.1

Inclusionary and Exclusionary Criteria for the Expert Reviewers in Phase 2

Group	Expert group
Inclusionary criteria	- Recognised degree and licensure/registration in the respective field. - Minimum of 3 years of clinical experience working with children diagnosed with ASD. - Current practice in a clinical, academic, or rehabilitation setting in India. - Experience in parent training or parental counselling related to ASD. - Should be fluent in the English language. - Willingness to provide written informed consent and participate in content validation process.
Exclusionary criteria	- Neurological or psychiatric disorders, cognitive impairments, or severe anxiety and attention deficits that could interfere with participation.

Table 3.2

Inclusionary and Exclusionary Criteria for the Parent Reviewers in Phase 2

Group	Parent reviewers
Inclusionary criteria	- Parent or a primary caregiver of a child diagnosed with autism spectrum disorder by a qualified professional. - The child with ASD should be between 3 and 12 years old. - Parent must have been actively involved in the child's therapy, schooling, or home management for at least 6 months. - Should be fluent in the English language. - Willing to provide informed consent and participate in the face validation process.

Group	Parent reviewers
Exclusionary criteria	- Parents/caregivers with neurological or psychiatric disorders, cognitive impairments, or severe anxiety and attention deficits that could interfere with participation. - Participation in the field testing in phase 4.

In Phase 4, another 10 parents/caregivers of children with ASD participated for the field testing of developed PEP's.

Table 3.3

Inclusionary and Exclusionary Criteria for the Parent Group in Phase 4

Group	Parent group
Inclusionary criteria	- Primary caregiver of a child aged between 3 and 12 years who had been formally diagnosed with ASD within the past 6 months by a qualified professional. - Their child had not attended any therapeutic intervention prior to participation. -Fluency in English, the language in which the materials were developed. - Willingness to provide informed consent and actively participate in both pre and post-exposure assessments. -Pre-test scores of less than 60% to identify the need for public education.
Exclusionary criteria	- Severe psychiatric or communication difficulties that would impede meaningful participation. - Prior participation in the content validation phase. - Unwillingness or inability to provide informed consent and complete assessments.

3.3 Procedure

This study was conducted in the following four phases:

Phase 1: Literature review and material development.

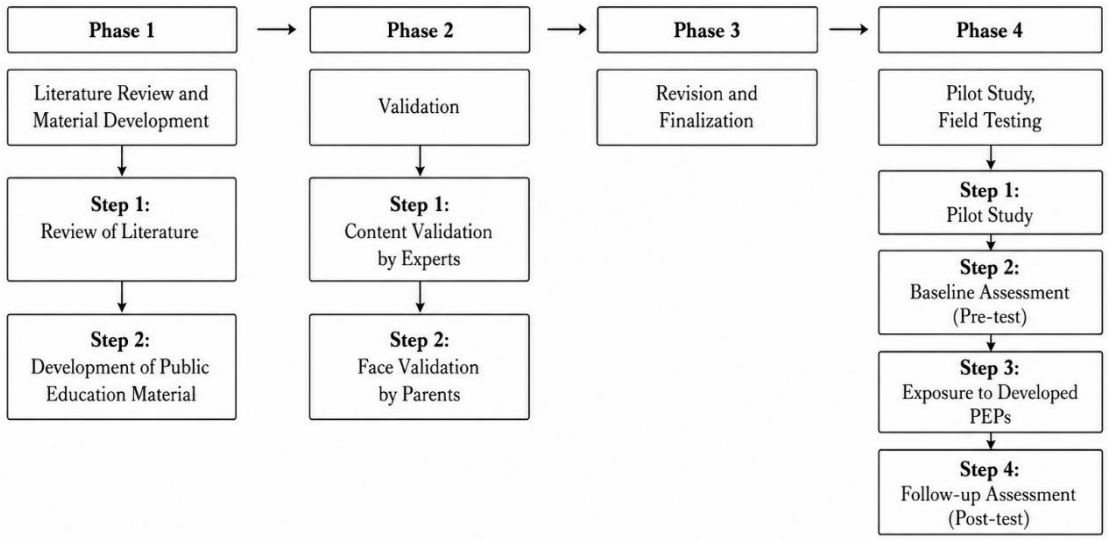
Phase 2: Content and face validation of the PEPs.

Phase 3: Revision and finalisation of the PEPs.

Phase 4: Pilot study, field testing, and impact assessment of the PEPs

FIGURE 3.1

Flowchart Illustrating the Different Phases of the Study



Note. PEPs = public education pamphlets

3.3.1 Phase I: Literature review and material development

This phase was carried out in two steps, which are explained below.

Step 1: Compilation of Review of literature

Step 2: Development of Public Education Material.

Step 1: Compilation of Review of literature

A comprehensive literature review was undertaken to identify content relevant to the development of culturally appropriate educational pamphlets on ASD. Search terms included autism spectrum disorder, early signs of autism, parent education, caregiver support, inclusive education in India, communication issues in ASD, behavioural issues in children with ASD, sensory issues in ASD, activities of daily living in ASD, and disability rights and certification for ASD in India. Peer-reviewed journal articles, clinical practice guidelines, educational toolkits, dissertations, textbooks, and reliable web-based sources were reviewed, focusing on literature addressing ASD in Indian contexts. Reports and guidelines from All India Institute of Speech and Hearing (AIISH), Mysore, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru, Rehabilitation Council of India (RCI), the Ministry of Health and Family Welfare (MoH&FW), the Ministry of Social Justice and Empowerment (MoSJE) and other relevant government and non-governmental organisations. All other existing materials supporting public education, caregiver training, and community awareness about ASD were also reviewed.

Step 2: Development of Public Education Material.

Based on the findings from the review of literature and inputs from ASD domain experts, a preliminary draft for all the five PEPs were developed. The PEPs were developed using plain-language principles, simple sentence structures, informative headings, and supportive visual cues to enhance comprehension and user engagement for

parents and caregivers from diverse socio-educational backgrounds. Their design was informed by established health-literacy frameworks such as the Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) and the Suitability Assessment of Materials (SAM), which assess understandability, actionability, readability, layout, and cultural suitability (Shoemaker et al., 2014; Doak et al., 1996).

The official letter head of the All India Institute of Speech and Hearing (AIISH), Mysore, including its logo, address, contact address and website link was included in all the PEPs with permission from the competent authority. The PEPs were developed in the English language. All the five PEPs are presented in Appendix I to Appendix V, respectively.

The title of five developed PEPs and their content are as follows:

PEP 1: Understanding Autism and Rights.

This pamphlet included the DSM-5 definition of autism in simple terms, autism as a spectrum with emphasis on variability, core characteristics related to communication, social interaction, and repetitive behaviours, myths versus facts about autism, early signs and red flags by age group, the importance of early identification, rights in India under the RPwD Act, 2016, disability certificate process and benefits, frequently asked questions, relevant schemes and support services such as Niramaya Health Insurance and Samagra Shiksha, and QR codes linking to resources (See Appendix I)

PEP 2: Diagnosis, Evaluation and Intervention Planning.

This pamphlet included early signs, how autism is diagnosed, the interdisciplinary team involved and commonly used tools such as ISAA and INCLEN, what parents should expect in the assessment process, the importance of early intervention and school planning, and parental support during the intervention phase (See Appendix II).

PEP 3: Communication and Language Development.

This pamphlet included primary communication challenges such as speech delay, echolalia, and pragmatic difficulties, the role of the Speech-Language Pathologist, simple activities for home practice, dos and don'ts for the parents and caregivers and visual supports and strategies to follow in daily routine (See Appendix III).

PEP 4: Behaviour, Sensory Skills, and Social Development.

This pamphlet included understanding behaviour such as rigidity, transitions, and peer interaction, a simple explanation of ABC Model with practical examples, parent dos and don'ts for behaviour modification, sensory processing difficulties including hypersensitivity and hyposensitivity, the role of Occupational Therapy, and home strategies for sensory challenges (See Appendix IV).

PEP 5: Daily Living, Home Routine and Schooling.

This pamphlet included activities of daily living such as toilet training, feeding, and dressing with stepwise guidance, visual schedule examples for home routines, school readiness factors such as attention and tolerance, inclusive and special schools, teacher-parent collaboration, and strategies for promoting independence and open communication with educators (See Appendix V).

3.3.2 Phase II: Content and Face validation of the PEPs

For each PEP, separate content validation questionnaires (CVQ)for experts and face validation questionnaires (FVQ)for parents were developed, psychometrically validated and considered appropriate by three speech language pathologists. All five expert CVQs are presented in Annexure VI to Annexure X and five FVQs are presented in Annexure XI to Annexure XV respectively. CVQs and FVQs were developed for experts and parents/caregivers respectively according to their respective roles in the validation process.

To facilitate ease of response and efficient data collection, the CVQs and FVQs were converted into the Google Forms. This digital format enabled participants to submit their responses conveniently and facilitated data collection and analysis.

Content validation and face validation was conducted sequentially. The initial drafts of the developed PEPs were first reviewed by experts to assess their accuracy, clarity, cultural sensitivity, and clinical relevance. Based on the expert feedback, the PEPs were revised before being submitted for parent/caregiver for face validation. The revised PEPs were then reviewed by parents/caregivers to assess their face validity with respect to readability, relevance, and usefulness for daily caregiving and advocacy needs.

This phase was carried out in two steps, as explained below.

Step 1: Content Validation of the PEPs by Experts

Step 2: Face Validation of PEPs by Parents/Caregivers

Step 1: Content Validation of the PEPs by Experts

In this phase, the initial drafts of the PEPs were submitted for content validation to 11 experts meeting the inclusionary and exclusionary criteria, including five Speech-Language Pathologists and one each of a Clinical Psychologist, Psychiatrist, Paediatrician, Occupational Therapist, Special Educator and Medical Social Worker. Each expert independently reviewed the pamphlets.

For content validation of PEPs by experts Five CVQs were developed and psychometrically validated and considered appropriate by three expert Speech Language pathologists for expert review of each PEP to assess the content, layout and illustrations used in the pamphlets. The expert CVQs for all the PEPs are presented in Annexure VI to Annexure X respectively. It included items related to the clarity and organisation of the

content, appropriateness of language, cultural relevance, inclusion of key information and overall usefulness of the material. An open-ended section was also provided for comments, suggestions, and recommendations for improvement. Sample questions from expert CVQ for the PEP1, titled 'Understanding Autism' are as follows:

Q: Inclusion of a clear and parent-friendly title in this pamphlet is:

Q: Inclusion of core features of autism (communication, social interaction, repetitive behaviours) is:

Instructions: Please read each item carefully and decide whether it is 'Essential', 'Useful but not Essential' or 'Not Necessary' for inclusion in the educational material. Mark your choice for each item accordingly. Your expert judgment will help in refining the content for maximum relevance and accuracy.

The content validity was assessed using the Content Validity Ratio (CVR) method (Lawshe, 1975). The feedback obtained from experts was used to revise the pamphlets before parent review was initiated.

Step 2: Face Validation of PEPs by Parents/Caregivers

After incorporating the expert suggestions, the revised PEPs were shared with parents/caregivers for review. The parent review was conducted with five parents/caregivers of children with ASD meeting the inclusionary and exclusionary criteria.

For Face validation of PEPs by parents, five FVQs were developed and psychometrically validated and considered appropriate by three expert Speech Language pathologists for each PEP, to assess their face validity with respect to readability, relevance, and usefulness for daily caregiving and advocacy needs. An open-ended section

was also provided for comments, suggestions, and recommendations for improvement. The parent FVQs for all the PEPs are presented in Annexure XI to Annexure XV respectively. Sample questions form the parent validation questionnaire for the PEP 1, titled 'Understanding Autism and Rights', are as follows:

Q: The language used in the booklet is easy for me to understand.

Q: The booklet helped me understand the early signs of autism.

Q: The information about disability certificate / UDID card is useful for parents.

Instructions: Please read each statement carefully and select the option that best reflects your opinion: 'agree', 'neutral' or 'disagree'. There are no right or wrong answers. Your honest opinion highly valuable and appreciated. You may also write any suggestions in the space provided.

3.3.3 Phase III: Revision and finalisation of the PEPs

Following the sequential content and face validation, all ratings and feedback were systematically reviewed for final revision. Quantitative feedback from the experts was analysed using Lawshe's Content Validity Ratio (CVR) (Lawshe, 1975) to identify items and sections to be retained or revised. Content with CVR values above the critical threshold was retained without modification, whereas items with CVR values below the threshold were revised or removed based on expert suggestions. In addition, the open-ended responses provided by experts were subjected to qualitative content analysis to identify common themes, concerns, and recommendations, and the pamphlets were modified accordingly to improve accuracy, clarity, and clinical relevance.

Parent feedback collected through the 3-point rating scale was analysed to identify areas requiring improvement in readability, cultural relevance, and usefulness. Sections or images rated as 'agree' were retained as such, whereas those rated as 'neutral' or 'disagree'

were revised based on the suggestions received from parents. The open-ended responses provided by parents were subjected to qualitative face validation analysis to assess the readability, relevance, and usefulness for daily caregiving and advocacy needs, and the suggested changes were incorporated to further improve the materials.

After revision, proof reading of the developed PEPs was done to recheck typing errors, readability, and cultural fit. Following proofreading, the final versions of all five PEPs were compiled for field testing.

The copyright application for all five developed PEPs was submitted in compliance with the relevant statutory provisions.

3.3.4 Phase IV: Pilot study and Field Testing of the PEPs

This phase aimed to evaluate the effectiveness of the developed PEPs in improving parent/caregiver knowledge of Autism Spectrum Disorder and their confidence in applying the information in caregiving situations. The ten parents/caregivers recruited in this phase were distinct from those who participated in Phase 2, to avoid practice effects, response bias, or any influence of prior exposure to the materials during content validation.

A 25-item pre-test and post-test questionnaire was developed and psychometrically validated and considered appropriate by three expert Speech Language pathologists to ensure reliability and validity for the pre and post assessment scores. The developed questionnaire is presented in Annexure XVI. It consisted of 15 dichotomously scored multiple-choice knowledge items where correct responses were scored as ‘1’and incorrect responses or ‘I don’t know / Not aware about this’ were scored as ‘0’ to assess parental knowledge about areas such as understanding autism, rights and supports, early intervention, communication, sensory issues, behaviour, daily living skills, and school collaboration. And 10 confidence-based items rated on a 5-point Likert scale where 5

indicated ‘Very confident’, 4 indicated ‘Confident’, 3 indicated ‘Moderately confident, 2 indicated ‘Slightly confident’, and 1 indicated ‘Not confident at all’ to assessed parental confidence in applying the knowledge in practical settings.

This phase was carried out in two steps, as described below.

Step 1: Pilot Testing of the PEPs

Step 2: Field Testing of the PEPs

Step 1: Pilot Testing of the PEPs

The pilot study was conducted to check the feasibility of the developed PEPs, study procedures and to identify any possible issues before the main field testing. One parent/caregiver of a child diagnosed with ASD was recruited using the same inclusion and exclusion criteria as the field testing. The structured pre and post-intervention assessments used the developed questionnaire to gather preliminary feedback on parental knowledge and confidence in applying this information in practical settings.

Step 2: Field Testing of the PEPs

This step was carried out to evaluate the effectiveness and impact of the developed PEPs among the parents and caregivers of children with ASD. Five parents or caregivers of children with ASD, meeting the inclusion and exclusion criteria specified in Table 3.3, were recruited. Initially, a baseline assessment was conducted using the developed pre and post-evaluation questionnaire. Thereafter, all participants were provided with the complete set of five finalised PEPs and asked to carefully go through the materials over a period of not more than 2 weeks.

After exposure to the pamphlets, the same questionnaire was administered again to assess changes in parental knowledge and confidence in applying the knowledge in

practical settings. The higher post-test scores compared to pre-test scores were interpreted as improvement in parental and confidence in applying the knowledge in practical settings. Qualitative feedback was also collected to record participants' experiences with the materials, perceived usefulness, cultural relevance, and suggestions for improvement. The findings from this phase informed any necessary modifications before wider dissemination in clinical and community settings.

Step 2: Field Testing of the PEPs

This step was carried to evaluate effectiveness of the developed PEPs in improving the knowledge and confidence in applying this information in practical settings, among the parents and caregivers of children with ASD. In this step the ten parents or caregivers of children with ASD, meeting the inclusion and exclusion criteria as specified in Table 3.3 were recruited. First of all, a baseline assessment was carried out using the developed pre and post-evaluation questionnaire, after that all participants were provided with the complete set of five finalised public education pamphlets and asked to read the materials over a period not exceeding 2 weeks.

After exposure to the PEPs, the same questionnaire was administered again to assess changes in parental knowledge and confidence in applying this information in practical settings. The higher post-test scores compared to pre-test scores were interpreted as improvement in parents' knowledge of ASD, early sign recognition, communication strategies, awareness of rights and services, and confidence in caregiving practices. Qualitative feedback was also collected to capture participants' experiences with the materials, perceived usefulness, cultural relevance, and suggestions for improvement. Findings from this phase informed any necessary modifications before wider dissemination in clinical and community settings.

3.4 Statistical analysis

The scores obtained from the validation and field-testing phases were tabulated and subjected to descriptive and inferential statistics. Content validity of the PEPs was assessed using Lawshe's Content Validity Ratio (CVR) method (Lawshe, 1975), while the qualitative comments provided by the experts were analysed using content analysis. The responses obtained from parents was used to establish face validity, and their responses were summarized descriptively to identify areas requiring modification.

For the field-testing phase, the pre-test and post-test scores were entered and analysed using Statistical Package for the Social Sciences (SPSS v26.0 for Mac; SPSS Inc., Chicago, IL). Shapiro-Wilk's test of normality was carried out, and the data were found to be normally distributed ($p > 0.05$). Hence, for further analysis, paired sample t-tests were used for the total scores, and the Wilcoxon signed-rank test was used for item-wise paired comparisons where required.

CHAPTER IV

RESULTS

The present study aimed to develop and validate a set of five Public Education Pamphlets (PEPs) for parents and caregivers of children with Autism Spectrum Disorder (ASD) in the Indian context. The present study also aimed to evaluate the effectiveness of the developed PEPs in improving parent/caregiver knowledge of Autism Spectrum Disorder and their confidence in applying this information in caregiving situations.

The first objective of the present study was to compile the contextually relevant, accessible, and evidence-based information and practical strategies on Autism Spectrum Disorder (ASD) for parents/caregivers, covering key areas, namely 'Understanding Autism and Rights', 'Diagnosis, Evaluation, and Intervention Planning', 'Communication and Language Development', 'Behaviour, Sensory Skills, and Social Development' and 'Daily Living Skills, Home Routines, and Schooling'. The second objective was to develop a set of five culturally adapted PEPs for parents and caregivers of children with ASD in the Indian context. The third objective was to establish the content validity and face validity of the developed PEPs through expert and parent/caregiver validation, respectively. The fourth objective was to conduct a pilot testing to evaluate the feasibility, design and methodological framework of the developed PEPs. And to a conduct field testing to evaluate their effectiveness in improving the caregiver knowledge of Autism spectrum disorder and confidence in applying this information in the caregiving situations through pre and post-test comparison.

As part of Objective 1, a detailed review of research literature and existing educational resources was done to identify key content domains for parent and caregiver education on ASD in the Indian context. The review covered evidence on ASD

characteristics, early signs and diagnosis, parent-mediated interventions, communication and language development, behaviour and sensory regulation, daily living skills, and school participation, along with Indian guidelines and policy documents on disability rights and certification. Existing public education materials and caregiver guides from national and international organisations were also examined to avoid duplication and to identify content gaps. Based on this synthesis, five content areas were finalised for the PEPs: (1) Understanding autism and rights, (2) Diagnosis, evaluation, and intervention planning, (3) Communication and language development, Behaviour, sensory skills and social development and (5) Daily living skills, home routines and schooling. All the five PEPs are presented in Appendix I to Appendix V, respectively.

First of all, a detailed review of research literature and existing educational resources was carried out to identify key content domains for parent and caregiver education on ASD in the Indian context. The review covered evidence on ASD characteristics, early signs and diagnosis, parent-mediated interventions, communication and language development, behavior and sensory regulation, daily living skills, and school participation, along with Indian guidelines and policy documents on disability rights and certification. Existing public education materials and caregiver guides from national and international organizations were also examined to avoid the duplication and to identify existing gaps.

Based on this review, five content areas were finalized for the PEPs namely, ‘Understanding Autism and Rights’, ‘Diagnosis, Evaluation, and Intervention Planning’, ‘Communication and Language Development’, ‘Behaviour, Sensory Skills, and Social Development’ and ‘Daily Living Skills, Home Routines, and Schooling’. Based on the complied information and input from domain experts set of five culturally adapted PEPs were developed in the Indian context.

After development content and face validity of the developed PEPs was established. For content validation the PEPs were validated by a multidisciplinary panel of 11 experts and revised based on their feedback. Afterwards, face validity was established by five parents/caregivers of children with ASD. The responses obtained from experts and parents were analysed quantitatively and qualitatively to assess the content validity and face validity respectively. Expert quantitative responses were analysed using Lawshe's Content Validity Ratio (CVR) method (Lawshe, 1975) and parent/caregiver responses were analysed descriptively using the 3-point rating scale.

This step was followed by a pilot study to evaluate the feasibility, design and methodological framework of the developed PEPs. The pilot study findings indicated that the developed PEPs, required duration of exposure, instructions given, pre and post assessment evaluation procedures were clear, acceptable and practical to administer. Therefore, no modifications were required before proceeding to field testing. The field testing of the developed PEPs was conducted among ten parents/caregivers of children with ASD. To avoid bias and ensure independent evaluation, a separate group of parents/caregivers, distinct from those who participated in the validation phase, was recruited for the field testing. The data obtained after field testing of the finalised materials were then subjected to statistical analysis. The total raw scores obtained during field testing were computed, tabulated, and analysed using Statistical Package for the Social Sciences (SPSS v26.0 for Mac; SPSS Inc., Chicago, IL). Shapiro-Wilk test of normality was performed on the data and the results revealed that the data followed a normal distribution ($p > 0.05$). Hence, parametric tests were applied to the data. Accordingly, a paired samples t-test was used for the total scores, and the Wilcoxon signed-rank test was used for item-wise pre and post-test comparisons.

The results of the present study are presented under the following sections:

A. Development and validation of PEPs

4.1 Content validation of the PEPs by experts

4.1.1 Quantitative content validity results

4.1.2 Qualitative analysis of expert feedback

4.1.3 Revisions made based on expert suggestions

4.2 Face validity of the PEPs by parents/caregivers

4.2.1 Quantitative face validity results

4.2.2 Qualitative analysis of parent feedback

4.2.3 Revisions made based on parent suggestions

B. Field testing of the PEPs

4.3 Pre-test and post-test assessment of parental knowledge and confidence

4.3.1 Item-wise pre-test and post-test analysis of knowledge items

4.3.2 Descriptive statistics of total knowledge and confidence scores

4.3.3 Wilcoxon Signed Ranks Test for confidence statements

4.3.4 Paired samples t-test for total knowledge and confidence scores

A. Development and validation of PEPs

4.1 Content validation of the PEPs by experts:

4.1.1 Quantitative content validity results

The Expert's quantitative content validity responses were analysed using Lawshe's Content Validity Ratio (CVR) method (Lawshe, 1975), in which the experts were required to classify each item as 'essential,' 'useful but not essential,' or 'not necessary'. The results Quantitative content validity results for PEP 1, PEP 2, PEP 3, PEP 4, and PEP 5 are presented below.

4.1.1.1 Quantitative content validity results for PEP 1

4.1.1.2 Quantitative content validity results for PEP 2

4.1.1.3 Quantitative content validity results for PEP 3

4.1.1.4 Quantitative content validity results for PEP 4

4.1.1.5 Quantitative content validity results for PEP 5

4.1.1.1 Quantitative content validity results for PEP 1

Table 4.1 presents the content validity ratio (CVR) values obtained for PEP 1 based on the ratings of 11 experts. (Expert PEP 1 CVQ presented in Appendix VI)

Table 4.1

Content Validity Ratio (CVR) for PEP 1 (N = 11 experts)

S. No.	Item No.	n_e (Essential)	CVR
1	1	11	1.00
2	2	10	0.82
3	3	10	0.82
4	4	11	1.00

S. No.	Item No.	n_e (Essential)	CVR
5	5	10	0.82
6	6	11	1.00
7	7	10	0.82
8	8	11	1.00
9	9	11	1.00
10	10	11	1.00
11	11	10	0.82
12	12	10	0.82
13	13	11	1.00
14	14	11	1.00
15	15	11	1.00
16	16	11	1.00
17	17	11	1.00
18	18	11	1.00

Note. Critical CVR value for 11 experts = 0.59. Items retained = 18/18.

As presented in Table 4.1, CVR values for all 18 items in PEP 1 ranged from 0.82 to 1.00, thereby exceeding the critical CVR value of 0.59 for 11 experts. Hence, all 18 items in PEP 1 were retained.

4.1.1.2 Quantitative content validity results for PEP 2

Table 4.2 presents the content validity ratio (CVR) values obtained for PEP 2 based on the ratings of 11 experts. (Expert PEP 2 CVQ presented in Appendix VII)

Table 4.2

Content Validity Ratio (CVR) for PEP 2 (N = 11 experts)

S. No.	Item No.	n_e (Essential)	CVR
1	1	11	1.00
2	2	10	0.82
3	3	10	0.82
4	4	11	1.00
5	5	10	0.82
6	6	11	1.00
7	7	10	0.82
8	8	11	1.00
9	9	11	1.00
10	10	11	1.00
11	11	10	0.82
12	12	10	0.82
13	13	11	1.00
14	14	11	1.00
15	15	11	1.00
16	16	11	1.00
17	17	11	1.00
18	18	11	1.00
19	19	11	1.00
20	20	11	1.00

Note. Number of experts (N) = 11. Critical CVR value = 0.59. Items retained = 20/20.

As presented in Table 4.2, CVR values for all 20 items in PEP 2 ranged from 0.82 to 1.00, thereby exceeding the critical CVR value of 0.59 for 11 experts. Hence, all 20 items in PEP 2 were retained.

4.1.1.3 Quantitative content validity results for PEP 3

Table 4.3 presents the content validity ratio (CVR) values obtained for PEP 3 based on the ratings of 11 experts. (Expert PEP 3 CVQ presented in Appendix VIII)

Table 4.3

Content Validity Ratio (CVR) for PEP 3 (N = 11 experts)

S. No.	Item No.	n_e (Essential)	CVR
1	1	11	1.00
2	2	10	0.82
3	3	10	0.82
4	4	11	1.00
5	5	10	0.82
6	6	11	1.00
7	7	10	0.82
8	8	11	1.00
9	9	11	1.00
10	10	11	1.00
11	11	10	0.82
12	12	10	0.82
13	13	11	1.00
14	14	11	1.00
15	15	11	1.00
16	16	11	1.00
17	17	11	1.00
18	18	11	1.00
19	19	11	1.00
20	20	11	1.00

Note. Number of experts (N) = 11. Critical CVR value = 0.59. Items retained = 20/20.

As presented in Table 4.3, CVR values for all 20 items in PEP 3 ranged from 0.82 to 1.00, thereby exceeding the critical CVR value of 0.59 for 11 experts. Hence, all 20 items in PEP 3 were retained.

4.1.1.4 Quantitative content validity results for PEP 4

Table 4.4 presents the content validity ratio (CVR) values obtained for PEP 4 based on the ratings of 11 experts. (Expert PEP 4 CVQ presented in Appendix IX)

Table 4.4

Content Validity Ratio (CVR) for PEP 4 (N = 11 experts)

S. No.	Item No.	n_e (Essential)	CVR
1	1	11	1.00
2	2	11	1.00
3	3	11	1.00
4	4	11	1.00
5	5	11	1.00
6	6	10	0.82
7	7	9	0.64
8	8	9	0.64
9	9	11	1.00
10	10	11	1.00
11	11	10	0.82
12	12	9	0.64
13	13	10	0.82
14	14	9	0.64
15	15	11	1.00
16	16	10	0.82
17	17	11	1.00
18	18	11	1.00
19	19	11	1.00
20	20	11	1.00

Note. Number of experts (N) = 11. Critical CVR value = 0.59. Items retained = 20/20.

As presented in Table 4.4, CVR values for all 20 items in PEP 4 ranged from 0.64 to 1.00, thereby exceeding the critical CVR value of 0.59 for 11 experts. Hence, all 20 items in PEP 4 were retained.

4.1.1.5 Quantitative content validity results for PEP 5

Table 4.5 presents the content validity ratio (CVR) values obtained for PEP 5 based on the ratings of 11 experts. (Expert PEP 5 CVQ presented in Appendix X)

Table 4.5

Content Validity Ratio (CVR) for PEP 5 (N = 11 experts)

S. No.	Item No.	n_e (Essential)	CVR
1	1	11	1.00
2	2	10	0.82
3	3	11	1.00
4	4	9	0.64
5	5	10	0.82
6	6	11	1.00
7	7	10	0.82
8	8	9	0.64
9	9	10	0.82
10	10	10	0.82
11	11	10	0.82
12	12	9	0.64
13	13	11	1.00
14	14	11	1.00
15	15	10	0.82
16	16	9	0.64
17	17	10	0.82
18	18	11	1.00
19	19	9	0.64
20	20	11	1.00
21	21	10	0.82
22	22	10	0.82

Note. Number of experts (N) = 11. Critical CVR value = 0.59. Items retained = 22/22.

As presented in Table 4.5, CVR values for all 22 items in PEP 5 ranged from 0.64 to 1.00, thereby exceeding the critical CVR value of 0.59 for 11 experts. Hence, all 22 items in PEP 5 were retained.

4.1.2 Qualitative analysis of expert feedback

The quantitative content validity results for PEP 1, PEP 2, PEP 3, PEP 4 and PEP 5 are presented below.

4.1.2.1 Qualitative analysis of expert feedback for PEP 1

4.1.2.2 Qualitative analysis of expert feedback for PEP 2

4.1.2.3 Qualitative analysis of expert feedback for PEP 3

4.1.2.4 Qualitative analysis of expert feedback for PEP 4

4.1.2.5 Qualitative analysis of expert feedback for PEP 5

4.1.2.1 Qualitative analysis of expert feedback for PEP 1

The open-ended responses obtained from the experts for PEP 1 were analysed using content analysis. Table 4.6 presents the individual expert responses and Table 4.7 summarises the responses into broad themes. (Expert PEP 1 CVQ presented in Appendix VI)

Table 4.6

Themes identified from expert open-ended responses for PEP 1 (n = 11)

S. No.	Expert	Open-ended feedback
1	Expert 1	In page 6, DSM-5 and ISAA are mentioned but not explained. A brief explanation such as “DSM-5 is a guideline used by doctors to diagnose autism” would improve clarity. In addition, the title on page 1 contains a grammatical error (“children’s with ASD”), which should

S. No.	Expert	Open-ended feedback
		be corrected to “children with ASD”. The cover page is visually engaging; however, the subtitle font may be slightly increased.
2	Expert 2	UDID section (page 19) is useful but steps can be written clearly (Step 1: apply, Step 2: documents, Step 3: benefits). Early identification section (page 17) is clear an adding example like “child identified early showed improvement after intervention” will help parents take timely decision.
3	Expert 3	In the early identification section (page 17), an example such as “early therapy can help the child start using words or gestures” may be included. The diagnosis section (page 6) requires further explanation, and ISAA may be described as a tool used in India for disability certification. It was also suggested that diagnosis be explained as a multidisciplinary process involving a paediatrician and psychologist.
4	Expert 4	FAQ section (pages 21–24) is relevant. More questions can be added like “Can my child go to regular school?” or “Will speech improve?”. Answers can be slightly simplified. Overall content is easy to understand.
5	Expert 5	On page 10, the term “hand-flapping” may be explained as “moving hands repeatedly when excited”. On page 11, an example such as “playing only with the same toy repeatedly” would help clarify strong interests. The title wording requires correction, and minor grammatical revisions are needed throughout the PEP.
6	Expert 6	The emotional expression example on page 13 is effective, and similar examples may be added in other sections. The myths section (pages 12–14) is informative but somewhat crowded, and the spacing between myth and fact may be improved. The overall colour contrast may also be enhanced.
7	Expert 7	In page 17, an example such as “a child who did not speak may start using gestures after therapy” may be included. The early signs section (pages 15–16) is important, and the content may be organised by age

S. No.	Expert	Open-ended feedback
		group, such as 12 months and 24 months, with emphasis on loss of language. Bullet formatting would also improve readability.
8	Expert 8	In the early signs section (page 15), key points such as “no babbling by 12 months” may be highlighted in bold. The “What is Autism” section (page 5) is clear and parent-friendly, although some long sentences may be shortened. In the spectrum section (page 7), an example such as one child speaking late while another speaks well but struggles socially would improve clarity.
9	Expert 9	UDID section (page 19) provides good information, but parents may find it confusing. Suggest presenting it in bullet steps and adding example of benefits (e.g., travel concession, school support). Also, mention where to apply (district hospital).
10	Expert 10	The core features sections (pages 8–11) are appropriate but may be converted into bullet points rather than sentence form. In the myths section (page 12), spacing may be improved. The spectrum explanation (page 7) is appropriate; however, including a contrast example representing mild and severe presentations would be beneficial. The FAQ section may include a question such as “Will my child go to a normal school?”.
11	Expert 11	Images in pages 8–11 are relevant but can be improved in clarity or variation. Some sections can use more spacing to avoid dense text. Overall, the PEP is useful and well structured, appropriate for parents.

Table 4.6 presents the specific suggestions provided by the experts regarding the content, language, and presentation of PEP 1. The comments show that the PEP 1 was generally considered useful and parent-friendly, but it required minor revisions to improve clarity, explanation of technical terms, formatting, and layout.

Table 4.7

Themes identified from expert open-ended responses for PEP 1 (n = 11)

Themes Identified	Description	Frequency (n = 11)
Clarity and understandability	Content is generally clear but requires simplification in certain sections	9
Usefulness of content	The material is relevant and useful for parents	11
Content refinement suggestions	Suggestions related to examples, explanations, and structural organisation	10
Grammatical corrections	Errors in title wording and minor language issues	5
Presentation improvements	Suggestions concerning layout, spacing, and visual design	4

Table 4.7 summarises the expert feedback into five broad themes. It shows that all 11 experts regarded the content as useful, while 10 experts suggested refinements in explanation and organisation, 9 commented on clarity and understandability, 5 identified grammatical issues, and 4 recommended presentation-related improvements. This thematic distribution indicates that the PEP1 was broadly acceptable, but still required targeted revisions to strengthen readability and visual presentation.

4.1.2.2 Qualitative analysis of expert feedback for PEP 2

The open-ended responses obtained from the experts for PEP 2 were analysed using content analysis. Table 4.8 presents the individual expert responses, while Table 4.9 summarises the responses into broad themes. (Expert PEP 2 CVQ presented in Appendix VII)

Table 4.8

Expert open-ended responses for PEP 2 (n = 11)

S. No.	Expert	Open-ended feedback
1	Expert 1	In page 18, INCLEN tool is not explained and one line explanation may be added. The multidisciplinary team section (page 17) is clear, but the roles can be simplified, for example, "speech therapist helps child talk and understand words." EEG/MRI mention is good, but a note such as "only done if doctor suspects another condition" may be added.
2	Expert 2	In page 11, vaccine clarification is good; a line such as "many studies worldwide show vaccines are safe" can be added. The ASD definition (page 5) is clear, but the explanation can be simplified, for example, "brain works differently." In the causes section (page 10), grouping into headings like "genetic," "brain development," and "risk factors" will improve clarity.
3	Expert 3	In page 25, RPwD Act is mentioned; the language can be simplified for parents. School planning (page 24) is useful, and a comparison of inclusive and special school in table form may be added. An example such as "a child in inclusive school may need a shadow teacher" can also be included.
4	Expert 4	In early intervention (pages 17–18), an example such as "a child who started therapy early may improve eye contact and communication" can be added. The causes section (page 10) is informative but slightly dense; bullet grouping will help readability. In page 11, the statement about vaccines is important, and adding reassurance such as "vaccines do not cause autism and are necessary for child health" will help parents.

S. No.	Expert	Open-ended feedback
5	Expert 5	In page 20 (assessment), steps can be numbered, such as Step 1: interview, Step 2: observation, and so on. The early signs section (page 12) is very important; key warning signs such as “no pointing,” “no response to name,” and “loss of speech” may be highlighted. Grouping signs by age, such as before 1 year and 1–2 years, can improve usability.
6	Expert 6	Overall, the PEP is informative and structured. Some sections such as early signs and causes can be simplified. The visuals are good, but adding icons for key sections such as early signs and therapies will improve engagement and quick understanding.
7	Expert 7	The assessment process (page 20) is detailed but may be difficult for parents, so numbering steps will help. Adding an example such as “doctor observes how child plays with toys” will improve understanding. In early intervention section, an example such as “speech therapy helps child use words or gestures to ask for needs” can be added.
8	Expert 8	In the therapies section (page 23), examples for each therapy, such as speech, occupational therapy, and behaviour therapy, can improve clarity. Early intervention (pages 21–23) is well explained, and adding a case example such as “a child who started therapy at 2 years improved communication” may help parents relate.
9	Expert 9	In page 14, tools like ISAA and INCLEN are mentioned; an explanation such as “ISAA is used for diagnosis and disability certificate in India” may be added. The prevalence section (page 8) is useful, but mentioning “recent Indian studies” without citation is vague and can be replaced with a specific source. In early signs (page 12), strong points like “loss of words” should be highlighted.

S. No.	Expert	Open-ended feedback
10	Expert 10	The supporting at home section (pages 26–27) is practical and well written. Adding examples such as “use picture cards for daily routine (eat, play, sleep)” will improve usability. In addition, points such as “do not force eye contact” can be highlighted.
11	Expert 11	On page 8, prevalence (1 in 68) is mentioned; adding source and year would improve credibility. The title is clear, but adding a simpler subtitle such as “What parents should know after noticing early signs” may improve accessibility. In page 5, the sentence “affects the way a person understands, communicates, and behaves” can be broken into shorter lines. Also, early signs (page 12) can highlight key items like “not responding to name” in bold.

Table 4.8 presents the specific suggestions provided by the experts regarding the content, language, and presentation of PEP 2. The comments show that the PEP2 was considered useful and parent-friendly. It required minor revisions to improve clarity, explanation of technical terms, formatting, and layout.

Table 4.9

Themes identified from expert open-ended responses for PEP 2 (n = 11)

Themes Identified	Description	Frequency (n = 11)
Clarity and understandability	Need for simplifying language and improving readability	9
Usefulness and applicability	Content helpful for understanding diagnosis and intervention	11

Content refinement suggestions	Need for examples, explanations, and structuring	10
Awareness of diagnostic and intervention process	Information about assessment, tools, and team	9
Presentation improvements	Suggestions related to layout, highlighting, and visuals	4

Table 4.9 summarises the expert feedback into five broad themes. It shows that all 11 experts regarded the content as useful and applicable, while 10 experts suggested refinements in explanation and organisation, 9 commented on clarity and understandability, 9 highlighted the need for better explanation of diagnostic and intervention processes, and 4 recommended presentation-related improvements. This thematic distribution indicates that the PEP2 was broadly acceptable. And required minor revisions to strengthen readability, understanding, and visual presentation.

4.1.2.3 Qualitative analysis of expert feedback for PEP 3

The open-ended responses obtained from the experts for PEP 3 were analysed using content analysis. Table 4.10 presents the individual expert responses, while Table 4.11 summarises the responses into broad themes. (Expert PEP 3 CVQ presented in Appendix VIII)

Table 4.10

Expert open-ended responses for PEP 3 (n = 11)

S. No.	Expert	Open-ended feedback
1	Expert 1	In page 8 (SLP session), the points are good but formatting can be made consistent through bullet points. The SLP role section (page 7) is well written, and adding examples such as “SLP

S. No.	Expert	Open-ended feedback
		may use picture cards to help the child request food or toys" will improve clarity. Also, "home plan" can be explained briefly, for example, as daily 5–10 minute practice tasks.
2	Expert 2	On page 6, the statement "child can't learn" is reassuring, and adding an example such as "child may learn to ask using pictures or gestures" would strengthen it. The communication challenges section (page 5) is clear; adding an example such as "child may repeat words instead of answering questions" will improve understanding.
3	Expert 3	In page 5, adding a short introductory line such as "Each child may show different communication patterns" will help framing. The examples in this section are good but may be spaced slightly for readability. In addition, the title on page 1 contains a grammatical error ("children's with ASD"), which should be corrected to "children with ASD". The subtitle is clear but slightly long; simplifying it may improve readability.
4	Expert 4	The home strategies section (pages 26–27) is practical. Adding an example such as "use picture card for 'eat' during meal time" will improve usability. In addition, highlighting key points such as "short frequent practice" will help parents focus.
5	Expert 5	In page 13 ("Don'ts"), an explanation should be added. For example, forcing eye contact may make the child uncomfortable. The routines section (page 12) is useful, and an example such as "Wash hands → Sit → Eat" is appropriate; similar routines for bath time and school can be added. Grammar consistency can also be improved across sections.
6	Expert 6	Overall, the PEP is very useful and well structured. The activities and visual supports sections are strong. Minor improvements in spacing, formatting, and consistency of

S. No.	Expert	Open-ended feedback
		examples will further improve readability and parent engagement.
7	Expert 7	In imitation play (page 16), an example such as “clap hands and wait for the child to copy” can be highlighted more clearly. The activity steps are clear, but adding time guidance such as “practice 5–10 minutes” will improve consistency.
8	Expert 8	The visual supports section (pages 19–21) is very useful. Adding one full example layout, such as a daily schedule showing wake, brush, eat, and school, will help parents implement it. Also, explaining the “first–then board” with an example such as “First homework, then TV” is helpful.
9	Expert 9	The minimally verbal children section (page 23) is important. Adding an example such as “child gives picture of juice to request” will improve clarity. AAC explanation can also be simplified further, for example, as using a phone app to communicate.
10	Expert 10	In “Model — don’t quiz” (page 11), the example can be expanded. Instead of asking “What is this?”, the parent can say “Ball” and wait. The “Do’s” section (pages 10–12) is practical, but a minor formatting issue such as “E.g..” should be corrected. Also, in “use choices,” an example such as “apple or biscuit?” can be added.
11	Expert 11	The activities section (pages 14–18) is strong and practical. For each activity, the expected outcome can be added. For example, in “Look and Share,” the child may start looking at the parent or object. In “Choice cards,” the expected response may be pointing or giving the picture.

Table 4.10 presents the specific suggestions provided by the experts regarding the content, language, and presentation of PEP 3. The comments show that the PEP 3 was

generally considered useful and parent-friendly. And it required minor revisions to improve clarity, explanation of communication strategies, formatting, and layout.

Table 4.11

Themes identified from expert open-ended responses for PEP 3 (n = 11)

Themes Identified	Description	Frequency (n = 11)
Clarity and understandability	Need for improving sentence structure, formatting, and readability	9
Practical usefulness	Strong applicability for home-based communication strategies	11
Content refinement suggestions	Need for examples, explanations, and expected outcomes	10
Conceptual clarity	Need for better explanation of communication strategies	8
Presentation improvements	Suggestions related to formatting, spacing, and visuals	4

Table 4.11 summarises the expert feedback into five broad themes. It shows that all 11 experts regarded the content as practically useful, while 10 experts suggested refinements in examples and explanation, 9 commented on clarity and understandability, 8 highlighted the need for greater conceptual clarity, and 4 recommended presentation-related improvements. This thematic distribution indicates that the PEP 3 was broadly acceptable, but still required targeted revisions to strengthen readability, explanation, and visual presentation.

4.1.2.4 Qualitative analysis of expert feedback for PEP 4

The open-ended responses obtained from the experts for PEP 4 were analysed using content analysis. Table 4.12 presents the individual expert responses, while Table

4.13 summarises the responses into broad themes. (Expert PEP 4 CVQ presented in Appendix IX)

Table 4.12

Expert open-ended responses for PEP 4 (n = 11)

S. No.	Expert	Open-ended feedback
1	Expert 1	The sensory processing section (pages 24–26) is comprehensive. Adding a summary such as "hyper = avoids input, hypo = seeks input" will help quick understanding. In sensory activities (pages 27–30), grouping them into "calming" and "alerting" will improve clarity.
2	Expert 2	On page 6, the statement "behaviour becomes easier to handle" is good; an example such as "if a child covers ears due to noise, reducing sound may reduce behaviour" can be added. The section "Why children behave differently" (page 5) is well explained; grouping reasons into categories like "sensory," "communication," and "routine-related" may improve clarity.
3	Expert 3	The social skills section (page 21) is simple and practical. Adding an example such as "parent rolls ball → child returns → parent says 'your turn'" will improve usability. Also, grouping activities into "play," "daily routines," and "communication" may improve clarity.
4	Expert 4	In page 5, the explanation of behaviour reasons is clear; adding a summary line such as "Behaviour is often a way of communicating needs such as discomfort or escape" would strengthen understanding. Also, the examples like "I want break" can be formatted more clearly. The title on page 1 contains a grammatical issue ("children's with ASD"), which can be revised to "children with ASD."

S. No.	Expert	Open-ended feedback
5	Expert 5	The ABC model section (pages 11–13) is well explained. Adding a full example flow such as “A: loud mixer noise, B: child covers ears and cries ,C: parent switches off mixer and child learns crying stops noise” will improve clarity.
6	Expert 6	The ABC diagram (page 14) is visually useful. Adding a caption explaining the sequence will improve interpretation. Also, linking the diagram with a real example such as noise → behaviour → escape will help understanding.
7	Expert 7	The behaviour example (pages 15–17) is detailed. Key steps like “do not remove plate” and “reward immediately” can be highlighted. Also, adding an explanation such as “removing plate reinforces avoidance” will improve clarity.
8	Expert 8	The running away example (pages 18–20) is useful. Adding an explanation such as “a child may run due to sensory seeking or lack of danger awareness” will help understanding. Also, the example “use backpack leash” may need a brief explanation for safety context.
9	Expert 9	The “Common parent reactions that don’t help” section (page 7) is relevant. Adding a contrast example such as “instead of shouting, use short instruction ‘Sit here’” will improve understanding. Also, the example “giving mobile to stop meltdown” can be followed with an alternative such as “offer calm space or break.”
10	Expert 10	The reinforcement section (page 22) is clearly explained. Adding an example such as “reward sitting for 2 minutes with favourite toy or praise” will help parents apply it. Also, “do not reward negative behaviour” can be briefly explained.

S. No.	Expert	Open-ended feedback
11	Expert 11	The “What helps instead” section (pages 9–10) is practical. Strategies can be grouped into “communication,” “sensory,” and “behaviour” categories. The example “In 5 minutes we leave” is good; similar examples can be added for other strategies.

Table 4.12 presents the specific suggestions provided by the experts regarding the content, language, and presentation of PEP 4. The comments show that the PEP 4 was generally considered useful and parent-friendly, but it required minor revisions to improve clarity, explanation of behavioural concepts, formatting, and layout.

Table 4.13

Themes identified from expert open-ended responses for PEP 4 (n = 11)

Themes Identified	Description	Frequency (n = 11)
Clarity and conceptual understanding	Need for clearer explanations and summaries	9
Practical usefulness	Strong applicability for behaviour and sensory management	11
Content refinement suggestions	Need for examples, structuring, and explanation	10
Conceptual linking	Need to explain reasons behind behaviour and strategies	8
Presentation improvements	Suggestions related to formatting and visual clarity	4

Table 4.13 summarizes the expert feedback into five broad themes. It shows that all 11 experts regarded the content as practically useful, while 10 experts suggested refinements in examples and explanation, 9 commented on clarity and conceptual understanding, 8 highlighted the need to explain the reasons behind behaviour and

strategies, and 4 recommended presentation-related improvements. This thematic distribution indicates that the PEP 4 was broadly acceptable, but still required targeted revisions to strengthen readability, explanation, and visual presentation.

4.1.2.5 Qualitative analysis of expert feedback for PEP 5

The open-ended responses obtained from the experts for PEP 5 were analysed using content analysis. Table 4.14 presents the individual expert responses, while Table 4.15 summarises the responses into broad themes. (Expert PEP 5 CVQ presented in Appendix X)

Table 4.14

Expert open-ended responses for PEP 5 (n = 11)

S. No.	Expert	Open-ended feedback
1	Expert 1	The dressing section (pages 12–13) is appropriate. Steps can be numbered as Step 1 and Step 2 for easier following. An example such as “use loose clothes without buttons initially” will help parents practically.
2	Expert 2	In the daily activities section (page 6), the message “not lazy or careless” is good; adding an example such as “child may struggle to button shirt due to motor difficulty” will improve understanding. The introduction (page 5) is clear, but the sentences can be slightly simplified.
3	Expert 3	The school selection section (pages 30–35) is comprehensive. Presenting a comparison of inclusive and special school in table format will improve clarity. Also, decision questions on page 36 can be highlighted using bullets or a box.
4	Expert 4	The mealtime section (pages 10–11) is practical. Adding an example such as “offer rice with one spoon of new vegetable” or

S. No.	Expert	Open-ended feedback
		"allow child to touch food before eating" will improve clarity. Also, explaining "do not force feeding" with a reason such as sensory discomfort will strengthen understanding.
5	Expert 5	The independence section (pages 50–57) is strong and practical. Examples such as "pulling pants after toilet" and "throwing waste in dustbin" are useful, and similar examples can be emphasized. Key messages like "start small" and "break into steps" can be highlighted.
6	Expert 6	Instructions like "point to picture instead of repeating" (page 19) are good and can be highlighted. The visual schedules section (pages 15–19) is very useful; adding a full routine example such as wake, brush, eat, and school will improve usability.
7	Expert 7	The play and bedtime routines (pages 20–22) are well explained. An example such as "play routine: choose toy → play → clean up" can be visually represented. Also, a bedtime example such as "dim lights → story → sleep" will improve clarity.
8	Expert 8	The school readiness section (pages 23–25) is clear. Adding an example such as "start with 2–3 minutes sitting and increase gradually" will help application. Activities like sorting vegetables or puzzles can be highlighted.
9	Expert 9	The visual schedule shown (page 8–9) is useful and can be briefly explained for daily use. The toilet training section (pages 7–9) is well structured; adding an example such as "take child every 2 hours, sit for 2–3 minutes, praise even if no output" will help application.
10	Expert 10	The teamwork section (pages 40–45) is important. Adding an example such as "same instruction word used at home and school" will strengthen clarity. Also, "one child – one plan – many helpers" can be highlighted.

S. No.	Expert	Open-ended feedback
11	Expert 11	On page 5, the sentence "This guide will help parents" should be corrected. The introduction is reassuring, but adding a line such as "Children learn step by step with repeated practice" may strengthen the message. Also, the title on page 1 contains a grammatical issue ("children's with ASD"), which can be revised to "children with ASD."

Table 4.14 presents the specific suggestions provided by the experts regarding the content, language, and presentation of PEP 5. The comments show that the PEP5 was generally considered useful and parent-friendly, but it required minor revisions to improve clarity, explanation of daily routines, formatting, and layout.

Table 4.15

Themes identified from expert open-ended responses for PEP 5 (n = 11)

Themes Identified	Description	Frequency (n = 11)
Clarity and grammatical accuracy	Need for minor corrections and clearer phrasing	8
Practical usefulness	Strong applicability for daily routines and school support	11
Content refinement suggestions	Need for examples, structuring, and explanation	10
Conceptual clarity	Need for reinforcing key ideas through examples and summaries	9
Presentation improvements	Suggestions related to formatting, sequencing, and highlighting	4

Table 4.15 summarises the expert feedback into five broad themes. It shows that all 11 experts regarded the content as practically useful, while 10 experts suggested refinements in examples and explanation, 9 commented on conceptual clarity, 8 noted grammatical accuracy issues and 4 recommended presentation-related improvements. This

thematic distribution indicates that the PEP 5 was broadly acceptable, but still required targeted revisions to strengthen readability, explanation and visual presentation.

4.1.3 Revisions made based on expert suggestions

The revisions made based on expert suggestions for PEP 1, PEP 2, PEP 3, PEP 4, and PEP 5 are presented below.

4.1.3.1 Revisions made based on expert suggestions for PEP 1

4.1.3.2 Revisions made based on expert suggestions for PEP 2

4.1.3.3 Revisions made based on expert suggestions for PEP 3

4.1.3.4 Revisions made based on expert suggestions for PEP 4

4.1.3.5 Revisions made based on expert suggestions for PEP 5

4.1.3.1 Revisions made based on expert suggestions for PEP 1

The suggestions provided by the experts for PEP 1 were reviewed and the recommended revisions were incorporated. The modifications made based on the expert suggestions are presented in Table 4.16.

Table 4.16

Suggestions and action taken for PEP 1

Suggestion	**Action taken**
Correct grammatical errors (title and text)	Title and grammatical errors corrected
Add explanation of technical terms (DSM-5, ISAA)	Brief parent-friendly explanations added
Include practical real-life examples	Examples incorporated across sections

Suggestion	Action taken
Improve structure (bullet points, grouping)	Content reorganized into clearer format
Enhance early signs section	Key signs highlighted and grouped
Simplify UDID process	Converted into step-wise format
Improve layout and spacing	Formatting adjusted for readability
Enhance visual clarity	Images reviewed and improved

Table 4.16 presents the suggestions given by the experts for PEP 1 and the corresponding actions taken. The revisions included correction of grammatical errors, addition of explanations for technical terms, incorporation of examples, reorganisation of content, highlighting of key signs, simplification of the UDID process, and improvement in formatting and visual presentation.

4.1.3.2 Revisions made based on expert suggestions for PEP 2

The suggestions provided by the experts for PEP 2 were reviewed, and the recommended revisions were incorporated. The modifications made based on the expert suggestions are presented in Table 4.17.

Table 4.17

Suggestions and action taken for PEP 2

Suggestion	Action taken
Simplify long sentences and language	Content revised into shorter, parent-friendly statements
Add explanation of technical terms (ISAA, INCLEN)	Brief explanations incorporated
Improve structure of causes and assessment sections	Content reorganized into categorized and step-wise format
Highlight key early signs	Important signs emphasized using formatting

Suggestion	Action taken
Include practical real-life examples	Examples added across intervention and home sections
Improve clarity of school planning	Comparison and simplified explanations added
Enhance visual presentation	Icons, spacing, and layout improved
Add credibility to prevalence data	Source/reference added

Table 4.17 presents the suggestions given by the experts for PEP 2 and the corresponding actions taken. The revisions included simplification of language, addition of explanations for technical terms, reorganisation of causes and assessment sections, highlighting of early signs, incorporation of examples, clarification of school planning, improvement of visual presentation, and addition of source information for prevalence data.

4.1.3.3 Revisions made based on expert suggestions for PEP 3

The suggestions provided by the experts for PEP 3 were reviewed, and the recommended revisions were incorporated. The modifications made based on the expert suggestions are presented in Table 4.18.

Table 4.18

Suggestions and action taken for PEP 3

Suggestion	Action taken
Correct grammatical and formatting errors	Errors corrected across document
Add practical examples in all sections	Examples incorporated for better understanding
Improve conceptual explanations	Additional explanatory statements included
Add expected outcomes for activities	Outcomes included to guide parent understanding

Suggestion	Action taken
Improve formatting consistency	Bullet points, spacing, and structure standardized
Enhance visual supports section	Sample layouts and examples added
Clarify “Don’ts” with rationale	Explanations added for better understanding

Table 4.18 presents the suggestions given by the experts for PEP 3 and the corresponding actions taken. The revisions included correction of grammatical and formatting errors, incorporation of practical examples, addition of explanatory statements, inclusion of expected outcomes for activities, standardization of formatting, enhancement of the visual supports section and clarification of “Don’ts” with appropriate rationale.

4.1.3.4 Revisions made based on expert suggestions for PEP 4

The suggestions provided by the experts for PEP 4 were reviewed and the recommended revisions were incorporated. The modifications made based on the expert suggestions are presented in Table 4.19.

Table 4.19

Suggestions and action taken for PEP 4

Suggestion	Action taken
Correct grammatical errors	Errors corrected across document
Add conceptual summaries	Key summary statements added
Include real-life examples (ABC, behaviour)	Practical examples incorporated
Improve structure of strategies	Content grouped under clear categories
Highlight key steps	Important steps emphasized using formatting
Add rationale behind behaviours	Explanations included for better understanding
Improve diagram clarity	Captions and examples added

Suggestion	Action taken
Enhance sensory explanation	Summary comparisons and grouping included

Table 4.19 presents the suggestions given by the experts for PEP 4 and the corresponding actions taken. The revisions included correction of grammatical errors, addition of conceptual summaries, incorporation of real-life examples, grouping of strategies under clear categories, highlighting of key steps, inclusion of explanations for behaviours, improvement in diagram clarity and enhancement of sensory explanations.

4.1.3.5 Revisions made based on expert suggestions for PEP 5

The suggestions provided by the experts for PEP 5 were reviewed, and the recommended revisions were. The modifications made based on the expert suggestions are presented in Table 4.20.

Table 4.20

Suggestions and action taken for PEP 5

Suggestion	Action Taken
Correct grammatical errors	Errors corrected across document
Add practical examples across sections	Real-life examples incorporated
Improve conceptual clarity	Summary statements added where needed
Present steps in structured format	Steps reorganized into numbered sequences
Enhance visual schedules	Sample routines and layouts included
Improve school comparison clarity	Information reorganized for easier understanding
Strengthen consistency across settings	Examples added to reinforce shared strategies
Highlight key messages	Important points emphasized using formatting

Table 4.20 presents the suggestions given by the experts for PEP 5 and the corresponding actions taken. The revisions included correction of grammatical errors,

incorporation of practical examples, addition of summary statements, reorganisation of steps into numbered sequences, inclusion of sample routines and layouts, clarification of school-related information, reinforcement of shared strategies across settings, and highlighting of key messages.

To summarize the results of section 4.1 i.e., the content validation of the PEPs by the experts, every item exceeded the critical CVR value of "0.59" for "11" experts across all the five PEPs. Therefore, all items in PEP 1, PEP 2, PEP 3, PEP 4 and PEP 5 were retained. The expert feedback consistently pointed to the need for clearer explanations of technical terms such as DSM-5, ISAA, INCLEN and AAC, simpler and more parent-friendly language, stronger use of examples and better structural organization through bullet points, stepwise presentation and clearer grouping of ideas. Several PEPs also required presentation related revisions such as improved spacing, highlighting of key points, corrected grammatical errors, better font emphasis and clear visual support. Based on these suggestions, the PEPs were revised to make the content easier for parents and caregivers to understand, apply, and retain. Overall, the expert validation confirmed that the PEPs were content-valid, relevant and suitable for the intended audience after minor but meaningful refinements.

4.2 Face validity of the PEPs by parents/caregivers

4.2.1 Quantitative face validity results

The quantitative face validity results for PEP 1, PEP 2, PEP 3, PEP 4 and PEP 5 are presented below.

4.2.1.1 Quantitative face validity results for PEP 1

4.2.1.2 Quantitative face validity results for PEP 2

4.2.1.3 Quantitative face validity results for PEP 3

4.2.1.4 Quantitative face validity results for PEP 4

4.2.1.5 Quantitative face validity results for PEP 5

4.2.1.1 Quantitative face validity results for PEP 1

Table 4.21 presents the quantitative face validity results for PEP 1 based on the responses of five parents/caregivers. The face validity of PEP 1 was assessed in terms of language clarity, ease of reading, understanding of ASD, usefulness of information, and overall helpfulness of the PEP 1 (PEP 1 Parent FVQ presented in Appendix XI).

Table 4.21

Quantitative face validity results for PEP 1 (n = 5)

Item	Agree (n = 5)	Neutral	Disagree	Mean
Language easy to understand	5	0	0	3.0
Information clear and simple	5	0	0	3.0
Easy to read and follow	5	0	0	3.0
Better understanding of ASD	5	0	0	3.0
Understanding child differences	5	0	0	3.0
Understanding early signs	5	0	0	3.0
Clears myths	5	0	0	3.0

Confidence in supporting child	5	0	0	3.0
Awareness of rights	5	0	0	3.0
UDID info usefulness	4	1	0	2.8
PEP helpful	5	0	0	3.0
Recommend to others	5	0	0	3.0

Analysis of the results shown in Table 4.21 indicated that 11 out of 12 items received perfect agreement, with a mean score of 3.0. Only one item, relating to the usefulness of UDID information, received a slightly lower mean score of 2.8. No disagreement was reported for any item. Overall, the findings indicated very high clarity, understanding, usefulness, and relevance of the content in PEP 1.

4.2.1.2 Quantitative face validity results for PEP 2

Table 4.22 presents the quantitative face validity results for PEP 2 based on the responses of five parents/caregivers. The face validity of PEP 2 was assessed in terms of language clarity, explanation of technical terms, understanding of ASD, clarity of diagnosis and intervention-related information, and overall usefulness of the PEP (PEP 2 Parent FVQ presented in Appendix XII).

Table 4.22

Quantitative face validity results for PEP 2 (n = 5)

Item	**Agree (n = 5)**	**Neutral**	**Disagree**	**Mean**
Language easy to understand	5	0	0	3.0
Technical terms explained simply	5	0	0	3.0
Information clear and not confusing	5	0	0	3.0
Better understanding of ASD	5	0	0	3.0
Understanding early signs	5	0	0	3.0
Spectrum concept clarity	5	0	0	3.0
Understanding diagnosis	5	0	0	3.0
Roles of professionals clear	5	0	0	3.0

Item	Agree (n = 5)	Neutral	Disagree	Mean
Importance of early intervention	5	0	0	3.0
Therapies explained clearly	5	0	0	3.0
PEP helpful	5	0	0	3.0
Recommend to others	5	0	0	3.0

Analysis of the results shown in Table 4.22 indicated that all 12 items received complete agreement, with a mean score of 3.0 for every item. No “neutral” or “negative” responses were reported for any of the items. Overall, the findings indicated very high clarity, understanding, usefulness, and relevance of the content in PEP 2.

4.2.1.3 Quantitative face validity results for PEP 3

Table 4.23 presents the quantitative face validity results for PEP 3 based on the responses of five parents/caregivers. The face validity of PEP 3 was assessed in terms of understanding communication difficulties, clarity of examples, reassurance about child behaviour, explanation of the role of the Speech-Language Pathologist, and usefulness of communication strategies (PEP 3 Parent FVQ presented in Appendix XIII).

Table 4.23

Quantitative face validity results for PEP 3 (n = 5)

Item	Agree (n = 5)	Neutral	Disagree	Mean
Understanding communication difficulties	5	0	0	3.0
Examples of speech/communication	5	0	0	3.0
Reassurance about child behaviour	5	0	0	3.0
Role of Speech-Language Pathologist	5	0	0	3.0
Understanding parent role	5	0	0	3.0
Communication strategies	5	0	0	3.0
Play-based activities	5	0	0	3.0
Step-by-step examples	5	0	0	3.0

Item	Agree (n = 5)	Neutral	Disagree	Mean
Visual supports explanation	5	0	0	3.0
Confidence using strategies	5	0	0	3.0
PEP helpful	5	0	0	3.0
Recommend to others	5	0	0	3.0

Analysis of the results shown in Table 4.23 indicated that all 12 items received complete agreement, with a mean score of 3.0 for every item. No “neutral” or “negative” responses were reported for any of the items. Overall, the findings indicated very high clarity, understanding, usefulness, and relevance of the content in PEP 3.

4.2.1.4 Quantitative face validity results for PEP 4

Table 4.24 presents the quantitative face validity results for PEP 4 based on the responses of five parents/caregivers. The face validity of PEP 4 was assessed in terms of understanding behaviour in ASD, behaviour as communication, reduction of parental blame, clarity of behaviour management strategies, and its usefulness (PEP 4 Parent FVQ presented in Appendix XIV).

Table 4.24

Quantitative face validity results for PEP 4 (n = 5)

Item	Agree (n = 5)	Neutral	Disagree	Mean
Understanding behaviour in ASD	5	0	0	3.0
Behaviour as communication	5	0	0	3.0
Reduced parental blame	5	0	0	3.0
Behaviour management strategies	5	0	0	3.0
ABC model understanding	5	0	0	3.0
Identifying triggers	5	0	0	3.0
Social interaction activities	5	0	0	3.0
Reinforcement strategies	5	0	0	3.0
Sensory understanding	5	0	0	3.0

Item	Agree (n = 5)	Neutral	Disagree	Mean
Practical sensory strategies	5	0	0	3.0
Role of Occupational Therapist	5	0	0	3.0
Behaviour management usefulness	5	0	0	3.0
Recommend to others	5	0	0	3.0

Analysis of the results shown in Table 4.24 indicated that all 13 items received complete agreement, with a mean score of 3.0 for every item. No “neutral” or “negative” responses were reported for any of the items. Overall, the findings indicated very high clarity, understanding, usefulness, and relevance of the content in PEP 4.

4.2.1.5 Quantitative face validity results for PEP 5

Table 4.25 presents the quantitative face validity results for PEP 5 based on the responses of five parents/caregivers. The face validity of PEP 5 was assessed in terms of understanding daily living challenges, clarity of toilet training strategies, routines and visual schedules, school readiness, school options, collaboration and parent-professional communication (PEP 5 Parent FVQ presented in Appendix XV).

Table 4.25

Quantitative face validity results for PEP 5 (n = 5)

Item	Agree (n = 5)	Neutral	Disagree	Mean
Understanding daily living challenges	5	0	0	3.0
Toilet training strategies	5	0	0	3.0
Routines & visual schedules	5	0	0	3.0
Daily routine examples	5	0	0	3.0
School readiness understanding	5	0	0	3.0
Attention & behaviour strategies	5	0	0	3.0
School options clarity	5	0	0	3.0
Confidence in school decisions	5	0	0	3.0
Importance of collaboration	5	0	0	3.0

Item	Agree (n = 5)	Neutral	Disagree	Mean
Parent–professional communication	5	0	0	3.0

Analysis of the results shown in Table 4.25 indicated that all 10 items received complete agreement, with a mean score of 3.0 for every item. No “neutral” or “negative” responses were reported for any of the items. Overall, the findings indicated very high clarity, understanding, usefulness, and relevance of the content in PEP 5.

4.2.2 Qualitative analysis of parent feedback

The qualitative analysis of parent feedback for PEP 1, PEP 2, PEP 3, PEP 4 and PEP 5 is presented below.

4.2.2.1 Qualitative analysis of parent feedback for PEP 1

4.2.2.2 Qualitative analysis of parent feedback for PEP 2

4.2.2.3 Qualitative analysis of parent feedback for PEP 3

4.2.2.4 Qualitative analysis of parent feedback for PEP 4

4.2.2.5 Qualitative analysis of parent feedback for PEP 5

4.2.2.1 Qualitative analysis of parent feedback for PEP 1

The qualitative feedback obtained from parents/caregivers for PEP 1 was analysed in terms of face validity (PEP 1 Parent FVQ presented in Appendix XI). The responses mainly focused on language clarity, ease of reading, understanding of ASD, usefulness of information and its overall helpfulness. The feedback was generally positive, with only a few suggestions for improvement.

Table 4.26 summarises the themes identified from the parent/caregiver feedback for PEP 1. It shows that the PEP 1 was considered easy to understand and useful and it helped improve understanding of ASD and related support information. A few parents/caregivers

also suggested translation into the regional language and minor improvements in presentation.

Table 4.26

Themes identified from parent/caregiver feedback on face validity for PEP 1 (n = 5)

Themes Identified	Description	Frequency (n = 5)
Language clarity	Clear and understandable language	4
Ease of reading	Easy to read and follow	4
Understanding of ASD	Helped improve understanding of ASD	5
Usefulness of information	Information was relevant and useful	5
Overall helpfulness	PEP was helpful for parents/caregivers	5
Need for regional language	Suggested translation into regional language	2
Minor improvements	Few suggestions for better presentation	3

Overall, the parent/caregiver feedback indicated that the PEP 1 had strong face validity. The responses suggested that the language was clear, the information was easy to follow, and the content was helpful in improving understanding of ASD and related support information.

4.2.2.2 Qualitative analysis of parent feedback for PEP 2

The qualitative feedback obtained from parents/caregivers for PEP 2 was analysed in terms of face validity (PEP 2 Parent FVQ presented in Appendix XII). The responses mainly focused on ease of understanding, clarity of the assessment and intervention process, awareness of the importance of early intervention, overall positive feedback and minor suggestions for improvement. The feedback was generally positive, with only a few small suggestions.

Table 4.27 summarizes the themes identified from the parent/caregiver feedback for PEP 2. It shows that the PEP 2 was considered easy to understand and helpful in explaining the assessment and intervention process. The parents/caregivers also reported that the importance of early intervention was clearly conveyed. Overall, the feedback was positive and a few participants suggested including helpline numbers and making minor corrections.

Table 4.27

Themes identified from parent/caregiver feedback on face validity for PEP 2 (n = 5)

Themes Identified	Description	Frequency (n = 5)
Easy to understand	Simple explanation of complex topics	4
Helpful for understanding process	Assessment and intervention clarity	3
Early intervention awareness	Importance clearly conveyed	2
Overall positive feedback	"Everything is good", "enough information"	4
Minor suggestions	Add helpline numbers / small corrections	2

Overall, the parent/caregiver feedback indicated that the PEP 2 had strong face validity. The responses suggested that the language was simple, the process was clearly explained and the information was useful in improving understanding of ASD assessment and intervention.

4.2.2.3 Qualitative analysis of parent feedback for PEP 3

The qualitative feedback obtained from parents/caregivers for PEP 3 was analysed in terms of face validity (PEP 3 Parent FVQ presented in Appendix XIII). The responses mainly focused on practical communication strategies, clarity of examples, understanding

of the role of the Speech-Language Pathologist, confidence in using the explained strategies, and overall positive feedback. The feedback was generally favourable, with parents/caregivers appreciating the usefulness of the information provided.

Table 4.28 summarises the themes identified from the parent/caregiver feedback for PEP 3. It shows that the PEP 3 was considered practical and useful for communication support. The parents/caregivers also reported that the examples were clear and that the PEP 3 helped them understand the role of the Speech-Language Pathologist better. Overall, the feedback indicated that the PEP 3 improved parent confidence, and most responses were positive.

Table 4.28

Themes identified from parent/caregiver feedback on face validity for PEP 3 (n = 5)

Themes Identified	Description	Frequency (n = 5)
Practical strategies	Helpful techniques for communication	4
Clear examples	Step-by-step guidance appreciated	4
Role clarity	Understanding SLP role	3
Confidence building	Parents felt more confident	4
Overall positive feedback	“Helpful”, “useful”	4

Overall, the parent/caregiver feedback indicated that the PEP 3 had strong face validity. The responses suggested that the practical strategies were useful, the examples were clear, and the content helped improve confidence in supporting communication at home.

4.2.2.4 Qualitative analysis of parent feedback for PEP 4

The qualitative feedback obtained from parents/caregivers for PEP 4 was analysed in terms of face validity (PEP 4 Parent FVQ presented in Appendix XIV). The responses

mainly focused on better understanding of behaviour, emotional reassurance, practical strategies, awareness of sensory issues, and overall positive feedback. The feedback was generally favourable, with parents/caregivers reporting that the PEP 4 was highly useful.

Table 4.29 summarises the themes identified from the parent/caregiver feedback for PEP 4. It shows that the PEP 4 helped parents realise that behaviour has meaning and provided reassurance by reducing guilt and blame. The PEP 4 was also appreciated for its step-by-step practical guidance and helpful explanations of sensory-related concerns. Overall, the responses indicated that the PEP 4 was useful and meaningful for parent support.

Table 4.29

Themes identified from parent/caregiver feedback on face validity for PEP 4 (n = 5)

Themes Identified	**Description**	**Frequency (n = 5)**
Behaviour understanding	Realization that behaviour has meaning	4
Emotional reassurance	Reduced guilt/blame	3
Practical strategies	Useful step-by-step guidance	4
Sensory awareness	Helpful explanations	3
Overall positive feedback	Highly useful PEP	4

Overall, the parent/caregiver feedback indicated that the PEP 4 had strong face validity. The responses suggested that the content was easy to understand, reassuring, and useful in improving parental understanding of behaviour and sensory needs.

4.2.2.5 Qualitative analysis of parent feedback for PEP 5

The qualitative feedback obtained from parents/caregivers for PEP 5 was analysed in terms of face validity (PEP 5 Parent FVQ presented in Appendix XV). The responses mainly focused on practical strategies, structured routines, school-related guidance,

independence skills, and overall positive feedback. The feedback was highly favourable, with parents/caregivers describing the PEP 5 as very useful and complete.

Table 4.30 summarises the themes identified from the parent/caregiver feedback for PEP 5. It shows that the PEP 5 provided useful practical guidance and support for daily routines. The parents/caregivers also reported that it helped in planning school related decisions and teaching independence skills through a step by step approach. Overall, the responses indicated that the PEP 5 was comprehensive and helpful for day-to-day use.

Table 4.30

Themes identified from parent/caregiver feedback on face validity for PEP 5 (n = 5)

Themes Identified	Description	Frequency (n = 5)
Practical strategies	Useful real-life guidance	5
Structured routines	Help in daily organization	4
School-related guidance	Helpful for planning decisions	3
Independence skills	Step-by-step teaching appreciated	4
Overall positive feedback	“Very useful”, “complete”	5

Overall, the parent/caregiver feedback indicated that the PEP 5 had strong face validity. The responses suggested that the information was practical, well organized, and useful in supporting both daily routines and independence-building activities.

4.2.3 Revisions made based on parent suggestions

The revisions made based on parent feedback for PEP 1, PEP 2, PEP 3, PEP 4, and PEP 5 are presented below.

4.2.3.1 Revisions made in PEP 1

4.2.3.2 Revisions made in PEP 2

4.2.3.3 Revisions made in PEP 3

4.2.3.4 Revisions made in PEP 4

4.2.3.5 Revisions made in PEP 5

4.2.3.1 Revisions made in PEP 1

The suggestions provided by the parents/caregivers for PEP 1 were reviewed, and the recommended revisions were incorporated. The modifications made based on the parent suggestions are presented in Table 4.31.

Table 4.31

Suggestions and action taken for PEP 1

Suggestion	**Action Taken**
Add regional language versions	Considered for future adaptation
Include more examples	Additional examples incorporated
Improve awareness sections	Strengthened explanation of services, included QR to know more about available schemes and services.

Table 4.31 presents the suggestions given by the parents/caregivers for PEP 1 and the corresponding actions taken. The revisions included incorporation of additional examples and strengthening of the explanation related to available services, while the suggestion regarding regional language versions was considered for future adaptation.

4.2.3.2 Revisions made in PEP 2

The suggestions provided by the parents/caregivers for PEP 2 were reviewed and the recommended revisions were incorporated. The modifications made based on the parent suggestions are presented in Table 4.32.

Table 4.32

Suggestions and action taken for PEP 2

Suggestion	Action Taken
Add helpline/contact info	Included information on where parents can seek help and support
Minor corrections	Reviewed and refined content
Maintain clarity	Content reviewed and refined with minimal changes wherever required

Table 4.32 presents the suggestions given by the parents/caregivers for PEP 2 and the corresponding actions taken. The revisions included reviewing and refining the content to address minor corrections, while the suggestion regarding helpline or contact information was considered for inclusion. Since the PEP 2 was already perceived as clear, no major changes were required in relation to clarity.

4.2.3.3 Revisions made in PEP 3

The suggestions provided by the parents/caregivers for PEP 3 were reviewed and the recommended revisions were incorporated. The modifications made based on the parent suggestions are presented in Table 4.33.

Table 4.33

Suggestions and action taken for PEP 3

Suggestion	Action Taken
Maintain practical focus	Practical home-based structure retained
Improve examples	Minor refinements made for better clarity
Strengthen explanation of visual supports	Visual support section reviewed and clarified

Suggestion	Action Taken
Simplify technical terms like AAC	Added simpler explanations and examples

Table 4.33 presents the suggestions given by the parents/caregivers for PEP 3 and the corresponding actions taken. The revisions retained the practical structure of the PEP 3, included minor refinements to improve examples, and ensured visual clarity. Clear subheadings and direct reporting help maintain flow and consistency in thesis chapters.

4.2.3.4 Revisions made in PEP 4

The suggestions provided by the parents/caregivers for PEP 4 were reviewed, and the recommended revisions were incorporated. The modifications made based on the parent suggestions are presented in Table 4.34.

Table 4.34

Suggestions and action taken for PEP 4

Suggestion	Action Taken
Maintain clarity of behaviour explanations	Retained
Add more practical strategies	Added more practical home-based strategies
Improve sensory examples (if needed)	Minor refinements made for better clarity

Table 4.34 presents the suggestions given by the parents/caregivers for PEP 4 and the corresponding actions taken. The revisions retained the clarity of behaviour explanations, maintained the practical strategies, and made minor refinements to improve sensory examples where needed.

4.2.3.5 Revisions made in PEP 5

The suggestions provided by the parents/caregivers for PEP 5 were reviewed, and the recommended revisions were incorporated. The modifications made based on the parent suggestions are presented in Table 4.35.

Table 4.35

Suggestions and action taken for PEP 5

Suggestion	**Action Taken**
Maintain structured format	Retained
Reinforce practical examples	Added more practical home-based strategies
Expand independence section (if needed)	Minor refinements made for better clarity

Table 4.35 presents the suggestions given by the parents/caregivers for PEP 5 and the corresponding actions taken. The revisions retained the structured format of the PEP 3, maintained the practical examples and made minor refinements to the independence section where needed.

To summarize the results of section 4.2 i.e., Face validity of the PEPs by parents/caregivers, showed that all five PEPs were rated very highly by the five parents/caregivers who reviewed them. For PEP 1, 11 of the 12 items received complete agreement and only the item on UDID information had a slightly lower mean of 2.8. And for PEP 2, PEP 3, PEP 4 and PEP 5 all items received a mean score of 3.0 with no ‘neutral’ or ‘disagree responses. The qualitative feedback supported these findings, with parents/caregivers describing the PEPs as easy to understand, useful, practical and relevant to daily caregiving needs. For PEP 1, parents appreciated the clarity of language,

understanding of ASD and usefulness of the information, while suggesting regional language translation and minor presentation improvements. For PEP 2, parents reported that the assessment and intervention process was clear and that early intervention was well explained, with a few suggestions such as including helpline numbers and minor corrections. For PEP 3, parents found the communication strategies practical, the examples clear and the role of the Speech-Language Pathologist easy to understand, which increased their confidence in supporting communication at home. For PEP 4, parents reported that it helped them to understand that behaviour has meaning, reduced guilt and blame, and provided practical guidance for managing behaviour and sensory needs. For PEP 5, parents described the it as very useful and complete because it supported daily routines, school-related decisions and independence-building through a step-by-step approach. Based on these suggestions, only minor revisions were made, such as adding examples, refining content, and improving presentation where needed. Overall, the face validity findings showed that the PEPs were clear, acceptable, and helpful for parents/caregivers, and that the final versions were suitable for field testing.

B. Field testing of the PEPs

4.3 Pre-test and post-test assessment of parental knowledge and confidence

Field testing of the PEPs was conducted among 10 parents/caregivers of children with Autism Spectrum Disorder to assess the usefulness of the PEPs in improving knowledge and confidence related to ASD.

The 25 item pre-test and post-test questionnaire (see appendix XVI). It consisted of 15 dichotomously scored multiple-choice knowledge items, coded as K1 to K15, corresponding to Questions 1 to 15, and 10 confidence-based statements, coded as C1 to C10, corresponding to Statements 16 to 25. For example, K1 was ‘1. A mother feels guilty because her child has autism and thinks it happened because she did something wrong

during parenting. What is the most accurate understanding?' and K15 was '15. For better progress in school, parents should.' Similarly, C1 was '16. I feel confident in explaining what autism is to a family member' and C10 was '25. I feel confident in communicating and collaborating with teachers and therapists.'

The knowledge items correct responses were scored as 1 and incorrect responses or 'I don't know / Not aware about this' were scored as 0, whereas the confidence statements were rated on a 5-point Likert-type rating scale where 5 indicated 'Very confident', 4 indicated 'Confident', 3 indicated 'Moderately confident', 2 indicated 'Slightly confident' and 1 indicated 'Not confident at all.' The knowledge section covered key areas such as understanding autism, rights and supports, early intervention, communication, sensory issues, behaviour, daily living skills and school collaboration, while the confidence section assessed parental confidence in applying this information in practical settings.

The data obtained after administering the PEPs were subjected to statistical analysis. Item-wise pre and post-test comparison was performed for the 15 knowledge based mcq questions. Descriptive statistics were computed for the total knowledge and confidence scores. The Shapiro-Wilk test of normality was performed on the total scores and the results indicated that the data were normally distributed ($p > 0.05$). Therefore, parametric tests were applied for the total score analysis. The pre-test and post-test total knowledge scores and total confidence scores were analysed using paired samples t-tests. Item-wise analysis for knowledge based questions and the confidence-based statements was done using McNemar's test and the Wilcoxon Signed Ranks Test, respectively. and

The results of the field testing are presented under the following sections:

4.3.1 Descriptive and inferential analysis of total pre and post-test knowledge and confidence scores.

4.3.2 Item-wise pre and post-test analysis of knowledge and confidence scores

4.3.1 Descriptive and inferential analysis of total pre and post-test knowledge and confidence scores.

The descriptive analysis of the total knowledge and confidence scores are presented in Table 4.36.

Table 4.36

Descriptive analysis of total pre and post-test knowledge and confidence scores

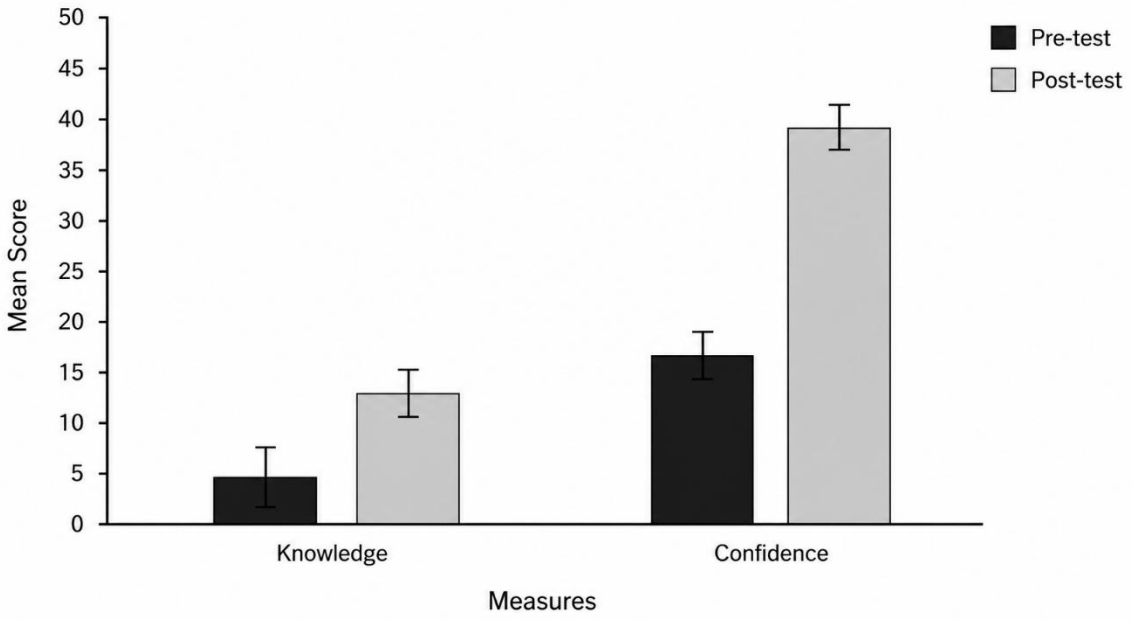
Measure	Mean	SD	Min	Max
Knowledge pre-test score	4.60	2.31	1.00	9.00
Knowledge post-test score	12.30	2.00	9.00	15.00
Confidence pre-test score	16.30	1.87	14.00	20.00
Confidence post-test score	39.20	1.83	38.00	44.00

Table 4.36 shows an improvement in both the total knowledge and confidence scores from pre-test to post-test. The mean total knowledge score increased from 4.60 (SD = 2.31) during the pre-test to 12.30 (SD = 2.00) during the post-test. Similarly, the mean total confidence score increased from 16.30 (SD = 1.87) in the pre-test to 39.20 (SD = 1.83) in the post-test.

Figure 4.1 shows an increase in the mean total knowledge and confidence scores from pre-test to post-test, where error bars represent standard deviations (SD) of the scores.

Figure 4.1

Mean Total Pre and Post-test Knowledge and Confidence Scores



From Figure 4.1, it can be observed that post-test mean scores were consistently higher than pre-test mean scores for both knowledge and confidence domains, indicating improvement following the exposure to the PEPs. Confidence scores showed the highest mean increase during the post-test phase. Overall, the figure illustrates positive changes in participants' performance with relatively consistent score distribution after the exposure to the PEPs.

Total pre-test and post-test knowledge and confidence scores were analysed using the paired-samples *t* test. The results showed a significant difference in total knowledge scores, $t(9) = 8.062$, $p < .001$, and total confidence scores, $t(9) = 27.392$, $p < .001$,

indicating that exposure to the PEPs had a significant effect on parental knowledge and confidence.

4.3.2 Item-wise pre and post-test analysis of knowledge and confidence scores

The item-wise pre and post-test score analysis was done using McNemar's test and Wilcoxon Signed Ranks test, respectively.

Table 4.37 represents the item-wise pre and post-test score for all 15 MCQ based knowledge questions. Although the post-test responses showed improvement across all items, the McNemar's test results were not statistically significant at the individual item level, possibly due to the small sample size and limited discordant responses. Therefore, the item-wise analysis is presented descriptively, while the item-wise significance values are not emphasized.

Table 4.37

Pre and post-test responses for knowledge questions (K1- K15)

Item	Pre-test incorrect, n	Pre-test correct, n	Post-test incorrect, n	Post-test correct, n
K1	6	4	1	9
K2	8	2	0	10
K3	9	1	4	6
K4	6	4	1	9
K5	5	5	2	8
K6	6	4	0	10
K7	9	1	4	6
K8	6	4	2	8
K9	8	2	1	9
K10	6	4	2	8
K11	10	0	1	9
K12	7	3	2	8

Item	Pre-test incorrect, n	Pre-test correct, n	Post-test incorrect, n	Post-test correct, n
K13	6	4	2	8
K14	6	4	3	7
K15	6	4	0	10

Table 4.37 shows the item-wise pre and post-test responses for the 15 knowledge items. Overall, the post-test scores showed improvement across most items after the exposure to the PEPs. For question K1, the number of correct responses increased from 4 during the pre-test to 9 during the post-test, while incorrect responses decreased from 6 to 1. Similarly, for question K2, correct responses increased from 2 in the pre-test to 10 in the post-test, with incorrect responses reducing from 8 to 0, indicating a marked improvement in knowledge. For question K3, the number of correct responses increased from 1 to 6, while incorrect responses reduced from 9 to 4. Likewise, question K4 demonstrated improvement, with correct responses increasing from 4 to 9 and incorrect responses decreasing from 6 to 1, as shown in Table 4.37.

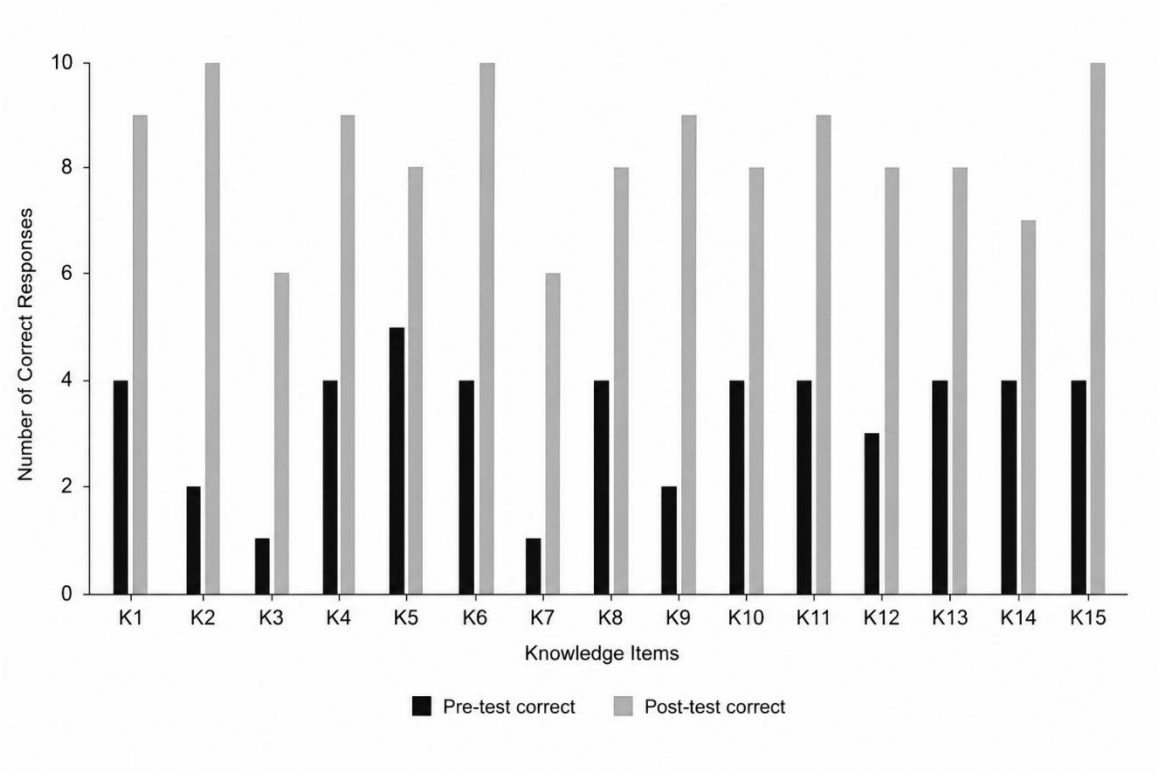
Questions K5 to K10 also demonstrated improvement in responses following exposure to the PEPs, as presented in Table 4.37. For question K5, correct responses increased from 5 to 8, while incorrect responses reduced from 5 to 2. In question K6, all parents/caregivers answered correctly during the post-test compared to 4 correct responses during the pre-test. Similarly, question K7 showed an increase in correct responses from 1 to 6, with incorrect responses reducing from 9 to 4. For question K8, correct responses increased from 4 to 8 and incorrect responses reduced from 6 to 2. Question K9 demonstrated marked improvement, with correct responses increasing from 2 to 9 and incorrect responses decreasing from 8 to 1. Likewise, for question K10, correct responses increased from 4 to 8, while incorrect responses reduced from 6 to 2.

Substantial improvement was also observed for questions K11 to K15, as shown in Table 4.37. In question K11, none of the parents/caregivers answered correctly during the pre-test, whereas 9 answered correctly during the post-test, with incorrect responses correspondingly reducing from 10 to 1. Similarly, question K12 showed an increase in correct responses from 3 to 8 and a reduction in incorrect responses from 7 to 2. For question K13, correct responses increased from 4 to 8, while incorrect responses reduced from 6 to 2. Question K14 demonstrated improvement, with correct responses increasing from 4 to 7 and incorrect responses reducing from 6 to 3. For question K15, all parents/caregivers answered correctly during the post-test compared to 4 correct responses during the pre-test, with incorrect responses reducing from 6 to 0. Overall, the findings indicated improved parental knowledge across all knowledge-based questions following exposure to the PEPs.

Figure 4.2 shows an overall increase in the number of correct responses from pre-test to post-test across knowledge items K1 to K15 following the exposure to the PEPS.

Figure 4.2

Item-wise comparison of pre-test and post-test correct responses for knowledge questions (K1–K15).



From Figure 4.2, it can be observed that the item-wise comparison of pre-test and post-test correct responses for knowledge questions K1 to K15 that post-test correct responses were consistently higher than pre-test correct responses across all questions, indicating improvement in participants' knowledge following the exposure to the PEPs. The greatest improvements were noted for question K2, K6, K11 and K15, where post-test correct responses increased markedly. In contrast, comparatively smaller improvements were observed for question K3 and K7. Overall, the figure demonstrates a positive trend in knowledge acquisition after the exposure to the PEPs program

Since the confidence statement scores were paired and ordinal in nature, the Wilcoxon Signed Ranks Test was used to compare the pre-test and post-test responses. The

Wilcoxon Signed Ranks Test results for the confidence statements are presented in Table 4.38.

Table 4.38

Wilcoxon Signed Ranks Test for confidence statements (C1-C10)

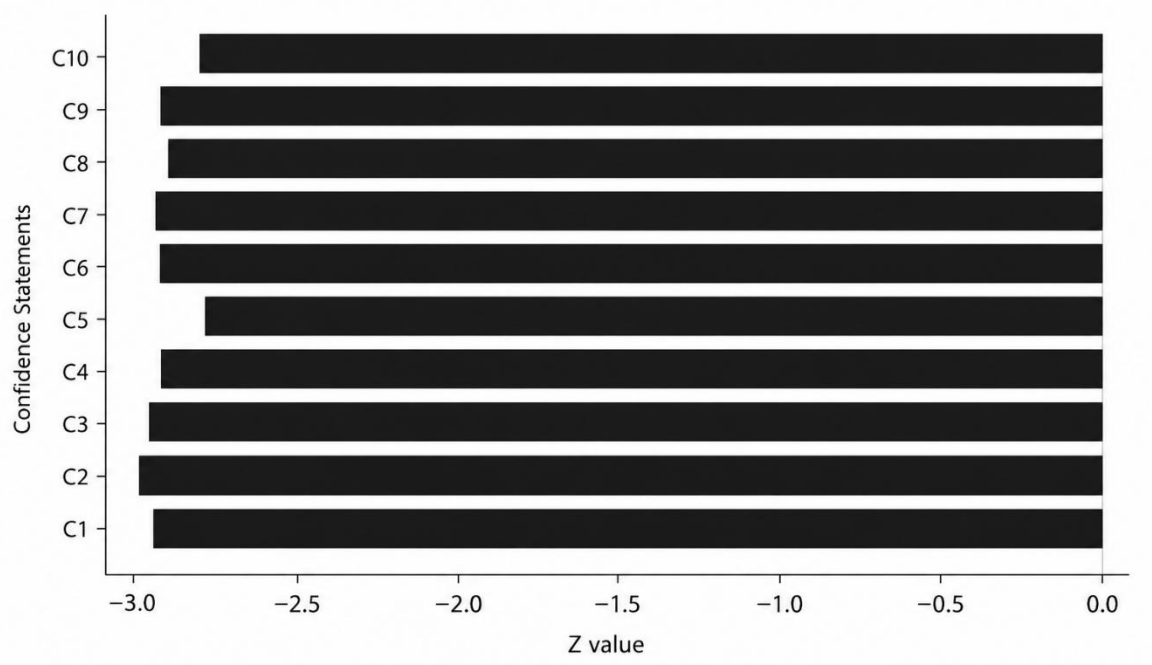
Confidence statement	Z value	Asymp. Sig. (2-tailed)
C1_Post - C1_Pre	-2.871	.004
C2_Post - C2_Pre	-2.913	.004
C3_Post - C3_Pre	-2.879	.004
C4_Post - C4_Pre	-2.836	.005
C5_Post - C5_Pre	-2.699	.007
C6_Post - C6_Pre	-2.844	.004
C7_Post - C7_Pre	-2.848	.004
C8_Post - C8_Pre	-2.825	.005
C9_Post - C9_Pre	-2.831	.005
C10_Post - C10_Pre	-2.699	.007

Table 4.38 shows statistically significant differences between pre and post-test scores for all 10 confidence statements (For e.g., for C1 Pre and Post-test, $|Z|= 2.87$, $p<0.01$ and for C10 Pre and Post-test, $|Z|= 2.69$, $p<0.01$). The results indicate that the exposure to the PEPs improved parental confidence.

Figure 4.3 shows the Z-values obtained from the Wilcoxon Signed Ranks Test for confidence statements C1 to C10 following the exposure to the PEPs.

Figure 4.3

Wilcoxon Signed-Ranks Test Z Values for Confidence Statements (C1–C10)



Note. Negative Z values indicate improvement in post-test confidence scores compared to pre-test scores across confidence statements (C1–C10).

From Figure 4.3, it can be observed that all confidence statements demonstrated negative Z values with statistically significant differences between pre and post-test responses. The magnitude of change was comparatively greater for statements C2 and C3, while relatively smaller changes were observed for statements C5 and C10. Overall, the figure indicates significant improvement in participants' confidence levels following the exposure to the PEPs.

To summarize, the results of the field testing presented under Section 4.3, namely the pre-test and post-test assessment of parental knowledge and confidence, showed a clear improvement in both parental knowledge and confidence following exposure to the PEPs. In the knowledge section, the item-wise post-test responses improved across all 15 knowledge-based questions, with several questions showing substantial gains. For

example, the number of correct responses for questions K2, K6, and K15 increased from 2, 4, and 4 during the pre-test to 10 correct responses during the post-test, while correct responses for question K11 improved from 0 to 9.

The descriptive and inferential statistics further confirmed this improvement, as the mean total knowledge score increased from 4.60 during the pre-test to 12.30 during the post-test, whereas the mean total confidence score increased from 16.30 to 39.20. The Wilcoxon Signed-Ranks Test showed statistically significant improvement across all 10 confidence statements ($p < .01$). Similarly, the paired-samples t test showed a highly significant difference between the pre-test and post-test scores for total knowledge, $t(9) = 8.062$, $p < .001$, and total confidence scores, $t(9) = 27.392$, $p < .001$. These findings indicate that the PEPs were effective in improving parental understanding of ASD as well as their confidence in managing and supporting children with ASD.

CHAPTER V

DISCUSSION

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that requires long-term multidisciplinary intervention and active family involvement across developmental stages. Parents and caregivers play a central role in supporting communication, behaviour, social participation, daily living skills, and educational planning for children with ASD. However, many families, particularly in the Indian context, experience challenges related to limited awareness, delayed recognition, difficulty understanding intervention procedures, and lack of access to clear and culturally relevant educational resources. Therefore, the availability of structured, accessible, evidence-based, and parent-friendly public education materials becomes important for improving caregiver understanding and supporting informed caregiving practices.

Based on the findings from existing literature, currently available public education resources, and inputs obtained from multidisciplinary experts, key content areas related to ASD were identified and systematically compiled. These content areas included understanding autism and rights, diagnosis and intervention planning, communication and language development, behaviour and sensory skills, and daily living skills and schooling. Using this compiled information, five culturally adapted Public Education Pamphlets (PEPs) were developed for parents and caregivers of children with ASD in the Indian context, namely ‘Understanding Autism and Rights’, ‘Diagnosis, Evaluation, and Intervention Planning’, ‘Communication and Language Development’, ‘Behaviour, Sensory Skills, and Social Development’, and ‘Daily Living Skills, Home Routines, and Schooling’. The developed PEPs are presented in Appendix I to Appendix V, respectively.

The developed PEPs were subsequently subjected to content and face validation, pilot testing, and field testing in order to evaluate their relevance, acceptability, feasibility, and effectiveness in improving parental knowledge and confidence related to ASD. Therefore, this chapter discusses the findings of the present study in relation to the stated objectives, existing literature, and their clinical relevance in the Indian context. The discussion is presented under the following sections:

5.1 Development of the PEPs for Parents and Caregivers of Children With ASD

5.2 Validation of the PEPs for Parents and Caregivers of Children With ASD

5.3 Effectiveness of the PEPs in Improving Parental Knowledge and Confidence About ASD

5.1 Development of the PEPs for Parents and Caregivers of Children With ASD

The development of the Public Education Pamphlets (PEPs) in the present study was undertaken in response to the growing need for structured, accessible, evidence-based and culturally relevant educational resources for parents and caregivers of children with Autism Spectrum Disorder (ASD). Parents and caregivers play a central role in supporting communication, behaviour, social interaction, daily living skills and educational participation of children with ASD. However, many families experience challenges related to limited awareness, delayed recognition, uncertainty regarding intervention planning and difficulty accessing clear and practical information related to ASD. In the Indian context these challenges are often further compounded by uneven service availability, limited public awareness and difficulties navigating support systems and intervention services (Chakrabarti, 2023; Chattopadhyay, 2024; Srivastava et al., 2023). Therefore, the development of parent-friendly educational materials was considered important to support caregiver understanding and informed caregiving practices.

The content included in the developed PEPs was systematically compiled based on findings from existing literature, publicly available educational resources, institutional materials and expert inputs. The selected content areas addressed major domains commonly associated with ASD management and caregiving needs, namely understanding autism and rights, diagnosis and intervention planning, communication and language development, behaviour and sensory regulation and daily living skills and schooling. These domains were selected because the literature consistently shows that parents require practical guidance not only regarding the nature of ASD but also regarding communication support, behaviour management, educational planning, early intervention, sensory regulation and functional independence within everyday routines (Oono et al., 2013; Schreibman et al., 2015; Hyman et al., 2020). Similarly, studies have highlighted that parent education programmes are most effective when they provide actionable information that can be incorporated into daily caregiving activities and home routines (Burrell & Borrego, 2012; Karst & Van Hecke, 2012).

The need for parent education materials is particularly important in ASD because parents often become the primary coordinators of home-based intervention and daily support. Research has shown that informed parents are better able to understand their child's needs, implement communication and behavioural strategies, collaborate with professionals and maintain intervention gains within natural environments (Oono et al., 2013; Schreibman et al., 2015; Wainer & Ingersoll, 2013). Parent-mediated approaches are also reported to improve caregiver confidence and reduce confusion following diagnosis especially when information is presented in a practical and understandable form (Karst & Van Hecke, 2012; Musetti et al., 2021). Therefore, the present PEPs were designed not merely as informational documents but as practical educational resources intended to support day-to-day caregiving and informed participation in intervention planning.

The literature also emphasises that educational materials for parents should be accessible, culturally appropriate and easy to understand in order to support meaningful utilisation by families (Autism Society, 2024; CDC, 2025; NHS England, n.d.). In the Indian setting culturally relevant and locally adaptable parent resources are particularly important because families may differ in literacy levels, awareness regarding ASD, access to professional services and familiarity with intervention terminology (Srivastava et al., 2023; Dey et al., 2024). Previous Indian studies and institutional resources have similarly highlighted the importance of providing simple, practical and family-oriented autism information that parents can apply within real-life caregiving situations (Barua & Daley, 2008; All India Institute of Medical Sciences New Delhi, 2015; All India Institute of Medical Sciences Guwahati, n.d.; National Institute for Empowerment of Persons with Multiple Disabilities, 2024). These findings guided the development process of the present PEPs.

Based on these considerations the compiled information was transformed into five culturally adapted PEPs for parents and caregivers of children with ASD in the Indian context. During development emphasis was placed on ensuring simplicity, readability, practical relevance and parent-friendliness. Technical information was simplified using parent-friendly language while practical examples and caregiving strategies were incorporated to improve understanding and applicability in daily routines. The content was also organised systematically using headings, thematic grouping, bullet points, numbered steps and highlighted key information in order to improve readability and ease of navigation. Visual presentation aspects such as spacing, layout clarity, font readability and structured presentation were also considered during development to enhance usability and reduce cognitive load for parents and caregivers.

The developed PEPs were intended to move beyond general awareness materials and function as structured educational supports that could assist parents in understanding ASD and applying practical strategies within home and caregiving settings. This approach is supported by previous literature indicating that parent education materials are more useful when they are culturally adapted, practically oriented and aligned with the realities of everyday caregiving (Bearss et al., 2015; Hyman et al., 2020; Singh, 2023). The present PEPs therefore attempted to integrate evidence-based information with culturally relevant presentation and practical applicability for Indian families caring for children with ASD.

Overall, the development process ensured that the PEPs addressed both informational and practical caregiving needs of parents and caregivers of children with ASD. The content areas selected for inclusion were based on evidence from existing literature, clinical relevance and caregiver requirements while the presentation style focused on accessibility, simplification, cultural adaptation and practical usability. *Thus, the first objective of compiling contextually relevant, accessible, evidence-based information and practical strategies related to ASD was achieved. Further, based on this compiled information a set of five culturally adapted Public Education Pamphlets (PEPs) for parents and caregivers of children with ASD in the Indian context was successfully developed thereby achieving the second objective of the present study.*

5.2 Validation of the PEPs for Parents and Caregivers of Children With ASD

Validation of the developed Public Education Pamphlets (PEPs) was carried out to determine the relevance, adequacy, clarity, usability and acceptability of the materials for parents and caregivers of children with Autism Spectrum Disorder (ASD). The validation process included both content validation by a multidisciplinary panel of experts and face

validation by parents/caregivers of children with ASD. Validation of educational materials is important because parent education resources are most effective when they are accurate, understandable, practical and suitable for the intended population (Fernandes Moll et al., 2024). In ASD-related parent education particularly, the usefulness of educational materials depends not only on the scientific accuracy of the content but also on how effectively the information can be understood and applied by families in real-life caregiving situations (Hyman et al., 2020).

The content validation findings showed that all five PEPs demonstrated strong content validity. All items across PEP 1 to PEP 5 exceeded the critical CVR value of 0.59 for a panel of 11 experts and were therefore retained. These findings indicate a high level of agreement among experts regarding the relevance, adequacy and appropriateness of the content included in the PEPs for parents and caregivers of children with ASD. The high agreement among experts suggests that the selected content areas appropriately addressed major domains related to ASD including understanding autism, intervention planning, communication, behaviour, sensory regulation and daily living skills. This is consistent with the literature emphasising that educational resources for families should contain evidence-based and clinically meaningful information that supports caregiver understanding and informed participation in intervention processes (Bearss et al., 2015; Hyman et al., 2020).

The expert qualitative feedback further contributed to strengthening the developed PEPs. The major suggestions included the use of simple and parent-friendly language, clearer explanations of technical terms such as DSM-5, ISAA, INCLEN and AAC and the inclusion of more practical examples related to everyday caregiving situations. Experts also suggested better organisation of information through bullet points, numbered steps and thematic grouping of content. Additional recommendations were related to formatting,

spacing, grammatical corrections and visual clarity. These findings are consistent with previous literature reporting that educational materials are more effective when information is presented in a structured, readable and practically usable format (Ministry of Education, 2021; Fernandes Moll et al., 2024). The expert feedback therefore not only validated the relevance of the content but also highlighted important aspects related to readability, usability and caregiver comprehension.

Face validation by parents and caregivers further demonstrated that the developed PEPs were understandable, acceptable and practically useful for the intended users. Most items across all five PEPs received complete agreement from parents/caregivers and no "neutral" or "disagree" responses were reported for the majority of the items. The high ratings obtained during face validation indicate that the materials were considered easy to understand, relevant and useful for daily caregiving needs. Parents/caregivers reported that the PEPs helped them better understand ASD and clarified important areas such as diagnosis, intervention, communication, behaviour, sensory needs, school planning and daily living skills. These findings support the view that parent education materials are most meaningful when they translate complex clinical concepts into practical and understandable information that families can apply in everyday situations (Autism Society, 2024; CDC, 2025; NHS England, n.d.).

The positive caregiver feedback obtained during face validation is particularly important in the Indian context where awareness regarding ASD, service accessibility and understanding of intervention processes may vary considerably across families (Chakrabarti, 2023; Chattopadhyay, 2024; Srivastava et al., 2023). Previous Indian studies have similarly highlighted the importance of culturally sensitive, family-oriented and practically useful educational resources for parents of children with ASD (Desai et al., 2012; Ramachandran, 2020). The findings of the present study therefore suggest that the

developed PEPs were appropriate for Indian parents/caregivers and addressed practical caregiving concerns in a culturally relevant and understandable manner.

The suggestions provided by parents/caregivers were comparatively minor and mainly included the need for regional language adaptations, inclusion of additional practical examples, addition of helpline or support contact details and small presentation-related refinements. The limited nature of these suggestions is consistent with the high face validity ratings obtained across all five PEPs and indicates that the materials were already acceptable and usable for the intended population. Similar findings have been reported in literature showing that educational materials become more acceptable and family-friendly when they use simple language, practical illustrations and culturally relevant presentation styles (Srivastava et al., 2023; Singh, 2023).

The revisions made based on expert and parent/caregiver feedback played an important role in strengthening the final versions of the PEPs. Revisions after expert validation mainly focused on simplification of language, clarification of technical concepts, inclusion of practical examples and improvement of structural organisation and visual presentation. Technical terms such as AAC, DSM-5, ISAA and INCLEN were explained more clearly to improve parent comprehension. The content was further organised using bullet points, thematic grouping, numbering and clearer formatting to improve readability and ease of navigation. Improvements were also made in spacing, highlighting of key points, visual presentation and layout organisation. These revisions are consistent with recommendations from literature indicating that simplified presentation and structured formatting improve usability and support better comprehension of educational information among caregivers (Ministry of Education, 2021; Fernandes Moll et al., 2024).

The revisions suggested by parents/caregivers mainly focused on strengthening examples, simplifying explanations further, including support-related information and considering regional language versions for future adaptation. Such suggestions are important because culturally adapted and locally understandable educational materials are reported to improve caregiver engagement and practical utilisation of information in home environments (Singh, 2023; Ramachandran, 2020). The incorporation of these suggestions therefore enhanced the parent-friendliness and practical applicability of the final PEPs.

Overall, the validation findings demonstrated that the developed PEPs were strong in both content and presentation. The high content validity ratings obtained from experts confirmed that the information included in the PEPs was relevant, adequate and clinically appropriate, while the strong face validity findings indicated that the materials were understandable, acceptable and useful for parents and caregivers of children with ASD. The revisions made following expert and caregiver feedback further improved the clarity, readability, usability and practical relevance of the PEPs. *Thus, the third objective of establishing the content validity and face validity of the developed PEPs through quantitative and qualitative evaluation by a multidisciplinary panel of experts and by parents/caregivers of children diagnosed with ASD was achieved.*

5.3 Effectiveness of the PEPs in Improving Parental Knowledge and Confidence About ASD

5.3.1 Pilot Testing and Feasibility of the PEPs

The effectiveness of the developed Public Education Pamphlets (PEPs) in improving parental knowledge and confidence related to Autism Spectrum Disorder (ASD) was examined using a pre-test and post-test comparison design. Initially, a pilot study was

conducted to evaluate the feasibility of the developed PEPs and the associated evaluation procedures before conducting the final field testing. The pilot study focused on examining the clarity, practicality, acceptability and feasibility of administering the developed PEPs and the pre-test and post-test evaluation questionnaire. The pilot study findings indicated that the developed PEPs, the required duration of exposure, the instructions provided and the assessment procedures were clear, acceptable and practical to administer. Participants were able to understand the instructions and complete the procedures without significant difficulty. These findings suggest that the developed PEPs and associated evaluation procedures were feasible and appropriate for use with parents/caregivers of children with ASD. Pilot testing is considered an important component in educational material development because it helps identify practical concerns related to administration, comprehension and usability before wider implementation (Fernandes Moll et al., 2024).

Thus, the pilot study findings supported the feasibility, practicality and acceptability of the developed PEPs and associated evaluation procedures, thereby achieving the pilot testing and feasibility component of the fourth objective of the present study.

5.3.2 Effectiveness of the PEPs in Improving Parental Knowledge

Following the pilot testing phase, final field testing was conducted using the developed pre-test and post-test questionnaire in order to evaluate the effectiveness of the Public Education Pamphlets (PEPs) in improving caregiver knowledge related to Autism Spectrum Disorder (ASD). The knowledge section of the questionnaire presented in Appendix XVI included 15 knowledge-based questions (K1–K15) covering major domains addressed in the developed PEPs, including understanding autism, rights and supports, diagnosis and intervention, communication, sensory issues, behaviour management, daily living skills and school collaboration. Field testing was carried out with a separate group of

ten parents/caregivers of children with ASD who were distinct from those who participated in the validation phase in order to ensure independent evaluation of the developed PEPs.

The descriptive statistics presented in Table 4.36 showed a marked improvement in total knowledge scores following exposure to the developed PEPs. The mean total knowledge score increased from the pre-test phase (M = 4.60, SD = 2.31) to the post-test phase (M = 12.30, SD = 2.00). Figure 4.1 further demonstrated that post-test knowledge scores were consistently higher than pre-test scores, indicating substantial improvement in parental understanding following exposure to the PEPs. The relatively stable error bars presented in Figure 4.1 additionally suggest consistency in post-test performance among participants. Overall, the descriptive findings indicate that the developed PEPs had a strong positive effect on parental knowledge related to ASD and its management.

The paired samples *t*-test findings further confirmed statistically significant improvement in total knowledge scores following exposure to the developed PEPs, $t(9) = 8.062$, $p < .001$. The significant difference observed between pre-test and post-test scores suggests that exposure to the developed PEPs was effective in improving parental understanding related to ASD. These findings indicate that the developed PEPs contributed meaningfully towards improving caregiver knowledge regarding autism, intervention planning, communication facilitation, behaviour understanding and practical caregiving strategies.

The findings of the present study are consistent with previous literature reporting that parent education interventions can significantly improve parental knowledge, understanding and self-efficacy related to ASD management and caregiving (Oono et al., 2013; Karst & Van Hecke, 2012). Parent education programmes have been shown to improve caregiver understanding of developmental needs, communication support

strategies and behavioural management approaches, thereby enabling parents to participate more actively in intervention processes (Schreibman et al., 2015). Previous studies have similarly shown that informed parents are better able to implement communication supports, behavioural strategies and structured routines within everyday home environments (Wainer & Ingersoll, 2013). Research has additionally highlighted that parent-mediated intervention approaches become more effective when caregivers are able to generalise learnt strategies across natural environments and daily routines (Vivanti et al., 2018; Yang, 2019).

The item-wise pre-test and post-test analysis of knowledge-based questions presented in Table 4.37 showed improvement across all 15 knowledge items following exposure to the developed PEPs. Figure 4.2 further demonstrated that post-test correct responses were consistently higher than pre-test correct responses across all knowledge questions, indicating overall improvement in parental understanding after exposure to the developed PEPs. The greatest improvements were observed for questions K2, K6, K11 and K15, whereas comparatively smaller improvements were noted for questions K3 and K7. Overall, the findings indicate that the intervention was effective in enhancing parental knowledge across the different domains addressed in the developed PEPs.

Improvement in question K1 indicated better understanding that autism is related to differences in brain development rather than parenting factors. Improvement in question K2 reflected stronger understanding regarding autism as a spectrum condition, with correct responses increasing markedly from the pre-test to the post-test phase. Improvement in question K3 suggested improved awareness regarding the rights and support systems available for children with ASD in India, although the gain remained comparatively smaller than several other items and may indicate the need for further simplification or stronger emphasis in this area. Improvement in question K4 reflected better understanding

that ASD diagnosis is based on behavioural observation and developmental assessment rather than medical tests.

Further improvement was observed in question K5, which indicated increased understanding regarding the importance of early professional consultation following developmental concerns. Improvement in question K6 reflected strong understanding regarding the importance of early intervention in ASD management, with all parents/caregivers responding correctly during the post-test phase. Improvement in question K7 showed better recognition of echolalia as a characteristic feature associated with ASD, although the gain remained comparatively modest and may suggest that the concept requires clearer explanation and additional practical examples. Improvement in question K8 reflected better understanding regarding the appropriate immediate response to a child's nonverbal communicative attempt. Similarly, improvement in question K9 demonstrated marked improvement in understanding communication facilitation strategies such as using short phrases and visual supports.

Improvement in question K10 reflected increased understanding regarding sensory hypersensitivity to sound. Question K11 demonstrated one of the strongest gains, with correct responses improving from none during the pre-test phase to almost all participants during the post-test phase, indicating that the ABC model-based explanation of behaviour was particularly effective and well understood by parents/caregivers. Improvement in question K12 suggested better understanding regarding sensory-seeking behaviours commonly observed in children with ASD. Improvement in question K13 reflected increased awareness regarding the usefulness of visual schedules within daily routines. Question K14 showed positive improvement regarding teaching dressing skills, although the gain remained comparatively smaller than most other items and may indicate the need for additional practical illustrations and examples. Improvement in question K15 reflected

stronger understanding regarding the importance of communication and collaboration with teachers and therapists for supporting school participation and overall progress of children with ASD, with all parents/caregivers answering correctly during the post-test phase.

Overall, the item-wise findings suggest that the developed PEPs contributed to improved parental understanding across all 15 knowledge-based questions included in the pre-test and post-test questionnaire presented in Appendix XVI. The stronger gains observed in questions K2, K6, K11 and K15 suggest that these concepts were communicated particularly effectively through the developed PEPs, whereas comparatively smaller gains in questions K3, K7 and K14 indicate areas that may benefit from further refinement, simplification and inclusion of additional practical examples prior to wider dissemination. These findings are consistent with previous literature showing that parent education programmes help families understand ASD better, respond more effectively to behaviour and use every day routines as learning opportunities (Oono et al., 2013; Schreibman et al., 2015). Parent education materials are also considered more meaningful when information is presented in a practical, understandable and family-friendly manner that supports application within natural environments (Bearss et al., 2015; Hyman et al., 2020).

Although descriptive findings showed improvement across all 15 knowledge items, the item-wise McNemar's test findings did not yield statistically significant results. This lack of statistical significance may primarily be attributed to the small sample size employed during the field testing phase, which likely limited the statistical power necessary to detect changes at the individual item level. McNemar's test is particularly sensitive to the number of discordant response pairs between pre-test and post-test conditions and low response shifts may reduce the ability of the test to detect statistically significant differences (McNemar, 1947). In the present study several questions exhibited a

low frequency of discordant responses and therefore even when descriptive improvements were observed, the limited number of response shifts reduced the statistical power of the analysis. These findings suggest that the absence of statistical significance should be interpreted cautiously and does not necessarily indicate lack of intervention effect, but rather reflects methodological limitations associated with sample size and response distribution.

The improvement in parental knowledge observed in the present study is clinically and practically important because parents/caregivers often serve as the primary facilitators of communication support, behaviour management and daily routine implementation within the home environment. Increased caregiver understanding may therefore contribute towards improved consistency in home-based intervention practices and more informed participation in decision-making related to the child's care and education. Public education materials are considered most useful when they improve both awareness and practical understanding in ways that can be applied within everyday family routines (Burrell & Borrego, 2012; Autism Society, 2024; CDC, 2025). The findings of the present study therefore support the usefulness of culturally adapted parent education materials in strengthening caregiver understanding and participation in ASD management.

The practical relevance of the developed PEPs is particularly important within the Indian context where families often experience delayed diagnosis, limited awareness, difficulty navigating intervention systems and unequal access to autism-related services (Chakrabarti, 2023; Chattopadhyay, 2024; Srivastava et al., 2023). Indian families have additionally been reported to require culturally sensitive, simple and practically applicable autism-related educational resources that reflect local caregiving realities and service structures (Desai et al., 2012; Ramachandran, 2020; Dey et al., 2024). The developed PEPs addressed multiple domains including understanding autism, communication, behaviour,

sensory regulation, schooling and daily living skills, thereby providing practical guidance that parents/caregivers could potentially apply within home and community settings. Similar Indian institutional resources and parent education initiatives have also emphasised the importance of accessible and culturally relevant autism education materials for families (All India Institute of Medical Sciences New Delhi, 2015; All India Institute of Medical Sciences Guwahati, n.d.; National Institute for Empowerment of Persons with Multiple Disabilities, 2024). The importance of cultural adaptation in improving the usability and effectiveness of educational resources has also been highlighted by Singh (2023).

Overall, the findings of the present study demonstrate that the developed PEPs were effective in improving parental knowledge related to ASD across all 15 knowledge-based questions included in the pre-test and post-test questionnaire presented in Appendix XVI. The significant improvement observed in total knowledge scores, along with positive item-wise improvement across all knowledge domains, indicates that the developed PEPs contributed meaningfully towards improving caregiver understanding of ASD and its management within everyday caregiving situations. *Thus, the field testing component related to improvement of caregiver knowledge in the fourth objective of the present study was achieved.*

5.3.3 Effectiveness of the PEPs in Improving Parental Confidence

The effectiveness of the developed Public Education Pamphlets (PEPs) in improving parental confidence related to Autism Spectrum Disorder (ASD) was examined using the confidence section of the pre-test and post-test questionnaire presented in Appendix XVI. The questionnaire included 10 confidence-based statements (C1–C10) related to understanding autism, awareness regarding rights and supports, intervention

participation, communication facilitation, behaviour management, sensory regulation, daily living skills and collaboration with teachers and therapists. The confidence statements were rated using a five-point Likert-type scale ranging from “Not confident at all” to “Very confident.”

The descriptive statistics presented in Table 4.36 demonstrated substantial improvement in total confidence scores following exposure to the developed PEPs. The mean total confidence score increased markedly from the pre-test phase (M = 16.30, SD = 1.87) to the post-test phase (M = 39.20, SD = 1.83). Figure 4.1 further showed consistently higher post-test confidence scores compared to pre-test scores, indicating notable improvement in caregiver confidence after exposure to the developed PEPs. The relatively stable distribution of scores additionally suggests that the improvement in confidence was observed consistently across participants. These findings indicate that the developed PEPs contributed positively towards improving parental self-confidence in understanding ASD and applying the information during caregiving situations.

The paired samples *t*-test findings further confirmed statistically significant improvement in total confidence scores following exposure to the developed PEPs, $t(9) = 27.392$, $p < .001$. The significant difference observed between pre-test and post-test scores suggests that the developed PEPs were effective in enhancing parental confidence related to ASD management and caregiving practices. The marked increase in confidence scores is clinically important because confidence influences the extent to which parents/caregivers actively use learnt strategies within everyday home routines and participate in intervention-related decision making.

The comparison of pre-test and post-test confidence scores further demonstrated statistically significant improvement across all 10 confidence statements included in the

questionnaire presented in Appendix XVI. The Wilcoxon Signed-Ranks Test findings presented in Table 4.38 showed statistically significant differences between pre-test and post-test scores for all 10 confidence statements ($p < .01$). Figure 4.3 additionally demonstrated negative Z values across all confidence statements, indicating improvement in post-test confidence scores compared to pre-test confidence scores following exposure to the PEPs. The magnitude of change was comparatively greater for statements C2 and C3, while relatively smaller changes were observed for statements C5 and C10. Overall, the findings demonstrated significant improvement in participants' confidence levels following exposure to the developed PEPs.

Significant improvement in confidence statement C1, related to explaining autism to a family member, indicated increased confidence in explaining ASD in a clear and understandable manner. Improvement in C2, related to understanding the child's legal rights and available supports, reflected one of the strongest gains and suggested improved awareness and confidence regarding rights and support systems available for children with ASD. Improvement in C3, related to knowing when to seek professional help, indicated increased confidence in recognising situations requiring professional consultation and timely intervention support.

Further improvement was observed in C4, related to participating actively in intervention planning, demonstrating enhanced confidence in engaging with professionals and contributing to intervention-related decision making for the child. Improvement in C5, related to using simple strategies to support communication at home, suggested improved confidence in implementing communication facilitation strategies within daily home routines, although practical application may require continued reinforcement and practice. Improvement in C6, related to using visual supports or simple routines to help the child

communicate, reflected enhanced confidence in using structured supports and routines to facilitate communication and participation in everyday activities.

Similarly, improvement in C7, related to identifying possible reasons behind challenging behaviour, indicated increased confidence in understanding and interpreting the possible functions of challenging behaviours in children with ASD. Improvement in C8, related to managing sensory difficulties at home in a calm manner, suggested improved confidence in handling sensory-related challenges using calm and supportive approaches within the home environment. Improvement in C9, related to teaching daily living skills step by step, reflected enhanced confidence in using structured and sequential methods to teach functional daily living skills. Improvement in C10, related to communicating and collaborating with teachers and therapists, indicated improved confidence in interacting and coordinating with professionals involved in the child's education and intervention, thereby supporting collaborative management of ASD.

Overall, the findings indicate that all five developed PEPs were effective in enhancing parental confidence across all 10 confidence statements included in the pre-test and post-test questionnaire. Greater improvements were observed in foundational areas such as understanding autism, awareness regarding rights and supports, help-seeking and participation in intervention planning, while comparatively smaller though statistically significant improvements were observed in practical application-based areas such as communication support and collaboration with professionals. These findings suggest that the developed PEPs contributed positively towards improving both caregiver self-efficacy and practical preparedness for caregiving situations.

The confidence-related findings of the present study are supported by previous literature showing that parent education and parent-mediated interventions improve

caregiver confidence, reduce confusion following diagnosis and strengthen practical caregiving participation (Karst & Van Hecke, 2012; Musetti et al., 2021). The significant confidence gains observed in the present study are particularly important because confidence affects whether parents actually use what they learn in real-life caregiving situations. When parents understand ASD better, they are more likely to use communication supports, behaviour strategies and structured routines consistently within the home environment and are also more likely to collaborate effectively with therapists and school systems (Schreibman et al., 2015; Wainer & Ingersoll, 2013; Brookman-Frazee & Koegel, 2004). Confidence therefore functions not merely as a secondary outcome but as an important mechanism through which parent education materials influence caregiving practices and long-term child outcomes (Karst & Van Hecke, 2012; Musetti et al., 2021).

The improvement in parental confidence observed in the present study also reflects increased caregiver empowerment and preparedness for active participation in intervention processes. Such findings are particularly important because parents/caregivers often experience uncertainty, stress and lack of confidence following an ASD diagnosis. Accessible and parent-friendly educational resources may therefore help families move from confusion towards informed caregiving action and collaborative participation with professionals. Parent education materials are considered most useful when they support both cognitive understanding and practical application within everyday family routines (Oono et al., 2013; Burrell & Borrego, 2012). Public education materials are additionally known to improve awareness, reduce stigma and facilitate more supportive responses from families and schools when the materials are clear, understandable and culturally adapted (Autism Society, 2024; CDC, 2025; NHS England, n.d.).

The practical utility of the developed PEPs is particularly relevant within the Indian context where many families continue to experience delayed diagnosis, limited awareness,

difficulty navigating intervention systems and unequal access to autism-related services (Chakrabarti, 2023; Chattopadhyay, 2024; Srivastava et al., 2023). Indian families have additionally been reported to require simple, culturally sensitive and practically useful autism-related educational resources that reflect local caregiving realities and service structures (Desai et al., 2012; Ramachandran, 2020; Dey et al., 2024). The developed PEPs addressed practical caregiving domains including communication support, behaviour understanding, sensory regulation, daily living skills and school collaboration, thereby providing guidance that parents/caregivers could potentially implement within home and community settings. Similar Indian institutional initiatives have also emphasised the importance of accessible and culturally relevant autism education materials for families (All India Institute of Medical Sciences New Delhi, 2015; All India Institute of Medical Sciences Guwahati, n.d.; National Institute for Empowerment of Persons with Multiple Disabilities, 2024). The importance of cultural adaptation in improving the usability and effectiveness of educational resources has also been highlighted by Singh (2023).

Following pilot testing and field testing, additional refinements were incorporated into the final versions of the PEPs based on participant feedback and observed usability considerations. Minor modifications included further simplification of explanations, strengthening of practical examples and refinement of presentation aspects to improve readability and caregiver comprehension. Technical concepts were further clarified and presentation features such as organisation, spacing and readability were refined to improve usability in real-world caregiving situations. These refinements enhanced the clarity, usability and dissemination readiness of the final materials prior to use within public and clinical settings. Similar recommendations regarding structured presentation, readability and accessible educational content have been highlighted by the Ministry of Education (2021). The process of revision following pilot implementation is important because

educational materials become more effective and user-friendly when they are refined based on real-world user experiences and feedback (Fernandes Moll et al., 2024).

Overall, the findings of the present study demonstrate that the developed PEPs were effective in improving parental confidence related to ASD across all 10 confidence-based statements included in the pre-test and post-test questionnaire presented in Appendix XVI. The significant improvement observed in total confidence scores and across all confidence domains indicates that the developed PEPs contributed meaningfully towards improving caregiver self-efficacy, practical preparedness and collaborative participation in caregiving situations. The developed materials also demonstrated practical utility, cultural relevance and dissemination readiness within the Indian context where accessible autism-related educational resources are greatly needed. Thus, the field testing findings indicated that the developed PEPs were effective in improving caregiver confidence related to ASD and its management. *Overall, the findings from the pilot study and field testing demonstrated the feasibility and effectiveness of the developed PEPs in improving caregiver knowledge and confidence, thereby achieving the fourth objective of the present study.*

CHAPTER VI

SUMMARY AND CONCLUSION

The present study primarily aimed to develop and validate five Public Education Pamphlets (PEPs) for parents and caregivers of children with Autism Spectrum Disorder (ASD) in the Indian context. It further aimed to evaluate their effectiveness in improving parental knowledge and confidence in applying the information in caregiving situations. The study followed a descriptive developmental research design with a preliminary evaluation component. It was carried out sequentially in four phases: review of literature, development of the PEPs, content and face validation followed by revision and finalization and pilot study followed by field testing. The PEPs were developed in English language using plain language principles, simple sentence structures, supportive visual cues and health-literacy frameworks such as the Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) and the Suitability Assessment of Materials (SAM) to improve readability, understandability, actionability and cultural suitability for families.

The five PEPs covered the major areas relevant to ASD caregiving, namely ‘Understanding Autism and Rights’, ‘Diagnosis, Evaluation, and Intervention Planning’, ‘Communication and Language Development’, ‘Behaviour, Sensory Skills, and Social Development’ and ‘Daily Living Skills, Home Routines, and Schooling’. The content was compiled through a detailed review of research studies, existing educational materials, standardized resources and input from domain experts. Subsequently, content validation of the developed PEPs was carried out by a multidisciplinary panel of 11 experts and face validity was established by five parents/caregivers of children with ASD. Both expert and parent responses were analysed qualitatively and quantitatively. Lawshe’s Content Validity Ratio (CVR) and a 3-point Likert-type rating scale were used for quantitative

analysis of expert and parent responses, respectively. A pilot study was performed on one parent/caregiver and the methodology was found suitable for implementation during field testing. A separate group of 10 parents/caregivers, distinct from the validation phase, participated in the field testing in order to minimise bias and practice effects. The field-test questionnaire included 15 knowledge items and 10 confidence items and the exposure period was limited to not more than two weeks. Responses obtained were subjected to statistical analysis; descriptive statistics, paired samples *t*-test for total scores and Wilcoxon Signed-Ranks Test for item-wise comparisons were performed.

The content validation findings showed that all five PEPs were rated highly by experts. All items in all five PEPs were retained, as all items exceeded the critical CVR value of 0.59 for 11 experts. The expert panel judged the materials for accuracy, clarity, cultural sensitivity and clinical relevance. The qualitative feedback from experts mainly suggested the use of simpler language, clearer explanations of technical terms such as DSM-5, ISAA, INCLEN and AAC, inclusion of more practical examples, better organisation through bullet points and numbered steps and improved spacing and visual clarity. These suggestions were incorporated into the revised versions of the PEPs, making them more readable, parent-friendly and clinically relevant.

The face validity findings also supported the acceptability of the materials. Parents/caregivers described the PEPs as easy to understand, useful, practical and relevant to daily caregiving needs. In PEP 1, 11 out of 12 items received complete agreement and one item related to UDID information received a slightly lower mean score of 2.8. In PEP 2, PEP 3, PEP 4 and PEP 5, all items received complete agreement with a mean score of 3.0 and no “neutral” or “disagree” responses were reported. The parent reviewers judged the materials for readability, relevance and usefulness for daily caregiving and advocacy. The parent feedback further suggested only minor improvements such as inclusion of

regional language versions, additional examples and helpline numbers. Overall, the validation process confirmed that the final PEPs were clear, acceptable and suitable for further field testing.

The field-testing findings demonstrated that exposure to the PEPs produced meaningful gains in both parental knowledge and confidence. The mean knowledge score increased from 4.60 in the pre-test phase to 12.30 in the post-test phase, while the mean confidence score increased from 16.30 to 39.20. The paired samples *t*-test showed statistically significant improvement in total knowledge scores, $t(9) = 8.062$, $p < .001$ and total confidence scores, $t(9) = 27.392$, $p < .001$. The Wilcoxon Signed-Ranks Test also showed statistically significant improvement across all 10 confidence statements. Item-wise analysis revealed improvement across all 15 knowledge items, with especially strong gains in understanding autism as a spectrum, early intervention, communication supports, behavioural explanations and collaboration with teachers and therapists. Smaller gains were observed in a few items such as rights-related knowledge, echolalia and dressing skills, suggesting that these areas may require further simplification and stronger practical examples in future versions. The greatest knowledge gains were observed in items such as K2, K6, K11 and K15, while comparatively smaller gains were observed in K3 and K7.

The overall findings indicate that the PEPs had a strong positive impact on both parental knowledge of ASD and confidence in applying that knowledge in caregiving situations. This is important because parent education is most effective when it helps caregivers apply learnt strategies within everyday routines and maintain intervention gains over time. The study also supports the idea that informed parents are better able to advocate for services, support communication and behaviour at home and collaborate effectively with school and therapy systems. The confidence-related findings additionally indicated improved caregiver self-efficacy and preparedness to participate actively in

intervention planning, home-based support and collaboration with professionals. In the Indian context, where awareness is uneven and families often face delayed diagnosis and weak referral pathways, structured public education materials can serve as an important bridge between recognition, intervention and daily caregiving support. This interpretation is aligned with research showing that Indian families of children with ASD experience unmet needs, coping strain, delayed care-seeking and gaps in awareness and referral support (Divan et al., 2012; Mahapatra et al., 2019; Chakrabarti, 2023; Chattopadhyay, 2024; Srivastava et al., 2023).

The present study concludes that the five Public Education Pamphlets developed for parents and caregivers of children with ASD were scientifically sound, parent-friendly, culturally relevant and effective in improving both knowledge and confidence. The robust content validity, face validity and significant pre- and post-test gains showed that the PEPs were not only accurate and acceptable but also practical in real caregiving situations. The revisions improved readability, usability and visual clarity, making the final versions more parent-friendly and practical. The final revised versions of the PEPs additionally demonstrated dissemination readiness for potential use in public awareness programmes, parent counselling and clinical settings. The findings support the use of structured, visually clear and culturally adapted educational materials as effective resources for parent education and early support in the Indian context. This conclusion is supported by literature showing that parent education and parent-mediated intervention improve child outcomes, parent engagement and daily caregiving capacity and should therefore be treated as an integral part of intervention rather than an optional add-on (Hyman et al., 2020; Oono et al., 2013; Schreibman et al., 2015; Bearss et al., 2015; Musetti et al., 2021).

The study also showed that parental knowledge and confidence are important outcomes in ASD education because they influence whether families apply what they learn

in everyday life. By improving understanding related to autism, communication, behaviour, sensory needs, daily living and schooling, the PEPs not only improved parental knowledge but also enhanced caregiver confidence in applying this information within caregiving situations. Thus, the final PEPs can be considered meaningful, culturally relevant and clinically applicable tools for strengthening caregiver empowerment and promoting informed participation in ASD management within the Indian context. Their usefulness is further reinforced by Indian literature emphasising the value of culturally relevant, parent-friendly autism information and family-professional partnerships in local service settings (Desai et al., 2012; Ramachandran, 2020; AIIMS New Delhi, 2015; AIIMS Guwahati, n.d.).

Implications of the Study

The findings of the present study have important implications for parent education, early support and family-centred caregiving practices in ASD. The developed PEPs may serve as practical educational resources for parents and caregivers to improve understanding of ASD and support implementation of home-based strategies. The materials may also assist clinicians during parent counselling, particularly at the time of diagnosis and early intervention planning when families require clear, accessible and structured information. This is especially relevant within the Indian context where delayed diagnosis, weak referral pathways and uneven awareness often affect timely access to intervention and informed decision-making (Divan et al., 2012; Mahapatra et al., 2019; Chakrabarti, 2023; Chattopadhyay, 2024; Srivastava et al., 2023).

The developed PEPs may be particularly useful in supporting everyday caregiving domains such as communication facilitation, behaviour management, sensory regulation, school participation and daily living skills. The materials may additionally support improved collaboration between families and professionals by helping caregivers better

understand intervention goals, strategies and available support systems. In the Indian setting, where many families experience limited access to specialist services and difficulties navigating intervention pathways, parent-friendly educational materials may help reduce confusion, strengthen caregiver confidence and promote more informed participation in caregiving and intervention processes.

The present findings are consistent with literature indicating that culturally adapted, practical and accessible educational materials are more usable and acceptable for families than highly technical resources and that expert and parent validation are essential for improving clarity, relevance and usability (Fernandes Moll et al., 2024; Ministry of Education, 2021; Desai et al., 2012; Ramachandran, 2020; AIIMS New Delhi, 2015; AIIMS Guwahati, n.d.).

The methodological framework adopted in the present study, including systematic literature review, development of culturally adapted educational materials, multidisciplinary expert validation, parent-based face validation, pilot testing and field testing using pre-test and post-test evaluation, may additionally serve as a replicable framework for future studies involving development and evaluation of parent education materials for other developmental disabilities and clinical populations. The structured validation and refinement procedures followed in the present study may therefore contribute towards development of evidence-based, culturally relevant and parent-friendly educational resources in diverse healthcare and rehabilitation settings.

Overall, the findings of the present study suggest that the developed Public Education Pamphlets (PEPs) are valid, acceptable, culturally relevant and practically useful educational resources that can support parents and caregivers of children with ASD within the Indian context.

Limitations and Future Directions

The present study had certain limitations. The sample size was limited, particularly for face validation and field testing, which may restrict the generalizability of the findings. In addition, field testing was conducted over a relatively short exposure period of two weeks and within a limited setting. The developed PEPs were also prepared only in the English language and their applicability across other Indian languages and sociocultural contexts was not examined in the present study.

Future studies should therefore validate the developed PEPs in larger and more diverse samples across different regions, languages and service settings. Further research may also evaluate the effectiveness of the PEPs in broader community-based and clinical populations in order to establish wider applicability. Adaptation of the materials into regional languages and audio-visual formats may further improve accessibility, usability and dissemination potential. Future studies may additionally examine the long-term effects of repeated exposure to the PEPs on parental knowledge, confidence, caregiving practices and family participation in intervention processes.

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Appendix I

Public Education Pamphlet 1

ALL INDIA INSTITUTE OF SPEECH AND HEARING
(An Autonomous Institute under the Ministry of Health and Family Welfare, Government of India)
Centre of Excellence- Assessed & Accredited by NAAC with "A" Grade;
ISO 9001-2015 Certified organisation
Naimisham Campus, Manasagangothri, Mysuru - 570 006

Understanding Autism & Rights

Simple, Practical Guide for Parents of Children with ASD

Pranjal Jain
Jayashree C. Shanbal

We would like to thank all the experts, parents and caregivers who contributed to this project.

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Purpose

This guide has been developed to provide parents and caregivers of children with Autism Spectrum Disorder (ASD) with foundational, accurate, and contextually relevant information about autism. The purpose of this material is:

- To enhance parental understanding of the nature of ASD, its early signs, and the process of identification and diagnosis.
- To address common misconceptions, increase awareness of the importance of early support.
- To inform families about the legal rights and entitlements available under the Rights of Persons with Disabilities (RPwD) Act, 2016.
- To empower parents to access appropriate services and advocate effectively for their child.

By presenting evidence-based information in clear and accessible language, this pamphlet seeks to reduce uncertainty, promote informed decision-making.

SAMPLE

Contents

What is Autism? 1

How is Autism Diagnosed? 2

Understanding Autism as a Spectrum 3

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Rights of People with Autism in India (RPwD Act 2016) 16

Disability Certificate: How to Get it and Why it Matters 17

Common Questions (FAQs) 18

Important Supports and Schemes 24

SAMPLE

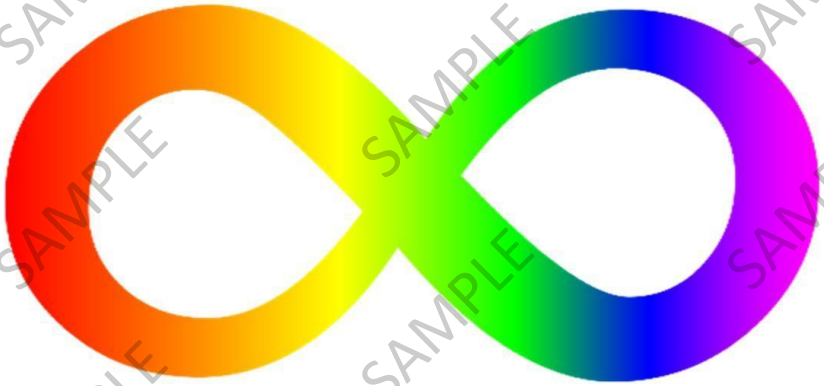
What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD), often called Autism, is a condition that affects how a person's brain develops and works. It changes the way they;

- Communicate
- Interact with people
- Behave

The word **"spectrum"** means that autism affects each person differently—with some having mild symptoms and others more severe. Autism usually shows signs before the age of 3 years.

Children with autism may learn and experience the world in unique ways, but they often need support in social and communication skills.



SAMPLE

How is Autism Diagnosed?

Doctors diagnose autism mainly by observing behaviour and development.

They look for ongoing difficulties with social communication and certain repetitive behaviours.

A careful check is done before age 3 to find signs early.

Tools like the ISAA, DSM-5 criteria and rating scales help professionals make a reliable diagnosis.

Sometimes, doctors may recommend tests like brain scans or genetic tests if there are unusual signs.

SAMPLE

Understanding Autism as a Spectrum

Autism is not the same for everyone. Some children might speak late or have trouble making eye contact, while others are very good with numbers or music.

People with autism have different strengths and challenges. It is important to remember each person's autism looks different.

SAMPLE

Core Features of Autism:

1. Difficulty in speaking and understanding others.

For example, your child :

- May make less eye contact than other children.
- May find it difficult to keep talking with others in a conversation.

SAMPLE

Core Features of Autism:

2. Finding it **difficult to interact socially**, such as playing with other children or sharing feelings.

SAMPLE

Core Features of Autism:

3. Repetitive actions or behaviors, like rocking, hand-flapping, or insisting on doing things the same way all the time.

Some children with autism repeat words or sentences that they hear from others instead of using their own words. This behavior is called **echolalia.**

SAMPLE

Core Features of Autism:

4. **Unusually strong interests** in specific topics or objects.

7

SAMPLE

Strengths Seen in Some Children with Autism

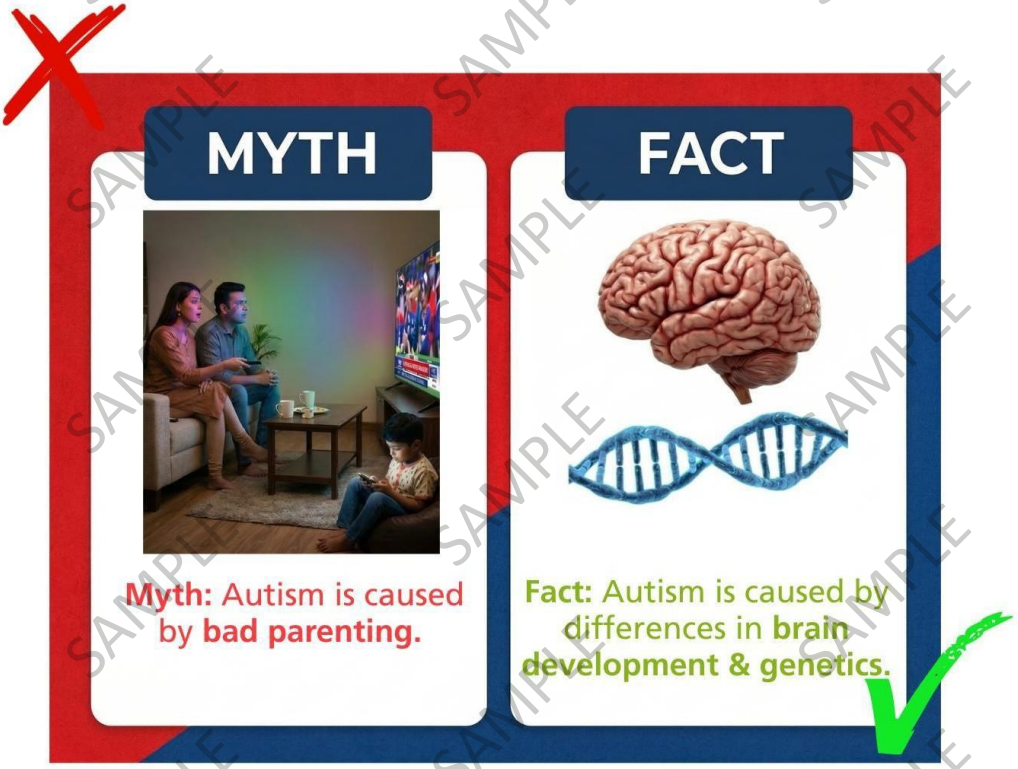
Children with autism may also show unique strengths, some children may have:

- Excellent memory
- Strong attention to detail
- Interest in numbers, music or patterns
- Ability to learn routines quickly
- Deep focus on favourite activities

These strengths can be used to **support learning and development.**

SAMPLE

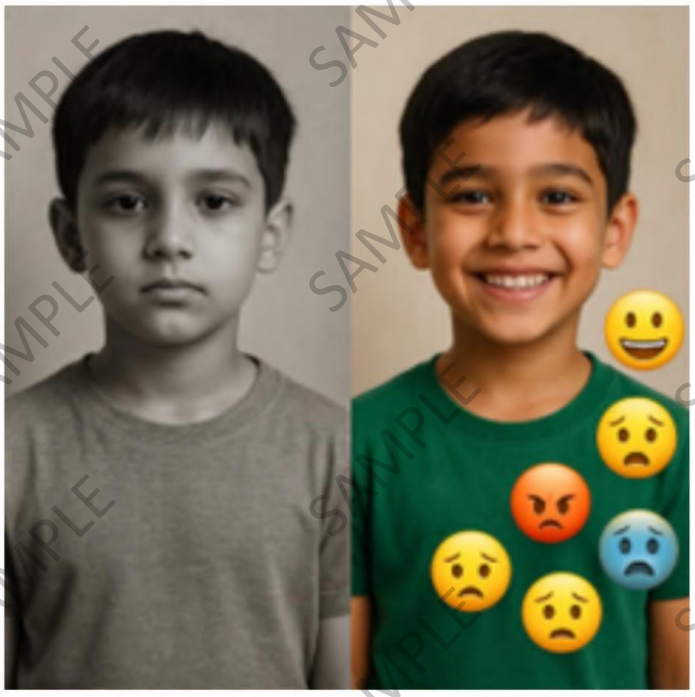
Common Myths About Autism:



"If your child has autism, it is not because of anything you did or did not do."

SAMPLE

Myth: People with autism do not feel emotions.

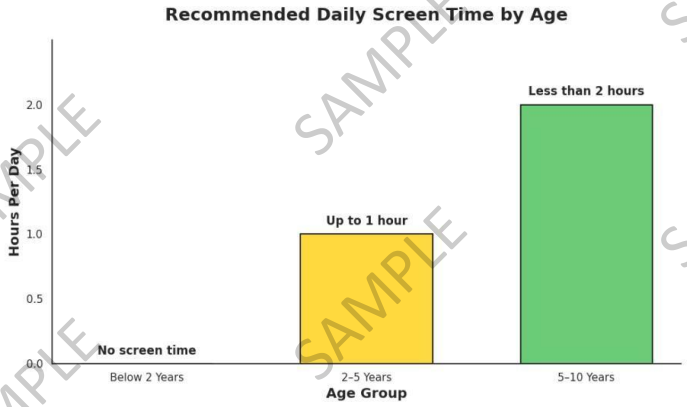


Fact: Children with autism do feel emotions but may show them differently.

SAMPLE

Important Message:

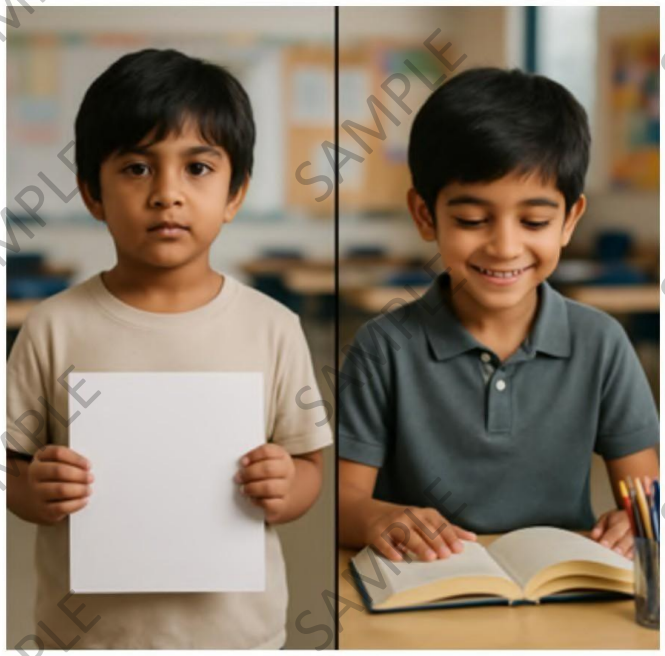
- Early childhood screen time does not directly cause ASD.
- Recent Indian studies have shown that children with high screen time before 18 months of age have a higher chance of developing ASD by 3 years of age.



Guidelines for Screen Use:

- Sit with your child and watch together (co-viewing).
- Do not use screens to calm, distract, or manage tantrums.
- Keep screens off during meals and 30–60 minutes before bedtime.
- Choose simple, slow-paced, and educational content.

Myth: All children with autism have intellectual disabilities.



Fact: Autism affects people differently—many have average or above-average intelligence.

Autism and intellectual disability are different conditions.

SAMPLE

Early Signs & Red Flags at Different Ages

Look for these signs and talk to a doctor if you notice:

- No babbling or gestures (like pointing or waving) by 12 months.
- No single word by 16 months
- No two-word phrases by 24 months

SAMPLE

Look for these signs and talk to a doctor if you notice:

- Poor response to their name
- Limited eye contact
- Lack of pointing or showing objects
- Losing language or social skills at any age

SAMPLE

Why is Early Identification Important?

Finding autism early helps children get the right support quickly. Early therapy can improve communication, behavior, and learning skills.

Regular checkups with pediatricians should include autism screening at 18 and 24 months.

SAMPLE

Rights of People with Autism in India (RPwD Act 2016)

The Rights of Persons with Disabilities Act protects the rights of autistic individuals.

It guarantees access equal opportunities in education, employment, and services.

India is also part of the United Nations Convention on the Rights of Persons with Disabilities, promoting dignity and inclusion.

16

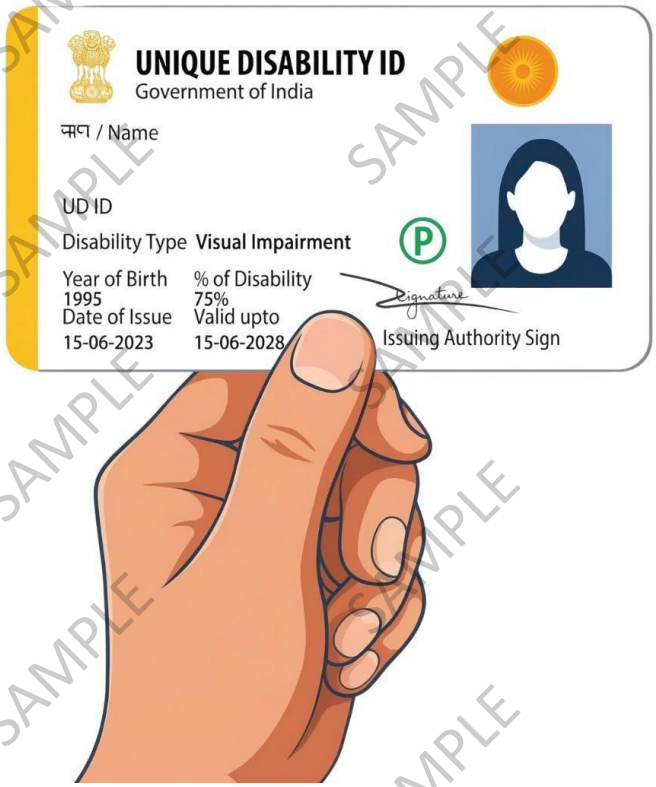
SAMPLE

Unique Disability ID Card (UDID) and Disability Certificate: How to Get it and Why it Matters

Apply at the nearest District Hospital with documents like photo ID, medical reports, and photos.

The certificate helps you get benefits like free or discounted travel, tax savings, special education, and government schemes.

Parents should check renewal requirements based on state guidelines.



SCAN HERE
For More Information

18

SAMPLE

Common Questions (FAQs)

Q: Can autism be cured?

A: There is no cure for autism, but with early therapy and support, many children can develop communication, independence and meaningful participation in school and society.

Early Therapy & Support

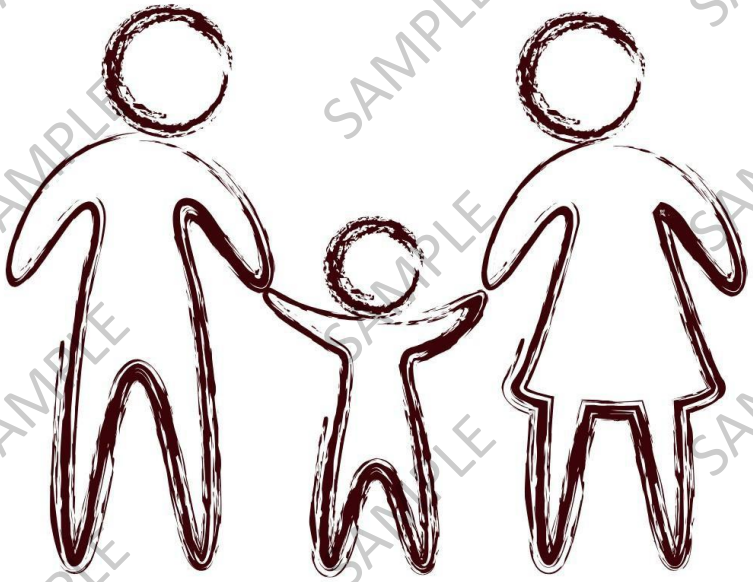
Brain development is fastest in the first 3–5 years.

SAMPLE

Common Questions (FAQs)

Q: Did I cause my child's autism?

A: Autism is not caused by bad parenting, it is not because of anything you did or did not do.



SAMPLE

Common Questions (FAQs)

Q: Can medications treat autism?

A: There is no medicine to treat autism itself, but some medicines can help with symptoms like anxiety, hyperactivity, or sleep problems.

Medicines should only be prescribed by qualified doctors.

SAMPLE

Common Questions (FAQs)

Q: Should I get a genetic test for my child?

A: Genetic testing is recommended if your child has unusual physical features or family history of autism or other conditions.

SAMPLE

Common Questions (FAQs)

Q: What professionals help in autism care?

A: A team of professionals including paediatricians, neurologists, clinical psychologists, speech language pathologist, occupational therapists and special educators work together to help children with autism.

SAMPLE

Important Supports and Schemes:

Niramaya Health Insurance:
Provides free or cashless inpatient and outpatient healthcare for people with disabilities, including autism.

Samagra Shiksha Abhiyan:
A program to help include children with disabilities in regular schools with extra support and scholarships like Gyan Prabha.

Special teachers, rehabilitation services, and help from **NGOs** are also available to support families and children.

SAMPLE

Trusted Websites & Support Services:
(Some Useful Resources)

Schemes:

National Trust Act

Samagra Shiksha – Inclusive Education for CWSN

UDID Portal (Disability ID Card Registration)

Guidelines for Certification of Autism (ISAA Tool)

Note: Because there are multiple QR codes on this page, your camera might accidentally scan the wrong one. Please cover the surrounding codes with a paper or your hand while scanning the code of your choice.

SAMPLE

Rehabilitation Council of India (RCI)

Department of Empowerment of Persons with Disabilities (MSJE)

Rights of Persons with Disabilities Act, 2016 (RPwD Act)

Note: Because there are multiple QR codes on this page, your camera might accidentally scan the wrong one. Please cover the surrounding codes with a paper or your hand while scanning the code of your choice.

Autism is a **lifelong condition**, but with early therapy and support, many children **develop communication, independence** and **meaningful participation** in school and society.

SAMPLE

DISCLAIMER!

This material is intended to provide general information and practical guidance for parents of children with Autism Spectrum Disorder (ASD).

The content is for educational purposes only and should not be considered a substitute for professional evaluation, diagnosis, or intervention.

As each child is unique, parents are advised to seek guidance from qualified professionals such as paediatricians, speech-language pathologists, occupational therapists, or psychologists and others for individualized support.

The suggestions provided may be adapted based on the child's needs, family context, and professional recommendations.

SAMPLE

SAMPLE

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Appendix II

Public Education Pamphlet 2

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Understanding Diagnosis, Assessment & Early Intervention

For Parents of Children with Autism Spectrum Disorder

Pranjal Jain
Jayashree C. Shanbal

We would like to thank all the experts, parents and caregivers who contributed to this project.

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Purpose

This guide has been developed to provide parents and caregivers of children with Autism Spectrum Disorder (ASD) with clear and structured information regarding diagnosis, assessment, and early intervention planning.

The purpose of this material is:

- To help families understand the early signs of autism, the multidisciplinary assessment process, and the roles of various professionals involved in evaluation and intervention.

- To explain what parents can expect during the diagnostic process, clarify commonly used assessment tools in the Indian context

- To highlight the importance of initiating early intervention and school planning at the earliest possible stage.

By presenting this information in accessible and practical language, the material seeks to reduce anxiety related to diagnosis, strengthen parental preparedness, and support informed participation in intervention planning.

SAMPLE

Contents

Autism Spectrum Disorder (ASD) 1

Early Signs to Watch For 8

How Autism is Diagnosed: The Team and the Tools 13

What Happens During the Assessment Process 15

Why Early Intervention is Important 18

Planning for Your Child's Schooling 21

Supporting Your Child During Intervention 23

Where to Get Help? 26

Other Health Conditions Sometimes Seen with Autism 27

Key Takeways 28

SAMPLE

What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD), often called Autism, is a condition that affects how a person's brain develops and works.

It affects the way a person understands, communicates, and behaves.

It usually starts showing signs before 3 years of age and continues throughout life.

Children with autism may find it harder to:

- Interact or play with others
- Communicate using words or gestures
- Adjust to changes or new routines

The word "**spectrum**" means that each child is different some have mild challenges, while others need more support in daily life.

"If my child was growing up in an autistic world, she wouldn't be the one with a disability — I would."

— Parent of a child with autism

2

SAMPLE

Autism is not caused by poor parenting or lack of love. It is a neurological difference, meaning the brain works and learns in a unique way.

SAMPLE

How Common is Autism?

Recent Indian studies estimate that about 1 in every 68 children may have autism.

It is seen more often in boys.

However, many girls go undiagnosed because they hide their difficulties or try to copy other children to "fit in."

SAMPLE

Autism may occur in any family — regardless of income, religion, or background.

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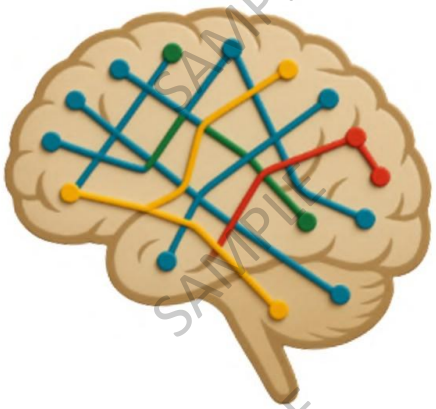
SAMPLE

Why Does Autism Happen?

The exact cause of autism is not fully known, but research shows that it develops due to a combination of genetic and brain development factors.

Some possible reasons why autism may happen include:

- The way the brain grows and connects may be a little different in some children.
- It may run in families — if someone in the family has autism or another developmental condition.
- Certain genetic or medical conditions.
- If parents are older during pregnancy, the chances may be slightly higher.
- Babies born very early or with very low birth weight may also have a higher chance.



SAMPLE

There is **no evidence** that vaccines, bad parenting, or emotional trauma cause autism.

7

SAMPLE

You might start noticing differences when your child is a baby or toddler.

Watch for these signs — especially in the first 2–3 years of life. Your child may:

- Avoiding eye contact or not understanding gestures like waving or nodding.
- Not pointing to things to show interest.
- Have little or no speech, or stop using words they had learned.
- Prefer to play alone or not notice other children.

AVOIDING EYE CONTACT

PLAYING ALONE

SAMPLE

Remember, not all children with autism show all these signs.

NOT RESPONDING TO NAME

AVOIDING EYE CONTACT

FLAPPING HANDS

PLAYING ALONE

SAMPLE

These signs can vary. Some children may talk early but struggle socially, while others may have delayed speech but good memory or music skills.

If you have any concern, talk to your child's doctor or pediatrician.

Early support makes a big difference.

SAMPLE

"I knew something was different when my son didn't play like other kids. But with early support, he started connecting more."

— Parent from Mysuru

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SAMPLE

How Autism is Diagnosed: The Team and the Tools

Autism is not a disease — it is a developmental condition that affects how a person understands, communicates, and behaves.

Some children may have mild symptoms, and some may need more support.

That's why it is called a spectrum.

There is no blood test or scan for autism. Diagnosis is made by watching your child's behavior and development.

SAMPLE

In India, the assessment is done by a team of experts, such as:

- **Developmental pediatrician or pediatric neurologist**: checks child's overall development.
- **Clinical psychologist**: studies behavior and emotions.
- **Speech-language pathologist (SLP)**: checks speech and communication.
- **Occupational therapist**: checks play, motor, and sensory skills.
- **Special educator:** looks at learning and classroom needs.
- **Social worker or counsellor**: guides parents and connects to services.

SAMPLE

Tools used in India include:

- ISAA (Indian Scale for Assessment of Autism): used for diagnosis and disability certificate.
- INCLEN Diagnostic Tool for Autism Spectrum Disorder

Usually, tests like EEG or MRI are not needed unless the doctor feels there may be other medical concerns, such as seizures or unusual head size.

SAMPLE

What Happens During an Autism Assessment

The process is detailed but gentle. The goal is to understand your child's strengths and needs, not to label them.

"The diagnosis didn't change my child — it just helped me understand him better and support him the right way."

— Parent from Bengaluru

SAMPLE

The assessment includes:

- **Parent interview:** You'll talk about your child's milestones, behavior, family history, and daily routine.
- **Direct observation:** The team observes how your child plays, communicates, and reacts.
- **Teacher/school input:** Helps understand your child's behavior in social settings.
- **Speech and language evaluation:** Checks understanding and expression.
- **Occupational therapy evaluation:** Studies sensory issues and daily activities.
- **Psychological evaluation:** Looks at learning and attention.

After the sessions, you'll get a report and a detailed discussion. The team will explain what it means and suggest therapies.

SAMPLE

Early Intervention:

Early intervention means starting therapies and support as soon as possible — even if you only suspect autism.

The earlier you start, the better the child learns communication, daily skills, and behavior.

Why Early Intervention Helps:

- The brain learns fastest in the early years.
- Early therapy improves speech, play and social skills.
- Children become more confident and independent.
- Parents learn how to manage behaviors calmly and positively.

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SAMPLE

Therapies that help:

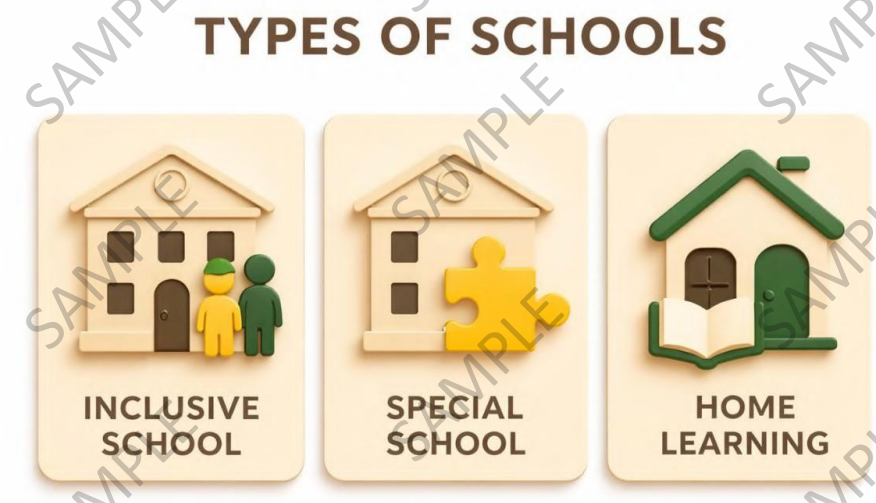
- **Speech therapy:** to develop communication, language skills and support feeding difficulties.
- **Occupational therapy:** to help with sitting, eating, dressing, and sensory needs.
- **Special education:** for learning and school preparation.
- **Behavior therapy:** to teach new skills step-by-step.
- **Parent training programs:** to help you use simple techniques at home.

SAMPLE

School Planning:

Children with autism can study in

- **Regular (inclusive) schools** – with extra support or a "shadow teacher."
- **Special schools** – for children who need more help.
- **Home-based or therapy-based learning** – for young children still developing early skills.



SAMPLE

Under the Right to Education (RTE) Act and the Rights of Persons with Disabilities (RPwD) Act, 2016, schools in India must include and support children with autism. You can ask for an Individualized Education Plan (IEP) for your child.

SAMPLE

Supporting Your Child at Home:

Your love and patience are your child's biggest strengths.

Therapies work best when parents and professionals work together.

Simple ways to support your child:

- Keep a daily routine — predictability helps them feel safe.
- Use simple language and repeat key words often.
- Use pictures, gestures, or signs to help communication.

SAMPLE

- Celebrate small steps — every effort matters!
- Don't force eye contact or social play — let it grow naturally.
- Teach through play and use your child's interests to motivate learning.
- Create a quiet corner for relaxation when your child feels overwhelmed.
- Stay calm and positive — children sense your emotions.

SAMPLE

Take Care of Yourself Too:

- Caring for a child with autism can be tiring.
- It's okay to ask for help or take short breaks.
- Join parent support groups — sharing experiences with other families can be helpful.

PARENT SELF-CARE

SAMPLE

Where to Get Help?

You can contact the nearest centre if you notice early signs or need guidance for therapy and support.

For Example;

- Government District Early Intervention Centres (DEIC) under Rashtriya Bal Swasthya Karyakram (RBSK).
- AIISH, Mysuru
- AYJNISHD(D), Mumbai
- PGIMER, Chandigarh

Local district hospitals, private clinics, and special schools may provide therapy services.

SAMPLE

Other Health Conditions Sometimes Seen with Autism

Some children with autism may also have conditions like speech delay, ADHD, sleep issues, or seizures.

Your doctor will help check for these and guide you to the right specialists.

SAMPLE

Key Takeaways:

- Autism is not a disease; it's a different way of understanding and reacting to the world.
- Early diagnosis and therapy can help your child learn and grow.
- Each child with autism is unique — focus on their strengths.
- You are not alone — help is available through government and community services.
- With love, patience, and consistency, your child can achieve amazing things.

SAMPLE

"Autism is not the end — it's the beginning of understanding your child's beautiful way of seeing the world."

SAMPLE

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The suggestions provided may be adapted based on the child's needs, family context, and professional recommendations.

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Appendix III

Public Education Pamphlet 3

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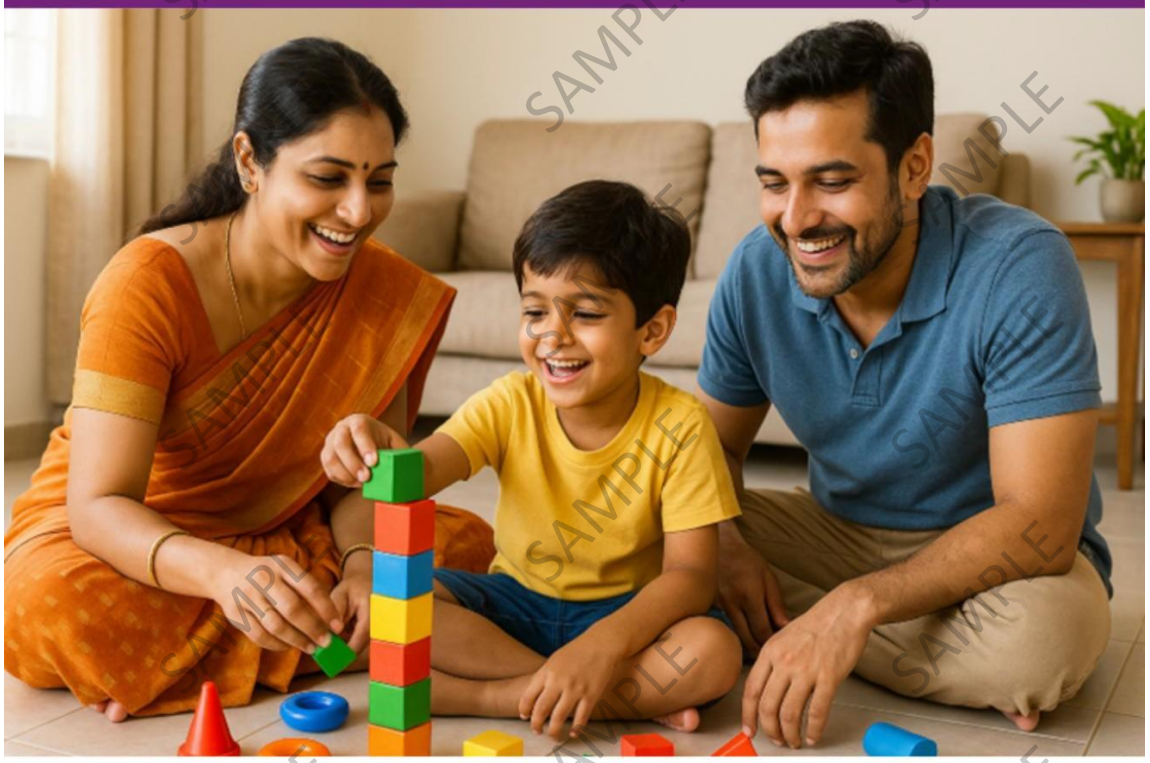
Helping Your Child Communicate and Develop Language

Simple, practical guide for parents of children with ASD



Pranjal Jain
Jayashree C. Shanbal

We would like to thank all the experts, parents and caregivers who contributed to this project.

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Purpose

This guide has been developed to provide parents and caregivers of children with Autism Spectrum Disorder (ASD) with practical guidance on communication and language development. The purpose of this material is:

- To enhance parental understanding of common communication challenges in autism, including speech delay, echolalia, and difficulties in social use of language.

- To explain the role of the Speech-Language Pathologist (SLP) and to equip parents with simple, evidence-based strategies that can be incorporated into everyday routines.

- To emphasize the importance of visual supports, structured interaction, and parent-led activities in fostering communication skills.

By presenting clear and actionable strategies, this pamphlet seeks to empower parents to actively support their child's communication development within home, school, and community settings.

SAMPLE

Contents

Understanding Communication Challenges in Autism 1

How a Speech-Language Pathologist (SLP) Helps Your Child 3

Simple Things You Can Do at Home (Do's and Don'ts) 5

Practical Activities & Step-by-Step Strategies 13

Using Visual Supports and Daily Activities to Build Communication 18

Parent-Led Play Programs 21

Minimally Verbal Children 22

School and Community 23

When to Seek Professional Support 25

Parents: Self-care & Support 28

SAMPLE

Understanding Communication Challenges in Autism:

Children with autism may have trouble with:

- Starting or keeping a back-and-forth (conversation, play, or looking at the same thing with you).
- Using words the way we expect (they may repeat phrases, use words for requests only, or speak oddly).
- Understanding gestures, tone, or jokes (they may take things literally).
- Playing in unusual ways (they may line up toys or play the same way again and again).

SAMPLE

These differences do not mean your child can't learn. They need different ways of teaching — more visual help, more practice in small steps, and lots of short, fun practice at home.

SAMPLE

How a Speech-Language Pathologist (SLP) Helps Your Child:

An SLP does much more than teach sounds. They will:

- Watch how your child play and talk.
- Through therapy, they will teach you simple ways to help your child use words.
- Reduce frustration by teaching alternative ways to communicate (gestures, pictures, or devices).
- Work on understanding (what your child hears) and expressing (what your child says).
- Suggest tools like picture cards, simple apps, or a communication book if your child needs them.
- Work with family members and teachers so everyone uses the same methods.

SAMPLE

What to Expect from an SLP Session:

You may expect:

- Short activities
- Fun games
- Modelling (they show you what to do)
- A home plan you can repeat daily

Ask the SLP for a short written plan (2–4 points) you can follow each day.

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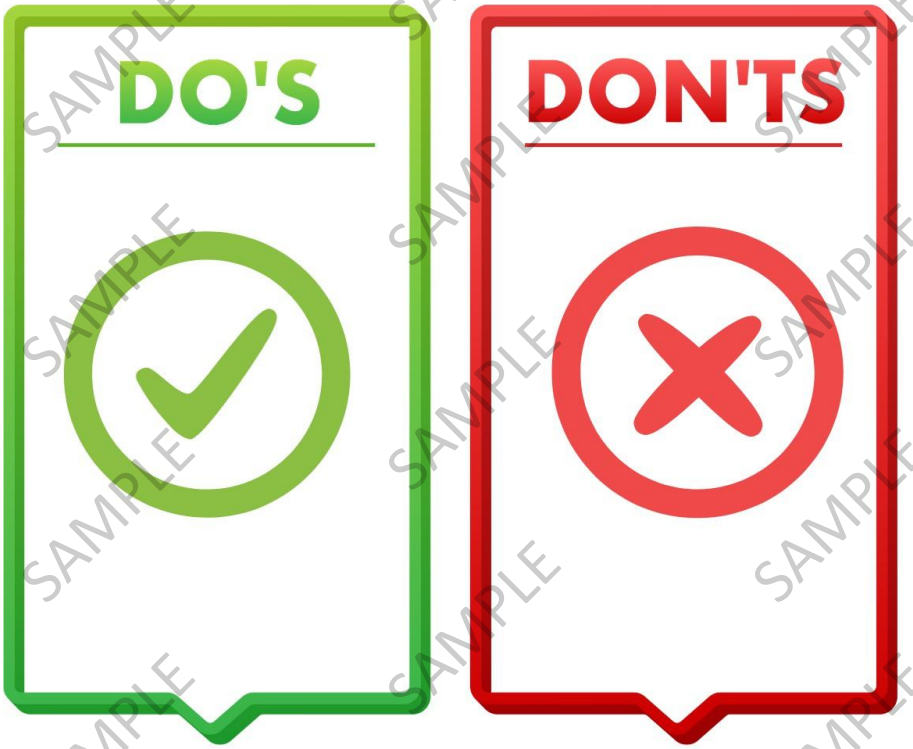

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SAMPLE

Do's — Simple Things You Can Do at Home:

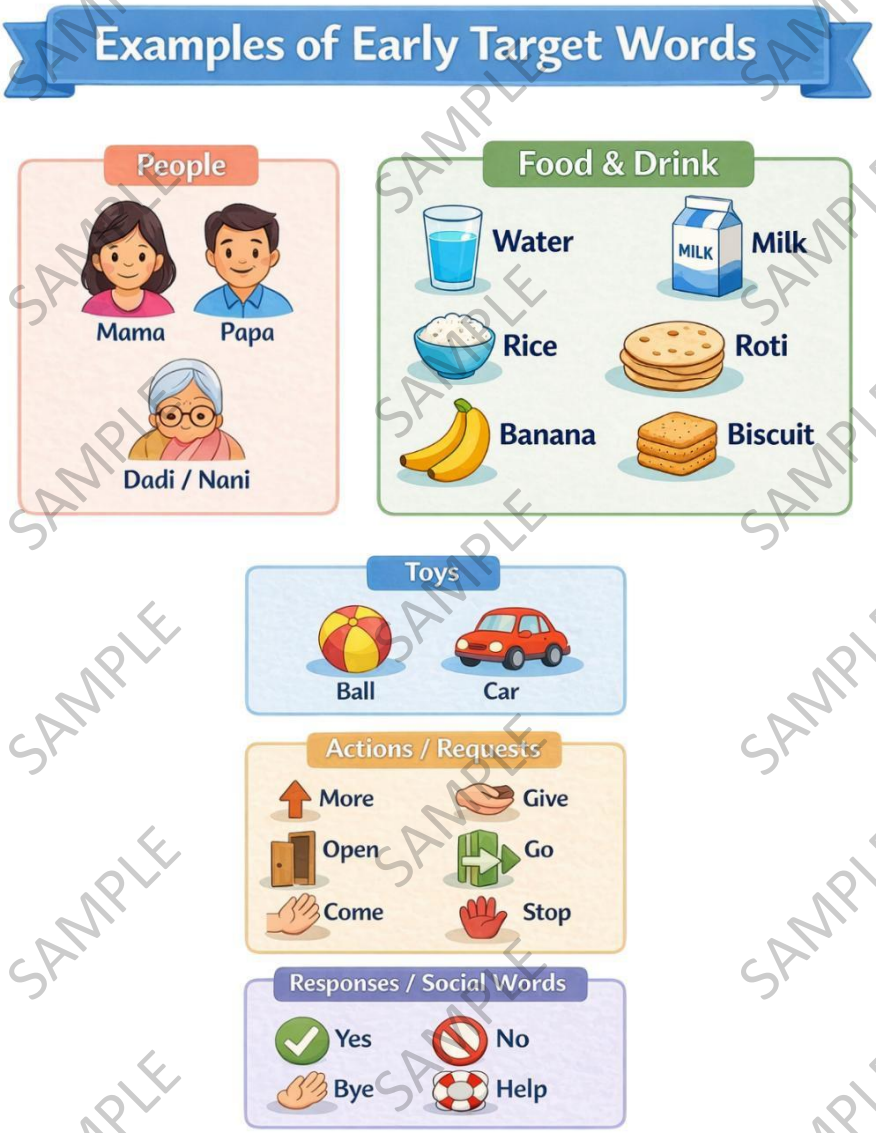
1. **Follow your child's lead.**
   - If they play with a car, join them with another car instead of changing the game.
   - Say short phrases:

   "Car go"→ wait for 10-15 seconds, then→ "Push car"

2. **Use short, simple language.**
   - One or two words first:
   - E.g., "More?", "Eat", "Ball."

SAMPLE

3. Early Functional Vocabulary Targets



Teach target words during daily activities, not by drilling or repeating alone.

Why these words matter:

- Ask for basic needs / request needs
- Express preferences
- Communicate with family members
- Participate in daily routines
- Reduce frustration
- Build communication confidence

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SAMPLE

How Communication typically Develops (Step-by-Step):

Looks / eye gaze
↓
Points / gestures
↓
Sounds / attempts
↓
Single words
↓
Two-word phrases

“All forms of communication are important — speech is not the only goal.”

SAMPLE

4. **Model** — don't quiz.
    - Instead of asking "What is this?" hold the toy and say "Ball."
    - Pause and wait for any reply.
5. **Respond to any attempt** (look, point, sound, word) — this encourages communication.
6. **Use choices to encourage words.**
    - Put two snacks in front of child and say: "Banana or biscuit?"
    - Pause for response; if none, model the word.
7. **Make requests** teach language.
    - Keep desired items slightly out of reach,
    - So your child has to ask or use a picture.

SAMPLE

8. **Build routines** with language.
   - Meal-time:

     "Wash hands" → "Sit" → "Eat"
   - Use the same words every time.
9. Use **visual supports** everywhere:
   - Daily routine
   - Shop
   - Temple
   - School bag
10. **Praise effort**, not only correctness.
    - "Good asking!" or "Well done!"
    - Even for a single sound or point.
11. **Short frequent practice,** beats long sessions.
    - 5–10 minutes
    - 4–6 times a day

Don’ts — what to avoid:

- Don’t repeat many instructions at once.
- Don’t force eye contact — it can be uncomfortable.
- Don’t correct every mistake harshly — gently model the right word.
- Don’t use complex language and long sentences expecting instant understanding.
- Don’t compare with other children — every child learns in their own way.

SAMPLE

Practical Activities & Step-by-Step Strategies:

1) Joint Attention Game — Look and Share:

Goal: Make your child notice what you notice and share interest.

- **Materials:** Any favourite toy or snack.
- **How:** Hold the toy, make a small sound, show it, and say "Look!" **Wait** 5–10 seconds. If child looks, smile and give toy. If not, tap toy gently and point.
- **Progress:** From looking at the toy→ pointing→ saying the word.

SAMPLE

2) Requesting with Choice Cards:

Goal: Encourage the child to ask (using gesture, picture, or word).

- **Materials:** Make 2–4 laminated pictures (magazine cutouts work). Put them on a board.
- **How:** When child wants something, show the board and wait.
- If they reach or point, respond quickly and give the item.
- **Model the word:** "Juice" + point to juice picture.

SAMPLE

3) One-Word Play:

Goal: Increase single-word vocabulary.

- Choose an action (push, clap, run).
- Do it and say the word each time:
- Clap. Then pause and wait.
- Reward with a small cheer and repeat. Use local songs or rhymes.

4) Imitation Play (mirror and actions):

Goal: Teach imitation and turn-taking.

- Sit across and copy your child's simple actions (clap, tap).
- Pause so child can copy you.
- Use short, fun turns:
  "My turn — your turn."

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SAMPLE

5) Turn-Taking Snack Routine:

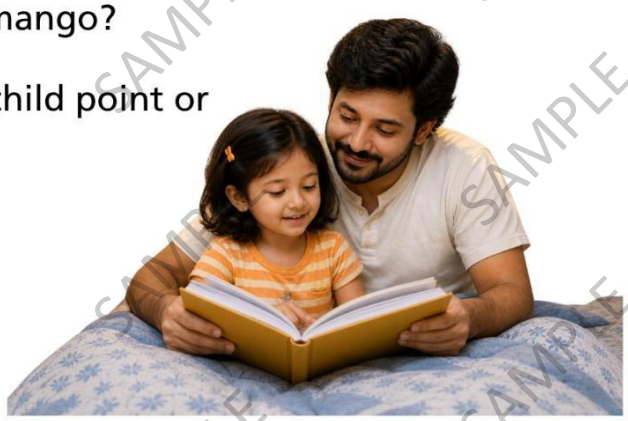
Goal: Teach waiting, eye contact, and simple exchange.

- Use small pieces of familiar foods (e.g., papad, chips, idli).
- Say "Your turn" then wait.
- If child gives any signal, say "Thank you" and give the snack.
- Gradually teach "Give" and "Thank you."

6) Picture Books with Predictable Phrases:

Goal: Build vocabulary and routine language.

- Use picture books (animals, fruits).
- Repeat the same line each page:
- Where is the mango?
- Mango!" Let child point or say the word.



SAMPLE

7) Daily Routine Visual Schedule

Goal: lower anxiety, increase understanding.

- Make 4–6 picture cards for daily routine (wake, brush, eat, school, play).
- Put them on a board. Remove each card after the task is done.

8) Praise effort, not only correctness.

- "Good asking!" or "Well done!"
- even for a single sound or point.

9) Short frequent practice beats long sessions

- 5–10 minutes, 4–6 times a day.

Using Visual Supports — low cost, high impact:

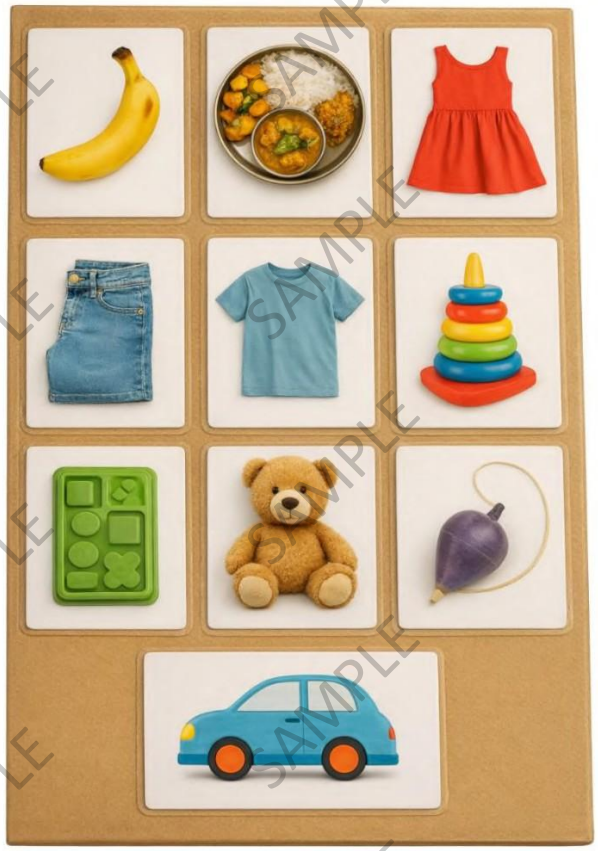
Examples of Visual Supports:

- **Picture cards** / photocopies of food, clothes, toilet, toys.
- **Visual schedule** (daily routine) — a row of 4–6 pictures.
- **Choice board** — 2–4 pictures for snacks or toys.
- **Social story card** — 3–4 pictures showing steps (e.g., "At the shop: stand, pay, take the item").
- **First-then board** — "First: homework, then: TV" (helps with transitions).

SAMPLE

How to make visuals cheaply:

- Use magazines, print photos from your phone, laminate with clear tape, or put in a small photo frame.
- Use cardboard, marker pen, and glue.
- Even simple drawings work.



SAMPLE

How to use visual support:

- Show, don't lecture.
  Hold up the card and say the word.
- Place visual where the child sees it
  (near the bed, in kitchen, on the school bag).
- Review the schedule every morning and before transitions (like leaving for school).

SAMPLE

Practical Tips for Daily Interaction:

Use these quick techniques often used in parent training programs:

- **Follow the child's lead** — join the activity they choose.
- **Match their pace** — slow down, don't rush.
- **Imitate and expand** — copy what they do, then add one more thing (child: "car"; parent: "car goes fast").
- **Create opportunities** — place a toy slightly out of reach so the child must communicate.
- **Use short sessions** — 5–10 minutes, multiple times daily in natural settings (kitchen, playtime, travel).

SAMPLE

Minimally Verbal Children:

What helps next:

- **Use simple picture communication:** your child gives a picture to ask for something and gets the item.
- **Use communication tools (AAC):** this means using pictures or simple apps to help your child communicate.

  Examples: a small photo book with common items, or a basic talking app on your phone.
- Ask your Speech-Language Pathologist (SLP) to guide you.
- Using these tools does not stop speech— it often helps children learn to speak.
- **Keep expectations small:** encourage any attempt to communicate (pointing, looking, reaching), then slowly shape it into words or using pictures.

SAMPLE

School and Community:

Working with Teachers & Extended Family:

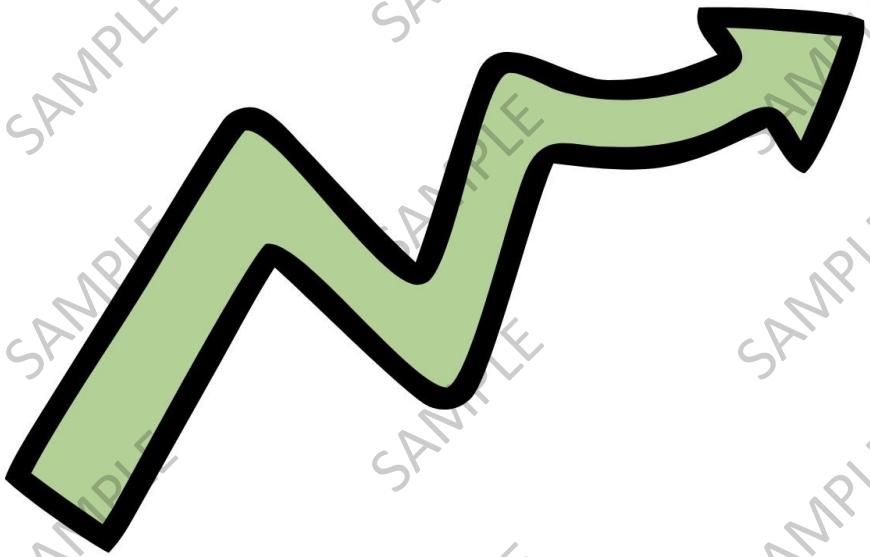
- Share the child's **2–3 home strategies** and the visual schedule with the school.
- Ask for a small "**communication box**" in class: picture cards and the daily visual.
- Train one trusted classmate (**peer buddy**) to include the child in structured play.
- Explain to relatives what helps and what upsets your child (no forcing hugs, give quiet space).

SAMPLE

Monitoring Progress — a very simple tracker:

Keep a notebook or phone note for 2 weeks. Each day, write:

- Day & date
- What activity (e.g., snack choice, book time)
- Child's response (point, word, gesture) — just a short note
- **One small win** (e.g., "Said 'ball' once")
- Share **this with the SLP every 4–6 weeks** — it helps show what's working.



SAMPLE

When to Seek Professional Help / SLP:

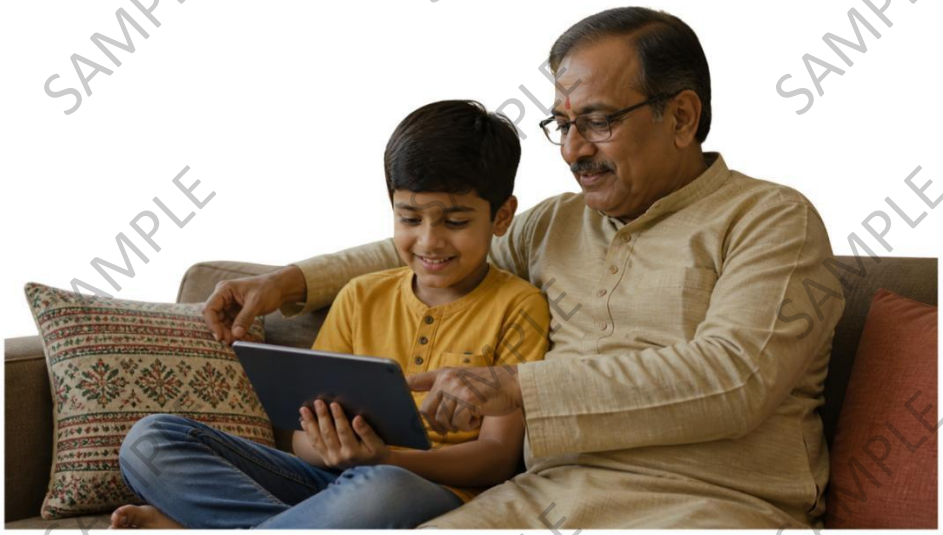
- If your child is not babbling or using gestures by 12 months.
- No single words by 16 months or no two-word phrases by 24 months.
- Limited response to name or lack of eye contact in interaction
- Sudden loss of words or social skills at any age.
- If you notice self-injury, severe sleep problems, or seizures — contact doctor immediately.

Bring your tracker and a short video of your child playing, to your Speech Pathologist — it helps diagnosis and planning.

SAMPLE

Simple Ways to Support Your Child at Home:

- Use **family members** (grandparents, aunt) as co-teachers — train them in one small routine.
- **Use everyday materials**: banana peels, bottles, bottle caps, clay — anything for play.
- **Use local songs and rhymes** — they are great for rhythm and language.
- If travel is difficult, ask about **tele-therapy (phone/video coaching for parents)**. Many SLPs now coach parents remotely.



SAMPLE

Simple Phrases You Can Use Daily:

Say it, then wait at least for 10-15 seconds :

Child reaches for toy

- → Parent: "Want car?"
- Then pause.
- If child responds, give toy and praise.

Child points to glass

- → Parent: "Juice?"
- Then pause.
- If no response, show picture of juice and say "Juice."

During play

- → Parent: "You push."
- Then pause.
- If child repeats or tries, say "Push car!" and clap.

Parents: Self-care & Support

- **Join local parent groups or WhatsApp groups** — share tips and small wins.
- **Take short breaks** — ask a relative to sit with the child for 10–20 minutes.
- **Celebrate progress** — even one new word or a calmer day is a big step.

SAMPLE

Start Now & Do it Today!

- Make **4 picture cards** for snacks and a simple visual schedule for the next day.
- **Try two joint attention games** (5 minutes each) today.
- Note one **win** in your tracker.
- If you don't already have an **SLP**, ask your paediatrician for a referral.

Small steps every day lead to meaningful communication over time.

SAMPLE

DISCLAIMER!

This material is intended to provide general information and practical guidance for parents of children with Autism Spectrum Disorder (ASD).

The content is for educational purposes only and should not be considered a substitute for professional evaluation, diagnosis, or intervention.

As each child is unique, parents are advised to seek guidance from qualified professionals such as paediatricians, speech-language pathologists, occupational therapists, or psychologists and others for individualized support.

The suggestions provided may be adapted based on the child's needs, family context, and professional recommendations.

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Appendix IV

Public Education Pamphlet 4

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Understanding Behaviour, Sensory Skills & Social Development

Simple, practical guide for parents of children with ASD

Pranjal Jain
Jayashree C. Shanbal

We would like to thank all the experts, parents and caregivers who contributed to this project.

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Purpose

This guide has been developed to provide parents and caregivers of children with Autism Spectrum Disorder (ASD) with practical and evidence-informed guidance on understanding behaviour, sensory processing differences, and social development. The purpose of this material is:

- To introduce simple behavioural understanding strategies to recognize underlying reasons for challenging behaviours , including identification of triggers and consequences
- To explain the role of Occupational Therapy in managing sensory and behavioural concerns.
- To explain sensory processing differences such as hypersensitivity and hyposensitivity.

By presenting structured yet parent-friendly guidance, this pamphlet seeks to promote positive behaviour management, improve emotional regulation, and support the child's social participation in daily environments.

SAMPLE

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SAMPLE

Understanding Your Child's Behaviour:

Behaviour is anything your child does — such as crying, shouting, avoiding, hitting, or even staying quiet.

Children with autism may find it difficult to use words to express their needs, feelings, or discomfort.

Because of this, they often use behaviour to communicate.

For example:

- Crying may mean "I am overwhelmed"
- Throwing things may mean "I don't want this"
- Walking away may mean "I need a break"

"Behaviour is not random — it usually has a reason behind it."

When we understand what the child is trying to communicate, it becomes easier to respond calmly and help them.

SAMPLE

Why Children with ASD Behave Differently:

Children with ASD behave in ways that may seem unusual because their brain processes information differently.

Common reasons include:

- Difficulty understanding language, instructions, or social rules
- Feeling unsafe in new environments, crowds, or noise
- Struggling with unexpected changes in routine
- Feeling overloaded by sensory input (lights, sounds, touch)
- Wanting predictability and sameness
- Using behaviour to communicate needs like: I want a break, I'm scared, I don't want this etc.

SAMPLE

How Parents Often React:

Many parents unknowingly respond in ways that increase challenging behaviour.

Common Parent Reactions that may not help:

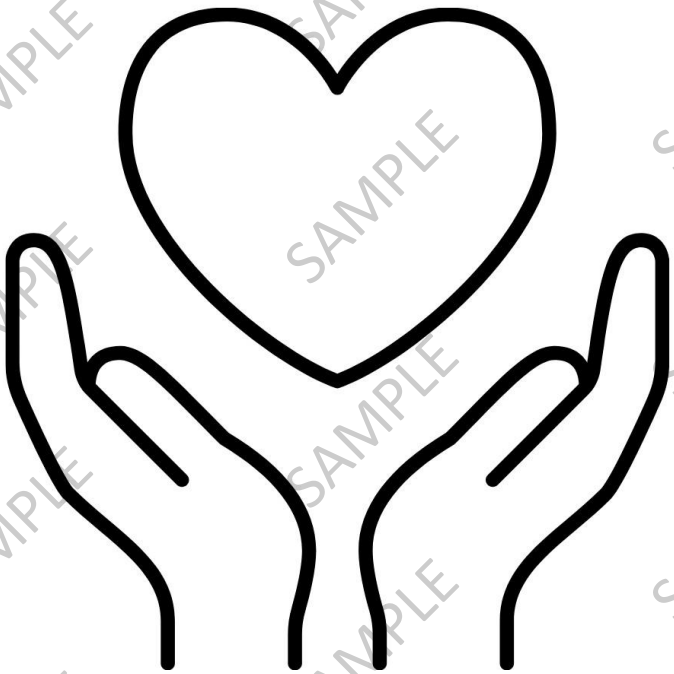
- Long lectures
- Saying "**Stop it!**" repeatedly
- Shouting or scolding
- Removing the child suddenly from the scene
- **Giving the child the mobile or snack** to end the meltdown
- Making the child "adjust" in sensory-heavy environments

SAMPLE

What Helps Instead

Easy Everyday Actions that helps:

- Using **short sentences** (“Sit here”, “Finish this”, “Come with me”)
- **Giving sensory breaks** (quiet corner, headphones, water breaks)
- Staying calm and neutral
- Rewarding small positive behaviours immediately
- Keeping routines **predictable**



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SAMPLE

- **Showing visuals** (“stop”, “wait”, “toilet”, “food”)
- **Preparing the child** for changes (“In 5 minutes we leave”)
- Offering **limited choices** (“Brush or wash face first?”)

Small daily changes create big improvements.

A Simple Tool That Helps Parents Identify Behaviour Triggers:

This helps you understand why the behaviour is happening and how to respond better.

ABC MODEL

1. A= Antecedent (What happened before?)

Ask yourself: What exactly happened 5–10 seconds before the behaviour?

Examples:

- **Fan made a sudden noise.**
- You said "Keep the phone away."
- Someone touched the child.
- Lights went off suddenly.
- A visitor entered.
- The child was asked to stop a favourite activity.

SAMPLE

ABC MODEL

Behaviour may occur to gain something (attention, item) or avoid something (task, noise).

2. B= Behaviour (What did the child do?)

Describe it without judgment:

- **He screamed and covered his ears.**
- She ran to the bedroom.
- He pushed the plate away.
- She cried and lay down on the floor.

Avoid describing the child as “naughty”, “stubborn”, “manipulating”.

Instead, Say what your child did, not what you think or feel.

❌ “He was being naughty.”
✅ “He threw the toy on the floor.”

SAMPLE

ABC MODEL

3. C= Consequence (What happened afterwards?)

Ask: What did the child gain or avoid because of the behaviour?

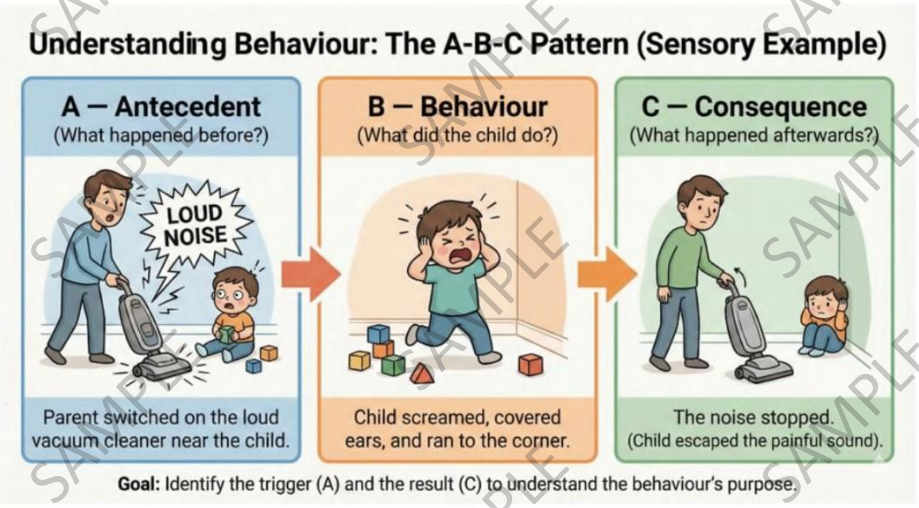
Examples:

- **The noise stopped**
- The task stopped
- Child got attention
- Child got his favourite toy
- Child was removed from the situation
- Child got physical comfort

This helps identify which behaviour is being unintentionally rewarded.

SAMPLE

ABC MODEL



Example of how behaviour can be understood using the ABC model

Detailed Practical Behaviour Example Before & After:

Example 1: Child throws things when asked to eat food

BEFORE:

Parent gives food

Child pushes plate, cries

Parent removes plate

Child gets snacks later

ABC Analysis:

A: Presented food

B: Throwing, crying

C: Food removed → child gets preferred food later

Child learns: "If I throw → I don't have to eat this."

SAMPLE

Example 1: Child throws things when asked to eat food

CORRECT PLAN:

- Give small portion first
- Sit together for 2 minutes only
- Give a sensory break before eating (jumping 10 times)
- Use visual card: "First eat → then bubbles"
- If child cries, stay calm but do not remove plate
- Offer one bite from parent's hand
- Reward immediately after 2 minutes sitting
- Increase time slowly each week

SAMPLE

Example 1: Child throws things when asked to eat food

<u>Outcome after 10–14 days:</u>

- Child throws plate less
- Sits for longer
- Attempts few bites
- Mealtime becomes smoother

NOTE: If your child shows **strong distress**, pause and try again later gradually.

SAMPLE

Some behaviours are also influenced by sensory differences.

Example 2: Child runs away in public places

Why it may happen:

- Hypo-sensitive = needs movement
- Does not understand danger
- Overwhelmed by crowd/noise
- Loves the thrill of running

Correct Strategy:

i. Before leaving home:

- Give heavy work (push chair, carry bag)
- Explain outing using visual schedule
- Use safety measures (e.g., holding hands, safety harness if needed)
- Hold hand firmly

SAMPLE

Example 2: Child runs away in public places

ii. During outing:

- Give breaks (sit on bench, deep pressure hug)
- Keep outings short
- Avoid peak crowd time
- Keep snacks, water, headphones

iii. After returning home:

- Praise: "You walked safely. Good job."
- Give reward (favourite activity)

Example 2: Child runs away in public places

Outcome after 3–4 weeks:

- Less running
- Better hand-holding
- More confidence in public places

SAMPLE

Improving Social Skills Naturally at Home:

Simple daily activities that help: Use these activities daily during routine interactions.

- Playing catch-catch
- Rolling ball back and forth
- Watering plants together
- Helping in cooking (washing vegetables)
- Sorting clothes
- Sharing snacks
- Practising simple social words (“hi”, “bye”, “thank you”)
- Turn-taking games (Ludo with simplified rules)

SAMPLE

Rewarding Good Behaviours (Reinforcement):

Golden Rules:

- ✓ Reward immediately
- ✓ Start with small goals
- ✓ Keep it specific (“sit for 2 minutes”)
- ✓ Never take back earned rewards
- ✓ Don’t reward negative behaviour
- ✓ Use visual reward charts

SAMPLE

Occupational Therapy (OT): What It Does for Your Child

OT helps with:

- Sensory issues
- Sitting tolerance
- Attention
- Hand skills
- Eating issues
- Balance and body awareness
- Dressing, bathing, toilet independence
- Play and social skills

OT uses sensory integration, it means

Giving the right sensory input
→
to help the child stay calm and organised.

SAMPLE

Understanding Sensory Processing:

Children with ASD often have sensory processing differences.

(Hyper vs Hypo)

SAMPLE

A. Hyper-sensitive: Feels too much

Child over-reacts to sensory input.

Example behaviours:

- Covers ears for mixer, pressure cooker
- Avoids touch, haircuts
- Does not like bright shops
- Cries in crowded places
- Refuses new clothes

SAMPLE

B. Hypo-sensitive: Feels too little

Child under-reacts and seeks strong input.

Example behaviours:

- Keeps jumping
- Runs everywhere
- Mouths objects
- Crashes into pillows
- High pain tolerance

Both can happen in the same child (for different senses).

SAMPLE

Practical Home Sensory Activities

A. For Hyper-Sensitive Kids: Too Sensitive

Helps calm down

Tactile:

- Soft cotton clothes
- Remove clothing tags
- Wrap your child gently in a blanket
- Slow lotion massage

Auditory:

- Noise-cancelling headphones
- Soft music
- Avoid loud functions

SAMPLE

Visual:

- Soft lighting
- Avoid flashing cartoons
- Sunglasses outdoors

Movement:

- Slow rocking
- Hugging pillow
- Pushing wall ("wall push-ups")

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SAMPLE

B. For Hypo-Sensitive Kids: Need Strong Input

Helps increase alertness and reduce rough behaviour

Tactile:

- Play with rice, rajma, sand
- Water play
- Textured cloth

Movement:

- Jump on mattress
- Crawl under chairs ("tunnel")
- Push bucket or stool
- Throw ball into bucket

SAMPLE

Oral-Motor:

- Thick milkshake through straw
- Chewing carrot sticks, roasted chana
- Blow bubbles
- Bubble balloon race

Auditory:

- Clapping games
- Singing at different volumes

Visual:

- "Find the object" game
- Flashlight follow game

SAMPLE

When to Seek Professional Help

Contact your therapist when:

- Meltdowns happen frequently
- Child hurts self/others
- Child stops eating certain textures
- Sleep is disturbed often
- Child is unaware of surroundings
- School refuses cooperation
- Sensory issues affect daily functioning

Early guidance creates long-term success.

SAMPLE

Final Note for Parents:

Your child is not giving you a hard time.

Your child is having a hard time.

With simple routines, sensory support, and consistent responses, behaviour improves and your child begins to thrive.

You are doing your best — and your child is trying too.

SAMPLE

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As each child is unique, parents are advised to seek guidance from qualified professionals such as paediatricians, speech-language pathologists, occupational therapists, or psychologists and others for individualized support.

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Appendix V

Public Education Pamphlet 5

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Daily Life, Home Routine & School Support

Simple, practical guide for parents of children with ASD

Pranjal Jain
Jayashree C. Shanbal

We would like to thank all the experts, parents and caregivers who contributed to this project.

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Purpose

This pamphlet has been developed to support parents and caregivers of children with Autism Spectrum Disorder (ASD) by providing guidance on daily living skills, home routines, school readiness, and collaborative support. The purpose of this material is:

- To help families understand how everyday activities such as toileting, eating and dressing can be taught using simple, step-by-step approaches.

- To provide practical strategies for creating predictable home routines using visual supports, preparing children for school, and making informed choices about inclusive or special schooling.

- To highlight the importance of collaboration between parents, teachers, and therapists, while promoting gradual independence across home and school settings.

By offering realistic and culturally relevant suggestions, this pamphlet aims to build parental confidence, support functional skill development, and enhance the child's participation in daily life.

SAMPLE

Contents

Helping Your Child in Daily Activities 1
(Toilet-training, eating and dressing step by step)

Creating Simple Home Routines Using Visual Schedules 11
(Morning routine, mealtime, playtime and bedtime)

Getting Your Child Ready for School 20
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(Inclusive school v/s special school)

Working Together: Parents, Teachers and Therapists 37
(Regular communication & shared goals)

Encouraging Independence at Home and in School 47
(Building confidence through small daily tasks)

SAMPLE

Daily Life, Home Routine and School Support:

Children with Autism Spectrum Disorder (ASD) often need extra support in daily activities, routines, and school adjustment.

This does not mean they cannot learn or become independent.

It means they learn differently, and at their own pace.

This guide will help parents understand what to expect, what to do at home, and how to support their child calmly and practically.

SAMPLE

Helping Your Child in Daily Activities:

Many parents worry when their child finds everyday activities difficult — using the toilet, eating meals properly, or getting dressed.

Please remember one important thing first:

"Your child is not refusing on purpose and is not lazy or careless."

Children with Autism Spectrum Disorder often find daily activities hard because their body, senses, and understanding work differently.

These skills usually take more time, more repetition, and more support.

Your role as a parent is not to rush the child, but to guide them calmly, one step at a time.

SAMPLE

Toilet Training: What parents commonly face

Many parents feel stressed about toilet training. This is one of the most common concerns in children with ASD.

You may notice that:

- Your child does not tell you when they need to use the toilet
- Accidents happen even after many attempts
- Your child avoids the bathroom
- They are scared of flushing sounds or water
- They don't like sitting on the toilet seat

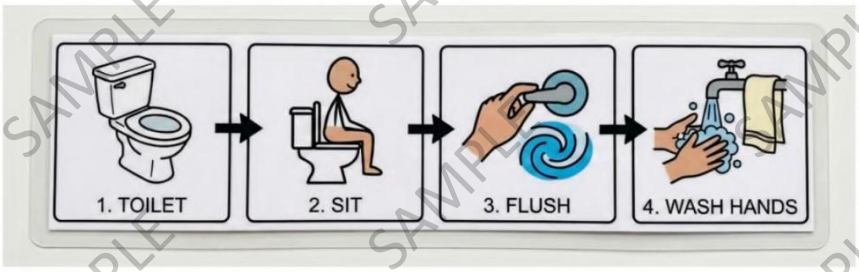
This happens because:

- Your child may not feel body signals clearly
- The bathroom may feel too noisy or uncomfortable
- The whole process feels confusing or scary

SAMPLE

Simple ways to help:

- **Start toilet training** only when your child shows some readiness
- Take your child to the toilet at the same time every day
- **Use simple pictures** showing toilet → sit → flush → wash hands



Visual Schedule for Toilet Training

SAMPLE

What parents can do at home:

- Allow your child to sit for a short time, even if nothing happens
- Do not punish or scold for accidents
- Praise your child for trying, even if they don't succeed
- What usually improves:
  - With routine and calm practice, fear reduces and awareness slowly increases.

Visual Schedule for Toilet Training

Eating and Mealtime – Understanding your child:

- Many children with ASD are picky eaters.
- This is usually due to **sensory sensitivity**, not bad behaviour.
- Understanding this helps you respond more calmly and choose the right strategy.
- **You may notice:**
  - Your child eats the same food every day
  - They refuse new foods
  - They gag or spit certain textures
  - They don't sit for long at meals
- This usually means the food feels uncomfortable to them, not that they are being difficult.

SAMPLE

Eating and Mealtime – Practical steps:

- Keep fixed mealtime timings
- Offer familiar food along with one small new item
- Let your child touch or smell food first
- Do not force your child to eat.
- Keep the eating area calm and quiet
- Eat together when possible

What usually improves:

Less stress during meals and slow acceptance of new foods.

SAMPLE

Dressing – Why it takes time:

Dressing is not a single skill. It involves:

- Understanding steps
- Using hands properly
- Tolerating clothing sensations

You may notice:

- Refusal to wear certain clothes
- Difficulty with buttons, zips, shoes
- Taking a long time to dress

SAMPLE

Try this at home:

- Choose soft, comfortable clothes
- Teach one step at a time
- Show pictures for dressing steps
- Give extra time and avoid rushing
- Appreciate effort, not perfection

What usually improves:

- Confidence, Cooperation and Gradual Independence.

Visual Schedule for Dressing

Important reminders for parents:

- Progress is slow but meaningful
- Some days will be harder than others
- Regression can happen during illness or stress
- Comparison with other children is not helpful
- Your calm behaviour helps your child feel safe

Daily activities improve best when your child feels supported, not pressured.

SAMPLE

Creating Simple Home Routines Using Visual Schedules:
(Morning routine, mealtime, playtime, bedtime)

Many parents feel that their child becomes upset, confused, or uncooperative during daily activities.

Very often, this happens not because the child is stubborn, but because they don't know what is coming next.

Children with Autism Spectrum Disorder usually feel safer and calmer when life is predictable.

Clear routines help your child understand:

- What will happen
- When it will happen
- What is expected from them

This is where simple home routines and visual schedules become very helpful.

SAMPLE

Why routines are especially important for your child

Your child may:

- Get upset during sudden changes
- Ask the same question again and again
- Resist moving from one activity to another
- Cry or have meltdowns during transitions

This happens because:

- Understanding spoken instructions is hard
- Time concepts like “later” or “after some time” are confusing
- Visual information is easier to understand than verbal instructions

Visual schedules show your child what will happen instead of only telling them.

SAMPLE

What is a visual schedule?

A visual schedule is:

- A set of pictures
- Arranged in order
- Showing your child what activities will happen

It can be:

- Drawings
- Printed pictures
- Photos taken on your phone
- Hand-drawn stick figures

You do not need expensive materials. Simple paper and pictures work well.

Morning Routine – Starting the day calmly

Mornings are often stressful for parents and children. Your child may:

- Refuse to get up
- Get distracted
- Take a long time to get ready
- Cry before school

A simple morning visual schedule can include:

- Wake up
- Brush teeth
- Bath
- Wear clothes
- Breakfast
- School or activity

"Preparing your child before transitions (e.g., '5 minutes more, then stop') can prevent many behaviour difficulties."

SAMPLE

Start with 2–3 pictures and increase gradually

Place the pictures:

- On the wall
- On the cupboard
- Near the bed

How parents should use it:

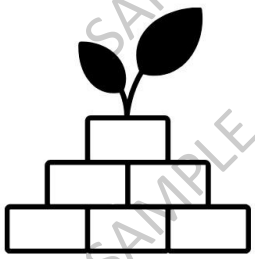
- Point to the picture instead of repeating instructions
- Say short sentences:

  "First brush, then bath"

- Let the child remove or tick off pictures as each step is done

What usually improves:

Less confusion, fewer arguments, smoother mornings.



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SAMPLE

Mealtime Routine – Reducing stress during eating

Children with ASD often feel overwhelmed during meals. **A simple mealtime visual routine can help, for eg.,**

1. Wash hands
2. Sit at table
3. Eat food
4. Drink water
5. Clean hands
6. Done

Parent tips:

- Keep mealtime timing fixed
- Avoid TV or mobile during meals
- Sit with the child initially
- Use the same place and utensils daily

What usually improves:

Better sitting tolerance and calmer meals.

SAMPLE

Playtime Routine – Helping your child play meaningfully

Play helps develop communication, attention, and social interaction skills.

Many parents say:

- "My child doesn't know how to play"
- "They only play with one thing"
- "They keep repeating the same activity"

This is common in ASD. Instead of expecting free play immediately, structure playtime.

Simple play routine:

1. Choose toy
2. Play
3. Clean up
4. Next activity

Start with:

- 5–10 minutes only
- Toys your child already likes

Use pictures for:

- Toy box, Play & Clean-up

What usually improves:

Better attention, reduced frustration, easier transitions.

SAMPLE

Bedtime Routine – Helping your child sleep better:

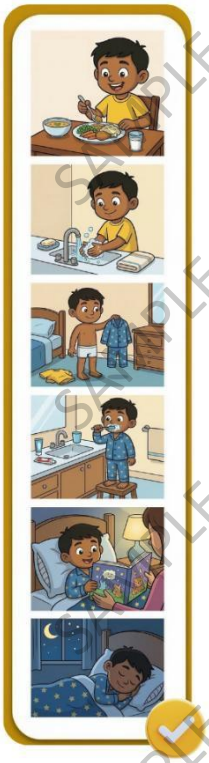
Sleep difficulties are very common in children with ASD. Your child may:

- Resist going to bed
- Take long to fall asleep
- Wake up frequently

A fixed bedtime routine helps the body understand it is time to rest.

Simple bedtime visual routine:

1. Dinner
2. Wash hands
3. Change clothes
4. Brush teeth
5. Story / quiet time
6. Sleep



Parent tips:

- Keep the same bedtime daily
- Reduce lights and noise before bed
- Avoid screen time before sleep
- Follow the same order every night

What usually improves:

Faster settling and better sleep patterns over time.

SAMPLE

How parents should talk while using routines:

Use:

- Short sentences
- Same words every day
- Calm tone
- Praising your child is called **positive reinforcement** — it helps the behaviour happen again.

Avoid:

- Too many instructions at once
- Rushing the child
- Changing routine suddenly without warning

If a change is unavoidable:

- Tell your child earlier
- Show the change visually
- Reassure them calmly

"Small steps done daily create big changes over time."

SAMPLE

Getting Your Child Ready for School:
(Attention, sitting tolerance and following instructions)

Many parents worry about school readiness and often ask:

- "My child doesn't sit in one place"
- "They don't listen to instructions"
- "How will they manage in school?"

It is important to understand that school readiness for a child with ASD is not about reading, writing, or academics.

It is mainly about comfort, tolerance, and basic participation.

Your child does not need to be **"perfect"** before starting school.

They need gradual preparation and realistic expectations.

SAMPLE

Understanding Attention in children with ASD:

Your child may:

- Focus well on favourite activities (mobile, toys, cartoons)
- Lose attention quickly during tasks they don't like
- Appear distracted or "lost"

This does not mean your child cannot attend.
It usually means:

- Attention is interest-based
- Long sitting is tiring
- Verbal instructions are hard to process

Attention can be trained slowly, not forced.

SAMPLE

How parents can build attention at home:

Start small and realistic.

At home, try:

- Sitting for 2–3 minutes initially
- Using activities your child enjoys
- Increasing time slowly (not suddenly)

Examples:

- Sorting vegetables
- Matching socks
- Looking at picture books
- Simple puzzles
- Coloring for a short time

"Praise effort, not duration

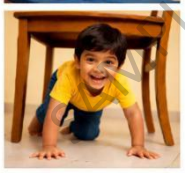
Stop before the child gets upset"

Outcome over time:

Your child learns that sitting is manageable, not stressful.

SAMPLE

Building sitting tolerance (without pressure):



Your child may:

- Stand up frequently
- Sit on the floor instead of a chair
- Rock or move while sitting

What parents should do:

- Allow movement breaks
- Use chairs with foot support
- Let the child sit on the floor if needed initially
- Keep sitting activities short and meaningful

Avoid:

- Forcing long sitting
- Scolding for movement
- Comparing with other children

Outcome over time:

The child slowly increases sitting time and feels safe.

“Sitting tolerance is about comfort, not discipline.”

SAMPLE

Helping your child follow instructions:

Children with ASD often struggle with verbal-only instructions.

Instead of saying: "Go inside, wash hands, sit down and eat". Break it into steps and show visually.

Parent strategies:

- Give one instruction at a time
- Use gestures or pictures
- Wait before repeating
- Use the same words daily

Examples:

- "Sit" (gesture to chair)
- "Eat" (show spoon)
- "Come" (hand gesture)

Use:

- Same instruction words
- Calm voice
- Always wait at least 5–10 seconds. Many children need extra time to understand and respond.

Preparing for classroom-like situations at home:

You can gently simulate school-like activities at home.

Try:

- Sitting at a table for short activities
- Group activities with siblings
- Waiting for turn during games
- Carrying school bag inside the house
- Following a small schedule

This helps your child get used to:

- Structure
- Adult instructions
- Transition between tasks

Important truths for parents to remember

- Your child does not need to "behave like others" to attend school
- Attention improves with routine, not force
- Sitting still is not the same as learning
- Movement helps some children focus better
- Progress is slow but meaningful

"School readiness is about helping your child feel safe and capable, not perfect."

SAMPLE

Choosing the Right School for Your Child (Inclusive school vs special school)

This is one of the most confusing and emotional decisions for parents of children with ASD.

Many parents ask:

- "Which school is better?"
- "Will my child be okay in a regular school?"
- "Is special school the only option?"

There is no single right answer.

SAMPLE

The right school is the one that matches your child's current needs, not labels or social pressure.

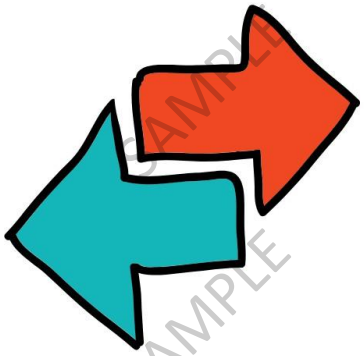
First, understand one important point:

"School choice is not permanent"

A child may:

- Start in a special school and later move to an inclusive school
- Start in an inclusive school and shift to a special school for support
- Attend both (school + therapy centre)

What matters is support and comfort, not the school's name.



SAMPLE

What is an inclusive (mainstream) **school?**

An inclusive school is a regular school where children with and without disabilities learn together.

Your child may:

- Sit in a regular classroom
- Follow the same timetable
- Receive support (resource teacher, shadow teacher, modified work)

Inclusive schools work better when:

- Child has some sitting tolerance
- Can follow simple instructions (with help)
- Is not extremely distressed by noise or crowd
- School is willing to cooperate

SAMPLE

Benefits of Inclusive School:

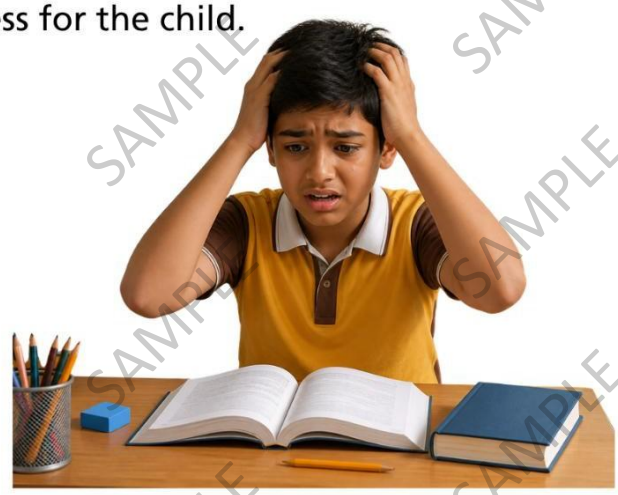
- Exposure to typically developing peers
- Better social learning
- Builds confidence and independence
- Prepares child for real-world settings

Common challenges:

- Large class size
- Less individual attention
- Teachers may lack autism awareness
- Noise and busy environment

Important:

- **Inclusion without support is not inclusion.**
- It becomes stress for the child.



SAMPLE

What is a special school?

Special schools are designed specifically for children with developmental difficulties.

Your child may get:

- Smaller class size
- Slower pace
- Structured teaching
- Therapy support within school

Special schools may help when:

- Child has very high support needs
- Limited communication
- Severe sensory sensitivities
- Difficulty coping in crowded settings

SAMPLE

Benefits of Special School:

- Individual attention
- Predictable routines
- Less pressure to match others
- Teachers trained in special education

Possible limitations:

- Less exposure to typically developing peers
- Limited academic expectations in some schools
- Risk of over-dependence if independence is not encouraged

SAMPLE

Choosing the Right School for Your Child: How parents should decide?

Instead of asking "Which school is best?", ask:

- ✓ Does my child feel calm here?
- ✓ Does the school listen to parents?
- ✓ Are teachers willing to adapt?
- ✓ Is my child learning something meaningful?
- ✓ Is my child coming home distressed every day?

SAMPLE

“Your child’s emotional well-being is more important than syllabus”

Red flags while choosing a school

Avoid schools that:

- Promise to “cure autism”
- Force eye contact or silence
- Punish meltdowns
- Do not allow parent communication
- Refuse accommodations
- Say “your child must adjust, we won’t change”

These approaches can harm your child’s self-confidence.

SAMPLE

Very important message for parents:

A child is not “less capable” because they attend a special school.

A child is not “more successful” just because they attend a regular school.

If you are still unsure, consult a Special Educator for guidance based on your child’s needs.

Success for a child with ASD means:

- Feeling safe
- Being understood
- Making progress at their own pace
- Developing independence

SAMPLE

Working Together: Parents, Teachers & Therapists: Regular communication and shared goals

For a child with ASD, progress happens fastest when all adults work as one team.

If parents, teachers, and therapists work separately, the child feels safe and learns better.

Think of it like this:

"One child – one plan – all working together"

SAMPLE

Why teamwork is so important:

"No single person can meet all your child's needs — teamwork is essential."

Your child:

- Behaves differently at home and at school
- Learns skills in therapy but may not use them outside
- Needs the same approach in different places

If:

- Teacher says one thing
- Therapist says something else
- Parent follows a third way

The child struggles more.

SAMPLE

Role of parents:

You are the most important person in your child's life.

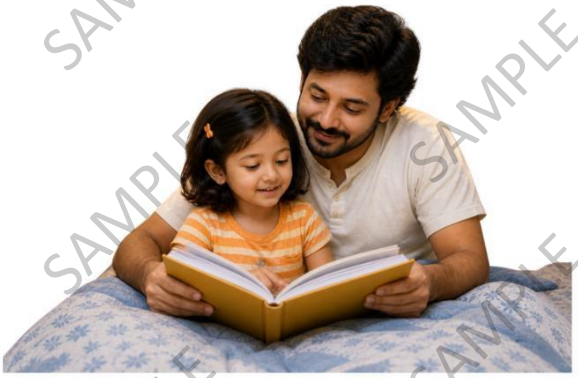
Parents:

- Know the child best
- See daily behaviour
- Understand likes, dislikes, fears, and strengths

What parents should do:

- Share updates honestly (both good and difficult)
- Ask questions freely
- Practice therapy strategies at home
- Observe what works and what doesn't

You are not just a caretaker, you are a partner



SAMPLE

Role of teachers:

Teachers:

- See the child in a group setting
- Help with learning, sitting tolerance, peer interaction
- Notice attention, behaviour, and adjustment issues

Good teachers:

- Are willing to adapt
- Don’t compare your child with others
- Focus on effort, not just results
- Communicate regularly with parents

Parents should feel comfortable asking:

- How is my child managing in class?
- What support helps my child most?
- Where is my child struggling?

SAMPLE

Role of therapists (SLP, OT, Special Educator, Clinical Psychologist)

Therapists:

- Break skills into small steps
- Teach communication, behaviour, sensory regulation, daily skills
- Guide parents on what to do at home

A good therapist:

- Explains goals in simple language
- Gives home activities
- Adjusts goals based on child's comfort
- Respects family routines and limitations

Home activities should fit into daily routine, not feel like extra burden.

SAMPLE

How parents can connect everyone:

You don’t need long meetings or formal language.

Simple ways:

- Share school notebook or WhatsApp updates
- Tell therapist what teacher is noticing
- Tell teacher what therapist is working on
- Use same words, same cues at home and school

Example:

If therapist teaches child to say “help”, teacher and parent should also encourage “help”, instead of guessing silently.

SAMPLE

Shared Goals for Your Child:

Shared goals mean:

- Everyone works on the same few skills
- Not too many targets at once

Good shared goals are:

- Sitting for 5–10 minutes
- Asking for basic needs
- Following 1–2 step instructions
- Toileting routine
- Reducing distress during transitions

Small goals + consistency = big improvement.

SAMPLE

Common mistakes parents should avoid:

- Expecting school to “fix everything”
- Expecting therapy alone to change behaviour
- Not sharing difficulties out of fear or guilt
- Comparing child’s progress with others

Remember:

Progress is slow, uneven, and different for every child with ASD.

SAMPLE

Dear Parents, In India:

- Teachers are often overloaded
- Schools may lack autism training
- Therapists may see many children per day

So parents should:

- Be polite but firm
- Advocate calmly
- Focus on child's needs, not arguments
- Choose cooperation over blame

You don't need to do everything perfectly. Even small, consistent efforts make a big difference.

SAMPLE

Dear Parents,

When a child sees:

- Same expectations
- Same support
- Same understanding

They feel:

- Safer
- Less confused
- More confident

SAMPLE

Encouraging Independence at Home and in School: Building confidence through small daily tasks

Every parent wants their child to become more independent.

For children with ASD, independence develops slowly, in small steps, and that is completely okay.

Independence does not mean doing everything alone.

It means doing as much as the child can, with support when needed.

SAMPLE

Why independence is important for children with ASD?

When children learn to do things on their own:

- They feel more confident
- They understand routines better
- Their frustration reduces
- Their behaviour improves

Independence also prepares them for:

- School demands
- Daily life skills
- Adulthood

Even small independence, makes a big difference.

SAMPLE

Start small – very small

Many parents wait and think: My child will do this later.

But independence grows only when practiced daily.

Examples of small starts:

- Pulling pants up after toilet
- Putting spoon in mouth
- Carrying school bag
- Throwing waste in dustbin
- Choosing clothes

Do not wait for perfection.

"Independence develops through repeated opportunities, not by waiting for readiness."

SAMPLE

Break every task into steps:

Children with ASD struggle when tasks feel too big.

Instead of:

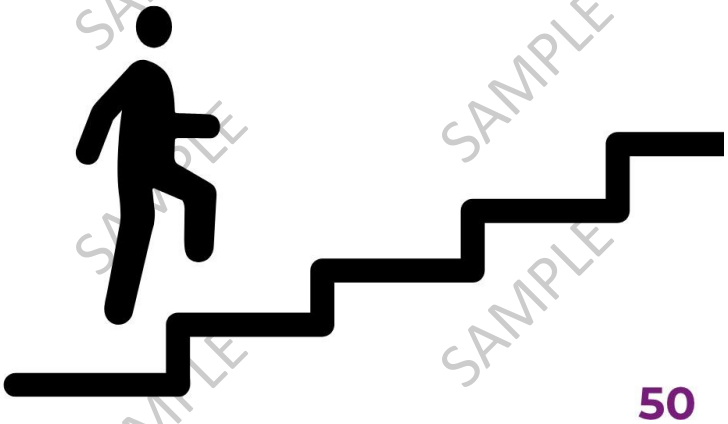
❌ "Get ready"

Try:

1. Wear underwear
2. Wear pants
3. Wear shirt
4. Button shirt
5. Wear socks

Help only where the child gets stuck.

This is called Stepwise support.



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SAMPLE

Let your child try (even if it's slow or messy):

Parents often help too quickly because:

- Child takes time
- Child does it "wrong"
- Parent is in a hurry

But if we always do it for them: child never learns.

- Yes, it will be slower.
- Yes, it may be messy.
- Yes, patience is required.

But learning happens only through doing.

"Children learn best when given chances to try, even if they need help."

SAMPLE

Use routine to build independence:

Children with ASD learn best when things happen the same way daily.

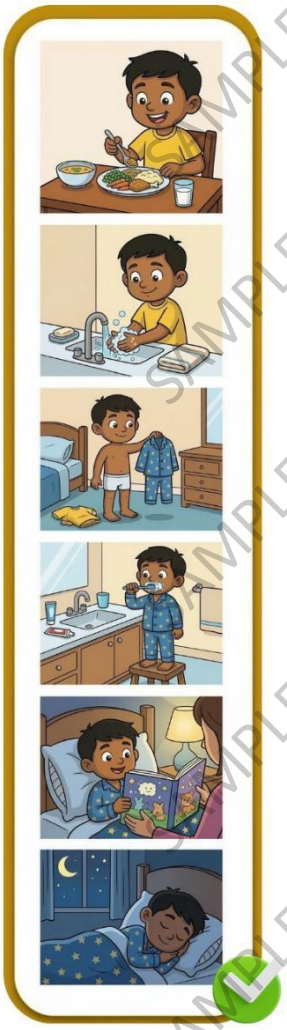
Example:

- Same time for brushing
- Same place for dressing
- Same order of steps

Routine reduces:

- Anxiety
- Resistance
- Confusion

Independence grows faster in predictable routines.



SAMPLE

Visual support increases independence:

Many children understand pictures better than words. Use:

- Picture charts
- Step-by-step photos
- Simple drawings

Example: pictures of

- Wearing clothes
- Brushing teeth
- Breakfast
- School

This helps the child:

- Remember steps
- Work without constant reminders
- Feel successful

SAMPLE

Encourage, don't pressure:

Children with ASD shut down when pressured.

Instead of:

❌ "Why can't you do this?"

❌ "Other kids can do it"

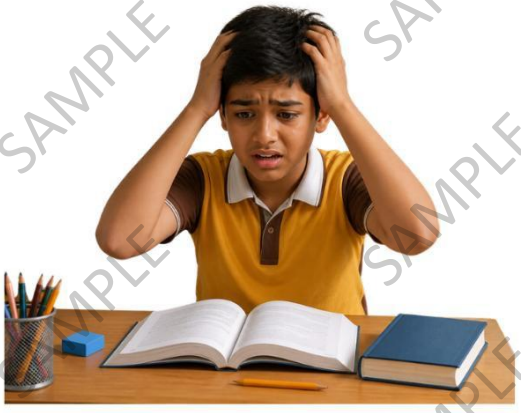
❌ "You're lazy"

Say:

✓ "Try once"

✓ "You're learning"

✓ "I'll help if needed"



Encouragement builds confidence, pressure builds fear.

SAMPLE

Encouraging Independence at Home and in School: Allow safe choices

Giving choices increases independence.

Examples:

- "Red shirt or blue shirt?"
- "Rice or roti?"
- "Drawing or puzzle?"

Choices:

- Reduce tantrums
- Give control
- Build decision-making skills

Avoid too many choices, two options are enough.

SAMPLE

Encouraging Independence at Home and in School: Accept that independence looks different

Some children:

- Will dress fully on their own
- Others may always need some help

Both are okay.

Independence is not a competition. It is personal growth.

SAMPLE

A message every parent needs to hear:

Your child is not behind.

Your child is not lazy.

Your child is not failing.

Your child is:

- Learning differently
- Growing at their own pace
- Doing their best

Your support today builds their confidence tomorrow.

SAMPLE

To Conclude:

You don’t need to do everything at once.

Choose one small daily task.

Work on it consistently.

- Small steps.
- Daily practice.
- Gentle support.

That is how independence grows in children with ASD.

SAMPLE

DISCLAIMER!

This material is intended to provide general information and practical guidance for parents of children with Autism Spectrum Disorder (ASD).

The content is for educational purposes only and should not be considered a substitute for professional evaluation, diagnosis, or intervention.

As each child is unique, parents are advised to seek guidance from qualified professionals such as paediatricians, speech-language pathologists, occupational therapists, or psychologists and others for individualized support.

The suggestions provided may be adapted based on the child's needs, family context, and professional recommendations.

SAMPLE

SAMPLE

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SAMPLE

Appendix VI

PEP 1: Understanding Autism and Rights

Dear Sir/Madam,

You are kindly requested to review the enclosed Parent Education Pamphlet developed for parents of children with Autism Spectrum Disorder (ASD). The purpose of this review is to evaluate the content for accuracy, clinical relevance, clarity, cultural appropriateness, and suitability for use with parents in the Indian context.

Your expert judgment is valuable in determining whether the material adequately addresses the intended objectives and reflects evidence-based practice. You are requested to review each item carefully and indicate whether it is **Essential**, **Useful but not Essential**, or **Not Necessary** for inclusion in the pamphlet. Space has also been provided for comments and suggestions to help refine and improve the material.

Your feedback will contribute significantly to strengthening the quality and validity of this educational resource. All responses will be used strictly for academic research purposes.

Thank you for your time and professional contribution.

Sincerely,

Pranjal Jain

II M.Sc SLP

All India Institute of Speech and Hearing, Mysuru

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* Indicates required question

Your Name *

Your Designation & Professional Qualification *

Area of Specialization *

Institution / Organization *

Years of Clinical/Professional Experience *

Contact Number *

SECTION A: OVERALL CONTENT & STRUCTURE

1. Inclusion of a clear and parent-friendly title in this pamphlet is… *

- Essential
- Useful but not Essential
- Not Necessary

2. Inclusion of logically organized and well-structured content is… *

- Essential
- Useful but not Essential
- Not Necessary

3. Use of language suitable for parents from diverse educational backgrounds is… *

- Essential
- Useful but not Essential
- Not Necessary

4. Inclusion of culturally relevant content for the Indian context is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION A: OVERALL CONTENT & STRUCTURE

SECTION B: CONTENT ACCURACY & CLINICAL RELEVANCE

5. Inclusion of a definition and explanation of Autism Spectrum Disorder is… *

- Essential
- Useful but not Essential
- Not Necessary

6. Inclusion of core features of autism (communication, social interaction, repetitive behaviours) is… *

- Essential
- Useful but not Essential
- Not Necessary

7. Inclusion of an explanation of autism as a "spectrum" is… *

- Essential
- Useful but not Essential
- Not Necessary

8. Inclusion of common myths and clarification of misconceptions about autism is… *

- Essential
- Useful but not Essential
- Not Necessary

9. Inclusion of early signs and red flags of autism is… *

- Essential
- Useful but not Essential
- Not Necessary

10. Inclusion of information emphasizing the importance of early identification is… *

- Essential
- Useful but not Essential
- Not Necessary

11. Inclusion of a description of the diagnostic process for autism is… *

- Essential
- Useful but not Essential
- Not Necessary

12. Inclusion of brief information regarding ISAA / DSM-5 in parent education material is… *

- Essential
- Useful but not Essential
- Not Necessary

13. Inclusion of information regarding the RPwD Act (2016) is… *

- Essential
- Useful but not Essential
- Not Necessary

14. Inclusion of information about disability certification / UDID procedure is… *

- Essential
- Useful but not Essential
- Not Necessary

15. Inclusion of information about government schemes and benefits is… *

- Essential
- Useful but not Essential
- Not Necessary

16. Inclusion of frequently asked questions (FAQs) addressing parental concerns is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION B: CONTENT ACCURACY & CLINICAL RELEVANCE

SECTION C: OVERALL EVALUATION

17. Overall, inclusion of this pamphlet as part of parent education material is… *

- Essential
- Useful but not Essential
- Not Necessary

18. Use of this pamphlet in clinical and community settings is… *

- Essential
- Useful but not Essential
- Not Necessary

General Suggestions for Improvement

Overall Recommendation *

- Accept without modification
- Accept with minor modifications
- Needs major revision

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Google Forms

Appendix VII

PEP 2: Understanding Diagnosis, Assessment & Early Intervention

Dear Sir/Madam,

You are kindly requested to review the enclosed Parent Education Pamphlet developed for parents of children with Autism Spectrum Disorder (ASD). The purpose of this review is to evaluate the content for accuracy, clinical relevance, clarity, cultural appropriateness, and suitability for use with parents in the Indian context.

Your expert judgment is valuable in determining whether the material adequately addresses the intended objectives and reflects evidence-based practice. You are requested to review each item carefully and indicate whether it is **Essential**, **Useful but not Essential**, or **Not Necessary** for inclusion in the pamphlet. Space has also been provided for comments and suggestions to help refine and improve the material.

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Thank you for your time and professional contribution.

Sincerely,

Pranjal Jain

II M.Sc SLP

All India Institute of Speech and Hearing, Mysuru

---

* Indicates required question

Your Name & Designation *

SECTION A: CORE CONCEPTS & EARLY IDENTIFICATION

1. Inclusion of a brief explanation of Autism Spectrum Disorder as a neurodevelopmental condition is… *

- Essential
- Useful but not Essential
- Not Necessary

2. Inclusion of clarification that autism presents as a spectrum with varied strengths and challenges is… *

- Essential
- Useful but not Essential
- Not Necessary

3. Inclusion of clarification that autism is not caused by parenting or vaccines is… *

- Essential
- Useful but not Essential
- Not Necessary

4. Inclusion of early signs and red flags of autism (including social communication and repetitive behaviours) is… *

- Essential

- Useful but not Essential
- Not Necessary

5. Inclusion of emphasis on the importance of early consultation and referral is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION A: CORE CONCEPTS & EARLY IDENTIFICATION

SECTION B: DIAGNOSTIC PROCESS & ASSESSMENT

6. Inclusion of clarification that autism diagnosis is behaviour-based is… *

- Essential
- Useful but not Essential
- Not Necessary

7. Inclusion of description of the multidisciplinary team involved in diagnosis is… *

- Essential
- Useful but not Essential
- Not Necessary

8. Inclusion of explanation of assessment procedures (parent interview, observation, speech/OT/psychological evaluation) is… *

- Essential
- Useful but not Essential
- Not Necessary

9. Inclusion of brief information about structured diagnostic tools used in India (e.g., ISAA) is… *

- Essential
- Useful but not Essential
- Not Necessary

10. Inclusion of clarification that medical tests are not routinely required unless clinically indicated is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION B: DIAGNOSTIC PROCESS & ASSESSMENT

SECTION C: EARLY INTERVENTION & SCHOOL PLANNING

11. Inclusion of emphasis on the importance of early intervention is… *

- Essential
- Useful but not Essential

- Not Necessary

12. Inclusion of description of major therapy options (Speech Therapy, Occupational Therapy, Special Education, Behaviour Therapy) is… *

- Essential
- Useful but not Essential
- Not Necessary

13. Inclusion of the role of parent training in intervention is… *

- Essential
- Useful but not Essential
- Not Necessary

14. Inclusion of information regarding school planning (inclusive vs special schooling and IEP) is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION C: EARLY INTERVENTION & SCHOOL PLANNING

SECTION D: PARENT SUPPORT & PRACTICAL VALUE

15. Inclusion of emotional reassurance for parents after diagnosis is… *

- Essential
- Useful but not Essential
- Not Necessary

16. Inclusion of practical home-based guidance during the intervention phase is… *

- Essential
- Useful but not Essential
- Not Necessary

17. Inclusion of encouragement for parent–professional collaboration is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION D: PARENT SUPPORT & PRACTICAL VALUE

SECTION E: LANGUAGE & OVERALL SUITABILITY

18. Use of simple, culturally appropriate language suitable for Indian parents is… *

- Essential
- Useful but not Essential
- Not Necessary

19. Overall inclusion of this pamphlet as part of structured parent education material is… *

- Essential
- Useful but not Essential
- Not Necessary

20. Use of this pamphlet in clinical and community settings is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION E: LANGUAGE & OVERALL SUITABILITY

Overall Suggestions for Improvement

Expert's Overall Recommendation *

- Accept without modification
- Accept with minor modifications
- Needs major revision

This content is neither created nor endorsed by Google.

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Appendix VIII

PEP 3: Helping Your Child Communicate and Develop Language

Dear Sir/Madam,

You are kindly requested to review the enclosed Parent Education Pamphlet developed for parents of children with Autism Spectrum Disorder (ASD). The purpose of this review is to evaluate the content for accuracy, clinical relevance, clarity, cultural appropriateness, and suitability for use with parents in the Indian context.

Your expert judgment is valuable in determining whether the material adequately addresses the intended objectives and reflects evidence-based practice. You are requested to review each item carefully and indicate whether it is **Essential**, **Useful but not Essential**, or **Not Necessary** for inclusion in the pamphlet. Space has also been provided for comments and suggestions to help refine and improve the material.

Your feedback will contribute significantly to strengthening the quality and validity of this educational resource. All responses will be used strictly for academic research purposes.

Thank you for your time and professional contribution.

Sincerely,

Pranjal Jain

II M.Sc SLP

All India Institute of Speech and Hearing, Mysuru

---

* Indicates required question

Your Name & Designation *

SECTION A: FOUNDATIONAL UNDERSTANDING

1. Inclusion of explanation of communication differences in children with autism (speech delay, echolalia, pragmatic challenges) is… *

- Essential
- Useful but not Essential
- Not Necessary

2. Inclusion of clarification that communication difficulties do not reflect lack of intelligence is… *

- Essential
- Useful but not Essential
- Not Necessary

3. Use of parent-friendly, non-blaming, culturally appropriate language is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions for SECTION A: FOUNDATIONAL UNDERSTANDING

SECTION B: ROLE OF THE SPEECH-LANGUAGE PATHOLOGIST

4. Inclusion of explanation of the broader role of the Speech-Language Pathologist (communication, play, social skills, AAC) is… *

- Essential
- Useful but not Essential
- Not Necessary

5. Inclusion of emphasis on parent coaching and home carryover as part of intervention is… *

- Essential
- Useful but not Essential
- Not Necessary

6. Inclusion of description of assessment through play and observation is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION B: ROLE OF THE SPEECH-LANGUAGE PATHOLOGIST

SECTION C: HOME-BASED COMMUNICATION STRATEGIES

7. Inclusion of core home strategies (following the child's lead, modelling language, using short phrases) is… *

- Essential

- Useful but not Essential
- Not Necessary

8. Inclusion of strategies to encourage communication (offering choices, creating communication opportunities) is… *

- Essential
- Useful but not Essential
- Not Necessary

9. Inclusion of guidance on what to avoid (forceful eye contact, excessive correction, comparisons) is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION C: HOME-BASED COMMUNICATION STRATEGIES

SECTION D: PRACTICAL ACTIVITIES & ROUTINES

10. Inclusion of structured activities such as joint attention, imitation, and turn-taking routines is… *

- Essential
- Useful but not Essential
- Not Necessary

11. Inclusion of use of predictable routines and picture-based activities to build communication is… *

- Essential
- Useful but not Essential
- Not Necessary

12. Inclusion of guidance for minimally verbal children, including use of pictures and AAC options is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION D: PRACTICAL ACTIVITIES & ROUTINES

SECTION E: VISUAL SUPPORTS & COLLABORATION

13. Inclusion of use of visual schedules, choice boards, and first–then boards is… *

- Essential
- Useful but not Essential
- Not Necessary

14. Inclusion of guidance on sharing communication strategies with teachers and family members is… *

- Essential

- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION E: VISUAL SUPPORTS & COLLABORATION

SECTION F: PARENT EMPOWERMENT & PRACTICAL VALUE

15. Inclusion of encouragement for short, frequent practice and routine-based learning is… *

- Essential
- Useful but not Essential
- Not Necessary

16. Inclusion of simple progress tracking by parents is… *

- Essential
- Useful but not Essential
- Not Necessary

17. Inclusion of caregiver reassurance and emotional support is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions – SECTION F: PARENT EMPOWERMENT & PRACTICAL VALUE

SECTION G: LANGUAGE & OVERALL SUITABILITY

18. Inclusion of clear, simple, and readable language suitable for parents is… *

- Essential
- Useful but not Essential
- Not Necessary

19. Inclusion of culturally appropriate examples relevant to Indian families is… *

- Essential
- Useful but not Essential
- Not Necessary

20. Inclusion of this pamphlet as part of structured parent education material for families of children with ASD is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION G: LANGUAGE & OVERALL SUITABILITY

General Suggestions for Improvement

Overall Recommendation *

- Accept without modification
- Accept with minor modifications
- Needs major revision

This content is neither created nor endorsed by Google.

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Appendix IX

PEP 4: Understanding Behavior, Sensory Skills & Social Development

Dear Sir/Madam,

You are kindly requested to review the enclosed Parent Education Pamphlet developed for parents of children with Autism Spectrum Disorder (ASD). The purpose of this review is to evaluate the content for accuracy, clinical relevance, clarity, cultural appropriateness, and suitability for use with parents in the Indian context.

Your expert judgment is valuable in determining whether the material adequately addresses the intended objectives and reflects evidence-based practice. You are requested to review each item carefully and indicate whether it is **Essential**, **Useful but not Essential**, or **Not Necessary** for inclusion in the pamphlet. Space has also been provided for comments and suggestions to help refine and improve the material.

Your feedback will contribute significantly to strengthening the quality and validity of this educational resource. All responses will be used strictly for academic research purposes.

Thank you for your time and professional contribution.

Sincerely,

Pranjal Jain

II M.Sc SLP

All India Institute of Speech and Hearing, Mysuru

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* Indicates required question

Your Name & Designation *

SECTION A: UNDERSTANDING BEHAVIOUR

1. Inclusion of explanation that behavioural differences in ASD are linked to differences in brain processing is… *

- Essential
- Useful but not Essential
- Not Necessary

2. Inclusion of common reasons for behavioural challenges (communication difficulty, sensory overload, need for routine) is… *

- Essential
- Useful but not Essential
- Not Necessary

3. Inclusion of clarification that behaviour is a form of communication rather than intentional misbehaviour is… *

- Essential
- Useful but not Essential
- Not Necessary

4. Inclusion of parent-friendly, non-blaming language throughout the behaviour section is… *

- Essential

- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION A: UNDERSTANDING BEHAVIOUR

SECTION B: BEHAVIOUR MANAGEMENT & ABC MODEL

5. Inclusion of guidance on common parental reactions and more effective alternative responses is… *

- Essential
- Useful but not Essential
- Not Necessary

6. Inclusion of the ABC (Antecedent–Behaviour–Consequence) model for understanding behaviour is… *

- Essential
- Useful but not Essential
- Not Necessary

7. Inclusion of clear, practical examples to explain the ABC model is… *

- Essential
- Useful but not Essential
- Not Necessary

8. Inclusion of step-by-step behaviour management strategies relevant to home and community settings is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION B: BEHAVIOUR MANAGEMENT & ABC MODEL

SECTION C: SENSORY PROCESSING

9. Inclusion of explanation of sensory processing differences in ASD is… *

- Essential
- Useful but not Essential
- Not Necessary

10. Inclusion of differentiation between hypersensitivity and hyposensitivity using everyday examples is… *

- Essential
- Useful but not Essential
- Not Necessary

11. Inclusion of accurate and parent-friendly descriptions of sensory behaviours is… *

- Essential

- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION C: SENSORY PROCESSING

SECTION D: HOME-BASED SENSORY STRATEGIES

12. Inclusion of practical, safe, and low-cost sensory strategies for hypersensitive children is… *

- Essential
- Useful but not Essential
- Not Necessary

13. Inclusion of practical, safe, and low-cost sensory strategies for hyposensitive children is… *

- Essential
- Useful but not Essential
- Not Necessary

14. Inclusion of guidance regarding safety and feasibility of suggested sensory activities is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION D: HOME-BASED SENSORY STRATEGIES

SECTION E: ROLE OF OCCUPATIONAL THERAPY & COLLABORATION

15. Inclusion of explanation of the role of Occupational Therapy in managing sensory and behavioural concerns is… *

- Essential
- Useful but not Essential
- Not Necessary

16. Inclusion of the link between sensory regulation and daily living/social skills is… *

- Essential
- Useful but not Essential
- Not Necessary

17. Inclusion of emphasis on parent–therapist collaboration is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION E: ROLE OF OCCUPATIONAL THERAPY & COLLABORATION

SECTION F: OVERALL SUITABILITY

18. Inclusion of clear and readable language suitable for parents is… *

- Essential
- Useful but not Essential
- Not Necessary

19. Inclusion of culturally appropriate examples relevant to Indian families is… *

- Essential
- Useful but not Essential
- Not Necessary

20. Inclusion of this pamphlet as part of structured parent education material is… *

- Essential
- Useful but not Essential
- Not Necessary

General Suggestions for Improvement

Overall Recommendation *

- Accept without modification
- Accept with minor modifications
- Needs major revision

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Appendix X

PEP 5: Daily Life, Home Routine & School Support for Your Child

Dear Sir/Madam,

You are kindly requested to review the enclosed Parent Education Pamphlet developed for parents of children with Autism Spectrum Disorder (ASD). The purpose of this review is to evaluate the content for accuracy, clinical relevance, clarity, cultural appropriateness, and suitability for use with parents in the Indian context.

Your expert judgment is valuable in determining whether the material adequately addresses the intended objectives and reflects evidence-based practice. You are requested to review each item carefully and indicate whether it is **Essential**, **Useful but not Essential**, or **Not Necessary** for inclusion in the pamphlet. Space has also been provided for comments and suggestions to help refine and improve the material.

Your feedback will contribute significantly to strengthening the quality and validity of this educational resource. All responses will be used strictly for academic research purposes.

Thank you for your time and professional contribution.

Sincerely,

Pranjal Jain

II M.Sc SLP

All India Institute of Speech and Hearing, Mysuru

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* Indicates required question

Your Name & Designation *

SECTION A: DAILY LIVING SKILLS (ADLs)

1. Inclusion of explanation that ADL difficulties (toilet use, feeding, dressing) are related to developmental and sensory differences is… *

- Essential
- Useful but not Essential
- Not Necessary

2. Inclusion of practical, stepwise toilet training strategies suitable for home settings is… *

- Essential
- Useful but not Essential
- Not Necessary

3. Inclusion of guidance on feeding challenges linked to sensory sensitivity is… *

- Essential
- Useful but not Essential
- Not Necessary

4. Inclusion of stepwise strategies for teaching dressing and self-care skills is… *

- Essential
- Useful but not Essential

- Not Necessary

5. Inclusion of emphasis on patience, routine, and positive reinforcement in daily skill training is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION A: DAILY LIVING SKILLS (ADLs)

SECTION B: HOME ROUTINES & VISUAL SCHEDULES

6. Inclusion of importance of predictable routines for children with ASD is… *

- Essential
- Useful but not Essential
- Not Necessary

7. Inclusion of explanation and examples of visual schedules for daily routines (morning, mealtime, bedtime, playtime) is… *

- Essential
- Useful but not Essential
- Not Necessary

8. Inclusion of guidance on how parents should communicate while using routines is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION B: HOME ROUTINES & VISUAL SCHEDULES

SECTION C: SCHOOL READINESS

9. Inclusion of clarification that school readiness focuses on participation and adjustment rather than academics is… *

- Essential
- Useful but not Essential
- Not Necessary

10. Inclusion of practical strategies to build attention and sitting tolerance at home is… *

- Essential
- Useful but not Essential
- Not Necessary

11. Inclusion of techniques to support following instructions and classroom-like behaviour is… *

- Essential
- Useful but not Essential

- Not Necessary

12. Inclusion of home-based preparation for classroom routines is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION C: SCHOOL READINESS

SECTION D: SCHOOL PLANNING & DECISION-MAKING

13. Inclusion of balanced explanation of inclusive versus special school options is… *

- Essential
- Useful but not Essential
- Not Necessary

14. Inclusion of practical guidance (checklist/red flags) for selecting appropriate schooling in the Indian context is… *

- Essential
- Useful but not Essential
- Not Necessary

15. Inclusion of clarification that school placement decisions are flexible and child-centered is… *

- Essential

- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION D: SCHOOL PLANNING & DECISION-MAKING

SECTION E: COLLABORATION & INDEPENDENCE

16. Inclusion of importance of teamwork among parents, teachers, and therapists is… *

- Essential
- Useful but not Essential
- Not Necessary

17. Inclusion of practical methods for communication and shared goals across settings is… *

- Essential
- Useful but not Essential
- Not Necessary

18. Inclusion of strategies to promote gradual independence through stepwise task breakdown and choice-making is… *

- Essential
- Useful but not Essential
- Not Necessary

19. Inclusion of guidance on promoting independence both at home and in school settings is… *

- Essential
- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION E: COLLABORATION & INDEPENDENCE

SECTION F: OVERALL SUITABILITY

20. Inclusion of clear, simple, and readable language suitable for Indian parents is… *

- Essential
- Useful but not Essential
- Not Necessary

21. Inclusion of culturally appropriate examples relevant to Indian family and school contexts is… *

- Essential
- Useful but not Essential
- Not Necessary

22. Inclusion of this pamphlet as part of structured parent education material is… *

- Essential

- Useful but not Essential
- Not Necessary

Comments/Suggestions on SECTION F: OVERALL SUITABILITY

General Suggestions for Improvement

Overall Recommendation *

- Accept without modification
- Accept with minor modifications
- Needs major revision

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Appendix XI

PEP 1: Understanding Autism and Rights

Dear Parent,

This booklet was developed to provide simple and practical information for families of children with Autism Spectrum Disorder (ASD). The aim is to help parents better understand autism and become aware of available supports and services.

As a parent of a child with ASD, your experience and feedback are very valuable. Your suggestions will help us improve this booklet so that it becomes more helpful for parents who may have recently received their child's diagnosis.

All responses will be used only for academic research purposes and your identity will remain confidential.

Instructions

1. Please read the booklet carefully.
2. For each statement, tick the option that best matches your opinion:
   Agree / Neutral / Disagree
3. There are no right or wrong answers. We value your honest opinion.
4. You may write any suggestions in the space provided.

Thank you for your valuable feedback.

Your responses will help improve support and understanding for families of children with Autism Spectrum Disorder.

---

* Indicates required question

Name of Parent/Caregiver *

SECTION A: CLARITY & READABILITY

1. The language used in the booklet is easy for me to understand. *

- Agree
- Neutral
- Disagree

2. The information is explained in a clear and simple way. *

- Agree
- Neutral
- Disagree

3. The booklet is easy for parents to read and follow. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION B: UNDERSTANDING AUTISM

4. After reading this booklet, I understand Autism Spectrum Disorder better. *

- Agree
- Neutral
- Disagree

5. The booklet helped me understand that every child with autism is different. *

- Agree
- Neutral
- Disagree

6. The booklet helped me understand the early signs of autism. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION C: PARENT SUPPORT & ATTITUDES

7. The booklet helped clear some common myths or misunderstandings about autism. *

- Agree
- Neutral
- Disagree

8. After reading this booklet, I feel more confident in supporting my child. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION D: RIGHTS & SUPPORT SERVICES

9. The booklet helped me understand the rights of children with autism in India. *

- Agree
- Neutral
- Disagree

10. The information about disability certificate / UDID card is useful for parents. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION E: OVERALL USEFULNESS

11. This booklet is helpful for parents of children with autism. *

- Agree

- Neutral
- Disagree

12. I would recommend this booklet to other parents. *

- Agree
- Neutral
- Disagree

Open Feedback

1. What did you find most helpful in this booklet?

2. What suggestions do you have to improve this booklet?

This content is neither created nor endorsed by Google.

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Appendix XII

PEP 2: Understanding Diagnosis, Assessment & Early Intervention

Dear Parent,

This booklet was developed to provide simple and practical information for families of children with Autism Spectrum Disorder (ASD). The aim is to help parents better understand autism and become aware of available supports and services.

As a parent of a child with ASD, your experience and feedback are very valuable. Your suggestions will help us improve this booklet so that it becomes more helpful for parents who may have recently received their child's diagnosis.

All responses will be used only for academic research purposes and your identity will remain confidential.

Instructions

1. Please read the booklet carefully.
2. For each statement, tick the option that best matches your opinion:
   Agree / Neutral / Disagree
3. There are no right or wrong answers. We value your honest opinion.
4. You may write any suggestions in the space provided.

Thank you for your valuable feedback.

Your responses will help improve support and understanding for families of children with Autism Spectrum Disorder.

---

* Indicates required question

Name of Parent/Caregiver *

SECTION A: CLARITY & UNDERSTANDING

1. The language used in this booklet is easy for me to understand. *

- Agree
- Neutral
- Disagree

2. Medical or technical terms are explained in a simple way. *

- Agree
- Neutral
- Disagree

3. The information in the booklet is clear and not confusing. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION B: UNDERSTANDING AUTISM

4. After reading this booklet, I understand Autism Spectrum Disorder better. *

- Agree
- Neutral
- Disagree

5. The booklet helped me understand early signs of autism. *

- Agree
- Neutral
- Disagree

6. The explanation of autism as a "spectrum" is easy to understand. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION C: DIAGNOSIS & ASSESSMENT

7. I understand better how autism is diagnosed. *

- Agree
- Neutral
- Disagree

8. The roles of different professionals involved in assessment are clearly explained. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION D: EARLY INTERVENTION & SCHOOL PLANNING

9. The booklet helped me understand why early intervention is important. *

- Agree
- Neutral
- Disagree

10. The therapies and support services mentioned are explained clearly. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION E: PRACTICAL USEFULNESS

11. This booklet is helpful for parents of children with autism. *

- Agree
- Neutral

- Disagree

12. I would recommend this booklet to other parents. *

- Agree
- Neutral
- Disagree

Open Feedback

1. What did you find most helpful in this booklet?

2. What suggestions do you have to improve this booklet?

This content is neither created nor endorsed by Google.

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Appendix XIII

PEP 3: Helping Your Child Communicate and Develop Language

Dear Parent,

This booklet was developed to provide simple and practical information for families of children with Autism Spectrum Disorder (ASD). The aim is to help parents better understand autism and become aware of available supports and services.

As a parent of a child with ASD, your experience and feedback are very valuable. Your suggestions will help us improve this booklet so that it becomes more helpful for parents who may have recently received their child's diagnosis.

All responses will be used only for academic research purposes and your identity will remain confidential.

Instructions

1. Please read the booklet carefully.
2. For each statement, tick the option that best matches your opinion:
   Agree / Neutral / Disagree
3. There are no right or wrong answers. We value your honest opinion.
4. You may write any suggestions in the space provided.

Thank you for your valuable feedback.

Your responses will help improve support and understanding for families of children with Autism Spectrum Disorder.

---

* Indicates required question

Name of Parent/Caregiver *

SECTION A: UNDERSTANDING COMMUNICATION IN AUTISM

1. The booklet helped me understand how communication may be different in children with autism. *

- Agree
- Neutral
- Disagree

2. The examples of speech delay, repeating words, and social communication were easy to understand. *

- Agree
- Neutral
- Disagree

3. The information reassured me that my child can learn to communicate with the right support. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION B: ROLE OF THE SPEECH-LANGUAGE PATHOLOGIST

4. I now understand how a Speech-Language Pathologist helps my child. *

- Agree
- Neutral
- Disagree

5. The booklet helped me understand my role as a parent in supporting communication. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION C: HOME STRATEGIES & ACTIVITIES

6. The suggested communication strategies are easy to try in daily life. *

- Agree
- Neutral
- Disagree

7. The play-based activities are simple and practical for home use. *

- Agree
- Neutral
- Disagree

8. The step-by-step examples helped me understand how to encourage communication. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION D: VISUAL SUPPORTS & COMMUNICATION TOOLS

9. The explanation of visual supports (pictures, schedules) was easy to understand. *

- Agree
- Neutral
- Disagree

10. I feel confident trying visual supports or simple communication tools with my child. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION E: OVERALL USEFULNESS

11. This booklet is helpful for parents of children with autism. *

- Agree
- Neutral
- Disagree

12. I would recommend this booklet to other parents. *

- Agree
- Neutral
- Disagree

Open Feedback

1. What did you find most helpful in this booklet?

2. What suggestions do you have to improve this booklet?

This content is neither created nor endorsed by Google.

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Appendix XIV

PEP 4: Understanding Behaviour, Sensory Skills & Social Development

Dear Parent,

This booklet was developed to provide simple and practical information for families of children with Autism Spectrum Disorder (ASD). The aim is to help parents better understand autism and become aware of available supports and services.

As a parent of a child with ASD, your experience and feedback are very valuable. Your suggestions will help us improve this booklet so that it becomes more helpful for parents who may have recently received their child's diagnosis.

All responses will be used only for academic research purposes and your identity will remain confidential.

Instructions

1. Please read the booklet carefully.
2. For each statement, tick the option that best matches your opinion:
   Agree / Neutral / Disagree
3. There are no right or wrong answers. We value your honest opinion.
4. You may write any suggestions in the space provided.

Thank you for your valuable feedback.

Your responses will help improve support and understanding for families of children with Autism Spectrum Disorder.

---

* Indicates required question

Name of Parent/Caregiver *

SECTION A: UNDERSTANDING BEHAVIOUR

1. The booklet helped me understand why children with autism may behave differently. *

- Agree
- Neutral
- Disagree

2. The explanation that behaviour is a form of communication was clear to me. *

- Agree
- Neutral
- Disagree

3. After reading this section, I feel less blame or guilt about my child's behaviour. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION B: BEHAVIOUR MANAGEMENT STRATEGIES

4. The suggested responses to behaviour problems are practical for daily life. *

- Agree
- Neutral
- Disagree

5. The ABC model (Antecedent–Behaviour–Consequence) was easy to understand. *

- Agree
- Neutral
- Disagree

6. The examples helped me identify triggers for my child's behaviour. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION C: SOCIAL SKILLS & POSITIVE REINFORCEMENT

7. The suggested activities for improving social skills are simple and practical for home. *

- Agree
- Neutral

- Disagree

8. The explanation of rewards and positive reinforcement was easy to understand. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION D: SENSORY PROCESSING & SUPPORT

9. The difference between hypersensitivity and hyposensitivity was clearly explained. *

- Agree
- Neutral
- Disagree

10. The sensory strategies suggested are practical and possible to try at home. *

- Agree
- Neutral
- Disagree

11. I better understand how Occupational Therapy can help my child. *

- Agree
- Neutral

- Disagree

Comments/Suggestions

SECTION E: OVERALL USEFULNESS

12. This booklet is helpful for managing behaviour and sensory challenges in children with autism. *

- Agree
- Neutral
- Disagree

13. I would recommend this booklet to other parents. *

- Agree
- Neutral
- Disagree

Open Feedback

1. What did you find most helpful in this booklet?

2. What suggestions do you have to improve this booklet?

This content is neither created nor endorsed by Google.

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Appendix XV

PEP 5: Daily Life, Home Routine & School Support for Your Child

Dear Parent,

This booklet was developed to provide simple and practical information for families of children with Autism Spectrum Disorder (ASD). The aim is to help parents better understand autism and become aware of available supports and services.

As a parent of a child with ASD, your experience and feedback are very valuable. Your suggestions will help us improve this booklet so that it becomes more helpful for parents who may have recently received their child's diagnosis.

All responses will be used only for academic research purposes and your identity will remain confidential.

Instructions

1. Please read the booklet carefully.
2. For each statement, tick the option that best matches your opinion:
   Agree / Neutral / Disagree
3. There are no right or wrong answers. We value your honest opinion.
4. You may write any suggestions in the space provided.

Thank you for your valuable feedback.

Your responses will help improve support and understanding for families of children with Autism Spectrum Disorder.

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* Indicates required question

Name of Parent/Caregiver *

SECTION A: DAILY ACTIVITIES (TOILET, EATING, DRESSING)

1. The booklet helped me understand why my child may find daily activities (toilet, eating, dressing) difficult. *

- Agree
- Neutral
- Disagree

2. The practical suggestions for toilet training, eating, and dressing are helpful for home use. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION B: HOME ROUTINES & VISUAL SCHEDULES

3. The explanation of routines and visual schedules was easy to understand. *

- Agree

- Neutral
- Disagree

4. The examples of morning, mealtime, playtime, or bedtime routines are useful for daily life. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION C: SCHOOL READINESS

5. The booklet helped me understand that school readiness is not only about academics. *

- Agree
- Neutral
- Disagree

6. The suggestions for improving attention, sitting tolerance, and following instructions are practical. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION D: CHOOSING A SCHOOL

7. The explanation of inclusive schools and special schools was clear. *

- Agree
- Neutral
- Disagree

8. This section helped me feel more confident about making school decisions for my child. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION E: TEAMWORK WITH TEACHERS & THERAPISTS

9. The booklet helped me understand the importance of working together with teachers and therapists. *

- Agree
- Neutral
- Disagree

10. The suggestions for communication between parents, teachers, and therapists are practical. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION F: ENCOURAGING INDEPENDENCE

11. The booklet helped me understand how to encourage independence in small daily tasks. *

- Agree
- Neutral
- Disagree

12. The step-by-step approach to teaching independence feels realistic for my child. *

- Agree
- Neutral
- Disagree

Comments/Suggestions

SECTION G: OVERALL FEEDBACK

13. The language used in this booklet is simple and easy to understand. *

- Agree
- Neutral
- Disagree

14. The booklet provides practical ideas that I can try at home. *

- Agree
- Neutral
- Disagree

15. I would recommend this booklet to other parents of children with autism. *

- Agree
- Neutral
- Disagree

Open Feedback

1. What did you find most helpful in this booklet?

2. What suggestions do you have to improve this booklet?

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Appendix XVI

Development and Validation of Public Education Pamphlets on Autism Spectrum Disorder for Parents and Caregivers in the Indian Context

Pre/Post-Intervention Questionnaire (Before/After Reading the Parent Education Pamphlets)

Dear Parent/Caregiver,

Thank you for taking part in this study. You are being requested to complete this questionnaire **before/after reading** the Parent Education Pamphlets (PEPs).

This is not a test and there are no right or wrong answers meant to judge you. The purpose of this questionnaire is to understand your current knowledge, understanding, and confidence related to Autism Spectrum Disorder (ASD) **before/after exposure to the booklet series**.

Your honest responses will help us evaluate how helpful and informative the pamphlets are for parents and caregivers. All responses will be kept confidential and used only for academic research purposes.

Please read each question carefully and answer based on your current understanding and confidence. Try to respond independently without discussing answers with others.

Your participation is voluntary, and you may choose to stop at any time.

Thank you for your time and valuable contribution.

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* Indicates required question

Name of Parent/Caregiver *

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1. A mother feels guilty because her child has autism and thinks it happened because she did something wrong during parenting. What is the most accurate understanding? *

- A. Autism happens because parents are too strict
- B. Autism is caused by differences in brain development
- C. Autism develops when children watch too much TV
- D. Autism happens only in certain families
- E. I don’t know / Not aware about this

---

2. A child with autism has strong memory skills but struggles socially. This means: *

- A. The child does not really have autism
- B. Autism affects everyone in exactly the same way
- C. Autism is a spectrum and each child is different
- D. The child will outgrow autism automatically
- E. I don’t know / Not aware about this

---

3. Which of the following is TRUE regarding rights in India? *

- A. Children with autism do not qualify for disability support
- B. Only adults with disabilities get legal protection

- C. Children with autism are protected under RPwD Act, 2016
- D. Schools can refuse admission to children with autism
- E. I don't know / Not aware about this

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4. A parent asks for a blood test to confirm autism. What is correct? *

- A. Autism is diagnosed only through brain scan
- B. Autism is diagnosed through behavioural observation and assessment
- C. Blood tests always confirm autism
- D. Autism cannot be diagnosed before 3 years
- E. I don't know / Not aware about this

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5. A 2-year-old child does not respond to name and has no words yet. What is the best step? *

- A. Wait until 5 years
- B. Scold the child to speak
- C. Consult a developmental professional early
- D. Ignore because boys talk late
- E. I don't know / Not aware about this

---

6. Why is early intervention important? *

- A. It cures autism completely
- B. The brain learns faster in early years
- C. It guarantees normal development
- D. It replaces schooling
- E. I don't know / Not aware about this

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7. A child repeats the sentence "Open the door" instead of answering a question. This behaviour is: *

- A. Misbehaviour
- B. Echolalia, which can be part of autism
- C. Attention-seeking only
- D. Proof that the child understands everything
- E. I don't know / Not aware about this

---

8. A child does not speak but pulls mother's hand to the fridge. The best immediate response is: *

- A. Ignore the child
- B. Say "Use words properly"
- C. Model the word and show a picture for "juice"
- D. Punish for not speaking

- E. I don’t know / Not aware about this

---

9. Which strategy best supports communication? *

- A. Long explanations
- B. Forcing eye contact
- C. Short phrases and visual support
- D. Comparing with other children
- E. I don’t know / Not aware about this

---

10. A child screams when the mixer grinder starts. This may be due to: *

- A. Stubborn behaviour
- B. Hypersensitivity to sound
- C. Laziness
- D. Lack of discipline
- E. I don’t know / Not aware about this

---

11. A child throws food when asked to eat. According to ABC understanding, parents should first: *

- A. Punish immediately
- B. Identify what happened before the behaviour

- C. Ignore forever
- D. Force feeding
- E. I don’t know / Not aware about this

---

12. A child keeps jumping and crashing into cushions. This may indicate: *

- A. Hyperactivity only
- B. Need for sensory movement input
- C. Intentional disobedience
- D. Hunger
- E. I don’t know / Not aware about this

---

13. A child becomes upset during morning routine. What is most helpful? *

- A. Change routine daily
- B. Use a visual schedule with clear steps
- C. Shout to hurry
- D. Skip school
- E. I don’t know / Not aware about this

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14. When teaching dressing skills, the best approach is: *

- A. Do everything for the child

- B. Teach all steps at once
- C. Break the task into small steps
- D. Compare with siblings
- E. I don't know / Not aware about this

---

15. For better progress in school, parents should: *

- A. Leave everything to teachers
- B. Avoid talking to therapists
- C. Work together with teachers and therapists
- D. Change schools frequently
- E. I don't know / Not aware about this

Confidence Rating Section (Before/After Reading the PEPs)

Please rate your current confidence level.

16. Before/After reading the pamphlets, I feel confident in explaining what autism is to a family member. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

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17. Before/After reading the pamphlets, I feel confident in understanding my child's legal rights and available supports. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

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18. Before/After reading the pamphlets, I feel confident in knowing when to seek professional help for my child. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

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19. Before/After reading the pamphlets, I feel confident in participating actively in my child's intervention planning. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

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20. Before/After reading the pamphlets, I feel confident in using simple strategies to support my child's communication at home. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

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21. Before/After reading the pamphlets, I feel confident in using visual supports or simple routines to help my child communicate. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

---

22. Before/After reading the pamphlets, I feel confident in identifying possible reasons behind my child's challenging behaviour. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

---

23. Before/After reading the pamphlets, I feel confident in managing sensory difficulties at home in a calm manner. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

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24. Before/After reading the pamphlets, I feel confident in teaching daily living skills step by step. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

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25. Before/After reading the pamphlets, I feel confident in communicating and collaborating with teachers and therapists. *

1 = Not confident at all

2 = Slightly confident

3 = Moderately confident

4 = Confident

5 = Very confident

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