# DEVELOPMENT OF A PARENT MEDIATED INTERVENTION PROGRAM FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

*Thesis Submitted for the Degree of*

**DOCTOR OF PHILOSOPHY (Ph.D.)**
**IN**
**PSYCHOLOGY**


**NIGESH K.**

*Guide*
**Prof. (Dr.) C. Jayan**

*Co-Guide*
**Dr. Sukanya B. Menon**

**DEPARTMENT OF PSYCHOLOGY**
**UNIVERSITY OF CALICUT**

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# DEPARTMENT OF PSYCHOLOGY
# UNIVERSITY OF CALICUT

**Prof. (Dr.) C. JAYAN**
**Professor (Rtd.)**

Grams : UNICAL
Phone : (Office) 0494-2407358
Fax : 0494 2402845
E-mail : drcjayan@gmail.com
CALICUT UNIVERSITY P.O.
Pin: 673 635, KERALA, INDIA


## CERTIFICATE

Certified that this thesis entitled '**DEVELOPMENT OF A PARENT MEDIATED INTERVENTION PROGRAM FOR CHILDREN WITH AUTISM SPECTRUM DISORDER**' submitted to the University of Calicut for the award of the Degree of Doctor of Philosophy in Psychology is a bonafide record of the research work carried by **Nigesh K.**, under our supervision and guidance. No part of this has been submitted earlier for any other purpose.

C.U. Campus
.... / ..... / 2022

**Prof. (Dr.) C. Jayan**
(Supervising Guide)

**Dr. Sukanya B. Menon**
(Co-Guide)

# DECLARATION

I, **NIGESH K.**, do hereby declare that this thesis, titled '**DEVELOPMENT OF A PARENT MEDIATED INTERVENTION PROGRAM FOR CHILDREN WITH AUTISM SPECTRUM DISORDER**' is a bonafide record of the research work done by me under the guidance of Prof. (Dr.) C. Jayan, Professor in Psychology (Retd), Department of Psychology, University of Calicut and Dr. Sukanya B. Menon, Assistant Professor, Department of psychology, Prajyoti Niketan College, Pudukkad, Thrissur. I further declare that this dissertation has not previously formed the basis for the award of any degree, diploma, associateship, fellowship, or other similar title of recognition.

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**NIGESH K.**

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# LIST OF ABBREVIATIONS

| | |
|---|---|
| ABA | Applied Behavioural Analysis |
| ABI | Antecedent-Based interventions |
| ADAS | Abbreviated Dyadic Adjustment Scale |
| ADI-R | Autism Diagnostic Interview - Revised |
| ADL | Activity Daily Living |
| ADOS | Autism Diagnostic Observation Schedule |
| ASD | Autism Spectrum Disorders |
| CDMRP | Community Disability Management and Rehabilitation programme |
| DD | Developmental Disorders/Developmental Delay |
| FBA | Functional Behaviour Assessment |
| IS | Insistence on Sameness |
| ISAA | Indian Scale for Assessment of Autism |
| PA | Parents |
| PMI | Parent Mediated Intervention |
| PR | Professionals |
| RBS-R | Repetitive Behaviour Scale-Revised |
| RRB | Restricted and Repetitive Behaviours |
| RSM | Repetitive Sensorimotor |
| TD | Typical Development |
| TEACCH | Treatment and Education of Autistic and Related Communication Handicapped Children |
| ToM | Theory of Mind |
| VAS | Visual Analogous Scale |
| VSMS | Vineland's Social Maturity Scale |

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# ABSTRACT

Parent-Mediated Intervention (PMI) Program frameworks can be included for developing cost-effective interventions for children with ASD. However, there is a scarcity of such universal intervention programs, particularly in India, that adopts frameworks which target parents and children with autism spectrum disorder. In this background the present study was undertaken to explore the perspectives and felt needs of parents and professionals about a parent mediated intervention program, design the same and conduct its preliminary evaluation to examine the feasibility, receptivity, and changes in outcome variables. The study employed a sequential, mixed-methods design and was conducted under two broad phases, a pilot phase and a main phase. Pilot phase started with getting familiar with the psychological variable in the context of interventions for children with ASD. An extensive analysis of previous studies was done and a focused group discussion with parents and unstructured interview with professionals were conducted for understanding their perspectives on the felt needs, practicability and utility of a parent mediated interventions for children with ASD. These sources of data, helped to prepare a schedule for semi structured interview to be conducted in main phase of the research. The main phase of the research was carried out through three stages, namely, exploratory stage, program design, and preliminary evaluation/program pilot trail run stage.

The first stage explored the perspectives of parents (n=28) and professionals (n=23) through semi structured interviews (one-to-one) about felt needs, feasibility, potential content, and structure of the proposed PMI program. Exploratory phase results indicated a consensus among stakeholders about the need for the proposed PMI program with parent and child outcome related components. The stakeholders also perceived that the parents would be receptive of the proposed program. However, long-duration programs were not considered feasible. Awareness about the importance of the program, conviction of parents and family members, appeal of the program, and prior planning were considered as important factors influencing the uptake of the program. Suggestions for potential content could be finalized by

employing ranking of potential content list by parents (n=20) and professional experts (n=10). This potential contents were grouped under two broad categories viz. parent related and child related.

In the second stage, the proposed PMI program was developed based on the data from the exploratory phase, literature review, and insights from on-field experiences. The program included five modules on five core themes (psychoeducation and parental support; social adaptive skills; basic communication skills; managing problem behaviours; and fine-motor skills). Fine-tuning of the program (through evaluation by six experts and five parents) and informal pre-pilot runs of the modules resulted in a comprehensive, 2-3 months program deliverable in individual or group setting with providing training on parent and child components, for children with ASD through their parents.

During the third stage, the program was pilot tested using a small n, pre-post follow-up design on a sample of children with ASD (n=2) who completed the program and provided assessment data. Significant gains in knowledge about ASD on multiple indices, increase in favorable attitude towards ASD and developmental disabilities, and a significant improvement in self-esteem and confidence following program participation were observed. The gains on self-esteem and confidence were maintained at one-month follow-up.

Further, significant improvements were seen on problematic behaviours, activities of daily living such as eating, brushing, toilet skills and dressing, similarly basic communication skills (responding to name calling) from baseline to follow-up on visual analogous scale evaluation. There were no changes on measures of Vineland's social maturity scale and Indian scale for assessment of autism. However, field observations, and feedbacks indicated significant parental engagement in individual level activities for PMI. There was a significant increase in the proportion of participants recommending professional help-seeking. The qualitative data yielded rich information on perceived gains and strengthened the findings. Observations during the trial indicated that the program as delivered was feasible. Receptivity of the program was high, as indicated through satisfactory rate of expressed interest and low

attrition, high level of engagement of the parents in the program, in addition to perceived program impact and high likelihood of the participants recommending the program to other beneficiaries. Limitations, strengths, and implications of the study for further research and practice have been highlighted.

**Keywords**: Autism spectrum disorder, parent-mediated intervention program, feasibility, and receptivity.

# CHAPTER I
# INTRODUCTION

# INTRODUCTION

The present chapter provides brief descriptions on key themes of the current research. The following sections provide accounts of the history of autism spectrum disorder (ASD), current diagnostic features, epidemiology, causes, and theories regarding ASD. At the end, the chapter also includes a brief write-up on the interventions for autism spectrum related issues.

***Autism: Brief history***

It was in the year 1911 that Eugen Bleuler first used the term "autism" (LeMay et al., 2019). However, the same was used to describe an individual who retreated into a state of self-absorption, which had to do with schizophrenia. In the beginning of the year 1943, Kanner used the term to refer to individuals with similar presentations, whom he described as having severe "autistic aloneness". Again, this was used in connection with early-onset schizophrenia (LeMay et al., 2019). However, subsequent research and studies, particularly by Kanner, revealed that autism is not a symptom of schizophrenia, but a distinct condition characterised by difficulties associated with neurodevelopment (Goldstein & Ozonoff, 2009). It can be found that the core features described by Kanner in the early years themselves still remain in the diagnostic characteristics of schizophrenia. It is also to be noted that during the same time period as Kanner described autism, Hans Asperger, in Germany, was also researching the features of autism, which came to public notice only later as his works were done in German (LeMay et al., 2019). Despite the many insights into the condition, for a long time, autism was considered by many as a condition associated with infantile psychosis. But findings from research over a period of time showed that it would be incorrect to consider autism as an infantile psychosis (Rimland, 1964; Rutter, 1972). Further, several individuals with autism also showed intellectual disability, leading some to consider these as instances of intellectual disability. However, the intellectual difficulties reported in individuals with autism differed from those with general

intellectual disability in several domains, including sex-ratio, neuropathology, and the nature of cognitive difficulties (Rutter & Schopler, 1987).

Despite several indicators suggesting that this condition is not psychosis, in the first two editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM), *childhood schizophrenia* was the only diagnostic category available where autism could be described. According to Volkmar and Klin (2005), the works of Kolvin and Rutter established the clear and distinctive features of autism from those of early-onset schizophrenia. Rutter expanded on Kanner's work and identified four key features: early onset, distinct impairments in social development, distinct impairment in communication, and unusual behaviours (Rutter, 1978). The impairments in social and communication abilities were considered distinct as Rutter observed that they were not just an outcome of the associated intellectual disability. Thus, it was only in the year 1980, in the third edition of the DSM, that autism was included with distinct diagnostic criteria.

While the inclusion of autism in the DSM-III was unduly specific and narrow, it did show some marked differences in the same compared to the previous versions. In the DSM-III, autism was placed in a new class of childhood-onset disorders named pervasive developmental disorders. In addition, the section included Asperger's disorder and atypical pervasive developmental disorders (DSM-III, 1980). The revision of the DSM-III, the DSM-III-R (American Psychiatric Association, 1987), adopted a polythetic approach, which was more developmentally focused than the previous versions, but held on to the earlier description of the disorder as based on the three major areas of dysfunction (Volkmar et al., 2009). Another notable change in the DSM-III-R was the change of the diagnostic label from infantile autism to autistic disorder (Volkmar et al., 2009). With the next version of the DSM, DSM-IV, and that of the International Classification of Diseases—tenth edition (ICD-10; World Health Organization, 1992), there were tremendous efforts made to provide clarity on the diagnosis of autism-related conditions. Extensive data collection and analysis showed the social criteria of autism diagnosis as the most potent single diagnostic factor, and the decision was taken to weigh the same more in the diagnosis of ASD (Volkmar et

al., 2009). While there was a continuing effort to approach autism from a developmental perspective, the new version also did not have a lot of information on the condition before the age of three. It was also reported that the DSM diagnosis of autism has more stability when made for children aged 3 and above (Volkmar et al., 2009). The latest versions of the DSM and the ICD added further changes to the diagnostic entity of autism, which are described briefly below.

***Diagnosis of autism: DSM 5 and ICD 11***

Since the publication of the DSM–IV and the ICD–10 during the early 1990s, the scientific understanding of autism and most other mental health conditions have been improving exponentially. The latest versions of DSM and the ICD reflect these understandings.

The ICD-11 and the DSM-5 have attempted to streamline and unify the conceptualization of autism in their diagnostic systems. Thus, both systems overlap for the most part in their diagnostic description. Considering this, only the diagnostic criteria for ASD in the DSM-5 is reported in this thesis.

**A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):**

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts;

to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify current severity*: Severity is based on social communication impairments and restricted repetitive patterns of behavior.

**B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):**

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify current severity*: Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

**C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).**

**D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.**

**E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.**

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

- **With or without accompanying intellectual impairment**
- **With or without accompanying language impairment**
  - (Coding note: Use additional code to identify the associated medical or genetic condition.)
- **Associated with another neurodevelopmental, mental, or behavioral disorder**
  - (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)
- **With catatonia**
- **Associated with a known medical or genetic condition or environmental factor**

***Figure 1.1: ASD diagnostic criteria (DSM-5, APA)***

In the DSM-5, there is only a single diagnosis for the condition; that is, ASD. This way, the DSM-5 considers autism as a single continuous spectrum with differences in the symptoms and the way these symptoms are presented. In the ICD-10, autism had three subtypes, viz., childhood autism, Asperger syndrome, and pervasive developmental disorder (PDD) – unspecified, where the 11$^{th}$ version of the ICD has adopted a similar approach to that of the DSM-5. However, one notable difference is that the ICD-11 has a specifier which mentions the presence or absence of intellectual disability. As for the main diagnostic criteria, the original requirement of impairments in three areas of functioning (communication, social interaction, and restrictive, repetitive activities) was reduced to two, where the communication and social interaction issues were combined into a single social communication symptom cluster. This change is accepted in both ICD-11 and DSM-5. Further, the need for functional impairment to be present in early childhood was removed while the social communication difficulties and repetitive behaviour requirements were kept intact. This way, those cases where the functional impairments become apparent at later ages could be considered as being in the same continuum of the autism spectrum rather than a separate diagnostic entity, i.e., Asperger syndrome. Yet another difference was the inclusion of sensory issues as a part of the restrictive and repetitive activities and interests. The same is true in both ICD-11 and DSM-5. In addition, instead of the mild, moderate, or severe categorisation of the symptom-severity, the severity evaluation in the form of three levels has become an integral part of the diagnosis. These include the major changes that were adopted in the diagnostic features of ASD in the ICD-11 and the DSM-5. However, one needs to keep in mind that, while the DSM-5 is already in use, the formal reporting of mental health conditions based on the ICD-11 has only begun in the year 2022.

## Epidemiology

Being a neurodevelopmental condition, the prevalence of autism has significant implications for several levels of human life. For example, accurate prevalence data on autism would help us to determine the economic and health service burden, allocation of resources, need for service, and so on (Chiarotti & Venerosi, 2020).

However, prevalence studies on autism show wide variations, which suggests a strong need to look into the various factors affecting the same (Chiarotti & Venerosi, 2020). This being said, there has been a significant increase in the prevalence of autism disorder in the past decades. The increase was so great that there were thoughts of the condition as an "epidemic" (Fombonne, 2001).

However, there have been several attempts to determine the prevalence of the condition. In one such attempt, Elsabbagh et al. (2012) conducted a comprehensive review of published studies till 2012, which found a prevalence rate ranging from 0.19/1000 to 11.6/1000. In a review of the study by Elsabbagh et al. (2012) and Tsai (2014) reported a median prevalence of 1.32/1000 for autistic disorder and 6.19/1000 for PDD/ASD. The findings reported only negligible differences from those of the Elsabbagh study. The existing literature, thus, varies to a great extent. Across Europe, the Middle East, Asia, Australia, New Zealand, and North America, the prevalence data shows significant variations (Hodges et al., 2020). Another worldwide estimate shows the prevalence of autism to be one in 270 (GBD 2019 Diseases and Injuries Collaborators, 2020).

In India, there seems to be a lack of high-quality epidemiological studies on the prevalence of autism. According to the 2011 census report, 1.3 percent of the Indian population reported having a neurodevelopmental disorder. However, this seems to be an underestimation. In a more recent study by Arora et al. (2018), including about 4000 samples from five geographically diverse populations, found that among the 2–6, the prevalence of a neurodevelopmental disorder ranged from 2.9% to 18.7%, and for six-to-nine-years old, it ranged from 6.5% to 18.5%. Combined estimates showed the estimate of neurodevelopmental disorders among the former group to be 9.2% and 13.6% for the latter. In a systematic review of studies on the prevalence of autism, Chauhan et al. (2019) reported a prevalence rate of 0.11% in children aged 1–18 years of age and 0.09% among children aged 0–15 years.

**Causes**

When it comes to the question of what causes autism, the debate is still ongoing. Much like several other psychiatric conditions, a definitive causative factor for autism seems

less likely. The available evidence indicates that an interplay between genetic, environmental, and immunological factors contributes to the pathogenesis of autism (Kidd, 2002). There are also suggestions that autism is not just a brain disorder but a multisystem metabolic disease (Jepson & Johnson, 2007). Nevertheless, there is an active debate going on about the role of genetic and environmental factors and the interactions between these two elements in determining the variations in the autism symptom presentation in the affected person's cognitive, emotional, and developmental features (Pendergrass et al., 2014). However, with continuing research and studies, our understanding of various factors that may contribute to a child developing autism has increased steadily in the past decades. In general, discussions about the causes of autism revolve around two major topics: genetics and environmental factors. The following sections provide a brief outline of the research done on these two areas.

### *Genetic factors*

The role of genetic factors in ASD has been indicated in studies starting as early as the 1970s (Kaerney et al., 2011). Twin and family studies, for example, by Folstein and Rutter (1977), and Steffenburg et al. (1989), did show a higher rate of heritability for the autistic disorders, which implied a genetic risk. Later studies also showed the same, that there was about a 15-20% risk of autism among siblings of individuals with autism, which is markedly higher than the rate found among the general population (Baird et al., 2006; Fombonne, 2005). As such, there is a consensus that genes are one of the risk factors for autism (Bai et al., 2019). Also, as mentioned earlier, having a sibling with autism puts one at a higher risk of having autism, compared to those children who have typically developing siblings (Hallmayer et al., 2011; Ozonoff et al., 2011). Among monozygotic twins, if one has autism, the probability of the other sibling having autism is found to be from 60% (Muhle et al., 2004) to 90% (DeFrancesco, 2001). Further, studies also report that certain genetic and chromosomal conditions, such as tuberous sclerosis and fragile X syndrome, are also associated with a high risk of autism (DiGuiseppi et al., 2010; Sztainberg & Zoghbi, 2016). Research into the genetic foundation of autism has improved our insights

exponentially in the last couple of decades. While it is still inconclusive and research is still coming up with further understandings about the aetiology of the condition, there is more clarity on the same. With the advancement of technology and tools, it is now able to analyse the genetic material with much more precision. Thus, at present, several genes are found to have variations in individuals with autism. CNTNAP2, CDH10, SHANK3, NRXN1, and neuroligin genes have been identified as particularly promising in understanding of autism aetiology (Kaerney et al., 2011).

***Environmental factors***

As mentioned above, there is a universal acceptance to the multi-factorial origin of autism. It is also important to keep in mind that this is true for the population in general as well as for individuals (Volk et al., 2011). While, at times, genetic factors alone may be sufficient to cause autism, several studies have shown the critical role various non-inherited and environmental factors play in the development of autism.

The existing literature suggests the possible role of socioeconomic factors, race, ethnicity, place of birth, season of birth, parental age, and child's sex. Some of these factors are briefly mentioned below.

Among the various environmental factors associated with the origin of autism, socioeconomic status has been prominent. In general, autism prevalence was associated with a higher socioeconomic status. For example, when compared to children of mothers who do not have a high school graduation, the likelihood of diagnosis of autism was twice among children whose mothers had a post-graduate degree with the risk rising incrementally with increase in the level of maternal education (Croen et al., 2002). However, in general, several studies have failed to show any concrete evidence on the relationship between autism and indicators of socioeconomic status. For example, in a study from Denmark, which included all births from 1972 and all the diagnoses till 1999, maternal education and paternal wealth was found to have no relationship (Larsson et al., 2005). Overall, the relationship between socioeconomic variables and autism prevalence depends on the place where the studies were conducted (mostly reported from the United States), the data collection procedure (for example, from databases with passive surveillance), and

nature of healthcare access. It is suggested that, at present, differences in the socioeconomic status are unlikely to provide insights into the role of environmental factors in the development of autism (Volk et al., 2011).

Coming to race/ethnicity as a potential factor in the development of autism, the findings are similar to that of socioeconomic status, and inconsistent. For instance, the study by Croen et al. (2002) from California found that African-American children are at a higher risk for autism compared to Caucasian children. This rather than being expression of the role of race/ethnicity, may show some other factors. For example, it can be an expression of differences in care-seeking and clinician practices (Volk et al., 2011). As is seen with socioeconomic status, the present data suggests that race/ethnicity may not help a lot in understanding the aetiology of autism.

As mentioned above, there is a universal acceptance of the multi-factorial origin of autism. It is also important to keep in mind that this is true for the population in general as well as for individuals (Volk et al., 2011). While, at times, genetic factors alone may be sufficient to cause autism, several studies have shown the critical role various non-inherited and environmental factors play in the development of autism.

The present evidence implies that socioeconomic circumstances, race, ethnicity, location of birth, season of birth, parental age, and child's sex may all have a role. Another factor reported to be associated with autism is the place of birth and residence. While there have been studies which reported an increased association between a high risk of autism and living in urban areas compared to rural areas (Lauritsen et al., 2005), this is probably due to the fact that the availability of health providers is greater in urban areas, leading to more diagnoses being made compared to rural areas where the concentration of qualified health workers is lower (Volk et al., 2011). Nevertheless, the immigration status of the mothers is reported to be associated with a high risk of autism. For instance, a study from Australia has found that those children whose mothers were born outside the country were found to be at a higher risk, with the risk being greatest for those from southeast or northeast Asia (Williams et al., 2008). At present, the hypothesis is that immigration may expose mothers to unfamiliar microbes, which may lead to high risk or the various stressors

associated with migration may put the foetus or the infant at increased risk (O'Donnell et al., 2009).

Inconsistent results have also been reported in association with parental age and the risk of autism. While some studies report an association between the two (Bhasin & Schendel, 2007; Croen et al., 2002), some other studies show no relationship (Larsson et al., 2005) or even an inverse relationship (Burd et al., 1999). While the relationship between age and autism risk is not conclusive, there are some arguments that support the possibility of advanced age and high risk for autism. For instance, advancing age, both that of the father and mother, is associated with aberrations in chromosomes, low birth weight, and congenital anomalies (Djahanbakhch et al., 2007; Reichman & Teitler, 2006). Use of assisted productive technologies, placental insufficiency, health conditions such as cardiovascular issues that increase the chance of hypoxia, less favourable hormonal milieu, etc. are also implicated in relation to increasing age and high risk for autism (Volk et al., 2011).

Yet another factor relevant to the discussion is the sex of the child. One finding that is consistently seen in autism studies is a skewed prevalence of the same based on gender. Overall, the literature suggests that the male-female prevalence ratio for autism is 4:1 (Fombonne, 2003). It is also important to keep in mind that there is a sizeable variation in this number from study to study. Endogenous hormones (Knickmeyer & Baron-Cohen, 2006) and epigenetic alterations such as X-chromosome inactivation (Nagarajan et al., 2008) are reported to be possible contributors in this regard. In general, it could be that male embryos are more susceptible to certain pre-peri-post conceptional/natal insults compared to female embryos (Volk et al., 2011).

The season of birth is also being studied in connection to the aetiology of autism. While there are some indications towards the role of the season of birth, for example, that March and August months are implicated in a higher rate of children with autism, there is nothing conclusive yet (Volk et al., 2011).

Medical factors such as infections and immunological factors, fertility treatments, obstetric factors, medical treatments, and vaccines are also implicated in the aetiology

of autism. In addition, chemicals in the environment, especially metals, air pollutants, pesticides, and endocrine disruptors, are also implicated in the development of autism spectrum disorder.

In sum, there is no doubt that autism has a multifactorial aetiology, with both genetic and environmental factors playing a crucial role. Even large-scale epidemiological studies fail to provide conclusive evidence. Whether it is genetic or environmental factors, so far, all we have are clues and not confirmations. It is expected that large-scale studies with cutting-edge technologies and advanced investigation methods will provide us with further insights into the aetiology of the complex, multi-layered, and less understood condition of autism spectrum disorder.

## Theories of ASD

It can be said that autism is a behaviorally defined disorder with a biological basis. Several biological factors associated with the development of autism have already been discussed. However, if we look into the diagnostic guidelines for autism spectrum disorder, it can be seen that it is a behaviorally defined disorder. Diagnostic guidelines also specify autism as behaviourally defined disorder. Two models, the behavioural and the neurobiological model of autism, are considered the descriptive models of autism. A third level of explanation is also there, which, according to Morton and Frith (1995), is necessary to develop a causal model of autism. This third model pertains to the cognitive or psychological level. As of now, there is no direct link between the biological processes and the behavioural expression of autism (Lind & Williams, 2011). Lind and Williams suggested that to understand the mechanisms by which genetic and biological factors influence behavior, it is necessary to understand the various cognitive processes that mediate a particular behaviour. In this regard, there have been several theories proposed. Among those, three theories are reported to be the most influential (Lind & Williams, 2011).

### *Theory of Mind Hypothesis*

Among the theories trying to explain the cognitive and psychological underpinnings behind behaviours associated with autism, probably the most well-known is the

"theory of mind" hypothesis. Simply put, a theory of mind is the ability of an individual to attribute mental states such as beliefs, desires, and intentions to oneself as well as others and predict behaviour (Premack & Woodruff, 1978). Those who favour this hypothesis state that several of the behaviours characteristic of autism can be adequately explained by deficits in the theory of mind.

According to Leslie (1987), during the first one and a half years of life, a child who is developing typically represents the external world purely veridically, which is called "primary representations." By the time the child is about 18 months old, the child acquires the ability to form representations of these representations. When this happens, the child is capable of forming a representation of the external reality that is de-coupled from it, called "M-representations" (Leslie & Roth, 1993). When this ability is present, the child no longer thinks about the single reality that is out there but is also capable of realising that there are representations in the minds of other people also. This enables the child to manipulate the upcoming information in various ways. This mechanism, called the theory of mind, is stipulated to be damaged in individuals with autism.

This argument does make sense considering that individuals with autism have significant difficulty initiating or responding to social cues. It may be that they do not recognise the different mental representations that other people have. There have been several studies looking into this possibility, and probably Baron-Cohen et al., (1985) study can be considered one of the most important. Further support for the theory of mind hypothesis was found in studies conducted by Happé (1995), Williams and Happé (2010), Lind & Bowler (2010), and so on. In addition, the theory of mind hypothesis has received support from neurobiological studies as well. Specifically, it is found that there is an under-activation of the medial prefrontal cortex in individuals with autism during theory of mind-related tasks (Castelli et al., 2002). The medial prefrontal cortex is the brain part that plays an important role in the theory of mind tasks (Carrington & Bailey, 2009).

While there is evidence supporting the theory of mind hypothesis, there have been challenges also. For instance, the universality of the theory of mind deficit in autism

has been questioned in several research studies. In one of the meta-analyses, it was found that 16.6% to 60% of individuals with ASD had successful false-belief tests (a measure of theory of mind), compared to 58.8% of individuals with moderate learning disability (Happé, 1995). If the theory of mind deficit was the underlying cognitive factor in the development of autism, then this should not have been the case. Another challenge with the theory of mind hypothesis is its diagnostic specificity. Some studies have shown that children with conditions other than autism also have deficits in this ability. For example, a theory of mind deficit is found in children with congenital deafness (Peterson & Seigal, 1995), congenital blindness (Peterson et al., 2000), and in children with general intellectual deficits (Yirmiya et al., 1998). Yet another difficulty in the theory of mind hypothesis being used as an explanatory model for autism is that there is no conclusive direct link between the theory of mind deficit and the severity of the clinical features. Studies have found that there was a significant difference between children who passed or failed the theory of mind tests in the level of behavioural problems reported (Frith & Happé, 1994). Among the various challenges raised against this hypothesis, probably the most important one is its inability to explain how some of the features of ASD, such as social smile, maintenance of eye contact, etc., which require very little mentalization, are also affected in ASD (Lind & Williams, 2011). Alternatively, it is suggested that difficulty engaging emotionally with others leads to a diminished theory of mind rather than results from a defective theory of mind (Hobson, 1989, 2002). According to Hobson (2002), the inability to identify with others leads to the characteristic features of ASD rather than a diminished theory of mind.

### *The Executive Dysfunction Hypothesis*

There is no consensus regarding the definition of executive functions yet. However, in general, the term is used to describe a broad range of cognitive functions, located primarily in the frontal lobes (Stuss et al., 2002). These functions include planning, set-shifting, working memory, inhibitory control, and generativity (Hill, 2004). As such, these functions play an integral part in day-to-day human functioning.

Among the various difficulties reported among patients with specific frontal lobe damage, cognitive and behavioural inflexibility similar to that seen in people with ASD. This leading to an early argument that deficits in executive functions can underpin the behavioural difficulties reported in ASD (Hughes et al., 1994). The limited number of activities that a person with ASD engages in may have to do with difficulty in generating and planning (Turner, 1999). Deficits in set-shifting or cognitive flexibility can explain the difficulties in joint-attention tasks in individuals with ASD (McEvoy et al., 1993). In addition, pretend play deficits are thought to be due to a limited ability to generate multiple pretend scenarios (Jarrold, 2003) rather than being caused by difficulties in mental representation as argued in the theory of mind hypothesis.

Lind and Williams (2011) consider the works of Russell (1996) as probably the most theoretically developed account of executive dysfunction in ASD. Russell postulates that the basic pre-requisite for all higher-order executive functioning is the ability called "action monitoring" (Russel, 1996). Hill and Russel (2002) define it as an individual's ability to distinguish between the changes caused by "self" and by "world" in an experience. A failure in this action monitoring ability will lead to difficulty in understanding the existence of others with their own mental states.

The executive dysfunction hypothesis in ASD does have support from several studies which show impairments in the executive functioning of individuals with ASD. For example, in tasks that require planning ability, individuals with autism significantly more frequently fail than those without (Pellicano, 2007). On tests assessing cognitive flexibility, children with autism are found to have significant difficulty (Ambery et al., 2006). Working memory, another key component in the executive function repertoire, is also found to be disrupted in ASD (Sinzig et al., 2008). Furthermore, it is also noted that the executive dysfunction hypothesis in ASD explains the repetitive behaviour patterns seen in ASD. Several studies show a significant correlation between executive dysfunction and the level of restricted, repetitive behaviours and interests (RRBIs) (Lopez et al. 2005).

Nevertheless, the executive dysfunction hypothesis has also been met with several challenges. One of the most important challenges to the executive dysfunction hypothesis in ASD is the finding that basic action monitoring skills that are proposed to be impaired in ASD seem to be preserved in several cases (Williams & Happé, 2009). While it is true that some of the higher-order executive functions are impaired in people with ASD, the above finding questions the basic tenet of the executive function hypothesis as Russell (1996) proposed originally. There are further queries about the universality and specificity of this hypothesis in explaining ASD. There seems to be, for example, significant within-group variations in the degree of executive dysfunction among individuals with ASD (Pellicano et al., 2006). Also, several studies show that executive dysfunction is not specific to ASD alone. There is executive dysfunction in other conditions such as attention-deficit hyperactivity disorder and Tourette syndrome (Lind & Williams, 2011).

### *The Weak Central Coherence Hypothesis*

The central coherence hypothesis (Frith, 1989, 2003) refers to a "built-in propensity to form coherence over as wide a range of stimuli as possible, and to generalise over as wide a range of contexts." In the ASD literature, it is suggested that children with autism have a deficit in this ability. As defined as a core deficit in extracting meaning and gestalt processing, the current literature suggests that weak central coherence is more of a cognitive style than a cognitive deficit (Happé, 1999). Thus, in a continuum of central coherence, an individual may have a preference for processing parts, called a local bias, or a preference for processing wholes, called global bias. It is suggested that individuals with autism have a preference for processing parts, that is, a local bias (Lind & Williams, 2011).

Originally, it was thought that it is the deficit in central coherence that leads to the social deficits in children and adults with ASD. Frith (1989) proposed that this could be the fundamental deficit underlying the theory of mind impairments. However, in recent times, this argument has been rejected in favour of the new postulation that it is the weak central coherence that can explain other non-social and perceptual difficulties associated with ASD (Happé & Frith, 2006). Indeed, in the original

description of the condition by Kanner (1943) itself, the "inability to experience wholes without full attention to the constituent parts" was noticed. Findings such as individuals with ASD performing exceptionally on tasks requiring local processing (Happé & Frith, 2006) are considered to provide support for the weak central coherence hypothesis. Further support for the weak central coherence hypothesis comes from the findings that individuals with ASD have superior performance on the block design test (Caron et al, 2006) and embedded figures test (Kaland et al., 2008).

Similar to the other cognitive models of ASD, one major challenge to the weak central coherence hypothesis is that it lacks universality. While there is a higher percentage of individuals with ASD who show weak central coherence, the same was not universally found in several studies (Teunisse et al., 2001). Further, how this hypothesis can explain the entire ASD presentation is also doubtful. Some argue that the hypothesis is capable of explaining only a limited aspect of the behavioural phenotype seen in individuals with ASD (Lind & Williams, 2011). Further, the "enhanced perceptual functioning theory" (Mottron & Burack, 2001; Mottron et al., 2006) postulates that it is not that individuals with ASD do not have a deficit in global processing, nor do they show any local bias, but rather that they have enhanced perceptual processing leading to a local bias.

**From Theories to Treatment**

Understanding the nature of ASD, its aetiology, and its theoretical explanations is integral to the efforts to deal with the challenges posed by the condition. Only when these insights and understandings are put to use in assisting individuals with ASD-related issues will the process be complete. As a result, the following section provides a brief overview of the theoretical influences on ASD treatments.

Fundamentally, therapies and interventions for ASD are based on theories. These theories guide the practitioner in the planning, development, implementation, and evaluation of the newly developed interventions. Treatment theories provide hypotheses about the various factors leading to a particular problem and also the mechanisms through which these can change a particular behaviour or a set of behaviours can be changed (Kazdin, 1999; Rapport, 2001). These theories are then

translated into various hypotheses, which aid in designing a particular intervention and its evaluation methods. The evaluation process provides feedback to the theory, providing further insights and helping the researcher with scope for refining the initial ideas and hypotheses.

In the area of ASD, it can be seen that there is no single theoretical framework informing the treatment options. Rather, there are several treatment strategies based on different theoretical orientations. This variation, to a great extent, can be due to a lack of knowledge about the mechanisms behind the various symptoms of ASD that are targeted through these interventions and therapies (Colombi et al., 2019).

Among the various theories that had an influence on the interventions for ASD, the first one would be psychodynamic psychotherapy. Standing on the notion that the mother-child relationship is an integral part in the development of psychopathology (Freud, 1911), psychoanalytic theories suggest that inadequate parenting lies behind the symptoms associated with ASD (Bettelheim, 1967). However, with the emergence of overwhelming scientific evidence, the psychodynamic postulation of ASD-related issues has been debunked. Then came the biggest and most influential behavioural theories with the introduction of operant conditioning, described by B. F. Skinner (1953), in the treatment of ASD by practitioners like Ferster (1964) and Lovaas (1968), the Applied Behaviour Analysis (ABA) based interventions became the most prominent among the available interventions for ASD. Behavioral interventions are guided by the assumption that atypical behaviours, for example, seen in children with ASD, are a result of the same laws of learning that shape typical behaviours (Lovaas & Smith, 1989). Hence, behavioural interventions focus on manipulating the variables such as the antecedents and consequences involved in learning a particular behaviour.

Developmental theories have also had a significant impact on the evolution of ASD-related interventions. Briefly, these theories focus on the idea that at each stage of development, the child acquires a set of skills that form the basis for the next stage of development. This is possible through active engagement in the environment where adults provide the child with activities that are age-appropriate. These activities help the child build knowledge upon what he already has acquired, a process often called

constructivism (Piaget, 1929; Vygotsky, 1978). Thus, developmentally informed interventions for ASD focus on providing "developmentally appropriate" treatment targets and procedures and emphasise the use of procedures like scaffolding rather than didactic teaching in our efforts to promote skill acquisition among children with ASD (Rogers, 1999).

Recently, the social neuroscience conceptualization has also been gaining momentum. At its core, social neuroscience focuses on how the human brain processes social information and how these social experiences in turn influence brain development (Lieberman, 2007). A key idea in this field is the conceptualization of the experience-expectant nature of our social brain (Brownell, 2013; Sullivan et al., 2014). What is meant by this is that there are hardwired, specialised neural circuits in the brain that bias children to seek out opportunities for social engagement. When given opportunities to engage in social situations routinely, the same is fed to the system and the child learns more and more skills in various aspects of social interaction. Thus, social neuroscience-based interventions for ASD focus on exposing the child to typical social routines from an early age, providing the opportunity to facilitate brain growth, leading to an increased valance for social engagement, leading to an increased appreciation of interactions with others (Rogers & Dawson, 2010).

Another field that has influenced the interventions in ASD is what is known as "implementation science." This particular stream of thought focuses on the various factors that would affect the successful implementation of various interventions in real-world scenarios (Eccles et al., 2009; Brennan et al., 2012). They look into the context in which a particular intervention is being implemented. In other words, they argue that the successful implementation of an intervention as intended will depend on the perceived compatibility of the intervention features and the context in which it is implemented. Towards this end, implementation science encourages participatory research methods where various stakeholders are included from the very early stages of designing and planning of a new intervention (Locke et al., 2016).

In conclusion, it can be said that theoretical guidance is integral to the development of interventions for ASD. As we have seen, all these theories have heavily influenced the development of various intervention protocols and the testing of their effectiveness. While these theories are in themselves not sufficient to explain the psychopathology of ASD, they are nevertheless important. A theory-driven intervention can help the practitioners in the field of ASD plan, design, implement, and test the efficacy of an intervention in the most robust fashion, adding to our efforts to promote the health and wellbeing of children and adults with autism spectrum disorder.

**Development of Evidence-Based Interventions**

The development of an intervention is an iterative process that goes through different stages. While there are different ways of looking at the various stages of developing an intervention, the conceptualization given by Smith et al. (2007) on developing an evidence-based intervention is given very briefly below.

According to Smith et al. (2007), the development of an evidence-based intervention includes four phases: (a) formulation and systematic implementation of a new intervention, (b) development of a manual and a cross-site evaluation of the intervention, (c) randomised control trials (RCTs), and (d) effectiveness studies in communities. For the present study, the first two phases are more relevant, and only those two are discussed in detail.

The aim of the first phase is to prove that the newly developed intervention is efficacious. In this phase, information regarding the targeted behaviour is collected at baseline, that is, before the intervention is provided. Information regarding the target behaviour is also collected in one or more intervention phases. If a comparison of the baseline assessment and assessments made at other times shows that there is an improvement in the targeted behaviour after the intervention, it is possible to suggest that the intervention was efficacious. This phase is usually conducted on a very small sample, as small as one subject. While single subject designs require very little resources, the findings from these are not well suited for generalisation. Other designs, such as between-groups designs, provide more generalizable data than single-subject

studies. At this stage, if the intervention is not showing any efficacy, it can either be due to the intervention not being effective or due to inappropriate statistical power.

The second phase of developing an evidence-based intervention includes the compilation of a manual. During this phase, a research plan is also developed. These manuals must include specific and clear guidelines regarding how the intervention should be implemented. It should also include measures for fidelity of implementation. Afterwards, the feasibility of the newly developed intervention has to be assessed with a small number of participants. The feasibility testing will inform the researcher about the level of acceptance that the new intervention has among the practitioners and patients. Subjecting the intervention to a randomised clinical trial at this stage can help further the validity of the intervention and also test its effectiveness. In the next phase, multisite RCTs are conducted, including a representative sample. In the final stage, the intervention is introduced into community settings, where its effectiveness is evaluated. This is different from the testing of the intervention in RCTs, where there is rigorous research oversight. In the community setups, the intervention is implemented in the real-world settings, which will give us additional insights into how the intervention works.

At present, given the differences in the theoretical understanding of the condition called ASD and the heterogeneity of its individual level presentations, there are a plethora of interventions available. While the applied behaviour analysis (ABA) based therapies are the ones with the most evidence-base, there are other therapies also. At present, therapies exist for the core features of ASD, including communication issues, social skills deficits, and repetitive and stereotypical behaviours. Furthermore, therapies are also available with a focus on the setting where they are delivered. For example, there are therapies that help the client function better in various phases of life, such as school, work, recreation, and so on. It is a source of relief and satisfaction to see that we are finding more and more ways of dealing with the issues associated with such challenging conditions like autism spectrum disorder. We can also hope that we get closer and closer to providing optimal life experiences to a large number of individuals, all over the world, who are affected by this condition.

**Review of relevant related literature**

There is empirical research work that has been conducted in the areas of parent-mediated interventions and autism spectrum disorder. A review of the literature on these aspects is arranged under the following sections.

- Autism spectrum disorder: Epidemiological Studies
- Impairments in ASD
- Parent Mediated Intervention Programs among Children with ASD
- Indian Studies Relevant to Parent Mediated Interventions for Children with ASD
- Evidence based Interventions for ASD
- Critique and Rationale for the Present Study

***Autism spectrum disorder: Epidemiological Studies***

The study of the incidence and prevalence of autism spectrum disorder is referred to as epidemiology of autism. According to Elsabbagh et al. 2012 study of global prevalence estimates for autism spectrum disorder, there are 62 instances per 10,000 persons on average. According to the Centers for Disease Control and Prevention in the United States, the prevalence of children with autism has increased dramatically from one in 150 individuals in the early 2000s to one in 59 children now (Baio et al., 2018). According to published reports, the male-to-female ratio was between 4.3 and 6.8:1. (Fombonne, 2005; Itzchak & Zachor, 2009). This worrying increase in autism prevalence may be a result of increasing awareness among parents and healthcare providers, or it may be a result of results from a large body of scientific studies that aid early detection. Since 2000, the prevalence of ASD has been estimated to be 13.9 per 10,000 individuals in Asia (Elsabbagh et al., 2012). In India, there are very few isolated prevalence studies of ASD. Rudra et al. (2017) conducted a pilot study in India to evaluate the prevalence of autism among schoolchildren. The study's findings

indicated a weighted prevalence estimate of 0.23 percent and recommended using this figure as the lower bound for the genuine prevalence of ASD in India.

There has been a surge in interest and media coverage of ASD in recent years. This increase in attention is somewhat explained by the observed increase in the prevalence of ASD during the last three decades (Rutter, 2005; Schreibman, 2005; Howlin, 2006). Changing diagnosis criteria, expanding the scope of studies, improving services for individuals with ASD, and more awareness of ASD all contribute to the growing prevalence of ASD (Wing & Potter, 2002). Regardless of the reason for the increase in prevalence, ASD is the second most common major developmental impairment in the United States (Nicholas et al., 2008), and, with the exception of Rett syndrome (RTT), affects more males (APA, 2000).

Autism is the most prevalent neurodevelopmental condition in children, affecting brain development beginning in the second trimester of pregnancy and lasting into adulthood. In clinical terms, it is defined by difficulties with social contact and communication, as well as constrained repetitive behaviours and interests. Autistic persons exhibit a wide variety of phenotypes and degrees of severity, making diagnosis difficult; hence, highly trained and experienced clinicians are required. The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) incorporates all subtypes of autism, including Pervasive Developmental Disorders (PDD), Autistic Disorder (classic autism), Asperger's Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Childhood Disintegrative Disorder (CDD), under the umbrella term Autism spectrum disorder (ASD).

According to the Centers for Disease Control and Prevention (CDC), ASD affects around 1% of the global population and has a prevalence of 7.6 cases per 1000. (Baxter et al., 2014). According to a pan-India study conducted by Arora et al. (2018), around one in every 100 children under the age of ten has autism, and roughly one in every eighty has at least one neurodevelopmental disorder. Boys are more likely to have ASD than girls.

According to the most comprehensive meta-analysis, the male-to-female ratio is approximately 3.25 males for every girl (Loomes et al., 2017). It has been

hypothesised that autism in females goes undiagnosed because of their intrinsic tendency to be more socially oriented, masking their autistic characteristics through imitation of their neurotypical friends (Dean et al., 2017). The prevalence of autism varies significantly according on diagnostic criteria, the age of children examined, and geographic location (Williams et al., 2006). Autism spectrum disorder is prevalent across all racial, ethnic, and socioeconomic categories (Durkin et al., 2010). While sociocommunication impairment and restrictive repetitive behaviours are common to all subtypes of ASD, they are frequently accompanied by one or more associated comorbidities such as Intellectual Disability, which affects 31% of ASD patients (Srivastava & Schwartz, 2014), Epilepsy, which affects 20-25% of ASD patients (Canitano, 2006); additionally, gastrointestinal disturbances, motor coordination and sensory integration issues, and Attention Deficit Hyperactivity Disorder (ADHD). One or more non-ASD developmental diagnoses occurs in 83 percent of cases, while one or more psychiatric diagnosis occurs in 10% of cases (Levy et al., 2010).

Autism rates appear to have increased in recent years. The current estimated prevalence of ASD is roughly 1:100, a 15-fold increase from half-century-old studies (Zachor, 2012). According to some researchers, such as Fombonne (2005), this increase may be partially explained by a broader definition of autism, particularly at the less severe end of the spectrum; methodological differences in prevalence surveys, particularly in methods of case finding; and an increased use of autism diagnosis.

Males are three to four times more likely to develop autism than females (Volkmar et al., 1993; Bryson & Smith, 1998; Fombonne, 1999, 2005; Yeargin-Allsopp et al., 2003). Females with the disease, on the other hand, are more likely to fall into the severe intellectual disability category (IQ 35) and exhibit more severe symptoms than males with the disorder (Volkmar et al., 1993). Autism impacts people from all socioeconomic backgrounds (Wing & Gould, 1979; Steffenburg & Gillberg, 1986; Fombonne, 1999, 2003).

Although ASDs affect roughly 60 children out of every 10,000 (Charman, 2002; Fombonne, 2005; Howlin, 2006; Nicholas et al., 2008), they are not the most common major developmental disorder. Intellectual impairment (ID) is the most common type

of significant developmental disability, occurring at a rate of 120 per 10,000. (Nicholoas et al., 2008).

Fombonne (2005) estimates that the prevalence of Childhood disintegrative disorder (CDD) is around 2 per 10,000 people based on a study of epidemiological studies of ASD from fourteen countries. Rett syndrome (RTT) is the least common of the PDDs, with prevalence rates ranging from one in 10,000 to two in twenty-two thousand people (Ghidoni, 2007).

According to the DSM-IV-TR and other studies, PDD has linked characteristics and co-morbid diagnoses. Although sensory difficulties and demanding behaviours are not essential symptoms of autism spectrum disorder, they are connected with it (APA, 2000). In terms of co-morbidity, ASDs are associated with intellectual disability, seizures, and a variety of psychopathologies. Up to 75% of patients with ASD also have an ID diagnosis (Matson & Nebel-Schwalm, 2007).

Additionally, there is a growing body of evidence arguing that a significant portion of the seemingly increased incidence of autism in contemporary times may be the result of altered diagnostic criteria, diagnostic inaccuracies, and substitutions, which are concurrently shrinking the numbers of other child psychiatry categories (Venkatesan, 2015; Leonard et al. 2010).

From Kanner's first report of an autistic child to now, extensive studies have been conducted to document these children's characteristics. The triad symptoms of autism have been narrowed down throughout time. Previously, the term "autism" was widely used. The term "Autism spectrum disorder" (ASD) gained popularity later. ASD was regarded as an umbrella term for illnesses on the spectrum such as autism, Asperger's syndrome, PDD-NOS, Rett syndrome, and childhood disintegrative disorder (APA, 2000). The DSM 5 has altered the diagnostic criteria for autism spectrum disorder (APA, 2013). The DSM-5 standardised diagnostic criteria for ASD identification include the following: Restrictive, repetitive patterns of behaviour, interests, or activities must be evident in the early developmental period and must cause clinically significant impairment in social, occupational, or other essential areas of current functioning.

Given the aforementioned criteria and the areas that appear to be impaired in children with ASD, it is critical to pinpoint the exact impairments in each of these areas. The most significantly affected areas in children with ASDs include communication, daily living activities, sensory motor functioning, and behavioural difficulties.

***Impairments in Children with Autism spectrum disorder***

Communication is impaired in ASD children, whether verbal or nonverbal (APA, 2000). These children's conversation was described as lacking intentionality (Wetherby et al., 2000; Noens & Van Berckelaer-Onnes, 2004). Intentional communication was found to be lower in autistic children than in normally developing and delayed children (Shumway & Wetherby, 2009). A kid with autism may show evidence of poor social skills and communication before their first birthday. A lack of synchronised verbal patterns with the caregiver (Trevarthen & Daniel, 2005; Yirmiya et al., 2006) to poor use of gestures for communication and limited responding to others communication (Trevarthen & Daniel, 2005). In the first year of life, children with ASDs had significant abnormalities in orienting to social stimuli, such as name calling, social engagement, gaze exchange, anticipation of social stimuli and language production (Adrien et al., 1993; Osterling& Dawson, 1994; Baranek, 1999; Osterling et al., 2002). However, research shows that social abilities including joint attention, mimicry, and affective communication distinguish children with ASDs from typically developing infants at 24 months (Charman et al., 1997); Landa & Garrett Mayer, 2006; Sullivan et al., 2007). These social signals are particularly important for successful social communication and interaction especially in the presymbolic stage of language development.

Since Kanner's description of autism, lack of eye contact is one of the early symptoms described. Regarding eye contact, gaze patterns refer to the infant maintaining eye contact with the caregiver/listener throughout social exchanges of ideas. Atypically developing children's prelinguistic and linguistic skills are built on mutual gaze, gaze coupling, and deictic gaze (Smith & Fluck, 2000; Määttä et al, 2016). According to reports, babies as young as four weeks old start making eye contact, which is the foundation for both non-verbal and vocal social interactions. Thus, inability to make

eye contact may negatively impact the development of language and social communication abilities. Various prospective studies have shown that lack of eye contact is an early sign in children with ASDs (Zwaigenbaum et al., 2005). Studies also link inadequate eye contact to autism-related face processing deficits.

In 2013, Tanaka and Sung (2013) suggested the eye avoidance hypothesis of autism facial processing. Eye fixation research (Peterson & Eckstein, 2011) found that the region below the eyes is critical and optimum for forming gender and emotion judgments (Vinette et al., 2004; Sekuler et al., 2004). During facial processing, people with autism focus more on the mouth than the eyes (Dalton et al., 2005). Klin et al. (2009) studied a 15-month-old autistic toddler. The child's gaze was drawn to the actor's mouth while watching the films. This matched the findings of Jones et al. (2008) comparative investigation. The researcher showed films of childhood games to 15 ASD two-year-olds, 36 generally developing children, and 15 non-autistic developmentally delayed youngsters. Children with ASD spent more time focusing on the mouth than the eyes. The study also found a link between eye fixation time and social ability. The preference for mouth over eye when evaluating a face was linked to either their deliberate avoidance of social connection or a 17 spontaneous preference for mouth over eye. Most research backed active avoidance explanation for lack of eye contact in autistic youngsters (Kliemann et al., 2012). Most standardised diagnostic methods included lack of eye contact as a sign of autism.

The joint attention skill is another well-studied social marker in children with ASD. Tomasello et al. (2005) claim that while infants are engaged in goal-directed intentional action, they are concurrently observing others' goal-directed intentional behaviour. Then, around 9-12 months of age, kids arrive to a conditional thesis that if self-intention may result in goal-related behaviour, then others' goal-related behaviour should follow. Joint attention normally arises around 9-12 months of age (Meltzoff & Brooks, 2004). Early shared attention activities include sharing the sight of an object or event, following and directing others' attention (Carpenter et al., 1998). With the caregiver's help, babies learn to relate words and phrases to objects and experiences. In this way, cooperative attention skill improves early language learning and can

predict later language results in typically developing children (Mundy & Gomes, 1998; Meltzoff & Brooks, 2004; Chiat & Roy, 2008).

The proto-declarative joint attention skill is more severely damaged than the proto-imperative counterpart in children with autism (Charman, 1997; Chiang et al., 2008). The purpose of proto-imperative function is to obtain certain objects and not to influence the caregiver's mental state (Mundy et al., 1990). The infant uses the caregiver to meet their requirements. An infant may point to an object and request it from a caregiver. The proto-imperative function can be a request, command, or action demand. Proto-declarative function is more social than proto-imperative function. The purpose of newborn communication is to impact the caregiver's mental state by commenting on their sensory experiences. For example, an infant may point to an appealing thing at the caregiver to get him to notice it and share similar experiences. The proto-declarative function tries to share and is conversational.

Joint attention skills were found to be impaired in children with ASDs (Kasari & Sigman, 1996; Baron Cohen et al., 1997; Sigman & Ruskin, 1999; Mundy & Neal, 2001). The ability to respond to joint attention as well as initiate joint attention was consistently decreased in children with ASDs, according to Kasari and Sigman (1996). Sigman and Ruskin (1999) also studied two types of joint attention and peer social involvement. The results revealed that joint attention initiating capacity was linked to social development. Mundy and Neal (2001) argued that an early deficiency in joint attention skill restricts a child's social information processing, creating a negative loop that could further impede social development. According to Cohen and Volkmar (1997), reacting to joint attention of the speaker would help the infant learn labels of shared objects through word mapping and therefore boost language development. Dawson et al. (2004) found a substantial link between joint attention frequency and language development. Studies by Delinicolas and Young (2007) and Pry et al. (2009) found a high association between joint attention and linguistic skills of children with ASDs. In pre-school children with autism, cooperative attention skill predicts current and future language development (Bono et al., 2003; Toth et al., 2003). After 12 months of treatment, children with autism showed considerable progress in language

abilities compared to their non-autistic peers (Kasari et al., 2004). Another group of researchers used children's responses to joint attention as index markers (Siller & Sigman, 2002) to predict long-term language outcomes in children with autism.

Language delay is a major concern for parents of children with ASDs. A few researchers started a parallel study on language development in children with ASD. Mitchell et al. (2006) undertook a prospective study on early communication and language development in a group of high-risk infants for ASD and low risk control group utilising MacArthur Communicative and Development Inventory –Infant form (Fenson et al., 1993) at two points of time, 12months and 18 months. At 24 months, the samples were classified as sibling with ASD, sibling without ASD, and low risk controls. At 12 and 18 months of age, siblings with ASDs showed less understanding of phrases, gestures, and poor comprehension and expression of words. At 18 months, the non-ASD sibling generated less play motions than the low-risk controls. Hence, the prospective study revealed that abnormalities in early social and communicative development were evident among the high-risk infants for ASD as early as of 12 months of age. The earlier communication profile of children with ASDs include lack of pointing and exhibiting gesture, frequent use of physical cues such as instrumental pointing and dragging other`s hand towards appealing objects, etc.

Delayed or impaired language abilities were typically documented in children with ASDs during their earlier phase of life. They used language to request or protest for objects, i.e., for environmental rather than social repercussions. On the other hand, prior language profiles of infants with ASDs indicated inadequate responsiveness to conversational exchanges; neglect partner's vocal inputs; occurrence of echolalic utterances, etc. (Rutter et al., 1992; Happe & Frith, 2006; Mitchell et al., 2006; Mody & Belliveau, 2013). However, children with ASDs had delayed language abilities, used jargon words, and used abnormal suprasegmental indicators including rhythm, intonation, and stress (Lord & Paul, 1997; Peppe et al., 2007).

The language use of children with ASDs has been found to be grammatically impaired. Tager-Flusberg (2006) proposed two types of ASD children based on verbal disability. The first group includes children with ASD who have no or few words in

their spoken language (Tager-Flusberg & Kasari, 2013), while the latter includes talkative children with ASD who have either typical language skills or language deficiencies pertaining to grammar use (Eigsti et al., 2007; Naigles et al., 2016; Norbury, 2017). Landa and Garett-Mayer (2006) found a slowing of receptive and expressive language development in autistic children aged 6 to 24 months. This distinguished an autistic youngster from a language delayed child. In a retrospective research, parents of affected children observed an abnormal developmental trajectory marked by regression in social and communicative skills (Goldberg et al., 2003; Ozonoff et al., 2005). Many autistic children can learn basic spoken language skills. Approximately 80% of autistic children can utter five or more spoken words (Lord et al., 2004). Unlike other juvenile communication impairments, autism does not cause children to compensate for their inadequate verbal skills with gestures or movements. These kids' gestures are usually unique and unorthodox. Using spontaneous speech samples, Wittke et al. (2017) found grammatical language impairment in a group of children with ASDs. The study found three subgroups based on language abilities: normal language, intact vocabulary and grammatical impairment, and low language abilities.

The most common grammatical errors in children with ASDs were pronoun reversals (Evans & Demuth, 2012; Naigles et al., 2016; Tager-Flusberg, 1994). Using pronouns correctly requires knowledge of other grammatical structures involving person, number, and case. Preliminary research has linked pronoun reversals in young infants to linguistic immaturity (Charney, 1980; Chiat, 1982; Loveland & Landry, 1986; Oshima-Takanae, 1992; Evans & Demuth, 2012;). This may be due to grammatical dysfunction (Tager-Flusberg, 2006; Eigsti et al., 2007) or delayed language onset in children with ASD (Tager-Flusberg et al., 1990; Tek et al., 2014). Shetty (2019) has compared the application of case markers in a group of 30 Kannada-speaking children aged 4-5 years with ASD of spoken language abilities to children with usual development. The study found that children with ASDs used case markers less frequently than their peers without ASDs. According to the study, children with ASD produced dative and locative case markers more than 50% of the time, while children with usual development did so more frequently (more than 60% of the time).

Mohan et al. (2015) explored case markers in 3–8-year-old Malayalam speakers. In this case, the picture description task was used. The study found that as people aged, their use of case indicators increased. Nominative, accusative, and locative case markers were more common in 3-4- and 4–5-year-olds. Children aged 4-5 employed dative, genitive, and instrumental case markers. On average, 5-6 years old. The older children (6-7 years) obtained all case markers except locative case marker (/kkal/). In short, typically developing children aged 3-8 years learned all case markers except locative 2 in Malayalam by the age of 8. There were no more research conducted in Malayalam or among the Kerala population.

Atypical language markers in children with ASDs include echolalia, jargon words, and neologisms (Kanner, 1943; Rutter, 1978; Prizant, 1983). Echolalia is the youngster repeating another's speech. Echolalia is defined as immediate or delayed based on the time between the actual utterances and the child's repetition (Prizant, 1983).

Encouraging children with autism to speak is difficult since they rely on limited verbal and nonverbal skills. Autism youngsters also perform worse in early basic abilities of social interaction and communication such eye contact, shared gaze, joint attention, etc. Pronouns, case markers, and other grammatical indicators were also lacking in ASD children's language profiles.

As children develop and engage with caregivers, their communication needs, purposes, and complexity change, expanding their circle of communicative functions. The next part discussed the numerous communicative functions observed in ASD children's functional profiles.

Researchers have found that children with ASDs have considerable pragmatic deficits. Context-dependent aspects of language structure, principles of language usage, and an understanding that have nothing or little to do with linguistic structure. Bates (1976) defined pragmatics as the rules controlling the use of language in context. However, according to Prutting (1982), pragmatics included pre-requisite cognitive-social skills, communicative function, conversational rules, narrative abilities, and the use of language for problem-solving, thinking, and play. Prizant (1983) defined

pragmatic impairments as a set of communication issues displayed by autistic youngsters. Roth and Spekman (1984) organised a framework for assessing children's pragmatic abilities. That is, communicative intents, presuppositions, and the social order of discourse. A variable in this organisational framework, context dictates the type and shape of communicative purpose to be expressed, the knowledge to be assumed, and the conversational structure (Halliday, 1975; Roth & Spekman, 1984). The first level of communicative intention studied the range and form of intentions as well as the explicitness of messages. Attention seeking, requesting, greeting, objecting, and 'informing' were included. Take turns, make their participation relevant, etc. (Roth & Spekman, 1984).

The proportion and pattern of communicative functions in children with ASDs were studied regardless of communication frequency. Curcio (1978) studied ASD children's communicative functions. The researcher also discovered that children with ASD made few requests, refused, or showed gestures. Among the different communicative functions, children with ASD prefer to communicate for behavioural management over shared attention and social interaction (Shumway et al., 2009). A 2008 study by Chianget et al. found that children with autism are as likely to communicate for social engagement and behavioural management as children without autism. Various studies found that children with ASDs develop communicative function in a sequential order from behavioural regulation and social interaction to joint attention (Crais et al., 2004).

Wetherby and Prutting (1984) studied four children with autism and four with usual development. All autistic kids employed more interactive environmental activities like asking for and refusing things. On the other hand, typically growing infants (8 to 15 months) frequently demonstrate protest and request function (Dale, 1980; Carpenter et al., 1983; Wetherby& Rodriguez, 1992). The interactive behaviour of asking for permission, recognising, showing and commenting were reported to be less frequent in children with autism. These talents may be used by autistic youngsters not to recognise people but to complete rituals (Wetherby, 1986). In a review of pragmatic language and social skills of children with autism, Papadopoulos (2018) concluded

that pragmatic abilities develop as newborns begin to communicate with caretakers efficiently. Attention to a person or object, gaze and gesture sequencing, body posturing, responsiveness to linguistic, sensory and emotional stimuli, body postures expressing proximity, etc. Children with autism have trouble using language of thinking, making inferences and informing, expressing requests or instructions, judging or approving individual behaviour, etc. In this demographic, absence of theory of mind causes these issues. Among the most prevalent 24 pragmatic difficulties among autistic children are carrying on a conversation, following a discussion topic, and switching between speakers. This includes greetings, expressing wishes and emotions, asking for something, narrating, verbal obsessions, lack of courtesy and a lack of awareness about one's place and job. According to Papadopoulos (2018), autistic children think egocentrically, preventing them from expressing themselves verbally.

Many studies have shown that people with ASDs struggle to initiate conversations, take turns appropriately, contribute new information to the topic, and make sudden shifts in the topic being discussed (Nadig et al., 2010; Lam &Yeung, 2012; Schoen et al., 2014). Individuals with ASDs have difficulty inferring and understanding the thoughts of others, a deficit in Theory of mind (Baron-cohen et al., 1986). Yet, other scientists (Hyter & Sloane, 2013; Wang et al., 2017) ascribed the deficiencies to conversational skills and cognitive functioning (Bishop & Norbury, 2005) such as impairment in working memory functioning.

Volden (2004) studied requests for clarification (RQCL) in nine school-aged high functioning children with ASD and nine age-matched typically developing children. The study found that children with ASDs responded to RQCLs and use repair strategies in a similar way to children without ASDs. However, children with ASD responded inappropriately to RQCL, such as discontinuing or shifting the topic (Eales, 1993). Again, RQCL deficiencies in ASD are ascribed to difficulty comprehending listeners' viewpoints and responding appropriately during conversation. Children with ASD, seldom asked questions during conversations and they are required to be taught explicitly on how to ask questions (Charlop & Milstein, 1989), whereas TDC are more

interested in the causal understanding of an event, natural and social phenomenon (Callanan & Oakes, 1992) and often use 'why' and 'how' questions in their daily conversations (Chouinard et al., 2007). This was proven in the study by Frazier et al., (2016), who revealed that typically developing youngsters between 2-4 years were more interested in causal explanation than non-explanatory function. Moreover, few children inquired further about the event. This study found that preschoolers with high functioning autism (HFA) had poorer conversation repair skills, unannounced topic shifts, frequent interruptions, and lower quality exchanges than their standard peer group (Paul et al., 2009). While repairing a dialogue, a youngster would monitor their own speech, grasp the listener's beliefs, and modify their own words (Baker & Nelson, 1984; Wootton, 1994). Studies (Gallagher, 1977; Alexander et al., 1997; Forrester & Cherington, 2009) found conversational repair in early typically developing children under 3 years old. Autism sufferers fail to "impute mental states to themselves and others," according to the Theory of Mind (Premack & Woodruff, 1978). In general, Theory of Mind (ToM) aids in understanding people' beliefs, desires, and attitudes, and predicting their actions. Studies show that ToM is critical for successful social communication. Lack of ToM is linked to poor pragmatic abilities in ASD kids. Because these ASD kids couldn't understand their partner's views, desires, and attitudes, they couldn't understand communication repair, conversational rules, and other pragmatic abilities.

Aside from the pragmatic skills, humour has been linked to ASD youngsters. Studies have shown that people with autism and Asperger syndrome don't grasp comedy (Asperger, 1944; Wing, 1996). In addition to an emotive reaction, humour requires a range of cognitive activities (Lyons & Fitzgerald, 2004). James and Tager-Flusberg (1994) studied humour appreciation in children with ASD and Down syndrome. They found that children with ASD could appreciate humour, but not as much as their peers. However, Angeleri and Airenti (2014) found that youngsters as young as 3 years old could appreciate jokes and ironies. Also, younger children's awareness of irony grew with age and was linked to their language proficiency. McGhee (1979, 1989) says children learn humour in four stages. The first two stages appear between 18 months and 3 years and consist of discordant object actions and labelling. Around 4 years, the

third stage emerges with conceptual incongruity, jokes, and puzzles. The fourth stage develops about 6-7 years and involves telling jokes that require ambiguity and various meanings.

Play is another skill that needs concentration and thought, and is typically linked to a child's cognitive and language development. Play facilitates social connection and allows for the conceptualization of world knowledge (Bloom, 1993; Lifter & Bloom, 1998). Rubin (1977) researched children's play from two perspectives: social participation and cognitive level. In terms of social participation, the author used Parten's play categories (1932). Aspects of idle activity include watching, lonely play and parallel play. These play behaviours vary in their social interaction. Unoccupied play behaviour is characterised by a child's lack of interest in others or their activities. In observer play, a kid observes others, their play activity, and attempts verbal interaction. A child's solo play is defined as self-play with accessible toys. During solitary play, the child was alone. Parallel play is exactly what it sounds like: a child playing alongside others but without regulating their actions. So, the child plays alone in a group. Associative play involves stronger socialisation skills, as youngsters play together, swap toys, and even chat about their play. The associative play has no purpose. In cooperative play, children work together to attain a common goal. Sensorimotor play, functional play, and symbolic/imaginary play are all types of play that can be characterised by cognitive elements. Sensorimotor play involves youngsters manipulating items. The children's play activity including the right use of an object, such as combing a doll's hair, indicates functional play. Symbolic play requires an object's representation (parten, 1932). In this type of play, children pretend an object is present when it is not, and try to swap its functions (Leslie, 1987). Play in children evolves from sensorimotor to functional to symbolic (Lifter et al., 1993).

When compared to generally developing toddlers and children with delayed development, children with autism show a lack of symbolic play behaviour by the age of 18 months (Wing et al., 1977). Autism children's play routines were shown to be abnormal and odd. This can range from limiting play to a few selected objects (Van Berckelaer-Onnes, 2003) to obsessing on the smell, touch, and taste of objects

(Williams, 2003). Autism children lack originality and show repetitive play behaviours (Atlas, 1990; Williams et al., 2001) with few functional acts (Mundy et al., 1990).

One of the first theories presented to explain the impairment in symbolic play was the absence of Theory of Mind (ToM) in ASD. Baron-Cohen et al. (1985) proposed ToM to explain ASD children's lack of symbolic play. Leslie (1987) proposed that pretend play requires the same cognitive skills as theory of mind. Using this notion to explain ASD children's lack of symbolic play skills, it may be argued that ASD children lack meta-representation skills (Leslie, 1987). They have trouble separating the actual representation from the desired object. Leslie (1987) claims that children with ASD lack a true pretence, resulting in deficiencies in symbolic play (Riguet et al., 1982; Sigman&Ungerer, 1984; Leslie, 1987; Rutherford et al., 2007). Rutherford et al. (2007) compared sensorimotor and pretend play behaviours in a sample of children with ASD over two time points. The study found that children with ASD (mean age 33.9 months) have deficiencies in both sensorimotor and pretend play behaviours compared to their normal counterparts. However, children with ASD (mean age 57.6 months) only demonstrated difficulties in pretend play. But functional play does not require pretence. Baron-Cohen et al. (1985) found that whereas children with ASD had much lower symbolic play than children matched for verbal understanding and non-verbal mental age, both groups had equivalent functional play acts. But Lewis and Boucher (1988) disputed this and found that children with ASDs could play meta-representational qualities when prompted by another individual and also reported that autistic children of low linguistic mental age produce fewer functional play acts.

There were other researchers who also documented poor functional play behaviours in children with ASDs (Sigman & Ungerer 1984, Lewis & Boucher 1988, Atlas 1990, Jarrold et al., 1997). Functional play deficiencies comprised less time spent on functional play and less diversified, integrated, and other-directed play compared to controls of similar mental age. Executive function deficits in ASD children may explain their poor functional play behaviours (Jarrold & Russell, 1997). In this view, autistic people struggle to think of new play acts or tend to repeat old ones. So, they

couldn't advance to more intricate games like pretend play. The social deficit hypothesis also accounted for reduced functional play in ASD children (Leontiev, 1981; Rocissano, 1982; Williams et al., 1999). The researchers who backed this idea claim that children with ASDs have trouble asking for instruction on how to use an object functionally (Leontiev, 1981; Rocissano, 1982; Williams et al., 1999). Further the functional usage of an object and its conspicuous qualities can be taught to children through explicit parental education and modelling. These social mediation processes help youngsters learn to use objects. These deficiencies in social mediation lead to less elaborate functional play schemes in ASD children (Leontiev, 1981; Rocissano, 1982; Williams et al., 1999).

William et al. (2001) used video to assess functional play behaviours in a group of young children with autism, Down's syndrome, and generally developing children. A ten-minute movie was coded for the presence of twenty-nine integrated play acts, the duration of each functional play act, and the frequency of each functional play act. Compared to typically developing children, children with autism engaged in functional play for shorter periods of time and generated less intricate functional play acts. A 15-minute video study found that autistic kids created more exploratory, sensorimotor, and relational play than typically developing kids. Moreover, autistic children chose newborn toys, dress-up accessories, gross motor toys, plastic animals, and action figures. Typically developing children favoured building, housing, and doll toys (Dominguez et al., 2006)

Both functional and symbolic play may be indicators of subsequent language performance in autistic children. Functional play is linked to a child's long-term expressive language ability (Sigman& Ruskin, 1999). Wetherby et al. (2007) found that children with ASD differed from typically developing children in pretend play actions and functional play actions. Both ASD and developmental delay children performed similarly in pretend play and functional play.

Chamberlain et al. (2007) evaluated children with high functioning autism in conventional classrooms from 2nd through 5th grade. The study looked at four aspects of classroom social interaction: nomination, reciprocity, peer acceptability, and social

networks. The study found that children with high functioning autism had lower social network scores, implying they were less active in the classroom social structure. The study found that children with high functioning autism spend less time with their greatest friends and are less nominated by their peers. Despite poorer peer acceptance, children with ASD did not experience loneliness.

Kasari et al. (2011) evaluated the social relationships of 30 high functioning children with ASD in grades 1 to 5. Compared to their peers, children with ASD have fewer reciprocal friendships, a smaller social network in the classroom, and prefer solitary/unengaged or parallel play. McGee et al. (1997) used 5-minute video clips to examine the social behaviours of 64 preschool-aged children with ASDs and usual development. The study found that children with ASDs performed worse than usual peers in the following social behaviours. These included child engagement, proximity to children, verbalization background factors, child social bids, adult attentiveness, and aberrant behaviour. The amount of time spent engaged and focused on toys did not differ significantly. Other studies examining ASD children's social behaviour in the classroom found similar results (Holmes & Willoughby, 2005; Jahr et al., 2007). Children with ASD have trouble seeking social relationships, which may explain their social deficiencies. The findings were explained using Klin et al.'s Enactive mind hypothesis (2003). Klin et al. (2003) claim that people with ASD are less socially aware than people with neurotypical minds. As a result, people with ASD are less interested in social relationships and less engaged in social interactions. This idea was tested on adults with high functioning autism, autism, Asperger's syndrome, and neurotic adults. They saw a visual animation with geometric shapes moving but no soundtrack. To narrate/describe and explain the video sequence. In contrast to the neurotypical adults, the autistic adults explained it in geometric terms. This difference in ASD social attribution task supports the inactive mind hypothesis. According to this hypothesis, children with ASDs who are socially impaired do not seek out social relationships and do not engage in social play with peers.

The DSM-5 (APA, 2013) includes aberrant sensory response patterns as evidence for ASD diagnosis under the criteria of limited repetitive patterns of behaviour, interests,

or activities. Sensory processing is the process through which the brain receives, interprets, and responds to sensory information from the sensory systems (e.g., taste, touch, smell, sight, auditory, vestibular). A multitude of studies examined sensory processing abnormalities in ASD youngsters (Osterling & Dawson, 1994; Kientz& Dunn, 1997; Baranek, 1999). Earlier studies on ASD children concentrated on social and communicative abilities, while current studies on sensory domains showed the impairment in sensory processing regardless of age and severity (Baum et al., 2015; Marco et al., 2011). Sensory difficulties were noted in 69-93 percent of ASD patients (Baranek et al., 2006; Leekam et al., 2007; Klintwall et al., 2011). Sensory processing issues in children with ASDs include deficiencies in auditory (Gillberg & Coleman, 1996), visual (Kientz & Dunn, 1997; Gillberg & Coleman, 2000), and tactile (Cesaroni& Garber, 1991; Baranek et al., 1997; Simmons et al., 2009). Hearing loss (Khalfa et al., 2004), absence of auditory orientation (Chawarska et al., 2007), and decreased auditory stream segregation (Teder-Sälejärvi et al., 2005) are all examples of auditory processing abnormalities in ASD. They found visual perceptual deficiencies (contrast sensitivity, border detection, field of view size, and colour perception) as well as lower susceptibility to illusions, spatial attention deficits, and altered oculomotor function in children with ASD. Early social aspects of autism include avoidance of eye contact and poor eye gaze utilisation (Gillberg, 1990; Kientz& Dunn, 1997; Baranek, 1999; Gillberg& Coleman, 2000;). There are varied data on the age of onset of sensory symptoms and their developmental trajectory in ASD children. However, 32 investigations in a sample of high-risk newborns for ASD (Zwaigenbaum et al., 2005; Ozonoff et al., 2010) revealed the existence of the sensory symptoms as early as the symptoms in social and communicative skills. However, parental reports and behavioural observations routinely confirm substantial sensory symptoms in children with autism as young as 2 years old (Rogers et al., 2003; Baranek et al., 2007; Leekam et al., 2007). There was also discrepancy in research on sensory symptoms development. Few studies observed a rise in sensory symptoms with age (Ben-Sasson et al., 2007), whereas another group reported increased sensory symptoms in younger age groups (Leekam et al., 2007; Green et al., 2012; Ausderau et al., 2014). Several research (Dunn, 1994; Dunn & Daniel, 2002; Bar-Shalita et al.,

2005) examined the distribution of sensory items on a sensory profile measure. These investigations found no evidence of altered sensory complaints in children with usual development. The sensory processing difficulties in tactile modality was seen and attributed to the kid moving from a highly tactile environment like the womb to one where tactile sensitivity is varied. (Herschkowitz, 2000).

Sensory problems have been linked to delayed joint attention and language development (Baranek et al., 2013), social play development (Kuhaneck & Britner, 2013), and social impairment in individuals with ASD (Hilton. Et al., 2010). There is also evidence of a significant bidirectional and interdependent relationship between social and sensory aspects (Ronconi et al., 2016). Sensory processing disorders have varying effects on social skills. Eye contact and collaborative attention are both dependent on intact visual processing, which is impaired in ASD (Charman et al., 1997; Leekam et al., 1997; Sigman et al., 1999). The quick, complex visual information supplied by human faces in social interactions may worsen ASD socio-cognitive problems.

Brock et al. (2002) presented temporal binding theory to explain sensory dysregulation in ASDs. Time information is critical for the integration and processing of linked stimuli (Shams et al., 2000; Stevenson et al., 2012). Sensory inputs that occur close together in time (falls in temporal binding window) are integrated and regarded as coming from the same source. However, studies on individuals with ASDs reported that the temporal binding window is extended and leads to an alteration in sensory processing (Kwakye et al., 2011; Stevenson et al., 2014; Wallace & Stevenson,2014), more specifically leads to a guzzier, unpredictable sensory environment (Wallace & Stevenson, 2014). Further, owing to this changed temporal binding window, it was revealed that people failed to perceive the social signals such as facial expression, voice of communication partner and demonstrated a predisposition to participate in Restricted and Repetitive Behaviors. Atypical information processing is another notion that explains the link between sensory disruption and social difficulties in ASD (Knill&Pouget, 2004). In general, humans employ both the bottom–up processing and top-down processing to operate successfully in this dynamic context (Knill & Pouget,

2004). Bottom-up processes assist to detect and perceive the incoming sensory information, and top-down processes aid to infer the incoming sensory information based on the past experience and context. However, research indicated an underutilization of top-down process and undue dependence on bottom-up sensory input in person with ASDs (Mottron et al., 2006; Pellicano & Burr, 2012). This idea accounted for the superior perception seen in persons with ASD. As the ordinary social interaction and social communication process need central coherence, integration of context and exploitation of past knowledge, a person with ASD with such an information processing profile, would fail to satisfy the social functions. Brain studies of children with ASDs also reported an abnormal neural connectivity with high local connectivity along with low long–range connectivity (between functional areas of brain) (Just et al., 2004) and with high physical connectivity and low computational connectivity (Computational connectivity much required for information processing) (Rubenstein, & Merzenich, 2003; Belmonte et al., 2004). According to the intense world syndrome concept of Markram et al. (2008).

McCormick et al., (2016) compared 79 children with ASD, Developmental Delay, and Typical Development (TD). All participants were monitored for three years between 2 and 8. At each time point, parents were asked about sensory symptoms (SSP) and adaptive functions (Vineland adaptive behaviour scale) (VABS). The research found that ASD children had greater sensory complaints on all SSP subscales than TD children at all three time points. Less severe sensory symptoms on smell/taste sensitivity and auditory filtering were seen in ASD children. The research also found that children with ASD had higher sensory symptoms at all time periods, demonstrating a consistent nature of heightened sensory symptoms in the ASD group. Tomcheck and Dunn (2007) compared sensory processing in children with ASD and normally developing children aged 3-6. A SSP was utilised to gather sensory processing data from parents. Auditory filtering, visual/auditory sensitivity, under responsive/seeking tactile sensitivity, movement sensitivity, taste/smell sensitivity, and low energy/weak sensitivity were all measured. Compared to the TD group, children with ASD had greater scores for sensory processing problems in all parts. Auditory filtering, tactile sensitivity, and taste and smell sensitivity were identified as

having the most difficulties in the ASD group. McCormick et al. (2016) found similar results.

The first procedure is to draw the person's attention to a specific sensory stimulus in the environment, and the second is to decode the information for improved comprehension (Romo & Salinas, 2001). Humans contain photoreceptors, mechanoreceptors, chemoreceptors, and thermo receptors to register environmental sensory information (Singer et al., 2009). The relay neurons in the brainstem process the sensory receptors' recordings (Skoe & Kraus, 2010). Visual inputs are processed in the lateral geniculate nucleus, auditory information in the medial geniculate nucleus, and somatosensory information in the ventroposterior nucleus. Signals from numerous sensory inputs are decoded and sent to primary sensory cortex (Jones et al., 1982). The main sensory cortex sends signals to higher order regions that project into multimodal association areas where information is integrated. However, ASD patients have a poor multimodal integration. This is due to inadequate information integration in the insular cortex (Stevenson et al. 2014). Further, neurophysiological research revealed reduced long-distance connection and increased local connectivity in ASD patients (Kana et al., 2011; Wass, 2011). Adolescents with ASD have more aberrant connections (Barttfeld, 2012; Hasegawa et al., 2015).

Behavioural impairments in children with ASDs include a plethora of undesired difficult behaviours (Ogundele, 2018) displayed by children with ASDs such as social anxiety behaviour, emotional dysregulations behaviour and restricted repetitive behaviour (RRB) or patterns of interest (DSM-IV, 1994) However, children with ASDs generally demonstrated RRBs at a larger frequency throughout their early years.

Restricted and repetitive behaviours (RRBs) are a collection of behaviours often linked with autism spectrum disorder (ASDs). RRBs consists of two subcategories, repetitive sensory motor (RSM) activities and insistence on sameness (IS). RRBs consists of behaviour such as motor mannerisms, repetitive usage of things and sensory seeking behaviours. On the other hand, IS category-included behaviours such as rituals, compulsions and problems to adjust the changes in routines (Cuccaro et al.,

2003). The two dimensions of RRBs in ASD was created based on the research concentrated on the component analysis of Autism Diagnostic Interview-Revised (ADI-R) as well as from the usage of Repetitive Behaviour Scale-Revised (RBS-R) (Bodfish et al., 2000) scale. The RBS-R is a 43-item questionnaire distributed in six subscales: stereotyped behaviour, self-injurious behaviour, compulsive behaviour, ritualistic behaviour, sameness behaviour, and limited conduct. The replies are rated on a 4-point scale where '0' indicate behaviour does not occur and '3' indicate, behaviour happens and is a major concern. According to DSM–IV and ICD-10, four kinds of RRBs are there: (a) obsession with confined interests; (b) non-functional routines or rituals; (c) repeated motor mannerisms (stereotypies); and (chronic concern with portions of things) (persistent preoccupation with parts of objects). These RRBs were further categorised as lower-level behaviour comprising of the latter two RRBs (Prior & Macmillan, 1973; Turner,1997) and higher-level behaviour explaining the concern with confined interests and the non-functional routines or rituals (Turner,1999). Among the higher-level behaviour, behaviours linked to the concern with specified objects, activities, or information or with selected themes are defined as limited interest (Attwood, 2003).

A group of researchers reported that lower level behaviours were more evident in younger and developmentally delayed cases whereas, preoccupation, obsession and special interest were apparent in older and cases with higher language and cognitive capacities (Bishop et al., 2006; Richler et al., (2007; Esbensen et al., 2009; Richler et al., (2010)) investigated the distribution of RRBs in a population of children aged below 3 years with ASD, developmental disorder a (DD) and typical development (TD), based on factor analysis of ADI-R items. The results of the study demonstrated that both the repetitive sensorimotor (RSM) factor and insistence on sameness (IS) factor were present in children with ASD. On the other hand, a third of the ASD sample had abnormal/idiosyncratic reaction to sensory inputs and atypical focus. ASD children had considerably higher RRBs than Typical development (TD) and developmental disorders (DD) youngsters. Compared to the DD and TD groups, ASD children exhibited a significant difference on four RSM items: unique sensory preferences, repeated use of objects, hand/finger mannerisms, and complex

mannerisms. Compared to the DD and TD groups, ASD youngsters demonstrated just one item (difficulties with change in routines) as a significant difference.

RRBs have a neurological explanation (Langen et al., 2012). As seen in Rett, Fragile, Prader-Willi, and Tourette syndromes, Lewis and Kim (2009) argued that RRBs are disrupted gene-environment neuroadaptation. According to Szatmari et al. (2006), a family aggregation of RRBs (Shao et al., 2003) with some linkage evidence in the 15q11-q13 region is associated with higher Insistence on Sameness (IS) factors. Studies have suggested that alterations in cortical basal ganglia circuitry might cause stereotypies (Lewis & Kim, 2009). Langen et al. (2012) hypothesised a neurostructural and neurophysiological circuit linking basal ganglia and cortical components to explain for different forms of RRBs. One is the sensory-motor loop extending the macro circuits between motor, premotor cortex and striatum, related to simple motor stereotypies, the other is the cognitive or associative loop linked to dorsolateral prefrontal cortex, related to rigidity and repetitive behaviour, and the third is the limbic circuit related to compulsive and addictive behaviour. Another study team linked RRBs to poor executive function (EF) in children, leading to poor behaviour control and regulation (Turner, 1997; Russell, 1997). Turner (1997) suggested two RRB ideas, one relating to their failure to suppress existing behaviour and the other to their incapacity to produce fresh events. But studies found conflicting results (Prior & Ozonoff, 2007). Using a visual-spatial Executive Function test, Yerys et al. (2009) assessed Executive Function skills in a group of 2–3-year-old children from ASD, DD, and TD. The study found no significant Executive Function deficiencies in ASD children compared to Typically Developed Children. However, Prior and Ozonoff (2007) found a link between EF deficits and children's general cognitive ability.

A developmental viewpoint was also provided by Thelen (1981). The formation of stereotypies, according to Tinbergen (1951), might be the consequence of evolution, a long process of brain maturation wherein automatic rhythmic behaviours were subsequently moulded by children's adaptive skills, or an expression prompted by immediate antecedents. That is, early in life, stereotypies are involuntary and

susceptible to various stimuli, but with maturity, child learns to manage stereotypies for a goal-directed behaviour. To overcome stereotypy, a higher arousal level is necessary. ASD children may have a longer time of immature behavioural reactions, which they may fail to regulate and modify for meaningful goal-oriented behaviour such as communication and social engagement, based on this notion. Barber (2008) found RRBs in younger toddlers aged 18-24 months in video samples. The study found that children with ASDs demonstrated more repeated sensory motor behaviours with unfamiliar items than children with developmental delay or usual development of the same age. Moreover, compared to other groups, children with ASD showed less well-regulated behaviour.

Both parents and professionals dealing with autistic children have stressed the negative impacts of emotional dysregulation (Geller, 2005). Anger management problems, temper tantrums, self-injurious conduct, violence, and mood dysregulation are all common in autistic children (Lecavalier et al., 2006; Prizant& Laurent, 2011; Quek et al., 2012). Studies have examined the influence of emotional disturbances in ASD youngsters (Laurent & Rubin, 2004; Mazefsky et al., 2012; Samson et al., 2012). Adaptive emotion management methods are less efficient in ASD children and adults than in the general population (Jahromi et al., 2012). Children and adults with ASD can understand fundamental emotions like anger, fear, disgust, and happiness if given enough time to respond (Rump et al., 2009). The findings on complicated emotions are clear.

To conclude, the research described above indicate that children with ASDs require special care in some areas. Communication, pragmatics, play, sensory, and behavioural deficiencies sometimes prevent children with ASDs from developing these abilities on par with their peers. Some of these deficiencies can be found early in autism research using a few indicators that anticipate issues in children with ASDs.

***Parent Mediated Intervention Programs among Children with Autism spectrum disorder***

In the intervention process, parents of children with ASD play a vital role. According to research, parental and therapeutic factors are likely to have an effect on a child's response to treatment (Van Adel et al., 2012). Parent engagement in developing intervention measures to assist their autistic child dates back at least three decades (Schopler, 1971). Through such therapies Parents and children are likely to gain greater abilities alike and can have decreased stress. Increased parental ability enables continuous learning chances in a variety of scenarios. Parent training as 'therapists' enables early intervention and assures that intervention is effective in boosting children's earliest social ties (Diggle & McConachie, 2013).

Numerous studies have been conducted to evaluate specific parent-mediated early intervention approaches for addressing behaviour problems (Howlin, 1987; McConachie and Diggle, 2007), improving parent-child interaction (Koegel et al., 1996), facilitating communication (Prizant et al., 1997), and implementing a behaviour analytic approach (Prizant et al., 1997; Smith et al., 2000). Jocelyn's (1998) study discovered that parent-mediated early intervention had a significant effect on infant language development. Why the intervention had such a big positive effect on children's language is still unknown. It is possible that as parents gain a better knowledge of their children, they modify their behaviour to facilitate communication and allow the children to demonstrate and exercise their verbal competence (Jocelyn, 1998).

Lovaas' (1987) pioneering efforts laid the groundwork for the behavioural approach to ASD treatment. These approaches emphasise the development of appropriate behaviours, such as speech, social skills, classroom skills, and self-help abilities, while simultaneously minimising negative, dysfunctional behaviours. Therapists in behavioural therapy employ concepts of learning such as operant conditioning and modelling. For example, therapists reinforce desired target behaviours by first moulding them (cutting them down into manageable steps) and then clearly and consistently rewarding each step. Additionally, functional behaviour evaluation,

differential reinforcement, prompting, task analysis and chaining, stimulus control and environment modification, and extinction can be utilised to steer a desired behaviour. Differential reinforcement strategies, in particular, have been used to attempt to replace improper and occasionally dangerous behaviours (e.g., self-injury, violence) with more appropriate or less dangerous behaviours. When treating persons with ASD, behavioural therapists can employ imitation or modelling techniques. They model a desired behaviour and assist autistic individuals in replicating it. Imitation or modelling strategies are frequently employed to teach individuals with ASD to communicate. With sufficient design and execution, the aforementioned behavioural procedures frequently result in the development of new, more functional behaviours.

Bibby et al., (2001) examined the progress and outcomes of children with autism receiving intensive parent-managed interventions and discovered that, while parent-managed programs may result in gains in language, adaptive, and intellectual functioning, they may not be as large as those reported by center-based programs, which typically result in 20 IQ point increases (Lovaas, 1987; Harris et al., 1991; McEachin et al., 1993). Similar to this study, Sheinkopf and Siegel (1998) analysed the progress of nine children receiving 19 hours of treatment per week for 16 months and reported that the children's IQ increased by an average of 27 points. Smith et al., (2000) also investigated the effect of parent-managed programs and found that, while the results were varied, two of the children improved by more than ten points on standardised measures of IQ, language, and adaptive behaviour. These results lend some support to the hypothesis that parent-managed programs can help children with autism function better.

Strauss et al., (2012) found that parent training and consistent parent-mediated treatment provision resulted in decreased challenging behaviour from children, increased treatment fidelity, and child-directed behaviour change as evaluated by performance on behaviour objectives. These findings contribute critical scientific and clinical knowledge on the parental and therapeutic factors that may influence a child's response to treatment.

The study, titled "Parent-implemented early intervention for young children with autism spectrum disorder: a systematic review," was conducted in 2007 by McConachie and Diggle. The current study focuses on new estimates of autism spectrum disorder (ASD) prevalence, which indicate that at least one in every 200 children is affected. These children and families have significant service need. Parent involvement in the implementation of intervention measures aimed at assisting their autistic children has long been acknowledged as beneficial. The possible benefits include improved skills and decreased stress for both parents and children. This systematic review examined interventions for children aged 1–6 years and included a comprehensive search of psychiatric, educational, and biomedical databases, as well as bibliographies and reference lists of relevant papers, contact with area experts, and a hand search of key periodicals. We considered only studies that incorporated a concurrent element of control. The study identified just a few papers with an adequate research design from which judgments about the effectiveness of parent-implemented early intervention could be drawn. Both randomised and controlled studies indicated that parent training improves child communicative behaviour, increases maternal knowledge about autism, improves maternal communication style and parent-child interaction, and decreases maternal depression. Parent training appears to be an effective method of intervention for young children with ASD. However, the study emphasises the importance of conducting additional research in this area.

Casenhiser et al. (2013) discovered a relationship between enhanced parental responsiveness and favourable child outcomes. Solomon et al., (2007) also assessed the efficacy of adding monthly home consultations with parents to the floor time. "Play and Language for Autistic Children (PLAY)" is the name of this program. The PLAY group children shown significant changes in their ASD classification, social-emotional abilities, and the quality of parent-child interactions. The course, however, did not result in improvements in ASD symptoms, communication abilities, or developmental level.

Roberts et al. (2011) compared the treatment outcomes of an individualised home-based Developmental social pragmatic (DSP) program to those of a small-group

center-based DSP program including parent training and support group components, as well as to those of a waitlist control. The outcomes for children were the development of social and communication skills, whereas the outcomes for parents were quality of life and stress. Twelve months of interventions were offered. The results indicated that children enrolled in the center-based program made the greatest gains in terms of social and communicative skills development. Additionally, parents of children enrolled in the center-based program reported the greatest improvements in their children's perceptions of competence and quality of life. The findings of Roberts et al. (2011) indicate that center-based DSP therapies that combine parent training and support group components may be an effective treatment option for children with ASD, with beneficial outcomes for both children and parents.

Oono et al. (2013) conducted a study to determine the efficacy and advantages of parent-mediated early interventions for children with autism spectrum disorder and their parents. The study included only randomised controlled trials in which parents mediated the interventions in the experimental condition; control conditions included no treatment, treatment as usual, waiting list, alternative child-centered intervention not mediated by parents, or alternative parent-mediated intervention with a hypothesised lesser effect than the experimental condition. The analysis included 17 studies from six countries (the United States of America, the United Kingdom, Australia, Canada, Thailand, and China), recruiting 919 children with autism. In general, the study discovered no evidence of significant increases from parent-mediated techniques for the majority of the primary outcomes tested. However, the evidence for beneficial change in parent–child interaction patterns was substantial and statistically significant. Additionally, there is some evidence that kid language understanding improves as reported by parents. Additionally, there was indications that children's autistic traits were less severe.

Kasari et al. (2015) conducted a study to examine the impact of two parent-mediated interventions on joint engagement outcomes when used in conjunction with an early intervention program for toddlers with autism spectrum disorder (ASD). 86 children (range 22–36 months) with ASD and their primary caregiver were involved in the

study. Caregiver-child dyads were randomly randomised to receive 10 weeks of hands-on parent training in a naturalistic, developmental behavioural intervention (joint attention, symbolic play, engagement, and regulation—JASPER) or a parent-only psychoeducational intervention (PEI) (PEI). The results indicated that the JASPER intervention had a substantial effect on the primary outcome of joint involvement. Secondary outcomes of play diversity, highest degree of play accomplished, and generalisation to the child's classroom for child-initiated joint engagement were also found to be affected by JASPER. PEI was proven to be useful at reducing parenting stress caused by child features.

Stadnick et al. (2015) conducted a pilot study to determine the efficacy of Project ImPACT, a parent-mediated intervention for autism spectrum disorder administered in a community program. The primary objective was to evaluate child and parent outcomes at baseline and 12 weeks between the intervention group and a community comparison group of 30 young children with ASD. Between baseline and 12 weeks, the results demonstrated a significant improvement in children's communication abilities and a strong tendency toward parent intervention adherence for the intervention group. Increased baseline parental stress was associated with a decline in child social development from baseline to 12 weeks.

Pickles et al. (2016) published a paper titled Parent-mediated social communication treatment for young children with autism (PACT): long-term follow-up of a randomised controlled trial. They conducted a follow-up study of the Preschool Autistic Communication Trial (PACT) to see whether the PACT intervention had a long-term effect on autism symptoms and on parent-child social interaction. PACT was a randomised controlled experiment evaluating a parent-mediated social communication intervention for children with core autism who were 2–4 years old. Follow-up was conducted at three specialised clinical services centres in the United Kingdom (London, Manchester, and Newcastle) at a median age of 5.75 years (IQR 5.42–5.92) following the trial's endpoint. The primary blinded outcomes were the Autism Diagnostic Observation Schedule (ADOS) comparative severity score (CSS),

the Dyadic Communication Assessment Measure (DCMA) of child initiating interactions with the parent, and an expressive-receptive language composite.

Bradshaw et al. (2017) conducted a study on enhancing functional language and social motivation with a parent-mediated intervention for toddlers with ASD. Using a multiple baseline design across 15–to 21-month-old toddlers, this study used a brief, parent-mediated, Pivotal Response Treatment program, focusing on enhancing expressive communication. The results suggested that verbal communication increased as a consequence of the intervention, with parallel improvements in untreated areas for all participants. Following the intervention, symptoms of autism diminished, and parents indicated satisfaction with the program's ease of implementation and observable child benefits.

Parsons et al., (2017) conducted a systematic review to gain a better understanding of the available evidence on parent-mediated intervention training offered remotely to children with autism spectrum disorder who live in rural locations. They conducted a comprehensive review across five electronic databases, in which two independent researchers assessed the methodological quality of seven studies that met the inclusion criteria, including two pre-post cohort studies, three multiple baseline studies, and two randomised controlled trials (RCTs). The findings indicated that remotely provided parent-mediated intervention training may improve parent knowledge, increase parent intervention fidelity, and improve children with ASD's social behaviour and communication skills.

Nevill et al. (2018) conducted a meta-analysis of 19 randomised controlled trials evaluating parent-mediated therapies for children with autism spectrum disorder between the ages of one and six years. Autism spectrum disorder symptom severity, socialisation, communication-language, and cognition were the outcomes of the meta-analysis. For autistic spectrum disorder symptom severity, communication-language, and cognitive, the evidence quality was assessed as moderate; for socialising, the evidence quality was graded as extremely low. The outcomes did not differ significantly according to the dose of treatment. When parent training was compared to routine care, the treatment effects were not statistically different than when parent

training was compared to an active comparison group. Treatment effects were significant for communication-language and non-significant for socialisation based on parent reports alone, but the opposite was found using clinician-rated tools. While the majority of parent-delivered intervention outcome domains are associated with small effects, this meta-analysis indicates that the quality of research is improving.

Siller and Morgan (2018) published a pair of systematic assessments of the literature on the efficacy and effectiveness of behavioural therapies, including parent-mediated techniques, for the Agency for Healthcare Research and Quality (AHRQ) in 2011 and 2014. These assessments, however, do not effectively incorporate works published in 2013 and subsequent years. Using the same methodologies and criteria as the original AHRQ reports, the current update of the literature review identified twenty more studies published between 2013 and 2015.

Althoff et al., (2019) conducted a systematic analysis of parent-mediated therapies for children with autism spectrum disorder in order to analyse the evidence for parent-mediated interventions' impact on the occupational performance of children with ASD. They used academic databases to search for terms such as autism spectrum disorder, parent, caregiver, and intervention. 582 articles were evaluated, and 109 were chosen for full-text review. Thirteen articles were included in the final analysis. There is compelling evidence that parent-mediated intervention is effective at increasing children's joint attention. There was moderate evidence for language scores, expressive language, nonverbal communication, interaction initiation and response, behaviour, play, adaptive functioning, ASD symptoms, and social communication improvement.

Trembath et al. (2019) did a systematic analysis of 41 papers in order to determine the factors that may affect the outcomes and generalizability of parent-mediated therapies for young children with autism spectrum disorder. There was considerable variation in the type of intervention, its intensity, and the study's quality. Notably, 46 distinct inclusion/exclusion criteria were reported across trials, including developmental variables, access to additional treatments, comorbidities, parental considerations, and access to the intervention. Fifteen publications examined 45 different variables that

could be linked with or influence intervention results, including child (e.g., language skills, ASD severity, cognitive) and parent (e.g., adherence and fidelity, education) variables. Although there is compelling evidence for a more sophisticated (e.g., systematic phased research for some interventions) and diverse (e.g., studies in geographically diverse contexts, including low-resource communities) approach to research on parent-mediated interventions, there is still a need for increased study quality and measurement consistency, as well as a detailed examination of factors that may predict, moderate, and mediate intervention efficacy.

There is growing evidence for the use of blended parent-implemented behavioural and developmental techniques to address ASD's basic difficulties (i.e., communication, engagement, and joint attention) and early developmental communication and cognition deficiencies (Wallace and Rogers, 2010; Rogers et al., 2012; Ingersoll & Wainer, 2013). These strategies place a premium on the development of the child's relationship with people involved in the intervention, and hence emphasis the development of reciprocity, social engagement, and shared affect during adult-child interactions. Additionally, blended techniques teach specific social-communication skills through the use of behavioural strategies (e.g., direct prompting, contingency reinforcement).

Each study evaluated parent-mediated therapies for young children with autism using a controlled group design. The findings from these studies and discusses whether the available evidence (defined broadly in terms of quality, quantity, and consistency) is sufficient to confidently conclude that parent-mediated intervention approaches are effective for improving children's language and communication abilities, reducing autism symptoms, and supporting parents' use of developmentally beneficial parenting practices.

***Indian Studies Relevant to Parent Mediated Interventions for Children with ASD***

A research by Juneja et al. (2012), used Pre and post study design. This study evaluated the customised program designed to improve a child's attention, communication, social skills, and behaviour; a specialist demonstrated methods to parents; Parents acted as therapist; Parents expected to spend 45-90 minutes daily in

one-to-one setting with child; average duration of therapy was 19.5±11.78 months. The research indicated child results of considerable increase in development quotient (p=0.015), social quotient (p=0.004), expressive language quotient (p=0.03), CARS (p=0.001), ABC (p=0.014) scores. Study hasn't explored any parenting associated outcomes.

Nair et al. (2014), performed a research among 52 ASD-diagnosed children less than 6 years of age. The research used a Pre and post study design. In this research, developmental and speech therapists assisted mothers in assembling low-cost training kits based on the child's developmental age, and provided initial training in the fundamental behavioural technique for addressing the three clusters of autistic symptoms at home. On a weekly, biweekly, or monthly basis, help was provided as a follow-up. The duration of each clinical session was between 15 and 20 minutes. This research documents the child outcomes of reduced severity of autistic symptoms, learning of social skills, receptive language, and expressive language (all p0.001)

Brezis et al. (2015) performed a research using 40 samples of three successive cohorts of participants, who were recruited in January (n=16), July (n=12), and September (n=12) of 2012, respectively. Control, n information were not supplied. This research used a pre and post study design. The influence of home-based intervention strategies for enhancing socialisation, communication, and behavioural issues on parental stress and understanding of ASD is investigated. Child and family outcomes of improved self-reflection, an enhanced capacity to project beyond the here and now, and a feeling of empowerment resulted from a better knowledge of ASD and better behaviour management, according to the findings.

Louis et al. (2015) performed an Intervention research among 15 participants (intervention group) and control, n= 15 and the age of the participants were between 30- 60 months. Diagnostic and Statistical Manual, Fourth Edition, Text Revision (DSM-IV, TR) criteria were used to confirm the diagnosis. The research was a randomised controlled trial; fathers in the treatment group were required to watch how the therapist engaged with the child, interact with the child one-on-one, and show how they would approach the child at home. The duration of this therapeutic program was

six months, following which children were reviewed. For the control group, a written group home program were supplied for use by the main caregiver at home. Reported child outcomes included beneficial effects on the child's communication, understanding of play, and social skills, as well as improved communication intent, the ability to react constructively to social signals, and basic tasks of daily living.

Patra et al. (2015), performed a research on 18 children with ASD between the ages of 30 and 60 months, using Diagnostic and statistical manual, 4th edition, text revision (DSM-IV, TR) criteria to confirm the diagnosis. In this research, both qualitative and quantitative methodologies were used in a pre-post design. In this research, the module was taught to the parent group in 12 sessions, each lasting around 2 hours and occurring every two weeks. Using a standardised questionnaire, the impact of this module on parental stress and knowledge was evaluated. This study examines the effects of home-based intervention strategies on children's sociability, communication, and behavioural issues.

Krishnan et al. (2016) performed a research on 77 toddlers diagnosed using ICD-10 diagnostic criteria. The pre-intervention and post-intervention trial lasted 12 weeks. Frequency, intervention program, and frequent practise at home were extracted from the database of a teaching hospital. Sessions were held five days a week. It is possible to provide an effective parent-mediated early intervention for mild to severe autism, according to the study's findings. The intervention improves developmental age significantly, develops play behaviours, reduces autism symptoms, and improves other abilities such as perceptual and fine-motor functioning. Further cognitive, language, and social/emotional skills were improved.

Rahman et al. (2016) used a randomised controlled experiment to determine the effectiveness of a parent-mediated intervention for children with autism spectrum disorder (PASS), a single-blind randomised trial comparing 12 sessions of PASS (plus usual care) to usual care alone delivered by non-specialist health workers was done. Children with autism spectrum disorder aged 2–9 years were randomly assigned (1:1) using probabilistic minimisation, with treatment centre (Goa or Rawalpindi) and age (6 years or 6 years) being controlled (Vineland Adaptive Behaviour Scale Composite

score of 65 or 65). At eight months, the primary outcome was the quality of parent–child contact as measured by the Dyadic Communication Measure for Autism. After adjusting for minimising factors and baseline result, the primary outcome indicated that PASS had a treatment effect on parental synchrony and the child initiating contact with the parent. Additionally, the findings mirror the beneficial primary outcome treatment effects observed in the original UK Preschool Autism Communication Trial with a parent-mediated communication-focused intervention.

Divan et al. (2019) performed an intervention study with 19 study participants and 21 control group individuals between the ages of 2 and 9 years old. Autism spectrum disorder diagnoses were validated by diagnostic examinations utilising the INCLEN diagnostic instrument. The research used a two-arm, single-blind, randomised, controlled trial design; the "PMI for autism spectrum disorder plus" (PASS plus) therapy included of one-on-one home sessions between the parent and a lay health professional. Large treatment effects on proximal outcomes of proportion of synchronous parent responses and proportion of child communication initiations with parent; mutual shared attention and co-morbid symptoms are shown in this study. Further exposes the benefits of parental mental health improvement.

Padmanabha et al. (2019) conducted a research study with 21 Intervention participants. Control, n=19. Age between 3-12 years. The research used a pilot randomised controlled trial with parallel groups; this was a 12-week pilot randomised controlled experiment with parallel groups. During the duration of the study, the sensory intervention group got home-based sensory treatments from parents/caregivers in addition to normal therapy, while the standard therapy group received speech therapy and applied behaviour analysis from professionals. In children who received sensory therapies, reduced hyperactivity, motor stereotypies, and auditory sensitivity were seen. Home-based sensory interventions feasible in developing country and suggested to beneficial role in ASD.

Manohar et al. 2019 conducted a study titled "Brief Parent-Mediated Intervention for Children with Autism Spectrum Disorder: A Feasibility Study in 2019. The study evaluated the acceptability and feasibility of a brief parent-mediated home-based

intervention for children with autism spectrum disorder (ASD), deliverable in resource-limited settings, with an emphasis on addressing parental stress 50 children (2–6 years) with an ASD diagnosis as defined by the DSM 5 were randomly allocated to an intervention group (n = 26) or an active control group (n = 24). The intervention was organised to be administered in five outpatient sessions over a 12-week period, utilising a naturalistic developmental behavioural approach and concentrating on joint attention, imitation, and social and adaptive skills. Each kid was followed for four, eight, and twelve weeks. Parents of children randomly assigned to the intervention group reported greater improvements in parental stress and child outcome measures than parents of children randomly assigned to the control group. The intervention was determined to be acceptable and practicable, with high levels of fidelity and retention.

Sengupta et al. (2020) adapted Project ImPACT (Ingersoll & Dvortcsak, 2009), a parent-mediated Naturalistic Developmental Behavioral Intervention (NDBI) for young children with ASD that has been shown to improve social communication, engagement, and play, and then implemented it in an urban child development centre in India to meet community needs. A quasi-experimental pre-post study design was employed to collect data on family satisfaction, parental perceptions of children's social-communication abilities, and parental stress. Parent faithfulness was determined by coding video recordings of parent-child interaction. For 39 (n = 39) of the 57 children enrolled in the intervention, caregivers had comprehensive data on the intervention's feasibility and acceptability, as well as parent-perceived results. The intervention was found to be viable and acceptable by urban Indian parents, who were able to demonstrate the tactics taught and saw an improvement in their children's social communication abilities. Additionally, parent stress levels fell following the intervention's conclusion.

## *Evidence based Interventions for ASD*

### Interventional Research

As indicated previously in this chapter, numerous research focus on the use of intervention tactics to aid in the improvement of autistic children's behaviour. The majority of research are confined to a small number of cases since they were undertaken to assist autistic youngsters seeking treatment from professionals. However, the results are fairly encouraging. A brief survey of those available during the last few years is presented here. These studies, upon evaluation, fall mostly into five categories: intervention to improve behavioural skills; social skills; communication skills; and parental intervention.

### Intervening behaviorally

Current behavioural therapies have their origins in early 1960's investigations. Ferster and DeMyer (1961, 1962) were among the first to demonstrate that children with autism could and would learn if operant discriminate learning procedures were applied systematically. Lovaas and his colleagues (Lovaas et al., 1965; Lovaas et al., 1966; Lovaas et al., 1973; Lovaas, 1977) pioneered the development of a comprehensive, systematic package of behaviour therapies for children with autism (Schreibman & Ingersoll, 2005). According to one often cited study, 47% of preschool-aged children with autism who underwent extensive (40 hours per week) discrete trial intervention for two years reached normal intellectual and educational performance, compared to 2% who got less intensive engagement (Lovaas,1987).

Ozonoff and Cathcart (1998) discovered that kids who received home-based structured instruction improved considerably on developmental and cognitive tasks involving imitation and fine motor skills when compared to students who did not get this form of intervention. Additionally, the experimental group outperformed the control group by two to three times on other developmental measures and gained 9.6 months after four months of therapy.

Ben-Itzchak and Zachor (2007) discovered considerable progress in six developmental-behavioral domains after one year of intervention, including imitation,

receptive language, expressive language, nonverbal communication skills, play skills, and stereotyped behaviours. Children with stronger initial cognitive abilities and fewer measured early social interaction deficiencies demonstrated improved skill acquisition in three developmental domains: receptive language, expressive language, and play skills.

Green et al. (2002) discovered similar advantages with applied behaviour analysis in a toddler who had high risk for autism at the age of roughly one year. Treatment was place in the child's home and in other locations. Three years of intensive treatment were required; by the fourth year, the kid was spending the majority of her time in a typical preschool classroom. Over the course of treatment, direct observational data and norm-referenced tests revealed significant gains in language, social, cognitive, and daily living skills.

There has been interest in determining if targeting early social communicative behaviours associated with later emerging behaviours in typical development results in greater development of these later emerging behaviours in autism. For instance, Whalen (2001) employed behavioural methods to teach young children with autism how to initiate joint attention and observed advances in language despite the fact that language was not explicitly targeted. Similarly, Ingersoll et al. (2003) discovered that focusing on reciprocal imitation increased language, play, and cooperative attention.

As Ingersoll and Schreibman (2007) demonstrated, a multiple-baseline approach was used to test the benefit of a naturalistic behavioural technique for teaching object imitation across five young children with autism. Participants improved their ability to imitate and generalised their imitation abilities to novel contexts. Additionally, participants demonstrated increases in additional social-communicative behaviours, such as speaking, pretend play, and collaborative attention. Another study by Ingersoll et al., (2007) discovered that using reciprocal imitation training, five young children with autism increased their spontaneous use of descriptive gestures.

In comparison, cognitive behavioural techniques have been employed and examined specifically in autism treatments only infrequently. Bauminger (2002) conducted a study to determine the efficacy of a seven-month cognitive behavioural intervention

in improving the social-emotional knowledge and social interaction of 15 high-functioning children with autism. The results indicated improvements in social interaction, problem solving, and emotion comprehension. Following treatment, children also improved their teacher-rated social skills in assertiveness and cooperation.

Koegal et al. (2001) conducted a review of numerous research demonstrating the efficacy of crucial response training and long-term improvements in disruptive behaviour, linguistic, social and academic skills, as well as attitude toward learning and enthusiasm. PRT teaches self-management and self-initiation through behavioural procedures such as self-recording and self-reinforcement.

Several research examined whether the 'intensity' of service delivery and the age at which behavioural intervention was initiated had an effect on developmental rating scale progress evaluations. Children who participated in service before and after the age of three revealed substantial changes in six developmental domains when measured before and after intervention, but no significant differences existed between these groups. The duration of a child's home-based intervention predicted overall progress in communication, cognitive, and social-emotional functioning (Luiselli et al., 2000).

Another effort at an early behavioural intervention program may be impacted by the use of various cognitive assessment tools to draw conclusions about the progress of preschool children. The Bayley, Merrill-Palmer, and Vineland measures were administered to 24 children with autism ranging in age from 27 to 58 months as part of a longitudinal treatment outcome study. Researchers compared their results on each of these assessments. While test results were highly correlated, actual test scores varied significantly, with the Bayley producing the lowest IQ levels and the Merrill-Palmer producing the highest. These findings have substantial consequences, as it is clear that the tests chosen for pre- and post-treatment assessments can have a significant effect on judgments regarding the outcomes of therapy (Magiati & Howlin, 2001).

**Intervention on the social front**

Hwang and Hughes (2000) conducted a meta-analysis of sixteen empirical studies examining the impact of social interactive therapies aimed at improving the early social communication abilities of young children with autism by enhancing their role as initiators of social contacts. Social and affective behaviours, nonverbal and verbal communication, eye contact, collaborative attention, and imitative play all showed increases. There was evidence of little generalisation or maintenance of goal behaviours.

Smith (2001) identified a number of potential benefits of social stories, including the possibility that taught social skills will transfer to new contexts. Numerous research have shown that social storytelling can promote social behaviour and decrease problem behaviour. Lorimer et al., (2002) proved through an ABAB design that social stories reduced tantrums in a high-functioning 5-year-old kid, but Smith's optimism about generalisation was not validated. When social stories are not employed, tantrums become more frequent.

Kuoch and Mirenda (2003) investigated the effect of social stories on issue behaviour in three children aged three to six years old using an ABA design. They discovered that social stories resulted in a reduction in problem behaviour that persisted after social stories were not provided. Barry and Burlew (2004), by contrast, employed social stories to teach new abilities rather than to address negative behaviour. They taught two autistic youngsters with lower functioning to make proper decisions and engage in appropriate play. Because the study lacked a phase in which social stories were eliminated, no conclusions regarding generalisation could be proven.

Additionally, Crozier and Tincani (2005) utilised a reversal design to examine the impact of a modified social story with and without verbal instructions on a student with autism's disruptive behaviour. Disruptive behaviour decreased significantly following the intervention, but even more so when the tale was combined with prompting.

The most frequently employed technique for teaching children with autism in inclusion settings how to play and other social skills is to recruit the assistance of a typically developing peer. DiSalvo and Oswald (2002) conducted a review of the data on peer-mediated methods and concluded that they are generally effective at

increasing social initiations or reactions, but not both. In a recent study of a 4-year-old kid in an inclusion preschool, researchers discovered an increase in peer initiations and an increase in target child initiations (McGrath et al., 2003). Peer-mediated education in social skills has also been a critical component of the LEAP preschool curriculum, which has demonstrated outstanding long-term benefits (Strain & Hoyson, 2000).

Garfinkle and Schwartz (2002) make another attempt at simplifying the program. Three children with ASD were taught to imitate peers in an inclusionary preschool classroom through small group activities. The results indicate that participants increased peer imitation behaviour during training and adapted it to free play. Other social behaviours, such as proximity to peers and peer interactions, were also shown to be increasing. McGrath et al. (2003) conducted a recent study to determine the efficacy of peer and individual social skills training for a preschooler diagnosed with autism. The results suggested that the frequency of suitable initiations and answers increased, and that these changes were socially valid when compared to conventional peer-to-peer social behaviour.

Chung et al. (2007) recently investigated the effectiveness of a peer-mediated social skills training (SST) program integrated with video feedback, positive reinforcement, and a token system in developing social communication abilities in young children with high-functioning autism. The study enrolled four boys with high-functioning autism, ages 6–7 years. Three out of four children improved, while individual disparities in changes on two global measures as well as subscales were found. These findings indicate that social skills training was helpful in enhancing social communication skills in a subgroup of children with high-functioning autism.

Attending to the appropriate social stimulus is a deficiency in almost every child with autism, and hence successful intervention requires more than exposure to a model. Jahr et al. (2000) discovered that modelling alone was ineffective in teaching children with autism to engage in cooperative play. When the researcher added an auditory description of the modelled action, all six children learned to initiate and sustain episodes of cooperative play, to diversify their play, and to transfer their skills to other play partners. Another study on preschool social communication intervention discovered that when adequate supports are offered, children with autism do demonstrate an increase in social play (Rogers, 2000).

**Intervention in communication**

As mentioned in Paul and Sutherland (2005), the most fundamental method, discrete trial instruction (DTI), has been extensively utilised to teach receptive language to children with autism. Lovaas (1987) used this technique to the therapy of autism-related speech, and the results appear to be confined to eliciting verbal production in high-functioning individuals. Nonetheless, a sizable study has proved the efficiency of this strategy in triggering vocal imitation and speech in nonverbal children (Ross & Greer, 2003). To elicit the first word in children with autism, Tsiouri and Greer (2003) proposed the rapid motor imitation (RMI) response strategy. This method uses structured operant training to generate quick motor imitation sequences of actions that the kid is already capable of performing in order to engage youngsters in an imitation mode and produce meaningful results.

Milieu techniques such as mand-modal, prompt-free, and incidental instruction have been connected with an increase in children's ability to initiate communication (Matson et al., 1993). These strategies have been used to create speech in non-verbal youngsters, as well as to increase the frequency, spontaneity, and elaboration of language (Delprato, 2001; Goldstein, 2002; Koegel, 2000).

One area of frequent difficulties in the treatment of children with autism is teaching nonverbal youngsters communication methods. PECS is the most extensively used pictorial system for nonverbal children (Bondy & Frost, 1998). While studies on the effectiveness of PECS is sparse, it has gained widespread adoption in school-based intervention programs. Charlop-Christy et al. (2002) conducted a study to determine the effect of PECS use on speech development in three preschool children with autism. The study's findings suggested that all children met the learning criterion for PECS and shown an increase in speech use. Kravits et al. (2002) examined the influence of PECS on the spontaneous communication abilities of a 6-year-old girl with autism. The results demonstrated an increase in spontaneous expressive communication across all situations where PECS was trained.

Additionally, manual signals have been commonly utilised as a mode of communication for children with autism who do not talk. Goldstein (2002) evaluated a number of research that used manual signals in conjunction with speech and concluded that total communication (TC) approaches can be helpful for teaching both

receptive and expressive vocabulary in early childhood. Martin et al. (2005) used functional communication training to teach a 10-year-old student with autism and severe language delays to reject items by touching an icon rather than pushing them away through the use of prompting, differential reinforcement, and error correction procedures. The results indicate that training was successful in substituting a touch of an icon for pushing aside items.

There is limited evidence that non-speaking autistic individuals can benefit from high-tech device exposure as well. Romski and Sevcik (1997) studied juveniles with autism and found that they improved their spoken language and ability to use a computerised voice output communication aids (VOCAs) device over the course of a two-year study in which naturalistic teaching approaches were used to teach the device's use. In another study (Schepis et al., 1998), this strategy resulted in an increase in the use of communicative behaviours to seek objects, answer to queries, and make comments among four children with autism. Light et al., (1998) also observed positive language outcomes when a VOCA was implemented as a component of a comprehensive communicative system for one kid with autism. Additionally, gestures, natural speech, and a communication book were incorporated.

Krantz and McClannanhan (1998) conducted script-fading experiments with preschoolers who lacked basic reading abilities. Children were trained to utilise the written cues "Look" and "Watch me" to initiate conversation with adults who did not initiate but only reacted to guided discourse. By removing pieces of the cue cards, the letters were faded. It was discovered that unscripted conversations persist and generalise to new themes.

Keen et al. (2007) examined the impact of the Stronger Families Project, a social-pragmatic intervention, on the communicative and symbolic abilities of sixteen autistic children aged two to four years. According to parent reports, the Stronger Families Project intervention resulted in changes in some communication and symbolic behaviours.

Joint attention is believed to be a critical component of language development and has been demonstrated to be a significant predictor of language outcome in children with autism (Mundy, 2003). Few research, such as those conducted by Whalen and Schriebman (2003) and Kasari et al. (2004), have evaluated the efficacy of focused

intervention including joint attention and symbolic play in children with autism. The findings revealed that joint attention behaviours can be effectively taught and that targeted behaviours can be adapted to various contexts. Additionally, the children demonstrated a greater variety of symbolic play in their interactions with their moms, as well as higher play levels on both the play evaluation and in their interactions with their mothers.

Kalyva and Avramidis (2005) investigated the efficacy of intervention in enhancing the communicative abilities of five pre-school-aged children with autism - three in the intervention group and two in the control group. For three months, the 'circle of friends' was implemented for 30 minutes weekly in a nursery setting with the active participation of one teacher and five peers of each child with autism. The data analysis found that children in the intervention group had considerably greater rates of effective response and initiation post-intervention and follow-up than children in the control group.

Numerous research have detailed efforts to teach youngsters with autism theory of mind. As Charlop-Christy and Daneshvar (2003) noted, attempts to teach theory of mind have been mostly unsuccessful, with no indication that the abilities have extended to novel situations or to other cognitive and social behaviours. Chin and Bernard-Opitz (2000), for example, taught conversation skills to three boys with autism aged 5 to 7, but discovered that their conversation skills did not generalise to enhanced theory of mind performance on a standard assignment.

**Parental involvement**

In recent years, increased emphasis has been placed on intervention by parents and other caregivers in addition to children with autism. Symon (2005) and Seung et al. (2006) have undertaken parental education in the context of a family. The results indicated that parental training is effective at enhancing parents' ability to wait for their child to communicate verbally and to use verbal mimicry to facilitate engagement. Additionally, research indicates that children with autism can improve their social skills, behaviours, and communication. Parental training also prepared parents to be effective educators for other family caregivers.

Researchers such as Girolametto et al. (2007); Mahoney and Perales (2006); and Ingersoll and Gergans (2007) evaluated the effectiveness of parental training in a

clinical setting with 11–56 sessions. They observed an increase in parent-child contact, as well as increased attentiveness and ability to perform reciprocal imitation training. Additionally, the results indicate an improvement in language, social skills, imitation, and emotional functions.

Aldred et al. (2004) assessed a new theoretically based social communication intervention targeting parental communication with twenty-eight children with autism in a randomised design. The intervention was provided in addition to existing care and consisted of six months of monthly therapist interaction followed by six months of bimonthly consolidation sessions. Its objective was to educate parents and teach them in adapting communication to their child's unique abilities. The active treatment group demonstrated considerable improvement in reciprocal social interaction and expressive language, communicative initiation, and parent-child contact when compared to controls.

In comparison, Drew et al. (2002) reported the results of a pilot RCT for a parent training intervention focusing on the development of joint attention skills and joint action routines. Twenty-four children with autism were randomly assigned to receive parent training or to receive solely local services. A 12-month follow-up was undertaken. There was some evidence that the parent training group made more improvement than the local service group in terms of language development.

Swallows and Graupner (2005) compared 24 children with autism who were randomly assigned to a clinic-directed group for intense behavioural instruction with a parent-directed group for intensive hours supervised by similarly trained supervisors. After four years of treatment, both groups achieved comparable outcomes on cognitive, language, adaptive, social, and academic assessments. After combining the groups, they discovered that 48% of all students demonstrated quick learning and were achieving well in traditional education classrooms.

Smith et al. (2000) conducted a study on parent-directed, intensive early intervention for children diagnosed with Pervasive Developmental Disorder. Over a five-month period, parents and therapists attended six one-day workshops, followed by subsequent consultations over the next 2-3 years. Five of six children acquired skills rapidly when treatment began, but only two demonstrated significant improvement on standardised tests at the 2–3-year follow-up.

McConachie et al. (2005) evaluated a parent training course designed to improve social communication with their young children suspected of having autism spectrum disorder. Controlled trial for 51 children aged 24 to 48 months, whose parents got either immediate intervention or delayed access to the course. Seven months following recruitment, the outcome was assessed in terms of parents' use of facilitative tactics and adaptation to the kid, as well as children's vocabulary size, behavioural difficulties, and social communication skills. The intervention group had a significant advantage in parents' observed use of facilitative tactics and in children's vocabulary size.

Along with parent education, one study examined the joint effectiveness of parents and children. Solomon et al. (2004) described the results of a 20-week social adjustment enhancement program for children in which parents participated in a semi-structured concurrent psychoeducational training during the children's sessions. The findings indicate that there are statistically significant gains in face expression detection and problem solving.

Mc Conachie and Diggle (2007) recently conducted a review and discovered that there are relatively few papers with a suitable research design from which to make conclusions on the effectiveness of parent-implemented early intervention. Parent training appears to improve child communicative behaviour, maternal awareness of autism, and parent-child interaction in both randomised and controlled studies.

Another trend has been to involve family members and teachers in the planning and implementation of behavioural interventions, thereby enhancing the maintenance and generalizability of treatment effects across individuals and naturalistic environments (Horner et al., 2002). Contextualized behavioural support in early intervention for children with autism and their families increased the value of functional assessment techniques and increased the stability and durability of functional communication training in addressing the challenging behaviour of several children with autism, according to one study (Moes, & Frea, 2002). While parent-managed behaviour methods may be effective in addressing problem behaviours, developmental progress may be less robust than that accomplished by professionally directed program intervention (Bibby et al., 2002).

Parent-Mediated Intervention Programs have been demonstrated to be effective for dyslexia, anxiety disorders, and depression, in addition to ASD and other developmental difficulties (Kale & Landreth, 1999). Parents learn treatment approaches from experts and then apply them to their own children in parent-mediated interventions. Throughout the day, this strategy gives consistent reinforcement and training to children with autism spectrum disorder (ASD). Based on a review of the literature, Woods and Brown (2011) identified four global strategies to support family capacity building: addressing families' informational needs, using their natural environments as the intervention context, engaging parents to be active participants in the intervention process, and supporting caregivers' reflection and self-evaluation. This emphasises the significance of PMI as an effective intervention strategy.

The review revealed very few research with sufficient research design to draw conclusions on the effectiveness of parent-implemented early intervention. Parent training appears to improve child communicative behaviour, increase mothers' knowledge of autism, improve maternal communication style and parent-child relationship, and reduce maternal depression in both randomised and controlled studies. To summarise, parent training can substantially contribute to intervention for young children with ASD.

Autism spectrum disorder (ASD) services in India are limited. We searched the literature for research on ASD interventions in India. Nearly all of the articles reviewed documented efforts to culturally adapt treatments and/or outcome measures for Indians. Small urban research samples hindered generalizability. Few studies looked at young children, and none at adolescents or adults. There was improvement in all studies. Some did not effectively define their research designs or analytic methodologies. While looking into parent-mediated intervention for ASD In India, only a few Indian studies were found to prove that parent-mediated intervention is applicable and effective in Indian settings. Therefore, ASD interventions for Indian communities require further investigation.

As a result, the researcher intended to conduct an extensive investigation to ascertain the implications, potential intervention content, perceived feasibility, and receptivity of a Parent Mediated Intervention program for autism spectrum disorder, as well as to develop such an intervention, taking into account the perspectives of parents and experts, and to conduct a pilot trail run to conduct its preliminary evaluation.

***Figure 1.2 Overview of Literature Review***

**Critique and Rationale for the present study**

The present research is significant since it is the unique of its nature, both in terms of the topic it examines and the method it employs to address the research problem. The researcher is indeed a clinical psychologist; it was his experience in that discipline that finally piqued his interest in the topic he is currently investigating.

The majority of children with autism spectrum disorder reside in nations with low income and lack access to treatment. Recent national estimates indicate that India is home to more than 5 million children with autism spectrum disorder between the ages of 2 and 9 years old (Deshmukh, 2014). The lack of evidence for interventions that have been modified and tested for practicality in low-income countries and the scarcity of professional staff to provide interventions to large populations that are not near specialist facilities are the two major hurdles to treatment access (Patel et al., 2013).

Research to overcome obstacles to care for mental health issues in children is one of the top five big challenges in global mental health, where the treatment gap for community treatments is approximately 100 percent (Collins et al., 2011). The adaptation of therapies proven in high-income countries to local requirements and the implementation of these interventions by non-specialist health professionals are significant developments for reducing the treatment gap for various mental illnesses (Van Ginneken et al., 2013).

Although early treatments have been used to treat children in high-income countries, no substantial trials of the programs modified for use in low- and middle-income countries have been conducted (LMICs). Children with autism spectrum disorders and intellectual and developmental disabilities (ASD/IDD) may benefit from individualised, developmentally appropriate services that engage their parents (Schreibman et al., 2015). It has been demonstrated that family-centred treatments for ASD/IDD services reduce feelings of isolation, parental stress, and increase family functioning among families of children with ASD (Galpin et al., 2018; Warfield et al., 2014). Nonetheless, considerable gaps continue in the diagnosis and treatment of autism spectrum disorder (ASD) among children with ASD from low-resource

communities (Jo et al., 2015; Nguyen et al., 2016; Zuckerman et al., 2017). Programs that empower and equip parents to be the agents of change to support and enhance their child's developmental outcomes may be an effective means of addressing these gaps (Johnson et al., 2019).

Parent-mediated interventions (PMIs) capitalise on the crucial role that parents play in their children's developmental paths (Burrell & Borrego, 2012). They concentrate on modifying or strengthening parental reactions or interactions with youngsters (Bearss et al., 2015; Green et al., 2010). The child is the major beneficiary of PMIs, but parents may also gain by learning new knowledge about their child's symptoms or new tactics or approaches for addressing developmental requirements. These treatments may also differ based on the target domain or behaviour (e.g., language and communication issues, play skills, daily living skills, or challenging conduct), format (e.g., online, therapist-led, coaching), length (e.g., one week, three months, one year), or age range (Johnson et al., 2019). A comprehensive analysis showed that PMIs may have a considerable influence on both child and parent outcomes (e.g., language, joint attention, ASD symptom severity) (e.g., quality of parent-child interaction; Oono et al., 2016).

Thus, when offered in community settings, PMIs may be a cost-effective strategy for addressing the needs of children with ASD and other impairments by their parents (Kasari et al., 2010; Wetherby et al., 2014). In addition, Parent-Mediated Intervention (PMI) strategies have received a great deal of study interest in recent years and have been proven to be beneficial for parent and toddler learning. There are few studies among low-income and lower socioeconomic groups. Nonetheless, a number of studies using a rigorous study methodology (a randomised controlled trial) have shown that parent-mediated intervention may be effective under optimal, well-controlled settings.

Researchers and clinicians in the area of ASD must prioritise increasing the motivation of people who engage in the treatment process and discovering strategies to generalise and maintain treatment improvements. Attempts have been made to achieve these goals, such as the development of ways to encourage parents to engage

in parent training programs. Individual counselling and support groups have been more available in recent years to help parents of autistic children better manage their own emotions and needs. In light of the fact that parents are often exasperated and worried by their children's enormous obstacles, these initiatives look promising and useful.

In addition, several parent organisations and agencies exist to give emotional and practical support to the parents of autistic children. This is an area where future research should focus their efforts. Regarding maintenance and generalisation, the most effective intervention is to include as many members of the autistic child's environment as possible (such as parents, teachers, and classmates) and educate them how to function as intervention agents.

Currently no single intervention is believed to be the most effective treatment for children with autism spectrum condition. In evaluations of the research and practise recommendations, parental participation and education are often cited as crucial intervention components. Parent training is a cost-effective method for teaching parents how to assist their children in improving their abilities. It instructs parents on how to implement methods into their children's everyday activities so that they may begin to practise their talents.

Studies are needed more on the impacts on parents and families and utilise larger samples. Possible advantages include improved abilities and less stress for both parents and children. It was discovered that relatively few research employed the appropriate methodology to derive conclusions regarding the efficacy of parent-mediated early intervention. Parent training may increase child communication, parental understanding of autism, parental communication style, and parental stress, according to randomised controlled trials. Accessible parent-mediated intervention training may help children with autism spectrum disorder develop their social skills as well as their capacity to communicate and connect with others. (Green et al., 2010; Carter et al., 2011; Kasari et al., 2010; Siller & Sigman, 2002; 2008)

There is some evidence from the study conducted by Nevill et al. (2018) indicating that parents believe their child's language abilities have improved and that the severity

of their child's autistic symptoms has greatly diminished. This covers developmental characteristics, access to other services, comorbidities, parental factors, and intervention accessibility. This meta-analysis demonstrates that research quality is increasing. The majority of the time, parent-delivered therapies are more effective than the usual method of treating children with ASD.

Importantly, a broad-based parent-mediated intervention program, particularly for children with ASD, targets both child and parent-related outcomes by integrating evidence-based interventions, and the suitability and adaptability of such models within our cultural context is of the utmost importance. In addition, ensuring the participation of stakeholders at every step of research, from its beginning towards its completion. In existing parent-assisted or evidence-based intervention programs for children with ASD in India, they have not been adequately explored.

These considerations formed the rationale for undertaking the present study and its methodology. The study was aimed at developing and pilot testing a PMI program for parents of children with ASD.

## STATEMENT OF THE PROBLEM

The study's aim is to explore the perspectives of parents and experts on parent-mediated intervention programs for children with autism spectrum disorder (ASD), as well as develop and validate the parent mediated intervention program.

Thus, the current study is titled **'Development of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder'.**

### *Operational definition of terms used in research study*

**Parent mediated intervention (PMI) program for children with ASD:** For the purposes of this study, a parent-mediated intervention program for children with ASD is defined as a program that involves active parental participation in training activities, therapeutic interventions, and other possibilities that are likely to promote symptomatic changes. It's dubbed a parent-mediated intervention program since it

relies on parents to deliver the training under the supervision of a skilled therapist. (Meadan et al., 2017).

***Autism spectrum disorder (ASD)****:* is a group of pervasive neurodevelopmental disorders characterised by moderate to severe disruptions in social skills and socialisation, expressive and receptive communication, and repetitive or stereotyped behaviours and interests. (ICD-10)

***Preliminary Evaluation:*** Examining the feasibility, receptivity, and changes in PMI relevant outcomes through a pilot-trial.

***Preliminary Evaluation:*** In the present study, the term preliminary evaluation of the parent mediated intervention program was defined in terms of examining the feasibility, receptivity, and changes in PMI relevant outcomes through conducting a pilot-trial.

***Feasibility:*** In the current study, feasibility assessment will include documentation of stakeholder and professional expert perspectives on various barriers and potential hindrances that may arise during program planning and implementation.

***Receptivity:*** Receptivity is defined in this study as the perceived readiness to participate and engage in the proposed parent-mediated intervention program. Receptivity would be measured in terms of the proportion of parents who expressed an interest in participating, the proportion of parents who agreed to participate in the program, and their willingness to participate in this program on a consistent basis without fail. The interview with parents was used to determine receptivity by rating their self-perceived engagement in the program.

***Exploration:*** Exploration refers to the attempt to discover the potential content of the proposed intervention program through the analysis of semi-structured interviews with parents of children with ASD and professionals who work with children with ASD.

## OBJECTIVES

### Set I: Exploring stakeholder perspectives

1. To explore the perspectives of parents in terms of felt needs, feasibility, potential content, and structure of a parent-mediated intervention program for children with ASD.

2. To explore the perspectives of professionals dealing with children with ASD regarding the felt needs, feasibility, potential content, and structure of a parent-mediated intervention program for children with ASD.

### Set II: Designing of the parent mediated intervention (PMI) program

1. To design a parent-mediated intervention program suitable for children with ASD.

2. To examine and validate the content, structure, feasibility, receptivity, and suitability of the designed program through a stakeholder's and expert's rating.

### Set III: Validation and pilot trial run of the PMI program

1. To examine the feasibility and receptivity of the PMI program through a pilot-trial for fine tuning of the intervention.

## RESEARCH QUESTION

The 'key research question' has been developed based on the current study's aim and objectives. Sub questions were formulated from the key research question, which would be addressed during the course of the research.

***Key research question:***

How can the perspectives of parents and professional experts be addressed in the development of a parent-mediated intervention program for children with ASD?

***The sub questions proposed are:***

- What are parents' perspectives on the perceived needs, feasibility, potential content, and structure of a parent-mediated intervention program appropriate for children with ASD?
- What are professionals' perspectives on the perceived needs, feasibility, potential content, and structure of a parent-mediated intervention program appropriate for children with ASD?
- How can we develop a parent-mediated intervention program for children with autism?
- How can the PMI Program be validated and fine-tuned?

**CHAPTER SUMMARY**

This chapter provides background information on autism, its symptoms, aetiology, including genetic and environmental factors, theories of ASD, including the theory of mind hypothesis, executive dysfunction hypothesis, and weak central coherence hypothesis, as well as existing evidence-based interventions. Additionally, it presents the concept of parent-mediated treatments, the psychological principles and theories that underpin it, and lastly, the concept's clinical uses and relevance. The final section conducts an in-depth evaluation of the literature on parent-mediated therapies in general, parent-mediated interventions for children with ASD, and finally, parent-mediated interventions for children with ASD in the Indian population.

# CHAPTER II
# METHOD

# METHOD

The methodology is regarded as the study's underlying support structure. It is also considered as the research framework since the research method chapter serves as a guide for the researcher. The method enables a researcher to attain their objective in a scientific and systematic manner. The method provides the guidelines for the careful adoption of the study design, the proper sampling strategy, appropriate procedures for data collection, the analysis of the data collected, and interpretation of the study findings.

**Research Design**

Goal of the research is to improve our understanding of how the world works. Any form of "knowledge" is created or strengthened through both qualitative and quantitative approach of research. These two methods vary in data collection, but both quantitative and qualitative research approaches serve and contribute to the fundamental objective of knowing. We live in a world that is extremely complicated and multi-layered in terms of social, personal, and relational constructs. Language, rituals, discussions, tales, memories, products, and other tools are used to think about, communicate about, and transmit our beliefs about this "created" reality. Many qualitative research methods and their applications aim to investigate these distinct "constructed" worlds.

Qualitative research is undertaken for a reason. This would address the fundamental question, both inside and beyond the field of why researcher should investigate any phenomenon about which researcher already know something, and sometimes quite a deal. When asked in a qualitative survey, the majority of people can provide some form of rational explanation or knowledge about why and how any given event or experience occurred. Researcher shall continue to do scientific analysis through qualitative research, as conventional wisdom is inconclusive in the present era. Individuals' impressions of events and how they are discussed change throughout time. Over time, the concept of a "happy life" has evolved. Axioms and standards evolve as

a result of social interactions. As a result, the phrase "common sense" may become meaningless at times. Qualitative research is critical in the first place.

Mixed methods approach is less well recognised than either the quantitative or qualitative techniques. The notion of blending multiple approaches emerged in 1959 when Campbell and Fisk utilised multi methods to explore validity of psychological qualities. They urged people to apply their multi method matrix to investigate different techniques to data collecting. This led others to blend techniques, and soon approaches associated with field methods, such as observations and interviews (qualitative data), were merged with regular surveys (quantitative data; Sieber, 1973). Recognizing that all approaches have limits, researchers thought that biases inherent in any one method may negate or cancel the biases of other methods. Triangulating data sources—a strategy for achieving convergence across qualitative and quantitative methods—was created (Jick, 1979). By the early 1990s, the notion of mixing progressed from seeking convergence to actually integrating or combining the quantitative and qualitative data. For example, the findings from one approach may assist identify subjects to research or questions to ask for the second way (Tashakkori & Teddlie, 1998). Alternatively, the qualitative and quantitative data may be integrated into one huge database or the findings utilised side by side to reinforce each other (e.g., qualitative quotes support statistical results; Creswell & Clark, 2007) or the tactics may have a bigger, transformational goal to fight for oppressed groups, such as women, ethnic/racial minorities, members of gay and lesbian communities, individuals with disabilities, and those who are impoverished (Mertens, 2003). These reasons for mixing methods have led writers from around the world to develop procedures for mixed methods strategies of inquiry, and these take the numerous terms found in the literature, such as multimethod, convergence, integrated, and combined (Creswell & Clark, 2007), and shape procedures for research (Tashakkori & Teddlie, 2003).

The present study adopts an exploratory sequential mixed method research design that integrates a variety of qualitative methods to achieve the study's objectives, which are generally exploratory in nature and span various phases of the research. The study consists of two stages: a pilot phase and the main phase. Each phase is distinct in terms

of its aims, designs, and metrics, as well as the methodology used to achieve them. Each stage aided in the planning and execution of succeeding stages. The linked stages provide detailed descriptions of each step, including participant characteristics, design, measures used, processes, and analytic methodologies used.

In nutshell, the present study adopted exploratory sequential mixed method design, involved an exploratory cross-sectional qualitative phase, followed by a short-term prospective trial using a small 'n' pre-posttest follow-up design, mixed-method approach.

**PILOT PHASE OF THE STUDY**

This was conducted before the main phases of the study. The pilot phase of the study included the necessary background work for the following phases. This phase included the preparation and development of a semi-structured interview schedule for the interviews with parents of children with ASD and professionals dealing with children with ASD. A pilot study was conducted on parents of children with ASD who fulfilled the criteria for the study. In this phase, the researchers contacted parents who registered in the Community Disability Management and Rehabilitation Program (CDMRP) clinics, and professionals working in CDMRP. Researchers also contacted nearby clinics and hospitals and initiated the necessary liaison for the later phases of the study, which helped in recruiting parents and professionals for the interviews for the main exploratory phase of the research, and also for the program validation phase. The drafts of the interviews with parents and professionals to be used during the program exploratory phase were also prepared based on the pilot phase outcomes.

The purpose of the pilot study was to make all the necessary preparations for the various phases of the main study, such as

1. To prepare semi-structured interview schedules for both stakeholders (parents and professionals).
2. To explore tentative tasks for the proposed intervention program
3. To explore the scope and challenges of the proposed program

4. To familiarize researcher with the potential hindrances that may occur during the research.

**The pilot phase of research includes the following:**

**1. Analysis of previous research studies:** The study's pilot phase was designed to familiarize participants with the existing intervention program for children with ASD, which includes both parent-mediated and non-parent-mediated therapies. Researchers undertook an exhaustive assessment of research in the domain of intervention programs for children with ASD. For this goal, all published sources, such as books, journals, and articles, were combed for related reviews of psychological therapies for ASD. Only pharmaceutical therapies were excluded from the study. The majority of the studies were completed within the last fifteen to twenty years, but a few studies from twenty years ago that were judged to be relevant to current research were also included. In our cultural setting, parent-mediated intervention programs for children with ASD, as well as other significant evidence-based interventions originating from applied behavioural analysis, were given top priority (Koly et al. 2021). The researcher gained a preliminary grasp of the most effective intervention options for children with ASD as a result of this.

**2. Focused Group Discussion with parents' group of Stakeholders:** The goal of this phase was to learn from parents of children with ASD about the challenges they have in raising their children with Autism, as well as the limitations they confront and how they deal with them at home. Furthermore, to identify the shortcomings of the currently accessible treatments or interventions, as well as any potential barriers to their accessing community-based treatments.

**a. Participants:** A total of 8 parents of children with ASD took part in the focus group discussion held at the University of Calicut's Department of Psychology. The samples were selected using a purposive sampling method.

**FGD Sample Inclusion Criteria**

- Parents of Children with ASD age range of children from 5 years -15 years of age

- Ability to speak, read, and write Malayalam

**FGD Composition:**

It was planned to conduct one FGDs with 8-10 participants as part of pilot study.

- Number of FGDs: 1
- Number of participants participated in FGD: 8
- Duration of each FGD: 60-90 minutes

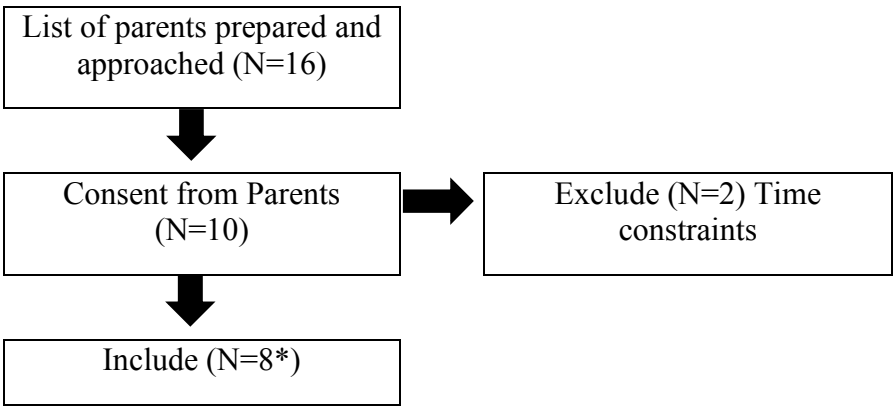
**b. Measures**:

**Focused Group Discussions* (FGDs) with Parents of children with ASD**

The goal of the focus group discussion was to learn about parents' feelings about their children's needs, as well as the feasibility, potential content, and structure of an intervention for children with ASD delivered by their parents. Focused group discussion is defined as a series of carefully structured discussions aimed at eliciting opinions on a certain topic in a relaxed, non-threatening setting (Krueger & Casey, 2000). It is a popular qualitative research method because it allows for the expansion of a topic's dimensions and points of view by investigating and eliciting stakeholders' subjective experiences and attitudes. This also allows people with comparable backgrounds or experience to discuss a specific topic of interest with the help of a moderator. This allows the researcher to learn more about how a group approaches a problem, the range of opinions and ideas they have, and the inconsistencies and differences in thoughts, experience, and practice they have. It adds to the understanding of a situation by including the comprehensive experiences of a variety of stakeholders rather than just the researcher's views and opinions. Given these characteristics, the current study has incorporated focus groups (FGDs) into it, with the expectation that the participants—parents of children with ASD in the current study—will be able to freely express their experiences, attitudes, and beliefs about their felt needs, as well as their opinions on the feasibility, receptivity, potential content, and structure of the parent-mediated intervention. This liberty is intended to result in data that is both authentic and diverse.

### c. Procedure

**FGD Participants' Selection Procedure:** An initial list of parents of children diagnosed with ASD and registered with the CDMRP clinic in the Department of Psychology at the University of Calicut was prepared for the purpose of choosing participants for focused group discussion. The parents' names and contact information were obtained, and they were approached for permission or willingness to participate in the FGD as part of a pilot study of a parent-mediated intervention program. The researcher met the parents at the CDMRP clinics and interviewed them when they went to the advanced clinic and community clinic for follow-ups at their convenience. They were given information about the study's purpose and the current phase's goal. After receiving consent for a focused Group Discussion [Appendix 1], the time and date of the FGD were scheduled at the mutual convenience of the participants and the researcher. The focus group took place in the department's conference room. Signatures on the informed consent document were obtained prior to beginning the focus group discussion. The focus group session lasted between 60 and 90 minutes. A total of one FGD was conducted utilising purposive sampling from the parents who gave consent; ten individuals were given consent to participate in the FGD, but only eight were present.




*Ten parents gave consent to participate, but two of them couldn't attend due to unexpected difficulties in their personal lives.

***Figure 2.1: FGD participants' selection procedure***

**FGD Procedure:** Once the participants were selected for the FGDs, the parents were asked to come up with a potential date for conducting the FGD. Based on the suggestions made by the parents, a date was selected to conduct the FGD. Most of them suggested a Saturday, so Saturday was chosen to conduct the FGD. Following the decision on a date, the department conference room was chosen to conduct the FGD with the approval of authorities.

On the day of the FGD, the participants were given basic datasheets [Appendix 2] and informed consent forms. Written informed consent [Appendix 1] was taken from each of the participants, which included a statement explicitly seeking consent for audio-recording of the whole discussion. The FGDs started with a very brief presentation by the investigator. This was planned in order to focus and limit the discussion to the study objective of exploring the potential content, receptivity, and feasibility estimates of a parent-mediated intervention program for children with ASD. This was deemed necessary as previous studies with similar samples have shown gaps in understanding of the scope and utility of parent-mediated interventions for autism. Moreover, such an intervention in our cultural context is rare.

A brief presentation by the researcher regarding the proposed program and the goal of conducting this FGD helped in creating a shared understanding among the participants at the onset about how the terms parent mediated intervention program and felt needs, potential content, structure, feasibility, and receptivity were being used in the present study, bringing focus and clarity to the discussions, and serving as a starting point. Further, the introduction also served as an icebreaker, which in turn helped to improve participants' comfort level in talking about the topic. Researcher encouraged the experts to express their ideas as freely as possible and to include examples from their personal experience. The investigator moderated the whole session with the help of FGD probes. There were three master's level internship students in the CDMRP who helped the researcher to prepare the transcript of the whole FGD apart from the audio record. Consent was also taken from the FGD participants to be approached at a later stage to obtain feedback and suggestions on the draft version of the parent-mediated intervention program for children with ASD.

### 3. Unstructured Interview with Professional Experts:

Interviews with professionals who work with children with ASD, such as clinical psychologists, speech-language pathologists, special educators, and occupational therapists, are part of this step. In addition to the literature review analysis completed earlier, this is regarded as an additional source of data for obtaining information on the prospective content and structure of the intervention to be devised.

**a. Participants**: One professional from each of the specialties of Clinical Psychology, Speech Language Pathology, Occupational Therapy, and Special Education (N=4) with at least 5 years of experience was included in the study. The samples were selected using a purposive sampling method.

**Unstructured Interview Sample Inclusion Criteria:**

- Multi-disciplinary professionals, including Clinical Psychologists, Speech Language Therapists, Occupational Therapists, and Special Educators
- Multi-disciplinary professionals have experience of treating children with ASD for at least 5 years.

**b. Measures**

**Unstructured interview with Professional Experts in the field of ASD:** An unstructured interview was used to collect information regarding the topic of research. A one to-one interview method was employed. The participants were asked to express their experiences and observations regarding the treatments or intervention strategies for children with ASD. The major areas included in the interview were:

- Need analysis of a parent-mediated intervention program for children with ASD
- Feasibility and receptivity of such a program in our community
- Exploration of potential content and structure of the program

- Role of parents in dealing with children with ASD
- What pharmacological and non-pharmacological treatments are useful for children with ASD?
- The need for a comprehensive treatment protocol includes psychological interventions, speech and language therapy, occupational therapy, and special education services for children with ASD.
- Opinion about existing non-pharmacological interventions programs suitable for children with ASD

**c. Procedure:**

An initial list of multidisciplinary professionals having a minimum of 5 years of experience in the field of autism treatments was prepared from the available professionals in different hospitals and clinics in the nearby localities of Kozhikode and Malapuram districts. The names and contact details of the professionals were collected. The researcher either met the participants directly at their place of work or interviewed them over the phone as per their convenience. The purpose of the study and the objective of the current phase were explained to them. After obtaining consent [Appendix 1] for a one-to-one interview, the time and date of the interview were fixed on the basis of mutual convenience of the participant and the researcher. All the interviews were held in their consulting rooms. All the interviews were done on a one-to-one basis and in a single session. Before conducting the interview, a signature on the informed consent sheet was obtained. Each interview lasted 40-60 minutes. Researcher encouraged the experts to express their ideas as freely as possible and to include examples from their professional experience.

**Pilot Phase Data Analysis**

**Data Analysis of focus group discussion**

Content analysis was used to get the essence of the focused group discussion. Both quantitative and qualitative measures have been used. Frequency of responses, in terms of most preferred techniques to address the key factors relevant to ASD, was

taken into consideration for designing intervention. Participants who disagreed with or less frequently opted for techniques or psychological principles were also carefully noted down. The qualitative side of content analysis was used to understand the explanations participants gave for various questions, the mechanism of action of various strategies or tasks, and the areas of target they have suggested.

**Data analysis of Unstructured Interview:**

The collected data from multi-disciplinary professional experts was also analysed using content analysis. This analysis helped the researcher to identify the need for the proposed intervention program, and potential content, and structure it in a suitable way for our cultural context.

**Preparation of semi-structured interview schedule:**

Based on these sources of data, obtained through literature review and FGD with parents of children with ASD, and interviews with multi-disciplinary professionals, a semi-structured interview schedule to be conducted with stakeholders, including parents of children with ASD, and multi-disciplinary professionals, has been prepared [Appendix 3&5]. The major areas included need analysis, potential content, structure of the program, techniques to be used, major theoretical and intervention models to be incorporated into the program, and assumed feasibility and receptivity of the program.

Researchers chose to conduct a semi-structured interview for the exploratory phase of the main study since it was important to get free expression of their thoughts, emotions, and experiences. The overall areas to be covered and the width of data to be obtained were pre planned and the themes were kept in a sequential order based on logic and sensitiveness. Though the semi-structured interview mostly utilized open-ended and general questions, a few specific questions were also incorporated. These specific questions were in fact used as prompts when the client was unable to provide enough details. All the items were framed as neutral rather than value-laden. Jargons were carefully avoided to make questions easily comprehended by the participants based on their culture, language, and education. Each participant was encouraged to speak and provide maximum details.

## MAIN PHASE OF THE STUDY

The main phase was conducted in a sequential manner. It was further divided into three sections, as Stage-I: Exploratory stage, Stage-II: Intervention development stage, and Stage-III: Validation and fine tuning of the intervention program stage.

### Exploratory sequential qualitative method design

| | |
|---|---|
| Stage-I: Exploratory cross-sectional stage<br> | – Semi structured Interview with Parents of children with ASD<br>– Semi structured Interview with Multi-disciplinary Professional Experts<br>– Ranking of potential content list by selected participants from parents and professional group of stake holders |
| Stage-II: Parent Mediated Intervention (PMI) program design stage<br> | – Review of existing research in the field<br>– Analysis of commonly used techniques to address certain issues or skill deficits in children with ASD<br>– Triangulation of data<br>– Development of PMI program |
| Stage-III: Preliminary Evaluation Stage | – Stakeholder's and Expert validation of the developed program<br>– Clinical Pilot trial run of PMI |

***Figure 2.2: Overall design of the main study with its different stages***

## 1. STAGE-I: EXPLORATORY STAGE

**Purpose:** Phase one of the present study is designed to address the set I objectives. This would involve two parts conducted in parallel to explore stakeholder perspectives regarding the Parent-mediated training program. Perspectives of parents and professional experts were obtained through one-to-one semi-structured interview.

Details of the interviews are explained below.

The first stage of the main phase was carried out to explore and identify the potential content and structure of the program in order to attain the first objective of the study, which is to "*explore the perspectives of parents and professionals in terms of felt needs, feasibility, potential content, and structure of a parent-mediated intervention program for children with ASD."* It included the actual administration of the interview schedule into two sections for stakeholders, including parents and professionals, separately. After analysis of the obtained data, a potential content list was prepared, and the ranking of the potential content list by selected participants from parents and professional stakeholder groups was done. The relevance of this main phase stage-I was that the researcher wanted to contextualise the intervention to be designed.

**Section I: Interview with parents of children with ASD**

**a. Participants**

**Parents of children with ASD:** The population of the study consisted of the parents of children who have been diagnosed with ASD. 28 parents, including 8 fathers and 20 mothers, who have children with the primary diagnosis of ASD who met the inclusion criteria for the study were selected for the interview. The sampling procedure adopted here is purposive sampling. It is a non-probability sampling technique. It makes use of people who best suit the criteria of the research as well as those who are available and willing to participate in the study were chosen for the study.

**Sample Selection Criteria for Parents' Participants**

**Inclusion criteria for parents of children with ASD**

- Parents of children with a diagnosis of autism spectrum disorder
- Either the father or mother from a family
- Age range within 50 years
- Parents don't have any other major medical or psychiatric co-morbidities.

- Ability to speak, read and write in Malayalam

**Exclusion criteria for parents of children with ASD**

- Illiterate parents
- Parents who have children with ASD aged more than 14 years.
- Single parent
- More than one child has ASD in a family.
- Parents with significant psychiatric/medical illness

**Interview of parents' Participants' Composition**

- Number of interviews conducted: 28
- Total number of participants across interviews: 28
- Duration of each interview: 45-60 minutes

**b. Measures**

**Semi-structured interview**

It is a method most frequently used in social science research in which the interviewer asks more open-ended questions, allowing the interviewee to express their responses in a discussion manner rather than a linear question-answer format. The rationale for using semi-structured interviews was that the researchers wanted detailed and vivid data from the participants, which would reflect a clear picture of the parents' experience of having children with ASD.

**c. Procedure**

For the purpose of selecting participants for interview, parents of children who were diagnosed as ASD in CDMRP clinics and nearby clinics were contacted for permission or willingness to attend the interview. With the parents' giving consent, a total of 28 one-to-one interviews were conducted, using purposive sampling. Basic

socio-demographic data sheets [Appendix 3] were given to the participants, and they collected the filled forms prior to the interview. The researcher ensured the participants got enough time to open up and express their ideas freely and completely. For this reason, interview time was pre-fixed considering the availability and suitability of the participants' convenience. To build rapport, the interview started with small talk about some general matters. We gradually moved on with the semi-structured interview schedule probes prepared. Researchers encouraged the parents to give examples related to various experiences in order to get details and a clearer picture of the problems they were facing with having a child with ASD. Researchers validated their responses by rephrasing what they said. Though the interview schedule was used, it was not followed in a strict manner. The major themes of the interview were very clear and specific as far as the researcher was concerned. So, the schedule was kept as a guide only. Before winding up, the interview schedule was checked to make sure that all major areas had been covered. Each interview lasted 60–90 minutes, and all interviews were audio recorded with participants' permission.

**d. Data Analysis ***(data analysis is the same for Sections I and II, i.e., interviews with parents and professionals; thus, it is written after the procedure for professional participants).

**Section II: Interview with Professionals**

**a. Participants**

**Professional Experts:** The sample for this stage of study includes professionals who have been dealing with children with ASD for a minimum of 5 years of experience at least. The professionals included in this section were 10 clinical psychologists, 5 speech-language therapists, 3 occupational therapists, and 5 special educators.

**Professionals' participants Interview**

This would be done in order to achieve the Set I objectives-to explore the perspectives of mental health professionals regarding the felt needs, feasibility, and potential content and structure of a parent-based training program.

**Inclusion criteria for Professional Interview Participants**

- Professionals have a minimum of 5 years of experience in treating children with ASD.
- Ability to speak, read and write in Malayalam
- Preferably a native of Kerala or have stayed for at least a continuous period of 5 years in Kerala.

**Exclusion criteria for Professional Interview Participants**

- Professionals who don't fulfil the inclusion criteria
- Professionals who don't know Malayalam and do not belong to Kerala
- Foreign nationals

**Interview of professional Participants' Composition**

- Total sample size for the interview: 23
- Duration of each interview: 45-60 minutes.

**b. Measures**

**Semi-structured interview**

It is a method in which interviewer asks more open-ended questions, allowing the interviewee to express their responses in a discussion manner rather than a linear question-answer format. The rationale for using semi-structured interviews was that the researchers wanted detailed and vivid data from the participants, which would reflect a clear picture of the professionals' experience of treating children with ASD.

**c. Procedure**

The researcher compiled a list of professionals (clinical psychologists or rehabilitation psychologists, speech and language pathologists, occupational therapists, and special educators) who have a minimum of five years of professional experience working with children who have autism spectrum disorder. The researcher then approached

these participants in an effort to obtain their consent for a one-on-one interview. Those participants who accepted to participate in the study were chosen. In order to recruit people, we used a technique called purposive sampling. The professional participants were provided with basic data sheets [Appendix 4], and after filling out the forms, they returned them to the researchers before the interview began. The researcher made sure that the participants had adequate time to fully and openly share their thoughts and feelings without feeling rushed. Because of this, the interview time was scheduled ahead of time taking into account the participants' capacity to participate as well as their convenience. In order to get to know one other better, we began the interview with some light conversation about some broad topics proceeded forward progressively towards the semi-structured interview schedule that had been planned. In order to acquire more information and a more accurate depiction of how to intervene with children who have autism spectrum disorder (ASD), the researchers urged the experts to share examples relating to a variety of situations. The comments of the participants were verified by the researchers by paraphrasing what they stated. Despite the fact that the interview schedule was used, it was not adhered to in a stringent fashion. As far as the researcher was concerned, the primary topics that were discussed in the interview were crystal clear and highly detailed. Therefore, the schedule was simply preserved as a reference point. Prior to drawing to a close, the interview schedule was double-checked to make certain that all of the important topics had been discussed. Between forty-five and sixty minutes were spent on each interview, and the participants' consent was obtained before audio recording any of the interviews.

### d. Data Analysis* (section-I and section-II)

**Thematic analysis**

Recorded data was transcribed verbatim. Thematic analysis (TA) has been used to derive major themes. It is a widely used and recognized method in behavioral science and in the social and health sciences. It is considered to be a method for analysing the concepts underpinning the production of scientific knowledge (Holton, 1973). Thematic analysis varies to a great extent based on the nature and depth of analysis,

such as inductive thematic analysis, deductive thematic analysis, semantic thematic analysis, latent thematic analysis, descriptive thematic analysis, and interpretive thematic analysis. The Latent thematic analysis method is used here, which focuses on meanings that lie under the surface of data. So, the analysis brings out assumptions, frameworks, or world views that underpin semantic meanings. In latent thematic analysis, participants are not explicitly aware of the essential meaning of their expressions, but the researcher's interpretive work brings it out. The researcher went through the six phases of analysis as recommended by Braun and Clarke (2006), beginning with familiarization of data-reading and rereading transcripts and making notes of any initial analytic observations. After familiarization, coding has been done, which is the first step in identifying a common pattern in the data. Relevant factors in connection with the research question (felt needs, potential content, structure, assumed feasibility, receptivity of the intervention program) were identified and labelled. 'Searching for a theme' was the next phase, wherein the researcher clustered together the identified codes to generate a more obvious pattern in the data. It's not a simple 'discovery', but the recognition of the association and commonalities between the codes that constitute broader themes. After identifying the initial themes, researchers reviewed the themes to make sure that the candidate themes show a good fit with the coded data and the entire data set. Reviewing is also meant to evaluate whether the identified themes have a central organizing concept. As a result, certain themes were discarded, and necessary modifications were made. Next, key themes were defined and named. Selecting an appropriate theme name and defining it provided conceptual clarity. The final work was 'writing the report', in which the researcher associates together the analytic extracts of the data to make it a more comprehensive and integrated piece of knowledge. Analytic conclusions were generated from the pattern of themes. The major themes identified were later used for preparing the intervention module.

**Establishing validity**

To minimise the subjectivity in analysis and selection of codes, inter-rater coding was adopted. The transcribed data was given to 3 experts in research (Academicians in Clinical Psychology) and they were asked to code them independently and then these codes were compared for mutual agreements.

**Section-III: Ranking of potential content list by selected participants from parents and professional group of stake holders**

**Participants and Procedure:** In this section, 20 parents of children with ASD and 10 multidisciplinary professionals who are working in the field of children with ASD were approached over the telephone and mail. These selected participants were given a potential content ranking list [Appendix 6], with a list of 33 specific content themes being considered for inclusion in the PMI program. This list was prepared based on the nature of content-related suggestions given by the interviewed parents and professionals, and a review of relevant literature. This approach, participants indicated all the themes they considered relevant for inclusion and ranked the ten most useful themes from their perspective. The rankings by individual participants helped to elicit stakeholders' preferences on the entire range of themes being considered by the researcher, irrespective of whether or not these emerged in the interviews. They were also asked to give a score (1-5) for each selected theme, where '1' is the lower score and '5' is the higher score. This was used for the weighted score calculation. Consent was also taken from the selected participants to be approached at a later stage to obtain feedback and suggestions on the draft version of the PMI program.

**STAGE-II: DESIGNING OF THE INTERVENTION**

The purpose of this stage was to meet the second set of objectives of the study-that is to develop a parent-mediated intervention program suitable for children with ASD that can address the therapeutic management needs of children with ASD in their own home environment by parents under the direction of a professional therapist.

During this phase, the proposed parent-mediated intervention program was developed using the data from FGD with parents and unstructured interviews with professional

experts, and interviews with parents of children with ASD and multi-disciplinary professional experts, and the inputs from the literature review.

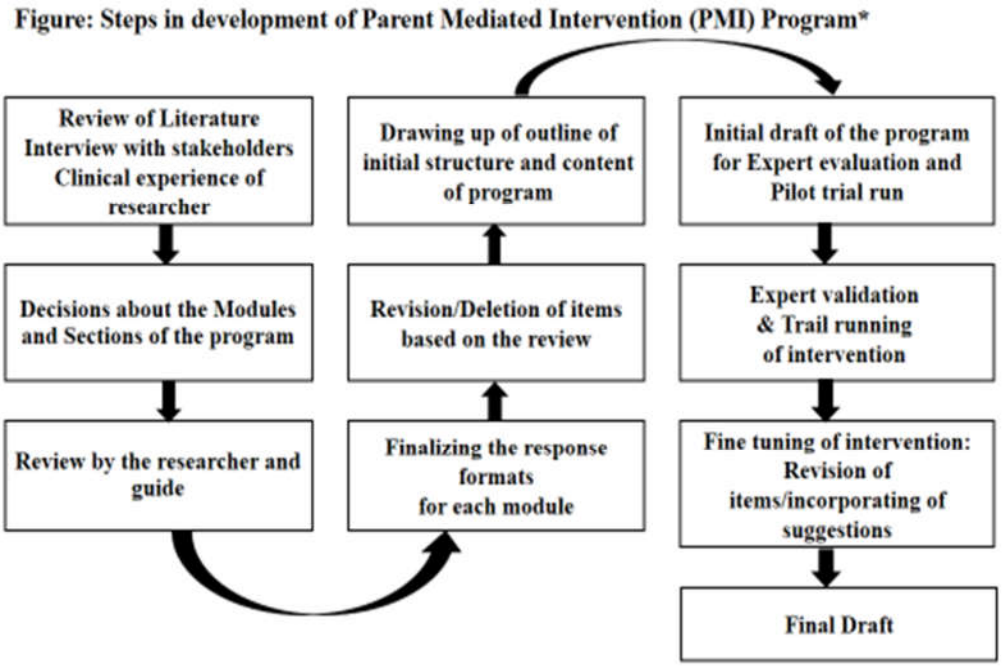
Literature analysis as a method was used here along with interview data. During this phase, using inputs from three different sources, such as 1) analysis of the common techniques used to address similar issues or problems, 2) literature review on existing interventions and management programs for ASD with special emphasis on parent-mediated intervention programs and the related theoretical foundations, and 3) data from the semi-structured interview with multi-disciplinary professional experts, the proposed intervention program was developed through the method of data triangulation.

Triangulation is a method of developing validity in qualitative research in which different sources of data on a common topic of interest are corroborated. "It enriches the understanding of a phenomenon by viewing it from different perspectives, rather than converging on a single, consistent account of the phenomenon" (Flick, 1992).

Consequently, it was examined by two sets of evaluators: 1) five parents and 2) six expert validators. The parent evaluators were selected from those who took part in the FGDs in the initial phase of the study as well as new parents those who enrolled in the CDMRP clinic was also contacted. All the participants who had given consent (during the initial FGD phase) were contacted, one by one. It was planned to include based on the convenience of parents, three participants each from two interviews conducted in pilot phase and main phase to maintain the diversity of the evaluators. However, out of the two interview participants, consent could not be received from more than 5 participants. Hence, two evaluators from the pilot phase interview participants and three of them from the main phase interview participants were included, making it five. The expert validators included five clinical psychologists with more than five years of clinical and community experience and holding doctoral level degrees with both research and training experience (six to ten years of experience) in the field of autism spectrum disorder. And further, two from each other professionals, like speech and language pathologists, occupational therapists, and special educators with more than five years of experience and expertise in using different therapeutic frameworks for children with ASD were included in the expert evaluators list. Evaluators were personally met, and the details of the study and designed intervention were provided.

After providing such an orientation regarding the study, a copy of the proposed intervention module was provided, and they were asked to evaluate it based on the intervention designing criteria. Experts had to verify whether the designed intervention meets the criteria, and they were also encouraged to provide suggestions. The details of this phase are discussed in the following sections. The following sources of data have been triangulated to ensure the validity of the intervention program.

The program development phase also included conduction of the newly developed program modules (hereafter referred to as pre-pilot runs) for parents of children with ASD, who comes for therapy for their child in CDMRP, this has been conducted not only to make the facilitator familiar with implementation process but also to get additional feedback from participants. The details of this section and the program developed are described in the following pages.




*****The details of the PMI program developed are presented in the Analysis and Discussion chapter.

***Figure 2.3: Steps in development of Parent Mediated Intervention (PMI) Program****

**Examine analysis of review as an approach**

The literature review may be termed a technique since the researcher performs a comprehensive analysis of the relevant current literature and determines the processes and tactics utilised to comprehend and address the problem at concern. Performing a literature review is analogous to conducting a research study, with the data collected by the literature reviewer reflecting the research findings (Onwuegbuzie et al., 2011). In accordance with this perspective, the researcher conducted a comprehensive literature analysis in order to collect information addressing two distinct topics. First, procedures often utilised to intervene the concerns comparable to those revealed in phase 1 of the primary study were discovered. Two, existent intervention programs for children with ASD and their theoretical basis were identified and listed.

**a. Analysis of existing theories and intervention techniques**

Before designing intervention, an extensive review of literature has been conducted on existing psychosocial interventions and ASD management programs. The most commonly used frameworks are educational, behavioral and teaching models. Among the behavioral interventions that are most extensively used, and frequently integrated techniques are: Antecedent Based Interventions, Self-Management, Functional Behavior Assessment, and Parent Implemented Interventions, etc. Each technique was examined in terms of mechanism of change, what they address, conditions in which they have been applied, indications and contraindications for use, mostly applied areas, and empirical data related to the applicability of techniques. On the basis of this, the techniques most suitable for addressing the factors to be included were carefully selected. The researcher's rationale for selecting them for the Parent Mediated Intervention Program for Children with ASD was matched with the rationale of the technique itself.

In a similar line, existing theories as explanatory models of autism spectrum disorder were examined to get familiar with the process behind them. Major theoretical frameworks explaining the relevant processes contributing to the maintenance as well as exacerbation of Autism symptoms are read in detail.

However, the primary data for designing interventions was the themes identified from the need assessment phase. The main themes that emerged from the data were self-help/adaptive behaviors, social communication, cognitive training, speech and language skills, behavioral management and parental counseling, and management of stress, etc. Each theme represents the broader areas to be intervened in. Hence, on the basis of identified themes, most applied techniques, and theoretical basis, 'Behavioral Based Interventions' has been chosen as the therapeutic framework for designing the intervention. The rationale for this is,

- There is a gap in literature on the application of Behavioural based intervention in a parent-mediated way for children with ASD.
- Behavioural Interventions were found to be very efficacious for ASD.

**b. Analysis of focused group discussion and interviews with parents and professionals**

Content analysis was used to get the essence of the focused group discussion. Both quantitative and qualitative measures have been used. Frequency of responses, in terms of most preferred techniques to address the key factors relevant to ASD, was taken into consideration for designing intervention. Participants who disagreed with or less frequently opted for techniques or psychological principles were also carefully noted down. The qualitative side of content analysis was used to understand the explanations participants gave for various questions, the mechanism of action of various psychotherapeutic techniques they have suggested, etc.

**c. Researcher's own clinical experience**

The researcher had more than eight years of experience in managing and intervening with children with ASD. As part of the two-year training in M.Phil. in clinical psychology, researchers got training in dealing with and intervening in a wide variety of psychopathologies, ranging from all developmental disabilities, various neuropsychological conditions, anxiety spectrum, psychotic disorders, mood disorders, personality disorders, and addiction, as well as general medical conditions. As part of the academic side of the training program, researchers had to formulate

cases using different theoretical models, such as psychoanalytic, behavioristic, cognitive, humanistic, and bio-psychosocial, etc. Apart from this, the research was exclusively involved in developmental disability evaluation, management, and rehabilitation with a special focus on children with ASD at the Community Disability Management and Rehabilitation Program (CDMRP) jointly conducted by the Social Justice Department, Government of Kerala and the Department of Psychology, University of Calicut. The researcher worked as a Disability Management Officer (Consultant Clinical Psychologist) for about 3 years and 8 months and got immense opportunities in research, training, and conducting a wide variety of therapeutic interventions for children with various developmental disabilities. These factors helped the researchers to design the intervention program by corroborating both theory and therapeutic techniques. This foundation shaped the design of the intervention in the following ways.

**Designing of the Program**

The parent mediated intervention program was designed using data gathered from the focused group discussions, interviews with the health professionals, and from the review of relevant literature on the topic. The designing of the program would be done in such a way that, from the planning stage through the delivery of the program, the parents themselves would be actively involved. As the data obtained from the FGDs is used, the perspectives of parents about programs intended for them are expected to be fully reflected. Also, as the basic framework of the program was taken into account, the perspectives of yet another important stakeholder in the lives of parents of children with ASD – mental health professionals. This is because the support from the different therapists is considered important for implementation of the program.

**Tentative Program Structure**

It is designed as a series of sessions delivered in individual or group format (specific number of individual or group sessions to be finalized after program design). The tentative plan is to have a single introductory session for all the participants if a group of participants registers, otherwise a one-to-one, two-hour long session will be conducted as an initial session. Following this, a baseline assessment will be

conducted for individual participants separately (based on convenience; an attempt will be made to finish the assessment in one week). Following this, it is planned to have 15 sessions of about 1-2 hours duration each, once every week. This would help in completing it within a 3–4-month period.

The sessions would be based on pre-selected themes and involve small didactic input along with extensive opportunities for learning about and engaging with the themes through multiple activities and exercises drawn from literature review of different therapeutic models and FGD and interview data. Each session would be structured such that the parents can apply this to their children for the next one-week period.

**Guidelines for Developing Program Content**

The following guidelines were used for development of the program content:

1. Relevance to children diagnosed with autism spectrum disorder.
2. In synchrony with the felt needs ascertained during the initial phase.
3. Based on the available theoretical and empirical literature on interventions for ASD,
4. Feasibility and ease of delivery by non-professional parents with minimal orientation and training in the field.

**Tentative Program Content**

The tentative contents for the present program covered various themes under the broad frameworks of psychoeducation, communication, fine motor, adaptive behaviours, and management of behavioural issues. Various themes and sub-themes under these broad frameworks for the present program were finalized after the focused group discussions and interviews with health professionals.

**Finalization of Assessment Tools**

The program design phase would also include finalization of the assessment measures (for baseline and post assessment in stage 3) as well as feedback and report forms to be used during the program implementation.

**Finalisation of the first draft of PMI**

During this phase, the document was finalised in preparation for the validation procedure. Included in the final document were all revisions proposed by the guide, co-guide, and specialists.

**Validation of the Program**

**Purpose:** The final phase of the present research is designed to achieve the Set 3 objectives of the study. It would assess the feasibility and receptivity of the parent-based training program through a pilot trial and would also assess the changes in the training contents with parents and experts rating.

The validation phase would entail a parent participants and professional expert's rating of the program on each aspect of the developed parent-mediated intervention package.

**a.** **Participants:** Parents of children with ASD and professionals who have 5-9 years of experience in dealing with children with ASD participated in the potential content ranking list.

**Sample Size:** 5 (parents), 6 (professionals)

**Sampling Procedure:** Multistage random sampling from the parents and professionals participated in ranking of potential content stage were shortlisted and lottery method of random sampling was adopted to choose the validators.

**Sample Selection Criteria of Parents Evaluators:**

**Inclusion criteria**

- Parents of children with a diagnosis of autism spectrum disorder
- Either the father or mother from a family
- Age range within 50 years
- Parents don't have any other major medical or psychiatric co-morbidities.

- Ability to speak, read and write in Malayalam

**Exclusion criteria**

- Illiterate parents
- Parents who have children with ASD have more than 15 years.
- Single parent
- More than one child has ASD in a family.
- Parents with significant psychiatric/medical illness
- Foreign nationals

**Sample Selection Criteria of Professional Evaluators**

**Inclusion criteria**

- Professionals have a minimum of 5 years of experience in treating children with ASD
- Ability to speak, read and write in Malayalam
- Preferably a native of Kerala or have stayed for at least a continuous period of 5 years in Kerala

**Exclusion criteria**

- Professionals who don't fulfil the inclusion criteria
- Professionals who don't know Malayalam and do not belong to Kerala
- Foreign nationals

**Sample Selection Procedure for the program validation**

**Sample selection criteria of parents' evaluators:** The parent evaluators were selected from those who took part in the ranking of themes in the initial stage of the

study. All the participants who had given consent [Appendix 7] (during the ranking time) were contacted, one by one. By using multi-stage random sampling method (lottery) 5 participants were selected to maintain the diversity of the evaluators.

**Sample selection criteria of professional evaluators:** by using multi-stage random sampling technique, 3 experts from clinical/rehabilitation psychology and one expert from speech and language therapy, Occupational Therapy, and special education were approached, and consent was obtained [Appendix 7].

The investigator would meet or contact over the phone each participant (parents & professional experts) and give them the designed program and a validation form [Appendix 8&9] prepared to them and fill it in and collect and analyse the data.

**b. Measures used**

Validation form prepared by the researcher

**c. Validation Procedure**

Towards the beginning of third phase, after preparing a draft of the program, a preliminary content validation of the program was conducted. The objective of this would be to facilitate the fine tuning of the program. This would help in making further changes in the structure and content of the program, if any are required. The validation would be done by two separate groups of evaluators. The validation would be conducted by a team of 5 parents, selected randomly (lottery method) from those ranking of theme participants who provide consent to be re-approached for this purpose. The program content was shown and discussed with each of them independently in a single session and their feedback and suggestions were documented. A similar exercise was conducted with a panel of three experts from the field of psychology/mental health, each from speech and language therapy, occupational therapy, and special education, with at least 5-9 years of experience working with ASD. After the validation from both groups, the suggested changes were made to the program content.

### d. Data Analysis

Content analysis was used to get the essence of the validation of the PMI Module. Both quantitative and qualitative measures have been used. The frequency of responses, in terms of most preferred and rated techniques to address the key factors relevant in ASD, was taken into consideration for refining intervention. Participants who disagreed with or less frequently opted for techniques were also carefully noted down. The qualitative side of content analysis was used to understand the explanations participants gave for various questions and the mechanism of action of various psychotherapeutic techniques they suggested. Hence, the completed validation forms were thoroughly analysed. Each module rated by the experts was analysed, and the total frequency was calculated.

## STAGE-III-PRELIMINARY EVALUATION OF THE DESIGNED PROGRAM

## CLINICAL TRIAL RUN OF THE INTERVENTION

Purpose: The third and final stage of the present research also involved the clinical trial run of the developed intervention program. The PMI program pilot trial involved a pre-post design. Clinical trials are experiments or observations conducted with the specific goal of determining the efficacy and/or feasibility of biomedical or behavioural therapies. Clinical trials that are well planned increase the validity of the data and also assist the researcher in making clinical judgments and facilitating practise (Thorat et al., 2010). The methodological, procedural, and clinical issues were resolved, and the intervention was fine-tuned as a result. Prior to initiating the intervention, a thorough case analysis of the participants was conducted.

### Case analysis

Case analysis is a qualitative research method to obtain in-depth analysis of a person or phenomenon. As an idiographic method it allows researcher to explore in depth about a topic of interest. This provides understanding about the interaction and influence of various psychological processes within person. Case analysis makes use of interpretive phenomenological analysis, text interpretations, grounded theory etc.,

for analysing the elicited data (Hayes, 2000). From the clinical point of view case analysis allows not only an exploration of a phenomenon, but also provides information for diagnosis and treatment. Current research used case study method because of following reasons:

Before delivering an intervention a clear understanding about the participant was required in terms of presenting complaints, history of present condition, history of developmental milestones, behavioural patterns, significant events in childhood, associated or comorbid conditions if any, how the condition affected the child and their parents, etc.

Having an in-depth knowledge about the child with ASD would facilitate customization of the designed PMI program (based on the assumption that, as individual difference would be considered before implementing any intervention program).

**a. Participants**

Initially, four cases having a diagnosis of ASD were selected. All the four cases were analysed in detail to make sure about the possibility of participation. Among the four, one participant expressed the difficulty of attending sessions due to personal reasons (the other child's illness) among the three, one participant dropped out after the first session, and the final sample composition consists of two children with ASD and not on any other interventions. Both the participants were male children who were diagnosed with ASD. All the participants matched the inclusion and exclusion criteria of the study. Convenient sampling was used as it allows the researcher to include people who are willing and available to participate.

***Selection of the program participants:*** After finalization of the intervention module based on the expert validation, it was decided to do a pilot trail on two clients in order to further fine tune the intervention and also to understand the feasibility and receptivity of the newly designed intervention program. The researcher approached the parents of children with ASD those who are taking intervention in different clinics in Kozhikode and Malappuram districts with the help of the multi-disciplinary

professionals participated in the study. As soon as people who were given consent for the pilot trial of the proposed intervention, researcher started taking session on one-to-one basis. Master session were conducted bi-weekly.

***Inclusion criteria*:**

The following inclusion criteria were used for inclusion in the pilot trial of the newly developed program.

- Parents of children with ASD between the ages of 3 and 15 who have been diagnosed with autism according to ICD-10 criteria (WHO, 2012) by a clinical psychologist.
- Either father or mother from a family, with age range within 50 years for parents
- Parents don't have any other major medical or psychiatric co-morbidities
- Children with ASD without any comorbidities other than Intellectual disability
- Ability to speak, read and write in Malayalam

***Exclusion criteria*:**

The following exclusion criteria were used for exclusion in the pilot trial of the newly developed program.

- Children with comorbid neurological disorders were excluded
- Children receiving structured behaviour-based therapy along the same lines from any other place at the time of the study.
- Illiterate parents of children with ASD
- Parents who have child with ASD age more than 15 years and less than 3 years
- Single parent
- More than one child having ASD in a family

- Parents with significant psychiatric/Medical illness
- Children with ASD with any comorbidities other than Intellectual disability
- Foreign nationals

***Sample size:*** The sample size of the program pilot-trial was five children with ASD fulfilling the inclusion criteria (N=2), who were recruited on a giving consent at first-cum-first-serve policy.

The children's parents completed an informed consent form [Appendix 10] accepting the use of diagnostic and intervention data for study. Researchers did not collect any fees for delivering therapeutic intervention to the participants, nor did parents get any monetary compensation for participating in the study.

**b. Measures used**

As part of case analysis, the following measures were incorporated.

**Basic socio-demographic data with Case History:** This data sheet was developed by the researcher to be used in the PMI program pilot trial. It included all socio-demographic details of the participants. Apart from this which included the standard case history format containing is a detailed history about the condition as well as about the child. It encompasses details about the onset, duration, and impact of ASD on the participant. Psychosocial aspects refer to the life history of the person such as information relevant at her childhood, birth history, family dynamics, history of medical or psychiatric illness, social adaptive functioning, etc. [Appendix 11].

**Behavioral Observation/Mental Status Examination:** It describes the mental state and behaviour of the child. A clinician assesses various domains such as mood/affect, behavior, cognitive functions that has been seen in the client. It includes both objective observations made by a clinician or investigator and subjective details provided by the client [Appendix 12].

**Assessment of social adaptive functioning of the child:**

**Vineland Social Maturity Scale (VSMS):**

Social quotient was assessed by Malin's Vineland social maturity scale for 0-15 years consisting of 89 items, by the interview with a parent or other primary care giver. Social skills were evaluated in the following areas:

- Daily living skills (general self- help, eating, and dressing),
- Communication (listening, speaking. writing),
- Motor skills (fine and gross, including locomotion),
- Socialization (interpersonal relationships, play and leisure, and coping skills),
- Occupational skills, and Self-direction.

Raw scores are converted to an age equivalent score (expressed as social age) and a social quotient. Social Quotient was calculated using formula: Social age / Actual age x 100.

SQ less than 85 was considered as impaired social maturity [Appendix 13].

**Assessment of severity of Autism:**

**Indian Scale for Assessment of Autism (ISAA):** Indian Scale for Assessment of Autism (ISAA) was used for assessing the severity of autism. ISAA rates autism in six domains: Social relationship and reciprocity; emotional responsiveness; speech, language, and communication; behavior patterns; sensory aspects; and cognitive components. Items are rated from 1 to 5 and take about 15–20 min to administer [Appendix 14].

**Visual Analogue Scale (VAS):** It is a measurement instrument that helps to measure a characteristic or attitude that is expected to range across a continuum of values and can't be measured directly, and it is one of the most extensively used measures of the intensity of symptoms in clinical research (Wewers & Lowe, 1990). VAS is

specifically used in research on the effectiveness of any health intervention in which a correlation between parental perception of improvements (using VAS) and objective measures of skill behaviours on psychometric tools can be established (Gupta, et al., 2000; Sponheim et al., 2002). In the current study, VAS was used at two points; one at the beginning of the first session and another at the end of the final session. Participants were asked to rate their perceived attainment of various dimensions of the target areas, such as knowledge about autism spectrum disorder, reduction in problem behaviours, management of behavioural issues such as tantrums, skills of activities in daily life of a child, interaction or communication skills of the child, and fine motor skills, on a 0–10 visual scale, where 0 indicates the least level of attainment of the target dimensions and 10 indicates the highest level of attainment. A visual analogue scale differs from a normal numeric scale in such a way that the scale used in the former takes a visual form (like a printed geometric scale), whereas in the latter, the participants are asked to assign a number to rate a specific attribute [Appendix 15].

**Assessment of Knowledge about ASD:**

An MCQ of 10 questions to quantify the knowledge of parents on various aspects of ASD like definition of autism, cause, presentation, course, prognosis, and treatment of ASD, was utilized and administered before and after presentation of module [Appendix 16].

**Feedback form:** A session feedback form of PMI program was used to obtain ratings on the following dimensions: 'personally relevant,' 'interesting,' 'motivated to take actions,' 'want to tell others,' 'have confidence to apply what I learned,' and 'well organized.' Open-ended items were used to elicit the most liked aspects. At post-assessment, salient learnings from the program and the most inspiring aspects of the program were inquired into through two open-ended items. At one-month follow-up, in addition to the above, an 11-item Likert-type survey was used to tap the perceived impact of the program participation. The survey included items covering the impact on both Child's and parents' domain. Another item documented whether the

participants have suggested someone in their family/social circle to this PMI Program [Appendix 17&18].

**PMI Feedback form (one-month follow-up):** The same feedback form used during post assessment of pilot trial run [Appendix 17&18] with minor modifications were used for this purpose.

**Setting**

The research was carried out in both home and therapeutic settings. In the therapeutic context, the baseline and post evaluations of the PMI, as well as the sessions for parents focusing on parental outcomes in the PMI and teaching on presenting modules to the child, were done individually. In accordance with the therapist's instructions, the parents conducted PMI sessions at home. In treatment, the therapist monitored the child's development every two weeks.

**c. Procedure**

Stage three of the main phase was the clinical trial run of the designed intervention. The purpose of this was to assess the feasibility and practicability of the intervention while actually implementing it on people. Informed consent was obtained from the parent, which ensures the parent/caregiver about the confidential nature of participation and nature of research. Parent/caregiver read the consent form carefully and signed it to record his/her willingness to participate. Before beginning the training program, a session was provided to orient the parents about the PMI program. Nature of intervention, what parents is expected to do, what therapist would be doing, how long sessions would last were explained and parents were encouraged to clarify their doubts if any. A detailed case history and mental status examination or behavioral observation was done, along with psychological assessments of autism severity and social adaptive functioning of the child which provided information for the baseline, along with that participant were asked to complete the rating on VAS and self-report of the participants on their awareness, knowledge about ASD were estimated.

To obtain data for the research, the Indian Scale for Assessment of Autism and Vineland's Social Maturity Scale were administered individually to each child to

establish a baseline for each child's problems and behavioural symptoms. The parents/caregivers were included as the informants for the data collection. Consistent with the ethical criteria governing such investigations, informed consent was obtained, and anonymity of responses was ensured. After the baseline data were collected, the PMI looked at two children with ASD for its preliminary evaluation.

As a part of preliminary evaluation, based on the selected children's deficits areas few objectives were short listed covering different skills (social adaptive skills (skills required for activities of daily living), basic communication skills, and fine motor functioning skills) and problem behaviour for each child. Apart from this Psychoeducation (parental goals of improving knowledge about ASD and reduction of stress among caregivers) were also covered. For attaining reduction of problem behavior module, instances detailing what occurs "before," "during," and/or "after" the occurrence of problem behaviour were elicited. It was recorded how often, for how long, with whom, where, and when problematic behaviours happened in both home and school contexts. This detailed mapping served as the foundation for the development, planning, and programming of a module addressing problematic behaviours in children with ASD (Behavioral Intervention) based on Antecedent-Based Intervention (ABI) approaches. Same way skill behavior were estimated based on the case history, behavioral observation, test findings of ISAA and VSMS. The intervention was carried out in a home set up by the parents or caregiver, whereas the researcher met the parent/ caregiver every week and child in every bi weekly to monitor the development and to decide whether any modifications in treatments are necessary or not. In addition, each enrolled parent received verbal and written instructions on how to instruct their child in the selected target behaviours or manage problem behaviours, as well as simple or pragmatic record keeping procedures, behavioural techniques to be implemented, bibliotherapeutic materials, reward or incentive systems to be used, etc. Teaching aids/materials relevant to the chosen behavioural objectives were exemplified. Written instructions accompanied the verbal explanations such that record keeping was simple, pragmatic, direct and immediate during home training. There was at least one follow up in every week ranging for a period of one to three months. The entire intervention was implemented across 10-20

structured sessions for the selected two cases. The behavioral achievements of each child were recorded during every follow up along with information on items not achieved or those marked as “ongoing” activities for further training.

As in the pilot trial stage, the chosen two children got PMI from their parents for a minimum of two hours each day for two to three months. A program feedback survey was taken on the day following the post-assessment to reduce respondent burden and due to time constraints. A modified version of the same survey, with additional questions, was used to assess the program impact after one-month. Two months after the completion of the pilot trial, a follow-up assessment was also done. The feedback survey and the follow-up assessments were done online, using Google Forms, where the link was sent to the participants over the WhatsApp. This reduced several practical and logistical barriers (e.g., time constraints). Further, using online means for assessment and communication, in general, was very much accepted by the participants.

**d. Analysis of qualitative measures**

The method of "content analysis" was used to analyse qualitative measures used in study. Researchers used this strategy to extract meaningful insights from the disparate data that was collected from the individuals. In addition to this, the frequent feedback that parents provide was also subjected to a primary analysis to comprehend the pattern of difficulties that parents experience over the duration of the intervention. In addition to this, a personal perspective of the investigator was supplied on the delivery of the intervention. This reflection included topics such as the process assessment, internal and external facilitators and obstacles impacted, deviation of adherence, etc.

**Ethical Considerations**

- Written informed consent was taken from all participants at various phases of the study.
- Confidentiality of the individual-specific data on measures obtained during the baseline and post/follow up was maintained.

- It was informed that the data collected for the purpose of the present study will not be used for any other purpose without prior written permission from the participants.

- Audio recording of the one-to-one interviews and FGDs were carried out after obtaining separate written consent for the same. Those unwilling for audio recording will not be excluded from the study, except in case of focus group discussions.

- The participants were also be informed about the freedom to withdraw from the study, at any stage, without providing any reasons for doing so.

- Participants were informed that there would not be any tangible benefits for participation in the study.

- In case of any of the participant needing any clarification regarding the research at any point of time, the participants were assured of the availability of the investigator and the means of contacting him/the research supervisor were also be provided.

- Any participants requiring or seeking any form of psychological help or intervention were provided referral related guidance.

## CHAPTER SUMMARY

This chapter is about how the study was carried out through different sequential phases using specific methods, measures, procedures, and analyses. The current study was conducted as two broad phases: a pilot phase and a main phase. The pilot phase includes all the preparatory work done prior to the main study, such as analysis of reviews and meetings, and conducting a FGD with parents of children with ASD and an unstructured interview with professional experts to get a preliminary understanding regarding the need for analysis, potential content, and structure of a proposed parent mediated intervention program suitable for children with ASD. On this basis, a semi-structured interview schedule was prepared to be conducted with both parents and professional experts. The main phase consists of 3 sequential stages, designed as

stage-I, stage-II and stage in stage-I, a semi-structured interview was conducted with parents of children with ASD and professional experts in the field of ASD. The audio recorded responses from the interview were then transcribed. The researcher then read the interview transcripts several times to increase familiarity with the data. Thematic analysis was used to analyse the data. Initial codes were generated by using the interview probe as the frame of reference. Following the generation of the initial codes, broader categories were identified and grouped under different themes. During analysis, responses to some probes were combined, considering significant overlap in the information provided. The initial codes and the themes were cross-checked by the supervisor to ensure the accuracy of the analysis process. The themes identified from the analysis of the interview data were used in the program development phase for planning the content and structure of the PMI for children with ASD. Based on this, techniques empirically and theoretically proven as effective in addressing these identified themes were carefully selected by the researcher. For which, ranking of potential content lists by selected participants from parents and professional groups of stakeholders was also done at this stage. A total of twenty parents of children with ASD and ten multidisciplinary professionals were interviewed. They were given a list of 25 specific content themes being considered for inclusion in the PMI program. Participants indicated all the themes they considered relevant for inclusion and ranked the ten most useful themes. This was considered one of the sources of data for triangulation carried out in stage-II. Stage-II was done to design the intervention, for which data from multiple sources was triangulated to ensure the validity of the proposed intervention. As part of this, an interview was conducted with multi-disciplinary professionals, for the purpose of exploring the possible content and structure of the proposed intervention. Content analysis was used as an analytical strategy. As a third source of data, an extensive review of existing interventions and techniques for management and skill training strategies for ASD was done, and the theoretical basis was also carefully considered. On this basis, an initial draft of the intervention was prepared. In stage-III, the developed intervention was given for expert validation and a clinical trial run of the developed program on two participants. Furthermore, fine tuning of the intervention was done based on the remarks and suggestions given by experts on the developed program as well as insights from the pilot trial run of the intervention program.

# CHAPTER III
# ANALYSIS & DISCUSSION

# ANALYSIS & DISCUSSION

The inferences of the present study are organized under three broad headings, corresponding to the three main stages of the study.

- Stage I: Exploratory cross-sectional stage (Objective Set I)
  - Section I: Interview with parents of children with autism spectrum disorder
  - Section II: Interview with Professionals
  - Section III: Ranking of potential content list
- Stage II: PMI Program Design Stage (Objective Set II)
  - Section I: Design of a PMI program
  - Section II: Program Validation through experts and parents rating
- Stage III: Preliminary Evaluation
  - Section I: Clinical Pilot trial run of PMI

This chapter discusses the findings drawn from the research in light of the current empirical and theoretical data. Since the present study was conducted in two sequential phases, with multiple stages in the main phase of the study, each of which used different tools for data collection and analysis, results obtained from each of these stages will be discussed in a similar manner, beginning with the results from the pilot phase and continuing through the main phases of exploration of stakeholders' perspectives on the perceived needs, potential content, feasibility, and receptivity of the proposed PMI program and development of the intervention, and concluding with a clinical pilot trial run of the designed intervention. Inferences drawn from the pilot phase of the study are very briefly stated but are substantially incorporated into the main phase of the study. The majority of the "verbatim responses" from research

participants were included in the analysis and discussion since this material interacts with the intended audience more effectively.

## PILOT PHASE

The pilot phase of the study aimed to collect preliminary data that would aid in the development of a parent-mediated intervention program for children with autism spectrum disorder. A review of the literature in this area was conducted in order to collect and understand empirical studies pertaining to parent-mediated interventions for autism spectrum disorder. Additionally, a focused group discussion with parents and an unstructured interview with professionals were conducted as additional sources of data. Combining these three sources of information provided the researcher with a preliminary understanding of the proposed programs' perceived need, potential tasks, and contents to be included in the program, potential hurdles that may arise during subsequent phases of study, and overall, this further familiarises the researcher regarding the scope, benefits, and identifying obstacles associated with developing and implementing such a program successfully.

These data were used to create a semi-structured interview schedule for the research's main phase.

### 1. Analysis of previous research studies

The reviews of empirical studies indicate that the following skills or deficits have been most extensively intervened upon and that parent-mediated interventions have resulted in improvements in those areas. They include the following:

- Child’s attention, communication, social skills, and behaviour (Juneja, 2012)
- Amelioration of severity of autism symptoms, and acquisition of social skills, receptive language, and expressive language (Nair et al., 2014)
- Socialization, communication and behavioural problems in children and PMIs impacts on parental stress and knowledge about ASD studied and found it helping in positive ways. Parental outcome: enhance self-reflection, an increased ability

to project beyond here and-now, and sense of empowerment that stems from better understanding of ASD along with better behaviour management skills in parents (Brezis et al., 2015).

- Positive impact on the child's communication, understanding of play and social skills, better communication intent, respond constructively to social cues and simple activities of daily living (Louis et al., 2015).

- Home based intervention techniques for improving socialization, communication, and behavioural problems (Patra et al., 2015).

- It is feasible to provide an effective parent mediated early intervention for mild to severe autism they improve developmental age significantly develops play behaviours decreases symptoms of autism improves other abilities like perceptual-Fine-motor, cognition, language, social/emotional skills (Krishnan et al., 2016).

- Feasibility of adapting and task-shifting an intervention used in a high- income context to low- and middle-income countries (Rahman et al., 2016).

- Large treatment effects on proximal outcomes of proportion of parent synchronous responses and proportion of child communication initiations with parent; mutual shared attention and co-morbid symptoms and further helps to improve parental mental health (Divan et al., 2019).

- Reduction of hyperactivity, motor- stereotypies, auditory sensitivity in those who underwent sensory interventions. Home-based sensory interventions feasible in developing country and suggested to beneficial role in ASD (Padmanabha et al., 2019).

- Children showed significant improvement in relating to people, imitation skills, visual response, and overall autism severity. Parental outcomes: reported more improvements across parental stress (Manohar et al., 2019).

- Improvement in children's social communication skills. Parental outcomes: urban Indian parents found the intervention feasible and acceptable, were able to

demonstrate the strategies taught and perceived. Parental outcomes: In addition, parent stress levels decreased after completion of intervention (Sengupta et al., 2020).

- Improvement in child's social communication skills, social engagement, expressive language, understanding directions and social imitation, play skills. Parental outcomes: Many parents perceived enhanced sense of confidence in their abilities to understand and support children's skills, across situations and settings (Sengupta et al., 2021).

- Improved developmental outcomes on communication, social interaction adaptive behaviours. Parental outcomes: improved caregiver skills knowledge, reduction in stress (Sengupta et al., 2021).

**2. Focused Group Discussion with parents**

The pilot phase of the study also included focus group discussion with parents' group of stakeholders. The purpose of the FGDs was to explore their perspectives regarding felt needs, scope and challenges of the PMI program, and potential contents or task to be included and to know the perceived hurdles for implementing a Parent mediated intervention program.

**3. Unstructured Interview with Professional Experts**

The pilot phase of the study further included unstructured interview with the multi-disciplinary professionals. They provided an experiential data which portray how multi-disciplinary intervention work for children with ASD, they also expressed their experience regarding parents' expectations, therapy adherences, compliances to the homework assigned, regularity of attending sessions, possible hurdles they face during intervention process, frequent reasons for poor therapeutic compliance or drop out, etc. Further, severity of ASD and time taking to see changes, stigma and other related problems faced by the parents. Perspectives about the parent assisted interventions for children with ASD. How the symptoms manifest in clinical presentations and interfere with the management. The significant responses which

have been considered as a background data for the preparation of semi-structured interview schedule are:

The information gathered through the analysis of the review of literature and focused group discussion with parents was combined with expert interview data and used to develop the semi-structured interview schedule for the main phase of the study; ultimately, these findings aided in the development of the proposed PMI.

**MAIN PHASE**

**STAGE-I: EXPLORATORY CROSS-SECTIONAL STAGE (OBJECTIVE SET - I)**

The first phase of the study aimed to explore the stakeholder perspectives (parents and professionals) in terms of felt needs, feasibility, potential content, and structure of a parent mediated intervention (PMI) program.

**Section I: Interview with Parents**

One-to-one, semi-structured interviews were carried out in the first phase of the study for exploring the perspectives of parents regarding felt needs, feasibility, potential content, and structure of a parent mediated intervention program suitable for children with ASD.

Table 3.1

*Interview sample details (N=28)*

| **Variables** | | **Freq.** | **%** |
|---|---|---|---|
| Gender | Male | 8 | 29% |
| | Female | 20 | 71% |
| Average age of participants | Mean (38.3) | Sd* (4.5) | |
| Education | Up to intermediate | 10 | 36% |
| | Graduation & above | 18 | 64% |
| Socio Economic Status | Lower | 10 | 36% |
| | Middle | 13 | 46% |
| | Upper | 5 | 18% |

*Standard deviation

As shown in Table 3.1, there was a higher proportion of female participants in the interview sample compared to male participants. An average interviewee age was 38 years with 4.5 (SD). More than half of the interview participants were graduates or above in educational qualification, only 36% of participants were educated up to intermediate level and 64% were graduate or above educated. Majority of the participants belongs to middle socio-economic strata of the society.

**Felt needs and potential benefits**

Table 3.2

*Interviewee opinion on the felt needs and potential benefits of a PMI program for children with ASD (N=28)*

| **Need for a PMI program specifically for Children with ASD** | **Freq.** | **Percentage** |
|---|---|---|
| Certainly Needed | 9 | 32.1% |
| Needed | 16 | 57.1% |
| Mandatory | 2 | 7.1% |
| Not sure/probably good | 1 | 3.6% |

Table 3.2 shows the opinion of the interview participants on having a parent mediated intervention program specifically for children with ASD. The interview participants were asked whether there was a need for a specific parent mediated program for children with ASD, considering there are several intervention programs available for developmental disabilities including ASD, which may help their development and improve the overall functioning.

A majority (57.1%) of the interviewees believed that a parent mediated intervention program specifically focusing on children with ASD was needed. Among those who said it is certainly needed (32%), five emphasized further, saying such programs are '*very much or unquestionably needed*.' For example, one opined that *"...parents know their children better way... it (PMI programs) is needed because we have always been neglecting the role of parents in the development and growth of their children"*. Another interviewee expressed the need saying that *"there is a definite need for*

*parental involvement… therapeutic service is not enough to improve overall functioning of the child especially their self-help skills, communication and overall cognitive or intellectual capacities of our children"*. Two participants (7.1%) expressed that PMI programs need to be made mandatory (*"It should be mandatory… children with ASD many at times are not getting needed care and support from their parents. Most of the parents provide therapeutic help which is mostly insufficient. Getting thirty minutes of intervention once in a week and getting trained daily at their home environment makes drastic difference. If the treatment program, make sure parental involvement. This can make the child's change or development in the right direction with optimal improvements- that is important*).

One of the interviewees reported being unsure about the need for a PMI program specifically for children with ASD (*Not sure about the need for a specific program for children with ASD- as not having a personal experience about dealing or treating children with ASD. how a no- professional person can provide training to own child in real-life situations- as it is not just making them play at home*).

**Potential Content**

Table 3.3

*Suggestions for potential content of the proposed program (N=28)*

| **Response:** Potential content suggestions | | No. of interviewees suggesting the theme | | |
|---|---|---|---|---|
| **Main Themes** | **Sub-themes** | **Freq.** | **Percentage** | **Main Themes Percentage (Average)** |
| Social Adaptive Skills | Toileting skills | 20 | 71% | 62% |
| | Brushing skills | 17 | 61% | |
| | Self-eating skills | 17 | 61% | |
| | Self-dressing skills | 17 | 61% | |
| | Bathing skills | 15 | 54% | |
| Basic Communication | Says or indicates basic needs | 16 | 57% | |
| | Basic requests | 12 | 43% | |

| | | | | |
|---|---|---|---|---|
| skills | Knowing basic words | 11 | 39% | 28% |
| | Initiate conversation | 9 | 32% | |
| | Smiling at others | 7 | 25% | |
| | Shake hand | 6 | 21% | |
| | Interact with others | 5 | 18% | |
| | Reduce repetitive talks | 4 | 14% | |
| | Sharing with others | 2 | 7% | |
| Reducing problematic behaviors | Reduce inappropriate behaviors (removing dress in public, etc.) | 6 | 21% | 14% |
| | Harming self and others | 5 | 18% | |
| | Impulsivity | 4 | 14% | |
| | Reduce repetitive behaviors | 4 | 14% | |
| | Demanding behaviors | 3 | 11% | |
| | Temper tantrums | 3 | 11% | |
| | Disobedience | 2 | 7% | |
| Basic learning skills | Identification of letters | 4 | 14% | 13% |
| | Identification of numbers | 4 | 14% | |
| | Basic calculation | 4 | 14% | |
| | Basic copying | 3 | 11% | |
| Fine motor skills | Holding objects | 7 | 25% | 17% |
| | Buttoning | 7 | 25% | |
| | Eye hand coordination | 6 | 21% | |
| | Transferring objects | 5 | 18% | |
| | Wearing shoes | 4 | 14% | |
| | Pencil grip | 4 | 14% | |
| | Tying shoe lays | 3 | 11% | |
| | Throwing things | 3 | 11% | |
| Psychoeducation and parental training | Educating / awareness class | 8 | 28% | 25% |
| | Psychoeducation | 7 | 25% | |
| | Stress management | 6 | 21% | |

This section of the analysis describes the suggestions made by parents during the semi-structured interview. While parents were asked to come up with the potential content to be considered for the proposed program, several suggestions on the

potential content of the PMI program were provided by the participants. All the emerging themes could be grouped under six broad categories, viz. Social adaptive skills, Basic communication skills, Management of problematic behaviors, Basic learning skills, Fine motor skills, Psychoeducation and Parental training. Social adaptive functioning emerged as a single most endorsed theme (62%) of parents were recommended this theme. (*'Unlike other issues, developmental disabilities would last throughout the life. A child with autism or any disability should have self-independence at first that is the primary goal of each one. It is difficult to take care of the activities of daily living or primary adaptive functions of a person till his end. Everybody should, encourage independence of a child with ASD in at least in ADL or his or her social adaptive skills, and get help to acquire such skills as early as possible*).

Basic Communication skill training emerged as the second most frequent theme, it was endorsed by 28% of parents (*'There is a need to communicate the basic needs and wants of the child to their care takers, that's the essential requirement for any individual's survival. Basic communication could be by any means, if the child is not verbal at least if he or she could communicate their basic wants through some gestures or by any other means'*). A total of 25% of parents were endorsed the theme of psychoeducation and parental training module with the subthemes of psychoeducation, stress management and education and awareness. Fine motor skills, reducing problematic behavior and basic learning skills themes were endorsed by 17%, 14% and 13% of parents respectively.

**Feasibility observations**

Table 3.4

*Views on the feasibility of the proposed structure of the program (N=28)*

| Feasibility estimates | Freq. | Percentage |
|---|---|---|
| Feasible | 18 | 64% |
| Difficult | 7 | 25% |
| Clearly Not feasible | 3 | 11% |

A tentative structure of the intervention program was prepared by the researcher based on a review of the literature and initial ideas related to content coverage and spread of sessions. This tentative structure comprised of an initial, long session lasting for 1-2 hours, followed by sessions choosing their child's requirement, session numbers would be customized for each child based on the child's progress. This structure was shared with the participants, and they were requested to comment on implementation feasibility.

As shown, more than half of the participants (64%) reported that the proposed structure of the program was feasible. For example, one parent commented that *"this (the proposed structure) is a good structure"* and another participant said, *"it should not be a problem… we have time for everything else; we should have time for our children also, especially if that could improve their functioning"*. The remaining 25% reported that the proposed structure was 'difficult to implement' and rest of the 11% said 'clearly not feasible.' Some of the responses included: *"they (children with ASD) are difficult to deal with, and it will be difficult by a parent to do the training at home…"* and *"…consistency cannot be guaranteed. …must ensure that other things, other kids, and work at home also to be taken care, may not get the support of family members, etc."* Several suggestions were also made by the participants to improve the feasibility of the proposed program.

Table 3.5

*Suggestions to improve the feasibility of the proposed program structure (Top three suggestions)*

| **Suggestions for improving program feasibility** | **Freq.** | **Percentage** |
|---|---|---|
| Avoid the time frame of the sessions and reduce the number of tasks given | 9 | 32% |
| Reduce the number of areas to be targeted and participants in training for parents by therapist | 8 | 29% |
| Prior planning with parents and family members | 6 | 21% |

Table 3.5 shows the top three suggestions made by the interview participants to improve the feasibility of the proposed program. Out of the 28 interview participants, 9 recommended avoiding the time frame for sessions and reduce the number of tasks

given as a way of improving feasibility (*"Reduce the number of tasks…and duration…they (child with ASD), have many issues especially taking care of the child along with house cores and other children will be difficult"*). Prior planning with parents and family ("*Prior preparation is very important…differences between normal therapy sessions… that -prior planning- makes it easier for the parents how to go about the home based training, too…"*) and reducing the number of participants i.e., number of parents ("*It is difficult, taking time out of the family or house core time, …reduce the number of participants and include only those who are really interested"*) were suggested by eight participants, as a means to improve program feasibility. Other suggestions given by the participants included starting the program during holidays Saturday or Sunday, conducting the program sessions either morning or evening hours, convincing the family, making the program interesting, use of technology to communicate, and program conduction over multiple settings (social media platforms).

Table 3.6

*Feasibility of selecting children from different severity group and wide age range (N=28)*

| Feasibility of selecting children from different severity groups | Freq. | Percentage |
|---|---|---|
| Feasible | 19 | 67% |
| Difficult | 7 | 25% |
| Not feasible | 2 | 7% |

Table 3.6 shows the responses of the participants to the interview item about the feasibility of selecting children with ASD from wide range of age group and different severity levels. Of the 28 participants, the majority (67%) felt that selecting program participants from wide age range and different severity group is feasible while the remaining 25% reported it as 'difficult' and rest 7% reported as 'not feasible.'

Table 3.7

*Feasibility of conducting program sessions weekdays and holidays (N=28)*

| **Feasibility of conducting sessions during/after class hours** | **weekdays** | | **Holidays** | |
|---|---|---|---|---|
| | **Freq.** | **Percentage** | **Freq.** | **Percentage** |
| Feasible | 11 | 39% | 17 | 61% |
| Difficult | 19 | 69% | 9 | 32% |
| Not feasible | 23 | 82% | 5 | 18% |

Table 3.7 shows the responses of the interview participants to the question on the feasibility of conducting the master sessions with parents (2 sessions in a month) of the proposed program during holidays or weekdays. The majority (69% & 82%) thought that conducting program sessions during weekdays might be either difficult or not feasible. Remaining 39% opined that conducting program sessions during the weekdays was feasible. One of the participants who thought this was not feasible reported that *"it is (allowing to conduct sessions during weekdays) a challenge for us…taking leave from work and no one else would be at home for taking care of other kids or elderly parents and all, affects so many people."* In a similar manner, the majority (61%) opined that conducting program sessions during holidays was a feasible option. For example, one parent suggested that *"It should not be a problem. On holidays either of the parent would be free and other family members also be there at home to take care of others, therefore one parent could completely commit the day for the session."* The same message was reflected by another parent who said, *"'…can be done on the holidays as it is very important for our child but without affecting other kids functioning, if we could participate the program, we can give our complete focus without any worry or preoccupied thoughts about the home and others at home… it should not be difficult if other family members are aware of its needs"*. Only 32% thought it would be difficult, and 18% thought it was not feasible on holidays.

**Potential hindrances**

Table 3.8

*Potential hindrances in program implementation (Top 4 responses) (N=28)*

| Potential hindrances during program Implementation | Freq. | Percentage |
|---|---|---|
| Interest of the family members (child takes time to show improvements) | 15 | 54% |
| Lack of confidence of parents for being the therapist | 11 | 39% |
| Regularly finding time for practice as parents have other roles as well | 11 | 39% |
| Nature and Complexities of the activities | 8 | 29% |

Table 3.8 shows the top four potential hindrances during program implementation as reported by the interview participants to an open-ended question. Fifteen out of the 28 interview participants reported that 'low interest of the family members or spouse' could be a potential hindrance to program implementation. For example, one Participant observed that *"it (agreeableness to participate in the training program) would depend on the interest of the spouse or other family members as well. Some might think this is not good as like normal therapeutic intervention, so why spend effort and resources on such things, instead going for therapy". Similar comments were given by 54% of parents*. Another parent observed that *"it all depends on the improvements would show by child, to have sudden change in the beginning of sessions would be difficult, this might cause others to say 'no' because of time need to be invested, perceived low utility of program or benefit to the child, etc."* 'dealing unexpected things in life' (e.g., *"disease of other children, work pressure at office) can also be a hindrance. Especially on weekends, only the really interested will turn up"*) and 'dealing with the difficulties in initial phases (*"lack of confidence of parents about being the trainer"*) were considered as potential hindrances by 39% of the interview participants each. Safety issues, unpredictable changes, doubts regarding the utility of the program, complexities, or nature of the activities to be learned and

given to child, and availability of space at home were also reported as other potential hindrances.

Table 3.9

*Suggestions to deal with potential barriers (Top 3 responses) (N=28)*

| Suggestions to deal with potential implementation barriers | Freq. | Percentage |
|---|---|---|
| Educate and convince the other family members | 17 | 61% |
| Prior planning, providing confidence and motivation | 12 | 43% |
| Increase the appeal of the program by providing samples of tasks, eradicate the misconceptions regarding the activities | 12 | 43% |

Several suggestions were provided by the interview participants to deal with the potential hindrances to implementation. Educating and convincing the family members (e.g., *"it all depends on the master trainer… if the significant person in family understands the utility of the program, then it will be helpful, therefore in initial meeting they should be educated and get convinced about the program"*) emerged as the most cited suggestions. Prior planning (e.g., *"If planned properly all the hindrances can be managed. Usually parents could have other engagements as well, and if this training time also could be incorporated into that, then it should not be a problem"*) and increasing the appeal of the program' (*"If activities are interesting and simple and within the complexity where parents could learn it without much difficulty then most of them will be confident to participate"*) were the other top suggestions for dealing with the potential hindrances identified. Other suggestions included reducing the number of sessions, master sessions can be planned once or twice in a month instead of once in a week.

**Potential sources of support**

Table 3.10

*Potential sources of support in program implementation (N=28)*

| **Potential sources of support** | **Freq.** | **Percentage** |
|---|---|---|
| Family members | 24 | 86% |
| Candidates (Child) themselves | 4 | 14% |
| Therapists/professionals | 1 | 4% |

Table 3.10 shows the responses of the participants to the interview question about potential sources of support that can be sought while implementing the program for pilot testing. As shown, 24 out of 28 participants (86%) opined that the most important source of support in such an endeavor is the family members. For example, one of the participants observed that *"If the significant individuals in the family are interested in the program and their directions are well taken and therefore other will bound to follow the rules and regulations set up by the trainer"*. Children with ASD themselves were seen as a potential source of support only by 14% of the interview participants. One interviewee opined that promotion of the program by the therapists /professional's community might be of use.

**Estimate of receptivity**

Table 3.11

*Estimate of receptivity of parents of children with ASD for the intervention program (N=28)*

| Parents' receptivity estimate | Freq. | Percentage |
|---|---|---|
| Good | 24 | 86% |
| Poor | 2 | 7% |
| Not sure | 2 | 7% |

Table 3.11 shows the estimate of receptivity of the proposed program as given by the interview participants. A majority (86%) of the participants estimated the parents

'receptivity of the proposed program to be good (*"I think parents should be willing to participate in the program," "They will be Parents and their children would definitely get benefited by participating in this program…"*). Two (7%) of the participants opined that the receptivity of the parents might be poor and unsure about how receptive the parents' population will be of the proposed program.

**Potential benefits**

Table 3.12

*Potential benefits for the parents and their children with ASD from the proposed program (Top three benefits reported) (N=28)*

| **Potential benefits** | **Freq.** | **Percentage** |
|---|---|---|
| Improved overall functioning | 19 | 68% |
| Benefits for their daily living quality | 13 | 46% |
| Better adaptive abilities | 13 | 46% |

In response to a question on potential benefits, 19 out of 28 interview participants opined that participating in the proposed program will have a positive influence on the children with ASD. For example, one participant observed that, *"'…performance level goes up in their overall functioning especially the quality of their daily living… (as they will) have more skill acquisition and balance in daily life by reducing their problematic behaviors and improving the adaptive skills."* thirteen of the participants expressed that participating in the proposed program would benefit their social adaptive skills, independence in functioning along with improved communication capacity (e.g. *"It is going to have a ripple effect. If done for one child, whoever is connected to him/her will benefit. It is a multi-level benefit."*) Thirteen participants also reported that participation in such a program will lead to 'better quality of live with improved adaptive skills.' This was evident in the following statement made by one of the participants: *"It is all a part of the supporting system in the community, not a sacrifice…of any one… it is all about making better life for a vulnerable group of people, the quality of living for the people who are under privileged or needs etc. care by all of us."* Other potential benefits reported by the participants included improved

confidence in parents (25%), decreased stress level in parents (25%), latent benefits that may be manifested in future (15%), improved awareness (15%), collaboration with people who faces similar problems (10%), improved connections (10%), and knows how to do when there are any exigencies or where to seek help (10%).

**Miscellaneous suggestions**

The interview with parents focused primarily on eliciting their perspectives on the proposed PMI program. It also provided several valuable insights for the research. Additional suggestions that were offered by the interviewees are enumerated below. Several of these pertain to the deployment of the program after pilot testing.

- Need for continuing the program even after the study period and to provide the same in varied settings
- Decide carefully about the nature of the program (Free of cost vs. commercialized)
- Keeping novelty while also maintaining a sense of credibility and utility
- Sensitize and actively involve other family members for delivering the program, if parents can't take part.
- Seek the possibility of collaborating with more than one professional
- Include all stakeholders, including multi-disciplinary professionals
- Scale up the program so that it reaches a large number of children with ASD
- Provide support for individuals who might require special attention
- Need to sensitize the parents and community workers in appropriate way

**Section II: Interview with Professionals**

The exploratory phase of the study also included semi-structured interview of professionals who are dealing with children with ASD. The purpose of the interview was to explore their perspectives regarding felt needs, feasibility, and potential content and structure of a PMI program. The information collected through the interview with professionals to be integrated with the interview data of stakeholders group of parents and used for the development of the proposed PMI program.

Table 3.13

*Socio-demographic details of the Professionals group of Interview participants (N=23)*

| **Variable** | **Group** | **Mean** | **Standard deviation** |
|---|---|---|---|
| Age | Male | 42 | 5.27 |
| | Female | 38 | 3.02 |
| | **Group** | **N** | **Percentage** |
| Gender | Male | 12 | 52% |
| | Female | 11 | 48% |
| Professionals | Clinical Psychologists | 10 | 43% |
| | Speech Therapists | 5 | 22% |
| | Occupational Therapists | 3 | 13% |
| | Special educators | 5 | 22% |
| Years of experience | 7 years and above | 12 | 52% |
| | 5-7 years | 6 | 26% |
| | Minimum 5 years | 5 | 22% |
| Work setting | Government | 10 | 43% |
| | Private | 8 | 35% |
| | Independent practice | 5 | 22% |

The average age of the professional group of interview participants was 39. Males (52% of total participants) and females (48% of total participants) were present at this stage. The majority of the interview participants belonged to the professional categories of clinical psychologists (43%), speech therapists (22%), special educators

(22%), and occupational therapists (13%) with 7 years and above experience (52%), five to seven years (26%), and minimum five years of experience (22%). 43% of the interview participants were working in the government sector, while 35% were employed in private settings and 22% were engaged in independent practice.

**Hands on experience**

Table 3.14

*Hands on experience, personal knowledge/experience in working with children with ASD in interview participants (N=23)*

| Item | Response | N | Percentage |
|---|---|---|---|
| Previous experience in involving some or other form of Parent mediated interventions of children with ASD | Yes | 17 | 74% |
| | No | 6 | 26% |
| Personal knowledge/course attended/underwent training in the area of dealing children with ASD | Yes | 15 | 65% |
| | No | 8 | 35% |
| Personal experience of being involved in some form of innovative intervention approaches for children with ASD or any other developmental disabilities | Yes | 12 | 52% |
| | No | 11 | 48% |

Before the interview, the participants were asked to respond to a basic data sheet that included items on previous experience in some or other form of parent assisted interventions of children with ASD, personal knowledge/course attended/underwent training in the area of dealing children with ASD, Personal experience of some form of any intervention methods for children with ASD or any other developmental disabilities (Table 3.14). Majority (74%) of the participants reported being involved in some or other form of parent mediated interventions program. The proportion of professionals reporting personal knowledge or course, or training undergone in the area of interventions targeting of children with ASD (65%). About half of the interview, participants reported Personal experience of being involved in some form of innovative intervention approaches for children with ASD or any other developmental disabilities.

**Felt Needs for PMI**

Table 3.15

*Interviewee opinion on the need of a PMI program for children with ASD (interview participants, N=23)*

| Need for a PMI program specifically for Children with ASD | Freq. | Percentage |
|---|---|---|
| Certainly Needed | 21 | 91.3% |
| Needed | 1 | 4.3% |
| Not sure/probably good | 1 | 4.3% |

Table 3.15 shows twenty one out of twenty-three interview participants (91%) were strongly put forward that this proposed PMI program is certainly needed, one participant rated it as needed and another one believed not sure, this one would be probably good.

Table 3.16

*Reasons for need for PMI program for Children with ASD (interview participants, N=23)*

| Need of program for PMI themes | N | Percentage |
|---|---|---|
| Lack of awareness about ASD and high stigma | 18 | 78% |
| Non-accessibility of intervention centers in nearby localities | 17 | 74% |
| Helps to improve child's functioning | 14 | 61% |
| High levels of stress in parents | 12 | 52% |
| Improving self-confidence and motivation in parents | 11 | 48% |
| Poor parental involvement in the treatment | 11 | 48% |
| Poor treatment adherence | 9 | 39% |

Table 3.16 shows responses of the interview participants to the question about the need for a PMI program for children with ASD. There was a consensus across all the interviews that there is a need for such a program. The above table depicts the themes under which the reasons needed for such a program could be categorized. Across

eighteen interviews, 'lack of awareness about ASD issues and related stigma was cited as the reason for such a program (eighteen interviews). The same was evident in the following remarks: *"parents don't want bring those children to mainstream of family or social functions"* and *"even the word disability brings stigma." "Being the parent of disabled children means we did some bad things in our past lives"*. Non-accessibility of intervention centers in nearby localities (74%), helps to improve child's functioning (61%), high levels of stress in parents (52%), improving confidence and motivation in parents (48%), poor parental involvement in the treatment (48%) and poor treatment adherence (39%) were also cited as the reason for having a specific program for PMI for children with ASD. One participant stated it as probably good, *"we can't assure how much a parent could do at home with an ASD child, which is still unsure"*.

**Suitability of a proposed PMI**

Table 3.17

*Interviewee opinion on the suitability of a proposed PMI program considering the severity level of children with ASD (interview participants, N=23)*

| **Need for a PMI program specifically for Children with ASD** | **Freq.** | **Percentage** |
|---|---|---|
| Mild and Moderate | 13 | 57% |
| Mild Only | 5 | 22% |
| All severity group | 5 | 22% |

In the interview participants were asked to rate, which severity group of children would be most suitable for the PMI program. Table 3.17 shows that thirteen participants stated that mild and moderate category of children with ASD are the most appropriate beneficiary for the proposed PMI program. While five interview participants endorsed this PMI is suitable for only mild category of children with ASD. Another five out of twenty-three participants reported this program is found to be suitable for all severity group of children.

Table 3.18

*Interviewee opinion on the suitability of a proposed PMI program considering the age range of children with ASD (interview participants, N=23)*

| Need for a PMI program specifically for Children with ASD | Freq. | Percentage |
|---|---|---|
| Any age ranges up to 18 | 20 | 87% |
| 5-15 years of age | 2 | 9% |
| Below 10 | 1 | 4% |

Table 3.18 shows that interview participants were given the choice of selecting the age group, which is suitable for the proposed intervention program, where twenty out of twenty-three interview participants endorsed that any range of children from 3 years to 18 years can be benefited from this training, thus this is suitable for this wide age group. Thus, two interview participants recommended 5-15 years of children with ASD are the most suitable age group for this proposed PMI program, one among the twenty-three participants suggested any children below 10 would be the most suitable beneficiaries of the proposed program.

**Potential Contents**

Table 3.19

*Potential content suggestion for the PMI program (Interview participants, N=23)*

| **Potential content for PMI program** | | | | |
|---|---|---|---|---|
| **Themes** | **%** | **Sub-themes** | **N** | **%** |
| Activities of Daily Living/ Adaptive Behaviors | 57% | Toileting | 15 | 65% |
| | | Brushing | 14 | 61% |
| | | Bathing | 14 | 61% |
| | | Dressing/buttoning | 12 | 52% |
| | | Eating | 11 | 48% |
| Behavior Modification | 37% | Sitting behavior/ Sitting tolerance | 13 | 57% |
| | | Behavior problems | 10 | 43% |
| | | Social skills | 8 | 35% |
| | | Sharing skills | 3 | 13% |
| Cognitive activities | 24% | Attention activities | 7 | 30% |
| | | Taking turns | 6 | 26% |
| | | Play behaviors | 5 | 22% |
| | | Joint attention | 4 | 17% |

| | | | | |
|---|---|---|---|---|
| Social communication | 44% | Functional communication | 13 | 57% |
| | | Relating experiences | 10 | 43% |
| | | Social interaction | 9 | 39% |
| | | Responding to name calling | 8 | 35% |
| Fine motor functioning | 53% | Buttoning | 14 | 61% |
| | | Hand grip | 12 | 52% |
| | | Finger dexterity | 12 | 52% |
| | | Eye hand coordination | 11 | 48% |
| Parental education | 35% | Psychoeducation for parents | 9 | 39% |
| | | Stress management | 7 | 30% |

Table 3.19 shows the broad themes related to content suggestions as given by the interview participants. Activities of daily living or adaptive behaviors (57%) emerged as potential content suggestions in majority out of the twenty-three interview participants followed by fine motor functioning (53%) suggested by most of the interview participants. For example, one participant observed that *"everyone must be aware of this…they (children with ASD) always depended on anyone for their daily functioning. If everyone knew how to train them to be self-independent in activities of daily living, it would be great achievement for the differently abled and for their caregivers."* Another participant suggested that *"parents of children with developmental disabilities…the whole day, they might be bothered about their child… regarding their self-independence and functioning capacity (By) handling own self-care, essential tasks such as eating, toileting, dressing, communicating basic needs, etc. can be trained therefore huge amount of care giver burden can be taken away. Therefore, this promotes caregivers' mental health promotion."* Suggestions also included, *"so much stress and pressure… they feel their same age friends or colleagues' are so relaxed and happy while they say I feel tired and 'stressed.' We should add this topic also* (managing pressures/stress of parents or caregivers), and *"improving confidence by providing further knowledge in the management of their child's problems, understanding more regarding ASD…. One of my clients (parent of a child with ASD), she keeps losing confidence, despite we trying to help her and keep her confident. We need to learn what can be done about these things also" (*improving confidence of parents). The other suggestions pertained to themes of social communication, cognitive activities, behavioral modification, and parental education. Each of these suggestions emerged in the interviews.

**Structure of the program**

Table 3.20

*Program structure preference (Interview participants, N=23)*

| Program structure preference by professional Interview participants | No. interview participants preferring each structure | Percentage |
|---|---|---|
| Structure 1 | 17 | 74% |
| Structure 2 | 4 | 17% |
| Not sure | 2 | 9% |

**Structure 1: Free style-** it is designed as a series of sessions delivered in individual or group format to parents. The program will have an introductory session for the participants. Following this a baseline assessment will be conducted for individual participants' separately (based on convenience; attempt will be made to finish the assessment in one week). Following this, it is planned to have 15-20 sessions of about 1-2 hours duration each, on once in every week. Selection module would vary child to child. The sessions would be based on pre-selected themes and involve a small didactic input along with extensive opportunities for learning about and engaging with the themes through multiple activities and exercises. Each session would be structured such that the parents can apply this on their children for next one week period. Activities would vary child to child based on their progress and baseline scores.

**Structure 2: fixed Style-** a series of session would be given in predesigned manner, initial session with all the participants, later group session for 5-8 parents together and session will be conducted in every alternative week, so that 2 sessions per month. Caregiver or parents need to perform the trained activities with the child at home environment, every two weeks there will be a monitoring of progress.

During the interview with professionals, a tentative structure for the PMI program was proposed. The professional interview participants recommended a few changes to the proposed structure, including more frequent sessions and intermittent feedback or review, flexibility in the number of total sessions, and overall program duration, considering individual clients and their progress. Based on their feedback, the participants were asked to deliberate on the different options and come up with a

recommendation.

Table 3.20 shows the two options and the number of interview participants preferring each one of them. Each of the interview participants could arrive at an agreement on the option preferred by each of them based on their experience and expertise in the field. Seventeen out of the 23 interview participants endorsed the program structure one as the most suitable format (*"this one is the best out of two," the first one…it will be very flexible, where we can fit any severity level clients, as its customizable, there is no strict time limit for each domain. If child wouldn't improve with given time, parents have the flexibility of stretching those sessions until he gets mastery on it. If learned skills are not practiced or rehearsal not done, child might forget, so recaps/repeated training in scheduled intervals are also important."*). This format was planned in such a way that the program would commence with an initial full-day session (that included an orientation and baseline assessment) followed by a full day session after four weeks and another full day session after the next four weeks of the initial session. It also included two short sessions in between the full-day sessions. However, it was expressed that, the final structure and the duration of the program would depend highly on three factors – the parents' comfort and convenience, prior planning, and professional participants recommendations and suggestions. For example, it was stated that *"it is about their (parent group of stakeholders) priority. It is about them."* About the parents' group, it was said that *"if they find it useful or having any change in their children and comfortable for them to learn and implement, they will come, or they won't."*

**Potential hindrances**

Table 3.21

*Potential hindrances during program implementation (Top 4 responses) (Interview participants, N=23)*

| **Potential hindrances** | **Reported by (No. of participants)** | **%** |
|---|---|---|
| Nature and Complexities of the tasks involved | 4 | 17% |
| Dealing with unexpected changes | 3 | 13% |
| Non-cooperation of other family members | 3 | 13% |
| Level of impairments of the children and poor change in the beginning of the program | 2 | 9% |

Table 3.21 shows the top four potential hindrances to program implementation reported by the interview participants. Four out of the twenty-three interview participants expressed 'nature and complexities of the tasks involved' as a potential hindrance. For example, it was observed that *"not able to understand the tasks and make the child to practice the same given in the program (by parents or caregiver) in itself can be an issue."* Another participant said that *"you (clinicians) have to make them capable, to deal with the unforeseen changes or responses from the children with ASD."* Non-cooperation of other family members was also a theme that came up in three out of the twenty-three interviews. Level of impairments of the children and poor change in the beginning of the program (e.g., *"(being parents) there will be a lot of work and so much to do at home other than giving these training… if suppose even after few weeks, children wouldn't show any improvements in their functioning, (so) will not have the motivation to continue the training and they would tend to stop coming."*) Other potential hindrances identified included timing of the program (weekdays, weekends, etc.), logistic issues (where to conduct, space required at home, etc.), and other commitments (working parents, other personal engagements – any other ill children or elderly parents, taking care of them etc. any functions to be attended, if conducted on holidays).

**Views on Receptivity**

Table 3.22

*Factors influencing participants receptivity of the program: Perspectives of Interview participants (N=23)*

| **Factors influencing parents' receptivity of the Program** | **Reported by (No. of participants)** | **Percentage** |
|---|---|---|
| Individual interest and motivation | 12 | 52 % |
| Knowledge about the importance of the program | 11 | 48 % |
| Lack of other potential resources for training of their children | 9 | 39 % |

Three themes emerged in the interviews as the potential factors that would influence the receptivity of parents' or caregiver participants. First and most reported factor (52%) was 'individual interest and motivation.' For example, one interviewee opined that *"it is about their mindset regarding such a program; if they are interested, and found useful, then they will come."* Another participant remarked that *"it depends on us the professional and parents. If we could make them aware about the utility of such a program, if they got convinced and along with if they found it useful or interesting then most of them would join for these types of programs. So, it is important."* Knowledge about the importance of the program was the second related theme. Opinions on this theme included statements like, *"we need to convince the parents or caregivers that it is imperative so if we addressed this"* and *"many parents won't know about these things and may think that it is not important or that we don't need it, these all the things can be done only by therapists, these won't be useful, they may lack in confidence, etc."* As shown, these three broad themes appeared across all the interviews with professionals as potential factors influencing parents' receptivity.

Table 3.23

*Suggestions for improving participants receptivity of the program (Top three suggestions) (Interview participants, N=23)*

| **Suggestions to improve student receptivity** | **Reported by (No. of participants)** | **Percentage** |
|---|---|---|
| Make the program activity-based | 15 | 65% |
| Make the number of sessions and duration of the program flexible | 9 | 39% |
| Conduct at anywhere they are comfortable | 7 | 30% |
| Session focused on improving the parents' confidence and knowledge regarding this program | 7 | 30% |

Table 3.23 shows the top four suggestions that were made by the interview participants as a possible means to improve the receptivity of the proposed program. A suggestion that emerged across all the interviews was to 'make the program activity-based.' The role of activity-based programs in improving receptivity was strongly

emphasized. For example, it was said that *"no class and lecture, if they are given opportunities to engage in activities, then only they will be interested and do the tasks."* It was also mentioned that *"including activities, both child and parent can participate and do more. Like some people suggested, videos, role plays… also games…like they will play and learn. "Observe and imitate, modelling the parent etc.*

Conducting the program outside the home setting was also suggested in three of the five FGDs (e.g., *"something different from the usual pattern, not inside the room, the place should be different, that could be park, beach any outdoor"*) A number of other suggestions were also made by the participants to improve the receptivity of the program, which included: parents session may conduct on non-working days, include competitive elements like providing score and best performer from the side of parents, include more than one domains of training and different level of severity children, use social media like sending materials on WhatsApp, video sessions, etc. certificates and prizes for best performers as that would enhance motivation in parents, providing the program free of cost, real-life experience sharing by parents, and conducting the program-activities along with one or another established program/celebration/events (for example, autism day) in addition to enhancing awareness about the relevance of the program.

Table 3.24

*Opinions on using social media in the PMI program (Interview participants, N=23)*

| **Relevance of social media for the PYD program** | **Reported by (No. of participants)** | **Percentage** |
|---|---|---|
| Widely used | 11 | 48% |
| Finding healthy use | 5 | 22% |

Interviews with professional group was also included an item on exploring the scope of using social media in the proposed PMI program. It was observed that there was a consensus among the participants about its utility in the proposed program. Table 3.24 shows the reasons as cited in various interviews supporting the use of social media in

PMI programs for Children with ASD. Eleven out of twenty-three interview participants agreed that it should be used because it is already in 'wide use' among most of the people in our community and that *"one should make use of it as there is no house without any smart phone, either parents, siblings or any of the family members would be using that."* Five out of twenty-three interview participants additionally reasoned that it is already 'familiar to parents', *"requiring no further training or effort as we all use it"*. Another important reason for supporting the use of media in two of the interviews was that it would help people to find a 'healthy use' of social media. For example, one parent or sibling observed, *"Use it as a campaign. You cannot stop it completely as it is about amendable so better use it for good things like this. Use them in a fruitful way."* interview participants felt that social media could be effective for both communication purposes as well as for facilitating engagement in program-related activities or sharing supplementary materials of the program, if suppose some of the parent couldn't attend a master session, they could learn through the materials would be shared via social media. Another reason cited supporting the use of media was its 'capacity to reach maximum people, with minimal cost and effort.' If suppose a parent could not access the training due to logistics reasons, they may make use of the online materials.

Table 3.25

*Potential benefits of the proposed program for parents and children with ASD (Top Five benefits) (Interview participants, N=23)*

| **Potential benefits** | **Reported by (No. of participants)** | **Percentage** |
|---|---|---|
| Knowledge acquisition about the ASD Condition among the parents and family members | 14 | 61% |
| Improved confidence and feeling of control | 13 | 57% |
| Improved self-awareness, reduced care giver burden, act as respite care, decreased stress level | 11 | 48% |
| More stimulation and more time of interventions to the child | 7 | 30% |
| Better symptom profile improvement (outcome) | 6 | 26% |

Participants from fourteen out of the twenty-three interviews reported that taking part in the proposed intervention program will lead to 'knowledge acquisition about ASD condition among the parents and family members (*"they will know that these (Autism) are not uncommon, get some clarity on what is happening everywhere"*), and thirteen interview participants were reported 'improved confidence and feeling of control' (*"it may increase one's confidence. To do things, they won't get clueless when child would behave in a strange way, they will have more control over the situation"*). Thirteen interview participants were reported 'improved self-awareness, reduced care giver burden, act as respite care, decreased stress of level as the potential benefit for the program participants. Other potential benefits included the more stimulation and more time of interventions to the child, better symptom profile improvement (outcome).

**Section III: Ranking of potential content list**

**Potential contents list for program ranking**

After completion of the interviews, researcher prepared a potential contents list based on the data collected through interview with parents, professionals, and existing review of literature. Triangulation of data was used here to prepare the potential content list. The potential content list for proposed PMI program was given to selected participants includes a total of 30 participants, out of these thirty participants, 20 are parents of children with ASD and 10 are professionals working in the field of ASD (these participants were not included in the stake holders interview). They were asked to go through each of the items in the list and to select from the list, themes that they thought relevant for the PMI program for parents of children with ASD. From the themes that they thought relevant, they were further asked to rank top five themes. The findings from the ranking of the potential content are given below.

Table 3.26

*Endorsement of items on the potential content list (N=30)*

| Potential content items | Frequency | Percentage |
|---|---|---|
| **Adaptive Skill Training** | | |
| Toileting | 21 | 70% |
| Self-Eating | 20 | 67% |
| Brushing | 20 | 67% |
| Bathing | 19 | 63% |
| Self-Dressing/Grooming | 19 | 63% |
| **Psychoeducation** | | |
| Familiarizing the participants with the program | 12 | 40% |
| Familiarizing the participants with the concepts related to Autism | 11 | 37% |
| Assessment of the participants understanding about the ASD | 11 | 37% |
| Promoting knowledge, reducing stigma, in family members of children with ASD | 10 | 33% |
| **Managing Problem Behaviors** | | |
| Educate and familiarize the participants about the behavioral interventions | 14 | 47% |
| Familiarizing the participants with the concepts related to ABI techniques | 13 | 43% |
| Training to conduct Functional Behavior Analysis (FBA) | 13 | 43% |
| Teach to detect specific antecedent based intervention plans | 12 | 40% |
| Familiarizing and teaching the identified behavior management strategies | 11 | 37% |
| **Basic communication skills** | | |
| Familiarizing the participants regarding communication skills | 16 | 53% |
| Preparing the child to respond with gestures | 16 | 53% |
| Prepare the child to comprehend the instructions and react to it desirably | 16 | 53% |
| Prepare the child to nod head appropriately, and use ‘yes’ or ‘no’ in communication. | 14 | 47% |
| Prepare the child to understand and recognize familiar people and objects | 13 | 43% |
| Prepare the child to 3points, at least three body parts on self | 13 | 43% |
| Prepare the child to say own name | 13 | 43% |

| **Fine Motor Functioning** | | |
|---|---|---|
| Familiarizing the participants regarding fine motor functioning | 21 | 70% |
| Prepare the child to pick up objects using whole hands (Palmer grasp) | 14 | 47% |
| Prepare the child to grasp with both hands | 14 | 47% |
| Prepare the child releases objects | 13 | 43% |
| Prepare the child transfers from one hand to another | 13 | 43% |
| Prepare the child grasps two objects one in each hand | 13 | 43% |
| Prepare the child picks up using fingers | 12 | 40% |
| Prepare the child stacks objects | 12 | 40% |
| Prepare the child turns doorknobs/latches/bolts | 11 | 37% |
| Prepare the child screws and unscrews, opening and closing | 11 | 37% |
| Prepare the child in eye-hand coordination | 11 | 37% |
| Other Activities such as paste paper, inserts, and assembles objects, separate rolls of materials, wraps, cuts with scissors, draws and paints, sewing, etc. | 7 | 23% |

Among the potential contents suggestions provided, the item with highest rate of endorsement was ‘toileting, dressing, bathing and familiarizing the participants regarding fine motor functioning (70%) followed by ‘self-eating and brushing (67%), ‘familiarizing the basic communication skills training, preparing the child to respond with gestures, prepare the child to comprehend the instructions and react to it desirably’ (53%), ‘Educate and familiarize the participants about the behavioral interventions, prepare the child to nod head appropriately, and use ‘yes’ or ‘no’ in communication (47%), and ‘Familiarizing the participants with the concepts related to ABI techniques, Training to conduct Functional Behavior Analysis (FBA), Prepare the child to understand and recognize familiar people and objects, Prepare the child to 3points, at least three body parts on self and Prepare the child to say own name’ (43%). seven out of 30 (23%) of the participants endorsed all the items as relevant. Further, 9 out of the 33 items were endorsed by more than 50% of the participants. Even the least endorsed item was endorsed by more than one-third of the participants.

Table 3.27

*Potential content list ranking (Top 10 items based on weighted rank scores) (N=30)*

| Rank | Items (Top ten: from rank 1 to 10) | Core theme | Endorsed by | | Weighted score |
|---|---|---|---|---|---|
| | | | N | % | |
| 1 | Toileting | Adaptive Skill Training | 27 | 90% | 121 |
| 2 | Bathing | Adaptive Skill Training | 26 | 87% | 106 |
| 3 | Self-eating | Adaptive Skill Training | 24 | 80% | 101 |
| 4 | Communicating through gestures | Basic Communication Skills | 21 | 70% | 96 |
| 5 | Educating or familiarizing participants with the concepts related to Autism | Psychoeducation | 19 | 63% | 91 |
| 6 | Educate and familiarize the participants about the behavioral interventions | Managing behavioral problems | 17 | 57% | 90 |
| 7 | Comprehension of instructions and appropriate reactions | Basic Communication Skills | 19 | 63% | 87 |
| 8 | Prepare the child in eye-hand coordination | Fine motor skill training | 16 | 53% | 76 |
| 9 | Prepare the child to nod head appropriately, and use ‘yes’ or ‘no’ in communication. | Basic Communication Skills | 16 | 53% | 75 |
| 10 | Promoting knowledge, reducing stigma, in family members of children with ASD | Psychoeducation | 14 | 47% | 67 |

While the individual ranking of items was distributed across the five core themes, the weighted ranking was skewed in favor of themes belonging to the social adaptive skills category. It was also noted that promoting knowledge, reducing stigma, in family members of children with ASD themes received the lowest of the weightage with only one item from the same category finding a place in the top ten items. Though

skewed, one can see that all the core theme categories were represented in the top ten rankings of the themes.

Coming to the individual items, Toileting, Bathing and Self-eating were the top three items. Some of the items, while endorsed by a fewer number of participants, had a higher weighted rank due to higher individual rankings. For example, the number of people endorsing item 'Educate and familiarize the participants about the behavioral interventions' was less compared to 'comprehension of instructions and appropriate reactions' yet it was on the top of the list. The reason was that while endorsed by a lesser number of people, educate, and familiarize the participants about behavioral interventions received relatively higher individual rankings, leading to a higher weighted score. While deciding a theme for a program, one might look not just into the number of people who endorse it, but also how strongly it is endorsed. This was why weighted scores were also used.

**Exploratory Phase: Summary**

The first phase of the present study aimed at assessing the felt needs, potential content, and feasibility and receptivity estimates for a parent mediated intervention program for children with ASD from two sets of stakeholders – parents and professionals.

Throughout the exploratory phase, it was found that there was a consensus among the various stakeholders regarding the need and relevance for a PMI program aimed at intervening children with ASD through parent assisted way. Only a minority doubted the need for such efforts or were doubtful about the usefulness of the same.

Further, there was a consensus that PMI programs are feasible and likely to be received well by the stakeholders (parents). The need for careful planning and taking into consideration factors relevant to the clinical setting was emphasized. The exploratory phase also suggested a general agreement among the stakeholders regarding the potential content. The suggestions for potential contents further fell in line with the initial propositions made by the researcher based on the existing literature.

Both the groups of stakeholders strongly emphasized the key role parents and family members of children with ASD in the endorsement and implementation of the proposed program. There were differences of opinion on the optimal structure of the proposed program, but fixed style structure was considered difficult to implement by

several participants, particularly the interviewees (professionals). On the whole, it can be said that the exploratory phase of the present study provided several valuable inputs for the PMI program development and implementation phases of the study.

## STAGE II - PROGRAM DESIGN PHASE RESULTS (OBJECTIVES SET-II)

### Designing of the Program

The Parent Mediated Intervention (PMI) Program for Children with ASD was designed using data gathered from the semi structured interview with parents of children with ASD, and interviews with the multidisciplinary professionals, and the review of relevant literature on the topic. The designing of the program was done in such a way that from the planning stage through the delivery of the program, the stakeholders themselves would be actively involved. Using the data obtained from the Interviews helped in considering the views of the parents of children with ASD about the various aspects of the program. Also, the basic framework of the program considered the perspectives of yet another important stakeholder in the life of children with ASD – multidisciplinary professionals.

### Selection of the Program Content

The content for the program covered various themes under the broad frameworks of PMI for Children with ASD. The following guidelines were used to facilitate program content development:

1. Relevant to PMI programs in Indian community
2. In synchrony with the felt needs as ascertained during the exploratory phase (One-to-one interviews)
3. Based on the available theoretical and empirical literature on PMI and other interventions for children with ASD
4. Deliverable in individual or group format and suitable for a parent mediated program which is collective in nature.
5. Feasibility and ease of delivery in future by non-professional, parents/family members or caregivers or any health/community workers with minimal orientation and training.

The present program aimed at promoting various skills of children with ASD, through an intervention developed in line with the PMI framework. Based on the above-mentioned guidelines, the initial pool of various themes, under five core/board themes (social adaptive skills, psychoeducation, management of behavioral problems, basic communication skills and fine motor skills) was developed. The ranking of themes by the interview participants led to identifying the top ten preferred themes, which helped in trimming the content list. Information received from the interviews with parents and with multi-disciplinary professionals, along with the expert input from the research guides, facilitated selection of the topics to be covered during the intervention. The final content decisions were guided by triangulation of insights from stakeholder opinions, review of literature, and prior field experience of the research supervisors and researcher as well as feasibility constraints. Thus, a few topics found relevant in the review, or the exploratory phase could not be accommodated when all the pertinent factors were taken into consideration. The final themes of the program are provided in the table below.

Table 3.28

*Final Program themes*

| **Broad Themes** | **Emerged in** | | | |
|---|---|---|---|---|
| | **P1 (IV)** | **P2 (IV)** | **R** | **RoL** |
| Adaptive Skill Training | √ | √ | √ | √ |
| Psychoeducation | √ | √ | √ | √ |
| Management of Behavioral Problems | √ | √ | √ | √ |
| Basic Communication Skills | √ | √ | √ | √ |
| Fine motor functioning | √ | √ | √ | √ |
| P1 – Parents group of stakeholders; P2 – Professionals' group of stakeholders; IV – Interviews; R – Ranked list of themes; RoL: Review of Literature | | | | |

As shown in the above table (Table 3.28), there were five core themes. It is worth noting that the themes covered PMI frameworks while providing adequate space for themes that saw a convergence of felt needs of the two sets of stakeholders. An attempt was also made to map the components of the themes emerged through review of literature onto the PMI goals that might be addressed through the content.

PMI program goals should foster one or more of the following developmental outcomes in children with ASD: to learn social adaptive skills in the areas of toileting, bathing, eating, dressing, and brushing; enhancements in communication skills, behavioral, and fine-motor functioning; improvements in knowledge and confidence of handling children with ASD. The program has psycho-education section targeting on parents or caregivers. This module supporting parents to overcome their stress and anxieties also helps to improve parents' engagement in the activities.

The five core themes were covered in this training program. This treatment modules were categorized as five modules. Each core themes were considered as each module. All the modules included a set of sub-themes, detailed contents to be covered, activities to be used, response/activity sheets corresponding to each of the activities planned. It also included PowerPoint presentations which were to be used as an aid during the sessions.

**Designing the Program Structure**

The program was designed as a series of sessions delivered in an individual or group format in the community set up or clinic. The structure of the program evolved over time. Initially, it was planned that there would be a day-long introductory session (immediately after the baseline assessment) followed by bi-weekly master sessions of about two hours duration each, on once in 8-12 days basis. It was expected that this would cover about 15 hours of contact over a 2-3-month period.

However, during the exploratory phase, parents' group of stakeholders strongly recommended that to improve feasibility and receptivity overall length of the program as well as the number of sessions needs to be flexible, and a free style to be followed, session number and session themes to be chosen customized way and it would vary for client to client. Accordingly, two alternate program structures were developed and presented during interview with professionals. The program structure most preferred by the interview participants was used during the final implementation (Free style). This consisted of one full-day sessions interspersed with two brief sessions resulting in about 2 hours of program delivery or individual session with parents and child.

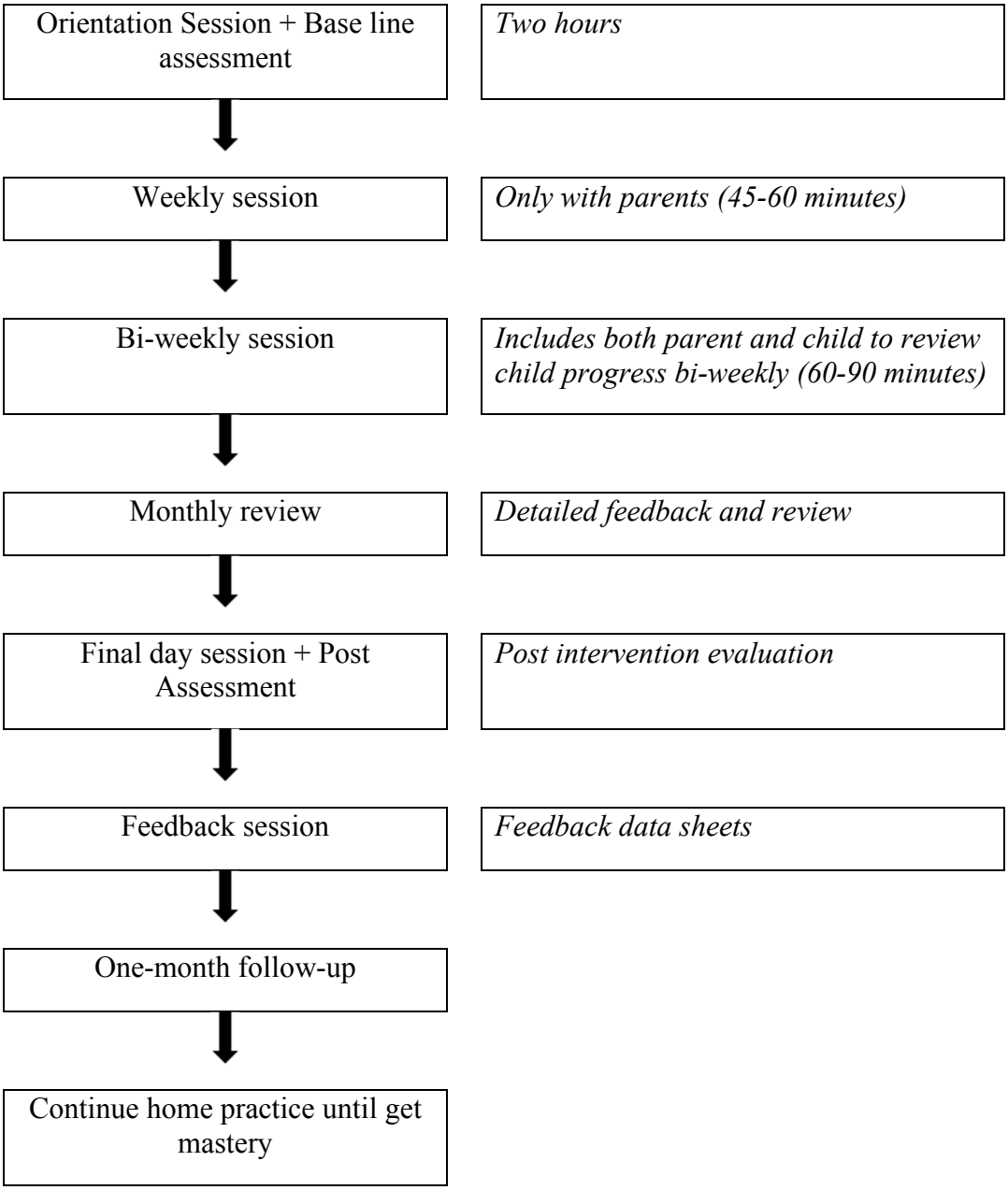



***Figure 3.1: The final structure of the program delivered is given below (Total approximate session duration 20 hours)***

Each session was structured to facilitate maximum participation from all the members. The six modules were planned as sessions that could be delivered independently. However, the program structure and spread of content across sessions allowed scope for accommodating changes in the delivery format during actual implementation.

Even though the final structure of the program is organized in the form for conducting session as a group, there is no limitation for this program that this can only be run as

a group session. If suppose, we have only one client to start with this parent mediated intervention program at a time, after base line assessment and brief orient we can skip one day full workshop, instead we can provide a long independent session with parents of the selected children with ASD, where we would discuss all details regarding this program and consent also will be taken for their willingness to participate.

**Section-II: Validation of the PMI Program**

**Program Validation:** After the finalization of the five modules and their content, the program was subjected to content validation. This was to help the researcher to make further changes as may be required. The validation process involved two separate groups of evaluators.

- ***Expert evaluation of the program modules:*** The expert evaluators included six expert validators, all from the field of multi-disciplinary disability management clinicians. They had at least five to nine years of experience working among children with ASD which included providing professional clinical services for ASD children, parent management training, early intervention services, engaging in community-based multi-disciplinary activities for children with all types of disabilities in general and autism spectrum disorder in particular.

- ***Parents' evaluation of the program modules:*** The second set of validators included five parents from the sample of parents who had participated in the ranking of content for the program in the early phase of research.

The prospective evaluators were contacted by the researcher for getting their consent to serve as evaluators. Once the permission was granted, the modules (Content details, PowerPoint presentation corresponding to each module, activity/response sheets) were sent to them individually over mail (as preferred by them) along with detailed instructions and a validation form.

The validation form comprised of seven items with options for rating each item on a 5- point scale (ranging from 'strongly agree' to 'strongly disagree') and an additional

remarks/suggestions column. The items assessed seven different parameters viz. (a) The module content adequately covering the stated objective, (b) appropriateness of the module content to the proposed target audience, (c) the logical sequencing of the content in each module, (d) the adequacy of the activities included in each module to sustain participants' interest, (e) link between the activities included and the stated objectives, and (f) user-friendliness of the materials, There was an additional item for other miscellaneous comments along with open ended suggestion space, where each validators were asked to write their suggestions or opinion regarding the program under following headings 1). Which age group would be most suitable for getting trained in this developed program, 2). Suggest which severity group of ASDs would be most suitable, 3). Time period required for training in this module 4). Any other modifications required for the structure of this module.

The validation was conducted by each of the validators independently. Each of them sent their filled validation form to the researcher. For each of the five modules, individual ratings across the three experts and five parent evaluators were averaged for each parameter. Ratings close to four indicate higher ratings on a given parameter. Average ratings were also calculated across the seven parameters for each of the five modules. These reflect global evaluations across validators.

**Results: Evaluation of the PMI program modules**

Table 3.29

*Average ratings of the PMI program modules (N=11)*

| **Item** | **Average ratings (0-4 scale)** | | | | |
|---|---|---|---|---|---|
| | **SAS** | **Psy.Ed** | **BCS** | **FMS** | **MPB** |
| 1. Adequacy of content | 3.4 | 3.2 | 3.1 | 2.8 | 4.0 |
| 2. Appropriateness of the content | 3.6 | 3.6 | 3.6 | 3.3 | 3.7 |
| 3. Logical order of content | 3.6 | 3.8 | 3.5 | 3.7 | 3.9 |
| 4. Adequacy of number of activities | 3.7 | 3.7 | 3.5 | 3.4 | 3.8 |
| 5. Objectives-activity link | 3.5 | 3.8 | 3.5 | 3.7 | 3.9 |
| 6. Mode of delivery | 3.6 | 2.9 | 3.3 | 3.2 | 3.6 |
| 7. Take-away materials – informative | 3.3 | 3.4 | 3.5 | 3.7 | 3.9 |
| **Average ratings** | **3.5** | **3.5** | **3.4** | **3.4** | **3.8** |

SAS – Social Adaptive Skills; Psy. Ed – Psychoeducation; BCS –Basic Communication Skills; FMS – Fine Motor Skills; MPB – Management of Problem Behaviors.

Table 3.29 provides the combined average ratings of the PMI program modules by the two sets of evaluators. The ratings were averaged, in view of the observation that these were highly similar across the two sets of evaluators. Thus, each of the six modules received average scores of three or more indicating higher ratings on each of the seven parameters. There were only two instances where the average rating for any given parameter was below three. One was regarding the adequacy of the content (module onpsychoeducation), and the other was on the friendliness of the presentation (psycho-education module).

Table 3.30

*Evaluation of PMI program modules: Qualitative feedback*

Several suggestions were made by the evaluators to improve the program modules. Various suggestions made by the validators for each of the modules were compiled

| **Suggestions by evaluators** | | **Modifications made/Remarks** |
|---|---|---|
| **Social Adaptive Skills** | | |
| Content | Simplify the content | Removed some of the technical jargon as suggested. Those kept were explained clearly during the actual presentation |
| | Reduce the content | The content was not modified in a major way but it was decided to focus more on critical areas during the actual presentation |
| | Contextualize the content to suit our culture Scenario | Information and examples from tour culture or Indian family context were included, wherever Available/applicable. |
| **Psychoeducation** | | |
| Content | Contextualize the content to suit for our culture and family set-up. | Information and examples provided from our cultural context, wherever Available/applicable. Included examples from our day today life situations. |
| | Reduce the number of reflective activities | Reduced individual-focused activities and added group activities. |
| | Make a clarity about stress management and awareness regarding ASD | A short input on the link between awareness regarding ASD and stress management was added |
| | Content too simple | Considering the purpose of the program, the input was deliberately kept simple. |
| **Basic Communication Skills** | | |
| Content | Introduce receptive speech and expressive speech as stand-alone section or module | While an important suggestion, this could not be incorporated due to time constraints and feasibility issues. In this module we are targeting a basic communication skills training for children, which includes basic receptive and expressive skills. However, there were no reflected need for a separate module. |
| | Include more content about all forms of Communication problems | Could not be included due to time constraints |
| | Provide information on Speech therapy services in the city | Provided at the end of the specific Module as well as at the end of the program |
| **Managing Problematic Behaviors** | | |
| Content | Reduce the content | The content was kept as earlier, critical aspects were emphasized during the presentation (training). |
| | Follow continuity in Module | A slight rearrangement of the content and order was made |
| **Fine motor Skills** | | |
| Content | Reduce the content | Content on the communication section reduced. |

| | | |
|---|---|---|
| | Reduce the number of Sub themes | Removed self-assessments but the tests were given as take-away material |
| | Focus only on Basic skills and specify it | Fine motor section was refined to focus more on basic and essential skills. |
| **General suggestions** | Reduce the overall length of the content. | On the modules managing problematic behaviors and fine motor skills, there was a strong recommendation to reduce the content. This was taken care of in terms of actual content and/or during the presentation (training). |
| | Have supplementary videos | Added videos to awareness of ASD, managing problem behaviors, building basic communication skills, and social adaptive skills modules. |

Several suggestions were made during the evaluation of the modules by the evaluators. As shown (Table 3.30) the majority of the suggestions were regarding the amount of content of the modules, and a few were about the Presentation. The above table also shows the actions taken by the researcher to incorporate the suggestions made by the expert and parent evaluators.

**Description of the PMI program modules**

Following the evaluation of the program modules, the contents (with supporting materials), mode of delivery, along with the estimated duration for each of the modules were finalized. These modules served as the core sessions of the newly developed PMI program.

**Sequencing of the PMI modules:** While each of the modules in the PMI package has a specific theme and a potential to be delivered as a stand-alone workshop, the modules and their order of use were decided in a logical sequence for the whole program.

1. Psychoeducation: In the second module, autism awareness and taking care of mental health in general, as well as some specifics about two of the most common issues to handle, are introduced. It was decided to introduce these parent-oriented modules as integral to goal achievement

2. Social Adaptive Skills: Keeping in mind the importance of having goal/goals in life and the role self-independency in life pursuit and its link to overall wellbeing or quality of living, thus the module on Social Adaptive Skills acquisition in children with ASD is very essential, therefore kept this as the initial module. This also ensured that the first module was on a theme that most stakeholders could easily connect to, and they wanted at the utmost. This is the basic things to work on other skills.

3. Basic Communication Skills: The third module focused on building basic communication skills in children with ASD and was kept here considering its overall implications for previous modules. If they able to express and comprehend the language then only, we can address the higher skills of the child.

4. Managing Problematic Behaviors: Subsequently, module on managing problematic behaviors was introduced as it was considered a logical follow up to the sections before starting fine motor skills. This module provided input related to managing destructive and disruptive behaviors as well as nurturing positive behaviors in the child. The role of managing problem behaviors in day-to-day life as a vital factor for their well-being was emphasized.

5. Fine Motor Skills: Module on fine motor skills was kept at the end due to a couple of reasons. Firstly, it was decided that this would provide a natural conclusion to a program that started with helping participants taking care of their own activities of daily living. The second reason was a practical one. This being the shortest of the modules was most suitable as the last one to afford a proper closure to the program and allow for enough time to recapitulate the overall program experience.

Thus, with the first module, the participants were provided a space to think about and revisit their goals and enhance further understanding about social adaptive skills in their children. Afterward, the facilitating/hindering influence of parents' mental health and awareness about ASD, stress management and overall motivation was discussed. Next, in the Basic communication skills module, they were given a chance to learn about the basic communication skills, at least to express their needs and wants through some non-verbal means. On the next module on Managing problem behaviors the role of positive and negative behaviors in day-to-day life and their regulation which in turn had an impact on one's attempts at leading a productive life. In the last module, the concept of fine motor skills training as a means for efficient use of other functions in daily living and its role in promoting overall growth and productive life in daily living was discussed. In addition to the core sessions, brief orientation and closure activities were included at the start and end part of the program, respectively. The details of the orientation session are given in the section below, where the core module descriptions are given.

Several suggestions were made by the expert validation phase for improving the modules. Across the modules, the most common suggestion was to include more videos. Regarding the content and length of the modules, there were opposing views wherein a few suggesting reducing the content and duration while the rest suggesting increasing these two. While modules Psychoeducation and Basic communication skills saw several participants asking to increase the time duration and content, fine motor skill and managing problem behaviors modules received comments that suggested a reduction in the content and overall time duration. Overall, it was found that, while the expert validation participants reported a positive program experience, improvements in several areas were still possible. Further, relevant suggestions from the experts' suggestions were incorporated, and the modules were finalized.

**Techniques or Strategies used in Intervention program**

The on-ground intervention techniques were drawn from several sources. The behavioural interventions in this study involved strategies that enabled children to acquire certain behaviours to cover deficits and/or to tone down excesses in typically

contrived environment before these changes become permanent characteristic of the child's behaviour. The emphasis was on analysis of here- and – now antecedents and/or consequences, which if manipulated was used to alter any given wrong behaviour.

The intervention typically included involvement of parents, peers, co-therapist, adoption of certain characteristic teaching methods, covering the particular curriculum spread across varied environmental settings, level and variety of skills and simultaneous reduction of aberrant behaviour.

The ground techniques used for the study involved compliance training, activity scheduling, use of rewards, careful selection of instructional materials and procedures like environmental manipulation, operant techniques like shaping, chaining, prompting, or fading, contingency contracting, token economy, time-out, extinction etc. Stress was given to the customised or individualised instructions as per the requirements of each child. Thereafter, the children as well as parents/caregivers were continuously shadowed across settings like school, home or during play to achieve transfer of learning, generalisation, integration, and mainstreaming.

The individualised remediation techniques implemented after functional analysis of each problem behaviour included extinction, differential reinforcement, time-out, physical restraint, restitution or over correction, conveying displeasure etc. additional guidelines given to parents/caregivers on home based program application included resolving disagreements between caregivers, enabling them correct identification of functions underlying specific problem behaviours, recommending them to desist against use of ad hoc, arbitrary or counter-productive techniques like false inducements, nagging, pleading, begging or bargaining with children.

**PMI Program Modules Details**

A brief description of the PMI orientation session is given below, followed by a brief description of each of the five modules with important details are presented in the following section.

**PMI for Children with ASD: Orientation Session**

Considering the importance of the induction process of participants for maximizing engagement throughout the program, a brief, 30 minutes activity-based orientation session will be conducted, after baseline-assessment.

The orientation included a brief introduction to the program, along with activity to promote bonding and cohesion among the participants. While the program name and what it entails was described in the announcement posters, it was felt that participants need to be given a chance to reflect on the same. Also, the orientation included a description of the disclaimers (limits/what not to expect) to help the participants keep realistic expectations about the program. After this, the participants were divided into three groups for an activity involving small teams. The task entailed solving fill in the blanks about Autism, make a skit regarding a child with autism and their problems, and a role play of doctor and patients. From one group one participant act as doctor and another group one parents, clarifying their doubts and facilitator would help them to fill the gaps. The quiz regarding autism also planned. This quiz would center on the five core themes of the PMI program. Following the game, the facilitator explained the purpose of the activity. The explanation was then connected to what the program aims to achieve and the rationale behind the same utilizing research on the role of intentional activities as a contributor to well-being.

Table 3.31

*A brief outline of the PMI Core-modules*

This table provides a concise description of Parent Mediated Intervention Core-modules.

| **Module – 1: Psychoeducation** |
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| **Rationale:** For the successful and efficient implementation of any therapy or intervention, it is imperative that the participants have a clear understanding about the program. Providing the participants with a chance to learn in-depth about the intervention would facilitate the same. Further, knowledge about the specific issue |

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| that is addressed is also crucial along with the intervention. It is found that improved knowledge facilitates a shift to positive attitude and improved self-efficacy to engage in the practices that are suggested. | |
| ***Duration*** | Two sessions (Approximate) |
| ***Module objectives*** | • To familiarize the participants with the program<br>• To enhance the knowledge of the participants with Autism and related concepts |
| ***Module subsections*** | |
| ***Section 1*** | **Familiarizing the participants with the program**<br>In this part, the therapist provides a detailed description about the program and its purpose to the participants. Opportunities are also provided to clarify doubts if any. |
| ***Section 2*** | **Familiarizing the participants with the concepts related to Autism**<br>Here the participants are provided with information regarding the following areas<br>Features of autism and autism spectrum disorder<br>Causes of Autism and autism spectrum disorder<br>Available management options for ASDs |
| ***Section 3*** | **Assessment of the participants understanding about the ASD**<br>Immediately before and after the psychoeducation is provided, a brief objective type assessment would be |

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| | performed to get an immediate change in the participants with respect to ASD. For this a self-developed checklist would be used. |
| ***Section 4*** | **Engagement of Parents and Improving communication with their ASD child**<br><br>Activities to enhance child-parent relationship, improving engagements of each parents assigned child's duties equally to both of them. Break from taking care of child for each parent's alternative basis: suggestions, planning and execution. |
| ***Section 5*** | **Addressing Parents stress Burden and Accessing Respite Care**<br><br>Accessing respite care complications<br><br>Knowledge about existing services available<br><br>Need for and importance of own mental health and availing Respite care services<br><br>The role of healthcare professionals in seeking respite care services and additional supports<br><br>Facilitating factors and barriers to accessing respite care services for children with autism |
| ***Procedure*** | This would be a session that would focus on the educating the parents about the components described above. It would be a one-to-one session between the therapist and the parents. The assessment of knowledge would be conducted separately for both parents. |

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| ***Materials required*** | Take-away awareness pamphlets and reading materials |
| ***Expected outcomes*** | • Enhanced knowledge of the participants about Autism and related concepts. |
| ***Delivery mode:*** | • Involves a group activity, group presentation, and Power point presentations. |
| ***Conclusion*** | • This section includes a summary of the overall content and feedback was taken along with the screening of a brief video. |
| **Module – 2: Self-help skills** | |
| **Rationale:** Self-help skills include brushing, toileting, bathing, eating, self-help dressing or grooming. Eating and drinking skills are essential and surviving self-help skills for any individual to fulfil his or her basic physiological and psychological needs. Learning life skills is critical for individuals with autism who seek to enhance their independence at home, school, and in the community. When these skills are taught early and gradually, people with autism get the tools they need to live on their own to some extent, with more self-esteem and more happiness in all areas of life.<br><br>When children practise self-help skills such as toileting, brushing, bathing, and grooming, as well as feeding and dressing themselves, they develop their gross and fine motor skills, gain confidence in their ability to try new things, and develop their self-esteem and pride in their independence. The term "self-help" is frequently used to refer to the following areas of independent behaviour: Toileting, bathing, brushing, grooming, eating, feeding, and drinking are all necessary activities. These abilities may include properly holding and using utensils; drinking without spilling; eating a variety of foods; using a napkin properly; cleaning up after toileting; table | |

<table>
<tr><td colspan="2">manners; and other mealtime routines, among others. So, this module is all about helping kids with ASD in all of the above areas of life.<br><br>Independence in self-help skills as well as social skills are so crucial to surviving his life. Over time, a healthy person can achieve this skill as a result of the opportunities given to him/her in the environment.<br><br>This module explains how to train a child with autism spectrum disorder (ASD) step-by-step so that he/she can independently acquire certain skills and participate in various functions in their day-to-day lives.</td></tr>
<tr><td>Duration</td><td>Would differ child to child</td></tr>
<tr><td>Module objectives</td><td>To train a child with autism spectrum disorder (ASD) step by step so that he/she can independently take his food and participate in various functions where he has to observe good manners in the company of his friends, relatives, and family members.<br><br>To learn independence in toilet skills by indicating the need to clean and dress up after the toileting<br><br>To attain full independence in oral hygienic functioning<br><br>To attain maximum independence in self-bathing<br><br>To attain the ability to dress on your own</td></tr>
<tr><td colspan="2">Module subsections</td></tr>
<tr><td>Section 1</td><td>Familiarizing the participants<br><br>In this part, the therapist provides a detailed description about the program and its purpose to the participants. Opportunities are also provided to clarify doubts if any.</td></tr>
<tr><td>Section 2</td><td>Prepare the child for attaining self-help eating skills</td></tr>
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| *Sub-module: Self – Eating Skills* | Step-by-step activities to teach self-eating were explained separately and included a task to train the child to suck, chew, and swallow, as well as prepare the child to recognise edible and non-edible substances.<br><br>Self-eating and drinking skills are essential and surviving self-help skills for any individual to fulfil his or her basic physiological needs of thirst and hunger. All infants are born with an oral reflex, which is the first reflex in every human being. These reflexes help the baby suck and swallow. Progressively, he/she learns to eat semi-solid and solid food. As he/she grows, suitable self-eating skills are required to endure his or her life in society. So, eating independence is a self-help skill as well as a social skill needed to survive in life. Over time, a healthy person can achieve this skill as a result of the opportunities given to him/her in the environment.<br><br>There is an affinity among parents to feed instead of training the children with ASD to eat by him/ herself. This action prevents him/her from achieving his eating skills. Most of the time, he is restricted from participating in social functions where he or she has to exhibit accepted mealtime manners.<br><br>This module explains how to train a child with autism spectrum disorder (ASD) step-by-step so that he/she can independently take his food and participate in various functions where he has to observe good manners in the company of his friends, relatives, and family members. |
| *Procedure* | Train the child to drink when he is thirsty**,** Train the child to eat when he is hungry**.** If the child does not indicate his |

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| | hunger or thirst, follow a schedule as the child starts to show his hunger or thirst to use that signal. If the child can use gestures for food, use this opportunity to train in eating and drinking**.** Progressively encourage him to indicate his hunger and thirst through gestures/words when he is hungry and thirsty and use that time for training. Let the child joining the family members during mealtime. Give him chances to observe mealtime manners. Give him opportunities to eat with relatives and friends and in restaurants. A child's physiological need to eat and drink is the first prerequisite for training.<br><br>1. We need to reinforce the child for what he/she would do<br><br>2. Find the levels to know where, when and what to train<br><br>3. Understand the problems and have the patience to train one step at a time<br><br>4. Use appropriate rewards for the child's cooperation and attempts<br><br>5. Training Activities in a step-by-step manner are explained in the following pages. Follow the methods during training. If needed, modify it appropriately depending on the needs/requirements of the child.<br><br>Training of self-help eating can be successfully accomplished through the following steps of training<br><br>• to train Sucking and Swallowing skills<br><br>• to train chewing and swallowing skills<br><br>• development of tongue movements<br><br>• recognizing edible and non-edible substances |

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| *Materials required* | Any materials which is suitable for the activities |
| *Expected outcomes* | To develop sucking, chewing, and swallowing abilities, as well as complete independence in tongue movements and the ability to discriminate between edible and inedible substances. |
| *Delivery mode:* | Involves an individual one-to one instruction to mother by involving power point presentation and showing videos, PowerPoint Presentation input. |
| *Section 3*<br><br>*Sub-module: Toilet Skills* | **Prepare the child for independent toileting**<br><br>Step-by-step activities to teach independent toileting were included in this section.<br><br>Toilet training is an essential skill to be attained for everyone. It refers to the training imparted on how to use the toilet appropriately whenever needed. Toilet training would include taking off one's clothes, urinating and defecating in the toilet or the right place, cleaning oneself afterward, flushing the toilet, and getting dressed again.<br><br>Unlike providing training in feeding, bathing, and dressing skills, toilet training is the one thing that cannot be done at the time a trainer wishes to do so but should train the child when he has the biological need to eliminate. Consequently, it commonly becomes the duty of the mother or caregiver at home.<br><br>Before starting training, we need to check whether the child is fit to get toilet training through the following points:<br><br>First, the child's physical condition is an essential factor |

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| | in toilet training. We need to check whether the child can always stay dry for one hour, with a regular intake of fluids in a non-rainy time of year. Another thing to think about is that we need to make sure that the child doesn't have any physical problems with bladder and bowel control.<br><br>In cases like this, another important thing is the child's level of comprehension ability. We need to see whether the child has a two-year-old's comprehension ability. Physical guidance and doing the action with the child at the same time as you say the word for what you're doing (come, go, sit, wash, etc.) are ways to teach a child to follow simple instructions if they aren't able to.<br><br>More importantly, the child's physical or motor ability to remove the dress, put on a dress, and reach the toilet is essential to train the child to do toileting independently. |
| *Procedure* | Toilet training can be done by attaining the following goals through specified activities:<br><br>1. Indicates the toilet needs based on the situation.<br>2. Ability to find the toilet and reach there physically.<br>3. Skills to open and close the door<br>4. Capability to remove and re-wear underwear or pants after toileting<br>5. Sitting on the toilet<br>6. Ability to detect when he eliminates<br>7. Abilities to wash one's bottom and hands<br>8. Flushes the toilet/pours water<br><br>We have set appropriate goals to make the child |

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| | independent in toileting to help the child achieve this skill. |
| *Materials required* | Any materials which is suitable for the activities |
| *Expected outcomes* | To achieve the ability to express his or her toilet needs<br>To accomplish the ability to finds the toileting area when needed.<br>To attain the ability to learn to open & closes the door<br>To attain the ability to removing/unbuttons/opens appropriate clothing before toileting<br>To attain the ability to sits/squats on the toilet<br>To attain the ability to recognize when elimination take place<br>To attain the ability to washes his bottom and hands after using toilets<br>To attain the ability to flush the toilet after completing the use of toilets |
| ***Delivery mode:*** | Involves an individual one-to one instruction to mother by involving power point presentation and showing videos, PowerPoint Presentation input. |
| ***Section 4***<br>*Sub-module: Brushing* | **Prepare the child in Brushing**<br>Step by step activities to teach independent brushing were included in the module. Care of the teeth and gum is an essential part of personal hygiene. Children with ASD require systematic training in this area. While we brush our teeth, we hardly pay attention to the steps involved, because brushing is part of our custom routine. Whereas, |

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| | training a child with ASD would require careful efforts at every step. Then only they will be able to attain full independence in this functioning. It helps to make a habit in the child that, after toileting, brushing is the first thing he must do. Helps him/her to link brushing habits with other activities of the day, such as getting up and before hitting the bed. Show him/her to squeeze the tube and apply the required amount of paste on the brush. Teach to put only the required amount of paste /powder (this might have to be repeated until he/she learns). For easy grasp: use toothbrush that has a large handle or covers the handle with cloth (if the child has reduced hand grips or sensory deficits or fine motor deficits) |
| *Procedure* | Keep the toothpaste and brush in a place where the child could access it easily. Preferably keep a different color toothbrush for him/her, so that they learn to identify it by color and discriminate it from others. Guide the child to carry toothpaste/powder, the bucket of water and mug, to the place of brushing (washbasin). Initially better to train the child with given water instead of using water taps. |
| *Materials required* | Toothpaste, Tooth Brush, mug, water, tap water, any other items required, etc. |
| *Expected outcomes* | – Child will get an idea successfully regarding the steps of brushing teeth<br>– Child will learn to brush with the physical prompt by the mother or any caregiver.<br>– child will learn to brush without any support and child also will learn the following skills |

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| | • Take water in the dominant hand<br>• Pour it in the mouth<br>• Gargle<br>• Spit<br>– child will learn to clean the tongue alone |
| *Delivery mode:* | Involves an individual one-to one instruction to mother by involving power point presentation and showing videos, PowerPoint Presentation input. |
| ***Section 5***<br>***Sub-module: Bathing*** | **Prepare the child in Bathing**<br>Step by step activities to teach independent bathing were included in the module. It is a general tendency of parents to assist their children in having a proper bath. Over time, healthy children become independent, while ASD children remain to be reliant on others. So, the accountability lies with the parents to lead their ASD children to independence by letting them learn. This module helps the parents, how to train/guide their child with ASD to achieve independence in bathing by using proper methods, appreciation, and rewards. Training to be covered in the domains of independence in bathing, self-satisfaction/ feeling of self-confidence, sense of achievement, awareness of privacy, sense of cleanliness, and personal independence. |
| ***Procedure*** | Bathing is one of the self-help skills to be taught to the child with ASD. It includes the following significant steps such as putting oil on body/hair is very common in Indian culture, afterward removing cloths and keeping the clothes |

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| | safely. Then move on washing body and hair with applying soap/body wash/shampoo and rubbing/scrubbing. After doing this correctly, the child would move on the next step of washing off soap/shampoo and wiping the body and drying hair. Finally, the child has to wear clothes. This is the stepwise functioning involved in the bathing task.<br><br>A healthy child baths self with minimal supervision by the age of 6 years. The child should attain the following abilities to qualify for the training to be conducted, and those are a child who can follow instructions, has proper eye-hand coordination, which is necessary for applying oil and soap, pouring water, and drying the entire body parts. If the child qualifies on these, he or she is eligible to get it trained. |
| ***Materials required*** | Any materials which is suitable for the activities |
| ***Expected outcomes*** | The following are the significant steps would be learned by the child through the training in this module.<br><br>1. Removing cloths<br>2. Applying soap<br>3. Rubbing/scrubbing<br>4. Pouring water<br>5. Wiping hair<br>6. Wiping the other body parts<br>7. Wearing cloths |

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| ***Delivery mode:*** | Involves an individual one-to one instruction to mother by involving power point presentation and showing videos, PowerPoint Presentation input. |
| **Module – 3: Basic communication skills** | |
| **Rationale:** Communication problems are a primary concern in autism spectrum disorder. An individual with ASD may begin talking very lately or may not learn to speak at all; some may learn to utter words and sentences but have difficulty using them effectively to make interactive social purposes. This area of skill became very much significant in the intervention programs for ASD, because of its importance in day-to-day functioning and the deficits of communication ability is predominant in comparison with other skill areas affected in ASD. Intervention for communication deficits in ASD would be categorized into two broad sections; first will discuss the development of early, pre-linguistic communicative behaviours that lead to the beginning of language, the second will examine intervention for children who produce speech but have difficulty using it appropriately for social interaction. In this module, we have chosen to take up the fundamental components of communication, which would help the child to function independently to an extent. | |
| ***Duration*** | Would differ child to child |
| ***Module objectives*** | • To teach communication skills at first, we need to prepare the child to react to sounds.<br>• To train the child to respond to sounds<br>• To train the child to respond with gestures<br>• To train the child to carries out simple instructions<br>• To train to learn to successfully respond by nodding or using simple words like yes/no<br>• To train the child to identify/recognize family |

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| | members by name and familiar objects and its name in his surroundings<br>• To train to identify and recognize his or her body parts and to show his/her body parts whenever is required<br>• Train to tell his/her name when and where requires |
| ***Module subsections*** | |
| ***Section 1*** | **Familiarizing the participants**<br>In this part, the therapist provides a detailed description about the program and its purpose to the participants. Opportunities are also provided to clarify doubts if any. |
| ***Section 2*** | **Prepare the child to react to sounds**<br>With the help of noise making toys, we produce sounds and watch for the child's response to it. If he responds by moving towards sounds, we need to appraise the child by clapping or tapping hands on desk or the way they desired. Preparing the child to react sounds by encouraging the child if he makes response to the noise we make. |
| ***Section 3*** | **Preparing the child to respond with gestures**<br>Through imitation strategies we teach the child to learn gestures and responds by imitation when parent does it. Likewise helps the child to learn to comprehend other gestures and express or reciprocate through gestures successfully. |
| ***Section 4*** | **Prepare the child to comprehend the instructions and react to it desirably** |

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| | Initially, parents must add visual cues by showing hands when the mother/caregiver tells him to come. When the mother tells him 'Take the ball,' get his attention and demonstrate the activity. Gradually reduce visual cues. Praise him when he follows instructions and carries out the action. Likewise, each target or work can be attained. If the mother wants the child to perform some activity, convey it straightforwardly. |
| ***Section 5*** | **Prepare the child to nod head appropriately, and use 'yes' or 'no' in communication.**<br><br>Almost all the experts suggested imitation techniques to teach this skill for the child. Same way at home, we can ensure that whenever the child tries to indicate any sort of negative or positive responses towards our questions by nodding or saying, 'yes' or 'no,.' parents need to reinforce this by shaking our heads and say 'yes' or 'no' then makes the child also repeat after us. This can be done in all social situations and helps the child to train in all the variety of conditions so that he/she can attain mastery over this task so quickly. |
| ***Section 6*** | **Prepare the child to understand and recognize familiar people and objects**<br><br>We can start this training at home by teaching the child to identify family members and other close relatives and everyday objects used at home. Reinforcement and repetition are the strategy can be employed to teach this skill. |

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| ***Section 7*** | **Prepare the child to point, at least three body parts on self**<br><br>Imitation techniques can be employed to teach with the activity of point to a parent's eyes and tell "eyes." Take the child's hands and make him touch his eyes and tell "eyes." Take him to a mirror and let him touch his eyes and tell "eyes." Tell the child to point to his eyes and parent's eyes. Follow the steps to teach, pointing to other parts of the body also. |
| ***Section 8*** | **Prepare the child to say own name**<br><br>Through practice and repetition make the child to learn to tell his/her name when and where requires. Reinforcement, imitation, modelling techniques can be used to train this skill. |
| ***Procedure*** | This would be a module that would focus on the educating and training the parents about the communication skills of children with ASD. It would be a one-to-one session between the therapist and the parents. This module would be conducted as group session for all parents. |
| ***Materials required*** | Audio recorder, rhythmic rhymes, noisemakers, ball, water, glass, door, any other appropriate material; this will vary based on the activities which we choose., food items, toys, anything which the child likes, any other objects found suitable, toys and play materials, family members photographs, Mirror, any suitable situations, and materials can be used, Mirror, belongings of the child's such as pencil, pen, bag, dress, slippers, comb, and brush. |

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| ***Expected outcomes*** | To train the child on fundamental components of communication, which would help the child to function independently to an extent. |
| ***Delivery mode:*** | • Involves a group activity, group presentation, and PowerPoint presentations. |
| ***Conclusion*** | • This section includes a summary of the overall content and feedback was taken along with the screening of a brief video. |

| **Module – 4: Managing problem behaviours** | |
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| **Rationale:** The rationale for this parent-mediated intervention module is because of the excessive interfering behaviours in children with ASD. Applied behaviour analysis based antecedent based intervention method was chosen as a basis for the present module. Many research studies also supporting that Antecedent Based Intervention (ABI) strategies particularly helpful in preventing or reducing interfering behaviours as well as increasing on-task behaviours in children with ASD. Another reason is that ABI is easy to implement and requires little additional effort by parents. Moreover, ABI strategies are found to be useful for a variety of children with ASD across all the age range. Due to all these factors, we have chosen ABI as a solid strategy for the current intervention module. Thus, this will helps to reduce or prevent interfering behaviours and helps to enhance engagement and positive on task behaviours in children. Evidence-based studies suggest ABI based interventions have effective for children with ASD with the age range of 3 to 16 years. | |
| ***Duration*** | Would differ child to child |
| ***Module objectives*** | • To educate the participants about the behaviour therapy |

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| | • To educate the participants about behaviour therapy in context of ASD and the specific techniques used to reduce the interfering behaviours.<br>• To train participants in reducing or preventing problem behaviours and helps to enhance engagement and positive on task behaviours |
| ***Module subsections*** | |
| ***Section 1*** | **Familiarizing the participants**<br>In this part, the therapist provides a detailed description about the program and its purpose to the participants. Opportunities are also provided to clarify doubts if any. |
| ***Section 2*** | **Familiarizing the participants with the concepts related to ABI techniques.**<br>Here the participants are provided with information regarding the following areas<br>Antecedent based intervention strategies<br>Causes of problem behaviours |
| ***Section 3*** | **Training to conduct Functional Behaviour Analysis (FBA)**<br>This section of module emphasizes to enhance parent's skills in collaboration with therapist to understand behaviours, therefore parents can identify the reason behind each and every problematic behaviours shown by their children with ASD. |

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| ***Section 4*** | **Teach to detect specific antecedent based intervention plans** These plans can be used to modify the environment or activity to prevent the interfering behaviour from reinforcing. Results of FBA analysis would guide the parents and therapist for selection of appropriate intervention strategies, and this would vary according to the needs of each child. |
| ***Section 5*** | **Familiarizing and teaching the identified intervention strategies**<br><br>After completing the triangulation of data (Review of studies, experts opinion, personal insights from the work experience, we have identified particular behavioral intervention strategies that are effective and recommended as follows: Arranging the environment, Changing the schedule/routine, Structuring time, Using highly preferred activities/items to increase the interest level, Offering choices, Altering how instruction is provided, Enriching the environment so that learners with ASD have access to sensory stimuli that serve the same function as the interfering behavior (e.g., clay to play with during class, toys/objects that require motor manipulation), and Implementing pre-activity interventions (e.g., issuing a cue about the next activity, providing information about schedule changes). |
| ***Procedure*** | This would be a module that would focus on the educating and training the parents about the components described above. It would be a one-to-one |

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| | session between the therapist and the parents. This module would be conducted separately for each parent separately, as the intervention strategies need to be chosen would vary considerably. |
| ***Materials required*** | Suitable materials based on activities |
| ***Expected outcomes*** | • Enhanced knowledge of the participants about intervention strategies<br>• Teach/ train the parents to know the real cause behind the interfering behaviours so that that can be prevented effectively<br>• Helps to find the suitable plan of intervention techniques to reduce the problem behaviours in the child |
| ***Delivery mode:*** | • Involves a group activity, group presentation, and PowerPoint Presentations. |
| ***Conclusion*** | • This section includes a summary of the overall content and feedback was taken. |
| **Module – 5: Fine Motor Functioning** | |
| **Rationale:** Fine motor skills, including coordination of fingers, hands, and arms, are essential and which plays a significant role in activities towards independence. Not only arms coordination but also the coordination of the limb's skills are also inevitable for our independence in daily living. Most children with ASD have impaired or abnormal level of development and functioning concerning fine motor development. If we can detect the delay in earlier, early intervention and professional guidance can be useful in improving the child in different kinds of fine | |

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| motor skills. Hence, this module tries to include the activities for children to enhance their fine motor coordination through different variety of tasks and activities with the help of their parents. This will further help the children to make some steps ahead from where they stand at present concerning their independence in daily living activities and also in the overall functioning. | |
| ***Duration*** | It would vary client to client |
| ***Module objectives*** | • To train the child in all fine motor activities such as to reach objects, transfer objects, pick-up objects, grasps with hands<br>• To train on eye hand coordination |
| ***Module subsections*** | |
| ***Section 1*** | **Familiarizing the participants**<br>In this part, the therapist provides a detailed description about the program and its purpose to the participants. Opportunities are also provided to clarify doubts if any. |
| ***Section 2*** | **Prepare the child to reach for objects**<br>We need to be very vigilant in choosing the objects as per the child's interest. The one mostly preferred by the child should be used at first. We can motivate the child by showing objects, slightly at a distance. After that, as the child moves hands towards the object, let us bring it closer to the child and appreciate him/her. As the child gains competence, increase the distance gradually. Change objects if needed, to sustain his/her interest. Allow him to reach for a suspended fluctuating object. Hold his/her hands and move towards an object suspended within the |

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| | field of vision. Gradually reduce the physical help and motivate him to reach for the suspended object. As the child learns to creep/crawl, we need to encourage him to move in the direction of the objects and stretch hands to it. Let us choose real-life situations to reach for objects, such as allowing the child to reach for eatables, toys with a child who wants to play. To receive things whenever the situation occurs and also provide opportunities to respond to the calls getting from the familiar people to him also improves the child's skills. |
| ***Section 3*** | **Prepare the child to pick up objects using whole hands (Palmer grasp)**<br><br>We need to provide as much as possible to the child. Once he starts to learn to grasp and reach for objects, let him begin to pick up things by using the whole hand. Mostly a six month old child would start to use the whole hand to pick up things. We can do this activity by keeping an object-small ball or such small things, hold his hand, and help him to pick up the objects using both hands. Slowly we need to reduce the physical support and motivate him through pushing his hand towards the objects to pick up. Very importantly, never forgot to praise the child and provide more opportunities to pick up objects using the whole hand in daily living situations. Likewise, while playing, let the child pick up a toy and play with it. We may also provide chances to the child in the kitchen in activities like picking up vegetables. While bathing time gives chances to the child to use his hand picking up mug and soap, applying soap, squeezing water from small clothes, and so on. |

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| ***Section 4*** | **Prepare the child to grasp with both hands**<br><br>Once the child gain's ability to grasp, he may reach towards objects and use the whole hand to pick up objects. Thus, we need to train him to use both hands for grasping. We can provide training to the child in a comfortable posture, whether it could be sitting, standing whatever is comfortable. To provide this training at first, we need to select suitable toys, like the ones which need both hands to grasp, such as balls, squeeze toys, to move toys, and tins. We need to be very particular in choosing likable objects for the child to be used for training. At first, select any one of them. Then keep it in front of the child, and if the child does not reach it, take his hands around the object. Then, help the child to grasp it and lift it with both hands. If the child does this, appreciate him for doing this. Then, gradually reduce physical help, and later the child will be able to perform this by self. We may try using activities of daily living while drinking, where we can make the child hold a plastic or steel tumbler with both hands if needed. Let him do this with an adequate grip. Initially, they have very little liquid in the tumbler so that it does not spill and bearable weight for the child too. Provide toys that require holding with both hands. It can provide different variety of toys to prevent boredom in the child. While learning to stand make the child hold places or objects like tables, doors, and chairs with both hands. |
| ***Section 5*** | **Prepare the child releases objects**<br><br>It has been observed that few children might have difficulty to release objects after grasping them. This |

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| | problem must be dealt with by a medical professional. If any of the children have this problem should seek medical help first. Usually, by the age of 5-8 months, normal children start releasing objects deliberately. If suppose child does not release by himself, let us hold his wrist, push on the back of the hand, and tell him to release it. We can hold an object and then tries to get his attention and release it. After showing the child how to release an object, let the child also repeat it. While teaching releasing objects, we can show the child that, how fragile objects like glass and breakable toys are kept on the surface before releasing hands. This has to be taught by using the chaining principle. We have an alternative task for children who have a problem in releasing objects, and they often respond well when asked to squeeze water from a sponge. We can do this, preferably before the child goes to the bath. Let us make the child sit comfortably. We need to keep water in a tub and two pieces of sponge in it. Then let us physically assist the child in picking the sponge out of the water and squeezing. Then release the sponge into water. Let the child do it with both hands alternating. We can make this task more interesting by adding colour to water or change of temperature of water within limits. Many parents have reported success with this procedure as per the inputs given by experts in this field. Similarly, where the child holds the toy as he likes it and may not want to release it, in this situation, we should not force him to release it instead sensitize him of things that would get damaged if he released from a height or whatever situation he is. |

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| ***Section 6*** | **Prepare the child transfers from one hand to another**<br><br>Usual children automatically learn to do this task. If the child fails to do this on his own, we need to provide individual training for him/her to achieve this ability. These are the steps that we need to follow to teach the child. At first, ask the child to pick up an object with one hand and tell him to do so, and also, we need to physically guide the child to move the hand with the object towards the direction of the other hand. We need to guide the child to transfer the toy/object from one hand to another. Then gradually, we need to reduce the physical support and give him verbal cues. We should not forget that for each attempt, we need to praise the child. Like other tasks, we need to be vigilant in choosing objects which are preferred by the child for the task. This is the factor that helps the child to be interested in this task. We can do this task in other situations as well. For example, during play, we can ask the child to sit in a circle with other children. We can choose games like passing the toys by transferring the object from one hand to another and to pass to the next child's hand. Praise the child whenever he attempts to do this. The same way we can train this skill in daily life situations/real-life situations where we can make use of all the possibilities comes. For example, imagine that if the child has a toy or anything in his right hand and if he/she has to receive something from another person. In this situation, tell the child to transfer the object in the right hand to the left hand and to receive the new object with the right hand. |

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| ***Section 7*** | **Prepare the child grasps two objects one in each hand**<br><br>Once the child can develop a palmer grasp (ability to close the hand when there are any objects placed in the palm of the child). As the child develops a palmer grasp, we can start training the child to hold objects in their hands. At first, we need to make opportunities for the child to pick up objects with one hand, preferably the dominant hand. Tell the child to hold it, while holding one object in the dominant hand, ask the child to pick up another object with the other hand and hold it. When the child reaches one minute of time of holding objects, we can tell the child to release it. We need to praise the child for each successive task completion. If the child is not able to succeed in the task, either unable to hold or fails to complete the period, we need to praise him for doing as much as possible for him and again motivate the child to repeat this. We can make this a game task for keeping the child interested in the task. We can arrange a game task to pick up small objects with a dominant hand at first and transfer to another hand or any container on the other hand. Once the child gets comfortable with this, let us give chances of transferring objects from non-dominant hands to dominant hands also. As per the age of the child, we need to make the more activities list. For an, e.g., when the child holds a vessel in the non-dominant hand, tell him to transfer this vessel to the dominant hand and pick up an apple and eat with the non-dominant hand. We can choose other activities such as picking up two toys, one in each hand and walking or running towards a point or the task like bringing two cups or fruits one in each hand. |

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| ***Section 8*** | **Prepare the child picks up using fingers**<br><br>More coordinated movements are required for the child to pick up objects by using thumb and fingers. If the child reports any sort of physical deformity or defects to need to consult medical practitioners and also advised to seek physiotherapeutic interventions. Inactivity, we need to hold the child's hand and get fingertips together, then let us help the child to move the hand towards the objects and assist the child in picking up with fingertips. Progressively let us reduce the support provided to the child. We also need to be very careful in using activities based on the child's interest. We need to remember this; also, we will not be able to carry out any activities without the child's cooperation. Hence that should be our priority while choosing things to do. Activities can carry out in different settings, like the therapy room, home, and school.<br><br>A wide variety of activities such as, we can ask the child to put things in a bowl and ask the child to take them out slowly can be an excellent task to train this goal. We can also make the child performing a task, then asking the child to take gem clips from a magnet pin container as this provides a more coordinated way of exercises for the child. Additional activities, like make the child pick up clips from the cloth line, asking the child to clean grocery items such as a variety of grains and daal. Besides this, picking stones and other wastes from rice and wheat and sort them separately. These games can plan with a group of other kids where we can give a specific time, within that stipulated time let the children pick up small objects. After |

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| | the completion of each task, we need to praise or reinforce the child in all possible ways. |
| ***Section 9*** | **Prepare the child stacks objects**<br><br>Provide training through daily living activities, we can train the child to pick up objects, to maintain grasp, and to release the object at his/her will. There are different situations in every body's life where we might have to stack objects. So, an initial period of training, we may use toys or play materials to the child to stack things. For example, building blocks, progressed cylinders, and so on. Later tins, cans, books, and such other items also can be used. Activities such as arranging own clothes in wardrobes, closing the tiffin box/carrier after filling foods, helping a mother to arrange or stack plates/glasses or other utensils, piling up and arranging magazines, newspapers, and books. |
| ***Section 10*** | **Prepare the child turns doorknobs/latches/bolts**<br><br>As we all know that adequate finger coordination and hand functioning are essential to perform many activities of daily living. When we look into the doors of different houses/buildings, we can observe that different varieties of knobs/latches/bolts are used. If the child has to be independent in opening or closing doors, we need to introduce training to the child in operating different types of latches and knobs where a child might have to confront in his later life. If he gets training now itself, he will not face many difficulties later. We can use the actual situation for training this, where the child will start manipulating the latches in a house first. As the child learns these skills, |

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| | gradually introduce verities of knobs and latches when the child is taken out to relatives' and friends' houses. In such a situation, make him open and close doors whenever needed. It is essential to train him to turn the doorknobs or fix latches of toilets so that the child can maintain privacy while using them. While doing this, make sure that the child does not lock him/herself inside the room. The readiness of the child to learn is crucial before starting the training. |
| ***Section 11*** | **Prepare the child in eye-hand coordination**<br><br>Eye-hand coordination skill is essential for performing very basic to the advanced level of daily living activities. Which is inevitable for each one. There are different types of activities, through which we can deliver fine motor skill training. Stringing is one such activity that needs the right level of eye-hand coordination. Ability to thread/string leading to making garlands and many other activities are enjoyable and useful in our life. To train on this, we need to choose beads/objects with big holes so that it will be easy for the child. At first, let the child see while the parent inserts the string through-hole of the bead/object. We need to help the child to hold a string edge in the right hand between thumb and index finger and the bead/object with a hole in the left hand. We need to ask the child to look at the hole clearly and move the string towards the hole slowly, then insert and pull the needle from the other side of the hole. In order to make it easy, the string should be preferably shoelace or a similar one with a hard edge. The edge can be made stiff by applying melted wax. Secure the other end of the string with a bead so that strung beads do |

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| | not fall off. We can provide different choices for the child. For example, make paper rings pasted at either ends or pieces of sticks which have holes. As the child gains competence, provide needle and thread-initially long blunt needles and gradually the sewing needles. Other activities like Inserting shoelace, making flower garlands, making paper garlands, making bead garland, threading for sewing, sewing patterns on boards are also can be used to train. |
| ***Procedure*** | We can ensure an adequate level of fine motor skill training by making the child engaged in activities. In order to implement that we need to choose activities of daily living depends on the age and ability of the child to train the child in fine motor skills. Fine motor skill training is always activity oriented. Thus, this helps to stimulate infants in early life for active movements of upper limbs to reach out and to grasp objects available in the surroundings. In order to reinforce the child, let the child get more chances to see how others are using their hands for grasping, and playing with toys. When a child gets older, allow him to use his hands to pick things up, to eat, to brush, to wash and wipe face, to play, and help a mother in daily chores. If we can provide, more recreational activities such as different types of play and games to the child, such as playing with toys, drawing, and painting can facilitate positively to the child's development in diverse ways. Usually, children get quickly reinforced and motivated to engage in such activities. Which, in turn, results in drastic progress in the fine motor functioning of the child. More importantly, we need to consistently |

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| | reinforce the child for each attempt and success he makes. Gradually, as the child attain the basic functional skills mother or caregiver can introduce other skills such as prevocational and domestic skills like gardening, packing, assembling, carpentry, spray painting, and washing dishes, and so on. Let give a chance to the child to observe these and learn from this. |
| ***Materials required*** | Suitable materials based on activities |
| ***Expected outcomes*** | a child will learn mastery over the fine motor skill involved activities |
| ***Delivery mode:*** | • Involves a group activity, group presentation, and PowerPoint presentation. |
| ***Conclusion*** | • This section includes a summary of the overall content and feedback was taken along with the screening of a brief video. |

**PMI Program Closure Session**

On the final day of the PMI implementation, immediately before the post- assessment, a brief closure session may conduct. The closure included a brief overview of what has been covered from the beginning, a brief Question and Answer session (a chance for the participants to clarify doubts, if any regarding the overall program), and a feedback session where the participants shared their experiences about the program.

**A note on session structure:** The five modules, as evident from above, were designed to be delivered using a mix of different methods of knowledge. An attempt was made to make all the modules as interactive as possible. While the content revolved around the core themes, informative elements were included wherever possible. This was in the form of additional activities, educative videos, brief games, short exercises, stimulating questions, etc. It was believed that a combination of various methods of

learning – reflective questions, discussions, debates, videos, individual and group activities (if possible) – will create an atmosphere of experiential learning for the participants.

While the above tables provide a glimpse into the actual program content, it is important to note that all the modules started with a warm-up activity and ended with a short video about the module content. Also, each module had a break-time of about 10 minutes in between. Further, the warm-up exercises at the beginning of the module and energizer activity immediately before the commencement of the afternoon session ensured that an element of fun, while keeping the core themes at the center, was achieved.

**A note on the videos and other supplementary materials used in the program:** A few videos were used in the program for enhancing the impact and for emphasizing core messages. These included videos which were available on online platforms and were free to use for non-commercial purposes. In all the instances, the videos were shown with due credits to the developers.

Among the various supplementary reading and-take away materials that were used, some of them were prepared by the researcher himself while others were used with permission (wherever it was required to obtain the same) and the rest were downloaded from online platforms (no special permission was required). In all instances, the original authors/owners were given due credit for the materials used.

**PMI program development phase: Results summary**

The PMI program development phase started with an extensive review of literature. Subsequently, an exploratory interview was conducted involving stakeholder consultations (professionals and parents) about the proposed program. Field experiences of the researcher and guides were also considered. Further, experts' validation and their opinion and suggestions of the program modules helped in fine-tuning program delivery. Triangulation of data from all these sources helped in developing the PMI program during the second phase of the study. Thus, the developed PMI program, with its five modules was ready for implementation.

## STAGE III – PRELIMINARY EVALUATION (CLINICAL PILOT-TRIAL RUN OF PMI) (OBJECTIVE SET III)

Following the PMI program's expert validation procedure, five parents (parents of four boys and one girl) were contacted for a pilot trial run of the intervention program developed (from the participants of various phases of the study), as well as clients who had registered but had not been assigned a therapy date due to the increased wait list. All parents were given a one-week time to express their willingness to participate in the program. Four of the five parents of children with ASD telephoned the researcher to express their interest in participating in the program. Because all four participants indicated difficulties deciding on a specific day and time for the event, and because one or more of them had concerns about the time and date being fixed, it was decided to have a separate individual orientation session for each participant. Out of four parents confirmed, only three attended the first two sessions. Thereafter, one parent couldn't continue to attend the session due to their younger child's health concerns, and some sessions were rescheduled owing to their logistical concerns that arose during the time period, but they couldn't pursue it further. Finally, only two people (the parents of two boys) were able to run a pilot study, and so only those two people's baseline and post-assessment data were chosen for the study of the PMI program's early evaluation.

### Section I: Basic sample characteristics

Table 3.32

*Socio-demographic characteristics of the Child Sample (N=2)*

| Variable | Group | N | Percentage |
|---|---|---|---|
| Gender | Males | 2 | 100% |
| | Females | 0 | 0% |
| Religion | Hindu | 1 | 50% |
| | Muslim | 1 | 50% |
| Order of birth | First | 1 | 50% |
| | Second | 2 | 50% |
| **Age Range**: 4-6 **Mean age**: 4.9 **SD**: 0.85 | | | |

The participants were within 4-6 years age range, with an average participant being 5 years old. All participants were male (100%) belonged to the Hindu community (50%), and Muslim (50%).

## CASE ANALYSIS

### Case-1

### Socio Demographic Details

Name : C

Age : 4 years 3 months

Sex : Male

Mother Tongue : Malayalam

Education : NA

Socio economic status : Middle Economic Status

Religion : Hindu

Residence : Urban

Family type : Nuclear

District : Kozhikode

Informant : Parents

Information : Reliable and adequate

**Presenting Complaints** (According to Informant)

- speech not developed as per age
- Poor eye contact and self-care
- Not following simple instructions
- Repetitive movements of hand spinning
- Making vocal sounds
- Doesn't sit at one place, restlessness

} since childhood

Onset: Insidious

Course of the illness: Continuous

Progress: Deteriorating

Perpetuating factor: Nil

**History of present Illness:**

The child was delivered at full term through caesarian section with no difficulties. All developmental milestones except motor were delayed. The informant states that the child's speech has not developed in line with his age. He uses his mouth to produce noises and seldom speaks more than one or two syllables. The youngster lacks self-help abilities. He is unable to accomplish a number of chores that other youngsters his age can. He maintains inadequate eye contact and does stereotype hand movements. Additionally, when he is not occupied, he would spin everything that comes into contact with. Additionally, he is incapable of following simple directions. There is evidence of bedwetting. He doesn't sit at one place for long, he would always observe to be restless and shows wandering behaviour. The child is having a myoclonic seizure. He is currently on medicine, and the most recent episode occurred six months ago.

Treatment history (for the present illness) reveals that the child was referred to a clinic for treatment of his condition and fits episodes. He has an autism spectrum disorder and has had a seizure. He is on medication for his seizures. There was no medication or treatment administered for other issues. Additionally, they referred the child to a clinical psychologist.

**Biological functioning:**

Sleep: Normal

Appetite: Normal

Bowel and bladder functioning: Normal

**Family history**

An index child is the second child born out of a non-consanguineous marriage. The father is 40 years old and an engineer working for a private company. His mother is 37 years old and a manager at a private firm. Their first child was aborted, and he has one younger brother, 4 years old and currently in LKG. This child is loved and cared for at home. There is a warm and cordial relationship with parents.

**Family interaction pattern**

Family interaction patterns reveal a direct mode of communication prominently present in the family. The family's leadership style was authoritative, decisions were taken in the family by the father after consulting with each member, the roles of each member were adequate, and there was no report of any specific family rituals being present in the family. Overall, cohesiveness was observed with no family burden and a warm way of expressing emotions currently in the family.

**Family history of psychiatric illness/mental retardation/substance dependence/epilepsy:** Major depressive disorder in grandfather.

**Personal History**

**Birth and developmental history**

A child was born out of a full-term caesarian delivery. No birth complications or significant prenatal or perinatal factors were reported. All developmental milestones except motor, were delayed. Current developmental status reveals age-appropriate motor development and a delay in speech and communication. No history of any childhood disorders was reported.

Academic history reveals he took admission to the school at the age of 3 years, presently going to play school. His peer relationships reveal that he does not mix much with children of his own age. His hobbies and interests were mainly listening to music and rhymes.

The Index client had no history of suggestive head injury, high grade fever, memory difficulty, use of psychoactive substances, psychotic symptoms, catatonic symptoms, affective symptoms, anxiety, or neurotic symptoms. There was no significant history of physical or psychiatric illness reported.

**General temperament and personality attributes** reveal that the child is not attentive and has difficulty sitting in one place for long periods of time. He is not aggressive. When he is idle and not occupied with any work, he likes to spin things that are present in front of him, or else he likes climbing things. He would show withdrawn behaviour in the presence of strangers. His intensity of reactions was reported to be high, and the quality of his mood was mostly quick to change. He was found to be very sensitive to the changes in the environment.

**Behavioral observation** showed that the child appeared to be well-kept and tidy with well-groomed hair. Eye contact was present, but it was inadequate. His attention and concentration couldn't be aroused. Stereotypical hand and finger movements were seen in terms of activity level and motor behaviour. At times, his speech and language abilities demonstrate the presence of noises. He was found to be restless mostly. His general intelligence and other cognitive abilities were evaluated to be below average.

***Baseline Assessment (Administration of tests)***

***1. Vineland Social Maturity Scale (VSMS):***

The social age (SA) of the child as assessed by VSMS is found to be 2 years 2 months, Social Quotient calculated to be 51 indicating impairments in social adaptive functioning. The scatter of scores in the 8 domains is as follows:

Table 3.33

*Profile analysis of VSMS (case 1)*

| | |
|---|---|
| *Self-help general* | *Developed up to 2 years 8 months* |
| *Self-help eating* | *Developed up to 1 year 9 months* |
| *Self-help dressing* | *Developed up to 2 years 8 months* |
| *Self-direction* | *Not yet developed.* |
| *Occupation* | *Developed up to 2 years 8 months* |
| *Communication* | *Developed up to 1 year 4 months* |
| *Locomotion* | *Developed up to 3 years 4 months* |
| *Socialization* | *Developed up to 9 months* |

### *3. Indian Scale for Assessment of Autism (ISAA):*

Table 3.34

*Profile analysis of VSMS (case 1)*

| Sl. No | Items | Description | Raw Score |
|---|---|---|---|
| *1* | *Social Relationship and Reciprocity* | *Child doesn't maintain eye contact adequately and shows lack of social smile which reflects social response and recognition, he has difficulty to relate people mostly and engage in solitary and repetitive play activities some times, and he has difficulty in responding to social cues adequately, he also found to have difficulty in taking turns in interactions and maintaining peer relationships.* | *18* |
| *2* | *Emotional Responsiveness* | *He sometimes shows inappropriate emotional responses and exaggerated emotions without an apparent reason. He frequently engages in self-stimulating emotions and sometimes he exhibits lack of fear of danger.* | *13* |
| *3* | *Speech and Language communication* | *He frequently produces infantile squeals/ unusual noises and shows difficulty in using non-verbal language or gestures to communicate. Sometimes he engages in stereotyped and repetitive use of language.* | *17* |
| *4* | *Behavior Pattern* | *He mostly shows hyperactivity/restlessness and sometimes exhibits aggressive behaviors as well.* | *12* |
| *5* | *Sensory Aspects* | *Frequently he is unusually sensitive to sensory stimuli such as taste and sounds and insensitive to pain. Sometimes he would face difficulty in tracking objects and responds to objects by smelling, touching, and tasting.* | *12* |
| *6* | *Cognitive component* | *Mostly his attention and concentration are inconsistent, and frequently shows delay in responding and has unusual memory of some.* | *11* |
| ***Total Score*** | | ***83*** | |
| ***Classification*** | | ***Mild features of Autism*** | |
| ***Percentage of Disability*** | | ***50%*** | |

***4. Visual Analogous Scale:*** comparative analysis of Visual Analogue Scale ratings is mentioned in post-assessment.

***Therapy process:***

Therapy sessions with parents were being conducted once in every week and session with child is twice in a month. Parents were asked to do the assigned tasks at home on daily basis. In this section, a brief description of 1-3 months sessions from the PMI is delineated. Every week one master session with parent was conducted. Likewise in alternative master session researcher met the child for review and monitor the progress and made changes in intervention plan accordingly. On an average, a single session was about 60 minute's duration. However, some of the sessions were longer, depending on the need. For example, in the beginning of the intervention, the psycho-education session lasted from one and a half hours to two hours. This was done keeping in mind that, several of parents, despite their children attending therapy for years, lack significant limits in their understanding of the condition of autism as well as the type of treatment child was receiving. Removing this barrier was considered integral to the present program, considering it focused significantly on the parental involvement.

***Summary of Parent-Mediated Intervention (PMI):***

*Treatment goals and relevant modules from therapy*

- Psychoeducation
- Basic communication skills
- Reduction of problem behaviour

*Specific goals identified/selected*

- to train toilet skills
- improve communication skills
- improve sitting tolerance
- reduce repetitive movement of hand

***Master Session 1:*** The researcher administered ISAA and VSMS during this session to gather baseline data (child and mother were present in this session as this is the intake session). Additionally, a visual analogue scale and a qualitative assessment of the child's pre-intervention level of functioning were completed. This session also included extensive psychoeducation. Primarily, the mother was informed that the child's behaviour was consistent with an ASD diagnosis and developmental delay. Following that, they describe developmental delay and autism spectrum disorder. Male and female prevalence; average age of onset; causes: ASD is caused by brain abnormalities. ASD is connected with sociocultural deprivation. What are the primary symptoms? Delayed milestones, memory deficits, difficulty learning social rules, difficulty problem-solving, delays in the development of self-care skills, lack of social inhibitors, common misconceptions and facts about ASD Following that, the mother was educated about other aspects of the diagnosis, such as: psychological interventions available—early intervention, behavioural treatment, family-oriented strategies, education, and inclusion programming; hyperactive, inattentive, aggressive, destructive, self-injurious, and sexually improper behaviour, among other characteristics.

***Master Session 2 (session with parent and Child):*** One-to-one interaction with the child along with the parent to finalise the goals to be taken up for the study. This session also covered gathering information on the prerequisites of toilet training; whether the child has the ability to comprehend the toilet need, adequate motor ability to express it through gestures, or adequate verbal ability to produce it through sounds. The session also looked at how to get the child to follow simple instructions, which the researcher looked at to see if he had the motor coordination and imitation skills that were needed to get him trained on the goal he had chosen. In this session, various reinforcers for the child and rapport building through singing rhymes and painting were also done. Prerequisite skills were found to be satisfactory through activities to improve motor coordination (picking up objects like blocks and cotton balls with forceps and moving them from one container to another), imitation skills (e.g., actions with objects (such as banging on a drum or pushing a car), gestures and body

movements (such as clapping hands or waving) sounds, or words were given and parents did those daily for 1-2 hours at home).

***Master Session 3:*** One-to-one sessions take up two goals at a time, using parents as co-therapists. The activities included expressing toilet needs and carrying out simple instructions provided to the child with a few changes using principles of structured teaching and/or Applied Behavioural Analysis. While the activities were carried out, the behavioural intervention techniques like activity rescheduling, use of rewards, etc., were also demonstrated to parents, so that the same could be followed at home.

Mainly, mothers were taught to keenly observe the child and try to pick up a signal that indicates that the child is about to begin or is in the process of defecating or urinating. It might be a change in the expression, or a sound produced by him, or a gesture. The mother was also instructed to take him to the toilet, potty, or other location where he needed to go defecate as soon as they received the signal. The mother also taught that if she is unable to pick up any signal, she should record the times when he urinates and defecates for a week. Take him to the toileting area around the same time he is expected to urinate or defecate. Pick up clues to associate toileting with an activity that precedes or follows it, such as waking up from sleep, after breakfast, and so on. While taking him to the toileting area, develop a signal that can be used by the child to indicate his needs. It can be a word or gesture, e.g., a word like "su-su", showing his little finger, or lifting his dress a little. "Typically, children urinate immediately after waking up and before going to bed," the mother also taught. Use these timings constantly for toilet training in the initial stage. "Use the same toilet and the same word for urinating all the time when the child is expected to urinate so that he associates the word used and the place with the act of urinating. This clue would help him to learn that any time he is taken to that place and the word is used, he is expected to urinate. If the child attends school, tell the teachers the method you use at home so that the child will not be confused by different ways of indication. If you take the child to your relatives' or friends' houses, be alert to look for his signal for his toilet needs and help him.

***Master Session 4 (session with parent and Child):*** The researcher reviewed the progress of the child in the session and found that the child shows difficulty expressing his needs through proper verbal commands. Therefore, the parent was again instructed to repeat the same content that was taught at the previous session. Mother provided demonstration training to identify his verbal output in the form of noises or sounds he makes, as well as all gestures or expressions he displays at any time he needs to use the restroom during the session. These were made clear to the parent during the session, and the mother was advised to carry out this at home or wherever the child has taken, whether it be a friend's place or a relative's home. Other activities that had been done in the past to improve motor coordination and imitative skills were also asked to continue.

***Master Session 5:*** The researcher reviewed the child's progress by checking the way the child was carrying out the activities to be done at home. The mother showed some videotapes she had recorded, which in fact helped the researcher to clearly identify the child's progress. Because it was clear from the recorded video that the child was easily picking up the tasks and making progress, therefore researcher decided to add one more goal for this week: find the toileting area when needed. The aim of this activity was to develop the ability to find the toileting area when needed. The mother was given the task of deciding which area she would train the child in. It can be a potty, or a regular toilet, or an outside area, depending on the resources available at home. The mother asked to take the child to that particular area as per the timings, signals, and indications. Use the same toileting area till he recognises that place as a toileting area. After recognising the need for toileting, check whether the child always goes to that particular place. If the child goes to that place consistently for toileting, it can be assumed that he has learned to associate that place with toileting. As a next step, show the child the regular toilets that are normally used in their house. When he indicates his toilet needs, allow him to use the regular toilet. If there are no toilets in the house, show the child where he has to go. It may be a place outside the house where he needs to urinate or defecate. If he attends school, one particular potty/toileting area in the school has to be used for training during the initial stage. When the child has learnt to associate the need with the toileting area, show him the

regular toilets in the school. Guide him to find the regular toilet when he needs to eliminate. Gradually, show him other toilets. When you take the child out into the community, guide him to find a place for toileting in case he needs to use one. The mother was also asked to reinforce the child by giving them praise and appreciation for every step they take in their learning, which will help them keep going.

***Master Session 6 (session with parent and Child):*** The child had shown significant improvements in the selected domain, hence new goals were also included from this session. To train the child to nod their heads appropriately and use 'yes' or 'no' in communication. The child showed adequate verbal comprehension and the ability to use these words meaningfully. The mother was taught to train the child to engage in an activity, then show one of his favourite objects. If he asks for the object, ask him, "Do you want it?" If he does not respond with an appropriate nod of the head, show him how to nod for 'yes'. When the trainee shakes his head and imitates, give him the toy. If possible, have the trainee repeat the word before giving the toy. In the same way, create situations for a positive response. Say 'no' with an appropriate gesture. Mother was asked to carry this activity for the entire week at home. By the end of the week, mother was asked to provide games like passing the parcel (which helped in following commands) and simple board games were suggested to be played. The parents were also instructed to keep a diary to note down even the smallest of changes.

***Master Session 7:*** The 2nd month's mid-week involved checking the improvements in children to review if any mid-course corrections or changes need to be incorporated into the therapy plan. As the intervention had shown improvements in his selected goals, this week too followed the same routine, with days 1–5 having activities to be done individually at home. Along with this, one new goal also added in this session was to train the child to understand and recognise familiar people and objects, for which the home environment was chosen as a training area. The parent was made to make the child identify family members and common objects used at home. Encourage the child to look at the people and objects when named. Repeat the activities explained in the training area during play time. Mom was taught how to carry out this activity at home. When a family member enters the room, ask the child, "What is his name?" Where is he from? etc., provides the maximum opportunity for

the child to learn. This was repeated in all possible situations. This session also included some sensory play activities wherein they had to use paint on their palms to do painting, sand play, and water play. The mother was taught how to carry out this task during this session. These activities were planned to keep the behavioural principles in mind, so that the goals could be met.

***Master session 8 (session with parent and Child):*** In this session, the therapist spent time reviewing each and every behaviour progress in detail and decided that the next five days would be planned with similar goals as before, with changes only in the activities. The child was now kept involved in the activities for a longer duration and with minimal prompts from the parents or therapists.

***Master Session 9:*** This week of the therapy program consisted of working on the goals that were yet to be targeted but crucial. For example, "to sit on a task for a minimum of 10 minutes", or "working independently", or "working towards reducing tantrums". In this session, it was more of a one-to-one interaction with the therapist and parent.

***Master Session 10 (session with parent and Child):*** In this session, the researcher evaluated the child in detail to verify the post-intervention changes, for which the researcher administered the VSMS, ISSA, and Visual Analogous Scale; detailed oral feedback was collected from the parents as to how effective the therapy was in addressing their problems and if they required any further help in dealing with the problems.

***Post Assessment:***

Repeated assessments of the baseline testing instruments (ISAA, and VSMS) revealed no significant changes in the score. A visual analogue scale and qualitative feedback were utilised to quantify the total changes in PMI in this study.

***Goals attained so far based on Visual Analogous Scale rating by Parents:***

Table 3.35

*VAS rating by parents (case 1)*

| ***Problem area*** | ***Initial level*** | ***Present level*** |
|---|---|---|
| Identify toilet need | 3/10 | 4/10 |
| Responding to verbal command | 0/10 | 1/10 |
| Improvements of restlessness | 0/10 | 2/10 |
| Recognizing objects | 1/10 | 2/10 |
| Self-help skills | 1/10 | 3/10 |

***Outcome of therapy:***

Other deficit behaviors need to be adhered to and the excess behaviors need to be taken into consideration.

***Therapist's reflections:***

The case presented had many challenges, since the child had a mild ASD and a mild impairment in social adaptive functioning, as well as a delay in intellectual functioning. The parent's compliance with parent-mediated intervention was admirable, and it contributed to the child's substantial improvement. A parent-mediated type of intervention aided the youngster in experiencing rapid changes in the targeted areas. Which in turn contribute greatly to training by educating parents and providing them with an opportunity to learn about their child's condition in depth. The parents' commitment in this child's rapid progress was incredibly inspiring and respectable.

***Qualitative Feedback of parents:***

Following the start of treatment, parents saw significant improvements in their child's behaviour. He has demonstrated progress in communicating his toilet requirements, locating the toilet space, expressing himself through gestures or vocal communication, as well as in problem behaviour. He also began responding to name-calling and scribbling, despite prior difficulties with pencils. He also began recognising family members and naming typical household objects and items.

**CASE-2**

**Socio Demographic Details**

Name : A. S.

Age : 5 years 6 months

Sex : Male

Mother Tongue : Malayalam

Education : NA

Socio economic status : Middle Economic Status

Religion : Islam

Residence : Rural

Family type : Nuclear

District : Malappuram

Informant : Parents

Information : Reliable and adequate

**Presenting Complaints** (According to Informant)

- Poor eye contact
- Screaming loudly
- Not interested in playing with other children since childhood since childhood
- Making vocal sounds
- Hyperactivity
- Temper tantrums.

Onset: Insidious

Course of the illness: Continuous

Progress: Deteriorating

Perpetuating factor: Negative reinforcement

**History of Present Illness**

Child A. S. is a 5-year-old boy who came with delayed milestone development. Informants noticed his poor eye contact, screaming loudly, and not interested in playing with other children. According to the informant, they noticed that the child was not responding when called by his name. He used to cry, scream, and be irritable most of the time. He used to make vocal noises for no apparent reason. He has not maintained eye-to-eye contact and did not mingle with anyone at home. The child also showed disinterest in any kind of play, which included a lack of curiosity towards toys, and he used to prefer to play alone. He was not interested in playing with his brother. He was always making vocal sounds of hyperactivity and temper tantrums. His mother reported that he loves to listen to music for long periods of time, even the same song 4-5 times. It is also observed by the informant that he is very restless. He won't sit in one place. Suddenly, he will walk here and also, as his mother reported, always needs to hold his hands, otherwise he will run away as he likes. He was very restless, day by day, increasing his temper tantrums. In toileting, he needs help cleaning his genitals. For all these reasons, they consulted a nearby clinic, but no treatment was taken. For all these reasons, the child will be brought to the CDMRP Clinic.

**Biological functioning:**

Sleep: Normal

Appetite: Normal

Bowel and bladder functioning: Normal

**Negative History**

No history suggestive head injury, high grade fever, memory difficulty, use of psychoactive substance use, psychotic symptoms and catatonic symptoms, affective symptoms, anxiety, and neurotic symptoms.

**History of past illness**

No significant history of Physical and psychiatric illness was reported.

**Treatment history**

The child was taken to a private hospital for his problem. He was diagnosed with autism spectrum disorder and ADHD symptoms. No medication or treatment was taken. They were also referred to a clinical psychologist, a speech pathologist, and an occupational therapist.

**Family History**

He was the second child born out of a non-consanguineous marriage. The father is a medical officer, and the mother is a homemaker. Their first child was aborted, and he has one older brother, who is 14 years old and studying in 9th grade. At home, the index client is loved and cared for.

**Family Interaction Pattern**

According to the informants, the interaction between the members is not direct. The father is an authoritative person. He was taking all the decisions about the family. Cohesiveness is not present in the family. The father did not directly interact with the child; he was always busy at work. But the mother is calm and caring for the child.

**Personal History**

**Prenatal history**

According to the parents, he was a planned and wanted child. He was born at full-term via caesarean. An immediate birth cry was reported to be present.

**Childhood History**

He has not achieved his developmental milestones on time (sitting, standing, walking, and speech) but after attaining one-word utterances, the speech has been delayed. Till 5 years ago, 2–3-word utterances were present. His social communication was

delayed. He was interested in solitary play. The child is not going to play school at 5 years of age.

**Temperament**

His activity level was found to be high, and his rhythmicity was observed to be irregular with a withdrawn approach. He shows difficulty adapting to changes and is very sensitive to the changes in the environment. Mostly, his reactions to the stimulus were of high intensity. His quality of mood is found to be quick to change. He is easily distracted by external stimuli. His attention span and persistence show difficulty maintaining his attention and low persistence.

**Behavioral Observation**

The child appeared to be not of his stated age, was well groomed and tidy. Eye contact was present but not maintained. He was running and making noises in the corridor before the session started. Rapport could be established with difficulty. His psychomotor activity was increased, and the child was restless throughout the session. He was crying and making inappropriate sounds. He was running and jumping around the room. Repetitive speech was present, making sounds of crying spontaneously and screaming loudly. His attention could be aroused but not sustained. The child was not cooperative for the assessment. He was easily distracted. But he was cherishing the mood.

***Baseline Assessment:***

***1. Vineland Social Maturity Scale (VSMS):***

The social age (SA) of the child as assessed by VSMS is found to be 2 years 07 months, social quotient calculated to be 52 indicating deficits in social adaptive functioning. The scatter of scores in the 8 domains is as follows:

Table 3.36

*Profile analysis of VSMS (case 2)*

| | |
|---|---|
| *Self-help general* | *Developed up to 2 years 8 months* |
| *Self-help eating* | *Developed up to 2 year 9 months* |
| *Self-help dressing* | *Developed up to 2 years 8 months* |
| *Self-direction* | *Not yet developed.* |
| *Occupation* | *Developed up to 2 years 8 months* |
| *Communication* | *Developed up to 2 year 4 months* |
| *Locomotion* | *Developed up to 3 years 4 months* |
| *Socialization* | *Developed up to 1 year 8 months* |

### *2. Indian Scale for Assessment of Autism (ISAA):*

Table 3.37

*Profile analysis of ISAA (case 2)*

| ***Sl. No*** | ***Items*** | ***Description*** | ***Raw Score*** |
|---|---|---|---|
| *1* | *Social Relationship and Reciprocity* | *Child doesn't maintain eye contact adequately and shows lack of social smile which reflects social response and recognition, he has difficulty to relate people mostly and engage in solitary and repetitive play activities some times, and he has difficulty in responding to social cues adequately, he also found to have difficulty in taking turns in interactions and maintaining peer relationships.* | *21* |
| *2* | *Emotional Responsiveness* | *He sometimes shows inappropriate emotional responses and exaggerated emotions without an apparent reason. He frequently engages in self-stimulating emotions and sometimes he exhibits lack of fear of danger.* | *15* |
| *3* | *Speech and Language communication* | *He frequently produces infantile squeals/ unusual noises and shows difficulty in using non-verbal language or gestures to communicate.* | *14* |

| | | | |
|---|---|---|---|
| | | *Sometimes he engages in stereotyped and repetitive use of language.* | |
| *4* | *Behavior Pattern* | *He mostly shows hyperactivity/restlessness and sometimes exhibits aggressive behaviors as well.* | *16* |
| *5* | *Sensory Aspects* | *Frequently he is unusually sensitive to sensory stimuli such as taste and sounds and insensitive to pain. Sometimes he would face difficulty in tracking objects and responds to objects by smelling, touching and tasting.* | *14* |
| *6* | *Cognitive component* | *Mostly his attention and concentration are inconsistent, and frequently shows delay in responding and has unusual memory of some.* | *13* |
| ***Total Score*** | | ***93*** | |
| ***Classification*** | | ***Mild features of Autism*** | |
| ***Percentage of Disability*** | | ***50%*** | |

Test Findings reveal that the score of the child (Total Score-93) falls in the 'Mild Autism' category of the autism spectrum disorder with 50% of impairments.

***3.*** ***Visual Analogous Scale:*** comparative analysis of Visual Analogue Scale ratings is mentioned in post-assessment.

***Therapy process:***

Parents had weekly sessions while children had twice monthly sessions. Parents were expected to do daily duties at home. This section describes the PMI's 1–3-month sessions. Every week a parent master session was held. In an alternate master session, the researcher met with the child to assess progress and adjust the intervention plan. A session lasted on average 60 minutes. Depending on the requirement, some sessions were longer. For example, the first psycho-education session lasted between 1.5 and 2 hours. Several parents, despite their children getting therapy for years, lack substantial limitations in their understanding of autism and the sort of care their kid

was receiving. The current approach, which emphasised family participation, deemed removing this obstacle essential.

***Parent-Mediated Intervention (PMI):***

*Reasons for Taking up the Case for PMI trail run:*

The child was presented with problem and deficit behaviors which were interfering in his day-to-day life. It was also associated with the parents' lacunae in dealing with the problem accurately. In fact, the problem has been getting worse due to the negative reinforcement from the side of parents. Thus, training the parents about the ways of handling the child was thought to be very crucial in this case. Therefore, modification of the environment along with the reinforcers and punishers would help his parents to deal effectively with the presenting problems. His parents were found to be motivated to access psychotherapeutic help and could be involved adequately. His other issues such as poor eye contact, screaming loudly, not interested in playing with other children, making vocal sounds, doesn't sit at one place and temper tantrums since childhood, poor communication and self-help skills also need to be addressed.

*Modules and treatment strategies chosen for this case:*

The PMI modules chosen for the child was psychoeducation in adjunct with reduction of problem behaviors. Behavior modification techniques mainly Antecedent based intervention strategies were used. Behavior modification has the greatest empirical support having positive results in treating ASD and mental retardation. Behavior modification is concerned with analyzing and modifying human behavior. The procedures are used to change socially insignificant behaviors, with the goal of improving some aspect of a person's life. Other than that basic communication skills, self-help skill training, and fine motor functioning tasks were also included.

*Goals taken for the PMI:*

For the present case, psychodeducation to parents, managing problem behaviors, and basic communication skills and training on self-help skills, were chosen. In below

given the short-term goals chosen with the aim of modifying the difficulties faced by the child.

- Eye contact
- Name call response
- Attention
- Reduction of hyperactivity
- Reduction of tongue biting
- ADL training

The long-term goals chosen for the case are social skill training, functional communication and group play. These goals can be achieved through the various activities developed in the PMI module.

*Techniques used are:*

- Compliance training, activity scheduling, operant techniques such as shaping, chaining, prompting, and fading, use of rewards and environmental manipulation

*Therapeutic program (key points to be focused):*

- Parent training in contingency management program
- Structured Routine

***Therapy process:***

Therapy sessions with parents were being conducted once in two weeks. Parents were asked to do the assigned tasks at home on daily basis. Here an account of 10 sessions is delineated with each session continuing for a period of 45 to 60 minutes.

***Master session 1:*** In this session therapist introduced himself and explained the need for the PMI intervention to the parents. The parent was informed about the process of

psychotherapy, its meaning and purpose. Informed consent was taken from the parent to take part in the therapy. Structure of the sessions in terms of the frequency and duration were explained. The parent was assured that confidentiality would be ensured. The researcher administered ISAA and VSMS during this session to gather baseline data. Additionally, a visual analogue scale and a qualitative assessment of the child's pre-intervention level of functioning were performed.

***Master session 2 (session with parent and child):*** In this session, the child entered the interview room with mother. During the session the child could not sit in one place and was making repeated sounds. Despite repeated efforts by the therapist, the child did not respond to his name being called. Child did not maintain eye contact with the therapist. The child frequently hitting on the table with his legs and makes sounds. While interrupting he gets angry, tongue biting is present in throughout session, he gets bored easily. He puts toys in his mouth, sometimes he spits on the table. The child was fidgety throughout the session. Finally, he pulls his mother to leave the room. When the child saw the wheelchair in the verandah. Child runs towards the wheelchair and cries for sitting in the chair. Mother met his demands. For last 4 years the child lived at abroad along with his parents and brother. Social interactions are poor in such situation. Father is always busy at his work, so he is not properly mingled with child. Mother is the primary caregiver of the child. Since child was shows temper tantrums, screaming loudly and hyperactive. Some time she met his all demands, but now a day's mother has difficult to handle with him. In that reason his mother won't take him to any sort of function. And she didn't send him to the school also. During the session her copying strategy was validated and was also informed regarding her importance in training the child. This intervention is completely parent mediated and therapist would be a guide for conducting interventions.

***Master session-3:*** This session was mainly focused on the psychoeducation module of PMI, during the sessions, the parents were given psychoeducation about childhood autism. She has numerous doubts cleared out, she asks lots of questions like, whether ASD is a disorder? Whether the child should be treated, or it will fade naturally? Whether the child needs to be given medicine? What may be the causes for such disorders to be occurred? What's the duration of this particular disorder? Or will it be

lasted for lifetime? The symptoms, causes, prevalence rate and prognostic factors were discussed with mother and clarified her doubts.

Analysis of the problem behaviors was chosen the goal of this particular session. During the session case formulation and analysis of the problem behaviors were drawn and taught the same to the mother in depth and clarified all her doubts and made her do the analysis of problem behaviour of few other problems faced by the child under the guidance of therapist.

Table 3.38

*Analysis of problem behaviours (case 2)*

| *Behavioural excess* | *Behavioural deficits* | *Behavioural assets* |
|---|---|---|
| Restlessness | Reduced Attention Span | Interested in music |
| Screaming loudly | Poor eye contact | Interested in dance |
| Tongue biting | Lack of Social emotional reciprocity | Playing mobile games |
| Repetition of speech | Isolated play | Obey someone who likes |
| Temper tantrums | Do not clean after toileting. | Say good boy |

1) The behavioural problem occurs at everywhere. When he did not meet his demands he will got so angry and will roll on the ground. He will bite or hits to others especially to his mother.

2) Others' problems such as tongue biting behaviours and making sounds occurred at every other place too. Such behaviours would be a response to him being left alone for a long time. When they tried to stop him, he cries loudly. Frequency of this was 5 times/day.

***Master Session 4 (session with parent and Child):*** *Motivational analysis also carried out and taught the mother how to perform this on the child time to time and the importance of the same.*

1) The child gets physical and verbal contact with the caregiver. The problem

behaviours (restlessness, screaming) increased when his demands not being met, and stopped once they're met the same.

2) The child expressed his frustration through his self-stimulating behaviours. (Skill deficits).

*Table 3.39*

*Case Formulation (case 2)*

| *Stimulus* | *Response* | *Organismic* | *Consequence* |
|---|---|---|---|
| When his demands not met.<br>✚<br>When gets anger<br>✚<br>When he gets bored | Hyperactivity<br>Autistic features<br>Skill deficits<br>Developmental delay<br>Autistic features | Screaming<br>Temper tantrums<br>Screaming loudly<br>Destroy things<br>Tongue biting<br>Repeated speech | Pay attention to him<br>Met his demands.<br>Expressing frustration<br>Self-stimulating |

In this session the formulation was demonstrated in the session and mother could understand the need for antecedent based interventions in order to improve his tantrums and behavioral issues.

***Master Session 5:*** In this session parent management training was taught and explained the need for this in managing problem behaviors of the child, this is the composition of both psychodeducation and management of problem behavior module. In which mother was explained about parent management training. She was asked to make the required modifications in their parenting. They were told about the consequences that children with this kind of learning may have. The mother was asked to cut down on attention rewards permanently, following problem behaviours such as screaming and showing restlessness. This included actions like not looking at the child, not met his unwanted demands with the child following the problem behaviours,

etc. This will reduce the child to repeat that behaviour again. Mother was asked to follow this at home for one week consistently.

***Master Session 6 (session with parent and Child):*** in this session the researcher created the problematic behaviour in therapy session by involving in a conversation with the mother. When child saw wheelchair in the veranda. Child runs towards the wheelchair and cries for sitting in the chair. When his mother tried to hold him, he beats, bites screaming loudly and rolled on the ground. At that time, therapist told to mother not to mind him and let him to be free. After which the therapist told her to come back, and after 5 minutes, the child his own will come back to therapist room. Child stopped screaming and sat in front of therapist. On that time therapist says, "good boy" Therapist asked to follow the same at home and also told to inform others at home and to be consistent. At the end of the session, therapist identified the rewards and charted his likes and dislikes with the help of mother.

Table 3.40

*Identification of reinforcement and punishment stimulus (case 2)*

| *Likes* | *Dislikes* |
|---|---|
| Say good boy<br>Clapping<br>Snacks and chocolates<br>Fruits<br>Listening to music<br>Colouring | Loud noises<br>Rigidness<br>Distractions while doing activities |

***Master Session 7:*** In this session, his mother reported improvements in his behaviors. His tantrums and stubbornness were reportedly decreased after the 6$^{th}$ week of training. Hence, in this session, the researcher decided to work on his eye contact, attention span, and fine motor skills. It was explained to the mother to give a peg board to the child at home to assess whether how much time he can retain his attention. If I suppose he is not responding, his mother was taught to give multiple verbal prompts

to complete the peg board. Find out the baseline data on how much time he could sit. To better understand the duration of his attention, the therapist also asked the mother to provide reinforcement and verbal prompting to increase the time duration.

***Master Session 8(session with parent and Child):*** In this session, his mother reported that he would hit the table and make noises while he was sitting with the peg board. Further, the mother reported that his attention could last for a few seconds. In this session, the researcher was given a peg board to give to the child. Initially, the first row of pegboard with five different colours was placed in front of him. The child frequently hits the table with his legs and makes loud noises. But he was interested and motivated to do the colour pegboard. At that time, the therapist noted the child forgot to hit the table when he was engaged in an interesting activity. It was observed that the child was calm and engaged whenever he was given preferred activities or items. Therefore, the therapist decided to use the child's highly preferred activities and items while making him engage in activities he doesn't like. The goal of this strategy is to include highly preferred items within these activities so that children will be motivated to participate and are no longer prompted to engage in interfering behaviours. The incorporation of highly preferred items into non-preferred activities changes the environmental conditions (e.g., non-preferred items, non-preferred activities) that have caused interfering behaviours in the past. This was explained to the mother, and she was taught how to carry them at home.

***Master Session 9:*** In this session, the mother reported she had continued with highly preferred activities that were linked with non-preferred activities at home and found effective. From the mother's report, it was clear that the child's attention duration had improved by 2 to 3 minutes compared to earlier sessions. However, verbal prompting was needed for the completion of the task given to him at home. His hitting the table with his leg's behaviour was also reduced while performing these tasks, according to his mother. Even though, when he completes the tasks, he will make loud noises. But when the child could control himself, he followed the instructions. Mothers also reported the need for ADL training; thus, sessions also focused on ADL training. To teach this, different tasks were given to the child. These tasks were divided into steps for three weeks, and the mother was to assess and monitor the child. Activity was

planned based on task analysis using shaping. His mother was advised to reward him with a toffee once he completed one task. Reinforcements are given when he has attained each step. The mother was also provided deatiled psychoeducation regarding the effects of immediate reinforcements.

***Master Session 10 (session with parent and Child):*** This session was conducted after 2 weeks because, for some personal reasons, the mother couldn't come to the session. Thus, the same activities were continued at home. The informant reported marked improvement in terms of his hyperactivity and self-stimulating behaviour. The researcher discussed with the mother the activities carried out by her at home, which included the planned activities, e.g., pegging tasks and colour discrimination. Sessions also focused on ADL training. Reviewing the home program suggested to the child, he shows better improvement in the following tasks: The sessions focused on working with the child in the communication aspects. The therapist's fixed goal was to work on proper sitting, attention task eye-to-eye contact, and name call response. The therapist asked the child to "sit down." The therapist praised the child once he sat on a chair for a minute. The therapist instructed the child to look at him to establish eye contact. The therapist verbally prompted the child to maintain eye contact for 5–10 seconds. The therapist used masks and verbal prompts to enhance his eye contact. The therapist draws a picture of the eye and asks the child to look at the eye picture. The therapist administered the animal pegboard. After the completion of the task, the therapist says, "Good boy." The therapist takes his favourite toys and calls his name. When he responds, the therapist gives the toys. Mother was advised to do the same at home. The therapist frequently calls his name throughout the session. During the interaction with the child, any material was presented to the child in front of the therapist's eyes in order to initiate eye-to-eye contact. The child was reinforced for verbal interaction with the therapist. The caregivers were informed about the importance of spending productive time with the child and also involving them in attention-oriented tasks such as bead sorting, shading colour, and matching tasks. The therapist also emphasised the importance of maintaining eye contact with the child and name calling during interaction at home. The therapist asked to involve the other kid at home to play with him. The therapist was asked to select one target activity of

daily living and verbally prompt the child to do it and gradually fade the prompt.

***Master Session-11:*** This session was majorly focused on the need for social skills training through parental psychoeducation. As a part of social skill training, a picture book was started and the therapist showed the pictures of wishing, hi, hello, bye, sorry, thank you, please and the therapist made mother to make him pronounce it aloud and in a real situation, and also showed the videos of such greetings on mobiles and asked her to do this at home. Sessions also focused on psychoeducation. To give psychoeducation to his mother for the importance of social interaction. Further, therapist monitored parent management training progress. There was found to be a marked reduction in the child's problematic behaviour compared to the beginning of sessions.

***Master Session 12 (session with parent and Child):*** Sessions focused on picture books for social skill training. Now a child is able to be aware of greetings. His mother would take her sons to all the places, including functions and outings. As a result, there is a significant difference in his social skills and behavior. The therapist observes his performance in natural environments and sends his best wishes to all the therapists. The researcher reviewed ADL training; currently the child is able to clean independently after using the toilet. In this session, the researcher evaluated the child in detail to verify the post-intervention changes, for which the researcher administered the VSMS, ISSA, and Visual Analogous Scale; detailed oral feedback was collected from the parents as to how effective the therapy was in addressing their problems and if they required any further help in dealing with the problems.

***Post Assessment:***

Repeated assessment of the baseline testing tools (ISAA & VSMS) were not showing any significant changes in the score, Visual analogous scale and qualitative feedback was used to estimate the comprehensive changes of PMI over here.

***Goals attained so far based on Visual Analogous Scale rating by Parents:***

Table 3.41

*VAS rating by parents (case 2)*

| *Problem area* | *Initial level* | *Present level* |
|---|---|---|
| Educating parents of the negative reinforcements and rectifying it | 0/10 | 5/10 |
| Attention | 0/10 | 1/10 |
| Improvements of restlessness | 0/10 | 2/10 |
| Recognizing objects | 1/10 | 2/10 |
| Self-help skills | 1/10 | 3/10 |

***Outcome of Therapy:***

The child's typically hyperactive behaviour has significantly improved as a result of this intervention program. There has been a discernible drop in the amount of yelling and temper outbursts. Increase in the amount of eye contact made with the therapist and other members of the family. He also begun making requests for further assistance, started responding to reinforcements in positive way (saying "good boy"). After completing the work, I immediately began colouring in the lines. Asking for meals at home. His habit of biting one's tongue has become less prevalent. he also improved to do activities of daily living without much support, such as dressing, brushing teeth, eating, and using the toilet. The child's ability to pay attention during the session and the tasks has considerably enhanced.

***Therapist Reflection:***

The child exhibited a mild level of ASD, a mild impairment in social adaptive functioning, and a delay in intellectual functioning. Consistent parent-mediated intervention led to the child's considerable progress. The significance of a multidisciplinary approach is that PMI has been shown to be quite successful. At times, the child's hyperactivity proved difficult to control. This parent-mediated intervention helped the child see quick changes in the targeted areas. which in turn

helps train parents by teaching them and allowing them to understand more about their child's condition. The parents' dedication to their child's quick growth was encouraging and admirable.

***Qualitative Feedback of parents:***

Parents reported significant changes in the child's behaviour in comparison with the pre-therapy days. He has been shown to have changes in the areas of problem behaviors, and he has started responding to name-calling and he is able to scribble, where earlier he found difficulty holding pencils. His attention, social skills, and daily activities like eating, brushing his teeth, going to the bathroom, and getting dressed have all gotten better.

**Changes in Primary Outcome Variables**

A) Changes in primary outcome variables (activities of daily living, basic communication, fine motor skills, problematic behaviors, parents knowledge and stress level) from Baseline to Post-assessment

**Activities of daily living: Parent's observations**

This section had two participants describing their children's changes with respect to self-eating, toileting, dressing/grooming, and the participants were asked to mark their perception about the nature of the changes noticed in the mentioned domains. There was a significant improvement from baseline to post-assessment in the participants identifying their child's activities of daily living were slightly improved. Furthermore, there was an increase in the participants report such as taking a first step in toilet skills, and brushing. For eating skills and grooming skills, the frequency of correct identification of the situation increased from baseline to post- assessment in visual analogous scale.

**Psychoeducation: Parent's observations**

This section had two participants describing their own changes with respect to psycho-education module. The proportion of participants reporting increased awareness regarding autism spectrum disorder was significantly increased from the baseline to

post-assessment. Out of 2, one parent reported, their awareness, knowledge about condition, available treatment options were improved after the session. The other parent reported fifty percent of improvements in overall knowledge about ASD.

**Basic Communication skills: Parent's observations**

This section had two participants describing their children's changes with respect to basic communication skill training. In the post-assessment, responses included child started responding to name calling in any means (verbal and non-verbal). Parents also reported of improvements in responding in gestures and changes in comprehending simple verbal instructions. Both parents reported changes in receptive and expressive domains of speech in the post- assessment, which was significantly higher from the baseline

**Managing problem behaviours: Parent's observations**

Comparison of baseline to post-assessment data showed that there was a significant change in the scores on problematic behaviors (stereotypic and repetitive behaviors) and irritability (reflecting more favorable behaviors). Also, a significant increase in obedience was noted from baseline to post-assessment. No significant changes were noted in the other areas of total scores or on its subscales from baseline to post-assessment.

**Fine motor functioning: Parent's observations**

Pre and post assessment indicated that the overall difference between the two time-points (baseline, and post assessment) was significant for eye hand coordination while there was a trend towards significance on overall fine motor functioning. Visual analogous scale analysis revealed that there was a significant rise in scores on 'engagement' from baseline to post and a trend towards an increase in scores on overall practice and planning from baseline to follow up.

**Feedback Survey Findings**

The study included a feedback survey at the end of each sessions, post-assessment, and one month after the program conclusion. The findings from these feedback

surveys are provided below.

Table 3.42

*Excerpts from individual session feedback*

A few relevant excerpts from the individual session's feedback are provided in the following table.

- Content is quite useful. It is effectively presented, and the manner in which it is conveyed is easy and understandable.
- Everything that is discussed in the program may be applied to every aspect of our lives. Sometimes I was puzzled or uncertain whether it was feasible, but following the training, I now know how to cope with the potential problems that may occur in the child and viable solutions.
- The intriguing things that help me figure out our lives from a different viewpoint, and we are adapted to live joyfully with our differently abled child.
- The intervention's content and format are suitable for working parents.
- There were no unwanted things in this training program, contents chosen for the training is inevitable for any children with ASD.
- The training was simple. It allowed me to be driven to achieve my goals and even to encourage my family members.

Session-wise feedback provided additional information about the perceptions of the participants about sessions. Across all the feedback dimensions assessed, both participants reported that the program was relevant, interesting, and motivated them to take action as it was effective for their child. Furthermore, they also agreed that the program was well organised and gave them confidence to do what they had learned during the sessions. Similarly, participants reported that they would like to tell others about the program. A few suggestions regarding the delivery of the program (including more activities, and examples) were also given.

Table 3.43

*Salient learning (Open-ended item)*

| **Salient learning: post-assessment feedback** | | **Freq. (n=2)** | **Percent (of total responses)** |
|---|---|---|---|
| Skills for managing behavioral issues in the child | Uses of reinforcement techniques | 1 | 50% |
| | Uses of prompting | 2 | 100% |
| | Managing negative behaviors | 2 | 100% |
| | Strengthening any positive behaviors found in child | 2 | 100% |
| | Improved knowledge and patience | 1 | 50% |
| Connecting/ caring/ supporting | Importance of mobilizing support | 2 | 100% |
| | Providing training to son | 1 | 50% |
| | Understand the child in better way | 2 | 100% |
| Self enhancement | Low stress | 2 | 100% |
| | Personal growth and knowledge | 1 | 50% |
| | Improved confidence, and ability to handle stress | 1 | 50% |

As shown the salient learnings from the program, as reported by the participants in the post-assessment and one month follow-up feedback survey, fell under three theme categories: skills for managing behavioural issues in the child, connecting/caring/supporting, and self-enhancement. There were no marked changes on these aspects from post assessment to one month follow-up were reported. Regarding the abilities for dealing with behavioural difficulties in children, one participant stated, *"When my child exhibits uncontrollable behaviours, I am capable of assisting both my child and me. After training, I feel more in control and confident. I want everyone to understand how vital it is.* (Connecting, caring, supporting). Another parent expressed that "*learning to be patient during the tough times and*

*handling children with more patience and care is very crucial, which I learned through this training."* (Self enhancement). Other responses included "I learned how precious and valuable training is for children with ASD" (appreciating the intervention program), ""*(learned to manage my anger; sometimes what goes on in the back of our minds has a profound effect on us; understanding my son's specific challenges and gaining further information in this area genuinely enlightened me and helped me better myself," (self-improvement),* and *"I learned so many things it increased my confidence level and helped me to handle my stress"* (self enhancement). The learnings related to connecting, caring, and supporting others included statements such as *"Motivated us greatly; we have learned to assist others in a more effective manner"* (assisting another), and *"Learn a great deal about ASD; it teaches us how to assist others who are going through a similar experience of having a disabled child, and also teaches us how to passionately assist children with ASD (with developmental disability)".*

**Program Feasibility and Receptivity Observations**

The present study is also aimed at providing observations regarding the receptivity and feasibility of the newly developed program. Several observations were made concerning these two parameters, as presented below.

Table 3.44

*Feasibility observations*

| | |
|---|---|
| **Program announcement** | Done through talking to the beneficiaries of clinic where research undertaken, also multi-disciplinary professionals in the clinic and nearby clinics were intimated about it to the beneficiaries. |
| **Number of times, the date was Changed** | Two |
| **Number of group activities** | Group activities had been scheduled but were |

| | |
|---|---|
| **carried out (During the program period)** | unable to take place owing to pandemic-related concerns. The format of the session was altered to an individual one-on-one. The following contents were planned to be conduct in group session.<br>– Sharing their knowledge about ASD to all.<br>– Preparing and displaying Autism posters in class<br>– Sharing their own experiences of dealing with taking care of children with ASD<br>– Obstacles faced by them and strategies they used to overcome such issues. |
| **General Observation** | In general, chosen participants were ecstatic to be a part of the program. Adherence to training and completion of prescribed homework were excellent. They were educating other parents of children with ASD about the high importance of attending this session. As a result, the researcher has received several inquiries from parents interested in enrolling their children in the program. |
| **Observation of the parents** | Sudden changes in work or home conditions, such as the illness of another kid or a change in daily routines, provided obstacles to attending the program and implementing the instructions at home in a timely manner. Generally, the husband and family members were extremely cooperative in attending the program after a few sessions, as they observed the child's increased involvement and response to activities assigned at home. Often, other |

| | |
|---|---|
| | members of the family (grandparents, siblings) were also there to help with tasks at home. |
| **Observation of the researcher** | Changes in the scheduling of general appointments: in some sessions, parents were informed of the difficulty of visiting for the master session on short notice; the researcher discovered that it was difficult to provide the next available time slot without significant delay, which means that the following day was found extremely difficult due to other professional commitments or engagements. Furthermore, not all parents will have access to the essential toys or devices for the intervention. The researcher distributed the peg board or toys to the pilot trial participants' parents. |

The researcher's observations before and during the program implementation provided several insights into the factors associated with the program feasibility. The feedback from the parents reiterated several factors affecting feasibility viz. changes in work schedules and pressure, coordinating with other engagements at family or work *("Finding a convenient time in every week is toughest issue, especially if there are others who are personally not inclined to such programs at first, but later on their attitude was changed"*). One parent participant emphasized the sickness of other children as the most important factor (*"It is so helpful, the programs, but so difficult when my other child falls sick, many at times he would fall sick very frequently, more over our total family got affected with covid, so there were delay in some sessions. It is like amidst of all these I have to take care of my family and other children, and don't want to miss the program either, what to do"*).

The PMI program could be done in the time frame. Further, it was found that individual and group activities could also be added. The field experience suggests that in the future, when the program is run again, giving parents more time to participate

in group activities will help them become more involved and keep their gains. Also, two factors, i.e., support from the family, along with the scope of flexibility from the facilitator, emerged as the key factors in facilitating a smooth implementation of the PMI program.

Table 3.45

*Receptivity observations*

| | |
|---|---|
| **Number of parents approached** | five |
| **Permission received** | four |
| **Participation rates (from time of registration)** | High<br>• Expression of interest within the time frame (N=5) > Confirmed individually (N=4) > Attended pre-assessment (N=4)<br>• Attended first two sessions (N=3)<br>• Dropout = 1<br>• Average attendance across sessions = 95% |
| **Engagement during sessions and post-session queries** | High |
| **Session feedback** | Positive |
| **Number of parents who approached for being included after program initiation** | Eight |
| **Percentage of participants likely to recommend the program to peers** | Very likely = 100% |
| *****Only 2 included in the analysis for whom both pre-post protocols were available | |

It was found that the program was received well by the parents as well as their family. Along with the above-mentioned information, participated parent feedback indicated the same *"I have never felt this much interest in any other time I visited for therapy or took training for my child. But after attending this program, I'm fully motivated and passionate about learning and helping my child. That's because here I got a complete education about my child's issues and how I could help him improve his life. This gave me a lot of confidence. Once I started sharing this with my group of friends, they also have children with ASD, and many were requesting me to get them also enrolled in this program. I mean, (even after the program started), other parents kept pushing me to let a few others in. Being aware of your (researcher's) time constraints, I had to say no to them at this time. After a month of the program's start, I received*

*more than five inquiries from known people about enrolling in the program."* On the receptivity of the program by another parent member, it was observed that *"It is a bit tough to manage. Most of them are burdened with a lot of work. I can't blame another if he or she is not able to perform it. They must finish the house cores. But yes, they know the importance. That is the reason they are so inclined to participate."*

Observations made by the researcher mirrored similar findings. It was found that the program was received well. Similarly, the parents' engagement across sessions was also found to be high, along with high levels of motivation to engage in out-of-session activities. Further indication for the high level of program receptivity was found in the fact that, during the program implementation, two parents, from within the center where the program was conducted, approached the researcher for having the same program for their child also. Also, two other parents from the community center of CDMRP expressed interest in being trained in conducting the program modules for the children with ASD and take part in that who were not a part of the original program implementation.

Finally, when asked on the likelihood of recommending the PMI program to the needy, all of them said that they are very likely to recommend the program to their known parents of children with ASD indicating high levels of receptivity for the PMI program.

**Summary of Analysis and Inferences: Preliminary Evaluation (Pilot-Trial) Phase Evaluation of the PMI Program**

It was found that there were gains in knowledge about ASD in general, management and prognosis among parents of children with ASD, increase in favorable attitude towards ASD, and also a significant improvement in their confidence level and reduction in stress following program participation. There was a significant increase in the recommendation for professional help-seeking in their suggestions were reflected. Majority of the participants reported having sought changes in their functional level including communication skills, fine motor functioning, and activities of daily living. Further, significant improvement was found in problematic behaviors from baseline to post assessment. The assessments also showed a number of

individuals engaged by themselves on several activities that were aimed at promoting important messages about parent assisted programs among their peers and social circles.

Feedback survey at post-assessment and one month after that provided additional insights into the effectiveness of the program. The program participation led to perceived learnings in certain key areas relevant to promoting better functioning for children with ASD and their parents as well as dealing with common issues. This included learning of skills for enhancing their quality of living and day to day functioning, importance of meaningful connection with the society and peers, caring and supporting others, and improving overall wellbeing of children with ASD and their family. The participants also reported an overall increase in their motivation to work towards promoting for their child's functioning learned from the program and a significant proportion reported having encouraged one or more than one distressed person in their family/social circle to seek help for their children with disability in general not only ASD. Overall observations suggested satisfactory feasibility and high receptivity of the program by parent participants.

## DISCUSSION OF THE KEY FINDINGS

The results of the study are discussed with reference to the available literature. This part of thesis is organized under the three stages and its sections, as outlined below.

- **Stage I: Exploratory cross-sectional stage (Objective Set I)**
  - Section I: Interview with parents of children with autism spectrum disorder
  - Section II: Interview with Professionals
- **Stage II: PMI Program Design Stage (Objective Set II)**
  - Section I: Design of a PMI program
  - Section II: Program Validation through experts and parents' rating
- **Stage III: Preliminary Evaluation (Objective Set III)**
  - Section I: Clinical Pilot trial run of PMI

### Stage I: Exploratory cross-sectional stage (Objective Set I)

### Section I: Exploration of stakeholder perspectives (both parents and professionals) regarding a PMI program for children with ASD (Objective Set I)

The current study's first phase was designed to look at the viewpoints of two main groups of stakeholders: parents (PA) and professionals (PR) on the PMI program's perceived needs, prospective content, practicality, and receptivity. One-on-one semi-structured interviews with parents and a professional group of stakeholders were used to obtain data for this study.

### Socio-demographic characteristics of the exploratory phase participants (Table 3.1 and 3.13)

Two groups of people took part in the exploratory phase: 28 parents of children with ASD and 23 professionals who participated in one-on-one interviews.

The interview sample (Parents) included an unequal number of male (8 fathers) and female (20 mothers) Parents participants ranging in age from 30 to 45 years. Interviews took place at the researcher's cabin at the CDMRP Advanced Clinic. This diversity meant that the interview data included the perspectives of both male and female parents of children with ASD.

Professionals from all multidisciplinary fields relevant to ASD could be fairly sampled in the Professional sample. The study included Professional participants ranging in age from 27 to 46. In the interview sample, the proportion of male professionals was slightly higher than that of female professionals, though the proportion of female professionals was close to fifty percent. This appears to be due in part to the male to female ratio in the professionals sampled equally. More than half of the number participants were had 7 years and above professional experience in the field. This was in keeping with the intention to develop a PMI program with the well experienced expertise professional's inputs. However, professionals having experience for 5-7 years and minimum 5 years were also represented in the interview participants sample to obtain additional insights into PMI needs and relevance of PMI programs of professionals who are in their early years of career. Across the interviews, the participants were joining up from different reputed institutions and practice own their own in Kerala. Thus, the interview sample had sufficient diversity of professionals. On the whole, the study was fairly successful in sampling the two groups of stakeholders, namely parents and professionals for the exploratory phase.

To better understand the nature of work environment, a few additional features of interview participants in terms of work setting were documented. Nearly half of the participants worked for the government, one-third worked in the commercial sector, and the remaining 22% practised independently. These figures suggest that the majority of participants work in the government sector, where they deal with a large number of patients on a regular basis, while the rest work in the private sector or run their own practise, where they have the freedom to choose how many patients, they see on a given day.

**Section 1.1: Felt needs and potential benefits of a PMI program**

The interviewed participants (Parents, PA) were specifically asked whether a Parent Mediated Intervention (PMI) program with a special focus on children with autism spectrum disorder (ASD) was needed, amidst multiple kinds of interventions and programs that are available or existing with the long-term goals of providing evidence based therapeutic services helps for overall development of children with developmental disabilities in general and specifically to ASD. It was seen that there is a consensus among the Parents (PA) regarding the need for a PMI program specifically for Children with ASD. Majority of the interviewed participants (57%) opined that such a program is needed, whereas 32% of parents reported that this program is certainly needed with two out of 28 participants, opining that it should be a mandatory program. Only one out of 28 participants reported that "not sure or probably good".

This may be due to the increasing awareness about the autism spectrum disorder and existing treatments and importance of such interventions, among the stakeholders. Moreover, the introduction provided by the researcher about PMI as the basis for the proposed program would also have helped the interviewed participants understand the scope of such a program. They expressed that training or therapy is often ignored/relegated to the background amidst efforts at improving the functional capacities of children with ASD and that it would help to channelize their energies in a positive direction and helps them to improve their skills and that can be utilized in effective ways in their day-to-day functioning. Although a majority of the parents expressed the need of a PMI program with a focus on children's outcome.

A major proportion of professionals opined that PMI program could be targeted at parents' outcome. Interestingly, this difference of opinion was evident in the group of Professionals (interview participants). All the interview participants were unanimous in sounding their agreement for the need for such a program with emphasizes on child outcome to an extent. It suggests that professional stakeholders have significant felt needs for such a program as they view it to be of universal relevance for all age and severity range of children with ASD. This may be due to self- experience of issues

about stress and wellbeing in various life-domains currently, as well as witnessing parents of children with ASD dealing with similar challenges. In the interviews, the needs of PMI program for ASD were expressed in the background of discussion on stigma among family members itself, the prevalence of high stress and need for managing work-life balance as taking care of child with disability along with other responsibilities at home and workplace was reported really a big challenge, improving parents' confidence as well as lack of easy access to therapeutic services served in nearby localities also considered.

Potential utility/benefits of a PMI program (Table 3.12) for children with ASD in home setting were also inquired into. For the most part, the perspectives by parents regarding the potential benefits of PMI program had a somewhat different focus. Most of the interviewed PA (68%) cited improved over all functioning as a potential benefit of the proposed program, followed by benefits for their daily living quality at large (46%), and making of better or improved adaptive abilities (46%). This probably reflects the inherent focus of all parents on daily living skills or day to day functional capacity achievement being a highly prioritized outcome from the perspectives of parents of children with ASD in our community context.

Table 3.25 Professionals' perception of potential benefits for program participation tended to focus primarily on non-functional outcomes than on purely functional ones (lack of awareness about ASD and high stigma, non-accessibility of intervention centers in nearby localities, and helps to improve child's functioning) although high stress and importance of improving self-confidence and motivation in parents, poor parental involvement in the treatment and poor treatment adherence were brought up when discussing the need for such a program. In other words, the expected benefits of the proposed program were cited in terms of parent-centric benefits (e.g., awareness, stigma, accessibility, knowledge, skills, and confidence). This was somewhat in contrast with the parents as stakeholders, as the parent participants emphasized on benefits in terms of overall functional capacity improvement as well as benefits at a broader level/larger scale in terms of overall daily living quality and, better and enhanced adaptive skills in children through the long-term aggregate advantages of a PMI program for children with ASD.

These differences may stem from a focus of parents stakeholders on their current felt needs and ongoing psychological concerns compared to parents, who by virtue of their life situation and position as professionals were more likely to focus on child's performance as well as take on a larger perspective when expressing potential benefits of a PMI program for children with ASD.

**Section 1.2: Potential content for the PMI program**

One of the key objectives of the exploratory interview was to identify the potential content considered as important by the two groups of stakeholders for the proposed PMI program.

All the content themes that came up in the exploratory phase of research (parents' perspective) could be grouped under six broad categories viz. psychoeducation, social adaptive skills, basic communication skills, reducing problematic behaviors, basic learning skills, and fine motor skills. Furthermore, within these six broad categories, there was a relatively higher proportion of themes belonging to the social adaptive skills. Probably this points to the fact that, while problems of children with ASDs is considering there is a strong tendency for being considered this aspect of attributes, because this has been found a crucial skill required for any one's existence. Also, there continues to be a strong influence of the 'basic communication skills' and 'fine motor skills' paradigm. This is likely to reflect the relatively greater emphasis of stakeholders on 'fixing' the deficits or problems faced by children with ASD that are essential for their day-to-day functioning or existence. Reducing problem behaviors, learning skills domains (e.g., reduce temper tantrums, reduce repetitive behaviors, impulsivity, basic copying, identification of numbers) were spoken about by a fewer proportion of Parents. In these instances, too, the discussions started with a deficit-based stance, in terms of what the children with ASDs are lacking.

In terms of content, the present study results highlight that while PMI programs for children with ASD adopt a strengths-based approach, these would need to invariably include elements addressing common problems in the children with ASD.

There was a significant overlap on the content considered to be important by both the

groups of stakeholders. This was specifically true for themes that fell under the activities of daily living, fine-motor skills and Psychoeducation. Herein toileting, brushing, bathing, dressing, eating, buttoning, eye hand coordination, psychoeducation and stress management emerged as relevant content in parents' interview as well as interviews with professionals. Activities of daily living or social adaptive skills can be considered the foundation of efforts at providing training for children with ASD.

Across the interviews, social adaptive skill training came as a key issue experienced by the parents, and there was a significant emphasis on including this component in the proposed program. Basic communication skill was emerged as the second most frequent theme by the parents' group of stakeholders, Whereas professional interview findings shows that fine motor skills and social communication skills were more or less equally endorsed by them along with reduction of problem behaviors. Parents have more importance for fine motor skills than reduction of problem behaviors, which is similar to Professional stakeholders' views. Coming to the remaining themes; psychoeducation, and cognitive skills were suggested by professional groups of stakeholders. However, parents group suggested for including learning skills along with psychoeducation components in the proposed PMI program.

It was surprising to see the difference of opinion in choosing learning skills as a priority by parents and cognitive skills were chosen by professionals. Parents were given the reason for choosing learning skills because, they believe that if the child could learn to read or understand basics, name boards or understanding common words or count or identify numbers would make their life at ease. Whereas clinicians are thinking more on scientific basis, if there is an adequate cognitive skill such as attention, concentration, memory functioning appropriately, he she would be able to learn things. This could be a reason for choosing cognitive skills by professionals and learning skills by parents' group of stakeholders.

Interestingly, the theme of 'basic communication skills,' that was strongly recommended for inclusion by the interviewees (parents) as a potential content did not appear directly in any of the interviews of professionals group of stakeholders.

Interviews (professionals) suggested the social communication theme including functional communication, relating experience, social interaction, responding to name calling as most endorsed sub-themes.

While interviewees (parents) recommended basic communication skills theme including sub-themes of says or indicates basic needs, basic requests, knowing basic words, initiate conversation, smiles at others, shake hand, interact with others, and reduce repetitive talks. Similarly, suggestions for inclusion of components on improving social connections point to the understanding amongst both the groups of the stakeholders that stigma associated with having child with ASD, they would be reluctant to be part of social gatherings or programs, which usually led them to deal almost a socially isolated lifestyle.

The participants expressed that while there is a stigma an increase in connectivity, one- to-one, face-to-face personal connections are on the decline, which in turn impacts the quality of connections parents have with other people in our community. Many are reported that they have even cut down their friendships because, they can't answer too many questions about their child. Also, nowadays not able to find time to keep these relationships alive due to so many responsibilities. The PA also stated their opinions that parents would benefit from content focusing on strengthening interpersonal skills as they seem to be having difficulties in maintaining quality relationships or to interact with other people who are facing similar issues. Yet another theme that was suggested by the professionals but did not emerge that frequent in the parents' interviews was the need for psychoeducation and stress management for parents. The professional group perceived that the parents tend to find difficulty to cope with stresses confronted by them on daily basis, they might more focus on what is lacking in their lives and seem to under-recognize and unknown about the resources and services available for them to deal with such difficult situations and overcome their difficulties. Whereas parent's interviewees hasn't brought this issue as much as the professionals pointed.

On the whole, it was found that the suggestions regarding the potential content of the proposed PMI program for children with ASD reflected significant convergence of

themes between the two groups of stakeholders, despite a few differences as mentioned above. These themes were compared with the potential content considered by the researcher based on the existing literature on PMI for children with ASD. Convergences and divergences at this level (stakeholders' and researcher's views) are taken up for discussion in a subsequent section while describing the program design phase.

**Section 1.3: Structure of the PMI program**

The exploratory phase of research also aimed at understanding the most suitable option that would guide the structuring of the proposed PMI program to ensure feasibility and flexibility of implementation. The feasibility estimates of the professionals indicated a prevailing opinion, wherein nearly 75% of them opined that in general, it was feasible to implement a PMI program that would be developed in a free style, which provides flexibility in choosing areas of training and time as per the requirement of each one separately. Including children from different age group and severity range was not considered a significant concern by professionals, though it was opined that it would require more planning and coordination.

The professionals preferred the inclusion of children from varied severity group and age range, as they felt it would improve connections with others and create a platform to know more people for the parents and be more predictive in what all the probable difficulties they would confront in future, and this would further helps to get information from others that how would they tackle certain issues in their past. Bringing participants together under a secure environment for a common cause is considered useful within PMI programming as well as for strengthening the network of relationships, mutual learning, and support while conducting the combined group session by therapist.

Also, the overall length of the program was kept as flexible had received a mixed response. While there was agreement on the usefulness of the relatively longer program if and when demands; many suggested to exclude time boundless in this program as ASD treatment responses would be different from child to child. Worries regarding the program coming in conflict with parent's other engagements were

voiced throughout the exploratory phase. All these pointed towards the need for a program that is structured in such ways that it was highly flexible to the changing demands of the parents' life routine. Indeed, program adaptability is proven to be a critical component in determining the effectiveness of health intervention implementation (Green & Kreuter, 2005).

**Section 1.4: Receptivity estimates of the PMI program**

The parents interviewed felt that, in general, the parents of children with ASD community would be receptive of the PMI program. The same opinion was expressed during the interviews with professionals themselves. A minority of the interviewed participants was of the opinion that the receptivity for a PMI program for children with ASD would be doubtful. Further, the interview participants perceived those two factors are important in determining if the parents of children with ASD will accept the program or not: (1) individual interest and motivation, and (2) knowledge about the importance of the program. It is logical that the personal predisposition of the parents to take part in the program is central to the interview discussions of receptivity of the newly developed PMI program. The second factor cited, (knowledge about the importance of the program) is closely connected to the first one. Knowledge about the universal and personal relevance of ASD is likely to be an important driver of interest to participate in the program. On the other hand, one of the goals of the program was to improve awareness about autism spectrum disorder and treatments in parent's community and help them realize the relevance of parental involvement in the treatment care for children with ASD. This meant that parents' friendly communication about the nature of the program and orientation to the program would have to be designed in ways that maximize inclination of parents to join for the program.

It was expected that interest in and understanding the significance of parent mediated intervention for children with ASD would develop further with exposure to the program.

Yet another factor that was considered relevant for the receptivity of the PMI program was the potential lack of conviction regarding its utility, as expressed by some of the

stakeholders. Both the groups of stakeholders expressed that compete against the heavy workloads at home and workplace, taking care of whole family and other kids, activities that are not directly related to it might be a strong predictor of parents' receptivity to the program. The novelty of the program and the quality of the program were also considered as important factors likely to influence receptivity. Sensitizing the parents and total family about the program relevance and uniqueness, as well as adequate information on the credibility of the program are strategies that can play a vital role during program implementation.

**Section 1.5: Feasibility estimates of the proposed PMI program and related suggestions**

Both the stakeholder groups came up with several potential hindrances for program implementation. While there were differences in emphasis, potential lack of interest from the family members and clash with routine daily chores were the most cited potential hindrances. It was opined and observed by the parents that with multiple responsibilities throughout the day, cooking tasks, taking care of other children and their academics, other family members, endless daily work at home, unpredictably changing and often unavoidable live circumstances as well as disrupted motivation due to various extraneous and internal factors make it difficult for the parents to commit to the exact program schedule and activities given that are perceived as not unavoidable but optional but definitely make difference in their child.

In addition, there was a perception that the existing daily series of works and responsibility being mother is often overwhelming, and both the parents (fathers and mothers) are finding it difficult to keep up with the steady demands. Among other factors affecting the feasibility of the program implementation was the concern about inadequate infrastructure at home. While the program may not require large scale investment, it would still require basic amnesties, especially the availability of space. Unfortunately, lack of adequate space, even to meet the demands of their adequate living, especially for few people belongs to lower socio economic strata. There was a general perception among parents that implementing a PMI program would largely depend on the perceptions and inclination of other family members to helps to provide

or give time and space for the same.

While there was a general consensus about program feasibility, there was a strong recommendation from the parents' group of stakeholders' that reducing the frequency of sessions will go a long way in improving the feasibility of the program. A similar theme came up in the professionals' interview too, though it was less emphasized by this group. The level of interest of the family members and child, along with competing other programs or daily chores were cited by the PA as potential hindrances for program implementation. The suggestions to deal with these hindrances followed a somewhat similar pattern: convincing the family members, prior planning, and increasing the appeal of the program. Along with reducing the number of sessions, reducing the number of participants was also suggested by the professionals. Prior planning of the program schedule jointly with the parents and family was among the top three suggestions from both the groups to improve feasibility.

It was observed that the suggestions from the PR for improving program feasibility pertained mostly to the structural aspects of the program- reducing the frequency of sessions, prior planning, reducing the number of participants. Perceptions of parents and family while overlapping with that of the PA, included low awareness among parents as the most cited potential hindrance. It is plausible that being in clinicians' roles, the interviewed participants recognized the relative importance of these aspects in improving program feasibility while the parents' might not have been aware of these concerns.

Another critical suggestion from the professionals to deal with hindrances was to increase the appeal of the program. Parents' interest and motivation, for example, was a factor that appeared in discussions on receptivity as well as feasibility. This is important as we have seen that among the potential hindrances to program implementation, child's interest and motivation, lack of awareness among parents and a clash with ongoing hectic routine featured prominently. Other suggestions came up that improving program feasibility by increase the appeal of the program by providing samples of tasks, eradicate the misconceptions regarding the activities for the parent's community.

It appears that perceptions of feasibility can be improved if one can improve the appeal (and receptivity) of the program for the stakeholders. It was opined by PA that

receptivity of parents/their interest in uptake and utilization would influence efforts by family members' cooperation by means of making time and space for such a program implementation at home, thereby impacting feasibility. On the whole, in the present study sample, receptivity and feasibility estimates were intertwined to a significant extent as per the stakeholders' opinions. Good receptivity was seen as an important factor determining perceived feasibility.

Other suggestions to improve feasibility were including parents and family members in the planning, use of technology to communicate. Involving parents and family in the planning can enhance feelings of inclusiveness as well as ownership and empowerment. PMI frameworks consider parents engagement and empowerment in program development and delivery as highly desired.

The interview participants were unanimous that social media should be used for communication, coordination, etc. during the program. It was expressed that it is already widely in use amongst normal population and its use could be directed towards a positive cause such as accessibility of intervention services, even if they are not physically present. A few professionals expressed that adequate safety measures need to be taken, particularly if the PMI program sessions/activities are conducted at home environment especially while training bathing, toileting skills as well as fine motor skills. When coming to a smooth implementation of the PMI program, the key source of support was seen as the family members. A small proportion felt the child with ASD could also be in control to provide the necessary support.

Among the various issues concerning the feasibility perceptions in the present study, majority revolve around the availability of time, perceived availability of time, to be precise. This was often linked to heavy house chore demands. While PR emphasized the potential benefits of PMI programs in terms of long-term benefits and benefits to the family, community, even country at large, they also simultaneously held a position that favored flexible duration programs with lesser sessions. A general sense of time constraints is likely to be based on the ground realities. But the stakeholder narratives suggest that it may also be influenced by overall lack of conviction about investing resources in autism care and its implications. Such investments are likely to have a distal impact, as compared to pressing felt needs in the here and now (e.g., functional improvements).

Moreover, study further strengthens the argument that there is a need for concentrated efforts on enhancing the salience of PMI in our community setting on the whole. This, in turn, requires a strong emphasis on and integration of theoretical and practical components at various levels in the interventional aspects with clear guidelines and mechanisms in place for successful implementation. It is noteworthy that there has been a shift of focus to these requirements in recent times (Rahman et al., 2016; Sengupta, 2021)

The observation during this phase of the study highlighted the need for PMI in general and comprehensive module in particular for embracing a parents' and family' perspective, engaging and utilising such ASD intervention programs and preventive interventions in the present-day Indian society.

**Section 3.46: Insights from the exploratory phase**

The exploratory stage provided several important lessons. While some of these are pertinent to the subsequent stages of the study, they all are relevant to the scientific community working in the field of children with ASD. The salient learnings from this phase of the study are summarized below:

| | |
|---|---|
| Need for a PMI program for Children with ASD | • A general consensus among both groups of stakeholders<br>• Perceived to be relevant and a need of the hour |
| Potential benefits identified | • Ranges from immediate and obvious to distal and latent<br>• Professionals focused more on latent, long-term, and larger scale benefits compared to Parents<br>• However, Professionals also focused more on functional benefits |
| Relevant contents identified | • Significant convergence of ideas between the two groups of stakeholders<br>• Contents identified as falling into two broad categories: prevention and management of mental health problems and promoting positive mental health<br>• Also, in line with the existing literature |
| Perceptions about receptivity and feasibility | • Receptivity estimated to be fairly satisfactory<br>• Perceived to be feasible (provided there is prior planning)<br>• Conviction of the Parents, parents and family's awareness of relevance and appeal of the program as well as time constraints- major factors to consider |

## Section II: Designing of the PMI program (Objective Set II)

### Section 2.1: PMI program content finalization and module development

The need for parent-assisted interventions for people with ASD that are appropriate for our cultural context was highlighted by a series of studies, and the emerging field of PMI was discovered to be a framework with great potential to achieve this, as parents play an important role in the overall development of every child around the world. We can consider parents to be the backbone of a child's growth, so implementing therapeutic interventions with the help of a parent will almost certainly produce better results.

A few guidelines that were established at the outset aided in the design of the program. Themes that are relevant to children with ASD and their underlying difficulties, as well as accessible theoretical and empirical literature on parent-mediated therapies for children with ASD, were among the criteria.

The guidelines also directed the researchers to content that would be appropriate for a culturally appropriate program in our community setting. These guidelines were consistent with the overall goal of having a program that was intended for children with ASD in general, rather than any specific subgroup (e.g., those with mild issues/those experiencing moderate, severe, or with any comorbid mental or physical issues/difficulties). It is thought that broad-based initiatives that reinforce many coping strategies and assist parents of children with ASD to deal with their issues. Furthermore, precautionary and simplistic approaches do share some techniques which will help the parents to function optimally. The program was created with a focus on basic functional skills (via rigorous and continuous exercise or training in real-life situations) and enhancing desirable outcomes in the form of improved positive attitude and knowledge about ASD and intervention strategies among family members and other family members. This boosts parents' willingness to seek treatment from rehabilitation professionals, as well as their promotion (strengthening competencies such as communication skills, fine motor skills, social adaptive skills, and reducing problematic behaviours in children with ASD). To demonstrate their long-term impact on well-being, these programs must be cost-effective, simple to

execute, acceptable, and accessible to a substantial proportion of the target population in a specific community.

As a result, it was deemed desirable that the program be constructed in such a way that non-professionals (e.g., parents/teachers/family members) could administer it one-on-one after receiving basic orientation and master training from a professional for each week. This was done to assure the program's scalability after enough evidence of its usefulness had been gathered. Task-shifting has been recommended globally as a useful approach for delivering simple, low-intensity interventions for addressing unmet rehabilitation or mental health needs (WHO, 2007). India faces an extreme shortage of trained rehabilitation professionals (Census report, 2011), and task-shifting has been recommended globally as a useful approach for delivering simple, low-intensity interventions for addressing unmet rehabilitation or mental health needs (WHO, 2007).

Task-shifting, which is defined as "the rational distribution of tasks among health workforce teams," entails shifting specific tasks from highly qualified health workers to health workers with less training and qualifications, where appropriate, in order to make more efficient use of the available human resources for rehabilitation or health areas (WHO, 2008). While this has not been considered in relation to community health promotion, it appears that there is room for it. Another way to use skilled non-professionals is through general promotional interventions. As a result, straightforward text with graphics, extensive delivery-related planning, the use of easy-to-implement individual or group activities (where possible), and additional materials were all part of the program creation.

The intervention program's actual content coverage was finalized by combining information from multiple sources. The supervisors' initial content ideas were based on a thorough review of the literature, as well as their own research and field observations in the urban Indian context, particularly through engagement with children with autism spectrum disorder, their parents, and families as part of various intervention programs. Some of these included the researcher in the delivery process. Interviews with parents and professionals, as well as extensive interaction with key

stakeholders, helped to better understand stakeholder needs and perspectives on the material. At the end of the exploratory part of the research, the potential ranking of material by professionals and parents offered additional data that aided in prioritising the content.

Involving the perspectives of stakeholders when developing therapeutic interventions is strongly recommended because it increases the likelihood of intervention effectiveness by improving fit with the target group's perceived needs and thus acceptability; practicality; evaluability, including causal pathway theorising; and uptake by practitioners and policymakers (Wight et al., 2015).

While the interviews helped to discover topics that stakeholder's thought were important, the ranking of material by parents and experts at the end of the exploratory phase of research added objectivity and clarity to the process. At the end of the exploratory phase 1, there was significant overlap between the themes from the three sources of data, namely interviews with parents, professionals, and the evaluation of the original content list by another set of both groups of stakeholders (Table 3.27).

Indeed, all the issues ranked in the top ten by professionals and parents spontaneously surfaced during the interviews. These included training to improve toileting, bathing, and self-eating skills, educating or familiarising the parents with concepts related to autism, and behavioural interventions, training to improve skills in comprehension of instructions and appropriate responses, preparing the child in eye-hand coordination, preparing the child to nod appropriately and use the words 'yes' or 'no'.

It may be noted that all the broad themes that were finally included were endorsed as a relevant theme by at least one-third of the interview participants in the ranking of the potential content. The triangulation of data from the various sources mentioned and the framework provided by the initial program content selection guidelines led to the identification of the final content to be included in a PMI program for children with ASD. From the time of the conceptualization itself, the structure options of the proposed program revolved around theme-based modules. Theme based modular structure was also expected to bring in clarity about the program goals, which is seen as a contributor to program effectiveness (Kirby et al., 2007). The broad program

themes/modules included, (1) activities of daily living, (2) basic communication skills, (3) psychoeducation, (4) managing behavioral problems, (5) fine motor skill training and (6) psychoeducation. Each of these is recognized as important in its own right in the existing empirical literature. For example, (Rahman et al., 2016; Padmanabha et al., 2019; Manohar et al., 2019; Divan et al., 2019; Krishnan et al., 2016; Nair et. al, 2014; Juneja et al., 2012).

**Section 2.2: Considerations on program structure to balance feasibility and comprehensiveness of coverage**

A primary difficulty was striking a balance between the demands of feasibility while offering enough breadth and depth of content coverage. The entire program duration that might be considered was determined by feasibility issues raised by stakeholders (especially parents). Other responsibilities at home and workplace limited the length of the program's implementation to a flexible time frame and eliminated the time frame. According to interviews with parents and professionals, flexible programs would be more possible to implement in this type of intervention program.

Though there are various PMI programs available around the world, and many of them have positive outcomes (Akin et al., 2017; Amador Buenabad et al., 2020; Parra-Cardona et al., 2017), they differ substantially in terms of the breadth and kind of material, the context of the application, the target audience, and the duration. As expected, there are no universally accepted guidelines for the ideal duration of a PMI program. According to the literature (Weare & Nind, 2011), longer program durations are likely to result in greater benefits related to extended contact with parent mentors and opportunities for beneficiaries, but they also require higher operational costs and system-level commitment and support from the settings targeted. The duration of the program has a significant impact on its long-term viability, adoption, and sustainability. Indeed, research indicates that time limitations and stakeholder perspectives influenced the curricula chosen for the formation of PMI programs (Henisz et al., 2014; Ott et al., 2011). Thus, the final subject selection, as well as the depth and breadth of material, were driven by the requirement to strike a compromise between stakeholders' perceived demands, PMI relevance, and feasibility estimations.

Throughout this period, not all of the content-based proposals could be executed. Some prospective themes/topics were covered in broad strokes based on their alignment with the core five modules, and extra material/links were provided for some other facets that could not be covered during the sessions.

Due to the restricted amount of time, it was necessary to reduce the core program hours to a more flexible schedule that could be tailored to the individual needs of each child. It was intended to maintain the time of each module adjustable in this manner, with the exception of the psycho-education module. This ensured that the program could be executed in accordance with the unique needs of each beneficiary in a particular location. Additionally, this allowed for considerable flexibility while assuring that at least required functional tasks could be covered entirely in a single session. Each module in the program was designed in a specific order. Each module had a distinct structure and content and could be administered individually or in conjunction with others at the therapist's discretion. However, it was deemed beneficial to design their delivery sequence in such a way that it would be meaningful and enhance learning. Effective therapies are found to take a sequential and step-by-step approach (Durlak et al., 2011).

**Section 2.3: Validating the PMI Program Modules**

The newly developed modules, including the detailed content and supporting materials, i.e., readymade reading materials, visual aids, and other activity-related materials, were sent for validation to two sets of evaluators. They included a group of experts from the field of rehabilitation and a group of parent participants. While expert validation helped in attaining scientific rigor (Hoddinott, 2015), the parent evaluators provided additional insights as the key stakeholders (target group for the program). Involvement of parents at various points during the program development is in keeping with the principles of PMI that stakeholders be given adequate space for expressing their views (London et al., 2003).

The validation by experts and parent evaluators looked into eight parameters relevant to program development. First of all, they rated each of the modules for its adequacy of the content. Indeed, the content of any program has direct implications for the

outcomes of the program and also on the way in which the program is carried out (McDonnell et al. 1997). Also, adequate 'dosage' was reported as a key factor in intervention programs that are found to be effective (Jones et al. 2014). The objectives for each of the broad themes/sessions facilitated ratings on the adequacy of content coverage. While experts were likely to utilize their professional experience, parent raters were expected to bring in their own lay perspectives, felt needs and experiences for these ratings.

Secondly, the evaluators commented on the appropriateness of the content for the target group, i.e., the children with autism spectrum disorder. Parenting stage, being a period of higher level of stress and parenting or child rearing promotes and supports the physical, emotional, social, and intellectual development of a child from infancy to adulthood. Parenting refers to the intricacies of raising a child and not exclusively for a biological relationship significant change in life, emotional stress, and behavioral domains (Karst et al., 2012), it is recommended that the contents of health intervention programs be developmentally appropriate (Pedlow & Carey, 2004) and take into consideration the changing needs of the individuals as they grow (Twigg et al., 2016).

The other parameters of program evaluation included logical order of the content, adequacy of the number of activities, objective-activity link, and mode of delivery. On all these parameters, it was found that the average ratings were satisfactory, with more than 95% of the ratings by each of the two groups of stakeholders being 4 or more out of 5. Along with the content adequacy and appropriateness, these factors can play an important role in the overall success of the intervention. The adequacy of the activities included, for example, can be an important factor for ensuring sustained interest and engagement of the parents in the program while providing opportunities to reflect and share views and experiences as well as learn from each other (McGuire et al., 2016). Herbert and Lohrman (2011) Effective programs have identified three active learning strategies, i.e., role play, group cooperation, and small group discussion, which were common to effective health interventions. The need for activity-based modality of delivery was strongly voiced by the present study stakeholders too. They have explicit learning goals, use a sequenced approach for the acquisition of knowledge and skills, and provide participants opportunities to apply

the material and practice skills (Durlak et al., 2011). These elements were taken into consideration while determining the flow of content and activities introduced in each of the program modules.

The program evaluation included a parameter about the adequacy of content and information in the takeaway materials that were included. On this too, there were satisfactory ratings from the evaluators. This was considered important as there was limited time for content delivery during sessions, and this necessitated a focus on introducing key concepts and core messages. Take-away materials provided additional details and clarifications for enhancing learning. These also served the purpose of facilitating the engagement of the participants in the relevant themes outside the core program sessions. Furthermore, it is also said that aspects that are not included in the core components should be kept open for discussions. While these may not be crucial for the intervention to be effective, they may play a larger role in how an intervention is perceived and accepted by the target population (Daele et al., 2012). Ease of self-learning a given topic, relevance to the key themes covered in the program sessions, availability/ease of creating material on the same were some of the issues taken into consideration while developing takeaway materials.

As shown in the previous sections, learnings from the review of existing literature were complemented equally by stakeholder perspectives and the hands-on experiences of the researcher, thus improving the quality of the proposed PMI program being designed. However, a well-designed program in itself is not sufficient to ensure a successful implementation of the same.

Indeed, discussions about the successful parent mediated interventions point to the quality of the implementation process as an important factor in the success of a program (Palinkas et al., 2011). Among the various aspects related to the quality of program implementation, improving the fidelity of the program delivery is one of the most influential strategies (Dumas et al., 2001). Fidelity is the “degree to which an intervention was implemented as described in the original protocol or as it was intended by the program developers” (Proctor et al., 2011). While not assessed in a formal manner, a draft containing detail for delivery was written up by the researcher

and scrutinized by the supervisor while developing the modules. This included detailed planning of delivery, slide-based inputs, specific content of the activities, instructions to go with the activities, nature of questions/discussions to be generated following the activities, nature of examples to be used, as well as other materials to be used during the program at appropriate junctures and supplementary materials, etc. This was helpful in improving fidelity at the time of delivery.

The researcher conducted informal pre-pilot runs of the program modules with clients who received intervention at the CDMRP Clinic, where the researcher worked. The parents were taught the designed contents, which were suited to the parents' children who had given consent to participate in this informal trail, and the parents' sought comments on the dimensions of content suitability, feasibility, ease of comprehension and implementation, and so on. Following that, more discussions with the supervisor were expected to ensure that the program was delivered as intended during the pilot-trial stage of the research.

The informal pre-pilot runs of the program modules were intended to enhance the chances of effective implementation. Once the program is developed, the main goal is to deliver the same under the conditions of the real-life context in a manner that ensures fidelity and maximizes impact. Program facilitation has become an important aspect of implementation research (Cranley et al., 2017). The facilitator is expected to catalyze the changes in the target audience (Daele et al., 2014). Hence it was considered important for the facilitator to have sufficient opportunities to learn by doing, through conducting trial runs and obtaining feedback from the participants.

These informal pre-pilot runs of the program modules provided the researcher with opportunities for learning further about the various processes involved in the actual program delivery and led to improved confidence in managing parents' groups, identifying potential logistical barriers and very importantly, improved skills at managing time during the program delivery. Reports from the prevention literature show that the confidence of the trainers and mentors in delivering an intervention is an important contributor to program effectiveness (Kirby et al., 2007).

The feedback of the pre-pilot run participants provided preliminary data on the

receptivity of the parents to the program modules and helped in fine-tuning of the modules. Responsiveness of the participants is another important aspect of program delivery (Mihalic, 2002). The average ratings of the pilot run participants indicated that the content was perceived to be appealing, relevant, useful, and well organized. Also, the pre-pilot run participants found the respective modules to be interesting and motivating and felt that their queries were adequately addressed. These informal findings provided additional support to the ratings of content made by the experts and the parent raters earlier and suggested that satisfactory ratings of the program content were likely to translate into adequate receptivity reported by the participants in the actual delivery contexts, too (Weare & Nind, 2011).

The third stage of the present study aimed at pilot-trail run of the newly developed PMI program for children with ASD. This phase was done on two children with ASD. This stage included baseline, post, and follow-up assessments on a number of PMI outcome variables grouped under two major categories viz. primary and secondary outcome variables. The primary outcome variables included skill acquisitions, improved functioning, and performs activities on to day basis, all functional deficits related to ASD. The secondary outcome variables included indicators of parents' self-confidence, improved knowledge about ASD, handling issues at home itself an index of PMI, and perceived program impact. This phase of the study also aimed at documenting observations on feasibility and receptivity of the PMI program. Reflections of the researcher are presented towards the end of this section.

**Stage-III: Preliminary evaluation of the PMI program (Objectives Set III)**

**Section 3.1: Socio-demographic Characteristics of the PMI Program Pilot Trial Participants**

Children from different 4 years and 5 years of age belonging to middle socio-economic strata of society were represented in the sample. An average PMI participant was 4 years old. The participants had varied religious affiliation with one child belonging to Hindu religion and another belongs to Islam. The sample had a preponderance of male participants, while parent participants (mothers) constituted common of the sample. The over representation of women participants may be

attributable to multiple factors. First of all, they are not working, and fathers are mostly the bread winner of majority of those families, more over mothers knows their child better than father as reported by the parent itself in one interview. They have more time to spend with child which formed the pilot trial setting. The inclination of women towards personal development or intervention programs may also partly explain the observed gender composition. Across studies, women tend to exhibit higher expressiveness and interest in people (Su et al., 2009). Gender differences are also prevalent in terms of higher rates of common mental health concerns in women (Riecher-Rössler, 2017).

All these differences may also explain greater uptake of the program by women. In fact, this pattern of gender composition has been observed in other phases of the study as well as another study on urban Indian college youth (Mehrotra et al., 2013). Across all age groups, more women than men tend to report engagement in volunteering (Bureau of Labor Statistics, 2008; Elias et al., 2016). Also, while education is positively correlated with engagement in volunteering activities (Brady et al., 1999), the relationship is stronger for engagement in professional activities in men, whereas for women it is related to engagement in social awareness and social justice activities (Gil-Lacruz et al., 2018). Two of the pilot-trial participants were unaware of parent mediated intervention programs or such programs can help for children with ASD.

**Section 3.3: Changes in Primary Outcome Variables**

***Section 3.3.1: Activities of daily living, Psychoeducation, Basic Communication skills, Managing problem behaviours, Fine motor functioning***

Gains in the child's performance on specified goals were examined in a variety of ways during the PMI study, as stated below. One of the intervention's five modules addressed everyday living activities. Inadequate awareness of problems is a significant factor in the delay in seeking help and the premature end of therapy (Lam, 2014). Recognizing disability or mental illness is the most frequently assessed characteristic in instruments assessing mental health literacy since it is a fundamental feature and a prerequisite for measuring other qualities (Yu et al., 2015). Here, parents' failure to intervene immediately results in the most severe deficits in children with

ASD. This program was deemed extremely beneficial for the stakeholders since it is one of the most fundamental and necessary skills to be trained for any child with ASD, as it mostly shows significant impairments with respect to self-help skills. This is the first step toward self-sufficiency. For parents, it was considered that their child had made considerable gains in his everyday life abilities.

In response to an open-ended item on improvements with respect to primary outcome variables in the child, baseline and post- assessment yielded a relatively similar pattern of findings- with knowledge level and educating parents regarding the importance of reinforcements, and other contingency management techniques to reduce child's problematic behaviors, and experience of stress, and changes in self-help skills were emerged as the major goals attained in the PMI.

A trend towards participants reporting many positive comments and validated usefulness of being part in the program at post-assessment as compared to baseline assessment phase or during the intervention process was observed in the present study.

This section also inquired about suggestions or recommendations that might help children (dealing with unexpected stubbornness or anger, making noises, destructive and disruptive behaviors). Overall, it was found that the suggestions mostly favoured psychosocial measures of various kinds to deal with such problems at hand. That is, behaviorally and socially oriented strategies came out as a measure to deal during the post-assessment stage. Parents expressed that it is possible that the dominance of psychosocial factors as causal factors may have contributed to this pattern of sudden behaviour in children with ASD. Thus, treating such problems behaviorally is better than taking medicine. In fact, a lot of studies have found that people who have behavioural problems tend to look for ways to get help from other people or through psychological interventions rather than pharmacological ones at the initial stages (Giasuddin et al., 2015).

In the present study, a notable change observed from baseline to post-assessment for all the two case vignettes (behavioral issues, self-help skills, and basic communication). Parents also expressed that they had made significant changes in terms of knowledge about ASD and reduction in stress, as described in the subsequent section.

In line with the above-mentioned gains in knowledge, the participants' perceptions about the likelihood of improvements from ASD symptoms and fear of stigma were also improved. Specifically, the likelihood of changes with external support increased significantly from baseline to post-assessment for all this condition. Indeed, perceptions that taking help and helping by self would lead to recovery is a key enable for parents to seek help, professional help in particular (Gulliver et al., 2010) as this finding is in consonance with increased rates of professional help-seeking and parents further promoted other parents who are having children with ASD would also seek help or enroll in this kind of program.

Overall, the PMI program participants' responses indicated an improved recognition of their child's problems in the primary care giver and their family members. Parents confidence to deal their child's problem, tackling issues which were unable to help by themselves, improvements in many areas of skills such as, toilet skills, basic communication, eye contact, reduced behavioral issues, etc. increased overall knowledge about ASD and as well as skills in dealing the problem behaviors and skill deficits in children with autism spectrum disorder and helping others who are facing the similar kind of issues.

Again, social media was also used extensively by the participants for engagement in the program and to access the materials were shared by the researcher. While the reach of the same could not be quantified, the participants found it to be a very useful and convenient way of reaching out to a large chunk of materials. It can also be a relatively inexpensive and acceptable medium to have conversations about ASD conditions, disseminate information amongst peers and challenge stigma (Betton et al., 2015).

## Section 3.4: Observations on feasibility, receptivity, and potential scope of implementation

Multiple outcomes of the PMI were discussed in the previous section. It becomes important to reflect upon the implementation aspects that can potentially deepen the impact and have a bearing on sustainability.

Stakeholder engagement at the beginning of the study provided a somewhat mixed picture with respect to estimates of the feasibility of a program of this kind. Majority of the professionals and parents were strongly expressed the need for a Parent mediated intervention program aimed at children with ASD and cited long-ranging, latent, and cumulative benefits that may ensue following program participation. These included a scope for the development of such children with respect to wide range of skills as well as a positive impact on them and their family's overall quality of living. A wide range of content themes related to child and parent focused aspects were brought up spontaneously as very relevant for inclusion in such a program. On the other hand, while discussing the options regarding the structure and the length of the program, several feasibility constraints were highlighted by a significant proportion of the interviewees, most of which revolved around parent's priorities and overload with many other problems in daily life. This necessitated selection of an option which had a modest duration and relatively lower frequency of program sessions.

Discussions on receptivity revealed that the majority of stakeholders believed the program would be well accepted by parents if given in a simple manner that is easily understood by the ordinary person. Additionally, it looked as if feasibility and receptivity were inextricably linked, with a few stakeholders stating that if there was a high level of receptivity (among parents), it would assist in overcoming the difficulties associated with views of feasibility. This may be related to the broader issue of a woman (the majority of parent participants were female) being responsible for all household chores and being the sole person responsible for the well-being of all other family members in the house, as such systems are prevalent in the Indian cultural context.

These observations highlight the need for promoting and sensitising the stakeholders

(parents and professionals) in our country to make space for the implementation of frameworks and guidelines that legitimise and prioritise structured PMI programs for ASD. Such programs can play a critical role in a country like India experiencing a "scarcity of rehabilitation professionals" and dealing with the significant burden of a huge number of cases in government sectors. Many parents are not in a position to access private sector interventions, as it would put a huge financial burden on an ordinary family. If these kinds of parent-mediated intervention programs were popularised or implemented in our community, it would help to enhance the accessibility of interventions for many parents who wanted to take part but were left with no other choice than to do nothing for their child with ASD. The recommendations of global bodies such as WHO also emphasise the need for promotive interventions to empower communities rather than exclusive reliance on developing specialist mental health services (WHO, 2007). It is well documented that merely making rehabilitation services available is insufficient to meet the broad range of rehabilitation needs of different disabilities, including ASD, and is also inadequate to ensure that those who are in need will avail such services (Jorm, 2000). All this, in turn, means that the active involvement of rehabilitation and mental health professionals is required in garnering support and buy-in from the rehabilitation service sector. This can be achieved through synthesising data available from various countries on the social and economic benefits of investing in the area of disability in different ways. If there is a child who is completely dependent on a family, one of the parents has to give up their jobs so they can take care of the child. In this situation, families' financial condition may deteriorate. At the same time, children with disabilities would not get timely interventions. It would lead to a total dependent situation for them and put a huge financial responsibility on the government to provide social security and financial support for the rest of their lives. Instead, if the government changes its policy and initiates a similar PMI program, it will help these children with ASD or any other disability to live on their own legs and be self-sufficient in every way.

In terms of feasibility and receptivity, as actually observed during the pilot-testing, PMI program appeared to be feasible to conduct at clinic and parents could carried

them out at home. The proposed training modules considered to be pretty demanding. Increasing coverage on a few relevant themes can be managed with the help of add-on optional modules. However, having an extended period of PMI would be very useful for percolation of effects on the participating parents and children as well as their family members.

The observations on Parents' receptivity were very positive, as evident from various stages feedbacks. This includes positive perceptions on need and utility by parent stakeholders during program design phase, encouraging feedback during pre-pilot runs of the program modules, satisfactory rate of registration and low attrition during program trial, positive session feedback, high level of engagement of the participants during and between sessions, in addition to perceived program impact reported by the participants and high likelihood of their recommending the program to others.

As has been discussed in a previous section, the impact of PMI program can be enhanced when implemented in a supportive environment. Working towards legitimizing and prioritizing rehabilitation services and parent assisted therapeutic initiatives are important to maximize the impact of programs such as PMI for children with ASD and ensure their sustainability. The PMI program as pilot-tested was limited in its purview due to the time-bound nature of this study and the multiple phases involved in the program development. For maximizing its impact, it would be important to view this as just one aspect in an overall system-level framework to support ASD community and their family. This framework could involve various other components such as a) sensitization and skill-building of parents for understanding basics of disability (ASD) needs of parents having supportive interactions with other parents going through the same situation b) developing offline/online, well-developed and moderated support forums and informational websites for addressing basic psycho-educating needs for the parents community, and c) extending the post intervention support period and actively supporting and recognizing the role of youth volunteers who could be trained through PMI program, to promote awareness regarding rehabilitation/ need for timely intervention amongst children with autism spectrum disorder.

The PMI program as developed focused on bringing about positive changes in child (varied domains of skills, reduction of problem behaviors and ability to perform self-help skills) and parents' outcome (engagement in intervening children, knowledge level, stress handling capacity, and attitude towards disability) and to some extent on their sense of self dependence and confidence. However, creating an enabling environment was addressed in a highly de-limited fashion through opportunities to connect with and take guidance from a supportive facilitator in and outside program sessions during the study period. Situating the Leading Minds program in the broader context of other system-level changes in the college campus for supporting youth initiatives on mental health can go a long way in furthering its impact over time.

**Researcher's Reflections**

**Choice of the topic:** The field of clinical psychology, in general, and developmental disorders, in particular, have always been quite interesting to me. My fascination in clinical conditions and psychopathology paradigms in psychology began when I graduated, and it has only grown since then. The specific topic was chosen because of an attraction with mental health care and rehabilitation, as well as a desire to do research that can be turned into a useful product. Ralph Waldo Emerson's words have served as a source of inspiration: *"Do not follow where the path may lead. Go instead, where there is no path, and leave a trail".* The desire to do something important, as well as an interest in this profession, led to the decision to work on this topic.

**Refining skills in design and delivery of Parent Mediated Intervention Program:** Joining the Community Disability Management and Rehabilitation Program (CDMRP) in the Department of Psychology at the University of Calicut offered the opportunity to begin actively pursuing the researcher's desire. Since joining the CDMRP in 2016, I've had several opportunities to learn about all types of disabilities, their management, and rehabilitation. From interfacing with diverse target groups, to creating and implementing training programs and materials, to planning and developing research-based programs for all types of disabilities, most notably autism spectrum disorder, my confidence grew significantly. Supervising the conduct of several ASD-related programs and receiving rapid feedback on component delivery, as well as vicarious learning through observing

co-facilitators in a multi-disciplinary area, honed my abilities. During my term at CDMRP, researcher also had the chance to participate in a national workshop on autism assessment as a Master Trainer from the state of Kerala, which was organised by the National Trust (Ministry of Social Justice and Empowerment, Government of India. These presentations, in conjunction with discussions with the research supervisor, gave an opportunity to practise the art of program design and execution.

While the focus of work was on autism spectrum disorder and its Management in general, the clinical skills and experiences also added to the overall understanding of the concept of Parent Mediated Intervention for Children with ASD. Appreciating the breadth and depth of management of autism and related issues, watching it closely added a lot more to the appreciation of rehabilitation services for developmental disabilities and its true meaning while adding to the repertoire of skills for recognizing clinical conditions and use of therapeutic/intervention strategies. The awareness about a significant proportion of ASD children experiencing common issues was concerning. However, the realization that experiential learning and parental engagement opportunities may serve as protective factors, promote their quality of living, and also involve them as key factor for improvements in their child's functioning was also crucial. Readings of developmental disabilities, Autism management, Parent mediated intervention attempts in the past, existing evidence based interventions for ASD, and continuing interest in the contemporary theories and practice guideline for the treatment for children with ASD added to the overall interest, thus adding to the background preparation.

**Researcher strengths, weaknesses, and biases:** Thinking back, the researcher's interest in the area, and the passion for working with the children with ASD proved the strong point. The ability to connect with children with ASD was another strength. The fact that the majority of the participants commented on the easily understandable ways in which the topics were covered in the program points to the role of communication skills in the overall program success. The biggest achievement may be that researcher could connect with the parent participants as a mentor (in their own words, "not a friend, not a clinician, someone in between). Some awareness of the stakeholders (parents of children with ASD) mindset also proved to be an advantage. The biggest

personal challenge was to conduct the various stages of the study. Involvement of multiple levels of work, demanding equal and simultaneous attention from the researcher was the toughest of them all. Managing time was yet another challenge.

The propensity for biases is a common concern in research, and the same was true for the present research also. The expectations, beliefs, and the thought process that the researcher brings into the research process could always lead to biases. While the elimination of various sources of biases was not possible, care was taken in each phase of the study to minimize the same. In the first phase of the study, where qualitative data collection was the main focus, constant supervisory discussions were expected to minimize the bias. Wherever possible, data triangulation from various sources was incorporated as the strategy to understand and interpret the data. Use of self-report questionnaires, session feedback, etc. minimized researcher's bias during the pilot trial of the program.

A personal bias that had played a role, specifically about the PMI program pilot trail stage, was the confidence that parents would be able to attend the program as per the schedule without absence. While there were genuine causes or reason brought by the participants for not able to attend the program as the way we scheduled, the implementation was taken more than expected due to practical constraints including personal concerns, illness etc.

**Challenges and sources of satisfaction:** A few challenges that made the journey difficult pertained to the specific population studied. For one, it required a lot of patience, but frequent unforeseen difficulties, particularly during the initial phase. For the initial interviews were conducted from parents of children with ASD children, who were taking treatment at CDMRP clinic. Engaging the children while the researcher conducting the interview was challenging. Mostly the interviews were conducted, while the child was engaged in other therapy services such as occupational therapy or speech therapy. The second phase of the study involving program development was also challenging. Owing to the feasibility considerations, all the content themes that emerged as useful in the initial phase could not be incorporated in the core program sessions. Most importantly, it required designing the program in such a way that it provides adequate intervention

while also making the intervention a simple and enjoyable process. Finding this balance was toughest as it was considered crucial by the stakeholders. Despite the extensive experiences in conducting workshops and doing interventions for the same group of children that I received being a part of the CDMRP, it required a lot more to address the concerns and clarifications of the participants, with full of confusions, stress, and sadness, and countless questions. Managing time, while keeping the limitations in mind proved yet another challenge.

The greatest of the joys was in being with the stakeholders such as parents of children with ASD and professionals from data collection, program conduction, to interactions outside core program hours If asked to choose a single most satisfying moment, it was when a participant told me that the PMI were the best time that happened to their life after they had a child with autism. Openness of parents in speaking about their doubts, sharing their own challenges, and being able to provide some supportive inputs in a limited fashion was alsorewarding.

As an individual, I got to know that I can make a difference. As a researcher and a clinician, I have learned a lot of skills: improved skills in quantitative and qualitative research, planning and developing Parent mediated intervention, improved knowledge about autism spectrum disorder, evidence-based interventions to mention a few. The key learning that I take home, the single insight that I would cherish, is that small acts can make a big difference. Everything that would follow from now, I am sure, will take a lot from this particular learning. On a more concrete level, I would like to work further on strengthening the PMI Program, its research-base as well as its dissemination. I wish to contribute my part to the efforts to make the world a place where children with disability are valued, cherished, and given the importance of interventions to the needy.

## CHAPTER SUMMARY

This chapter dealt with the analysis and inferences from various phases of the study. Pilot phase of the study included analysis of related literatures and focused group discussion with parent group of stake holders and expert interview with multi-disciplinary professionals working in the domain of autism spectrum disorder. Main phase of the study was conducted in 3 stages. Analysis of the main phase's stage-1

includes various themes emerged from the interview with parents and professionals. All the themes emerged, such as psychoeducation, activities of daily living, basic communication skills, cognitive skills, fine-motor skills, and stress management of parents represented different areas to be intervened as part of a Parent Mediated Intervention (PMI) program. In the stage 2 of the main phase, a parent mediated intervention program for children with ASD was designed. Data from three sources, such as (a) common techniques used to address similar conditions, (b) perspectives from the interviews of parents and professionals and (c) analysis of empirical works and theoretical models on autism management, were subjected to triangulation. Based on this, final contents for the PMI for children with ASD were selected. The developed PMI for Children with ASD consists of varied number of sessions as per the client's requirements. Contents incorporating strategies developed by researcher and modified from varied evidence based therapeutic models. However, the major frame of the intervention was determined by Applied Behaviour Analysis Principle. It was subjected to expert validation before implementing. In the phase 3, as a clinical trial run as a preliminary evaluation to understanding the feasibility and practicability of the designed PMI, the proposed intervention was implemented on 2 participants parents of children diagnosed with ASD. A detailed case analysis was done before beginning the intervention. Session notes were provided with verbatim examples to enhance the clarity of the delivery of the intervention components. Following this phase, the chapter presents the analysis of the psychometric tools used, visual analogue scale, self-reports of the participants, further followed by the fine tuning of the intervention and researcher's own reflections.

# CHAPTER IV
# SUMMARY AND CONCLUSION

# SUMMARY AND CONCLUSION

The present study aimed at exploring the perspectives and felt needs of parents of children with ASD and multi-disciplinary professionals about a parent mediated intervention (PMI) program, design the same and conduct its preliminary evaluation.

**Objectives**

**Set 1: Exploring stakeholder perspectives**

- To explore the perspectives of parents in terms of felt needs, feasibility, potential content and structure of a parent mediated intervention program for children with ASD
- To explore the perspectives of professionals regarding felt needs, feasibility and potential content and structure of a parent mediated intervention program for children with ASD

**Set 2: Designing of the parent mediated intervention (PMI) program**

- To design a parent mediated intervention program suitable for children with ASD
- To examine and validate the content, structure, feasibility, receptivity, and suitability of the designed program through a stakeholder's and expert's rating

**Set 3: Preliminary evaluation of the PMI program**

- To examine the feasibility* and receptivity* of the PMI program through a pilot-trial for fine tuning of the intervention.

**Operational Definitions**

**Parent mediated intervention program for children with ASD**: For the purposes of this study, a parent-mediated intervention program for children with ASD is defined as a program that involves active parental participation in training activities,

therapeutic interventions, and other possibilities that are likely to promote symptomatic changes. It's dubbed a parent-mediated intervention program since it relies on parents to deliver the training under the supervision of a skilled therapist.

***Autism spectrum disorder:*** autism spectrum disorder (ASD) is a group of pervasive neurodevelopmental disorders characterised by moderate to severe disruptions in social skills and socialisation, expressive and receptive communication, and repetitive or stereotyped behaviours and interests.

***Preliminary Evaluation:*** Examining the feasibility, receptivity, and changes in PMI relevant outcomes through a pilot-trial.

***Feasibility:*** In the current study, feasibility assessment will include documentation of stakeholder and professional expert perspectives on various barriers and potential hindrances that may arise during program planning and implementation.

***Receptivity:*** Receptivity is defined in this study as the perceived readiness to participate and engage in the proposed parent-mediated intervention program. Receptivity would be measured in terms of the proportion of parents who expressed an interest in participating, the proportion of parents who agreed to participate in the program, and their willingness to participate in this program on a consistent basis without fail. The interview with parents was used to determine receptivity by rating their self-perceived engagement in the program.

***Exploration*:** Exploration refers to the attempt to discover the potential content of the proposed intervention program through the analysis of semi-structured interviews with parents of children with ASD and professionals who work with children with ASD.

**Study Design**

Exploratory sequential qualitative method design, involving an exploratory cross-sectional qualitative phase, followed by a short-term prospective trial using a small n pre- post follow-up test, concurrent mixed-method approach.

The three sequential stages of the study were:

- Stage 1: Exploring stakeholder perspectives
- Stage 2: Designing of the parent mediated intervention (PMI) program
- Stage 3: Preliminary evaluation of the PMI program

**Three Stages in the Main Phase of the study**

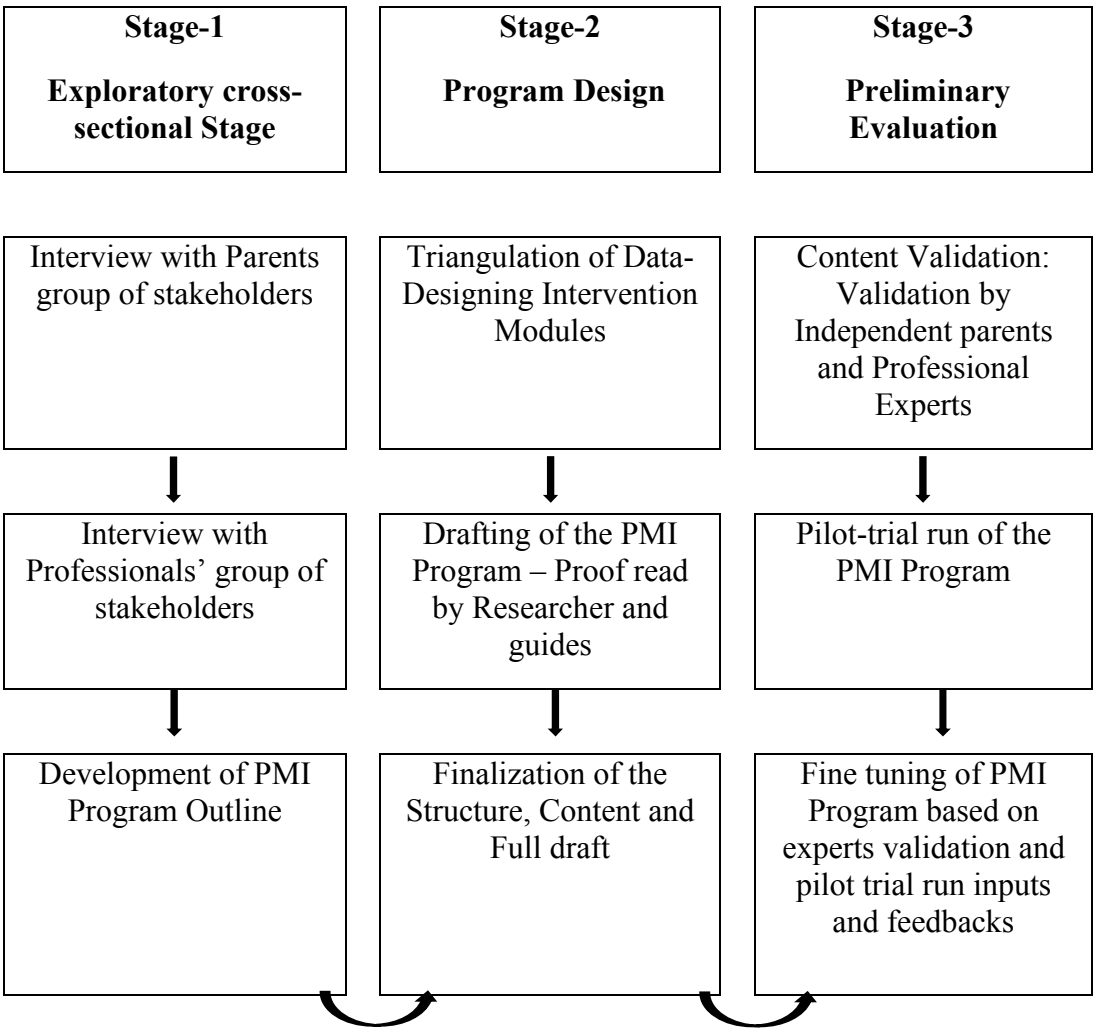


***Figure 4.1: Three sequential stages in the main phase of the study***

**Sample selection criteria and recruitment across stages***

**Stage 1:** This phase included one-to-one interviews with 28 parents of children with ASD. In addition, semi-structured interviews were conducted from a sample of twenty-three multi-disciplinary professionals within the range of 5-8 years of experience in dealing children with ASD and developmental disabilities, all the participants, who were able to speak, read, and write English. Professional participants were selected from different hospitals and clinics in and around Kozhikode and Malappuram districts of Kerala.

**Stage 2:** Data from focused group discussions, interviews with parents and professional stakeholders, and literature analysis were employed to design the parent-mediated intervention program. At this stage, the study included three multi-disciplinary professional experts who validated the content of the newly developed PMI program modules and five parents of children with ASD who provided feedback on the same from a parent's perspective. Furthermore, the suggestions were incorporated and made into a final draft of the program for pilot trial run.

**Stage 3:** The final phase of the study included preliminary evaluation of the designed PMI program. In this stage Pilot trial run was carried out in two parents of children with ASD for the duration of 2-3 months period.

*Individual written informed consent was obtained from the respondents/participants across all the phases.

**Brief description of the Study Procedures**

The study was conducted in two Phases- a Pilot Phase and Main Phase.

**Pilot Phase:**

The study's main phase was preceded by a pilot phase. This stage of the research was devoted to laying the groundwork for the succeeding stages. This phase aided in the planning and creation of a semi-structured interview schedule for interviews with parents and professionals who work with children with autism spectrum disorder. During this phase, the researcher contacted parents who had registered at Community

Disability Management and Rehabilitation Program (CDMRP) clinics as well as multidisciplinary professionals who worked in CDMRP clinics and conducted a focus group discussion with parents and an unstructured interview with professionals. Furthermore, the researcher had visited clinics and therapy service-providing centres in nearby areas and established crucial liaisons for the study's subsequent phases, which greatly helped in recruiting parents and professionals for interviews during the study's main exploratory phase, as well as during the program validation phase. Additionally, a draft of the interviews with parents and professionals to be used during the program's exploratory phase was developed based on the findings of the pilot phase.

**Main Phase:**

The main study was conducted in three stages viz. exploratory stage, program design, and preliminary program evaluation stage.

The ***exploratory phase*** (Objective Set I) aimed at assessing the perspectives of parents and professionals in terms of felt needs, feasibility, potential content, and structure of the PMI program (Objective set I). This phase included 28 one-to-one interviews with parents (CA) and 23 one-to-one interviews with professionals (10 clinical psychologists, 5 speech-language therapists, 3 occupational therapists, and 5 special educators). The participants were recruited using purposive sampling. The interviews for parents were conducted in the CDMRP Clinic, on a date and time that was mutually agreed upon. Interview with professionals were carried out at their offices, clinics based on the convenience. This phase also included the ranking of potential content by the selected participants from parents and professional group of stake holders. In this section, conveniently selected 20 parents and 10 multi-disciplinary professionals were again contacted in person and via emails and also asked to respond to a brief checklist aimed at assessing their preference for a number of potential themes that could be included in the proposed PMI program. All interviews were audio-recorded with prior consent.

The ***program design phase*** aimed at designing the proposed PMI program (Objective set II). The proposed PMI program was developed integrating data from the exploratory phase (interviews with parents and professionals), a review of literature, and insights from on-the-field experiences. Three experts and five professional experts independently examined the newly designed program. Following program

fine-tuning based on evaluator comments, the program modules were delivered as pre-pilot runs to children receiving intervention at the CDMRP clinic. This pre-pilot run was designed to familiarise the facilitator with the implementation process and to gather additional input from participants. The final PMI program was developed as a result of this. The final 20-hour program included five modules on five major themes (psychoeducation, self-help skill training, basic communication skills, problem behaviour reduction, fine–motor functioning).

The ***PMI program pilot trial*** is the final step of the current study and was designed to meet the study's Set 3 objectives. A pilot trial was used to test the feasibility and receptivity of the parent-mediated intervention program, as well as the changes in training content with specialist advice. During the validation phase, an expert rated the program on each facet of the designed parent-mediated intervention package. A preliminary content validation of the program was conducted towards the beginning of the third phase, after preparing a draught of the program. The objective of this was to facilitate the fine tuning of the program. This would help in making further changes in the structure and content of the program, if any are required. The validation would be done by two separate groups of evaluators. The validation would be conducted by a team of five parents, selected randomly (lottery method) from those ranked theme participants who provide consent to be re-approached for this purpose. The program content was shown and discussed with each of them independently in a single session, and their feedback and suggestions were documented. A similar exercise was conducted with a panel of three experts from the fields of psychology and mental health, each from speech and language therapy, occupational therapy, and special education, with at least five to nine years of experience working with ASD. After the program's validation by both groups, the suggested changes were made to the program content. Following expert validation of the intervention module, it was decided to conduct a pilot trial on two clients to fine tune the intervention and assess its feasibility and receptivity. The researcher approached parents of children with ASD who were receiving treatment at various clinics in Kozhikode and Malappuram districts. Following agreement for a pilot trial of an intervention, researchers began one-on-one sessions with participants. Weekly master sessions were held. Pilot-trial participants were selected from those who given consent, based on the inclusion criteria. The baseline-assessment along with brief orientation to the program was conducted on the

first day of the program pilot trial. As part of the main phase, a clinical trial was conducted for the designed intervention. So that the intervention could be trialed on participants to see whether it was feasible and practicable. Parents were informed of the research's purpose and confidentiality. The parent/caregiver read and signed the consent form. A session to educate parents about the PMI program was given prior to the training session beginning. Parental involvement, therapist duties and session length were all outlined in detail, and parents were encouraged to ask any concerns they had. In order to create a baseline, we took a complete case history and examined the child's mental state. In addition, individuals were asked to self-report their ASD awareness and knowledge. The program was conducted across once in every week spaced about 2-3 months apart. During the interval between the master sessions with alternate week, sessions with parent and child were held on each alternate weeks (One session with solely parent and another session with parent and child). Post-assessment was done at the end of the last day of program pilot trial.

**Tools Used**

In addition to the basic datasheets (customized to suit the needs of each phase) used to document the socio-demographic details of the sample, the present study used the following tools.

**Data Collection Tools for Exploratory Stage**

1. **Focus Group Discussion Probes:** Developed based on the review ofliterature, experiences from the field, and the insights from the unstructured interviews with parents, this tool included 12 queries which covered felt needs, potential content and structure of the program, feasibility and receptivity estimation, and potential outcomes of the proposed PMI program.

2. **Semi-structured Interview Schedule:** This tool, based on the review of literature and the experiences from the field, was developed with the purpose of eliciting the viewpoints of the parents and professionals on the PMI program to be developed. It included probes ranging from general to specific and included 14 key questions covering felt needs, potential contents, feasibility andreceptivity, and potential outcomes of the proposed PMI program.

3. **Potential Program Contents Ranking List:** Based on the exploratory phase findings and literature review, this list contained 16 potential content topics that were found to be relevant for a PMI program and were divided under four major/broader theme categories: psychoeducation, self-help skill training, basic communication skills, reduction of problem behaviors, and fine-motor skills. This was used with the parents and professional participants, who gave consent.

**Data Collection Tools for Program Design Phase**

4. **Program Validation Form:** Developed by the researcher, this included an introduction about the purpose and nature of the validation process and included seven items (regarding the adequacy of content, appropriateness of the content, logical sequencing of the content, etc.) rated on a 5-point Likert type scale which ranged from 'strongly agree' to 'strongly disagree.' Each item also had a column where the rater could give his/her suggestions and/or remarks.

5. **Pre-pilot Run Feedback Form:** This feedback form included 14 questions on the program modules (the clarity of the objectives and presentation, relevance, adequacy of the content covered, etc.) rated on a 5-point Likert type scale ranging from 'strongly agree' to 'strongly disagree.' Two open-ended questions pertained to the participants' perception of the 'best' aspect of the workshops as well as the aspects that needed improvement. In addition, a checklistcontaining 12 potential suggestions for improvement was used (e.g., reduce the content, include more activities).

**Data Collection Tools for PMI Program Pilot Trial**

6. **Basic Data Sheet:** A basic data sheet was developed by the researcher to be used in the PMI program pilot trial. It included items about age, gender, place of living, profession and education, income, and religious affiliation of the participants. It also included questions about the participants' knowledge about and experience of participating in any intervention programs related to developmental disability or autism programs or activities in the past, personal knowledge about someone with developmental disability issues.

7. **Psycho-social history:** This is a detailed history about the condition as well as about the child. It encompasses details about the onset, duration and impact of ASD on the participant. Psychosocial aspects refers to the life history of the person such as information relevant at her childhood, birth history, family dynamics, past history of medical or psychiatric illness, social adaptive functioning.

8. **Behavioral Observation/Mental Status Examination:** It describes the mental state and behaviour of the child. A clinician assesses various domains such as mood/affect, behavior, cognitive functions that has been seen in the client. It includes both objective observations made by a clinician or investigator and subjective details provided by the client.

9. **Visual Analogue Scale (VAS):** It is a measurement instrument that helps to measure a characteristic or attitude that is expected to range across a continuum of values and can't be measured directly, and it is one of the most extensively used measures of the intensity of symptoms in clinical research (Wewers & Lowe, 1990). In the current study, VAS was used at two points; one at the beginning of the first session and another at the end of the final session. Participants were asked to rate their perceived attainment of various dimensions of the target areas, such as knowledge about autism spectrum disorder, reduction in problem behaviours, management of behavioural issues such as tantrums, skills of activities in daily life of a child, interaction or communication skills of the child, and fine motor skills, on a 0–10 visual scale, where 0 indicates the least level of attainment of the target dimensions and 10 indicates the highest level of attainment.

10. **Indian Scale for Assessment of Autism (ISAA):** Indian Scale for Assessment of Autism (ISAA) was used for assessing the severity of autism. ISAA rates autism in six domains: Social relationship and reciprocity; emotional responsiveness; speech, language, and communication; behavior patterns; sensory aspects; and cognitive components. Items are rated from 1 to 5 and take about 15–20 minutes to administer. This scale was used at baseline, post, and two-month follow-up.

11. **Vineland Social Maturity Scale (VSMS):** Social quotient was assessed by Malin's Vineland social maturity scale for 0-15 years consisting of 89 items, by

the interview with a parent or other primary care giver. Social skills were evaluated in the following areas: Daily living skills (general self- help, eating, and dressing), Communication (listening, speaking. writing), Motor skills (fine and gross, including locomotion), Socialization (interpersonal relationships, play and leisure, and coping skills), Occupational skills, and Self-direction. This scale was used at baseline, post, and two-month follow-up.

12. **Assessment of Knowledge about ASD:** An MCQ of 10 questions to quantify the knowledge of parents on various aspects of ASD like definition of autism, cause, presentation, course, prognosis, and treatment of ASD, was utilized and administered before and after presentation of module.

13. **Feedback Form:** A session feedback form was used to obtain ratings on the following dimensions: 'personally relevant,' 'interesting,' 'motivated to take actions,' 'want to tell others,' 'have confidence to apply what I learned,' and 'well organized.' Open-ended items were used to elicit the most liked aspects. At post-assessment, salient learnings from the program and the most inspiring aspects of the program were inquired into through two open-ended items. At one-month follow-up, in addition to the above, an 11-item Likert-type survey was used to tap the perceived impact of the program participation. The survey included items covering the impact on both Child's and parent's domain. Another item documented whether the participants have suggested someone in their family/social circle to this PMI Program. In addition, a checklist type item was used to elicit whether the participants had sought any professional help for their child or themselves either due to becoming more self-aware or reduced hesitation to seek help.

**Data analysis across stages**

Both quantitative and qualitative methods were used to analyze the data in the present study. In the quantitative analyses, only descriptive measures like frequency, percentage, mean, and standard deviations were used. The qualitative data were analyzed using the guidelines for thematic analysis provided by Braun and Clarke (2006). Frequency and percentages were also used wherever suited. Across the stages,

the data entry, coding, analysis, and interpretation were closely supervised by the guide and were verified.

**Integration, triangulation, and interpretation**

Results from the three stages were integrated and the qualitative and quantitative results across the stages were triangulated. The findings from all the stages were interpreted based on the available theoretical and empirical literature. Findings are discussed against observed similarities and differences with the existing literature.

## RESULTS ACROSS PHASES

### Sample Description

**Exploratory stage sample:**

**Interview with Parents:** Interview with parents included eight male and twenty female participants (N=28) with an average age of 38 years were interviewed. The majority of the parents' group of interview participants belongs to lower (36%) and middle (46%) socio-economic strata of society. More than half of the interview participants were graduates or above in educational qualification. Only 36% of the participants were educated up to intermediate level and 64% were graduate or above educated.

**Interview with Professionals:** An interview with professionals included 23 participants (male-52%; female-48%). The average age of the professional group of interview participants was 39. Males (52% of total participants) and females (48% of total participants) were present at this stage. The majority of the interview participants belonged to the professional categories of clinical psychologists (43%), speech therapists (22%), special educators (22%), and occupational therapists (13%) with 5 years or more of experience (52%), three to five years (26%), and up to three years of experience (22%). 43% of the people who were interviewed worked for the government, 35% worked in private businesses, and 22% worked on their own.

**Ranking of potential content list:** The potential content list for proposed PMI program was given to selected participants includes a total of 30 participants, out of

these thirty participants, 20 are parents of children with ASD and 10 are professionals working in the field of ASD (these participants were not included in the stake holders interview).

**Program Design Stage Sample:**

**Program Validation:** Six professional validators from the area of multi-disciplinary disability management professionals were part in the validation procedure. They had five to nine years of experience working with children with ASD, including specialist clinical services. The second group of validators comprised five parents participated in the ranking of potential content list.

**PMI program preliminary evaluation sample:** The participants were within 4-6 years age range, with an average participant being 5 years old. All participants were male (100%) belonged to the Hindu community (50%), and Muslim (50%) and their mothers were taking part in the preliminary evaluation stage of research.

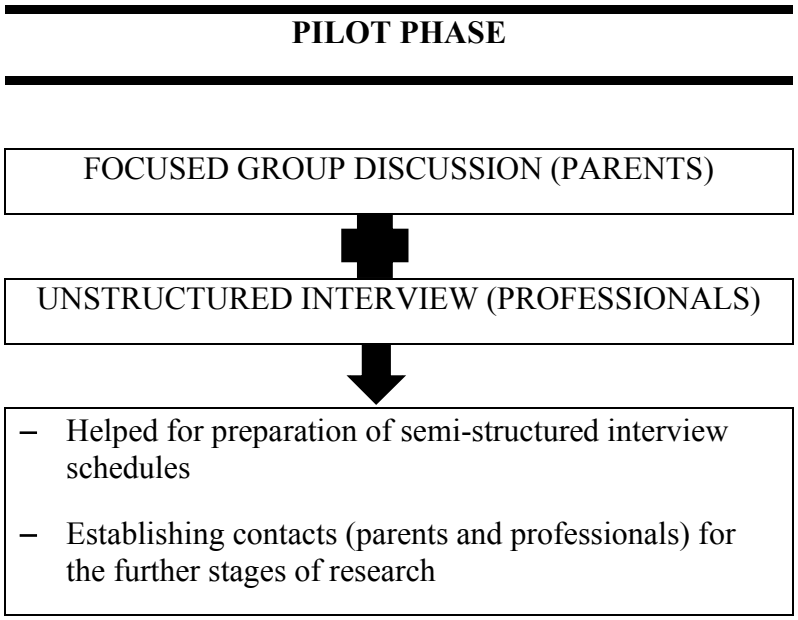


***Figure 4.2: Overall study stages and samples at a glance: pilot phase***

# MAIN PHASE

| | | |
|---|---|---|
| **Stage-1 Exploratory Stage** | | **Seeking consent for participating in Semi-structured interview from parents and professionals** |
| | | ↓ |
| | | **Interview with parents (n=28)** |
| | | ↓ |
| | | **Interview with professionals (n=23)** |
| | | ↓ |
| | | **Ranking of potential content list**<br>Parents' (n=20) + Professional Experts (n=10) |
| | | ↓ |
| **Stage-2 PMI Program design stage** | | **Program Designing**<br>(Triangulated data from review, field experience of the researcher and guides, and data from exploratory stage) |
| | | ↓ |
| | | **Program Validation/Evaluation**<br>Parents' evaluators (n=5) + Professional Expert evaluators (n=6) |
| | | ↓ |
| | | **Program fine tuning &**<br>**finalization of program module** |
| | | ↓ |
| **Stage-3 Preliminary evaluation stage** | | **Seeking consent for program implementation from parents** |
| | | ↓ |
| | | **Selection and finalisation of program participants** |
| | | ↓ |
| | | **Program Implementation (N=2, children, and mothers)**<br>(Baseline assessment + Orientation → Program Day-1 → Brief 40-60-minute sessions once in every week (every week parents present and child and parent together sessions conducted alternative weeks → Final day Session + Post-assessment + Feedback session → One-month feedback) |

***Figure 4.3 Overall study stages and samples at a glance: Main Phase***

## Major Findings/Inferences

### Exploratory Phase (Objectives Set I)

#### *Need and potential benefits of a PMI program*

- There was a consensus among the parents and the professionals regarding the need for a PMI program specifically for children with ASD.

- Most of the parents cited improved functional skills as a potential benefit, followed by benefits for their daily living quality and better adaptive abilities. Thus, the parents focused both on functional and skill level performance as well as benefits at a larger scale in terms of overall development of children with ASD and the daily living quality and better adaptive abilities as potential benefits of program participation. Professionals' perception of potential benefits for program participation tended to focus primarily on social, child related and parent related outcomes (reduce stigma, improved functioning of children, enhanced knowledge level of parents, self-confidence, self-awareness, more opportunity to access services, and helps to manage stress of parents, etc.) suggesting a focus on individual and social-centric benefits. Thus while both groups of stakeholders voiced potential benefits, they differed somewhat on the specific benefits expected from such programs.

#### *Potential content for the PMI program*

- The emerging content themes from the exploratory phase could be grouped into six categories viz. psychoeducation, social adaptive skills, basic communication skills, reducing problematic behaviors, basic learning skills, and fine motor skills. Within these six domains, most of the themes pertained to the social adaptive skills highlighting a need to include elements addressing basic function/skills of children with ASD.

- The content suggestions made by the two groups of stakeholders were highly overlapping. Daily living activities, fine motor skills, and psychoeducation. Toileting, brushing, bathing, dressing, eating, buttoning, eye-hand coordination,

psychoeducation, and stress management were all identified as significant topics during parent and professional interviews. Psychoeducation and cognitive abilities have been suggested by professional stakeholder groups. However, the parents group advocated for the inclusion of psychoeducational and learning skills components in the planned PMI program. It was fascinating to discover how parents prioritised learning skills while experts prioritised cognitive abilities.

- Notably, the theme of 'basic communication skills,' which was highly recommended for inclusion as a prospective content by interviewers (parents), didn't emerge explicitly in any of the interviews with the professional's group of stakeholders. According to interviews with experts, the most endorsed sub-themes were social communication, which included functional communication, relating experience, social interaction, and responding to name calling.

- While interviewees (parents) suggested a topic of basic communication skills, including sub-themes of expressing or indicating basic wants, making basic requests, understanding basic phrases, initiating conversation, smiling at others, shaking hands, and interacting with others. Similarly, suggestions for inclusion of components promoting social connections reflect an understanding among both groups of stakeholders that because of the stigma associated with having a child with ASD, they would be hesitant to participate in social gatherings or programs, which often resulted in a socially isolated lifestyle.

- There was significant overlap between the themes from the sources of data viz. Interviews with parents and professionals.

**Receptivity and feasibility estimate of the PMI program**

- According to the parents interviewed, the parents of children with ASD would be receptive to the PMI program in general. The similar thought was echoed during professional interviews. A minority of interviewees expressed doubts about the acceptability of a PMI program for children with ASD.

- Additionally, interview participants thought that two elements influence whether

or not parents of children with ASD would embrace the program: (1) individual desire and motivation, and (2) understanding of the program's value. It is reasonable that the parents' personal motivation to participate in the program is crucial to the interview talks about the newly established PMI program's receptivity.

- The second component mentioned (awareness of the program's value) is inextricably linked to the first. Understanding the universal and personal significance of ASD is likely to be a significant factor in determining interest in participating in the program. On the other hand, one of the program's objectives was to increase parental understanding of autism spectrum disorder and therapies and to assist them understand the critical role of parental engagement in the treatment of children with ASD. This meant that parents' courteous communication about the program's nature and orientation to the program would have to be arranged in such a manner as to maximise parents' willingness to participate.

- On the whole, in the present study, receptivity and feasibility estimates were intertwined to a significant extent as per the stakeholders' opinions. Good receptivity was seen as an important factor determining perceived feasibility.

- It was anticipated that exposure to the program would increase interest in and comprehension of parent-mediated intervention for children with ASD. Another aspect deemed crucial to the PMI program's responsiveness was a possible lack of belief over its value, as indicated by certain stakeholders.

- Both stakeholder groups noted that competing against severe responsibilities at home and at work, caring for the whole family and other children, and engaging in non-related activities may be a major predictor of parents' receptivity to the program.

- Sensitizing parents and the whole family about the program's importance and originality, as well as providing enough information regarding the program's credibility, are all techniques that might be critical throughout program

implementation.

- Both the stakeholder groups came up with several potential hindrances for program implementation.
- While there were differences in emphasis, potential lack of interest from the family members and clash with routine daily chores were the most cited potential hindrances.
- It was opined and observed by the parents that with multiple responsibilities throughout the day, cooking tasks, taking care of other children and their academics, other family members, endless daily work at home, unpredictably changing and often unavoidable live circumstances as well as disrupted motivation due to various extraneous and internal factors make it difficult for the parents to commit to the exact program schedule and activities given that are perceived as not unavoidable but optional but definitely make difference in their child.
- Among other factors affecting the feasibility of the program implementation was the concern about inadequate infrastructure at home.
- There was a general perception among parents that implementing a PMI program would largely depend on the perceptions and inclination of other family members to helps to provide or give time and space for the same.
- While there was a general consensus about program feasibility, there was a strong recommendation from the parents' group of stakeholders' that reducing the frequency of sessions will go a long way in improving the feasibility of the program.
- The level of interest of the family members and child, along with competing other programs or daily chores were cited by the parents as potential hindrances for program implementation.
- Prior planning of the program schedule jointly with the parents and family was

among the top three suggestions from both the groups to improve feasibility.

- It was observed that the suggestions from the professionals for improving program feasibility pertained mostly to the structural aspects of the program- reducing the frequency of sessions, prior planning, reducing the number of participants.

- It appears that perceptions of feasibility can be improved if one can improve the appeal (and receptivity) of the program for the stakeholders.

- It was opined by parents that receptivity of parents/their interest in uptake and utilization would influence efforts by family members' cooperation by means of making time and space for such a program implementation at home, thereby impacting feasibility.

- It was expressed that it is already widely in use amongst normal population and its use could be directed towards a positive cause such as accessibility of intervention services, even if they are not physically present.

- A few professionals expressed that adequate safety measures need to be taken, particularly if the PMI program sessions/activities are conducted at home environment especially while training bathing, toileting skills as well as fine motor skills.

- While professionals emphasized the potential benefits of PMI programs in terms of long-term benefits and benefits to the family, community, even country at large, they also simultaneously held a position that favored flexible duration programs with lesser sessions.

- Such investments are likely to have a distal impact, as compared to pressing felt needs in the here and now (e.g., functional improvements). Moreover, study further strengthens the argument that there is a need for concentrated efforts on enhancing the salience of PMI in our community setting on the whole.

- This, in turn, requires a strong emphasis on and integration of theoretical and practical components at various levels in the interventional aspects with clear

guidelines and mechanisms in place for successful implementation.

- The observation during this phase of the study highlighted the need for PMI in general and comprehensive module in particular for embracing a parents' and family' perspective, engaging and utilising such ASD intervention programs and preventive interventions in the present-day Indian society.

**PMI Program Design Phase (Objectives Set II)**

- A PMI program was designed during the second phase using the insights based on review of literature, exploratory phase data from two groups of stakeholders, and the on-field experiences of the researcher and the guides. Finding a balance between the demands of feasibility while providing adequate content coverage was a major challenge. The program was designed as a series of sessions delivered in a individual or group format in the community set up or clinic. The structure of the program evolved over time. Initially, it was planned that there would be a day-long introductory session (immediately after the baseline assessment) followed by bi-weekly master sessions of about two hours duration each, on once in 8-12 days basis. It was expected that this would cover about 15 hours of contact over a 2-3-month period.

- The ranking of the potential content list by parents and professional participants yielded additional insights. Improving ‘toileting, dressing, bathing skills and familiarizing the participants regarding fine motor functioning received the highest weightage rank. ‘self-eating and brushing, ‘familiarizing the basic communication skills training, preparing the child to respond with gestures, prepare the child to comprehend the instructions and react to it desirably’, ‘Educate and familiarize the participants about the behavioral interventions, prepare the child to nod head appropriately, and use ‘yes’ or ‘no’ in communication, were the other themes receiving highest weightage ranking. 9 out of the 33 items were endorsed by more than 50% of the participants. Even the least endorsed item was endorsed by more than one-third of the participants.

- The newly developed program was designed to be delivered in individual and

group format considering the universal nature of content as well as scalability. The program delivery included a variety of methods, including games, individual and group activities, self-assessments, reflective questions, videos, small didactic inputs, and role plays.

- The newly developed PMI program was evaluated by six professional experts and five parents (recruited from the participants in the ranking of potential contents).
- Each of the evaluators rated all the modules independently across seven parameters (e.g., adequacy of the content, appropriateness of the content). Overall, each parameter received satisfactory ratings. PMI module was fine-tuned based on the suggestions given by evaluators.

**PMI Program Pilot-Trial Phase (Objectives Set III)**

- The PMI program pilot-trial included 2 participants. Two participants were males and were within 4-6 years age range, with an average participant being 5 years old. All participants were male (100%) belonged to the Hindu community (50%), and Muslim (50%).
- Parents reported significant changes in the child's behaviour in comparison with the pre-therapy days. He has been shown to have changes in the areas of problem behaviors, basic communication and he has started responding to name-calling and he is able to scribble, where earlier he found difficulty holding pencils. His attention, social skills, and activities of daily living such as eating, brushing, toileting, dressing, and all have improved.
- Individual session response shows that Content is very valuable. The Excerpts from Individual session feedback as follows *"It is well presented and easily understood. Everything addressed in the seminar may be applied to our daily lives. I was often bewildered or unsure if it was realistic, but after the training, I now know how to deal with probable kid concerns and viable solutions. It's the exciting things that help me understand our life and how we can live happily with our differently abled kid. We designed the intervention for working parents. The*

*subject selected for the training is inevitable for every child with ASD. It was easy to learn. It helped me to achieve my objectives and even inspire my family".*

- The program's most significant learnings, as indicated by participants in a post-assessment feedback survey, fell into three theme categories: abilities for handling behavioural challenges in children, connecting/caring/supporting, and self-improvement.

- The researcher's observations before and during the program implementation provided several insights into the factors associated with the program feasibility. The feedback from the parents reiterated several factors affecting feasibility viz. changes in work schedules and pressure, coordinating with other engagements at family or work.

- The PMI program could be done in the time frame. Further, it was found that individual and group activities could also be added. The field experience suggests that in the future, when the program is run again, giving parents more time to participate in group activities will help them become more involved and keep their gains. Also, two factors, i.e., support from the family, along with the scope of flexibility from the facilitator, emerged as the key factors in facilitating a smooth implementation of the PMI program.

- The program was received well by the parents as well as their family. Along with the above-mentioned information, participated parent feedback indicated the same Observations made by the researcher mirrored similar findings. It was found that the program was received well. Similarly, the parents' engagement across sessions was also found to be high, along with high levels of motivation to engage in out-of-session activities. Further indication for the high level of program receptivity was found in the fact that, during the program implementation, two parents, from within the center where the program was conducted, approached the researcher for having the same program for their child also. Also, two other parents from the community center of CDMRP expressed interest in being trained in conducting the program modules for the children with ASD and take part in that who were

not a part of the original program implementation. Finally, when asked on the likelihood of recommending the PMI program to the needy, all of them said that they are very likely to recommend the program to their known parents of children with ASD indicating high levels of receptivity for the PMI program.

- No significant changes were noted on the scores of selected scales from baseline to post assessment and these remained stable at follow-up. In addition, significant increase in visual analogous ratings by parents were seen from post to follow-up assessment.

- Observations during the pilot trial indicated that the program as delivered was feasible, with prior planning.

- Receptivity of the program was high as indicated through satisfactory rate of registration and low attrition during program trial, positive session feedback, high level of engagement of the parents during and between sessions, in addition to perceived program impact reported by the participants and high likelihood of their recommending the program to others. The study findings provide directions for further research and have several implications for practice which have been detailed in the previous chapter.

**Conclusion**

A parent-mediated intervention program for children with autism spectrum disorder was designed based on a thorough study of the literature and the opinions of two sets of stakeholders (parents and professionals), as elicited through focus group discussions and one-on-one interviews. The title of this 1–3-month program was developed with assistance from parents and professional specialists. A pilot review of the program determined that it was viable to implement and had a high level of parent receptivity. Participation in the program resulted in considerable increases in knowledge as measured by numerous indices, as well as positive improvements in child and parent-related outcomes. Additionally, gains in child and parent-related outcomes were identified, including parental confidence and perceived competence, as well as skill acquisition and improvement in children. Additionally, participation

in the program prompted a considerable number of participants to increase their physical activity and assist their children in becoming more independent, as well as to urge other parents of children with ASD to do the same. The initiative was effective in promoting activities aimed at parent education. Qualitative responses from participants suggested that the training had a high perceived effect. The effect of the PMI program may be increased by extending the duration of parent participation, and deployment in an enabling community centre setting with policies and practises that support such programs would assist in moving this program forward.

## CHAPTER SUMMARY

To sum up, the purpose of this chapter is to offer an overview of the research's overall procedures and conclusions. It summarises the research's purpose, aims, and key questions, as well as its working definitions, objectives, methods, and major findings and implications. The chapter concludes with a discussion of the study's limitations and strengths, as well as its conceptual and practical implications

# CHAPTER V
# RECOMMENDATIONS

# RECOMMENDATIONS

## Limitations, Strengths, and Implications

The following sections present the limitations, strengths, and implications of the study for research and practice.

### Limitations of the Present Study

- As the overall study had multiple stages starting with gathering stakeholder opinions, the design of the program and pilot runs of the same, only a pre-post, follow-up design could be used for pilot evaluation of the intervention program developed. Although the pre-pilot runs of the program involved parents of children with ASD from CDMRP clinic, the final trial was carried out with two parents of children with ASD.

- In line with the study objectives, all phases of the study focused on parents of children with ASD (varied severity level), multi-disciplinary professionals with extensive experience in the field. While the study participants belong to a heterogeneous population, the generalizability of the findings of the present study needs to be examined for parents of children with ASD from underprivileged backgrounds, rural poor socio-economic background, in particular.

- Another limitation of the study was the under-representation of all severity group participants in the pilot evaluation of the program.

- Due to the time-bound nature of the study and a number of other practical constraints, the opportunities for parents (and its duration) were less than optimum during the span of program implementation.

- The study primarily included self-report measures. Supplementing these with relevant objective indicators (behavioral indicators or reports of significant others) would have added to the strength of the findings.

- A short follow-up period was used in the study. A longer-term follow-up and repeat assessment of all the key variables would have added to the robustness of the findings and helped understand the stability of gains.

**Strengths and contributions of the Present Study**

- The present study is one of the first of its kind in our community, in that it brought together the frameworks of PMI for designing a universal parent-mediated intervention program.

- The study addressed the gap in availability for parent-mediated intervention programs suitable for parents of children with ASD with minimum of $10^{th}$ class education or basic reading or writing skills - most of the existing empirically-based universal programs in the country target well educated population.

- The present study adopted an exploratory sequential mixed methods design (including an exploratory cross-sectional sequential qualitative phase followed by a short- term prospective small n pre-post mixed-methods design) which was appropriate to fulfill the overall aim and specific objectives of the present study across various stages.

- The PMI program development in the study used an intensive and extensive iterative process from the initial phase of selecting themes for finalizing the module contents. Multiple levels of participation and validation by stakeholders (parents as well as professionals), experts and the research guides ensured that the newly developed PMI program is of high quality and strikes a balance between felt- needs and perspectives of two different groups of stakeholders, on-field experiences, and review of literature.

- The PMI program, despite its brevity, incorporated components aimed at enhancing parents' engagements in activities directed towards other parents going through the similar situations.

- It is one of the few Indian studies that involved parent participation from the initial phases to program design and evaluation phase, thus following the principle of

parent participation in this PMI.

- Multiple outcome variables were used that were in alignment with PMI frameworks. Data triangulation from standardized measures, field observations of the researcher and the research guides, qualitative feedback as well as behavioral indicators in terms of child's behavioral observation and parents' involvement in PMI helped in enhancing methodological rigor.

**Recommendations for Further Research**

- The newly developed PMI program was pilot evaluated. There is a need to replicate the study findings in larger samples of parents of children with ASD using controlled designs.

- The extent of generalizability of findings needs to be examined using diverse samples of non-working parents and working parents from semi-urban, rural settings, with some adaptation as may be needed.

- The present study developed the PMI program as a universal intervention. Its utility as a alternative intervention for similar deficits found in other disability populations can be examined in future research.

- Future studies would benefit from prolonging the extended contact after the program sessions and providing a broader range of opportunities for parents' involvement in child's training or intervention during and after the core program sessions within a longitudinal research design.

- A longitudinal design along with a larger sample will also help in evaluating a broader range of outcomes such as parental stress, involvement in child's interventions, changes in skill domains, quality of life, and psychological well-being.

- Further research on larger samples is needed to examine potential moderators and mediators of outcomes of the PMI program.

- The newly developed program can be further fine-tuned and strengthened in terms

of increasing direct inputs on misconceptions about ASD as well as having add-on modules on Parents' skill training on Basic Education and Life skill training for Children with ASD that can be used over a longer implementation period, unlike the time-bound nature of the study.

- Online contact with the facilitator during the intervention program was well received by the participants, for quick clarification of doubts as well as to seek facilitator's perspective on issues relevant to the program content. This highlights the scope for using online platforms to supplement direct contact for strengthening the alliance between parents and the facilitator who may be seen as a mentor-like figure. Relationship of parents with mentors is considered an important factor for PMI. The role of alliance with the mentor-figure/program facilitator as a predictive variable of outcome can be taken up for examination.

**Implications for Practice**

- Demonstrating the effectiveness of delivery of this program by non-rehabilitation specialists, volunteers, and developing mechanisms for their training, support, and supervision, as deemed necessary, can ensure scalability through training of trainers.

- The whole program and delivery guidelines can be manualized and made available in multiple languages to standardise delivery and widen the reach of the program implementation.

- There is a need to develop brief and yet impactful orientation sensitization material for use with parents as well as policymakers to enhance the uptake of this program by rehabilitation institutes and support for the implementation of this program by public rehabilitation service sectors so that it can be used on a larger scale in a sustained fashion. These materials could be in the form of short videos of participating parents and experts, information that demonstrates benefits of such programs, related research evidence and highlights similar efforts in terms of practices in various institutions across the globe related to Parent Mediated Interventions.

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# APPENDICES

## Appendix-1

**Exploratory Stage (Understanding Stakeholder Perspectives) Informed consent forms**

**Department of Psychology**

**University of Calicut**

Informed Consent Form (Focused Group Discussion) – Pilot Phase

**Title of the study: Development of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder**

**Information about the Study:** I am conducting a study to develop a parent mediated intervention program for children with autism spectrum disorders (ASDs). The study is aimed at exploring the perspectives of the parents of children with ASD and professionals dealing with ASDs regarding the felt needs, receptivity and feasibility, and potential content and structure of a Parent mediated intervention program. The study aims at developing a program for the children diagnosed with autism spectrum disorders and to evaluate the preliminary outcomes of the same.

**Study Assessment:** The current phase of study involves participation in group discussion of about 60-90 minutes duration and would involve 10-15 participants. The group discussions will be conducted in CDMRP clinic and at a time that is convenient for all the participants. The discussion would focus on understanding the needs of a parent mediated intervention program for children with ASD and also community based interactive group sessions for discussing, sharing and engaging in activities to facilitate awareness, enhance quality of living and well-being. The views of parents about the feasibility of conducting such a program, structure and content the program would also be sought. The data generated during these discussions will be used by the researcher for the program development. The whole procedure of the focused group discussion will be audio recorded for the purpose of the evaluation of the content. At the end of the focus group discussion, you would be given a brief feedback form that would require an additional five minutes of your time. In addition, your consent for a one-to-one interview (of about half an hour) after about three months would be asked for, in the feedback form. This interview would be aimed at taking your opinion about the program which is developed by the researcher based on the views of the parents and professionals. You would be shown the content of the program developed for children with ASD and your opinion about its appeal and suitability would be sought during this interview. You can choose to participate only in the group discussion without giving consent to be contacted for participating in the brief interview to be conducted later.

**Risk and benefits:** There may be no direct benefits for participation in this phase of the study. However, the data gathered from the discussions will be helpful for the researcher during the various phases of research. If you wish to seek help for psychological problems during the study, you will be provided appropriate referral related information. There would be no costs for you in participating in the study and no payments will be made for the same.

**Confidentiality:** The individual-specific data collected during the focused group discussions and feedback would be kept confidential. The information provided by you will be open for scrutiny only by the Calicut University ethics committee. The findings from the research may be presented in various scientific meetings or publications without the identity of the participants being revealed. The audio recordings of the focused group discussions will be kept till the end of the research period and will be destroyed afterwards. You are free to ask researcher any questions about the study and make clarifications before the consent form is

signed.

**Undertaking by the Investigator:** Your consent to participation in this phase of the above study is sought by Mr. Nigesh K., Ph.D. scholar, Department of Psychology, University of Calicut. Your taking part in the study is voluntary. You have the right to refuse consent or withdraw the same during any part of the study without giving any reason. The study including the results will be submitted as thesis and may be published in scientific academic journals, without identifying the participants. There will be no monetary or other tangible benefits associated with participation in the study. You are welcome to contact the researcher (Mr. Nigesh K., Ph.D. Scholar, Dept. of Psychology, University of Calicut, Ph.: 9446950021), for further clarification, if you so desire. You may also contact the guide or joint guide for further clarification, if any.

The group discussion being conducted is a part of a research study that it is aimed at exploring the felt needs, receptivity and feasibility of a parent mediated intervention program and to test the preliminary outcomes of the same. Participating in this study requires participation in a group discussion of 60-90 minutes duration. After the group discussion, you would be requested to fill a feedback form and your consent would be asked for being contacted later for a brief one to one interview. You can choose to participate only in the group discussion without giving consent to be contacted for participating in the brief interview. The discussion will be audio recorded.

**Consent by the Participant**

I have been informed that the group discussion being conducted is a part of a research study and that it is aimed at exploring the felt needs, receptivity and feasibility of parent mediated intervention program and to test the preliminary outcomes of the same. I am aware that participating in this study requires me to participate in a group discussion of 60-90 minutes duration. I am aware that after the group discussion, I would be requested to fill a feedback form and my consent would be asked for being contacted later for a brief one to one interview. I understand that I can choose to participate only in the group discussion without giving consent to be contacted for participating in the brief interview.

I understand that my participation is voluntary and that I have the option to refuse my consent or withdraw it any time during the study without giving any reason. I understand that the information I provide will be used only for the purpose of research and will be kept strictly confidential. I also understand that I will not have any tangible or monetary benefits for participating in the study.

I have been given the assurance that I would be provided with appropriate referral information for psychological help if need arise. I have also been guaranteed the confidentiality of the personal-specific data I provide. The content of this consent form is explained to me in a language that I understand, and I was given opportunity to clarify all my questions regarding the study.

The audio recordings of the focused group discussions will be kept till the end of the research period and will be destroyed afterwards.

I have been explained that the focused group discussion will be audio recorded and I give my consent fort the same.

I, ……, the undersigned, give my consent to be a participant of the focused group discussion and to be contacted for the brief interview/ only to be a participant of the focused group discussions of the study **'**Development and Preliminary Evaluation of a

Parent mediated intervention program for children with ASD'.

**Signature (Participant)**

Name:
Address:
Ph. No.:

**Signature (Witness)**

Name:
Address:
Ph. No.:

**Signature (Investigator)**

Nigesh K.

Ph. D. Scholar, Dept. of Psychology, University of Calicut
Ph. No.: 9446950021

**Guide**

Dr. C. Jayan
Professor
Dept. of Psychology,
University of Calicut

**Co-Guide**

Dr. Sukanya B. Menon
Assistant Professor
Dept. of Psychology
Prajyoti Niketan College

**Department of Psychology**
**University of Calicut**

Informed Consent Form (Interview) – Main Phase (Parents)

Title of the study: Development of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

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**Information about the Study:** I am conducting a study to develop a parent mediated intervention program for children with autism spectrum disorder (ASD). The study is aimed at exploring the perspectives of the parents of children with ASD and professionals dealing with ASD regarding the felt needs, receptivity and feasibility, and potential content and structure of a Parent mediated intervention program. The study aims at developing a program for the children diagnosed with autism spectrum disorder and to evaluate the preliminary outcomes of the same.

**Study Assessment:** The current phase of study involves participation in semi-structured interview of about 60-90 minutes duration and would be conducted on a one-to-one basis. The interview will be conducted at a place and time that is convenient for the interviewer and the interviewee. The interview would focus on understanding the needs of a parent mediated intervention program for children with ASD and also community based interactive group sessions for discussing, sharing and engaging in activities to facilitate awareness, enhance quality of living and well-being. The views of parents about the feasibility of conducting such a program, structure and content the program would also be sought. The data generated during these discussions will be used by the researcher for the program development. The whole procedure of the interview will be audio recorded for the purpose of the evaluation of the content. At the end of the interview, you would be given a brief feedback form that would require an additional five minutes of your time. In addition, your consent for a one-to-one interview (of about half an hour) after about three months would be asked for, in the feedback form. This interview would be aimed at taking your opinion about the program which is developed by the researcher based on the views of the parents and professionals. You would be shown the content of the program developed for children with ASD and your opinion about its appeal and suitability would be sought during this interview. You can choose to participate only in the interview without giving consent to be contacted for participating in the brief interview to be conducted later.

**Risk and benefits:** There may be no direct benefits for participation in this phase of the study. However, the data gathered from the discussions will be helpful for the researcher during the various phases of research. If you wish to seek help for psychological problems during the study, you will be provided appropriate referral related information. There would be no costs for you in participating in the study and no payments will be made for the same.

**Confidentiality:** The individual-specific data collected during the focused group discussions and feedback would be kept confidential. The information provided by you will be open for scrutiny only by the Calicut University ethics committee. The findings from the research may be presented in various scientific meetings or publications without the identity of the participants being revealed. The audio recordings of the focused group discussions will be kept till the end of the research period and will be destroyed afterwards. You are free to ask researcher any questions about the study and make clarifications before the consent form is signed.

**Undertaking by the Investigator:** Your consent to participation in this phase of the above study is sought by Mr. Nigesh K., Ph.D. scholar, Department of Psychology, University of Calicut. Your taking part in the study is voluntary. You have the right to refuse consent or withdraw the same during any part of the study without giving any reason. The study including the results will be submitted as thesis and may be published in scientific academic journals, without identifying the participants. There will be no monetary or other tangible benefits associated with participation in the study. You are welcome to contact the researcher (Mr. Nigesh K., Ph.D. Scholar, Dept. of Psychology, University of Calicut, Ph.: 9446950021), for further clarification, if you so desire. You may also contact the guide or joint guide for further clarification, if any.

**Consent by the Participant**

I have been informed that the group discussion being conducted is a part of a research study and that it is aimed at exploring the felt needs, receptivity and feasibility of parent mediated intervention program and to test the preliminary outcomes of the same. I am aware that participating in this study requires me to participate in a group discussion of 60-90 minutes duration. I am aware that after the group discussion, I would be requested to fill a feedback form and my consent would be asked for being contacted later for a brief one to one interview. I understand that I can choose to participate only in the group discussion without giving consent to be contacted for participating in the brief interview.

I understand that my participation is voluntary and that I have the option to refuse my consent or withdraw it any time during the study without giving any reason. I understand that the information I provide will be used only for the purpose of research and will be kept strictly confidential. I also understand that I will not have any tangible or monetary benefits for participating in the study.

I have been given the assurance that I would be provided with appropriate referral information for psychological help if need arise. I have also been guaranteed the confidentiality of the personal-specific data I provide. The content of this consent form is explained to me in a language that I understand, and I was given opportunity to clarify all my questions regarding the study.

The audio recordings of the focused group discussions will be kept till the end of the research period and will be destroyed afterwards.

I have been explained that the focused group discussion will be audio recorded and I give my consent fort the same.

I, ……, the undersigned, give my consent to be a participant of the focused group discussion and to be contacted for the brief interview/ only to be a participant of the focused group discussions of the study 'Development and Preliminary Evaluation of a

Parent mediated intervention program for children with ASD'.

**Signature (Participant)**

Name:
Address:
Ph. No.:

**Signature (Witness)**

Name:
Address:
Ph. No.:

**Signature (Investigator)**

Nigesh K.

Ph. D. Scholar, Dept. of Psychology, University of Calicut
Ph. No.: 9446950021

**Guide**

Dr. C. Jayan
Professor
Dept. of Psychology,
University of Calicut

**Co-Guide**

Dr. Sukanya B. Menon
Assistant Professor
Dept. of Psychology
Prajyoti Niketan College

**Department of Psychology**

**University of Calicut**

Informed Consent Form (Interview) –Pilot and Main Phase (Professionals)

Title of the study: Development of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

---

**Information about the Study:** I am conducting a study to develop a parent mediated intervention program for children with autism spectrum disorders (ASDs). The study is aimed at exploring the perspectives of the parents of children with ASD and professionals dealing with ASDs regarding the felt needs, receptivity and feasibility, and potential content and structure of a Parent mediated intervention program. The study aims at developing a program for the children diagnosed with autism spectrum disorders and to evaluate the preliminary outcomes of the same.

**Study Assessment:** The current phase of study involves participation semi-structured interview of about 45-60 minutes and would be conducted on a one-to-one basis. The interview will be conducted at a place and time that is convenient for the interviewer and the interviewee. The interview would focus on the felt needs of the professionals dealing with children diagnosed of ASD, their views regarding the need for a parent mediated intervention program, as well as about the feasibility of conducting such a program. The data generated during the interviews will be used by the researcher for the program development.

**Risk and benefits:** There may be no direct benefits for participation in the interviews. However, the data gathered from the interviews will be helpful for the researcher during the program development as well as for the evaluation of the program. There would be no costs for you in participating in the study and no payments will be made for the same.

**Confidentiality:** The individual-specific data collected during the interview would be kept confidential. The information provided by you will be open for scrutiny only for the regulatory authorities and institution ethics committee. The findings from the research may be presented in various scientific meetings or publications without the identity of the participants/the institutes being revealed. The audio recordings of the interview will be kept till the end of the research period and will be destroyed afterwards. You are free to ask researcher any questions about the study and make clarifications before the consent form is signed.

**Undertaking by the Investigator:** Your consent to participation in this phase of the above study is sought by Mr. Nigesh K., Ph.D. scholar, Department of Psychology, University of Calicut. Your taking part in the study is voluntary. You have the right to refuse consent or withdraw the same during any part of the study without giving any reason. The study including the results will be submitted as thesis and may be published in scientific academic journals, without identifying the participants. There will be no monetary or other tangible benefits associated with participation in the study. You are welcome to contact the researcher (Mr. Nigesh K., Ph.D. Scholar, Dept. of Psychology, University of Calicut, Ph.: 9446950021), for further clarification, if you so desire.

**Consent by the Interview Participant**

I have been informed that the interview being conducted is a part of a research study and that it is aimed at exploring the felt needs, receptivity and feasibility of a development of parent mediated intervention program for children with autism spectrum disorder and to test the preliminary outcomes of the same. I am aware that participating in this study requires me to participate in a semi-structured interview of about 45 minutes duration. I understand that my participation is voluntary and that I have the option to refuse my consent or withdraw it any

time without giving any reason for doing so. I understand that the information I provide will be used only for the purpose of research and will be kept strictly confidential. I understand that I will not have any tangible or monetary benefits for participating in the study. I am also assured that the time and place of the interview will be decided on the basis of mutual convenience to the participant and the investigator.

I have been also explained that the interview will be audio recorded and I give my consent for the same.

I, ……, the undersigned, give my consent to be a participant of the semi-structured interview of the study **'**Development and Preliminary Evaluation of a

Parent mediated intervention program for children with ASD'.

**Signature (Interview Participant**)

Name:

Address:

Ph. No.:

**Signature (Investigator)**

Nigesh K.

Ph. D. Scholar, Dept. of Psychology, University of Calicut

Ph. No.: 9446950021

**Guide**

Dr. C. Jayan

Professor

Dept. of Psychology,

University of Calicut

**Co-Guide**

Dr. Sukanya B. Menon

Assistant Professor

Dept. of Psychology

Prajyoti Niketan College

## Appendix 2

**Department of Psychology**
**University of Calicut**

**Socio-demographic Data Sheet – Interview Participants (Parents)**

Title of the study: Development of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

Please read through the items carefully and fill in the details. The details provided will be kept confidential

1. Name:
2. Age:
3. Sex:
4. Religion:
5. Domicile:
6. Marital Status:
7. Education:
8. Occupation:
9. Family Income/Socio-economic strata:
10. Years of Marital life:
11. No. of children:
12. Living arrangement: Own House/rented house/apartment, etc.
13. Any other relevant information:

## Appendix 3

**Department of Psychology**
**University of Calicut**

**Semi-structured interview schedule (Parents)**

Title of the study: Development of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

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As explained, the present research is about developing and testing the receptivity, feasibility, and short-term outcomes of a parent-mediated intervention program. For this purpose, I have a pre-selected set of questions.

1. Being a parent of children with ASD, who would be spending a major time with the child and knows him/her in better way. What are your thoughts on having a program like "parent mediated intervention programme for children with ASD"?

   We are in the process of developing a program which will tentatively include elements such as psycho-education components, stress management, respite care for parents, child related modules such as training in activities of daily living or self-help skill training, enhancing communication skills, reducing repetitive behaviours, enhancing fine-motor functioning, social skills training, behavioural modification, etc. This program aims to increase and promote children and parental functioning and to equip participants to take care of functioning and skills effectively in day-to-day life. It will include other elements known to support parents and their coping skills. It would be a forum to learn, through experiences and activities where they take an active role. It would be about learning by doing, doing things for the self and others and not in a lecture mode
2. Considering these aspects in mind, do you feel a need to have such a program specifically for this purpose, when there may be several different programs available?
3. If you feel it is not/needed, could you tell us more on why it becomes relevant/irrelevant?
4. What are your thoughts on what needs to be included or addressed through such a program for parents of children with ASD? Are there any specific aspects that are relevant for the parents and children with ASD which must be included?

   We are tentatively planning a program which involves multiple sessions spread over a period of time to cover different themes. This is because it is established that multiple sessions spaced out in time are important for maximizing learning and impact. The rough plan is to cover about 10-15 sessions hours over 3-4 months.

1. To what extent you think a program of this duration and structure would be feasible?
2. Considering all these aspects in mind, would you like to make any suggestions or to give an opinion about the program (content and structure)?
3. How easy or difficult you think it would be to enroll students from different courses voluntarily?

   As mentioned before, about half of the sessions are planned to be conducted during the working hours. Also, the program is structured in such a way that the participants are expected to/encouraged to plan and engage in as many small activities as possible.
4. Do you think it would be feasible to hold some of the sessions during the working days?
5. Also, what do you think about using the clinic as a venue to hold some (30-50%) of the

sessions during the weekends?

6. How feasible, or how easy or difficult, you think it would be to implement such a program? What you think would be the possible difficulties or hindrances that can emerge? (Logistics, unforeseen circumstances, and other familial issues, work pressure, lack of time, etc.)? How to minimize the same?
7. Who can be the potential sources of support in implementing such a program?
8. How receptive you think you and the other parents would be towards a program of this nature?
9. Would you like to comment on the potential benefits for the parents as well as the children with ASD by taking part in such programs? If so, would you like to elaborate?
10. Is there is any other thing that you would want to share concerning the various issues that are discussed?

**Appendix 4**

**Department of Psychology**
**University of Calicut**

Socio-demographic Data Sheet – Interview Participants (Professionals)

Title of the study: Development of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

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1. Name:

2. Age:

3. Sex:

4. Religion:

5. Domicile:

6. Education:

7. Designation:

8. Institute Name:

9. Type of institution: (Govt./Pvt/ Self-employment, etc.)

10. Years of Experience:

a. Present Institute:

b. Past :

11. Any other areas of involvement in the research, training, workshop, course attended or teaching outside the regular clinical work? If YES, please specify (With duration)

## Appendix 5

**Department of Psychology**
**University of Calicut**

**Semi-structured interview schedule (Professionals)**

Title of the study: Development of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

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As explained, the present research is about developing and testing the receptivity, feasibility, and short-term outcomes of a parent-mediated intervention program. For this purpose, I have a pre-selected set of questions.

1. Being a person in charge of a treating professional for children with ASD, what are your thoughts on having a program like "parent mediated intervention programme for children with ASD"?

We are in the process of developing a program which will tentatively include elements such as psycho-education components, stress management, respite care for parents, child related modules such as training in activities of daily living or self-help skill training, enhancing communication skills, reducing repetitive behaviours, enhancing fine-motor functioning, social skills training, behavioural modification, etc. This program aims to increase and promote children and parental functioning and to equip participants to take care of functioning and skills effectively in day-to-day life. It will include other elements known to support parents and their coping skills. It would be a forum to learn, through experiences and activities where they take an active role. It would be about learning by doing, doing things for the self and others and not in a lecture mode

2. Considering these aspects in mind, do you feel a need to have such a program specifically for this purpose, when there may be several different programs available?
3. If you feel it is not/needed, could you tell us more on why it becomes relevant/irrelevant?
4. What are your thoughts on what needs to be included or addressed through such a program for parents of children with ASD? Are there any specific aspects that are relevant for the parents and children with ASD which must be included?

   We are tentatively planning a program which involves multiple sessions spread over a period of time to cover different themes. This is because it is established that multiple sessions spaced out in time are important for maximizing learning and impact. The rough plan is to cover about 10-15 sessions hours over 3-4 months.
5. To what extent you think a program of this duration and structure would be feasible?
6. Considering all these aspects in mind, would you like to make any suggestions or to give an opinion about the program (content and structure)?
7. How easy or difficult you think it would be to enroll students from different courses voluntarily?

   As mentioned before, about half of the sessions are planned to be conducted during the working hours. Also, the program is structured in such a way that the participants are expected to/encouraged to plan and engage in as many small activities as possible.
8. Do you think it would be feasible to hold some of the sessions during the working days?
9. Also, what do you think about using the clinic as a venue to hold some (30-50%) of the

sessions during the weekends?

10. How feasible, or how easy or difficult, you think it would be to implement such a program? What you think would be the possible difficulties or hindrances that can emerge? (Logistics, unforeseen circumstances, and other familial issues, work pressure, lack of time, etc.)? How to minimize the same?
11. Who can be the potential sources of support in implementing such a program?
12. How receptive you think the parents would be towards a program of this nature?
13. Would you like to comment on the potential benefits for the parents as well as the children with ASD by taking part in such programs? If so, would you like to elaborate?
14. Is there is any other thing that you would want to share concerning the various issues that are discussed?

## Appendix 6

**Department of Psychology**
**University of Calicut**

### Potential Contents Ranking List

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

**Name of the Respondent:**

As you are already told, the present study aims to understand the felt needs, receptivity, feasibility, and potential contents for the development of a parent mediated intervention program suitable for children with ASD.

Below given are several potential themes/topics. Please go through each of the topics carefully and indicate which of these are likely to be most useful and which are likely to be least useful for parents and their children with ASD.

Go through the entire list of possible themes/topics carefully. Put a tick (√) mark in '**most useful**' column against each of the themes that you find relevant for the program. Also, from the themes that you marked as relevant, select five themes that you feel most important and give those ranks from one to five. Write rank 1 for what you think is likely to be the most useful topic and rank five for the 5th most useful topic.

[Please select at least one option from each of the sections and assign your preference for the chosen themes]

**Please ask if there are any doubts, before starting.**

| **Themes/Topics** | **Most Useful** ✓ | **Rank** |
|---|---|---|
| **Reducing problematic behaviours** | | |
| 15. Reduce inappropriate behaviors (removing dress in public, etc.) | | |
| 16. Harming self and others | | |
| 17. Impulsivity | | |
| 18. Reduce repetitive behaviors | | |
| 19. Demanding behaviors | | |
| 20. Temper tantrums | | |
| 21. Disobedience | | |

| **Basic Learning Skills** |
|---|
| 22. Identification of letters |
| 23. Identification of numbers |
| 24. basic calculation |
| 25. Basic Copying |
| **Fine motor skills** |
| 26. Holding objects |
| 27. Buttoning |
| 28. Eye hand coordination |
| 29. Transferring objects |
| 30. Wearing shoes/tying shoe lays |
| 31. Pencil grip/throwing things |
| **Psychoeducation and parental training** |
| 32. Educating/awareness |
| 33. Stress management |

## Appendix 7

**PMI Program Validation Informed consent form**

**Department of Psychology**

**University of Calicut**

**Informed Consent Form (PMI Program Validation)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

**Information about the Study:** As a part of my Ph.D., which is aimed at developing a parent mediated intervention program for children with ASD, I have developed a parent mediated intervention program aimed at children with ASD targeting on both parents and child outcomes

**Study Assessment:** Your participation involves filling up a validation form do the evaluation of a PMI program modules in detail, which would take about 60-90 minutes.

**Risk and benefits:** There may be no direct benefits for participation in the study. There would be no costs for you in participating in the study, and no payments will be made for the same.

**Confidentiality:** The individual-specific data collected during the interview would be kept confidential. The information provided by you will be open for scrutiny only for the regulatory authorities and institution ethics committee. The findings from the research may be presented in various scientific meetings or publications without the identity of the participants/the institutes being revealed. You are free to ask the researcher any questions about the study and make clarifications before the consent form is signed.

**Undertaking by the Investigator:** Your consent to participate is sought by Mr. Nigesh K, Ph.D. scholar, Department of Psychology, University of Calicut. Your taking part in the program validation is voluntary. You have the right to refuse consent or withdraw the same without giving any reason. The study, including the results, will be submitted as a thesis and may be published in academic journals, without identifying the participants. There will be no monetary or other tangible benefits associated with participation in the study. You are welcome to contact the researcher for further clarification if you so desire.

**Consent by the Interview Participant**

I have been informed that the program validation being conducted is a part of a research study aimed at developing a parent mediated intervention program for children with ASD. I am aware that participating in this study requires me to spend about 60-90 minutes, filling up a validation form after going through the PMI modules designed. I understand that my participation is voluntary and that I have the option to refuse my consent or withdraw it any time without giving any reason for doing so. I understand that the information I provide will be used only for the purpose of research and will be kept strictly confidential. I understand that I will not have any tangible or monetary benefits for participating in the study.

I, ……, the undersigned, give my consent to be a participant of the above-mentioned validation.

**Signature (Participant)**

Name:
Address:
Ph. No.:

**Signature (Investigator)**

Nigesh K.
Ph. D. Scholar, Dept. of Psychology, University of Calicut
Ph. No.: 9446950021

**Guide**
Dr. C. Jayan
Professor
Dept. of Psychology,
University of Calicut

**Co-Guide**
Dr. Sukanya B. Menon
Assistant Professor
Dept. of Psychology
Prajyoti Niketan College

## Appendix 8

**PMI Program Validation Form**

**Department of Psychology**
**University of Calicut**

**PMI Program Validation Form (Experts)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

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**Dear Sir/Madam,**

I am sending you a copy of the various modules that are developed as a part of my Ph.D. work (Title: Development of a parent mediated intervention program for children with autism spectrum disorder). The program mentioned above is intended for a parent of children with ASD. The thesis work involves exploration of the perspectives of the parents of children with ASD and professionals dealing with ASDs regarding the felt needs, receptivity and feasibility, and potential content and structure of a Parent mediated intervention program. The study aims at developing a program for the children diagnosed with autism spectrum disorders.

**There is a total of six modules with different themes that have been finalized based on pilot phase data and expert opinion. You are requested to go through each of the modules and provide your valuable suggestions on several domains.** Please rate the various aspects of the modules based on the checklist/questionnaire and mention any suggestions for improvement.

Please indicate your responses for each module in the enclosed questionnaire.

**SA** = Strongly Agree
**A**= Agree
**N** = neither agree nor disagree
**D** = Disagree
**SD** = Strongly Disagree

| Sl. no. | | SA | A | N | D | SD | Remarks/suggestions/Comments (In detail) |
|---|---|---|---|---|---|---|---|
| 1 | The content is adequately covering the objectives cited | | | | | | |
| 2 | The content of the module is appropriate for the target audience (parents of children with ASD) | | | | | | |
| 3 | The content of the module follows a logical sequence | | | | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 4 | There is adequate number of activities included in the module to sustain the interest of child to achieve goals | | | | | | |
| 5 | The activities are linked to the objectives | | | | | | |
| 7 | Adequacy of title of the program | | | | | | |
| 8 | Mode of delivery | | | | | | |
| 9 | If any modifications are required for any activities | | | | | | |
| 10 | Any other comments or suggestions of activities | | | | | | |

## Qualitative Validation and Data sheet

| | | |
|---|---|---|
| 1 | Which age group of children with ASD would be most suitable for getting trained in this package? | |
| 2. | Suggest which severity group of ASDs would be most suitable for the training in this package | |
| 3. | Time period required for the training of this module | |
| 4. | Is there any need for changing the structure of this module, if then kindly suggest the changes | |

## Appendix 9

**PMI Program Validation Form**

**Department of Psychology**

**University of Calicut**

**PMI Program Validation Form (Parents)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

**Dear Sir/Madam,**

I am sending you a copy of the various modules that are developed as a part of my Ph.D. work (Title: Development of parent mediated intervention program for children with autism spectrum disorder). The program mentioned above is intended for a parent of children with ASD. The thesis work involves exploration of the perspectives of the parents of children with ASD and professionals dealing with ASDs regarding the felt needs, receptivity and feasibility, and potential content and structure of a Parent mediated intervention program. The study aims at developing a program for the children diagnosed with Autism Spectrum Disorder.

**There is a total of six modules with different themes that have been finalized based on pilot phase data and expert opinion. You are requested to go through each of the modules and provide your valuable suggestions on several domains.** Please rate the various aspects of the modules based on the checklist/questionnaire and mention any suggestions for improvement.

Please indicate your responses for each module in the enclosed questionnaire.

**SA** = Strongly Agree

**A**= Agree

**N** = neither agree nor disagree

**D** = Disagree

**SD** = Strongly Disagree

| Sl. no. | | SA | A | N | D | SD | Remarks/suggestions/Comments (In detail) |
|---|---|---|---|---|---|---|---|
| 1 | The content is adequately covering the objectives cited | | | | | | |
| 2 | The content of the module is appropriate for the target audience (parents of children with ASD) | | | | | | |
| 3 | The content of the module follows a logical sequence | | | | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 4 | There is adequate number of activities included in the module to sustain the interest of child to achieve goals | | | | | | |
| 5 | The activities are linked to the objectives | | | | | | |
| 7 | Adequacy of title of the program | | | | | | |
| 8 | Mode of delivery | | | | | | |
| 9 | If any modifications are required for any activities | | | | | | |
| 10 | Any other comments or suggestions of activities | | | | | | |

## Qualitative Validation and Data sheet

| | | |
|---|---|---|
| 1 | Which age group of children with ASD would be most suitable for getting trained in this package? | |
| 2. | Suggest which severity group of ASD would be most suitable for the training in this package | |
| 3. | Time period required for the training of this module | |
| 4. | Is there any need for changing the structure of this module, if then kindly suggest the changes | |

## Appendix 10

**PMI Program Preliminary Evaluation Informed consent form**

**Department of Psychology**
**University of Calicut**

**Informed Consent Form (PMI Program Pilot Trial Run)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

**Information about the Study:** As a part of my Ph.D., which is aimed at developing a parent mediated intervention program for children with ASD, I have developed a parent mediated intervention program aimed at children with ASD targeting on both parents and child outcomes. It has a pilot phase and a main phase where data will be collected from two stakeholders such as parents of children with ASD and professionals working among children with ASD.

The current phase of the study requires participation of clients in the pilot trial run conducted to test the feasibility and practicability of the developed parent mediated intervention program developed by the researcher and thereby to fine tune the same. The PMI program will be implemented in children diagnosed with ASD through parents. The intervention is scheduled as one session per week (weekly session with parents) and once in two weeks (both parents and child), with each session taking about 1-1.5 hours. So, it will take a total of two to three months to complete the intervention. This intervention is aimed at addressing both child and parent outcomes such as helps to enhance awareness, knowledge regarding ASD and its treatments among parents and reducing problematic behaviours, training on self-help skills, basic communication, fine-motor skills in children.

The intervention programme will not interfere with the current medical treatments undertaken by the participant, if any. And it is important to understand that this intervention is no way a substitute to medical treatments.

Because it is a clinical trial run, it is also important to understand that the benefits claimed or offered by the intervention are not guaranteed and instead, are only theoretically derived.

Participation in the interview is voluntary. The data derived through this clinical trial run will only be used for research purposes. Further, person-related data will not be used anywhere in the research, nor it will be exposed to a third party, under any circumstance. Participant can choose to stop and quit the intervention whenever they like to.

**Risk and benefits:** There may be no direct benefits for participation in the study. There would be no costs for you in participating in the study, and no payments will be made for the same.

**Confidentiality:** The individual-specific data collected during the interview would be kept confidential. The information provided by you will be open for scrutiny only for the regulatory authorities and institution ethics committee. The findings from the research may be presented in various scientific meetings or publications without the identity of the participants/the institutes being revealed. You are free to ask the researcher any questions about the study and make clarifications before the consent form is signed.

**Undertaking by the Investigator:** Your consent to participate is sought by Mr. Nigesh K, Ph.D. scholar, Department of Psychology, University of Calicut. Your taking part in the program is voluntary. You have the right to refuse consent or withdraw the same without giving any reason. The study, including the results, will be submitted as a thesis and may be published in academic journals, without identifying the participants. There will be no monetary or other tangible benefits associated with participation in the study. You are welcome to contact the researcher for further

clarification if you so desire.

**Consent by the Interview Participant**

I have been informed that the clinical pilot trails run being conducted is a part of a research study aimed at developing a parent mediated intervention program for children with ASD and its preliminary evaluation purpose for determining the feasibility and practicability of the PMI program developed by the researcher. I am aware that participating in this study requires me to spend about 60-90 minutes, weekly for about 2-3 months period. I understand that my participation is voluntary and that I have the option to refuse my consent or withdraw it any time without giving any reason for doing so. I understand that the information I provide will be used only for the purpose of research and will be kept strictly confidential. I understand that I will not have any tangible or monetary benefits for participating in the study I, ……, the undersigned, give my consent to be a participant of the above-mentioned validation.

**Signature (Participant)**

Name:
Address:
Ph. No.:

**Signature (Investigator)**

Nigesh K.
Ph. D. Scholar, Dept. of Psychology, University of Calicut
Ph. No.: 9446950021

**Guide**
Dr. C. Jayan
Professor
Dept. of Psychology,
University of Calicut

**Co-Guide**
Dr. Sukanya B. Menon
Assistant Professor
Dept. of Psychology
Prajyoti Niketan College

## Appendix 11

**PMI Program Preliminary Evaluation Case History Proforma**

**Department of Psychology**
**University of Calicut**

**Case History Proforma (PMI Program Pilot Trial Run)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

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**Socio Demographic Sheet:**

| | |
|---|---|
| Name | : |
| Age | : |
| Sex | : |
| Mother Tongue | |
| Education | : |
| Socio-economic status | : |
| Religion | : |
| Residence/Domicile | : |
| Family Type | : |
| District | : |
| Informant | : |
| Information | : |

**Clinical characteristics:**

| | |
|---|---|
| Presenting Complaints (Onset, progress, Course) | : |
| History of Present Illness | : |
| Biological functioning | : |
| Negative History | : |
| History of Past Illness | : |
| Treatment History | : |
| Family History | : |
| Family Interaction Pattern | : |
| Personal History | : |
| Prenatal history | : |
| Childhood History | : |
| Temperament | : |

**Appendix 12**

**PMI Program Preliminary Evaluation**
**Behavioural Observation/Mental Status Examination Proforma**

**Department of Psychology**
**University of Calicut**

**Behavioural Observation/Mental Status Examination**
**Proforma (PMI Program Pilot Trial Run)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

## Behavioural Observation/Mental Status Examination

### General appearance and behaviour:

*(Age (actual and apparent); Age-appropriate clothes,*
*Grooming and cleanliness.*
*Dysmorphic features, bruises, scars*
*Manner of relating to examiner and parents,*
*including ease of separation).*

### Speech and Language:

*Receptive speech:*
*Expressive speech*
*(Fluency, Volume, Rate & Language skills)*

### Mood:

*Type, range, and appropriateness of affect*
*(e.g., depressed, elated, irritable)*
*Anxiety (Fears, Phobias, Obsessions,*
*Compulsions or rituals,*
*Separation difficulties, etc.)*

### Psychomotor behavior:

(*Including Activity level and Unusual Motor Patterns such as*
*Tics, Mannerisms, Activity level, Coordination)*

### Thought form and content:

*(Delusions &Thought disorder)*

**Perception:**
*(Hallucinations, illusions)*

**Cognitive functions:**
*(Developmentally appropriate vocabulary,*
*Fund of knowledge, appropriate drawings)*
**Attention and concentration:**
**Memory:**
**Orientation:**
**Judgment and insight:**
**Three wish Test:**

**Impression:**

**Appendix 13**

**PMI Program Preliminary Evaluation**
**Vineland's Social Maturity Scale (VSMS)**

**Department of Psychology**
**University of Calicut**

## Vineland's Social Maturity Scale
## (PMI Program Pilot Trial Run)

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

**VINELAND SOCIAL MATURITY SCALE RECORD SHEET**

| S. No. | Test Items | S. No. | Test Items |
|---|---|---|---|
| | **0-1 Year** | 29. | Goes about hours or yard |
| 1. | "Crows", Laugh | 30. | Discriminates edible substances from non-edibles |
| 2. | Balance head | 31. | Uses names of familiar objects |
| 3. | Grasps objects within reach | 32. | Walks upstairs unassisted |
| 4. | Reaches for familiar persons | 33. | Unwraps sweets, chocolates |
| 5. | Rolls over, (unassisted) | 34. | Talks in short sentences |
| 6. | Reaches for nearby objects | | **2-3 Years** |
| 7. | Occupies self-upright | 35. | Signals to go to toilet |
| 8. | Sits unsupported | 36. | Initiates own play activities |
| 9. | Pulls self upright | 37. | Removes shirt to or frock if unbuttoned |
| 10. | "Talks", imitates sounds | 38. | Eats with spoon/hands (food) |
| 11. | Drinks from cup or glass assisted | 39. | Gets drink (water) unassisted |
| 12. | Moves about on floor (creeping, crawling) | 40. | Dries own hands |
| 13. | Grasps with thumb and finger | 41. | Avoids simple hazards |
| 14. | Demands personal attention | 42. | Puts on short or frock unassisted (need not button) |
| 15. | Stands alone | 43. | Can do paper folding |
| 16. | Does not drool | 44. | Relates experience |
| 17. | Follows simple instructions | | **3-4 Years** |
| | **1-2 Year** | 45. | Walks downstairs, one step at a time |
| 18. | Walks about room unattended | 46. | Plays co-operatively at kindergarten level. |
| 19. | Marks with pencil or crayon or chalk | 47. | Buttons shirt or frock |
| 20. | Masticates (chews) solid or semi-solid food | 48. | Helps at little household tasks |
| 21. | Pulls off clothes | 49. | "Performs" for others |
| 22. | Transfers objects | 50. | Washes hands unaided |
| 23. | Overcomes simple obstacles | | **4-5 Years** |
| 24. | Fetches or carries familiar objects | 51. | Cares for self at toilet |
| 25. | Drinks from cup or glass | 52. | Washes face unassisted |
| 26. | Walks without support | 53. | Goes about neighborhood Unattended |
| 27. | Plays with other children | | |
| 28. | Eats with own hands (biscuits, bread, etc.) | | |

| S. No. | Test Items |
|---|---|
| 54. | Dresses self expect for trying |
| 55. | Uses pencil or crayon or chalk for drawing |
| 56. | Plays competitive exercise games |
| | **5-6 Years** |
| 57. | Uses hoops, flies kites, or uses knife |
| 58. | Prints (writes) simple words |
| 59. | Plays simple games which require talking turns |
| 60. | Is trusted with money |
| 61. | Goes to school unattended |
| | **6-7 Years** |
| 62. | Mixex rice "properly unassisted |
| 63. | Use pencil or chalk for waiting |
| 64. | Bathes self assisted |
| 65. | Goes to bed unassisted |
| | **7-8 Years** |
| 66. | Can differentiate between AM & PM |
| 67. | Helps himself during meals |
| 68. | Understands and keeps family secrets |
| 69. | Participants in pre-adolescent |
| 70. | Combs or burses hair |
| | **8-9 Year** |
| 71. | Uses tools or utensils |
| 72. | Does routine household tasks |
| 73. | Reads on own initiative |
| 74. | Bathes self unaided |
| | **9-10 Years** |
| 75. | Cares for self at meals |
| 76. | Makes minor purchase |
| 77. | Goes about home town freely |

| S. No. | Test Items |
|---|---|
| | **10-11 Years** |
| 78. | Distinguishes between friends any play mates |
| 79. | Makes independent choice of shops |
| 80. | Does small remunerative work; makes articles |
| 81. | Follows local current events |
| | **11-12 Years** |
| 82. | Does simple creative work |
| 83. | Is left to care for self or others |
| 84. | Enjoys reading books, newspapers and magazines |
| | **12-15 Years** |
| 85. | Plays difficult games |
| 86. | Exercises complete care of dress |
| 87. | Buys own clothing accessories |
| 88. | Engages of adolescent group activities |
| 89. | Performs responsible routine chores |

## IV. TABLE FOR CONVERSION OF RAW SCALES TO SOCIAL AGE

| SCORE | SA | SCORE | SA | SCORE | SA |
|---|---|---|---|---|---|
| 1.0 | 0.06 | 31 | 1.83 | 64 | 6.8 |
| 1.5 | 0.09 | 32 | 1.89 | 65 | 7.0 |
| 2.0 | 0.12 | 33 | 1.94 | 66 | 7.2 |
| 2.5 | 0.15 | 34 | 2.00 | 67 | 7.4 |
| 3.0 | 0.18 | 35 | 2.1 | 68 | 7.6 |
| 3.5 | 0.21 | 36 | 2.2 | 69 | 7.8 |
| 4.0 | 0.24 | 37 | 2.3 | 70 | 8.0 |
| 5 | 0.30 | 38 | 2.4 | 71 | 8.3 |
| 6 | 0.35 | 39 | 2.5 | 72 | 8.5 |
| 7 | 0.41 | 40 | 2.6 | 73 | 8.8 |
| 8 | 0.47 | 41 | 2.7 | 74 | 9.0 |
| 9 | 0.53 | 42 | 2.8 | 75 | 9.3 |
| 10 | 0.59 | 43 | 2.9 | 76 | 9.7 |
| 11 | 0.65 | 44 | 3.0 | 77 | 10.0 |
| 12 | 0.71 | 45 | 3.2 | 78 | 10.3 |
| 13 | 0.77 | 46 | 3.3 | 79 | 10.5 |
| 14 | 0.83 | 47 | 3.5 | 80 | 10.8 |
| 15 | 0.89 | 48 | 3.7 | 81 | 11.0 |
| 16 | 0.94 | 49 | 3.8 | 82 | 11.3 |
| 17 | 1.00 | 50 | 4.0 | 83 | 11.7 |
| 18 | 1.06 | 51 | 4.2 | 84 | 12.0 |
| 19 | 1.12 | 52 | 4.3 | 85 | 12.6 |
| 20 | 1.18 | 53 | 4.5 | 86 | 13.2 |
| 21 | 1.24 | 54 | 4.7 | 87 | 13.8 |
| 22 | 1.30 | 55 | 4.8 | 88 | 14.4 |
| 23 | 1.35 | 56 | 5.0 | 89 | 15.0 |
| 24 | 1.41 | 57 | 5.2 | | |
| 25 | 1.47 | 58 | 5.4 | | |
| 26 | 1.53 | 59 | 5.6 | | |
| 27 | 1.59 | 60 | 5.8 | | |
| 28 | 1.65 | 61 | 6.0 | | |
| 29 | 1.71 | 62 | 6.3 | | |
| 30 | 1.77 | 63 | 6.3 | | |

**Appendix 14**

**PMI Program Preliminary Evaluation**
**Indian Scale for Assessment of Autism (ISAA)**

**Department of Psychology**
**University of Calicut**

**Indian scale for Assessment of Autism (ISAA)**
**(PMI Program Pilot Trial Run)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

# Indian scale for Assessment of Autism (ISAA)

**Directions:**

Below are given 40 statements which are divided under six domains, please tick (√) mark the appropriate rating for each item of the scale by observing the child and by interviewing the parents in order to assess Autism

| | Items | Rarely Upto 20% Score 1 | Sometimes 21 – 40 % Score 2 | Frequently 41 – 60% Score 3 | Mostly 61-80 % Score 4 | Always 81-100% Score 5 |
|---|---|---|---|---|---|---|
| **I. SOCIAL RELATIONSHIP AND RECIPROCITY** | | | | | | |
| 1 | Has poor eye contact | | | | | |
| 2 | Lacks social smile | | | | | |
| 3 | Remains aloof | | | | | |
| 4 | Does not reach out to others | | | | | |
| 5 | Unable to relate to people | | | | | |
| 6 | Unable to respond to social/ environmental cues | | | | | |
| 7 | Engages in solitary and repetitive play activities | | | | | |
| 8 | Unable to take turns in social interaction | | | | | |
| 9 | Does not maintain peer relationships | | | | | |
| **II. EMOTIONAL RESPONSIVENESS** | | | | | | |
| 10 | Shows inappropriate emotional response | | | | | |
| 11 | Shows exaggerated emotions | | | | | |
| 12 | Engages in self-stimulating emotions | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| 13 | Lacks fear of danger | | | | | |
| 14 | Excited or agitated for no apparent reason | | | | | |
| **III. SPEECH-LANGUAGE AND COMMUNICATION** | | | | | | |
| 15 | Acquired speech and lost it | | | | | |
| 16 | Has difficulty in using non-verbal language or gestures to communicate | | | | | |
| 17 | Engages in stereotyped and repetitive use of language | | | | | |
| 18 | Engages in echolalic speech | | | | | |
| 19 | Produces infantile squeals/ unusual noises | | | | | |
| 20 | Unable to initiate or sustain conversation with others | | | | | |
| | | | | | | |
| 21 | Uses jargon or meaningless words | | | | | |
| 22 | Uses pronoun reversals | | | | | |
| 23 | Unable to grasp pragmatics of communication (real meaning) | | | | | |
| | | | | | | |
| 24 | Engages in stereotyped and repetitive motor mannerisms | | | | | |
| 25 | Shows attachment to inanimate objects | | | | | |
| 26 | Shows hyperactivity/ restlessness | | | | | |
| 27 | Exhibits aggressive behavior | | | | | |
| 28 | Throws temper tantrums | | | | | |
| 29 | Engages in self-injurious behavior | | | | | |
| 30 | Insists on sameness | | | | | |
| | | | | | | |
| 31 | Unusually sensitive to sensory stimuli | | | | | |
| 32 | Stares into space for long periods of time | | | | | |
| 33 | Has difficulty in tracking objects | | | | | |
| 34 | Has unusual vision | | | | | |
| 35 | Insensitive to pain | | | | | |
| 36 | Responds to objects/people unusually by smelling, touching or tasting | | | | | |
| | | | | | | |
| 37 | Inconsistent attention and concentration | | | | | |
| 38 | Shows delay in responding | | | | | |
| 39 | Has unusual memory of some | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| | kind | | | | | |
| 40 | Has 'savant' ability | | | | | |

| **Classification** | **No Autism** < 70 | **Mild Autism** 70 to 106 | **Moderate Autism** 107 to 153 | **Severe Autism** > 153 |
|---|---|---|---|---|
| **Total score** | | | | |

***Norms of ISAA for Diagnosis of Autism***

| ISAA Scores | Degree of Autism |
|---|---|
| < 70 | Normal |
| 70 to 106 | Mild Autism |
| 107 to 153 | Moderate Autism |
| > 153 | Severe Autism |

***Percentage of Disability as per the score***

| Score | Percentage (%) |
|---|---|
| 70 | 40 |
| 71-88 | 50 |
| 89-105 | 60 |
| 106-123 | 70 |
| 124-140 | 80 |
| 141-158 | 90 |
| Above 158 | 100 |

***Conclusion:***

Indian Scale for Identification of Autism (ISAA) is a standardized tool with good psychometric properties. It is a reliable and valid tool for making diagnosis of persons with Autism.

**Appendix 15**

**PMI Program Preliminary Evaluation**
**Visual Analogue Scale**

**Department of Psychology**
**University of Calicut**

**Indian scale for Assessment of Autism (ISAA)**
**(PMI Program Pilot Trial Run)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

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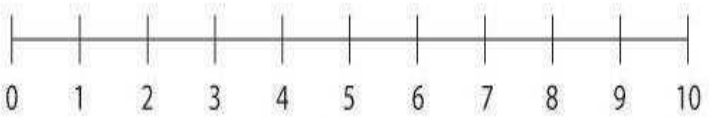
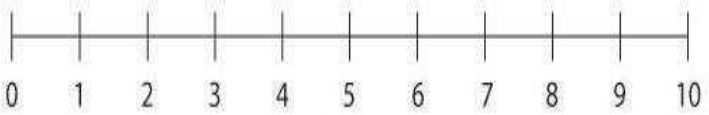
## VISUAL ANALOGUE SCALE

"This is a visual analogue scale, which is used to measure your perceived attainment of various outcome dimensions related to the intervention you are undergoing. It is a 0-10 visual scale, where 0 indicates least level of attainment of the target dimensions and 10 indicate highest level of attainment. You are requested to mark where you belong to in the given scale, on each dimension given below."

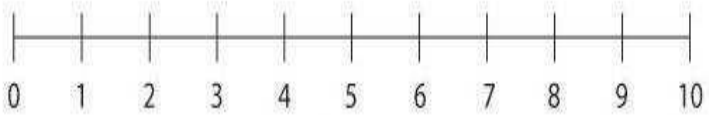
- Knowledge about ASD



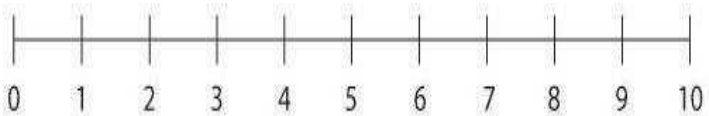

- Improvements in child's skill acquisitions



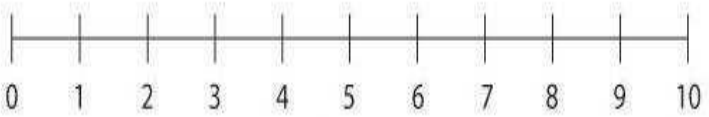

- Awareness of problem behaviours; Management of behavioural issues and ability to handle child alone during crisis



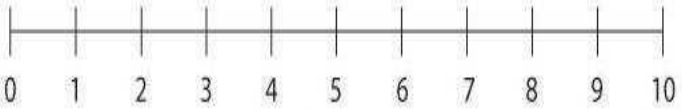

- Improvements in child's independence and involvement in given activities



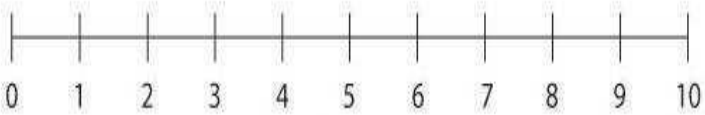
- Improvements in self-confidence, reduction in stress (parents)



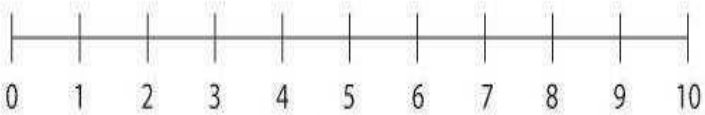

- Skills of problem solving in daily life




- Involvements of family members in PMI activities




- Sense of control over overall crisis and handling difficult situations



**Appendix 16**

**Assessment about Knowledge of ASD**

**Department of Psychology**
**University of Calicut**

**Assessment about Knowledge of ASD**
**(PMI Program Pilot Trial Run)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

1. **A person with autism finds it hard to interact with others. Which of these is an example of this?**

◉ A. The person won't look at other people ○ B. The person seems unaware of others' feelings toward him or her ○ C. The person often doesn't respond to his or her name being spoken ○ D. All of the above

2. **Autism varies widely in severity and symptoms. This makes it difficult to diagnose. Which of these behaviours should raise red flags for parents?**

○ A. The child does not babble or coo by 12 months of age ○ B. The child does not wave, point, grasp or make other gestures by 12 months of age ○ C. The child does not say single words by 16 months of age ◉ D. All of the above

3. **What causes autism?**

○ A. Mothers who don't bond with their new-born ○ B. A single gene on chromosome 12 ◉ C. Poor prenatal nutrition ○ D. There is no single cause of autism

4. **Autism can be cured with:**

○ A. Behavioural therapy ○ B. Medicine ○ C. Brain surgery ○ D. None of the above

5. **Autism is a developmental disability.**

○ A. True ○ B. False

6. **Who is more likely to develop autism?**

○ A. Boys ○ B. girls

7. **Autism is almost always genetic.**

☐ A. True ☐ B. False

**8. Symptoms of autism are usually the same in every child.**

☐ A. True ☐ B. False

**9. There are no treatments for autism.**

☐ A. True ☐ B. False

**10. Autism includes a broad spectrum of symptoms and disorders.**

☐ A. True ☐ B. False

**Appendix 17**

**PMI Program Feedback (post & one-month follow-up assessment)**

**Department of Psychology**
**University of Calicut**

**PMI Feedback (PMI Program Pilot Trial Run)**

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

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- How was the overall experience of the intervention?

- How did you benefit from the intervention program?

- What are the processes you assume behind the changes you have experienced?

- Were there any difficulties?

**Appendix 18**

**Qualitative feedback (post & one-month follow-up assessment)**

**Department of Psychology**
**University of Calicut**

## PMI Feedback (PMI Program Pilot Trial Run)

Title of the study: Development and Preliminary Evaluation of a Parent Mediated Intervention Program for Children with Autism Spectrum Disorder

**Your feedback is important to us!**

Your views on the impact of participation in PMI. Please read the following and rate the items given, using the options provided

E-mail ID :

Your name/initials :

| **Participation in the PMI program has...** | **Not influenced this aspect in me** | **To a little extent** | **To some extent** | **To a large extent** | **To a very large extent** |
|---|---|---|---|---|---|
| Increased my self-confidence | | | | | |
| Improved my awareness about matters related to ASD and self-care | | | | | |
| Improved the time I spend in activities that are truly meaningful for my child | | | | | |
| Has improved my inclination to help/support my child and others | | | | | |
| Has increased my hope about shaping my child's future | | | | | |
| Has helped me to improve my decision making, feeling more relaxed | | | | | |
| Has improved mymotivation to work on my personal goals | | | | | |
| Has helped me to learn how I can contribute to the cause of awareness about ASD to the society | | | | | |
| Has helped me to feel more connected to others especially those who has children with ASD | | | | | |
| Has helped me to manage my stress in better ways | | | | | |
| Has helped me to grow as a person on the whole | | | | | |
| | | | | | |

| In the last month, when I was feeling continuously stressed/overwhelmed | Almost all such times | Most of such times | On a few such times | Hardly or rarely | Never | Not applicable |
|---|---|---|---|---|---|---|
| I talked to a friend about it | | | | | | |
| I talked to a family member/ colleague/ neighbor/friend whom I trust | | | | | | |

1. Did the participation in PMI program result in you reaching out for professional help for you and your family's mental health and for your child's problem? Please choose one or more options which are true for you.

- Yes, because I became aware that I was having a significant psychological distress
- Yes, because the participation helped me reduce my hesitation to seek professional help and enhance my awareness about the common problems
- No, I just had some informal conversation about my stress with the PMI facilitator (Nigesh K,), and I did not need anything more
- No, I have not been experiencing any emotional issues as such
- I did not need to take professional help. But after the program, I have encouraged someone to seek professional help for their or child's or their own or family members issues.

2. After participating in PMI program, were you able to encourage someone to take professional help for mental health?

- No, I didn't get such a chance
- Encouraged on person
- Encouraged two persons
- Encouraged more than two persons

3. Please mention if your encouragement actually led to someone seeking professional help for their issues.

4. Has the participation in PMI program inspired you in any way? If yes, please specify…

5. After the participation in the PMI program, were you able to do something for in order to help yourself or your child, reduce stress and stigma associated with disability? (It can be anything, from an interaction with a friend/relative/neighbours or anything else)

6. Do you feel that the participation in PMI program has brought about some changes in you or in your life in any way? If yes, please elaborate…