**PARENTS' ACCEPTANCE, EXPERIENCE, CHALLENGES AND
EXPECTANCY FACTORS OF AAC INTERVENTION FOR
CHILDREN WITH AUTISM SPECTRUM DISORDER**

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CERTIFICATE

This is to certify that this dissertation entitled "**Parents' acceptance, experience, challenges and expectancy factors of AAC intervention for children with Autism Spectrum Disorder**". is a bonafide work submitted in part fulfilment for the degree of Master of Science (Speech-Language Pathology) of the student Registration Number: 20SLP037. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other University for an award of any other diploma or degree.

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CHAPTER I

INTRODUCTION

Autism Spectrum disorder (ASD) is a neurodevelopmental disorder with a broad spectrum of characteristics. Individuals with ASD have significant deficits in social and communication skills and repetitive, restricted, stereotypical interests and behaviours(American Psychiatric Association, 2013). These children exhibit variable features, including sensory integration deficits, poor emotional reciprocity, and difficulty socializing with others. Children with ASD show restricted interest in other people and the surrounding environment (Kuo et al., 2013). These poor socialization characteristics of children with ASD reduce their opportunity for communication and learning from the environment. This lack of opportunity to communicate with others drives them into children with the Complex Communication Needs (CCN) category.

Research evidence has reported wide variability in the language abilities and skills exhibited by children with ASD ranging from poor speech output to the limited usage of language skills to communicate with others (Grzadzinski et al., 2013; Matson et al., 2010). The lack of ability to use language appropriately for communication negatively impacts other aspects, including social, behavioural and academic development (Branson & Demchak, 2009).

The prevalence and incidence of Autism Spectrum Disorders (ASD) have increased over the decades. Research evidence showed the prevalence of ASD as 1 in 100 children (Zeidan et al., 2022). The prevalence and incidence in India have increased over the decades. A recent Indian study on the prevalence of neurodevelopmental disorders in children aged 2-9 years found that 44 out of 375 children with neurodevelopmental disorders are Autism Spectrum Disorders (ASD). This study also

revealed that ASD frequently co-existed with other neurodevelopmental disorders such as neuromotor impairments, cerebral palsy, intellectual disabilities, and epilepsy (Arora et al., 2018).

Various intervention methods are emerging in communication disorders, explicitly concerning ASD populations. One such emerging evidence-based practice method is the Augmentative and Alternative Communication (AAC). Augmentative and Alternative Communication refers to a communication option that can be used in addition to someone's communication (e.g., speech), or it can be an alternative to the current communication mode.

The definition of AAC states that it can be used as a compensatory method for a different mode of communication, including written and spoken, when there is a presence of comprehension and/or production of speech and language impairments (ASHA, 2005). The ultimate goal of AAC intervention is not just to find a technological solution for individuals with communication difficulties; its main focus is also to enable an effective and efficient interaction, engaging in activities of their own choices and participation (Beukelman & Light, 2020).

There are different AAC systems, including unaided and aided AAC systems. Unaided AAC systems refer to the system that does not require any external equipment to communicate (Light, 1988). Examples of unaided communication include hand gestures, signs, body movements and facial expressions. On the other hand, aided AAC systems to require some extra equipment to communicate. Aided AAC devices vary from low-tech, including single picture cards or drawings, to high-tech, which provides devices with various button or touch screen options to select the pictures or generate speech (McNaughton et al., 2008b).

Recent research evidence has reported the effectiveness of AAC in various developmental disabilities (Dada et al., 2021), children with complex communication needs (O'Neill et al., 2018), Cerebral Palsy (Avagyan et al., 2021), Intellectual Disability (Wilkinson et al., 2021) and Autism spectrum disorders (Syriopoulou-Delli & Eleni, 2021). Literature shows that children with ASD benefit from all forms of AAC systems. (Ganz et al., 2012). Also, studies have found that communication skills were improved to a greater extent than the outcomes for social interaction skills and challenging behaviours (Ganz et al., 2012). Studies have compared different types of AAC systems based on their effectiveness. The results revealed that Picture Exchange Communication Systems (PECS) and Speech Generating devices (SGDs) have more remarkable outcomes when compared to other communication systems which utilize pictures and symbols for children with ASD.

1.1 Family role in the intervention

In a multidisciplinary team, family members play an essential role in decision making, adapting the new systems into generalization etc. Preferences of family members in the AAC systems are critical for preventing disagreement, leading to the abandonment of the AAC system (Calculator & Black, 2009). The importance of family involvement in AAC intervention for children with ASD is crucial for mainly two reasons. Firstly, the children with ASD or any other complex communication needs spend most of their time with their family members other than during the scheduled therapy time, thereby getting more opportunities to learn communication skills. Secondly, as many of the aided devices have much-advanced technology, the literature shows that parents' understanding level of the child's severity of communication disorder directly impacts their parental stress level (Smith et al., 2011).

Therefore, indulging them in child intervention might influence the knowledge of the child's communication strengths and weaknesses, indirectly impacting the reduction of their parental stress. Studies show that parents with knowledge of their child's intervention process (AAC) have been found to integrate the intervention at home and thereby yield more remarkable outcomes than parents with less knowledge about the child's intervention process (Goldbart & Marshall, 2009). It is also essential to find the facilitators and barriers to using the AAC system to provide a multi-focused intervention to children with ASD.

1.2 Need for multifocal assessment and intervention for AAC users

It is crucial to assess the family members, caregivers, and AAC users. Many factors act as facilitators and barriers for the individuals using AAC. It is essential to analyse the factors influencing the communication systems (Beukelman & Light, 2020).

A model emphasizes the need for multiphase assessment and intervention for AAC users. It refers to the" Participation model for Augmentative and Alternative Communication" (Beukelman & Mirenda, 2013). This model has four components, which influence the AAC assessment, and intervention should be multifaceted. The assessment components include evaluation of the individuals' patterns of participation, communication needs, capabilities, environmental facilitators and barriers. The individuals' different ways of involvement in the environment give information about independence and assistance.

Regarding intervention, the model emphasizes the planning and implementation of the intervention and the follow-up. There are various barriers explained in this model related to the person and the environment. Individuals-related hindrances are referred

to as access barriers, whereas environmental related are considered opportunity barriers. The access barriers include the individual's physical and motor difficulties, cognitive status, literacy skills and auditory or visual sensitivity issues. Knowledge, attitude, policies and practice-related issues are the opportunity barriers postulated in this model, and all these barriers need to be taken into consideration during the assessment.

In summary, this model highlights the assessment itself is an ongoing process and assessing the participants' skills is not enough for successful interventions. Facilitators and barriers need to be considered, including access and opportunity barriers of the users to participate in AAC systems. This model also points out that family preferences and their perspective and attitudes should also be involved throughout the AAC assessment and intervention process. Figure 1.1 depicts the Participation Model for Augmentative Alternative Communication.

Figure 1.1

Participation Model
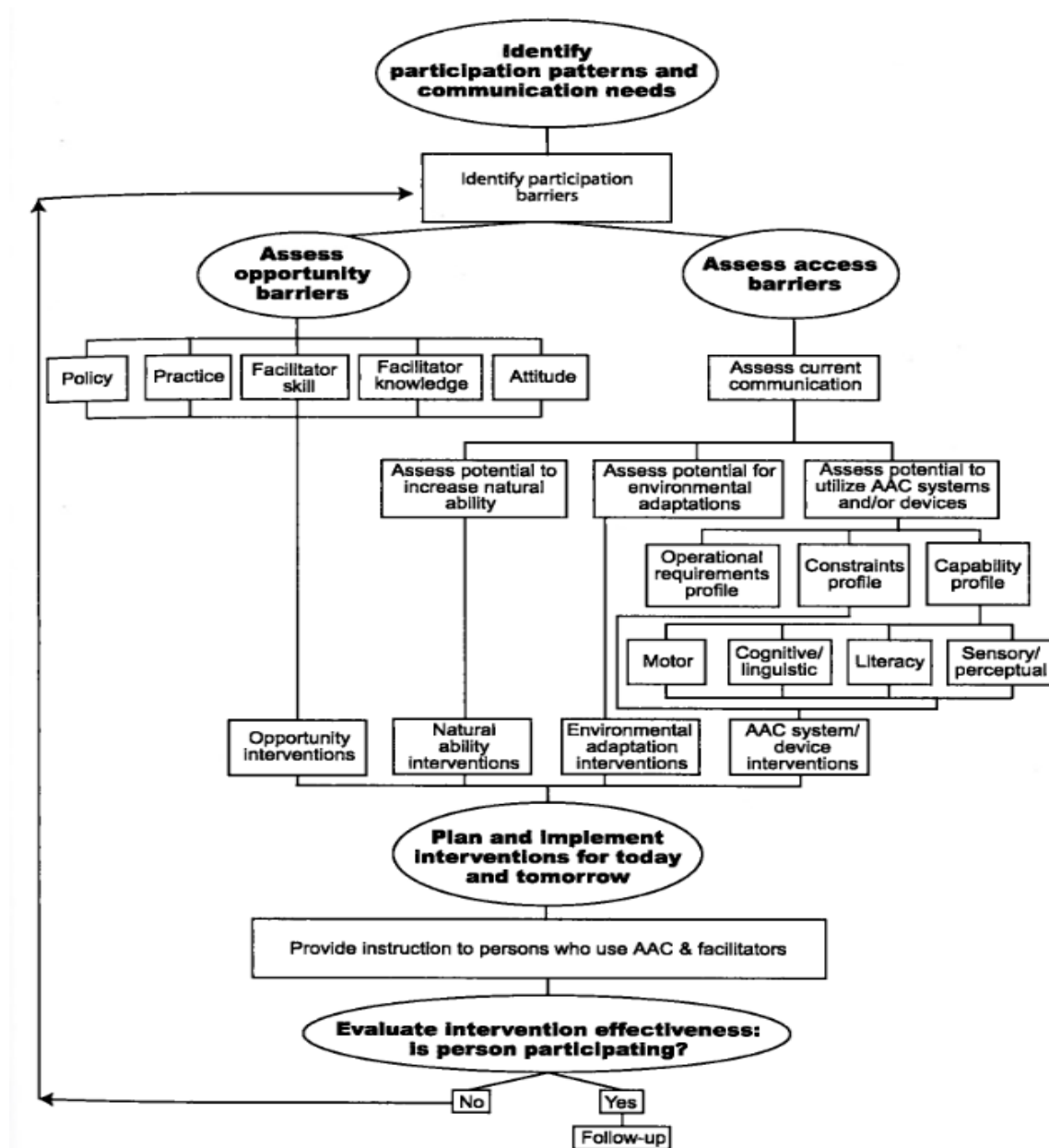
Note. Participation Model for Augmentative and Alternative Communication (Beukelman & Mirenda, 2013).

Need for the study

As India is a multicultural and multilingual country in the world, people from different parts of the country have their own cultural and linguistic variations. Understanding one's linguistic, cultural and social values are essential for effective intervention. Like others, children with communication disorders have influences from their social contexts and culture, which need to be considered in the intervention process. Since there is a shortage of Indian studies focusing on parental perspectives in AAC, analyzing parental attitudes will help derive lingua-cultural-based intervention in the Indian context.

A detailed cluster of information gives a clear idea about the researched topic. Hence, the interview method of collecting the data will lead to an in-depth analysis of the content and an in-depth exploration of their experiences and challenges. Therefore the present study aimed to determine parents' acceptance, experience, challenges and expectancy factors of AAC intervention for children with an Autism Spectrum Disorder (ASD).

Objectives of the study

To study the following using the qualitative method of semi-structured interview:

(i) Parents' acceptance regarding choosing AAC as an intervention.

(ii) Parents' experiences regarding using AAC as an intervention.

(iii) Challenges faced by the parents in AAC intervention.

(iv) Expectations in AAC devices/modes.

CHAPTER II

REVIEW OF LITERATURE

2.1 Augmentative and Alternative Communication

Augmentative and Alternative Communication (AAC) encloses different modalities that can augment or substitute the speech and communication skills that already exist in the person (Iacono et al., 2016). According to the definition given by Beukelman and Light (2020), AAC refers to an intervention method that can compensate for both speech comprehension and speech production deficits. The ultimate goal of AAC intervention is to find a technological solution for individuals with communication difficulties and to enable an effective and efficient interaction, engaging in activities of their own choices and participation. Accepting and selecting a multimodal communication is mainly influenced by the messages, or information individuals or children with communication disorders need to communicate across different contexts. Those messages fall under four major categories based on their functions. They are wants and needs, information sharing, social closeness and etiquette (Light, 1988). An alternative way of communication other than speech requires particular means to represent the meanings. Such means of representation of purposes are referred to as symbols. Symbols represent something else; the "something else" is referred to as a referent (Beukelman & Mirenda, 2013). There are mainly two types of AAC systems, unaided and aided (Ganz Ed. & Simpson Ed., 2019).

2.2 AAC for Children with Complex Communication Needs (CCN)

Children with Complex Communication Needs (CCN) refers to those who are unable to use speech as a mode to fulfil or meet the communication requirements of their age and culture (Porter & Kirkland, 1995). These children are characterised by

limited speech, language, cognition, and sensory-perceptual impairments. These limited communication skills directly impact their daily life opportunities, social interaction, and academic skills. Complex Communication Needs (CCN) includes children with various developmental disabilities such as Autism Spectrum Disorder (ASD), Down syndrome, Intellectual Disability, Cerebral Palsy and acquired conditions after a stroke or traumatic brain injury. These children are different in their representations, such as age and disabilities, including cognitive, language, motor, and sensory skills and severity of the disorder. These children or the individuals engaged in different social environments, such as educational or work environments, need rehabilitation services over their lifetime. The skills exhibited by them and their unmet needs of them vary across their life span (McNaughton et al., 2008a).

Research evidence has reported that AAC increases the communication opportunities of children with complex communication needs and positively impacts social interactions. Drager et al. (2010) studied the effect of AAC intervention in CCN, and the results showed significant improvements in five areas of development. These areas include basic functional communication skills, receptive language skills, expressive language skills, and speech production skills and showed a decrement in challenging behaviours exhibited by children with CCN. This study also discusses the importance of AAC intervention in children as young as three years and below. This discussion shows that interventions for infants, toddlers and children yield various progress across ages. Therefore, starting an AAC intervention as early as possible greatly influences the child's overall social and communication skills development.

2.3 AAC for Children with Autism Spectrum Disorder

The positive effects of using AAC for children with ASD have been reported in many pieces of research, which suggests that using it for communication increases their communication intent, socially acceptable behaviours and reduction in problem behaviours (Ganz et al., 2009).

There are various unaided and aided systems of AAC available for children with ASD, including no-tech, low tech and high-tech devices with multiple communication options. It is imperative to choose which method works best with the child despite many AAC options. Research evidence shows that aided systems are more useful in children with ASD than unaided systems like manual signs and gestures. The reason might be that children with ASD were limited to fewer signs, and making them learn and get used to them takes more time and effort (Shillingsburg & Valentino, 2011). Also, studies showed that low-tech and high-tech devices were effective for children with ASD. Many systematic reviews and meta-analyses discussed that both Picture Exchange Communication systems (PECS) and Voice output devices have a moderate effect on the communication skills of children with ASD (Ganz et al., 2012; Preston & Carter, 2009)

Recent research evidence showed that, in comparison, aided AAC systems had significant advantages over unaided AAC systems. The reason might be because it is an effective means of functional communication with a wide range of communication modes or options with a more extensive vocabulary and the possibility of adding new words (Ganz, 2015). Both low or high-tech-aided devices are more productive than unaided systems (Ganz et al., 2014).

2.3.1 Effectiveness of Low-tech aided AAC systems in children with ASD

Low-tech aided devices such as PECS are widely used for children with poor communication intent to facilitate functional communication in children with ASD (Ganz et al., 2012). Flippin et al. (2010) studied the effects of PECS on communication outcomes and speech outcomes in children with ASD. Communication outcomes showed that PECS is a 'fairly effective' treatment approach for children with ASD in developing appropriate communication skills. In comparison, single-subject literature showed limitations of PECS in terms of maintenance and generalization of communication. Thus, the cluster of study results showed overall small to moderate effectiveness in communication, especially in a short period with little maintenance. Speech outcomes in the studies were generally measured by spontaneous speech tasks and frequency of non-imitative spoken acts or words. The latter studies' results varied across different kinds of literature and participants included in the research. Thus, results showed 'questionable effectiveness' of the PECS approach in increasing the speech of children with ASD and their generalization. Single and group subjects' literature analyzed additional variables such as preintervention characteristics as an outcomes of PECS. The results showed three pre-interventional elements including, joint attention, object exploration, and motor imitation, were likely effective in the outcomes of PECS intervention.

Preston and Carter (2009) have done a systematic review to find the effectiveness of the Picture Exchange Communication system (PECS). In this review total of 27 studies were taken with the participants of 456 individuals. Of these, 394 individuals with ASD used PECS for their communication intervention. The study concluded that using PECS for training reduces challenging behaviours, increases the

child's social interactions, and enhances language comprehension. (Preston & Carter, 2009).

Yoder and Stone (2006) compared the outcomes of the PECS and Responsive Education and Prelinguistic Milieu teaching (RMPT) among 32 pre-schoolers with ASD based on two domains. Firstly, the frequency of using non-imitative spoken words. Secondly, the number of non-imitative words spoken by the child. The results revealed that PECS had facilitated a higher number of object exploration, thereby increasing the number of non-imitative words spoken compared to RMPT. Also, this study showed that PECS increased communication in children with limited joint attention skills, which is a prerequisite for communication (Yoder & Stone, 2006).

Ganz et al. (2012) reviewed 13 articles regarding using Picture Exchange Communication System (PECS) in children with developmental disabilities. The researchers divided the effectiveness of PECS into the target (functional communication skills) and non-target (speech production, reduction in problem-solving behaviours) outcomes. Seven articles reported the effects of the target outcomes, and five research papers reported the impact of non-target results. In this, two research articles implemented all the six stages of PECS, and eight studies with only three steps of PECS. Both have a significant difference in the effectiveness of target and non-target outcomes. Additional findings from the survey are that younger children (children in the preschool level) show more extensive effects than children in elementary school. Hence, the study's results concluded that PECS have a more significant impact on functional communication skills and a significant favourable influence on speech production and reduction in problem behaviours (Ganz et al., 2012).

Pereira et al. (2019) conducted a longitudinal case study on the impact of AAC intervention in the communication of children with autism spectrum disorder (ASD) using the PECS -Adapted approach. The authors included three subjects, and they were monitored over 1.4 years. The results showed that children significantly improved their communication skills, specifically verbal acts such as requesting information, comments and naming. Vocal production increased along with the reduction of communication acts, leading to the conclusion that oral output of words and phrases has increased. This improvement in communication has a direct impact on the behaviours of those individuals. The results also showed a slight decrease in the communication of object requests which can be attributed to the attainment of maturity in language by learning other communication acts such as narrating about the objects, situations or places rather than just requesting (Pereira et al., 2020).

2.3.2 Effectiveness of High-Tech Aided AAC in Children with ASD

Computer-assisted devices generally fall under high-tech aided devices of AAC, which have multiple benefits over the low-tech devices with various options like eye tracking, and voice generative devices such as Voice Output Communication Aids (VOCA). Researchers have reported that socialization behaviour and interaction between individuals have improved due to using speech-generated devices in children with ASD because of the speech output provided (Mirenda, 2003).

Desai (2014) investigated the effectiveness of high-tech AAC devices with 'Go talk Now' computer application in the apple iPad in school setups. Participants were children with ASD and cerebral palsy (CP). The results revealed significant improvement in children's academic and non-academic functioning. This study also

supported the importance of parents, teachers and school assistance in improving the skills of children with complex communication needs (Desai et al., 2014).

Naguib Bedwani (2015) studied evidence-based practice on AAC for ASD. This study evaluated the AAC language acquisition through the Motor planning programme (LAMP), using the Vintage Lite™ device. Pre and post-comparison of AAC in eight children with ASD with five weeks of training were done. The results showed improvement in spontaneous communication after the five-week trials. Parents in this study also reported that their children attained more incredible progress in these 5-week trials compared to the other therapy/interventions (Bedwani et al., 2015).

High-tech aided AAC systems demonstrated effective communication and language skills; they also influenced the literacy skills of children with Autism Spectrum Disorder. In comparing children with Down syndrome and ASD literacy skills using AAC, children with ASD demonstrated more excellent letter knowledge and letter-sound correspondence. These findings are essential in selecting AAC systems for literacy skills. Word readings and other activities such as word blending and segmenting can be used when incorporating reading instruction through AAC. Also, children considered for literacy skills development using AAC were older than preschool (Barton-Hulsey et al., 2021).

Caron (2021) investigated the effectiveness of AAC in single-word reading skills by adapting transition to literacy (T2L) software features into the AAC systems in four children with Autism Spectrum Disorder. The results showed that adjusting or redesigning the transition to literacy feature in AAC systems improved the reading accuracy in all four children and concluded that adding T2L positively affects single-word reading skills (Caron et al., 2021).

2.4 Parents' Role in Providing AAC Intervention for Children with CCN

Literature has shown the role of parents in a child's early language and communication development. Children's language exposure predominantly happens in the home environment where maximum credits belong to the parents. Hence, parents' role in communication intervention is inevitable in children with communication disorders (Roberts et al., 2019).

Family member, especially parents of children with CCN, acts as a facilitator for the child's communication development by implementing and continuing AAC supports for the children, ensuring adequate requirements of the individual such as appropriate positioning and adapting new strategies to the communication.

2.4.1 Parenting Model and Parents Implemented Approach

The parenting model is a developmental intervention approach from various research evidence to influence parents' role in child development. There are two significant concepts elicited from this model. One important concept is the parents-child interactive relationship. Another concept proposed that parents of children with disability are the primary agents in the child's communication and social well-being. Literature has focussed on interventions based on the parenting model for various developmental disorders, including children with ASD (Mahoney & Nam, 2011).

Parent-Implemented Intervention (PII) is another intervention method. Research evidence showed this intervention method found to be increasingly common for children with ASD. Because parents, most commonly mothers, spend most of their time with the child during the day, they become part of the child's intervention. Hence it is an inevitable factor in AAC intervention considering their importance, perspectives and challenges in the intervention process (Bartley, 2016).

Amsbary (2020) conducted a study to analyse parents' perception of the components of the child intervention process and the contextual factors that attribute to the success or challenges in intervention. In the results, the parents reported that the intervention components that provide skills and knowledge through video recordings and other modes positively affected the child's intervention. Integrating intervention in daily life was quite challenging concerning the contextual factors and family dynamics. This study concluded that involving the Parent-implemented intervention provides many benefits regarding knowledge and skills and creates a positive relationship with the child (Amsbary et al., 2020).

2.4.2 Effectiveness of Parents Embedded Intervention on AAC

Communication partners, including caregivers, parents and peers, play an integral role in assessing individuals with CCN and intervention. These communication partners try to change the pattern of approaching and communicating with the individual with complex communication, thereby eliciting more communication opportunities for the individuals (Kent-Walsh et al., 2015).

Gevarter (2021) experimented on parents' supported intervention using AAC systems. Three preschool children with ASD were enrolled, and the parents were taught to use grid-based AAC systems throughout the day with the child, including playtime and meal times. Requesting objects or assistance, commenting, and expressing social responses are the communication acts targeted using a two-step message strip response. Parents were asked to use behavioural strategies such as time delay and prompting. This study showed a more significant increment in overall requesting and responding to engage in communication and generalizing the responses found to be present (Gevarter et al., 2021).

2.5 Acceptance Factors of Using AAC as an Intervention

Acceptance of an intervention approach inevitably influences the child's progress as the result of using that method. Communication messages and unmet needs of the individuals in different contexts and environments directly affect the acceptance, selection and maintenance of usage of AAC in children or individuals with the necessity of AAC.

Many western studies have reported that parents abandon or reject the use of AAC for various reasons after enrolling on the intervention (Park, 2020). Johnson et al. (2009) surveyed 275 speech-language pathologists on their client's continuity of using AAC once trained as a communication intervention. The survey results showed that maintenance and continuity of using AAC systems in clients were found only in 40% of the population, where 60% of the AAC users terminate using AAC for various reasons. The main reason for this dropping out in using AAC might be the poor acceptance by parents and family members. Recent studies done by different authors have found that many factors act as a facilitator, and many other variables are attributed to the rejection of AAC as a communication intervention for their children. Decision-making to opt for AAC is crucial in the child's communication intervention. This process by parents indicates their acceptance of the AAC intervention for their children (Johnson et al., 2009).

A study was done in Hungary by Serpentine et al. (2010) on the decision-making process on AAC for children with ASD. 10 parents of children with ASD were interviewed based on the questions related to broad topics of AAC such as different types of devices, approaches that they used for their children. The collected data were put under six themes: information from various resources, different types of

intervention to support communication, intervention outcomes, factors facilitating or discontinuing intervention, expected interventions and the decision-making process. The results revealed that parents had highlighted three factors in the decision-making process. The first factor is that the parents highlighted that experience or opportunity to use the intervention method is vital to say whether the particular intervention benefitted or not. Most parents consider their child's skills, needs and abilities to make decisions, which are considered the second factor. Lastly, parents have accepted because providing communication intervention is only the option for their children with ASD (Serpentine et al., 2010).

Shin and Lee (2016) studied parents' perspectives on AAC in children with severe disabilities using a parental interview. The results show many parents are unaware of the AAC systems and are not utilizing AAC for their children because of their poor acceptance of the AAC systems over speech. Another reason given by parents for not using AAC is the poor generalization in various environments outside the therapy (Shin & Lee, 2016).

After engaging in a particular mode of intervention, Prognosis plays a crucial role in accepting and continuing the intervention method for the child. Many parents with ASD reported significant improvement in the child's communication abilities and overall reductions in the problem behaviours after enrolling in the AAC intervention method. Jones (2017) examined the parent's perspective after enrolling the children with ASD in the AAC intervention. The data were collected using multiple choice questions on 32 participants. The study results show that 46.88% of the participants reported that they are using any one of the AAC devices. Parents' perspectives from the study results were found to be mixed. Many parents said that they witnessed improvement in the child's communication, including requesting, initiating

communication with others, asking questions and engaging in recreations. Most participants (91.67%) reported noticeable improvements in children's communication ability after singing AAC intervention. 46.66% of the parents said there is an improvement in the social skills of the child and 73.33% of the parents reported their children's independence has improved (Jones, 2017).

A recent qualitative study by Moorcroft et al. (2021) consists of 12 participants who are the parents of children who refused or abandoned the use of AAC systems for their children. These study results are reported in the form of thematic analysis. Four main themes were reported as a reason or the factors for their abandonment. They were a dearth of emotional readiness and resilience, implementing AAC was found to be additional work for parents, the increase in work outside of everyday parenting, the child's surcease of AAC for communicative purposes because of their poor interests, and parents' dissatisfaction with AAC systems. Accepting and the process of continuing AAC in the initial six months is crucial because that is where the process of accepting happens, which is influenced by a wide variety of factors (Moorcroft et al., 2021).

Park (2021) did an extensive study to pile up parents' experiences during their AAC acceptance process and all the factors involved in accepting AAC. Results showed there are a total of 181 concepts which are put under 18 categories and 56 sub-categories. Some categories include casual conditions, where the parent's efforts to understand AAC, and central phenomena, including preoccupied perceptions. Contextual conditions are also taken into consideration which provides for accessibility of the AAC system (Park, 2021).

2.6 Experiences of Parents of Children with CCN in Using AAC as an Intervention

Parents' experiences with children with ASD are inevitably important to build interactive rapports and engage the child in successful communication. AAC as a communication intervention method for those children with ASD shows evidence for effective parent-child interactions. A lot of literature showed that parents reported having an opportunity to identify their child's ability, skills and interests using AAC communication. Park (2020) conducted a study on parents' experiences and acceptance of AAC for their children with CCN and revealed that parents had discovered their child's true potential, and experiencing AAC gives them the hope that their child can lead independent lives (Park, 2020).

Doak (2021) study dealt with the family members' perspectives on their engagement or disengagement in using AAC at home. Thematic analysis was done to extensively review the family members' views and categorize their experience in 4 broad domains, including AAC in the family/home, expressing communication in different manners such as using pointing and other gestures. Managing household priorities and challenging behaviours of the child and the overall parents' emotions are also categorized as the broach themes of family engagements (Doak, 2021).

2.7 Expectations of Parents in Using AAC as an Intervention

A study done by Bailey et al. (2006) aimed to examine the family's perspectives on using AAC for their children. Expectations put forward by parents in this study were categorized into two broad themes, including the impact of AAC devices on their users and the parental expectation on interactions between team members. The parents expected children's independence and communicative competence to the impact of AAC systems. Regarding team members' interactions, parents are expected to get

training and technological support for using the AAC devices. Knowing about their child's intervention method has a highly positive effect on the child's overall progress. Parents of children with complex communication needs, including children with ASD, expect parental education programs, training videos, and instructional and procedural advice from AAC professionals to effectively engage the child in communication. These expectations indicate the need for parents' education on AAC usage (Bailey et al., 2006).

One such study supporting the statement of the importance of parental education on AAC was done by Kim (2021). In this study, twenty-five mothers of children with complex communication were taken, and an AAC educational program for 40 minutes was given. The educational program includes Introduction to AAC, AAC systems explorations, competence in linguistics to use AAC, Tips and Strategies to use AAC at home and guidelines about financial support and policies. The study results showed that parents have a positive effect on using AAC after awareness of the systems (Kim et al., 2021).

2.8 Challenges of Parents in Using AAC as an Intervention

Reviews of the literature show that parents of children with communication disorders tend to be more frustrated, helpless and emotionally demanding compared to parents with clinically normal children (Bailey et al., 2006). Specifically, concerning mothers of ASD children, the literature showed that parents tend to be more frustrated and experience a sense of burden, distress, and vulnerability.

A recent study that supported these findings aimed to investigate the mothers' experience in raising their child with Autism Spectrum Disorder in Greece. Nine mothers of children with ASD participated in the study, and a semi-structured interview

was done to collect data and was categorized into themes and subthemes. The results revealed three major themes pertaining to the maternal burden, which include social, emotional and family responsibilities. Emotional burden consists of the parent's experience with their child's diagnosis and distress about the child's future. Relationships with the spouse and other family members are attributed to the family burden. Myths and stigma related to ASD in society pertain to social burdens (Papadopoulos, 2021).

In another study on parents' perspectives on the usage of AAC, results reported that AAC for their child with communication disorders relieved their communication problems but added additional stress to the child and the family(Bailey et al., 2006). In a study done by McNaughton (2008), seven participants were included to examine the benefits and challenges of using AAC. Six major themes emerged from their study results. These include those challenges started from the selection of AAC, which is attributed to the lack of knowledge or skills in handling AAC systems. Barriers to learning AAC were put forth by the parents due to the lack of trained professionals, difficulty in teaching individuals with AAC and in educating and making society aware of the skills needed by the child (McNaughton et al., 2008a).

2.9 Indian Studies on Perspectives of AAC Users

Compared to Western literature, Indian literature attributed to the perspectives of AAC by the users and the caregivers is limited. Dafiah (2020) explored the use of Communication inventory-children and youth (CSI-CY) in identifying the hindrances and facilitators of using AAC by the individuals in the southern part of India. Two parents of children with cerebral palsy and ASD were enrolled, and the CSI-CY tool was administered to find the various factors that inhibit and aid the usage of AAC. Myths, aid-related, and people-related, including child and clinician-related, are the

four sub-categories identified under the domain barriers. This study also proposed the importance of identifying culturally specific factors to support AAC in different places (Dafiah et al., 2020).

2.10 Research gaps

India is a culturally diverse country. Due to the multi-cultural and multi-linguistic diversity, the people's perspectives vary across different places in India. This diversity directly affects AAC decision-making, acceptance, and generalization of usage (Srinivasan et al., 2011). To gain a clear idea of the parental perspectives on AAC usage and experience, an intensive analysis needs to be done to get a clear picture of the information. Parents play a significant role in assisting children with complex communication needs; they have the position from the initial decision-making process through the overall progress in the intervention. Hence addressing their perspectives is more critical for a successful communication intervention. In the broad category of communication disorders, parents of children with ASD have special consideration because of the diversity in the characteristic of children with ASD. Due to the various features of the children with ASD, barriers or challenges faced by one child are not the same for the other; hence an overall approach to rectify the difficulties is practically impossible. So, these factors lead to extensive research to understand the Indian parents' perspective on using AAC for their children with ASD. Therefore, the current study aimed to determine parents' acceptance, experience, challenges and expectancy factors of AAC intervention for children with Autism Spectrum Disorder (ASD).

CHAPTER III

METHODS

The study aimed to investigate the acceptance, experience, expectations and challenges faced by the parents of children with ASD who uses AAC for their communication intervention. A qualitative content analysis was done to understand the parents' views about AAC intervention. Figure 3.1 depicts the flow chart of the methods.

Figure 3.1

Flow Chart of the Method
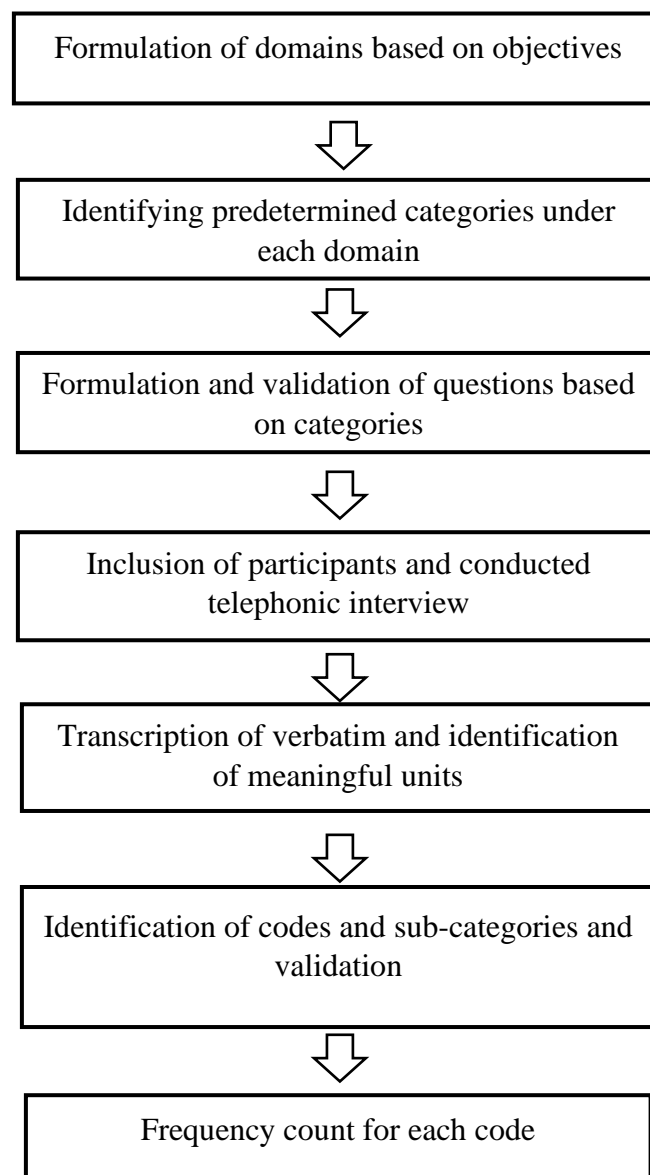
3.1 Participants

Fifteen parents of children with ASD who use AAC for their children participated in the study. Purposive sampling was done to select the participants. Participants were explained about the study, and informed written consent was taken from all the participants before collecting data.

3.1.1 Inclusion Criteria

The study included parents of children with ASD within the age range of 5-15 years (*M*=7.8, *SD*=2.8), with the severity of ASD from mild to a moderate degree based on the Indian Scale for Assessment of Autism (ISAA) developed by the National Trust, Ministry of Health and Family Welfare, and Ministry of Social Justice and Empowerment of the Government of India, (2009). Parents of children who use low-tech or high-tech aided systems for a minimum time of 6 months were included. A parent (father or mother) who interacts more with the child in assisting the use of AAC systems was included.

3.1.2 Exclusion Criteria

The current study excluded parents of children with other communication disorders and children with ASD who have siblings with developmental disorders. Parents having limited knowledge in using and assisting AAC systems and who enrol on some different communication mode other than or in addition to AAC are excluded from the study. Based on the selection criteria, data obtained from 15 participants was selected for analysis. These participants included 15 mothers of children with ASD who use AAC for their children. Table 3.1 shows the details of each participant.

Table 3.1

Demographic details of the participants

Parents	Age	Education	Child's Age / Gender	Type of AAC	Duration of usage
#P1	32y	PG	6.4y/M	PECS	6-7 months
#P2	41y	PG	14y/M	PECS, AVAZ	3 years; 6 months
#P3	35y	PG	10.3y/M	PECS	2years
#P4	38y	UG	13y/M	Communication Board	4-6 years
#P5	40y	UG	10y/M	Communication board, AVAZ	1.5years; 5months
#P6	36y	SE	10y/M	PECS, AVAZ	>1 year
#P7	29y	PG	6y/M	PECS	6 months
#P8	32y	UG	5.5y/M	PECS	6 months
#P9	32y	PG	7.10y/M	PECS, AVAZ	1 year; 2 months
#P10	32y	UG	6.2y/M	PECS	6-7 months
#P11	29y	UG	5.8y/M	PECS	7 months
#P12	31y	UG	5.11y/M	PECS	8 months
#P13	34y	PG	5.1y/M	PECS	6 months
#P14	34y	PG	7.5y/M	PECS	>3 years
#P15	35y	PG	6y/M	PECS	8 months

Note. M=Male, F=Female, y=Years, PECS=Picture Exchange Communication System, UG=Undergraduate, PG=Postgraduate, SE=Secondary Education

3.2 Procedure

The current study followed the "Directed Content Analysis method" (Hsieh & Shannon, 2005). This content analysis method uses a direct approach, identifying key concepts and variables as initial coding categories. The data are collected primarily through open-ended questions based on predetermined categories. The present study was conducted in three phases.

Phase I dealt with the development of open-ended questions. In the second phase, data collection was done using a semi-structured interview with the parents. The third phase included content analysis and from which qualitative and quantitative pieces of information were gained.

3.2.1 Phase 1: Development of open-ended questions for an interview

In phase 1, open-ended questions were developed by using the following steps.

3.2.1.1 Collecting the resources. Review of literature from journals, books, blogs, internet websites and other search engines regarding Autism Spectrum Disorder, Augmentative and Alternative Communication and the role of parents in a child's intervention were selected.

3.2.1.2 Formulation of Questions. Open-ended questions were formulated in Indian English for each domain from the collected resources. The first domain, acceptance, consisted of four open-ended questions. Three questions each were developed for the Experience and Expectancy domains, and the last part, challenges, included four open-ended questions.

3.2.1.3 Validation of questionnaire. The formulated questions were sent to a speech-language pathologist who has specialized in the AAC field for more than five years to validate the questionnaire. 3 point Likert scale was used for validation of each question based on their significance to the domain chosen (3- Most significant; 2- Moderate significant; 1: least significant). Questions with 2 or 3-point ratings were taken as the final questions, and suggestions from the validator were incorporated. After incorporating the recommendations, the final questionnaire was developed. (As shown in Appendix A)

3.2.2 Phase 2: Data collection using Semi-structured Interview

3.2.2.1 Enrolling participants. The participants in the present study were included from various settings such as ASD special schools, therapy centres and institutional setups offering therapy services. All the participants were approached through phone calls, and the study's purpose and willingness to participate were discussed. Informed consent was taken from all participants through google forms. (As shown in Appendix B)

3.2.2.2 Semi-structured interview. Participants were approached through telephone calls at their feasible time. A good rapport was developed by explaining the study's needs and goals. Each domain was described, and open-ended questions were asked to the participants to elaborate on their perspectives and views. Elaboration and revision of phrases in the questions were done if needed to gain specific information. The time duration for each of the participants' data was scheduled for 20-40 minutes. Every piece of information shared by the participants was recorded through call recording and stored for further analysis.

3.2.3 Phase 3: Content Analyses

The content analysis recruited the following steps:

3.2.3.1 Transcribing the data into written form. All the details collected through the interview in the form of verbal output were converted into graphical formats (written scripts) without losing any information. Familiarizing the data was done by listening to and reading the data several times.

3.2.3.2 Formation of Coding categories. The major categories are the predefined questions under each domain. An example of a category is 'reasons for acceptance' under the domain 'Acceptance'. This method of categorizing the concepts is called the selective reduction method in content analysis.

3.2.3.3 Content-coding. Meaningful units related to the questions from verbatim were selected. These meaningful units were assigned with specific codes. Each code was then further classified into sub-categories or sub-themes. (As shown in appendix C). For example, under the category reasons for Acceptance, the sub-categories were discontent with therapy approaches, alternative method/ trial for child's communication, understanding child's limitation, professional counselling, and facilitation of any mode to improve speech

3.2.3.4 Intercoder agreement check. Intercoder agreement check of the data was done where the coding of 3 randomly selected samples was done by another speech-language pathologist with knowledge about content analysis.

3.2.3.5 Determining frequency count. Frequency count refers to the number of times a particular code occurs. This was calculated by summing up the number of participants who shared similar kinds of content/ ideas under specific themes. This gives the overall percentage of participants having similar perspectives towards specific themes.

CHAPTER IV

RESULTS

The open-ended semi-structured interview with 15 participants included four significant variables. They are acceptance, experience, expectations and challenges. Each domain has various predetermined categories. The sub-categories, codes and meaningful units were extracted and analyzed.

4.1 Acceptance

Under the acceptance domain, four major categories were derived: Reasons for acceptance, family members' thoughts & acceptance, acceptance from behaviours, professionals, and members who helped in acceptance. Sub categories under each main category were grouped based on the codes and meaningful units. Figure 4.1 depicts the flow chart for the categories under the domain acceptance.

Figure 4.1

Flow Chart of Categories for Acceptance
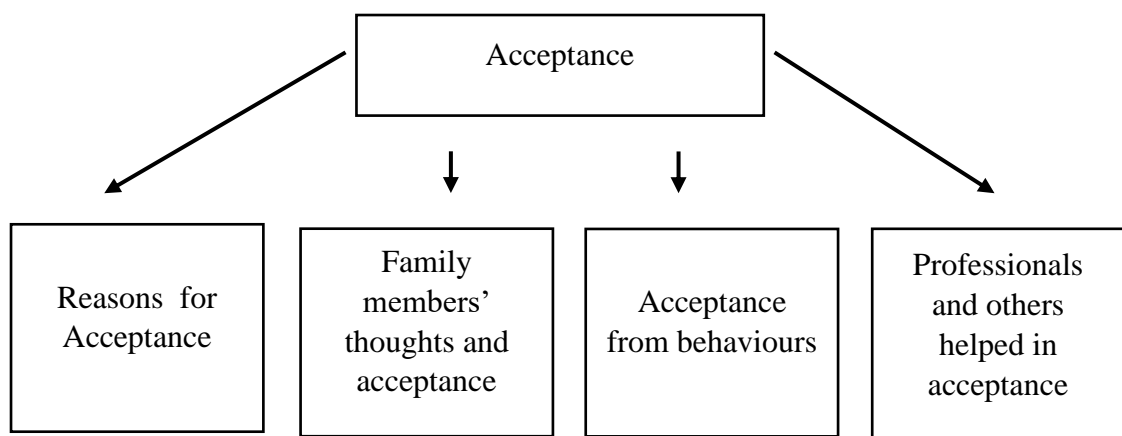
4.1.1 Reasons for Acceptance

Acceptance for a new intervention is a process rather than a single-time decision. The results from the participants, when asked to specify the reasons or the cause that made them accept AAC, revealed seven reasons for their process of obtaining AAC as their intervention method. These seven reasons are the sub-categories of the reasons for acceptance. Table 4.1.1 shows the category, sub-categories, codes and meaningful units for reasons for acceptance.

Table 4.1.1

Summary of codes and sub-categories for the reasons for acceptance

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Reasons for acceptance	Understood the child's limitations	Non-verbal	14	He didn't talk from his mouth	He didn't say any word from the mouth.
	Affective behaviours	Frustration	2	Frustrated due to no expression	He is frustrated because he cannot speak.
	Using a new intervention method	Therapist introduced	7	Therapist counselled regarding AAC	The speech therapist told me about the AAC as an option for communication
	Realized the communication importance	Need of communication	11	Want to communicate in any method	We want to start any communication method where

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
					he can express himself easily.
	Emergence of progress	Improvement seen	6	Started improving	I started trusting because I saw many improvements in him the way he expresses himself.
	Dissatisfaction with speech therapy	Speech therapy didn't work	1	Speech therapy won't work	I got to know that speech therapy won't work for my child.
	Associated conditions	Motor issues hinder communication	1	Because of motor issues can't communicate	Because of his other motor issues, he couldn't reach the items directly.

Note. N is the number of respondents

4.1.1.1 Understood the Child's limitations. Parents of children with ASD who participated in the study significantly identified their child's limitations to a greater extent. Most of the parents (93%; n=14) have reported the reason for acceptance is that their child is using a nonverbal mode of communication and cannot express themselves on their own.

Parents articulated their reasons for approval as "Now I have accepted because he is nonverbal so I can't understand what his needs, he can comprehend simple speech

like take this bottle, fill this bottle and all, but he can't able to speak as he is nonverbal" (#P1). Another parent expressed their reason as "he cannot tell what he wants, he does not make me understand what he wants, where he wants to go like going to the toilet" (#P10).

4.1.1.2 Affective behaviours. Many parents reported that because of the limitations, the child started showing some affective behaviours to overcome his limitations and make them understand what he wants. Few participants (13%; n=2) reported that the child usually gets frustrated and cries because of his inability to communicate. "He will keep on crying and getting angry if we don't understand what he wants" (#P8).

4.1.1.3 Using a new intervention method. Most participants (46%;n=7) expressed that they got an idea for an alternative communication method from the speech therapist. Parents wanted to try whether the new communication form would help them overcome the child's communication hurdles. Also, parents are not sure about the intervention method initially, but as the Therapist suggested, they wanted to try it for their children. A parent briefed as, "He didn't develop speech for many years, and after that, speech therapist counselled me regarding the AAC as another option for communication. We want to try whether that will work for him or not" (#P10).

4.1.1.4 Realized the communication importance. Most parents (73%; n=11) have acknowledged that communication is a crucial component, and the child can communicate in any way to express his needs and wants. Parents have wished their child to share in any form or option despite the type of intervention methods. A parent said her wish: "We want him to communicate in one or the other way" (#P1). A similar response from another parent was, "We didn't have any idea related to this. I just

wanted him to communicate." (#P10).

4.1.1.5 Emergence of progress. Few participants (40%; n=6) reported that they had seen improvements after enrolling on the AAC intervention, which made them accept the communication intervention. Parents said they could make a difference between before and after enrollment of AAC intervention. Parents expressed their enthusiasm as "it is really very great that it helps him a lot" (#P6) and "After using this within two days only we started seeing improvement that he come and gives the pictures of what he wants" (#P7).

4.1.1.6 Dissatisfaction with speech therapy. A parent (6.6%; n=1) reported that they are dissatisfied with speech therapy and want to go for another communication method that a speech therapist suggested. She said that "I got to know that speech therapy won't work for my child, and I need to find some other mode of communication where he can express himself" (#P14).

4.1.1.7 Associated conditions. A parent reported that their child has motor coordination issues, and hence he cannot reach for what he wants, so we prefer a way for him to express what he wants. The parent said that "because of his other motor issues, he couldn't reach the items directly. So, so I started using the pictures to point out what he wants". (#P14).

4.1.2 Family members' thoughts and acceptance:

Parents reported data on family members' thoughts and agreements are classified under major sub-categories: acceptance, supportiveness, encouragement, satisfaction, awareness, and perception. Table 4.1.2 shows the categories, sub-categories, codes and meaningful units of the family members' thoughts and acceptance.

Table 4.1.2

Summary of codes and sub-categories for family members' thoughts and acceptance

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Family members' thoughts and acceptance	Acceptance	Lack of acceptance	4	It is tough to accept	In a joint family, it is very difficult to accept him and his way of communication
		Emergence of acceptance	4	No acceptance to less acceptance	Initially, my husband didn't accept, but after explaining the need for his communication he started accepting.
		Presence of acceptance	4	All are accepting the new method	Not a challenging issue in my family; they all are accepting.
	Supportiveness	Inadequate support	1	Not helping with the method	They are not supporting this system.
		Existence of supportiveness	4	Supporting my decision	All my family members are very much supporting me

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
					in what I do. So, my decision was final.
	Encouragement	Motivated and encouraging	4	Very motivated in using and teaching	When I first introduced AVAZ to him, my dad would go and bring the tab and ask him to point out what he wants.
	Satisfaction	Dissatisfaction	3	Not satisfied with this communication	He is a little supportive but not satisfied with this picture using communication.
	Awareness	Lack of awareness	4	Not aware of the communication	Family members are unaware of this picture communication
	Perception	Poor perception	2	Hinders speech	Told that this training would limit his speech.

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
		Insist withdrawing AAC	2	Withdraw AAC and go for speech therapy	Family is encouraging me to use pecs; They says these things are useless; why are you wasting your time on this.

Note. N is the number of respondents

4.1.2.1 Acceptance. Responses for the acceptance of family members were very variable. Some participants reported that their family members are not accepting the child and his communication method. Few participants (26%; n=4) said their family members do not accept the communication method. One such parent reported that her husband was not taking his child with communication disorders and not getting through the process. She stated, "Actually, it's tough to accept him in the family. His father, even he has not accepted the child previously because of his lot of sensory issues and all putting everything into the mouth" (#P1). Another parent responded, "We are in a joint family, but the family members are not accepting and supporting the child himself and his communication way." (#P6).

Another group of parents (26%; n=4) reported that everyone in the family accepts the child and his communication method. One parent said that the family members would support whatever decision she takes for her child. The mother stated, "My decision was the final decision, so whatever I do will be the best for my child. It was not a challenging issue in my family; they all accepted" (#P14). Another parent

said that their family is a nuclear family, so everyone accepted. "Family members accepted his way of communication since we are a nuclear family with me, my husband and my younger son are there in the home" (#P5).

Few parents (26%; n=4) reported acceptance starts emerging from their family members. They began with no approval to less acceptance now. Parents have reported that their family members accepted after getting counselling and a clear explanation from the child's mother and the speech therapist. A parent said, "I am in a nuclear family, and hence initially my husband didn't accept, but after explaining the need for his communication, he started accepting the pictures communication system."

4.1.2.2 Supportiveness. A parent (6%; n=1) said that their family members were not supporting the communication method and didn't get any support from their family members for choosing this as an intervention method. For example, "just giving the pictures won't develop language is what they feel, so they are not supporting this system" (#P14) was the statement that participants gave.

Conversely, some parents (26%; N=4) said their family members support the mother, Child and the communication systems they use. One parent reported that accepting is different from supporting, which my family didn't get, but they are supporting the procedure for communication. The parent stated, "it's challenging to accept him in the family, but they will support. Support is different from acceptance" (#P1).

4.1.2.3 Encouragement. Parents who reported whose families are accepted have worked with the child, motivating and encouraging the child to communicate. Few parents (26%; n=4) said their family members would enthusiastically share and talk with the child and give encouragement and motivation. A participant said, "When I first

introduced AVAZ to him, my dad would go and bring the tab and ask him to point what he wants" (#P14).

4.1.2.4 Satisfaction. Participant's family members who are accepting and supportive also have dissatisfaction with the method but still hope it will work. One parent reported, "family is a little supporting, but not satisfied from this picture using communication. They only want him to speak" (#P10).

4.1.2.5 Awareness. Few participants (26%; n=4) reported that their family members are unaware of the AAC communication system; hence, they usually neither agree nor disagree. One parent said, "most of my family members are unaware of this picture communication" (#P4). Another parent said, "my husband was not aware of the communication he is using, so he won't interfere" (#P12).

4.1.2.6 Perception. Few participants (13%; n=2) reported that their family members negatively perceive AAC and are not accepting and supporting the systems. For example, a participant stated, "My family often tell me not to give such a training as the child would completely stop to speak by mouth" (#P3). Another few participants (13%; n=2) said their families insisted on withdrawing from this method and asked them to continue speech therapy. One such parent noted that "My family (even my husband) people are not encouraging me to use pecs; things are useless, why are you wasting your time on this; he should speak through the mouth" (#P10).

4.1.3   *Acceptance from behaviours:*

Acceptance of an intervention method emerges from various progress and improvements in the child. Participants in the study reported many behaviours that made them accept the AAC as a communication intervention. Table 4.1.3 Summary of

the categories, sub-categories, codes and meaningful units for the acceptance of behaviours.

Table 4.1.3

Summary of codes and sub-categories for acceptance from behaviours

Category	Sub-categories	N	Codes	Meaningful unit	Example of a statement
Acceptance from behaviours	Started expressing oneself	10	Expressing his needs	Show pictures if he wants	If he wants something, he will only come and show the picture.
	Emergence of communication intent	7	Initiating communication	Initiation of communication improved	He started initiating his communication clearly;
	Socialization skills	3	Increments in peer interaction	Interactions with peers improved	His overall peer interaction in school has improved.
	Identification skills	6	Identifying pictures	Understanding pictures and points when named	Understanding various action verbs, names of fruits, and vegetables, he starts pointing.

Category	Sub-categories	N	Codes	Meaningful unit	Example of a statement
	Comprehension ability	8	Understanding the conversations, commands	Understanding speech	He is understanding mostly whatever I speak
	Pointing skills	3	Pointing pictures on own and when named	Pointing skills increased with many pictures	He can point to pictures in the presence of 10-12 other pictures.
	Increased vocal production	5	Producing sounds and words	Sounds & words production started	He started producing sounds and words; He felt like speaking but didn't know where to place his tongue
	Typing skills	1	High-tech devices facilitate typing	Typing facilitated by AVAZ	Typing has improved after using AVAZ.
	Reduced emotional and behavioural issues	2	Behavioural issues reduced	He waits; reduced temper tantrum	Previously he will run and take water; now, he waits and shows water.

Category	Sub-categories	N	Codes	Meaningful unit	Example of a statement
		2	Frustration	Frustration level reduced	His frustration level has reduced to a greater extent.

Note. N is the number of respondents

4.1.3.1 Expressing oneself. More participants (66%; n=10) reported that their child has started expressing his needs by pointing to the pictures or getting them to the mother when he wants something. An example of a parent statement is, "He started communicating with the pictures a lot. If he wanted something, he would only come and show the image" (#P15).

4.1.3.2 Emergence of communication intent. Many parents (46%; n=7) have reported that the child started initiating communication and showed interest in communicating with others. Examples of the statements are, "He started initiating his communication. (#P13) and "He started showing interest in talking to the people." (#P6).

4.1.3.3 Socialization skills. Few participants (20%; n=3) said their child's peer interaction skills have started emerging in schools. A parent reported, "His overall peer interaction in preschool has improved" (#P10). Another parent said, "previously he was not mingling with people, but now it is okay. He started liking to see the children who are playing, and he will go and stand with them" (#P1).

4.1.3.4 Identification skills. Few parents of children with ASD (40%; n=6) have reported their child's identification of pictures and objects has increased. Some

example statements by parents are, "He understands various action verb colours and names of fruits, vegetables, animals and vehicles and starts pointing to it when asked to tell. (#P12) and "Identification improved for things in the presence and absence of pictures" (#P6).

4.1.3.5 Comprehension ability: Half of the participants (53%; n=8) observed their child's comprehension ability had improved to a significant level, where they could understand commands and conversations of the parents. A parent stated, "he is understanding mostly whatever I speak" (#P13). Another parent reported, "He started understanding my commands with or without pictures" (#P11).

4.1.3.6 Pointing skills. Few parents (20%; n=3) reported pointing skills of the child have improved for pictures and objects both spontaneously and on demand. A parent said, "His pointing skills have improved a lot; he can point photos in the presence of 10-12 other pictures. (#P2).

4.1.3.7 Increased vocal production. Parents reported that their child's verbal presentation has improved, ranging from sounds to phrases. Few parents (33%; n=5) stated that their children started vocalizing sounds and words, and one parent reported that their child had started adding words to form phrases. A parent said, "He started producing sounds to call and show(#P3). Another parent: "He started producing sounds and words; He feels like speaking but don't know where to place tongue" (#P2).

4.1.3.8 Typing skills. A parent (6%; n=1) using high-tech AAC devices (AVAZ app) reported that her child's typing skills had improved significantly. "Typing has improved after using AVAZ; it facilitates typing" (P2) was the statement given.

4.1.3.9 Reduced emotional and behavioural issues: Few participants (13%; n=2) reported reduced their child's frustration level. Some other parents (13%; n=2) of the parents said their child's behavioural issues, such as temper tantrums and aggressiveness reduced. Examples of statements are "His frustration level has reduced to a greater extent" (#P14) and "Irritations and temper tantrum issues decreased" (#P1).

4.1.4 Professionals and others helped in acceptance:

Professionals and parents of others play a vital role in favour of an intervention method for any child with communication disorders. Speech-language pathologists have an inevitable part in accepting AAC for any child or adult candidate for AAC interventions. Table 4.1.4 summarizes the categories, sub-categories, codes and meaningful units for professionals and members helped in acceptance.

Table 4.1.4

Summary of codes and sub-categories for professionals and others helped in acceptance

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Professionals and others helped in the acceptance	Speech language pathologists	SLP counselling	15	SLP told regarding the AAC systems	Speech therapist has counselled me regarding this initiative, and I have started using the pictures for him to communicate

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
	Psychologist	Psychologist Counselling	1	Psychologists assisted in the acceptance of AAC	Psychologists counselled on the importance of communication for expressing needs.
	Occupational Therapist	Occupational Therapist counselling	3	Occupational Therapist motivated parents to use AAC	Occupational Therapist informed me about my child's issues and encouraged me to use any method.
	Special educators	Special educators counselling	4	Special educators trained the parents on implementing AAC in school settings	Special educators guided the steps in implementing AAC at school.
	Parents	Observation of other parents of children with ASD using AAC	1	Parents of children with ASD utilizing AAC	Some parents asked me to do it as their child is improving.

Note. N is the number of respondents

4.1.4.1 Speech Language Pathologists. All the participants (100%; n=15) said Speech Language Pathologists (SLP) and their counselling helped them accept and follow AAC as an intervention method for their children. "Speech-language

pathologists have counselled me regarding this initiative, and I have started using the pictures for him to communicate" (#P15).

4.1.4.2 Psychologists. A parent (6%; n=1) said that psychologists have counselled regarding the importance of communication for expressing needs.

4.1.4.3 Occupational Therapist. Some participants (20%; n=3) told the occupational Therapist helped. OT informed me about my child's issues and motivated me to use any communication method(#P14).

4.1.4.4 Special educators. Few parents (26%; n=4) of the parents reported that special educators helped implement AAC in schools. "Teachers in the school, who also helped him to do things at school" (#P5).

4.1.4.5 Parents. A parent (6.6%; n=1) stated that parents of other children had influenced their acceptance. The parent said, "some parents asked me to do as their child is improving" (#P12).

4.2 Experience

The results showed ample information on the three major categories, indicating the parents' involvement and encouragement towards AAC usage for their children. Figure 4.2 depicts the flow chart for the categories under the domain experience.

Figure 4.2

Flow Chart of Categories for Experiences

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                    ┌─────────────────────────┐
                    │       Experience        │
                    └─────────────────────────┘
         ╱                      │                      ╲
        ↙                       ↓                       ↘
┌──────────────┐      ┌──────────────────┐      ┌──────────────┐
│ Modifications│      │  Frequency and   │      │ Experience   │
│ in the usage │      │   duration of    │      │ with AAC     │
│ of AAC       │      │ experience using │      │ outside      │
│              │      │      AAC         │      │ the home     │
└──────────────┘      └──────────────────┘      └──────────────┘
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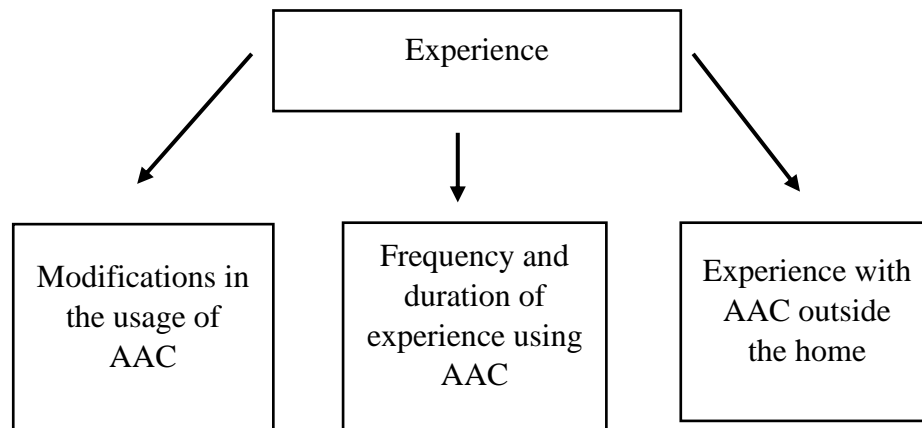
4.2.1 Modifications in the usage of AAC

Engaging and interacting the children with complex communication needs, such as children with ASD, need modifications and strategies. Parents of children with ASD who participated in this study have reported different accommodations, including environmental changes, alterations in stimuli, teaching strategies and techniques.

Parents of children with ASD who participated in this study have done a lot of modifications to the stimuli, teaching methods, environment and the applications they are using. In each subcategory, many codes are derived from the verbatim they told, about 17 codes. Table 4.2.1 shows the summary of the categories, sub-categories, codes and meaningful units for the modifications in the usage of AAC.

Table 4.2.1

Summary of codes and sub-categories for the modifications in the usage of AAC

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Modifications in the usage of AAC	Modifications in stimuli	Visualizing concepts using pictures	3	More interesting, colourful, attractive pictures	I have started to make more attractive, colourful pictures that attract and motivate my child to use them
		Avoiding visual crowding	2	More pictures cause less clarity	If we are using more pictures, he won't get clarity, so few I will use.
		Avoiding electronic photos	1	Won't prefer internet pictures	I usually won't use images from the internet.
	Teaching strategies and methods	Relate pictures to objects	8	Using natural objects and pictures to relate	I will usually have the real objects for each of the items which am showing as the pictures.
		Tailor-made activities	8	Play times and	Using play activities,

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
				choices	having playtime rather than making him sit in a single place and teach
		Scheduling routines	4	Routines	In school and at home, we made a routine for him using the pictures
		Steps wise teaching	6	Steps for activities	Using pictures for each activity in simple steps
		Adequate repetitions and response time	4	More trials and repetitions	He can't do it the first time. So, I will give more trials and repetitions till he learns the word.
		Multimodality teaching	2	Combining actions, pictures	Actions and words together, I will combine and teach
	Modifications in environments	Seating and positioning	2	Special chairs	we are using a special chair for him to sit; To reduce his hyperactivity

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
		Modifying home	1	Setting up home	I had set the house according to him
		Interactions in the home environment	5	Talking and sharing thoughts	I keep on talking with him all the time. Whatever I am doing, I keep on telling him that's how our general communication usually at home
		Treating similar as another child	2	Behave in the same way as other children	We usually behave in a way which is similar to my other child.
	Modifications in the applications	Adding customized pictures	1	Adding own pictures	For AVAZ, I added customized pictures
		Voice output modifications	1	Slowing down the rate	I have slowed down the speech for him to make him understand the words
		Making	1	Many	To avoid

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
		feasibility for pointing		pictures on the same screen	scrolling, I have kept 10-12 pictures on the same screen, and he is pointing correctly

Note. N is the number of respondents

4.2.1.1 Modifications in stimuli. Parents who participated in the study have changed how they present stimuli, either in the form of pictures or objects. The first significant thing parents (20%; n= 3) do is visualize the concepts using photographs or drawings to make the child visually pay attention to the context. "I have started making more interesting colourful pictures that attract and motivate my child to use them" (#P3).

Some parents (13%; n=2) reported that they would present one or two pictures at a time to avoid visual crowding for the child. "If we are using more pictures, he won't get clarity, so few I will use" (#P2). Preferably parents (6%; n=1) use a real picture of the child rather than electronic pictures from the internet. "I usually won't use pictures from the internet. I took real actions of him (example eating; brushing) and use those pictures for PECS" (#P2).

4.2.1.2. Teaching strategies and methods. Many parents (53%; n=8) use natural objects consistently with the pictures they are showing to make the child relate the things with the images by matching the similarity and comprehending the meaning. "I will usually have the real objects for each item I show as pictures. For example, If I

made idly for breakfast, I will ask Sanjay to get the idli picture and match that with the real object, and then I asked him to get that from the kitchen" (#P6).

Another primary technique is teaching the child customized activities rather than structured ones. Half of the parents (53%; n=8) have used fun activities for their children while teaching and interacting. "We usually teach him using play activities, having playtime rather than making him sit in a single place and teach. If I do strict teaching using charts and pictures in a structured way, his tolerance level is very less around half an hour" (#P4). Another parent reported, "we will always give him choices of activities" (#P15).

Visual scheduling of the activities is the other common technique used by parents of children (26%; n=4) with ASD using pictures. "In school and home, we made a routine for him using the pictures, like the daily schedule for getting up pictures, brushing, bathing, dressing up, having breakfast and going to school. He has the routine that he should tick the picture of brushing after completed brushing" (#P1). Another parent said, "I made a routine for him, and that works well for him. Even some days he was cranky, and he doesn't want to do anything I will make him sit in the routine place, and he can do whatever he wants" (#P14).

Most parents reported that they usually teach the concepts in steps. Most parents (40%; n=6) teach picture exchange communication step-wise. "To make him understand, I usually start with matching the pictures with the real objects, and from matching then I will move on to identifying the real objects" (#P8). Another parent said, "Initially, I have started working to make him sit in a place like giving him some stacking the rings and beads. Then after he achieves this step, the next step is to match the object to the object matching. For example, if I take the ball, he will take the ball.

Once he achieved this matching, then matching the pictures to the objects and then matching the written word to the objects was worked. Once he started giving attention to activities, I increased the timing from seconds to minutes" (#P14).

Parents (20%; n=4) give an adequate number of meaningful repetitions and response time for the children to engage in activities. "More meaningful repetitions of the same concept at different times and situations and places I will be giving to him. I will spend more time" (#P9). Few parents (13%; n=2) reported that they would use multimodality to teach concepts, for example, using actions or gestures along with pictures and rhymes. "From the initial, I am teaching him using actions(gestures), so whatever I am teaching, I will teach him through activities so he can grasp the information faster. I will combine actions and words and train him" (#P6).

4.2.1.3. Modifications in the environment. Making the child sit in a comfortable position is more important, as reported by a few parents (13%; n=2). They said they would provide specially equipped chairs for their children while teaching to make them comfortable. "Seating arrangements are difficult for him to set up" (#P12). A parent (6%; n=1) said they had modified the whole house in favour of the child. "I had set the house according to him, whatever he wants, his plate, his bottle to his reachable place" (#P14).

Few participants (33%; n=5) said that more interactions in the home are the most common thing they do in environmental modifications. "I keep on talking with him all the time, whatever I am doing I tell to him, whatever he does I keep on telling him, that's how our general communication usually at home" (#P4). Another parent reported, "I will always engage him in normal routine activities. I will give him specific

household tasks, such as putting the trash bag out, doing some vegetable cutting and making him engage in the daily activities whenever possible" (#P5).

Two parents reported (13%; n=2) that they will treat this Child with ASD like their other child at home. "We usually behave in a way which is similar to my other child. We usually play, share thoughts, scold if he does something wrong, behave like the normal child" (#P4). "I will usually treat him the same as my other child" (#P5).

4.2.1.4. Modifications in the applications. A parent (6%; n=1) reported that they had made some modifications, such as changing the voice output rate, adding customized pictures and making the screen feasible for pointing according to the child's need. "He is facing difficulty in scrolling the next pictures. So, I have kept 10-12 pictures on the same screen, and he is pointing correctly" (#P2).

4.2.2 Frequency and duration of experience using AAC

Participants in the study have mentioned that they were using AAC communication systems at various times throughout the day and in multiple contexts based on the child's needs. The data collected from the parents in the aspect of context revealed that they would be using speech and language therapy centres at home; some also reported they are using in schools. The duration of usage varies from 45 minutes to 4 hours, depending on the context. Table 4.2.2 summarises the categories, sub-categories, codes and meaningful units for the frequency and duration of experience with AAC.

Table 4.2.2

Summary of codes and sub-categories for the frequency and duration of the experience

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Frequency and time of experience using AAC	At home	Meal time	7	At meal times during leave days; dinner times;	During mealtimes on leave days and dinner time on school days, I will be showing cards to him to choose which one he wants
		Activity Time	7	Evening activity times approximately 1 hour	In the evening, I will sometimes spend teaching approximately 1 hour occasionally t uses teaches him
		At the time of need	7	Throughout the day, whenever needed	My elder daughter and I mostly use pictures throughout the day whenever needed
	At Therapy	Speech and language therapy	13	45 minutes of therapy session	During speech therapy, 45 minutes session, we are getting
	At school	Other activities	4	In school, using with other activities	At school, they will be using it along with other

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
		and PECS			activities. They have a communication therapist who will be taking the class for some time

Note. N is the number of respondents

4.2.2.1 At home. Some parents (46%; n=7) reported using picture exchange communication or AVAZ applications predominantly during their child's meal time to give choices and show food items along with the pictures. "I will use in all the meal times and snack times to choose what he wants. Usually, we will use approx ½ hour to 1 hour at home meal time" (#P7). Also, parents (46%; n=7) said they would use photos during activities and ask them to choose the activities they wanted. "In the evening, I will be using to make choices for activities he wants, e.g., typing, writing, puzzle boards" (#P2). Some parents (46%; n=7) said they would use pictures for communication throughout the day based on their child's needs and requirements. "My elder daughter and I mostly use pictures throughout the day whenever needed" (#P10). "It is need-based; we will use it according to his need" (#P14).

4.2.2.2 At speech therapy. Most parents (86%; n=13) attend speech and language therapy for their children, receiving 45 minutes weekly twice or thrice. In sessions, the child would be using PECS or AVAZ for communication. "At speech therapy, they will be using for around 45 minutes" (#P1)

4.2.2.3 At School. Few parents (26%; n=4) of the parents reported that their children use AAC communication systems in schools across various times and situations. "For preschool, Stories and rhymes pictures I have made for him for the school so what he wants he will show and the teacher will do that approximately 2 hours at school he will be using" (#P9). Another parent said, "In school, he will be using it for around 1-2 hours" (#P5).

4.2.3 Experience with AAC outside the home

Out of 15 participants, only a single participant (6%; n=1) said she would use PECS or AVAZ outside the home. Also, this parent reported she would be used only in familiar places. "I am not using it any of the social events, but outside home, sometimes I am using like singing class, swimming class, therapy session for all these things I made pictures of the places and using that whenever we go there" (#P15).

All other participants (93%; n=14) reported they are not using AAC systems outside the home and hence reasons for not using asked. Participants have reported various reasons for not using AAC systems outside the home. Table 4.2.3 summarises the reasons for not using the AAC systems outside the home.

Table 4.2.3

Summary of codes and sub-categories for the reasons for not using outside the home

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Reasons for not using outside the home	Adaptability and comfortability issues	Not adaptive and comfortable	8	Comfortable at home and outside the	He is comfortable at home and stays calm,

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
		with new places		home is uncomfortable	and in other places, he will be very hyperactive
	Perception of others	People look differently	7	Unusual if we teach outside	It will be unusual, People will look at us in different.
	Portability issues	Cannot carry cards	8	difficult to carry	It is difficult to carry
	Use of another mode of communication	Communicate using gestures	5	Communicate through gestures, no need for cards	He will be communicating using gestures or pointing, so there is no need for pictures to carry. I felt

Note. N is the number of respondents

4.2.3.1 Adaptability and comfortability issues. Half of the parents (53%; n=9) said they are not going out often because the child doesn't feel comfortable outside. The child has low adaptiveness to new places might exhibit hyper-activeness and aggressiveness. "Other places and all it not quite comfortable to use pictures outside the home. It is very difficult to handle him outside the home" (#P8). Another parent said, "Outside really it is not possible, we won't go very often outside because I feel he

is very calm inside than outside. I don't want to put him in a very noisy and busy place" (#P13).

4.2.3.2 Perception of others. Perception of others and their behaviours hinders most parents from using AAC systems outside the home. Some participants (46%; n=7) of the parents reported they faced many problems because of others' perceptions of the child and the system they are using. One parent said, "Here in a society, we need to think about people also, right? But still many people who are not educated, they think my child is mentally retarded, but they don't know his ability what all he can do" (#P1).

4.2.3.3 Portability issues. Half of the participants (53%; n=9) reported that they found it hard to carry picture cards and handle them outside the home. "Taking the cards outside the home is a little difficult or uncomfortable to handle. If am going to any functions or events that time, I cannot take that right know?" (#P9).

4.2.3.4 Use of another mode of communication. Parents (33%; n=5) reported that they never felt the necessity to use cards outside the home because their children would use a different method of communication (either gestures or pointing to the things they need) rather than pictures. "At times, he will be communicating using gestures or pointing, so no need of images to carry, I felt. In one or the other way, he will try to communicate, so I didn't feel any necessity for these cards to be taken with us (#P2). Another parent said, "In functions, he will communicate with me through pointing and gestures like if he wants food items, he will come and show me that food" (#P5).

4.3 Challenges:

Parents reported they had faced challenges in using AAC intervention for their child inside and outside the home. These challenges are divided into four major categories: associated problems, environmental and situational barriers, stigmas and myths that hinder intervention, and specific challenges related to high-tech AAC devices. Figure 4.3 depicts the flow chart for the categories under the domain challenges.

Figure 4.3

Flow Chart of Categories for Challenges
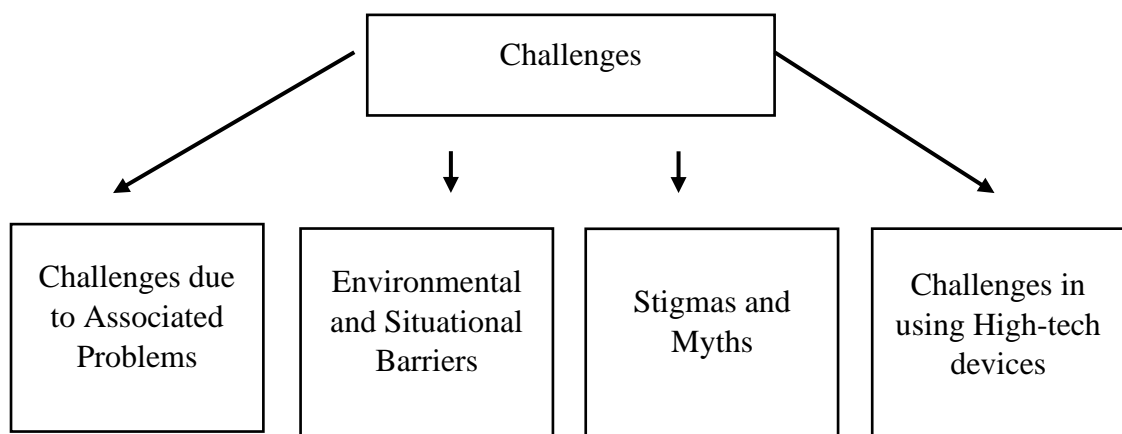
4.3.1 Challenges due to associated problems

Behavioural, sensory, motor and other issues are the most commonly reported challenges faced by children with ASD while using AAC. Table 4.3.1 summarises the categories, sub-categories, codes and meaningful units for the Challenges due to associated problems.

Table 4.3.1

Summary of codes and sub-categories for the challenges due to associated problems

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Challenges due to associated problems	Behavioural issues	Temper tantrums & aggressiveness	8	Angry, irritated, aggressive, restless, so stubborn,	He will be angry, irritated, restless, aggressive, and stubborn often that time; we should be polite to him and handle him in a polite way
		Damaging materials	7	Tearing & throwing pictures when frustrated	He will be really angry so he took the pictures and throw them away or tear them away. Again, we have to redo the pictures
		Hyperactivity	4	Hyper in nature	He usually explores all the pictures and is very hyper in

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
					nature and he unable to sit and do things for longer periods
	Sensory issues	Hypo or hypersensitivity	8	Sensitive to sounds	He is more sensitive to sounds and hence if we are teaching something in a loud voice, he will start closing his ears, and he won't listen
	Limited Cognitive skills	Attention and concentration	8	Don't listen while teaching	He won't listen to what we are telling or teaching most of the time
	Motor issues	Motor coordination issues	1	Problems with pointing the pictures	He is having motor coordination issues in pointing the pictures which are closely placed
	Other comorbidities	Sleep disturbances	2	Don't get sleep	he won't sleep properly at

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
				properly, and it affects learning	night; hence it indirectly influences on his performance in school, therapy centres

Note. N is the number of respondents

4.3.1.1 Behavioural issues. Most parents (53%; n=8) reported that their children would exhibit temper tantrums, affecting their learning process. "He will easily get distracted and irritated, quarrelling and showing temper tantrums for simple things" (#P5). Most parents (46%; n=7) of parents said that their children would damage the pictures or the materials of AAC by throwing and tearing them when they get frustrated. "He would start getting angry, throwing the pictures and the items (#P11). Some parents (26%; n=4) reported that their children have poor sitting tolerance and are hyper, which affects their learning behaviours. "It is very difficult to make him sit in a place and do the things and teach him. He always wants to wander around the places and hence it is very difficult to make him understand the concepts". (#P15).

4.3.1.2 Sensory issues. Half of the parents (53%; n=8) said that their children have either hypo or hypersensitivity issues, which affects their learning and using the process. "Sensory issues from the beginning are a big problem for him to engage in the communication" (#P13). Another parent said, "He is more sensitive to sounds, and hence if we are teaching something in a loud voice, he will start closing his ears, and

he won't listen. Still, after so many improvements, he has this ear closing behaviour which affects his learning" (#P6).

4.3.1.3 Limited Cognitive Skills: Half of the participants (53%; n=8) told their child won't pay attention while teaching, and it is challenging to make him attend to the stimuli. "He won't listen, and he will always be in a fluctuating mind" (#P7). Another parent reported," He is in a completely different thinking mode sometimes his mood is very bad that time he won't communicate" (#P13).

4.3.1.4 Motor Coordination Issues. One parent (6%; n=1) reported that her child has motor coordination issues, which affects pointing the needed items. "He is having motor coordination issues in pointing the closely placed pictures. Sometimes he wants to press another button, but sometimes he presses another button because of the motor issues, so he will be very irritated when that happens" (#P14).

4.3.1.4 Sleep disturbances. Two parents reported that their children have sleep disturbances, and it has an indirect effect on the performance of the child. "He has sleep disturbances and strategies to bring into a schedule is very difficult, and we end up in failure. Even a slight disturbance he cannot tolerate" (#P13).

4.3.2 Environmental and Situational Barriers

Parents of the current study reported various situations and many different environments as barriers for their children in using AAC outside the home. Table 4.3.2 summarises the categories, sub-categories, codes and meaningful units for the environmental and situational barriers.

Table 4.3.2

Summary of codes and sub-categories for the environmental and situational barriers

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Environmental and situational barriers	Social acceptability	Lack of awareness & poor perceptions	4	Thinks that child having mental issues	People outside are unaware of the conditions, and they think all the children are having some mental problem
		Uncommon and ill-judged behaviours	7	Not behaving properly with the child	If I am present, they will be good, and if I am not there, they will irritate him, and they will do things that he doesn't like.
	School-based challenges	Accommodation difficulty	7	Schools are not allowing AAC	Every school are not allowed to use PECS; some special schools and government schools- allowing

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
		Poor seating and positioning	6	Limited seating and assistance	Seating arrangements and other assistances are very limited
		Lack of awareness	4	Teachers unaware of the method of using	Teachers not knowing how to use AAC and how to handle him itself
		Poor peer understanding	4	Classmates lack perceptions.	Classmates are not understanding, and they don't become friends with him

Note. N is the number of respondents

4.3.2.1 Social acceptability. Few participants (26%; n=4) of the parents reported they faced challenges outside the environment due to people's poor perception and acceptability. "I stopped going to the places where people will think once the child behaves differently, he will never change, and he will be like that only they are sometimes considering like disturbances if the child is crying" (#P13). Another parent said, "Many people outside the therapy or home don't seem to be aware of his conditions, and they feel he is annoying all the time, and they don't know how to handle and respond to him if he wants something. So, taking him outside is very difficult work" (#P15).

Also, parents (46%; n=7) reported that they had faced some ill-judged or unusual behaviours from others in social environments. "People will weirdly look at my child because they don't understand my child's capability and what all my child can do. People outside don't have much awareness, so they don't support, especially in hotels and malls" (#P6). "People don't know him much, but still they will be thinking something on their own and do some behaviours like getting their child back if he tries to speak to them" (#P11).

4.3.2.2 School-based challenges. Parents (46%; n=7) reported difficulty accommodating schools for their children, and frequent shifts from schools happened because of poor adaptations in various regular schools. "In every school, they are not allowing him to use PECS for him. Some special schools and government schools are allowed" (#P9).

Most parents (40%; n=6) reported their children facing seating and positioning difficulties in schools. "Seating arrangements are very tough and challenging. Making him sit in a particular place, particularly in school, it's challenging to make him sit in a comfortable place" (#P1). Another parent said, "Seating arrangements and other assistances are minimal (#P3). Few participants (20%; n=3) of the parents said that school teachers lack awareness of handling intervention methods. "Teachers might not be known how to use AAC and how to handle him itself. If I am giving to him and sending him to school, the teachers might not know how to use" (#P9). Another parent reported. "I have put him into normal schools for one year. There didn't know how to handle this boy" (#P2). Few parents reported that the peer in the class has poor understanding, which becomes a challenging factor. Classmates might not be

understanding, and they don't become friends with him". (#P9). "Peers have not understood his behaviour, which is a problem for him" (#P10).

4.3.3 Stigmas and Myths

Many parents reported that they have come across many myths and stigmas, and most overcome them and choose the best intervention options for their children. Table 4.3.3 summarises the categories, sub-categories, codes and meaningful units for stigmas and myths.

Table 4.3.3

Summary of codes and sub-categories for the stigmas and myths

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Myths and stigmas	Social stigmas and myths	Pictures would limit speech	8	Stop trying to talk if he finds another mode	Once he is doing good with pictures, he won't try to speak
		Speech won't come after years.	5	Always nonverbal, won't speak after years	If he is not speaking within 5 -6 years, he might be mute all the time
		Medications needed than speech therapy	3	Medications to be taken for speech	People are told to show to a doctor and to take medications, and they are unaware of the therapy itself.

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
		Pictures communication is the last option	1	Pictures are the last chance	Picture communication and other applications are for those children who cannot speak anytime, and it is the last option for the child if he doesn't talk for years.
		Pictures are for younger kids	1	Pictures are for children who are young	They told them that colour pictures are for very younger children. He is old.
	Impacts of myths	Overcame myths and stigmas	5	Not considering myths	Now, I am not considering those people because I want him to speak and communicate.
		Negative effects of stigmas	1	Stopped speech therapy in the belief in myths	Because of their beliefs, I didn't take him to any speech therapists, Now I am regretting shouldn't stop speech therapy

Note. N is the number of respondents

4.3.3.1 Social stigmas and myths. Most parents (53%; n=8) reported that they had encountered the myth that "PECS will limit the speech". A parent said a statement she encountered from others "If we encourage him to use actions, gestures and pictures, he won't attempt to speak, he will think this is an alternative way so its easy so I can follow this rather than speaking" (#P15). Another parent reported, "if he is showing pictures all the time, the child might become addicted to the pictures rather than speaking" (#P12). The second ordinary myth parents (33%; n=5)face is that "Speech won't come after years." One parent stated that "He will be nonverbal always, he won't speak after some years" (#P7). Another parent said, "My neighbours and others told me that if he is not speaking within 5 -6 years, he might be mute all the time" (#P8).

Few parents (26%)told that their family members and others told medications were needed for the child, not speech therapy. "Go for some medications and other things rather than using colour pictures" (#P5). One parent faces the myth that "Pictures communication is the last option". One parent narrates that, Previously, everyone said that picture communication and other apps are for those children who cannot speak anytime, and it is the last option for the child if he doesn't talk for years. (#P9). Another myth reported was "Pictures are for younger kids" by a parent. "They usually say that colour pictures are for younger children, he is old, and hence he needs to speak and do the work independently (#P5).

4.3.3.2 Impacts of myths. Few participants (33%; n=6) reported overcoming the myths and stigmas. One parent stated, "But now it has changed. I have hope on AVAZ and other communication methods that he is improving, so any way of communication he can use to communicate. Now I am not thinking about others or social acceptance because it won't make a change in his life, and if I think of others, all

these things I cannot use for him, then he won't be good in life (#P9). One parent

reported that she got a negative impact after having the stigmas. "Everyone said like

stop going for speech therapy; he won't speak after certain years, and no child will

speak after a particular age. So, because of their beliefs, I didn't take him to any speech

therapist. Now I regret that if I had attended the therapy before only, he might have

started to communicate and speak much earlier" (#P2).

4.3.4 Challenges in using High-Tech Devices

Four of 15 participants use the AVAZ application as their AAC device. Parents reported

various challenges faced by them while using apps. Table 4.3.4 summarises the

categories, sub-categories, codes and meaningful units for challenges in using high-tech

devices.

Table 4.3.4

Summary of codes and sub-categories for challenges in using high-tech devices

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Challenges in using high-tech devices	Knowledge about application operations	Skill requirements for using applications	2	Don't have the ability to use	I don't have much knowledge about how to use the AVAZ app;
	Language Accent variations	Difference in pronunciations	3	Variations in pronunciation from the normal one.	Pronunciation of the language is entirely different

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
					from the normal speaking words
	Voice modification challenges	Robotic voice output	1	It seems to be a robotic voice	voice output from the AVAZ seems to be a little robotic, and I couldn't understand

Note. N is the number of respondents out of 4 participants.

4.3.4.1 Knowledge about Application Operations. Few participants (13%; n=2) reported lacking knowledge and skills for using apps and devices. "I don't know much about using the AVAZ app. Am exploring by myself like what all options are there and what all we can teach through this" (#P2).

4.3.4.2 Language Accent Variations. Some participants (20%; n=3) of the parents felt some slang difference in languages, which is quite challenging to understand. "The pronunciation of the language is entirely different from the normal words. Sometimes it is challenging to understand for me itself. So for special children, it will be even more difficult" (#P5).

4.3.4.3 Voice modification challenges. One parent reported that the voice output is entirely robotic, making it difficult for the child and the mother to understand.

"It is more robotic and system voice and different slang than what we are speaking, so it's tough for him to understand (#P5).

The results of the present study showed various perceptions, awareness, exploration, expectations and challenges faced by Indian parents while using AAC for their children in different environments, including home and outside environments.

4.4 Expectations;

Expectations of the parents were asked concerning device-related expectations and financial and professional guidance-related expectations. Figure 4.4 depicts the flow chart for the categories under the domain expectations.

Figure 4.4

Flow Chart of Categories for Expectations
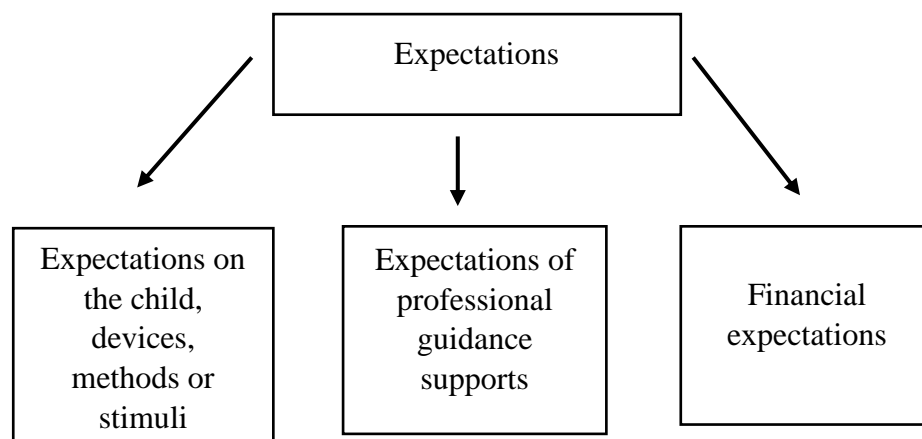
4.4.1 Expectations on the child, devices, methods or stimuli

Parents responded in a varied range from no expectations to more expectations on devices and the child's communication. Table 4.4.1 summarises the categories, sub-categories, codes and meaningful units for expectations on the child, devices, methods or stimuli.

Table 4.4.1

Summary of codes and sub-categories for expectations on the child, devices, methods or stimuli

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Expectations on the child, devices, methods or stimuli	Expectations of child's communication	The child expected to speak	7	The child needs to talk and independent	My only expectations are to make him speak
	No Device related expectations	Poor awareness leads to no expectations	4	Not much aware of the devices	I am not much aware of the devices, and I don't expect much about the devices
		Poor perception leads to no expectations	3	Addiction to phone	If I am giving some phone apps and all, he will be addicted to them again; but he should not get addicted to that
	Presence of device-related expectations	Expectations on trying devices	3	Want to try devices	I want to try new devices to see his improvements
		Expectations on language features	2	Language related settings	English which we are speaking and

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
					the English from the device output is different; We Need some colloquial language
		Expectations on voice outputs	4	Voice modification settings	I want to add his brother's voice and my voice because voices are familiar to him
		Expecting customization on devices	3	Customized based on needs	If the device is customized based on his needs, it will be even more helpful for him
	Expecting improvements in teaching methods	Improvisation in teaching methods	1	Easy grasp - teaching methods	Teaching methods can be improved in a way that he can grasp things so quickly

Note. N is the number of respondents

4.4.1.1 Expectations of Child's communication. Some parents (46%;n=7) of the parents reported expecting the child to speak and be independent. When parents of children were asked about expectations on instruments and techniques, they said having expectations of their child's speech more than device-related expectations. "I want him to be independent like he needs to express himself and he needs to do things on his own for him" (#P5).

4.4.1.2 No device-related expectations. Parents have reported two reasons for not having expectations on devices. The first was a lack of awareness about the technology that was reported by (26%; n=4) of the parents said the same." I am not much aware of the devices, and I don't expect much about the devices" (#P7). The second reason was the poor perception of technology and gadgets. Parents said that their children might become addicted to their phones if they use apps or other software for communication." If I go to any of the apps again he might be addicted to of that. He may not be speaking or communicating" (#P12).

4.4.1.3 Presence of device-related expectations. Few parents (20%; n=3) have reported that they want to try a new device for their children because most of them are so interested in gadgets and phones, so the parents want to try to see the improvements in them. "I haven't tried yet. But he is very interested in phones and laptops. He will unlock and play games. So I might go for that in some time, I guess" (#P3).

Some parents have features related expectations such as modifications in settings and customization of devices. Two participants expected language-related features where they felt there might be some slang differences in the language between the natural language and the language output from the device. "I need some colloquial language which we are speaking" (#P2)

Few participants (26%; n=4) said they expect improvements in voice output where they can add their voice instead of the computerized voice output. "I want to add his brother's voice and my voice because voices are familiar for him" (#P2). "If any apps where my voice or familiar voice we can record and use that I want him to try, I will get an idea about how he understands (#P5). Some participants (20%; n=3) of the parents expected customized devices for their children, so they would easily learn things. "If the device is customized based on his needs, it will be even more beneficial for him" (#P4).

4.4.1.3 Expecting improvements in teaching methods. A parent (6%; n=1) said that she needed variations or modifications in the teaching method to make the child grasp things quickly and easily. "Teaching methods can be improved in a way that he can learn things so quickly. For example, there are many steps or phases in PECS, and verbal communication comes at the end. So if we are making him do the 2nd or 3rd phase so a long time, he will grasp the things in his mind and he will think this enough, and he won't try to speak, so I want the Therapist also to move quickly from one phase to another so that he will think that we need to talk rather than just pointing (#P15).

4.4.2   *Expectations of professional guidance supports*

Parents said they need professional guidance to engage their children better and teach them the proper steps to understand the techniques. Table 4.4.2 summarises the categories, sub-categories, codes and meaningful units for the expectations of professional guidance support.

Table 4.4.2

Summary of codes and sub-categories for expectations of professional guidance supports

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Expectations of professional guidance supports	Knowledge related instructions	Steps in teaching	3	Guidelines to know about stages	Guidelines regarding how to go about the stages in teaching
		App operations	3	Guidance regarding AVAZ operations	Yes, I definitely need guidance, specifically for using AVAZ
		Methods and techniques	5	Guidelines for teaching methods and techniques	Yes, I need more guidelines to make him understand the concepts the teaching techniques I need to learn;
	Modes of guidance	Training Videos	11	Some videos that can be	I get any videos by seeing

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
				implemented at home	those, I will get an idea, and I can teach him better, and he can learn from the videos.
		Training programs	7	Training or demonstration videos	If I get a direct training or demonstration class, it will be
		Professional monitoring	2	Needs professional monitoring of my teaching	It would be helpful if anyone tells suggestions about my interaction
		Supportive videos	2	Videos of other children	I get some videos of children developing after using this communication mode; it will be useful for me.

Note. N is the number of respondents

4.4.2.1 Knowledge-related instructions. Parents have reported they need guidance and support for various reasons. One reason is to know about the steps in

teaching (20%; n=3). "I need to get some guidelines on how to teach exactly and the steps involved in PECS and specific techniques to teach him" (#P15). The second reason parents (20%; n=3) reported is that they need guidance to learn skills to operate apps and their settings on high-tech devices. I need to know how to use AVAZ and the various settings of the app in full detail. How to create various folders and add voice in it and some other information I need that I do not know much about the settings in it (#P9). The third reason most parents said is to gain skills in teaching methods and learning techniques. "To make him understand the concepts, I need to learn the teaching techniques" (#P5). "This is my first child, and I don't know much about the methods which speech therapists are teaching" (#P8).

4.4.2.1 Mode of guidance. Most parents (73%; n=11) said it would be helpful if I got any training videos to teach their child. "If I get videos of some teaching method, it will be really useful**.** (#P8); "I also want to see some videos of other parents of children using pecs so that I can get an idea on how the others perform with this PECS" (#P3). Many parents (46%; n=7) prefer direct training programs to gain knowledge and skills to work on AAC systems. "Training programs, if I get it, will be very useful to go about the steps in teaching" (#P7).

Two parents reported they need professional monitoring to understand their working methods and ways to modify them. "I need to monitor him and me so that I will know what I can teach him and what mistakes I am doing while teaching him using the AAC systems" (#P5). Some parents asked for videos of other children using and benefiting from any AAC communication systems to get motivation." If I get some videos of children who are developing after using this communication mode, it will be useful for me" (#P15).

4.4.3 Financial expectations

Parents of the current study answered variably from no financial expectations to the presence of economic expectations for the devices and AAC materials. Table 4.3.3 Summarises the categories, sub-categories, codes and meaningful units for financial expectations.

Table 4.3.3

Summary of codes and sub-categories for financial expectations

Category	Sub-categories	Codes	N	Meaningful unit	Example of a statement
Financial expectations	No expectations	Devoid expectations	8	No expectation from others	Not having any expectations from anyone
	Presence of financial expectations	Funds for fees	5	financial support for fees of therapy sessions	It will be helpful if we get some financial support for the fees of therapy sessions.
		Financial support for AAC materials & devices	5	Financial help to get devices	Any financial assistance in getting a device for him

Note. N is the number of respondents

4.4.3.1 No expectations. Half of the participants (*53%*; n=8) said they don't have any expectations of anything from any other people or government. One parent said, "I don't have any expectations from government and others" (#P3).

4.4.3.2 Presence of financial expectations. Parents reported they have financial expectations either in the form of fees or upgrading materials. Some parents (33%; n=5) said they need fees or funds for their therapy sessions. "It will be beneficial if I get some financial assistance, particularly in the educational setup. Some monthly payments if they are giving for the education or the therapy fees" (#P1). Others (33%; n=5) of the parents reported they needed funds to upgrade the devices. "If I get any financial assistance in getting a device for him, it will benefit his communication and overall development (#P5).

CHAPTER 5

DISCUSSION

The current study aimed to describe the acceptance, experience, expectations and challenges faced by the parents of children with ASD who use AAC as their communication intervention. This study's results have found culture-specific information on Indian parents' perspectives, usage and expectations. Also, this study understood the challenges parents of children with ASD faced while using low-tech and high-tech aided devices.

5.1 Acceptance

The results of the "Acceptance" domain were classified into four major categories: reasons for acceptance, family member's role in favour, child behaviours which aid in positive thoughts in the process of approval and the members who helped in the process of acceptance.

5.1.1 Reasons for acceptance

The parents who participated in the study reported that accepting AAC involves various steps. They are 'understanding child's limitations, the introduction of an AAC by experts, understanding the essence of communication despite the method, and acknowledging the child's improvements after the AAC. Park (2021) noted similar results in the previous study in which parents recognized their child's limitations, sought help from experts, understood that communication is essential and acknowledged the child's improvement. This latter study put forth these critical factors in accepting the AAC as a communication intervention.

One parent in the study reported having dissatisfaction with the speech therapy and hence opted for AAC. But after enrolling in the AAC communication system, parents said they had seen improvements in a child's overall communication and social behaviours. Similar results were seen in previous literature where parents initially expressed dissatisfaction with conventional speech therapy methods. Still, satisfaction has improved after finding positive improvements in social and language skills and reductions in challenging behaviours in children due to using AAC for children with complex communication needs (Park, 2020).

Parents took at least six months to accept the new intervention; hence, the present study included parents with minimum usage of AAC for six months. Previous works of literature supported the duration of the acceptance process. The result of a study showed that parents took a minimum of 6-12 months to adapt to and accept the new home therapy program for their children with complex communication (Piggot et al., 2002)

5.1.2 Family members' acceptance

The present study results have given various responses, from no acceptance to the presence of favour in the family. Some parents reported the emergence of acceptance in their family for using AAC systems. A similar number of participants have reported the presence of approval (26%) and no acceptance (26%). This result indicates the varied nature of the response from Indian families. In addition, parents reported negative perceptions and inadequate support from the family members. Similar disengagement in the family after enrolling into AAC was reported in previous studies (Doak, 2021), where people in the study denoted that AAC had a significantly limited acceptance in many families, and the parents encountered a wide range of

effective emotions such as self-blame and guilt.

Regarding the support from family members, participants' response varies from inadequate to presence of consent. Family members' support is an inevitable thing in the success of an intervention system. Inadequate support leads to a lack of divided responsibility toward the child. Previous studies which support these statements show that parents feel exhausted and overloaded when other family members are not supported (Moorcroft et al., 2021).

5.1.3 Behaviours that facilitated acceptance

Improvement in child's overall communication and social behaviour, increment in receptive, expressive language and cognitive skills are the behaviours reported by parents in accepting the AAC communication system. Parents said there is considerable improvement in the child's behaviour, which was supported by previous research. (Park, 2020; Serpentine et al., 2010). Specifically, parents of children with ASD who participated in the current study noted an increment in communication intent and the amount of interest the child showed in communicating. The communication intention increment after the introduction of AAC supported the previous finding showing similar results

5.1.4 Members who helped in acceptance

All the parents who participated in the study reported that the speech therapist helped immensely in the introduction and the AAC acceptance journey. Parents also said that their acceptance emerged from the counselling done by the professionals and the success stories of other children and parents who enrolled in AAc intervention systems. A parent said an experience shared by another parent helped in the acceptance. The effect of success stories and positive feedback from other family members on

acceptance was widely reported in many studies (Donato et al., 2014; Park, 2020). The latter studies highlighted that parents who experienced success in the AAC intervention introduce and share their experience with other parents of children with CCN.

5.2 Experiences

Experiences that are shared by parents widely enclose various pieces of information, including experiences with the devices, multiple environments and frequency of using AAC systems.

5.2.1 Modifications in the usage of AAC

Parents who participated in the study reported that they had done many modifications while engaging the child in AAC. It includes modifying the stimuli and teaching methods, increasing interaction at home and treating the child as typical. Many parents highlighted that they had customized the activities and other things in favour of the child to learn, and every child is unique, and tailor-made modifications are needed. Similar alterations in teaching methods and environmental changes have been acknowledged in previous studies (Nunes & Hanline, 2007).

Also, the study results showed parents use AAC systems consistently during meal time to interact with the child and give choices of the child's favourite items. Parents discussed their usage throughout the day when needed to indicate the effectiveness of using AAC as a communication option for their children.

5.2.2 Experience of using AAC outside the home

Many parents in the study reported that they are not using AAC systems outside the home for various reasons. One reason for abandoning the use of AAC systems outside the home environment is the portability issues. Parents said they need some

accessible devices outside the home to be free from portability issues. Park (2020) study results showed that parents have reported that carrying aids should not be an extra burden.

Parents also reported that they did not need picture cards outside the home because the child is already communicating through gestures, pointings and other facial and body movements. These results were similar to previous studies where they mentioned parents finding AAC as an additional demand if the child is already communicating using gestures or other actions (Bailey et al., 2006; Lindsay, 2010; Moorcroft et al., 2021).

5.3 Challenges

5.3.1 Challenges due to Associated Conditions

In the present study, parents reported that their child's behavioural issues, sensory and motor issues, and difficulty with specific cognitive components hinder the child's communication while using AAC. Parents said that these associated conditions are the most significant barrier to the child's learning and communication, which was supported by previous studies, where parents reported these issues as a reason for the abandonment of AAC systems (Moorcroft et al., 2021)

5.3.2 Environmental and Situational Barriers

Parents have reported their challenges based on the people, social acceptability, and situational barrier, for example, in school setups. Children using AAC face difficulty in school setups due to a lack of peer awareness. Parents reported that their children find difficulty in making friends in classrooms. Similar responses from parents were reported in another study, stating that it is tough to experience such a lack of

understanding from peers. It directly impacts their child's enthusiasm and motivation toward AAC (McNaughton et al., 2008b).

Parents have responded that negative perceptions and behaviours toward the child and his communication are a significant barrier to using AAC outside the home and in social events. Parents shared similar negative experiences in other studies (Goldbart & Marshall, 2009). One such inappropriate or uncommon behaviour reported by the parents in the current study was not allowing the peer group children to play with a child with ASD. These types of negative behaviours were reported in the previous literature (Papadopoulos, 2021).

5.3.3 Challenges faced by Parents related to Social stigmas

Parents of the current study reported that they had met a lot of stigmas and myths from the environment and family members related to their child's condition and the Augmentative and Alternative Communication(AAC). Parents reported that many times people around them think that the child has some broad mental issues and the child doesn't have the capabilities to speak or communicate, hindering the parents and the child's participation in society. Similar myths were reported in previous studies (Papadopoulos, 2021). The latter study showed identical experiences faced by mothers of children as they said that negative perceptions lead to social stigmas. It directly influences the parents and children to be ideal at home and prevents participation in social events.

Parents have reported that AAC devices or pictures will hinder the speech or verbal output because children will get addicted to the images and gadgets rather than trying to speak. Similar stigmas and myths related to AAC devices were reported in the previous studies (Parette & Scherer, 2004). The latter research denoted that stigmas

about AAC varied from people's perceptions and acceptability to device-related cosmetics and aesthetics. Parents of the current study also concluded that they have overcome the myths and stigmas and accepted the child and the way of communication.

5.3.4 Challenges faced by Parents related to Technological aspects

Parents incorporated in the present study reported a lack of knowledge and skills to operate AAC devices as their primary challenge. Regarding knowledge and abilities, parents reported similar issues regarding operational skills and learning through self-exploration of the devices. Parents said identical problems regarding the functional skills in a previous study (McNaughton et al., 2008), which showed that programming the AAC devices was the major challenge for parents. They learned to use them by reading the manuals and user-friendly videos. Another study reported similar issues that parents said while using AAC. They are difficulty finding the vocabulary in folders and other settings (Moorcroft et al., 2021)

The other two challenges highlighted were related to AAC technology's features concerning language variations and voice output quality. Parents incorporated in the previous study reported a similar concern (Moorcroft et al., 2021)

5.4 Expectations

5.4.1 Expectations on child's communication and independency

Expectations of a child's speech are the significant expectations reported by parents who participated in the study. Parents' concern about speech production was previously reported in many kinds of literature (Shin & Lee, 2016). Similar to previous studies (Park, 2020), parents in this study have difficulty changing their expectations of speech in children with ASD who were previously nonverbal. Also, parents reported

that they want their children to be independent to express their communication needs and choices to others.

5.4.2 Device-Related Expectations

Expectations regarding devices reported in the study were improvements in voice quality and language slang according to the child's needed. The parents who participated in other studies said similar expectations of the voice quality of AAC devices (Moorcroft et al., 2021; Park, 2020). Parents of the current research prefer to use customized devices for their children so they can quickly adapt and grasp things.

5.4.3 Expectations of Professional Guidelines

In the present study, parents of children with ASD have reported various reasons for needing a professional guide. They are: To gain knowledge and skills about teaching stages; skills for operating apps; teaching methods, and techniques. In addition to that, parents reported the mode of guidance they prefer. The results showed many parents need a practical training program or a demonstration class. Some parents said they need various training videos to learn about things mentioned earlier.

The need for a proper parent training program has been discussed in many previously done studies. Those studies insisted that parent programs helped them understand and accept AAC systems. Many western studies showed the abandonment of AAC and the misuse of the AAC system due to the lack of training programs for the parents and thus highlighted the need for good parent training programs (Park, 2020).

5.4.4 Financial Expectations

Regarding financial expectations, parents of the current study showed a wide range of responses from no expectations to the presence of economic expectations.

Parents' financial expectations have an indirect effect on parents' acceptance. Previous literature has reported similar to the current study results (Beukelman & Mirenda, 2013; Moorcroft et al., 2021). In the earlier studies, results have shown that parents' financial expectations of devices and materials and the feasibility of usage influences the parents' involvement in using AAC for their children.

The present study gave an idea about parents of children with ASD using AAC to communicate.

CHAPTER VI

SUMMARY AND CONCLUSIONS

Augmentative and Alternative Communication (AAC) is an emerging worldwide intervention field for the benefits of various communication disabilities. A wide range of children with Autism Spectrum Disorder was intervened using AAC systems and showed immense success in overall communication and social behaviours. Parents play an inevitable role in a child's decision-making, acceptance, and intervention process. Because India is a multicultural country, people have a wide range of perspectives on the intervention method and other communication systems. There is a shortage of detailed analyses about parents' views in the Indian scenario. Hence the present study aimed to determine the parent's acceptance, experience, challenges and expectancy factors of AAC intervention for children with an Autism Spectrum Disorder (ASD).

The present study was conducted using the qualitative content analysis method in three phases. Four significant domains were considered: acceptance, experience, expectations and challenges. Based on the selection criteria, data obtained from 15 mothers were selected for the study. The current study followed the "Directed Content Analysis method" (Hsieh & Shannon, 2005). The researchers conducted the study in three phases. Phase 1 involved the development of predefined categories from the literature review and formulating open-ended questions for the same. Phase 2 involved data collection using a semi-structured telephonic interview of 15 mothers of children with ASD using AAC for communication intervention for a minimum of 6 months. The time duration for each of the participants' data was scheduled for 20-40 minutes. Phase 3 involved the content analysis by converting the verbal output into graphic forms without losing any information. Familiarization of the data was done by reading the

data several times. Meaningful units related to the questions from the verbatim were selected. These meaningful units were assigned with specific codes. Each code was then further classified into sub-categories. The researcher did the frequency count for similar codes and descriptive statistical analysis to derive percentage scores. The predefined categories for each domain are depicted in the following flow chart.

6.1 Acceptance

The objective, parents' acceptance factors, include four major categories, and participants verbatim are coded under twenty-six sub-categories as shown in figure 6.1.

Figure 6.1

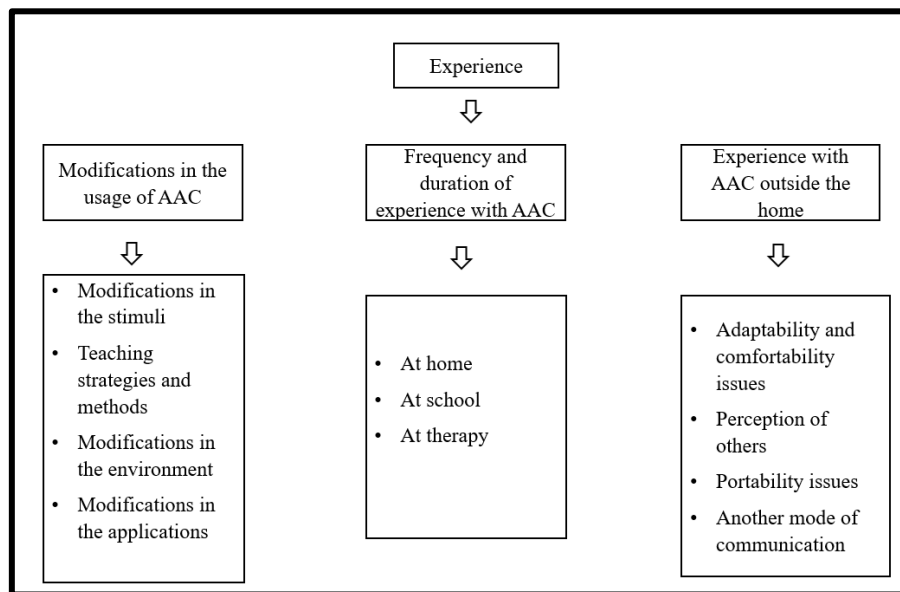*Categories and sub-categories of the domain Acceptance*
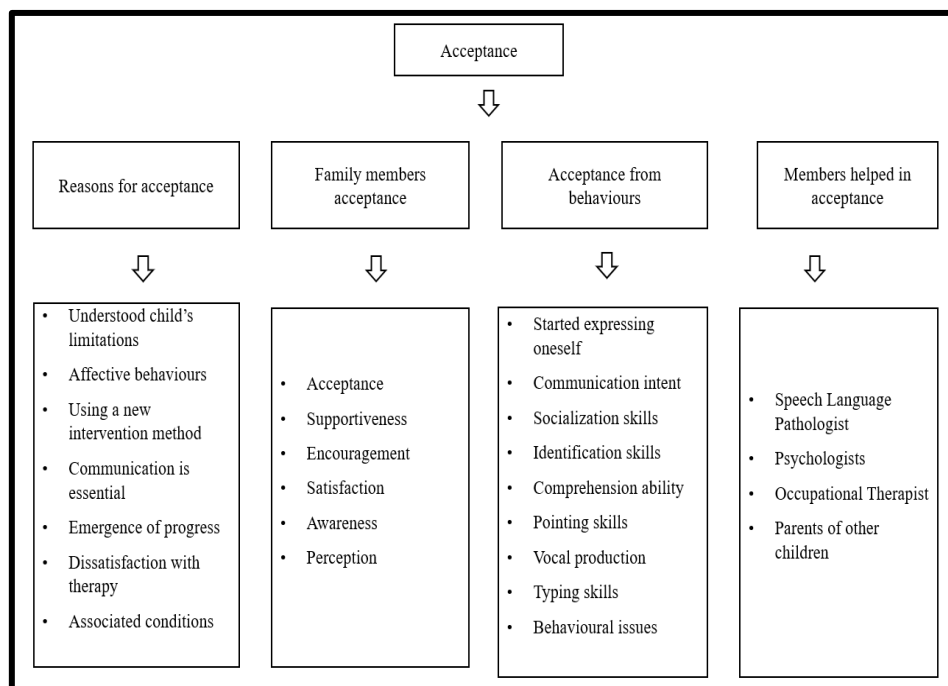
6.2 Experience

Parents' experience was addressed using three major categories: modifications, durations, frequency of usage, and venture outside the home. The flowchart for experience is depicted in figure 6.2.

Figure 6.2

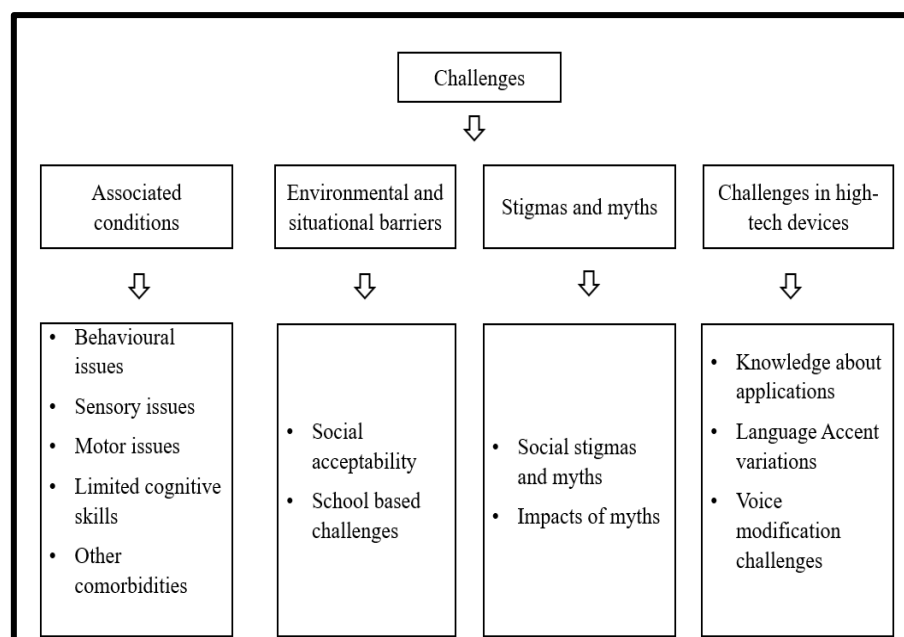*Categories and sub-categories of the domain Experience*

6.3 Challenges

Difficulties due to associated conditions, environmental barriers, stigmas and myths and the usage of high-tech devices are categorized under the domain challenges. The flow chart for challenges is depicted in figure 6.3.

Figure 6.3

*Categories and sub-categories of the domain Challenges*

6.4 Expectations

Expectations regarding a child's speech, up-gradation of devices, professional guidance and financial expectations are categorized under the domain expectation. The flow chart for the sub-categories is depicted in figure 6.4.

Figure 6.4

Categories and sub-categories of the domain Expectations
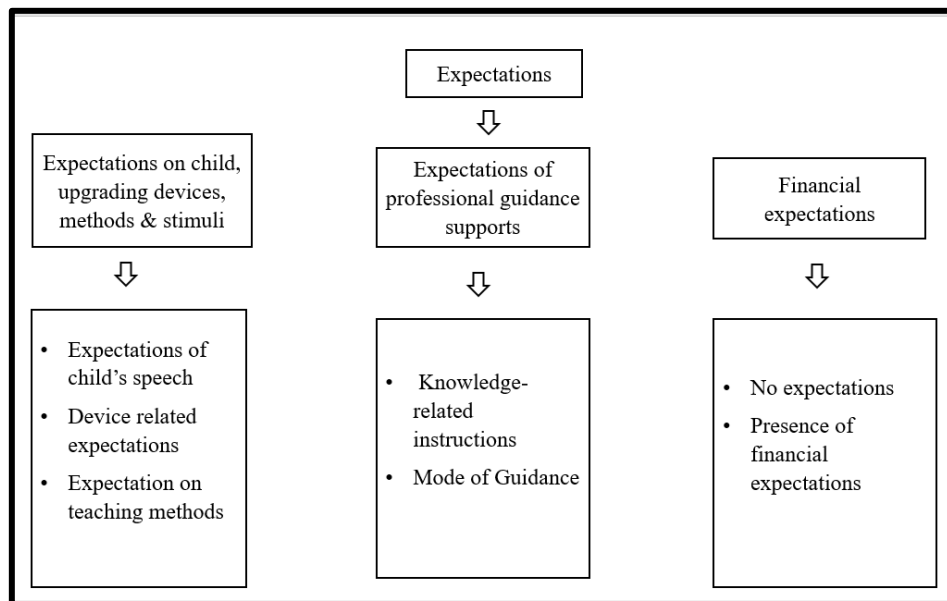
The present study concluded that parents of children with ASD have gone through many processes and stages in accepting AAC for their children as a communication intervention. Parents have encountered a wide range of experiences in using AAC inside and outside the home and still need social acceptance and responsibility to lead a successful future communication for their child. Challenges related to the associated conditions and high-tech devices indicate the need for teamwork in AAC rehabilitation services. Expectations put forth by the parents need to be taken into consideration for further development of AAC devices and research.

Limitations of the study

- The current study included less number of participants.

- An equal number of participants for high-tech and low-tech AAC users were not included.

- The study included most of the participants from the southern part of India.

Implications of the study

- The present study gives culture-specific information about the attitude, perspectives and expectations of parents who are using AAC, which helps maintain teamwork and professional relationships between the speech-language pathologist and the family members to improve the child's communication needs.

- Expectations and challenges reported by the parents related to aided AAC devices can be incorporated into the future development of AAC devices.

- Expectations of professional-parent training programs can be incorporated to develop teamwork and thereby reducing the functional and environmental limitations in the usage of AAC.

Future directions

- Further studies can include a large number of participants to generalize the perspectives among different geographical areas of India.

- Further studies can be carried out on comparing perspectives between parents using high-tech and low-tech aided AAC devices.

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APPENDIX A

OPEN-ENDED QUESTIONNAIRE

I.   ACCEPTANCE:

1. Specify the reasons or the causes that made you to / encourage/ motivate to accept AAC as a communication intervention for your child?

2. Elaborate about your family members thoughts, acceptance agreements towards using AAC as an intervention method.

3. Specify which behaviour of communication (e.g.: increase in communication, reduction in frustration, increase in social behaviour/ engagement with peer groups) exhibited by your child made you to accept this system for your child's intervention.

4. Elaborate on professionals and other members counselling helped you in considering AAC options as an intervention for your child. Specify who are all the members helped in the process of decision making.

II.   EXPERIENCE:

1. Elaborate about what all modifications (e.g.: giving more cues, repeating the words,) you are using in the way of teaching/ communication with the child during the usage of AAC intervention.

2. Specify how much and what all times the father, mother, grandparents and other family members and or teachers (if going to school) communicate with the child using the AAC method.

3. Elaborate on your experience when your child uses AAC for communication in any social events like functions, social gatherings

III.   EXPECTANCY

1. What all expectations (e.g.: upgrading your low tech AAC devices to high tech devices, expecting advancement in teaching methods, expecting others to use verbal communications along with the pointing) you are having related to the advancement in the devices?

2. Specify what all communications supports, guidelines, training you are expecting from the professional in order to increase the communication efficiency of your child.

3. Specify any expectations related to financial assistance in upgrading your child's AAC devices

IV.   CHALLENGES

1. What are the specific challenges faced by you and your child faced while using the AAC system for communication due to the associated problems (sensory issues, behavioural issues) of your child?

2. Any specific stigmas/ myths (child will be nonverbal throughout the life if in opt this) or any challenging factors (family members or others disagreements) that you faced that hinders you in using AAC communication at and out of your home environment.

3. What are situations and barriers (poor seating, poor Acceptance, lack of awareness) which act as a hindering factor for your child at home or school?

4. What are the specific challenges you faced in using low tech/high tech AAC devices while assisting the child to communicate using the same?

APPENDIX B

CONSENT FORM

Dissertation topic: Parent's acceptance, experience, challenges and expectancy factors of AAC intervention for children with Autism Spectrum Disorder

 Information to the participants:

I. Ms. Swathi. C, II MSC, studying at AIISH, Mysore is pursuing my dissertation titled "**Parents' acceptance, experience, challenges and expectancy factors of AAC intervention for children with Autism Spectrum Disorder**". This dissertation is done under the guidance of Dr. Reuben Thomas Varghese. Scientist-B. Dept. of Speech-Language Sciences. AIISH. Mysore. Investigator evaluates the perception of parents of regarding the Augmentative and Alternative communication intervention for their children with Autism Spectrum Disorder. Open ended interview will be done and the recording of the data from the parents will be done for further analysis. The procedure involved in the study is purely non-invasive and the duration of the procedure is about 30 minutes. There is also no risk involved to the participants. Further, I also assure you that the findings obtained from this study will be kept confidential. There is no influence or pressure of any kind by the research scholar. Your cooperation in the study will go a long way in helping us in understanding the perspectives, Acceptance, challenges and expectations of parents of children with ASD in Indian context.

Informed Consent

I have been informed about the aims, objectives, and procedure of the study. I understand that I have a right to refuse my participation as a participant or withdrawn my consent at any time.

I _____, undersigned, give my consent to be a participant in this investigation/study.

Signature of the participant   Signature of the investigator

Date:

APPENDIX C

A SAMPLE OF THE CODING METHOD

I.   ACCEPTANCE

1. Specify the reasons or the causes that made you to / encourage/motivated to accept AAC as a communication intervention for your child?

He is totally nonverbal from birth; he starts understanding things gradually but doesn't know how to tell that. So, he was very frustrated and angry when we didn't understand what he wants. So I want any option for him to communicate with me so I started using communication boards and AVAZ. Initially, I started with the communication board and later with AVAZ.

Meaningful units	Codes	Subcategories	Categories
Nonverbal from birth; Starts understanding things gradually but doesn't know how to tell that.	Non-verbal	Mode of communication	
He was very frustrated & angry when we didn't understand what he wants.	Frustration	Affective behaviours	**Reasons for Acceptance**
Want any option for him to communicate with me	Communicate in any way ; Need of communication	Realized the communication importance	

2. Elaborate about your family members' thoughts, acceptance agreements towards using AAC as an intervention method.

Family members <u>accepted his way of communication</u> since we are a nuclear family with me, my husband and my younger son are there in the home. We treat <u>both of them equally by interacting with them in all family times and events.</u>

Meaningful units	Codes	Subcategories	Categories
Family members accepted his way of communication since we are a nuclear family.	The nuclear family accepted his communication	Presence of Acceptance	**Family members' thoughts and acceptance**
We treat both of them equally by interacting them in all family times and events.	Treating equally	Equally treated	

3. **Specify which behavior of communication (e.g.: increase in communication, reduction in frustration, increase in social behavior/ engagement with peer groups) exhibited by your child made you to accept this system for your child's intervention**.

He will <u>show what he wants</u>, for example, he will come to the kitchen with the dosa picture when he wants dosa along with that he will point the dosa pan to me. <u>He understands my commands</u> and he starts doing that correctly. He <u>started showing his</u> emotions through pictures like example he will show whether he is happy or sad or angry. He will <u>point to the things also directly</u> when it is present.

Meaningful units	Codes	Subcategories	Categories
Will show what he wants e.g: pointing to dosa and pan	Show what he wants	Started expressing oneself	
Started showing emotions through pictures(happy or sad or angry)	Showing emotions through pictures		**Acceptance from behaviours**
Understands my commands and he starts doing that correctly	Understanding commands	Comprehension ability	
Point to the things also directly when it is present.	Pointing to the object or pictures	Pointing skills	

4. **Elaborate on professionals and other members counselling helped you in considering AAC options as an intervention for your child. Specify who are all the members helped in the process of decision making.**

Speech-language pathologists have helped me a lot to understand the PECS and how to use and all. There are teachers in the school who also helped him to do things at school

Meaningful units	Codes	Subcategories	Categories
Speech and language pathologists helped to understand	SLP counselling	Speech-language Pathologists	**Professionals and others helped in acceptance**
Teachers in the school, who also helped him to do things at school	Teachers helped in school.	Special educators	

II.   EXPERIENCE:

1. Elaborate about what all modifications (e.g.: giving more cues, repeating the words,) you are using in the way of teaching/ communication with the child during the usage of AAC intervention.

He will imitate all the actions which we are doing so I will repeat activities for him to do and I will teach him many times till he understands. I will usually treat him the same as my other child. I will always engage him in normal routine activities. I will give him specific household tasks, such as putting the trash bag out, doing some vegetable cutting, and making him engage in daily activities whenever possible.

Meaningful units	Codes	Subcategories	Categories
Will always engage him in normal routine activity I will give him certain house hold tasks such as putting the trash bag out, doing some vegetable cutting;	Interactions in the home environment	Modifications in environments	
make him engage in daily activities whenever possible.			**Modifications in the usage of AAC**
Will usually treat him the same as my other child.	Treating this child as same as other children		
Repeat activities and teach him many times	Adequate repetitions and response time	Teaching strategies and methods	

2. **Specify how much time and what all times the father, mother, grandparents and other family members and or teachers (if going to school) communicate with the child using AAC method**.

At home throughout the day, we will be using it whenever needed. whoever is communicating with him we will use the pictures to make him express. Writing and other activities he will be doing along with this in school he will be using for around 1-2 hours. At speech therapy weekly twice for about 40 minutes.

Meaningful units	Codes	Subcategories	Categories
Throughout the day, when needed.	At the time of need	At home	
At school, he will be using this along with other reading and writing activities for about 1-2 hours.	Other activities and PECS	At school	**Frequency and duration of experience with AAC**
At speech therapy weekly twice for about 40 minutes	Therapy session	At Therapy	

3. **Elaborate on your experience, when your child uses AAC for communication in any social events like functions, social gatherings**

No, during any functions and social events we will not be taking to the place, that time he will be communicating with me through pointing and gestures like if he wants food items he will come and show me that food.

Meaningful units	Codes	Subcategories	Categories
He will be communicating with me through pointing	Communicate using gestures	Use of another mode of communication	**Reasons for not experiencing outside the home**

Meaningful units	Codes	Subcategories	Categories
and gestures (e.g. pointing to the food)			

III.   CHALLENGES

1. What are the specific challenges faced by you and your child faced while using the AAC system for communication due to the associated problems (sensory issues, behavioural issues) of your child?

He has more sensory issues, he doesn't like little loud sounds also he will get irritated and hence it is very difficult to make him do an activity, initially he will tear and throw the pictures very often. Also, he will easily get distracted and irritated and he will quarrelling and showing temper tantrums for simple things.

Meaningful units	Codes	Subcategories	Categories
Initially, he will tear and throw the pictures very often; irritated and he will be quarrelling and showing temper tantrums for simple things.	Temper tantrums Lack of attention; Distractibility;	Behavioural issues	**Challenges due to associated problems**
Has more sensory issues, he doesn't like little loud sounds	Sensory issues	Sensory issues	

2. **What are situations and barriers (poor seating, poor acceptance, lack of awareness) which act as a hindering factor for your child at home or school?**

People's specifically <u>children nearby and relatives' children behave with him in a different way in the presence and absence of me.</u> If am present they will be good and if am not there they will irritate him and they will do things that he doesn't like.

Meaningful units	Codes	Subcategories	Categories
Relatives' children behave with him in a different way in his presence and absence of me.	Uncommon and ill-judged behaviours	Social acceptability	
If am present they will be good and if am not there they will irritate him and they will do things that he doesn't like.	Uncommon and ill-judged behaviours		**Environmental and situational barriers**

3. **Any specific stigmas/ myths (child will be nonverbal throughout the life if in opt this) or any challenging factors (family members or others disagreements) that you faced that hinders you in using AAC communication at and out of your home environment.**

A Lot of <u>challenges friend and relatives were there since this time.</u> They will be telling that my son in <u>mentally retarded and hence he won't do and he don't know.</u> Go for some <u>medications</u> and other things rather than using colour pictures. They usually say that <u>color pictures are for younger children</u>, he is old, and hence he needs to speak and do the work independently.

Meaningful units	Codes	Subcategories	Categories
Will be telling that my son in mentally retarded and hence he won't do and he don't know.	Lack of awareness & poor perceptions	Poor social acceptability	
Go for some medications and other things rather that using color pictures and all	Medications needed than speech therapy	Social stigmas and myths	**Stigmas and myths**
Tells that color pictures are for very younger children, he is old.	Pictures are for younger kids		

4. **What are the specific challenges you faced in using low tech/high tech AAC devices while assisting the child to communicate using the same?**

The voice output from the AVAZ seems to be little robotic and he couldn't understand the language slang the system produces. It is more robotic and system voice and different slang than what we are speaking so it's very difficult for him to understand. The pronunciation of the language is entirely different from the normal speaking words. Sometimes it is very difficult to understand for me itself. So for special children it will be even more difficult.

Meaningful units	Codes	Subcategories	Categories
Voice output from the AVAZ seems to be little robotic and he couldn't understand	Robotic voice – difficult to understand	Voice modification challenges	**Challenges facing during high-tech device usage**
Pronunciation of the language is entirely different from the normal speaking words	Colloquial language changes	Language slang variations	

IV.   EXPECTANCY

1. **What all expectations (e.g.: upgrading your low tech AAC devices to high tech devices, expecting advancement in teaching methods, expecting others to use verbal communications along with the pointing) you are having related to the advancement in the devices?**

I want him to be independent like he needs to express himself and he needs to do things on his own for him. Options are very less in the communication board and hence if I am upgrading to an apps.The voice output from the AVAZ seems to be a little robotic , system voice and different slang than what we are speaking so it's very difficult for him to understand. So, if any apps where my voice or familiar voice we can record and use that I want him to try, I will get an idea about how he is understanding.

Meaningful units	Codes	Subcategories	Categories
Want him to be independent, like he need to express	Expectation on independence and expression	Expectations of child's communication	**Expectations on the child,**

Meaningful units	Codes	Subcategories	Categories
himself and he need to do things on his own for him.			**devices, methods or stimuli**
Options are very less in comm board and hence if I am upgrading to an apps If any apps where my voice or familiar voice we can record Different slang than what we are speaking so it's very difficult for him to understand	Less options in comm board compared to apps Want to add customized voice Wants some changes in language slang	Presence of device-related expectations	**Expectations on devices and methods**

2. **Specify what all communications supports, guidelines, training you are expecting from the professional in order to increase the communication efficiency of your child**

   Yes, definitely I need more guidelines and support and teaching from professionals to use apps and devices. To make him understand the concepts the teaching techniques I need to learn. Also, I need to monitor him and me so that I will know what I can teach him and what mistakes I am doing while teaching him using the AAC systems. I want to know like what all should I do and what all effects I will get after using that. If I teach him in a different way what all improvements will be seeing in that, I need to know.

Meaningful units	Codes	Subcategories	Categories
Yes, definitely I need more guidelines and support and teaching from professionals	App operations	Knowledge related instructions	**Expectations of professional guidance supports**
To make him understand the concepts the teaching techniques I need to learn;	Methods and techniques		
I need to monitor him as well as me to find what mistakes am I doing while teaching him using the AAC	Need professional monitoring my teaching.	Professional monitoring	

3. **Specify any expectations related to financial assistances in upgrading your child's AAC devices**

Yes, communication devices with some advancement in that will be more in cost. So, if I get any financial assistances in getting a device for him it will be very useful for his communication and overall development.

Meaningful units	Codes	Sub categories	Categories
Any financial assistances in getting a device for him	Financial support for AAC materials & devices	Presence of financial expectations	Financial assistances