



Research Paper

The Resilience and Lived Experiences of the Parents of Children With Autism in India: A Mixed-method Study



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ABSTRACT

Background and Objectives: Families dealing with autism spectrum disorder (ASD) children try to adapt with different strategies. 1) To assess the resilience of parents dealing with children having ASD and its associated factors. 2) To explore the perspective and strategies of families dealing with children having ASD

Methods: This was a mixed-methods study done over a period of 3 months among parents having children diagnosed with ASD; undergoing institutional therapy for more than 6 months in duration. Data collection was done using the PREQ questionnaire and key informant interviews (KII). Informed consent was taken prior to each interview and audio recordings. Relevant tests of significance and deductive analysis followed.

Results: There was an equal divide observed between the low (50%) and high resilience (50%) groups. Binary logistic regression showed that the upper socio-economic class showed higher odds of better resilience (OR=4.038, 95% CI, 2.857%, 4.894%) as compared to the lower socio-economic class, and those with higher levels of education showed better resilience (OR=9.903, 95% CI, 2.502%, 3.483% than the lesser educated. KII explored different perspectives on personal experiences, concerns, challenges, attitudes, etc. where both perspectives such as benefits and hardships were addressed on an individual as well as a family basis, respectively

Conclusion: Education and socio-economic backgrounds played a role in mending the resilience and other active measures such as peer support mechanisms and self-coping strategies also influenced the attitude and improved determination of parents dealing with children having ASD.

Keywords: Autism spectrum disorder (ASD), Parents, Resilience



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↑ *What is “already known” in this topic:*

The parents of children with autism spectrum disorder are expected to experience social challenges more than physical concerns, which thereby reflects on their self-esteem, motivation for daily activities or nurturing resilience and various adaptive behaviors.

→ *What this article adds:*

Half of the parents of children with autism in India have low resilience. The educational level, occupation, and socio-economic status of these parents can predict their resilience. Peer support and coping strategies influenced the attitude of these parents.

Introduction

Autism spectrum disorder (ASD) is a range of developmental disorders which is primarily characterized by impairments in social, communication and cognitive skills along with restricted and repetitive patterns of behaviour, interests, or activities [1]. Resilience is a dynamic process at any level of functioning that encompasses the capacity by which these individuals adapt positively following adversity [1, 2].

The parents of children having ASD are expected to experience social challenges more than physical concerns, which thereby reflects on their self-esteem, motivation for daily activities or nurturing resilience and various adaptive behaviors doesn't come with ease, thereby measures such as continuous reinforcement, peer support initiatives and self-healing measures contribute as methods of consideration in view of individual level of mental health and consequently the bearing of their child's care and progress [1].

The quality of life, in case of parents with special children, is greatly a focus of concern as it relies on multiple aspects which all ultimately revolves around the care of the child; the support system in terms of family, relations, finances, health, etc are various areas which contribute towards the greater question of parental resilience and self-help measures [2].

Thereby, to address the need for this study, families of children with ASD experience an appreciable amount of stress relative to other families. Reasons begin with limited awareness to misconceptions and may even result in hesitant and non-supportive decisions at an individual, familial or community level. To date, little research has examined the relationship between social support, fam-

ily resilience and parental stress in families with a child diagnosed with ASD, thereby it was important and relevant to explore the perspectives from a caregiver's point of view towards dealing with such children so that we may be able to plan initiatives to improve care and facilitate well-being of both, the child as well as the parent or caregiver, respectively. This study mainly aimed at two aspects, being:

1) To assess the resilience of parents dealing with children having ASD and its associated factors; 2) To explore the perspective and strategies of families dealing with children having ASD.

Materials and Methods

This was a mixed-methods study done over a period of 3 months (April 2023 to July 2023) among parents having children <6 years of age who were diagnosed with ASD and undergoing institutional therapy for >6 months in duration. The study setting was at [National Institute for Empowerment of Persons with Multiple Disabilities \(NIEPMD\)](#), Chennai which is run under the [Ministry of Social Justice and Empowerment, Government of India](#). For the quantitative part of the study, a cross sectional study methodology was followed and purposive type of sampling was done. Sample size was calculated using the [Equation 1](#):

$$1. z^2pq/d^2$$

, where $p=0.23$, Poovathinal et al. (2016) [3]; $q=99.7$ and $d=3(d^2=9)$ Therefore, calculated sample size=9.78, Rounded off to 10 (estimated sample size). The quantitative data was collected using the parental resilience elements questionnaire (PREQ) [4] which is a self-reported scale that consists of 16 questions assessed by a Likert scoring and graded from a score of 0 to 4. It analyses

the outcome of parental resilience in the context of child welfare mainly looking at areas such as coping and problem-solving, self-efficacy, social support and meaningfulness under the broad umbrella of 3 sections, namely: Knowledge of child's characteristics, perceived social supports and positive perception of parenting. The total score for the PREQ was taken as the sum of all scores for the 3 factors and the mean value was noted as the cut off, below which it was considered as low resilience and above which it was taken as high resilience, respectively. The qualitative data was collected in the form of key informant interviews (KII) using a topic guide, with each interview lasting for 15-20 minutes, respectively. KIIs were taken from parents, special education teachers, paediatrician/developmental doctor, clinical psychologists, occupational therapists, speech/language pathologists and early interventionists. Informed consent was taken prior to each interview and audio recordings.

Data analysis was done using Microsoft Excel and SPSS software, version 21 using appropriate statistical tests of significance interpreted using tables and figures for the quantitative part and for the qualitative part, after using the narrative data for a grounded theory approach, a deductive analysis was done with the help of themes which were then further elaborated.

Results

Quantitative data: The total number of study participants were 10 and the mean age was 39 ± 10.5 years. The sociodemographic profile is given under Table 1. Certain questions in specific to the child's condition were also asked (Table 2) where it was found that among the total 10 cases, 6 of them were diagnosed before the age of 3 years and majority (9 out of 10) did not have any significant family history with respect to their condition. The outcome variable, parental resilience, was calculated using the PREQ scoring and an equal divide was observed between the low and high resilience group among our study respondents (Table 3). A further analysis was done in the form of bivariate analysis and logistic regression, (as shown under Tables 3, 4 and 5) and it was found that those who were gainfully employed had a higher odd of better resilience (OR:2.645, 95% CI, 0.465%, 3.126%) as compared to those who were homemakers. Similarly, those who were among the upper socio-economic class showed higher odds of better resilience (OR:4.038, 95% CI, 2.857%, 4.894%) as compared to those belonging to the lower socio-economic class and those who with higher levels of education had higher odds of better resilience (OR:9.903, 95% CI, 2.502%, 3.483%) as compared to those who were less educated, respectively.

Qualitative data

The qualitative data was done in the form of KIIs and the respondents included-parents, special education teachers, paediatrician/developmental doctor, clinical psychologists, occupational therapists, speech/language pathologists and early interventionists. Each interview was recorded with consent and a deductive analysis was done for the same, following which suitable themes were structured as listed below:

1) Events and elements of experience; 2) Concerns and criticality; 3) Being and beyond; 4) Fine line between faith and fate; 5) Pave the way.

Most of the interviews had one view in common, being "despite ASD being the common connecting diagnosis, the presentation of every child affected with the same varies from one another. It is indeed unique in features with only maybe a few common signs as such". The longest interview time were spent with the developmental paediatrician and the speech therapist, both who highlighted the importance of follow up as a big mandate for such children undergoing therapy.

Theme 1: Events and elements of experience

"I have been in this field of disability over 30 years and probably have seen over 5000 cases of ASD. The patterns are increasing as compared to the previous years and this could be taken a good thing (considering more awareness) as well as a difficult thing (considering the rise in number of cases)" (KII 1, developmental paediatrician). The prevalence of ASD is higher today, both globally as well as nationally; with more preponderance among male as compared to females. The rising number of cases could not only be due to a multi-factorial reason, but it could also be due to the increased awareness in present times about such developmental conditions.

"As compared to earlier times, we see parents bring their children to us as early as 8 to 9 months of age to 2 years and above; which is unusual as far as the previous times were considered. But I feel it is a good thing that they come to us early, as it helps us detect the problem earlier and intervene sooner thereby giving the child more time for therapy and rehabilitation to his/her highest function of ability" (KII 2, early interventionist).

"Earlier, not many knew about Autism. So, finding about this condition during childhood was rare. And this is why initially, Autism related to a form of childhood schizophrenia. But now due to better awareness and

Table 1. Socio-demographic profile of study participants (n=10)

Variables	Sub-category	No. (%)	Mean±SD
Age (y)	≤40	7(70)	
Mean age (y)	>40	3(30)	39±10.5
Gender	Male	1(10)	
	Female	9(90)	
Commitment	Married	6(60)	
	Separated	1(10)	
	Widow/Widower	3(30)	
Highest level of education	Illiterate	1(10)	
	Middle school	1(10)	
	High school	1(10)	
	Graduate	3(30)	
Occupation	Post graduate	4(40)	
	Homemaker	8(80)	
	Gainfully employed	2(20)	
Socio-economic classification (modified BG Prasad 2021)	Lower class	3(30)	
	Upper class	7(70)	
H/o persisting stress	Yes	9(90)	
	No	1(10)	

more studies, it has been framed under the spectrum of ASD and a multi-disciplinary approach has been sought as a part of therapy” (KII 3, clinical psychologist).

Mostly the interview respondents gave a comparative response to the question pertaining to increased number of ASD cases. They related it largely to the fact of “better awareness” which thereby led to “early detection or suspicion”.

Theme 2: Concerns and criticality

“One of the prime concerns from my side, that which I have repetitively encountered while dealing with children having ASD is that, they do not have any intent to communicate. Thereby it makes it very difficult to break that limitation and try training them for basic speech initiations” (KII 4, speech/language pathologist).

Mostly, the areas concerned with ASD children include-cognition, speech and social skills. It is these which make the parents notice the deviant behaviour and bring to the notice of the therapist.

“When parents ask us the questions, “Will my child get cured?” It gets very difficult to explain about the intensity of the condition. Also, to prepare a parent for such long-term measures, it is often worrying” (KII 2, Early interventionist).

The scenario of dealing with ASD children, both from the family side as well as the therapist side, gets taxing after a while due to the requirement of consistent, long-term measures for approach in different aspects. Not many would be willing to hold on their strength for that long a time which makes them give up and neglect beyond a certain period.

Table 2. Results pertaining to child's condition (ASD) (n=10)

Variables	Sub-category	No. (%)
Age of child (y)	<3	2(20)
	≥3	8(80)
Age at which child was diagnosed with ASD (y)	1-3	6(60)
	≥3	4(40)
Does the child have siblings?	Yes	5(50)
	No	5(50)
Family history of ASD or other DD	Yes	1(10)
	No	9(90)
Duration of therapy for ASD (y)	<1	3(30)
	≥1	7(70)

“How long will they have to be dependent? What will happen to them after I die? Will all these therapy sessions help them live alone tomorrow?” (KII 5, parent of child with ASD).

Most of the parents who were accompanying the children for therapy were either mothers or grand-parents. Very few fathers were found to be present with the child for therapy. This could be due to various reasons such as –earning member of the family, work needs, abandonment, and more.

With respect to this, when asked about the “support system” a parent replied:

“We were both working when we got married. Once I had a child, I took a break. But he continued pursuing his work. Now that we know our child is not well, I have completely resigned from work and dedicated my whole time for my child. I do not see that effort from my husband's side. Is it wrong to expect him to try as well?” (KII 5a, parent of ASD child).

However, to the above response, another parent had a different perspective, which was as follows:

“My in-laws have disowned me and my child from the moment they knew he is not a normal child. They blame it on me and my pregnancy care. My husband does not seem to object their opinions, but I do not feel wrong on his part. They are his support system just like I am for my child. I can raise my child alone. This is my destiny; I am accepting it. If my husband does not want to be a part of this, I will not force him. At least he is earning on behalf of us and helping me take care of my child. At this point, I do not think I should expect any further from anyone. That is life” (KII 5b, parent of ASD child).

The shaping of resilience was differently structured for different individuals. Some of them had a good support system, while the rest were going forward with the best they could. Some of them reported gaps in their care, questioned themselves; while some of them resorted to accepting their circumstances and pushing through.

Theme 3: Being and beyond

“Some children might not be good in academics, but they might be gifted otherwise. Like for example, we have a child in our class who is very good at art. He can

Table 3. Percentage distribution of resilience assessment (n=10)

PREQ Outcome	No. (%)
Low resilience	5(50)
High resilience	5(50)

Table 4. Results of bivariate analysis (n=10)

Variables	Sub-category	Resilience		P*
		Low	High	
Age (y) Mean age (39±10.5)	≤40	3	4	0.490
	>40	2	1	
Gender	Male	0	1	0.280
	Female	5	4	
Commitment	Married	2	4	0.368
	Single	1	0	
Highest level of education	Widow/widower	2	1	0.036
	Illiterate	1	0	
	Middle school	1	0	
	High school	1	0	
	Graduate	1	2	
Occupation	Post graduate	1	3	0.014
	Homemaker	5	3	
Socio-economic classification (modified BG Prasad 2021)	Gainfully employed	0	2	0.038
	Lower class	3	0	
H/o persisting stress	Upper class	2	5	0.294
	Yes	5	1	
	No	0	4	

*Chi square test.

Table 5. Results showing analysis of logistic regression (n=10)

Variables	Sub-category	Resilience		
		Odd's Ratio	95% CI	P
Occupation	Homemaker	1	-	-
	Gainfully employed	2.645	0.465-3.126	0.07
Socio-economic class	Lower class	1	-	-
	Upper class	4.038	2.857-4.894	0.019
Highest level of education	Illiterate	1	-	-
	Middle school	3.241	1.783-3.567	0.561
	High school	2.693	1.980-2.899	0.326
	Graduate	2.866	2.688-3.574	0.034
	Post graduate	2.903	2.502-3.483	0.018

colour very well and he is very skilled in clay modelling. So, we have counselled his parents to train him on such aspects instead of forcing him to study. He is channelled in a unique way, so it is up to us to shape it accordingly” (KII 6, special educator).

“Like us, some parents have tried putting their child in inclusive schools, but have come back reporting that other parents of children attending the same school complain that it is difficult for their child to be in the same class as a special child. These children may make inappropriate sounds or show difficulty in sitting tolerance. All these might also disturb the teacher while trying to guide a class in unison. So not all schools may be oriented enough to handle varied children, but it is up to the parents to be counselled about the same and shift to easier and less burdensome options in such cases” (KII 5, parent of ASD child).

The biggest challenge arises when our expectations do not match with the outcome. The acceptance is yet another worry. Most of all, along with child therapy, parent training programmes are also required which is incorporated in form of counselling, awareness programmes, peer interaction and follow up visits.

“Very often, we see ASD children struggle with certain sensory issues. Like they avoid a particular texture, or they engage constantly in a specific activity. Such behaviour requires dedicated sensory integration therapy. Most parents do not know about this, so we need to re-assure them and help them sustain what we teach to be repeated at home regularly” (KII 7, occupational therapist).

The therapist spends probably 30 to 45 minutes per child for a maximum duration of 3 days a week. The remaining days, the child is at home with their care-takers. So, it is necessary for the therapy to be sustained at home, as well. This is why, during therapy, it is good if the parents or care-takers also spend time observing and facilitating the session. This makes them more prepared and confident, rather than being dependent on an external source of aid for the same.

Theme 4: Fine line between faith and fate

“I can recall some parents who bring their child with so much of self-blame and guilt. They would have undergone stressful situations during pregnancy that they feel blamed when the child is differently-abled. But I tell them all, the best way to handle this is first to accept and then to try best to avoid further stress. Often children mimic our emotions, so we should try staying happy and

strong so that it will help them reflect the same” (KII 1, developmental paediatrician).

In our quantitative findings, we found that 9 out of the 10 respondents reported to have history of stress during pregnancy and when probed further, they reported stress in terms of familial issues, financial burdens, and other inter-personal relationship issues. Before we could counsel, most of them are already blaming themselves and feeling accused for the child’s outcome. In many a case, it is true that stress plays a big role in affecting the growth and development of a child. However, this does not act as a sole reason for a healthy development. There are several other reasons contributing to the child’s well-being, which includes the immediate environment, peer attention, care, good nourishment, etc.

“Initially I used to feel bad when my in-laws blame me for my child’s state, but now after coming here, after meeting so many other mothers, I know it is not my fault” (KII 5c, parent of ASD child).

“I was not keeping too well during my pregnancy time. I had stress, both physically as well as emotionally. But what made me feel helpless is when my family told me to bear it all. Now even if I have trouble, I know I am alone and I will have to deal with it” (KII 5b, parent of ASD child).

Antenatal stress was a common finding among most mothers, however the reason and response to the same varied. While some mothers felt helpless, most of them developed a sense of individuality and courage to work a way around their situation. Not all had a supportive environment, but with the little support they have, they felt adequate.

In an environment such as a common institute for therapy, the mothers and care givers find solace in each other’s company. They know each other’s story and they often step up in terms of care and support for them and the children. Every time a new parent comes, this attitude helps spread positivity to some extent and thereby helps in accepting their situation as their new normal and coping with the same.

Them 5: Pave the way

“We are worried when he does not attempt to communicate fluently. We fear that if something harmful happens to him, we will never know. More than anything, we want our child to feel safe” (KII 5, parent of ASD child).

“While communication is a larger picture, basic comprehension, and intent to communicate is rather a bigger concern here. So, we try all methods, be it prompting, picture cues, whatever it maybe, if it is reflecting well on the child, we encourage the parents to follow the same at home. Because if tomorrow he/ she must go to school even, they must be able to at least attempt to understand and participate in the activities” (KII 4, speech/language pathologist).

ASD children take time to communicate, as they have difficulty in comprehension. There are also high functioning cases of the ASD spectrum who speak but may sound monotonous or robotic. Either way, the fluency and pattern of speech is prioritized for training for basic social skills development and facilitation of his/her activities of daily living.

While training at the therapy centres, some therapists even help them get familiar with sound producing objects as assisted devices, for example- whistle hanging on their id cards, anklets, etc.

“Another common sequel of having such children is that, if there is another sibling (who is a normal child), chances are there to neglect this child as the parents are more worried about the special child. In such cases, the neglected other sibling either harms the affected child or they become a little emotionally detached and try to become independent sooner”(KII 3, clinical psychologist).

The environmental balance is a vital concern for families dealing with special children. It takes time for the families themselves to accept and adapt to their living changes after the birth and growing of a child with ASD, thereby orienting the immediate surrounding and people to the same will take more time eventually.

“During one of my workshops with parents of children having developmental delays, I had a particular session where each of them had to mention one difficulty or obstacle they are hurdling with on a constant basis (with respect to their child). Each time a participating parent gave a response, I found all the other parents nodding their heads and agreeing to that. Which means, all of them have encountered each of those obstacles at some point of time” (KII 3, clinical psychologist).

Activities of daily living, such as, brushing/bathing/toilet training, etc. are small events that take time to get accustomed to when it comes to such children. They may take longer time to adapt as compared to normal children

of their age. However, with continuous training and reinforcement, we can make this achievable as well.

Each case of ASD varies in presentation and adaptation time; therefore, it is best to have a regular follow up if a routine institutional therapy is not possible.

Discussion

Raising a child with ASD can get overwhelming beyond a point for the caretakers, parents and families and often, the birth of a child with ASD may alter the family dynamics due to challenging interactions between the child and parents requiring sheer effort leading to the emotional burden which may further lead to various forms of outcomes in terms of mental health issues, frustration, guilt, exhaustion and compromised effort sustain [5].

In a recent study done by Raju et al. (2023), the quality of life was compared between parents of typically normal children and parents of children with ASD; although parents from different psycho-social backgrounds showed different outcomes, few contributing factors towards a better quality of life included general health status, social relationships and immediate environmental domains [5]. In our study, the factors which helped in better resilience were observed to be higher socio-economic class, higher levels of education and employment status. Although in general our outcome showed a 50-50 divide between those parents with low resilience and those with high resilience, on further analysis we were able to see what factors significantly contributed towards the outcome status of resilience, respectively.

In a previously done study by Amr et al in 2012, the results showed that the mothers who were homemakers detected their child to have ASD sooner than the working mothers, but the same study also justifies the pattern of raising children could be the reason in this case as different countries have different norms of child care [6]. In our study, majority of the respondents were females (90%) and thereby, we were able to get only one perspective of child care and reasons associated with the same. In our qualitative follow up, we did address these gaps, where some parents reported that being a home-maker helped them spend more time with their child, thereby detecting signs earlier; however, those parents who were working did report they always had either a grand-parent or spouse taking turns to watch over the child while one of them were away for work, hence trying to make sure there were no gaps in their care towards the young child. All these could be reasons why the recent trends of ASD

early diagnosis are much higher than the previous times. Parents are more aware and there are better resources to refer these days than initially; thus, giving more preparatory time for the parents and families to accept and normalize their situations bringing about better chances of coping and resilience.

In another interesting study by Thomas et al. (2012), the association between socio-economic status and Autism were observed, where the prevalence of ASD was found to be higher among the higher income groups as compared to the lower income groups [7]; this could be due to higher access to facility-based diagnosis among the higher income areas which could be the reason for more reporting of cases. In our study, we found the parents from higher socio-economic status to have higher resilience as compared to those from lower socio-economic status. This could be because of their access to better facility, help measures or opportunities for higher centre rehabilitation and care.

In a population-based case-control study done by Dickerson et al. (2014), the role of parental occupation in ASD was assessed and their results suggested that the usual occupation of mothers (prior to diagnosis of their child) and occupational history of both parents, as well as field of educational study, may be important to consider with regards to the child's diagnosis and developmental progress [8]. Requiring "systemizing skills" and suggesting a distinct phenotype, but alternatively this may have been related to selection biases [8]. In a study, researchers conducted a population-based study to explore whether fathers, or mothers, of children with ASD are over-represented in fields requiring highly technical skills. Subjects included 284 children with ASD and 659 gender-matched controls, born in 1994 in the San Francisco Bay Area [9]. Parental occupation and industry were abstracted verbatim from birth certificates. Engineering, computer programming, and science were examined as highly technical occupations. To limit bias by parental socio-economic status, we selected a referent group of occupations that seemed professionally similar but of a less technical nature. Odds ratios (ORs in our study, we did not retrospectively evaluate the details of parental occupation and ASD, however in relation to resilience, we found that the parents who were gainfully employed were found to have more resilience than those who were homemakers; which could be justified as having another field of interest or effort to be engaged with, rather than spend one's entire time with the child feeling dependent and narrow in options [9].

Another study done by Sun et al. (2014) investigated the various parental concerns and risk of ASD. In this study, parents with higher social class seemed to express more concerns than those from lower social classes and higher the degree of parental concern over their child in terms of emotions, concentration, or other behavioral issues, the more likely was the child to have ASD independently of potential confounders. The study also justified their findings as them being the closest care-givers of their child, parents do have more opportunities to recognize abnormalities in their children [10].

In another existing study done by Lord et al. (2018), ASD was referred to as a term used to describe a constellation of early-appearing signs such as social communication deficits and repetitive sensory-motor behaviors associated with varied etiological causes for the same. It also suggested that all families, caregivers and personnel associated with individuals living with ASD, would be rather prepared with information regarding the current functioning of the person with ASD, which thereby helps them to anticipate transitions, or navigate referrals to service providers and specialists as and when required. Thereby, ASD weighs as a substantial economic burden, mainly owing to the environmental contribution, which results in higher needs and lower gaps in receiving due care [11]. In our study also, we observed that parents from lower socio-economic classes had more concerns, more history of stress and lower resilience as compared to those parents from higher socio-economic classes. This could be due to their environmental and personal limitations that are hindering them from higher access to support and rehabilitative measures, thereby increasing their anticipation and worries concerning their child and compromising on their resilience.

As the trend of research material goes, limited resources (man and material) serve as a major contributor to delayed diagnosis and likely delayed intervention in case of neuro-developmental conditions, such as ASD; thereby to improve the outcome in such cases, greater attention needs to be channelled towards research, capacity building, and culturally relevant and cost-effective interventions [12].

Conclusion

Parents from lower socio-economic backgrounds had lower resilience as compared to those from higher socio-economic classes. Also, parents who had higher education and who were gainfully employed had showed a higher resilience as an outcome.

Acceptance and perseverance are the biggest challenges for parents and families dealing with children having ASD, however once the awareness is better regarding the skill training and other rehabilitative measures, with regular follow up and a continuous monitoring, one can help their child towards a progress road of development, respectively.

Recommendations

Regular follow up on a 3-6 monthly basis (based on the severity of ASD) for the child's development; Institutional as well as home-based therapy to be followed as a complementary balance initiative; Parent training programmes and counselling sessions to be encouraged; To encourage more fathers to participate in child's therapy sessions for better acquaintance to dealing with ASD features; To acquaint the immediate environment and family circle regarding social interactions, in case of a special child.

Ethical Considerations

Compliance with ethical guidelines

Approval and institutional ethical clearance were sought from [National Institute for Empowerment of Persons with Multiple Disabilities \(NIEPMD\)](#), Chennai prior to initiation of the study along with informed consent from each study participant, respectively.

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Authors' contributions

Conceptualization, study design and final approval Minitta Maria Regy, Vijaya Lakshmi, and Deepthi N Shanbhag; Investigation, data acquisition, data analysis, statistical analysis and writing: Minitta Maria Regy.

Conflict of interest

The authors declared no conflicts of interest.

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