

Empowerment of parents of children diagnosed with Autism Spectrum Disorder (ASD) through parent training and intervention program

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Abstract

Parents are an untapped resource when it comes to their children's educational, social, and health development. Past research show that parental involvement is linked to greater developmental outcomes in children with a diagnosis of Autism Spectrum Disorder (ASD). Parents are now recognized for the key roles they can play in ongoing child training and skill generalization. Autism Society West Bengal (ASWB), Kolkata, India, a parent initiated, not for profit organization promoting the support and inclusion of individuals with Autism spectrum disorders (ASD) in the society, runs three-month parent- child training and intervention program, designed to provide parents with basic facts about individuals with autism spectrum disorders (ASD) and strategies for working with these individuals utilizing collaborative partnerships. Once trained, participants themselves became trainers for their child at home. The major aim of the program was to promote family empowerment through parent-professional collaboration. The objective of this study was to explore the

changes in the parental perceptions following parent training and intervention program for children newly diagnosed with Autism Spectrum Disorder (ASD) and the subsequent empowerment.

Keywords: Parent Empowerment, Autism Spectrum Disorder (ASD), parent training intervention.

1. Introduction

The understanding and perception of autism spectrum disorder (ASD) has undergone huge changes over the past 20 years.^{1, 2, 3} Autism spectrum disorder is characterized by difficulties in communication, impairment in social interactions and imaginative play, and behavioral symptoms involving repetitive behaviors and/or a restricted range of interest in activities.⁴⁻⁸ Individuals with autism demonstrate certain degree of impairment that may differ widely.⁹⁻¹¹ Autism, a global health crisis that knows no borders; it does not discriminate based on nationality, ethnicity or social status.¹²

Autism is a complex and often devastating disorder for both the individual affected and his or her family. Because of the complexity of the disorder, it is critically important to help families understand the disorder, manage stress, and sift through information that frequently includes erroneous media views and unsubstantiated claims of treatment efficacy.¹³ Parents are the people who spend the greatest amount of time with their children. From this perspective, parents are an untapped resource when it comes to their children's educational, social, and health development. Parents are now recognized for the key roles they can play in ongoing child training and skill generalization¹⁴ which has led to better child prognosis and long-term quality of life.

Past research clearly show that parental involvement is linked to greater developmental outcomes in children with a diagnosis of Autism Spectrum Disorder (ASD). Parent education and empowerment reduces family stress.¹⁵ Evidence also shows that parental involvement in the interventions of their children leads to better outcomes in measures such as nonverbal¹⁶ and verbal communication¹⁷ higher levels of appropriate play skills¹⁸ and greater levels of positive parent-child engagement¹⁹. Development of more family-focused interventions has resulted in a shift from didactic teaching and family therapy models to interactive approaches, in which parents are active participants in all levels of the training process.²⁰

Based on the assumption that everyone (i.e., parents, teachers, professionals, etc.) wants the most favorable outcome for a child with ASD²¹ the optimum search for "what is best" involves a collaborative partnership among parents, professionals, and, oftentimes, the child. Central to the formation and success of parent-professional partnerships within any community is the collaborative professional training offered to parents and professionals²².

Parental involvement and empowerment is the one invariable factor and an integral part of the success of early intervention programs for children with autism spectrum disorder (ASD). The collaboration between the parent and the professional working with the child in the program is critical to the effectiveness of programs²³. Research has also shown that early intervention programs can lead to considerable gains in cognitive, social, emotional, and motor functioning²⁴.

This project was conducted in conjunction with Autism Society West Bengal (ASWB), Kolkata, India, a not for profit organization, that seeks to spread awareness about autism, advocate for the rights of individuals with autism and their families, and support these individuals and families by providing various services such as consultations and training programs. ASWB runs three-month parent training and intervention designed to provide parents with basic facts about individuals with autism spectrum disorders (ASD) and strategies for working with these individuals utilizing collaborative partnerships. Once trained, participants themselves became trainers for their child at home. This program of ASWB provides a cost-effective training model that allows parents and professionals to collaboratively develop, maintain, and improve services for individuals with ASD. ASWB has expressed interest in better understanding the attitudes of parents toward autism prior and after the diagnosis. Based on these interests, we developed the following research goals:

Changes in the parental perceptions following parent training and intervention program for children newly diagnosed with Autism Spectrum Disorder (ASD). This was reflected in the participants' understanding of autism and management of their child's condition pre and post parent training. This investigation was carried out over a period of ten weeks from June, 2013 to August 2013.

2. Reversible Inhibition

I. Research Instruments

To address the aforementioned research goal, in-person interviews were conducted with parents of children newly diagnosed with autism, participating in the parent training program for the first time. The interviews were structured and guided by a list of qualitative questions created beforehand. All interviews were conducted in Bengali, the predominant local language, with the help of an interpreter.

II. Data Collection

Interview data were collected from June to August 2013. Parent interviews were conducted three separate times during weeks 1, 5, and 9 of the parent training program (referred to from here on as Week 1, Week 5, and Week 9). These time points, corresponding roughly to the beginning, midway point, and end of the program, were chosen so that the development of the parents' knowledge and views about autism could be followed over the course of the program.

III. Samples

Interviews were conducted with 12 (twelve) of the parents of children with autism, participating in the program for the first time, of which eleven were mothers and one was a father. In order to protect their identities, subjects are referred to in this report without names and are instead given letters A-L. These letters represent the same individuals across all three interviews. It should be noted that one parent (subject F) was not able to be interviewed in Week 9, so the data from Week 9 is analyzed on the basis of eleven participants.

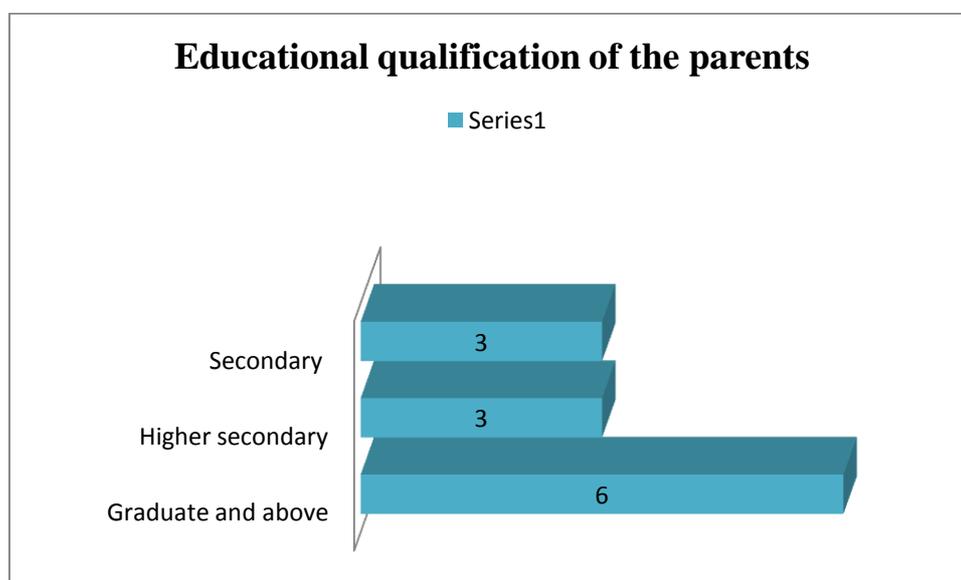
Individuals were not given any compensation or direct benefits for their participation in the study. Interviews were recorded on audiotape with the informed consent of the participants to facilitate the data collection process.

3. Results: Data Analysis

I. Demographic Information

Demographic information on subjects' educational was collected to provide a context for understanding their interview responses. This category was selected because the level of education of the parent may influence his or her knowledge, attitude, and behaviors regarding autism.

Education. 75% of new parent participants in the intervention program have completed higher education (higher secondary and/or graduate/professional school). This finding indicates that the participants in this study are generally more educated than the average person in India – it has been shown that in India about 12.4 percent of students go for higher education.²⁵



II. Understanding of Child's Condition Prior to Diagnosis

Parents were asked what they had thought might be the cause of their child's behaviors before learning of his or her diagnosis of autism. This information was expected to provide an

understanding of the specific areas in which the parents believed their children to be impaired and might allow one to understand the parents' treatment/intervention seeking behaviors. The responses of the participants are shown in Table 1.

Table 1. Perceptions of the child's condition prior to the diagnosis

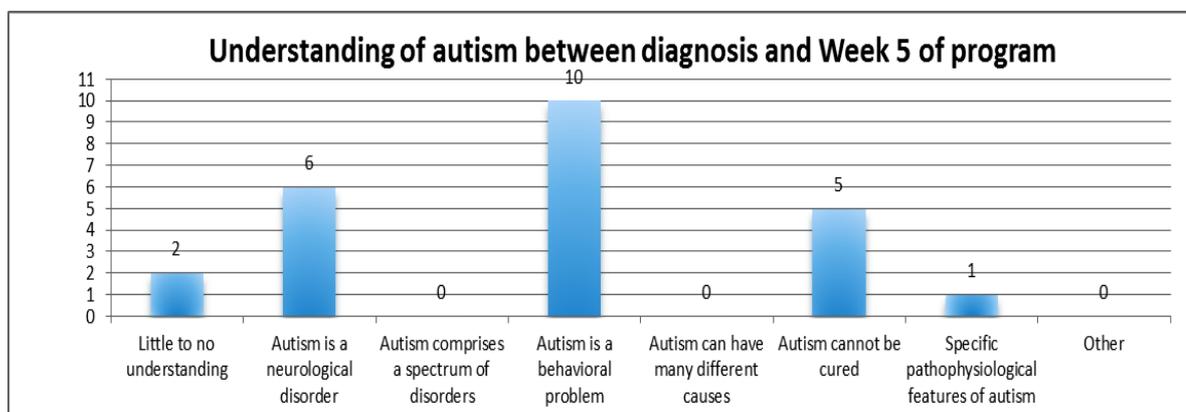
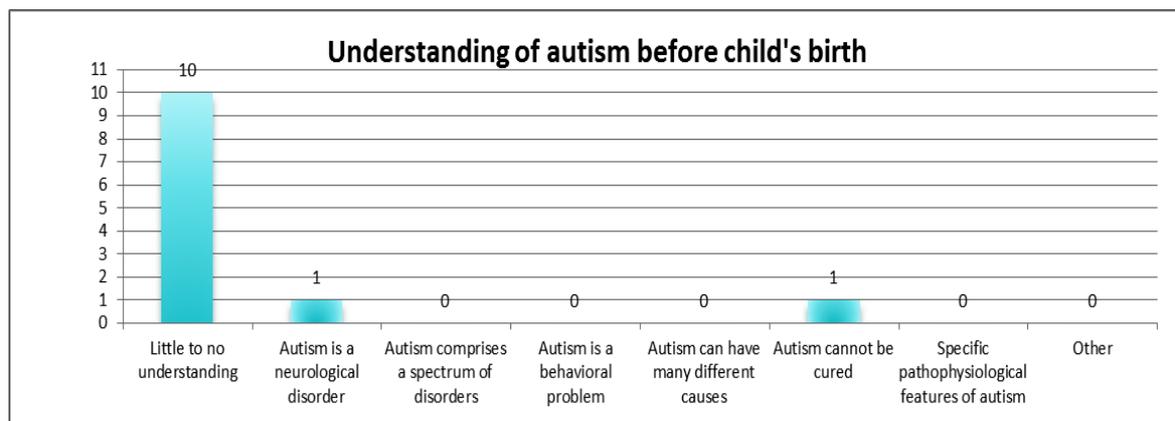
Understanding of child's condition prior to diagnosis		
Sl. No.	Probable cause of the child's aberrant behavior	Number of parents
1	Speech problem	3
2	Hearing problem	3
3	Other neurological problem	1
4	Aspect of the child's personality	4
5	Late development of the child	1
6	Environmental factor	0
7	Parents felt that something was different but not sure what exactly	2
8	Other cause	0

III. *Understanding of Autism*

We sought to discover whether and how the parent training program contributed to the parents' overall knowledge of autism. Parents were asked broadly what they knew or had learned about autism at the time of each interview, and responses were categorized according to key features of the disorder that the parent was able to name. We asked each parent what he or she knew about autism at three different points in time:

- 1) Before his or her child was born (asked in Week 1). Results are shown in Table 2.
- 2) Between diagnosis and Week 5 of the training program (asked in Week 5). Results are shown in Table 2.
- 3) Between Weeks 5 and 9 of the program (asked in Week 9).

Table 2. Perception of the parents prior and after the intervention program at parent training unit of Autism Society West Bengal (ASWB)



IV. Parent's Mindset

Parents were asked to describe whether and how their mindset had changed since learning that their child had autism. The data from this question was expected to provide another parameter by which to measure the effectiveness of the parent training program in helping parents of children with autism. Parents were asked in each of the three interviews how they manage their child's condition to see if they learned –and applied – any new behavioral management techniques throughout the three-month program and/or from outside sources.

Table 3. Change(s) in the mindset of the parents following parent training program during week 5.

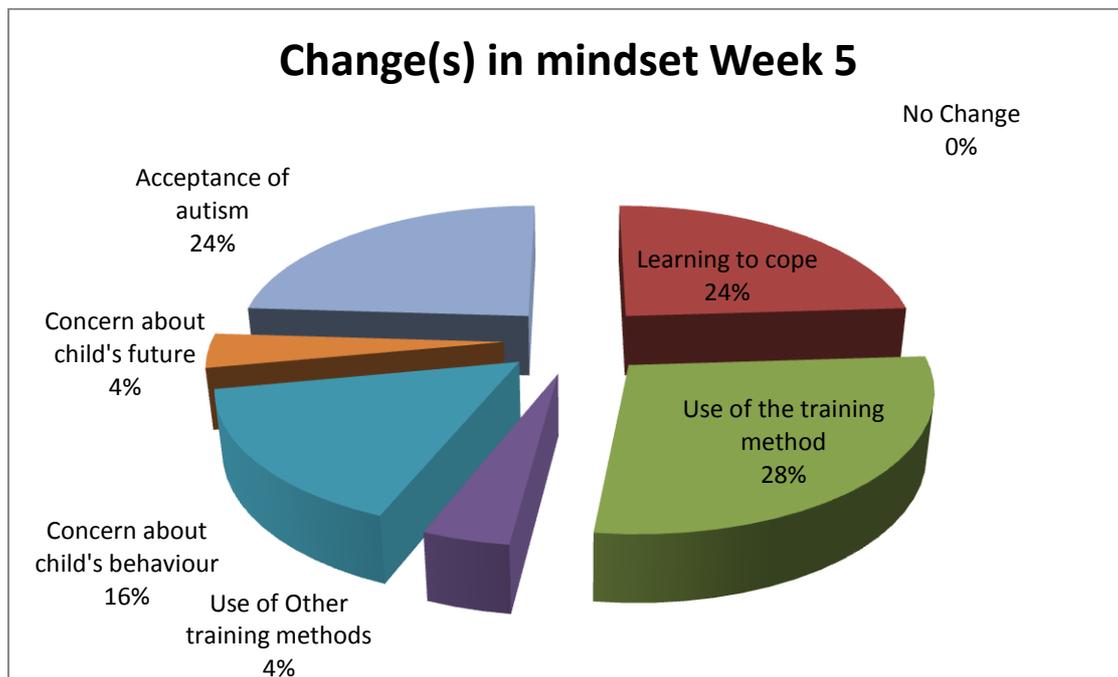
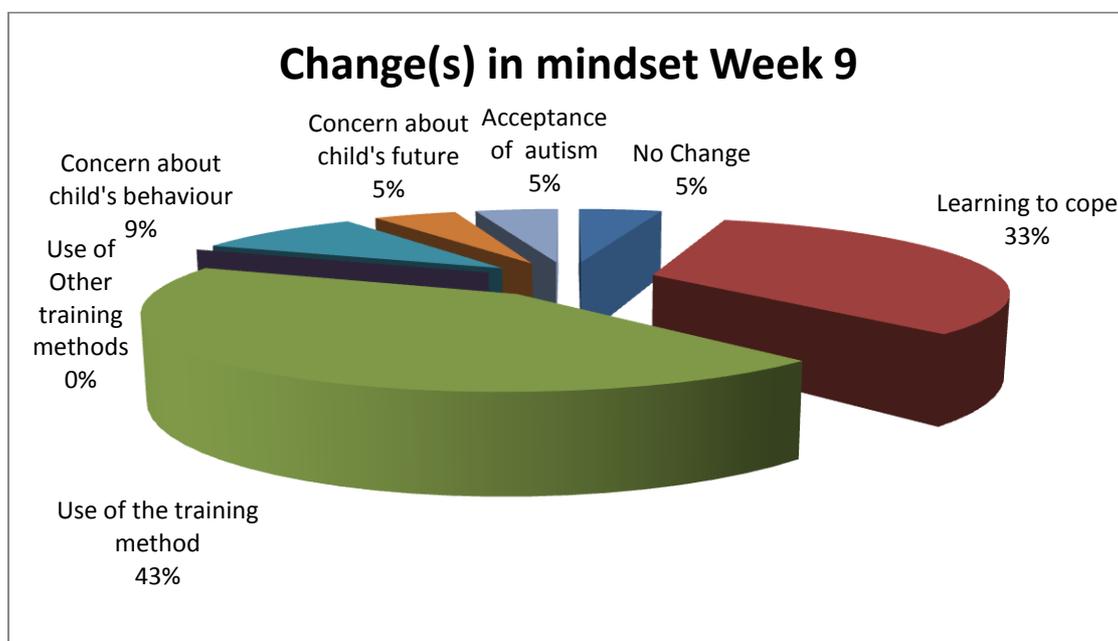


Table 4. Change(s) in the mindset of the parents following parent training program during week 9.



4. Conclusion

In India there is usually a time gap between noticing the initial symptoms of ASD and the formal diagnosis of ASD²⁶. It is only after the parents come to terms with the acceptance of autism that they are receptive to training methods to manage their child with ASD. When parents and professionals partner with one another to meet the needs of individuals with ASD, it can have a positive impact on the quality of their cognitive, social, and emotional development²⁷.

The results as shown in Table 1 revealed that four of twelve parents (33%) believed before diagnosis that the behaviors shown by their child were simply part of the child's personality. The two second most common beliefs among the parents were that the child's condition was a speech problem (25%) or a hearing problem (25%). 50% of parents said they believed their child's condition to be a speech or hearing problem, and indeed one of the first medical tests many parents reported having sought for their child was a hearing exam. After having a hearing exam and possibly additional tests conducted on their child, these parents were generally referred to psychologists or psychiatrists after seeing their primary care doctors/general practitioners. Some parents reported having seen multiple doctors before receiving an autism diagnosis. Had any of the parents perceived that the behaviors shown by their child might be associated with autism, it can be reasonably inferred that they may have approached a mental health professional directly. Understanding what problem the parent believes the child's behaviors to be symptomatic of is important to understanding their treatment-seeking behaviors. None of the participants thought that their child may be born mentally challenged. This result shows that there is a lack of awareness about developmental disorders, in particular Autism Spectrum Disorder (ASD).

From Table 2 it is seen that during Week 1, ten of the twelve parents interviewed (83%) reported having little to no understanding of autism before their child were born. During Week 5, the responses were much more varied. Some subjects gave responses that fit into multiple categories. By the midway point of the program, during Week 5, the majority of parents (83%) could describe autism as a behavioral problem. The parents' description of autism from the perspective of a behavioral problem as opposed to a disorder stemming from the brain may be because, without further knowledge of autism, they understand the condition as it is manifested by their child. Indeed, when asked how they understood autism, many parents characterized it by the specific symptoms shown by their child rather than by what they may have known to be characteristic of autism in general. The responses of the participants were the same during week 9 hence the data is not graphically displayed.

All parents expressed initial distress upon finding out their child's diagnosis, but *eleven of twelve* mentioned some improvement to their mindset by the midway point (Week 5) of the training program. *Seven of the eleven* who responded with a positive change to their mindset specifically mentioned the help of the three-month training. Parents cited various reasons for how the parent training program helped them – these are given in the Table 3. Three of the parents (B, D, H) who described a positive change to their mindset said that they are learning to cope but did not specifically mention the parent training program. Subject I described his or her mindset had changed since diagnosis in that he or she initially did not believe in autism or

that it could happen to his her child and originally did not know there was no cure. This subject stated that he or she has now accepted the child's condition and is trying to educate him- or herself and take the child to therapy. Subject C specifically mentioned the comfort of other resources outside of parent training program, namely the abundance of literature and cases of autism.

From Table 3 it is seen that 28% of the participants used the training methods imparted. There were a few (4%) who still thought about the child's future or were concerned about the child's behavior (16%) and some (4%) still used other methods to manage their child. 24% had accepted the child's ASD condition and another 24% parents were learning to cope with autism. There was a shift from accepting the child's ASD condition to a 'learning to cope' mindset. 28% of the parents felt empowered to use the training protocol that they were learning during the past 5 weeks.

From Table 4 it is observed that during week 9 as many as 43% of the parents felt empowered to use the training methodology imparted to them over the past 9 weeks. 33% of the parents had accepted the ASD condition of their child and were ready to learn to cope. They were open to training methods from ASWB. Only 5% of the parents were still toying with the issue of acceptance of autism. So over the 9 weeks the general trend was empowerment of the parents which can only start when the parents accept autism as a part of their lives. The empowered parents understood the need of specific evidence based training methods to manage their child.

Our results are similar to other intervention programs where parent involvement helps ensure the behaviors learned in the program can be generalized to the home environment.²⁸ Participants stated that they have a better understanding of their child around midway of the parent training and intervention program. As a result of this better understanding, the participants felt empowered to be effective change agents and contribute to the child's program at home. Literature review shows that our results were similar to other such parent training program conducted elsewhere.^{29, 30.}

Limitations

I. Sample: Size & Bias

As previously mentioned, we interviewed only twelve parents. We acknowledge that these are small sample sizes, and that it is difficult to draw general conclusions from such a limited data set. Additionally, it must be noted that the responses of all the individuals interviewed are inherently biased for two primary reasons. First, all of the parents interviewed elected to join the intervention program from their own desire to learn about autism and improve their child's condition. Second, because all of the parents were voluntary participants in our interviews, they were likely more comfortable with discussing autism in relation to their child and family than the typical parent of an autistic child would be. Their responses also cannot be generalized to the views of all parents of children with autism in India.

However such sample surveys highlight the importance of awareness programs regarding Autism spectrum Disorder (ASD). Early intervention can be possible only if there are good awareness campaigns about Autism spectrum Disorder (ASD).

Empowering parents with knowledge about autism; child management methods leads to better outcomes for the families, their loved one with ASD, and the professionals who serve them. The major goal of the 3 month parent training program and intervention at Autism Society West Bengal (ASWB) was to promote parent and subsequent family empowerment through training. Parents were provided with opportunities for empowerment through knowledge and access to an array of services and resources; the opportunity to participate in decision-making and problem-solving process training; and the opportunity to gain skills to effectively partner with professionals in order to meet the needs of individuals with ASD.

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