

OUTCOMES OF PARENT AND CHILD (PCT) INTERVENTION PROGRAM FOR CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD): CASE STUDY OF PARENT PROFESSIONAL COLLABORATION

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Abstract

One of the most devastating, life-changing events for parents is finding out their child has a developmental disorder. There is growing recognition that autism spectrum disorder (ASD) is a complex, multisystem neurodevelopmental condition. Differential development in different domains is more prominent in children with autism. The importance of early, intensive intervention for young children with or at risk for ASD is well-documented. Literature review suggests that early intervention can mitigate the severity of core and associated features of autism. Parents are the primary caregivers and educators in a child's life, making their role in autism management indispensable. 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 development. Autism Society West Bengal (ASWB's) runs Parent and Child Training (PCT) designed to provide parents with basic facts about individuals with autism spectrum disorders (ASD) and strategies for working with these individuals utilizing collaborative partnerships. This study is on a six-week intensive Parent and Child Training (PCT) at ASWB. The results showed improvement in all ten participants.

However, it was observed that there was uneven skill development among the participants which is in agreement with the literature review. This PCT is also seen as a parent empowerment program. It is a training that instills confidence among the parents themselves that they are capable of providing support for their autistic child. Parental empowerment is an approach that helps parents and other caregivers develop the confidence and skills they need to care for children with disabilities. As the training is done as a group the parents understand that they are not alone in this journey. This PCT was free for all participants irrespective of their economic background. This was possible as the organization received funding for this intensive intervention initiative for children with autism.

Keywords: Parent and Child Training (PCT), autism, parent empowerment

Introduction

Autism spectrum disorder (ASD) is complex and heterogeneous, with biological and behavioral features that cut across multiple developmental domains. ASD is characterized by social interaction difficulties, communication problems and restrictive and repetitive behavior, according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) in 2013 [1]. This triad of impairment viz. communication, social interaction and understanding, and imagination—was first studied by Lorna Wing also widely known as the “Lorna Wing triad” in autism [2]. ASD is a developmental condition that affects social interaction, behavior, and communication. Ability levels and the need for support vary enormously among individuals with the condition. It is quite common to find many individuals with ASD have accompanying comorbidities such as intellectual disability (ID), attention deficit hyperactivity disorder (ADHD) and other physical conditions.

Early intervention of children newly diagnosed with autism spectrum disorder (ASD)

The symptoms of ASD and their severity differ widely from child to child, making each child unique [3]. The service needs of children and youth with ASD in behavioral, educational, health, leisure, family support, and other areas are different [4]. Developmental domains are specific areas of any child's developmental progress and growth. Each child develops at their own pace, and many factors, including age, genetics, and the environment can affect how and when a child develops. Differential development in different domains is more prominent in children with autism. There is growing recognition that ASD is a complex, multisystem neurodevelopmental condition [5]. So autistic children respond differently to intervention and develop at their own pace [6]. Early childhood interventions are often strongly recommended for young autistic children to promote skill gain in areas that might contribute to positive long term outcomes [3,7].

The importance of early, intensive intervention for young children with or at risk for ASD is well-documented [8]. Research suggests that intervention beginning before age 3 yields greater positive outcomes as compared to intervention starting after 5 years of age [9]. Recent research suggests that early intervention can mitigate the severity of core and associated features of autism [10]. Also improve the long-term outcome of individuals with ASD [11]. Sometimes reverse some of the ASD symptoms [12]. Early intervention, therefore, has a role in shaping the brain to be receptive to the social world, and in doing so, preventing or mitigating the symptoms and severity associated with ASD [13].

Parent mediated intervention for children with autism

Parent-mediated early intervention for children with ASD results in improved child outcomes across a range of developmental domains, as well as improved parental self-efficacy and engagement [12, 14, 15, 16]. Parents are the primary caregivers and educators in a child's life, making their role in autism management indispensable. The nurturing environment provided by parents has a profound impact on an autistic child's overall development. From early intervention to ongoing support, parental involvement serves as a cornerstone in enhancing the child's quality of life. The collaboration between the parent and the professional working with the child in the program is critical to the effectiveness of programs [17]. Research has also shown that early intervention programs can lead to considerable gains in cognitive, social, emotional, and motor functioning [18].

The relentless effort required to provide optimal care, along with potential financial strains from therapy and medical expenses, can take a toll on parental well-being. Children with autism may have difficulty with communication, socialization, and behaviour, which can lead to frustration and stress for both the child and the family. Parents may also face challenges in accessing resources and support services, as well as dealing with the stigma and discrimination that can be associated with autism. Literature review has demonstrated that providing parents of children with ASD information about the diagnosis through parent education programs and support groups can decrease parenting stress [19, 20]. Parent mediated intervention also leads to parent empowerment.

Background of this study

Autism Society West Bengal (ASWB) has been working with individuals with autism, especially young ones for 20 (twenty) long years. The major hallmark of Autism Society West Bengal (ASWB) during her 20 years journey has been intensive early intervention, empowerment of parents and their families through the Parent and Child programs. Intervention services for individuals with developmental disability specifically ASD is scarce and expensive. Intervention services by Rehabilitation Council of India (RCI) accredited special educators are quite expensive even for a lower middle-class family. Over the years while working with individuals and their families, Autism Society West Bengal has witnessed the anxiety on the part of families as they go around in search of appropriate training and therapy for their child. The services for individuals with Autism are very few and there is also a lack of knowledge on the part of families regarding appropriate methods to be used during training.

The 2030 Agenda, pledging to “leave no one behind,” is an ambitious plan of action of the international community towards a peaceful and prosperous world, where dignity of an individual person and equality among all is applied as the fundamental principle, cutting across the three pillars of the work of the United Nations: Development, Human Rights and Peace and Security. It is critical to ensure, in this regard, the full and equal participation of Persons with Disabilities in all spheres of society and create enabling environments by, for and with Persons with Disabilities.

Autism Society West Bengal (ASWB) work is in sync with the SDGs Disability Inclusive 2030 Agenda. We believe that every individual with autism have the right to receive appropriate intervention early in his life. In recent times the organization witnessed the collateral impact the Covid-19 had on the families. Many parents lost their jobs and could not afford the program fees. Some parents have approached the organization for support. Since the ASWB policy is ‘Leave no Child’ which envisioned that every autistic child, irrespective of

caste, creed, and economic strength gets the early intervention. ASWB has been fortunate enough to get foreign funding in 2022 which enable the start of the free parent and child (PCT) course irrespective of the economic status of the family.

Research Methodology

Parent and Child Training (PCT) at Autism Society West Bengal (ASWB). This study was conducted in Autism Society West Bengal (ASWB), Kolkata, 21 year old a non for profit, non-government organization (NGO) in Kolkata, India 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. Autism Society West Bengal (ASWB's) runs Parent and Child Training (PCT) designed to provide parents with basic facts about individuals with autism spectrum disorders (ASD) and strategies for working with these individuals utilizing collaborative partnerships.

Hands on training program for management of the child as well as several theoretical classes to enhance the understanding of ASD are imparted to the parents over the training period. Both parents are encouraged to take the training along with their child. Once trained, participants themselves became trainers for their child at home. The PCT program of ASWB allows parents and professionals to collaboratively develop, maintain, and improve services for individuals with ASD.

These programs are very intensive and are carried on by special educators with RCI credentials. The groups are kept quite small, about 10-12 parents so that all the participants get individual attention. In general, these intensive programs are very expensive and often beyond the reach of lower middle-class families. The poor families often can't afford even the transport cost to the centre let alone the high program fees. Every individual with autism has the right to receive appropriate intervention early in his/her life. Research has shown that due to the neuroplasticity of the brain appropriate intensive early intervention can change the trajectories of lives of persons with autism. The funding made it possible to conduct the PCT program where none of the parents needed to pay for the intervention.

Objective of this study

Since November, 2022 ASWB started Outreach work in 24, Parganas (South) district with the hiring of RCI professionals under the funded project. Outreach work in the districts revealed that there were many children of various age groups who had never got an intervention services. In fact many of them never got any formal diagnosis. The parents of the districts who could afford to come to ASWB located at Mukundapur enrolled in the free Parent and Child training program which was under the funded Parent and Child Empowerment (PACE) program of ASWB.

Parent and Child Training span: 6 (Six weeks),

Training duration per day: 2 (two) hours a day for 4 (four) days a week. The training involved hands on training.

Implementation of the training: The training programme was implemented by Special educators and psychologists who are certified by Rehabilitation Council of India (RCI). These trained special educators showed the parents how to manage their child.

Training venue: Early Intervention Unit, Autism Society West Bengal (ASWB), 147, Krishakpally, Barakhola, Mukundapur, Kolkata 700099

Parent coaching: On the 5th day of the week the RCI certified special educators and psychologist took theory classes either in online or offline mode.

Data Collection: The pre and post training data was collected by the RCI certified special educators of the Early Intervention Unit of Autism Society West Bengal (ASWB).

Participants:

10 (ten) children ranging from 2 years and 3 months to 10 years were taken as participants for this study. Since all the children were receiving hands on parent mediated intervention for the first time in a fully funded project there was such a wide range in age of the participants. Some of the participants got an opportunity in this free parent and child (PCT) training after their child was diagnosed during a screening program by the ASWB Outreach team. Table I. Show the age and gender of the participants.

Table I. The gender and age of the participants along with their Identity (ID) No.

Sl. No.	ID No.	Age of the child	Gender
1	PF1	2 years and 3 months	Female
2	PF2	3 years and 4 months	Female
3	PM1	3 years and 6 months	Male
4	PM2	3 years and 6 months	Male
5	PM3	4 years and 6 months	Male
6	PF3	4 years and 9 months	Female
7	PM4	5 years and 4 months	Male
8	PM5	7 years and 8 months	Male
9	PF4	8 years and 8 months	Female
10	PM6	10 years	Male

Results: It was seen that in all participants there was improvement along the 10 (ten) parameters. However, the pace of the improvement varied greatly. The pre training level of most of the participants was more or less at the base level. The duration of training was six weeks which was same for all participants. The pre and post PCT data are depicted as graphs (Fig. 1 – Fig.10). The graphs clearly show the rate of improvement is not uniform along the ten parameters in one individual.

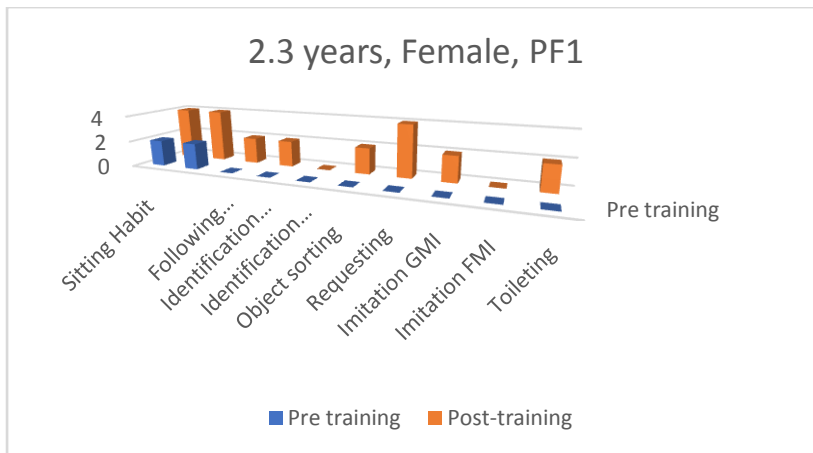


Fig. 1 Pre & post intervention improvement for child, PF1

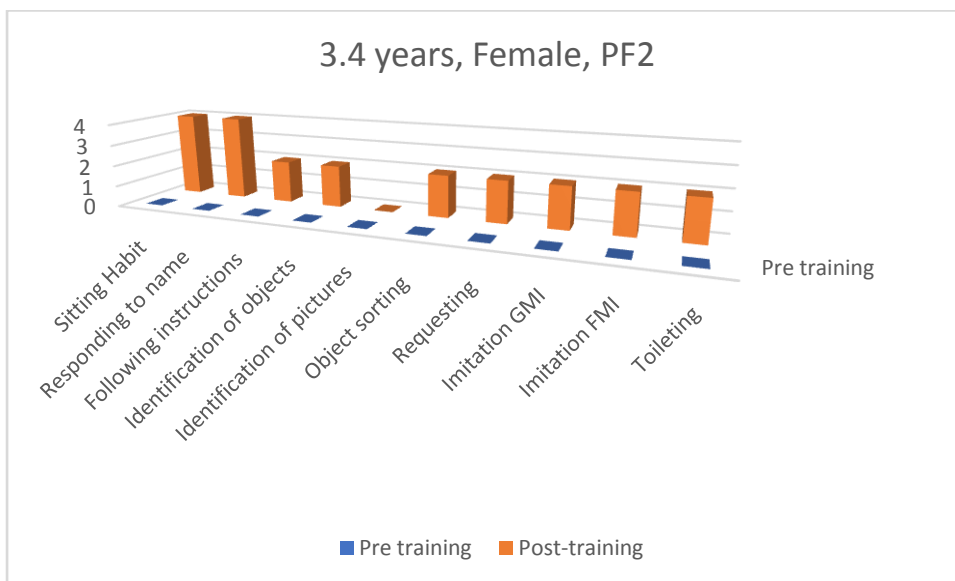


Fig. 2 Pre & post intervention improvement for child, PF2

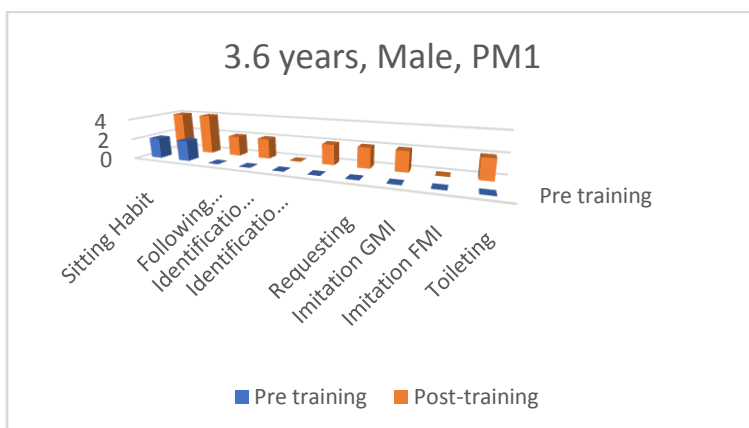


Fig. 3 Pre & post intervention improvement for child, PM1

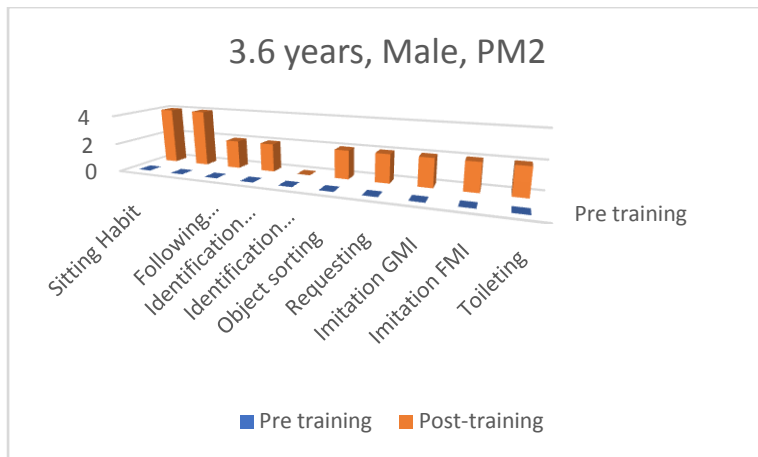


Fig. 4 Pre & post intervention improvement for child, PM2

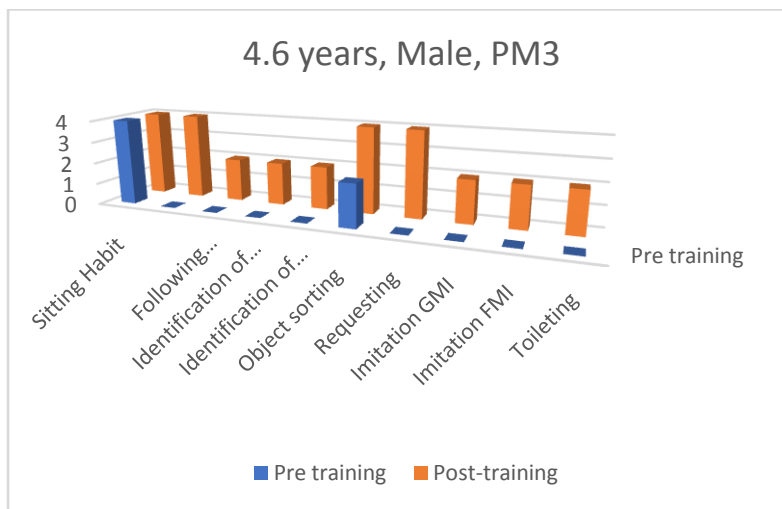


Fig. 5 Pre & post intervention improvement for child, PM3

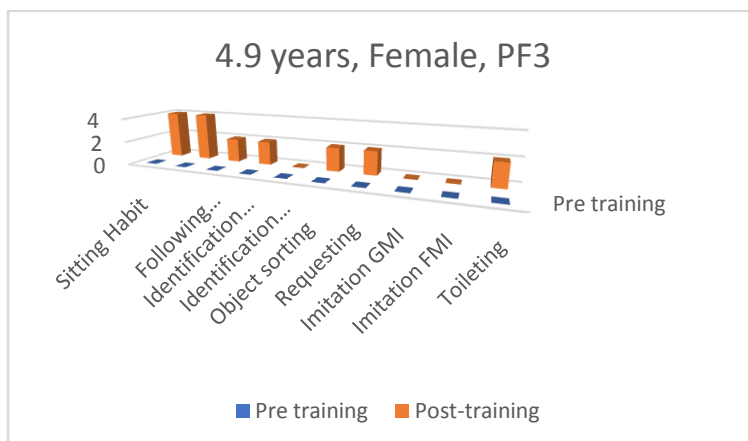


Fig. 6 Pre & post intervention improvement for child, PF3

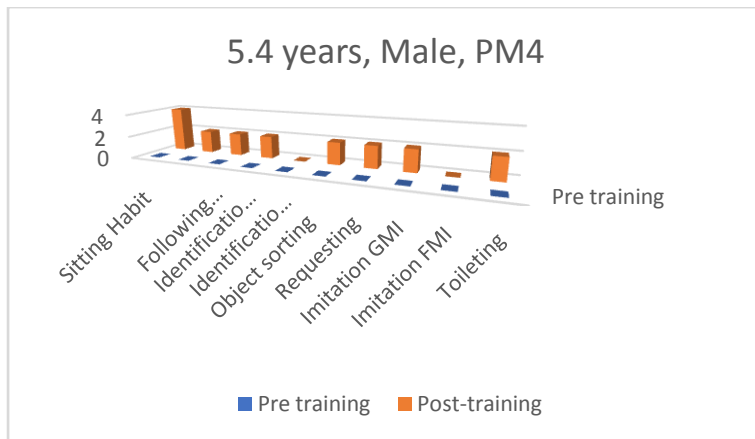


Fig. 7 Pre & post intervention improvement for child, PM4

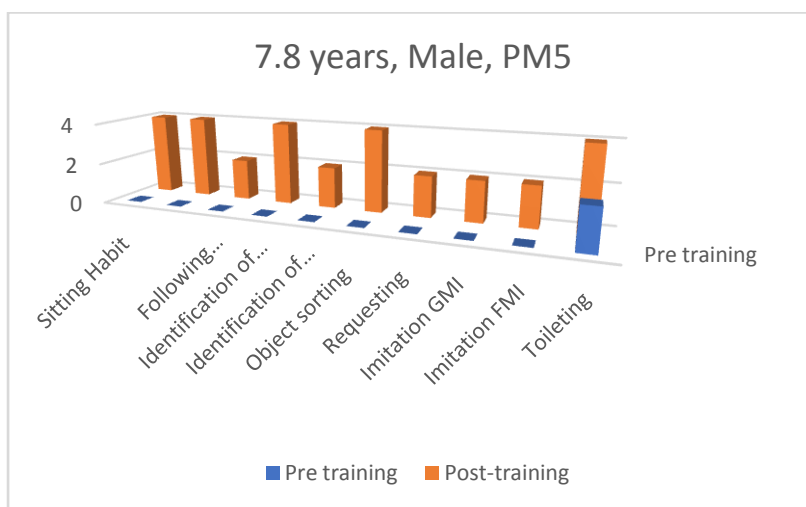


Fig. 8 Pre & post intervention improvement for child, PM5

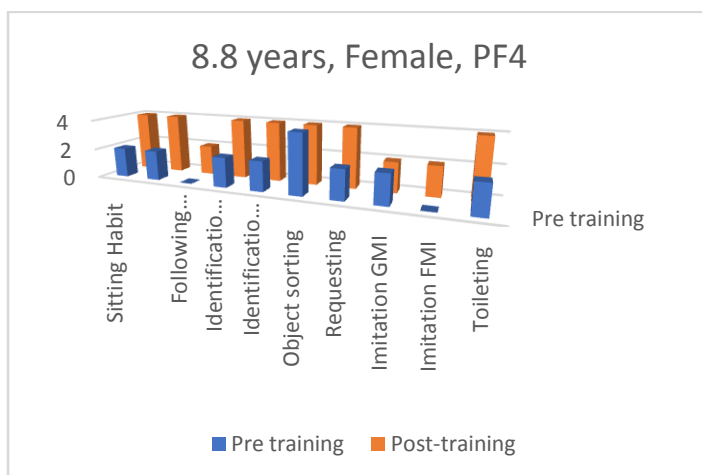


Fig. 9 Pre & post intervention improvement for child, PF4

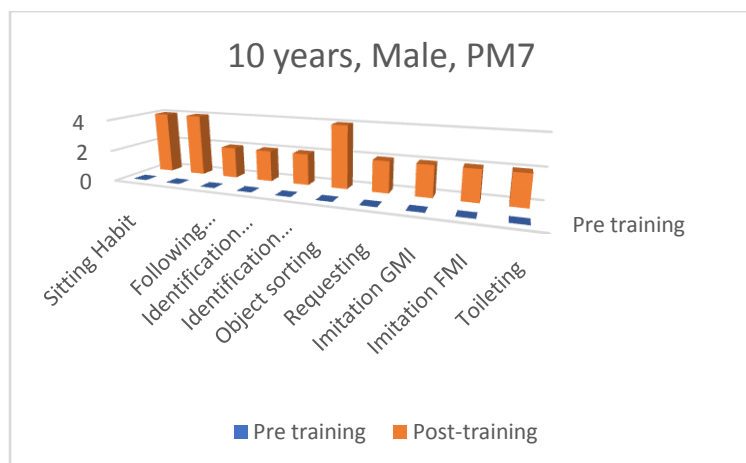


Fig. 10 Pre & post intervention improvement for child, PM7

Discussion

One of the most devastating, life-changing events for parents is finding out their child has a developmental disorder. Before diagnosis, parents had a vision of life with their child that changes drastically post-diagnosis [21]. There are a number of social factors associated with the experience of disability. Autism is a severe developmental disorder marked by a triad of deficits, including impairments in reciprocal social interaction, delays in early language and communication and the presence of restrictive, repetitive and stereotyped behaviors. Parents are considered key players in the process of student education [22]. 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 development [23].

The results of this investigation show that there is uneven improvement across the ten skills that were assessed during the training period per participant. The results are similar to other research studies which showed the incidence of uneven skill development among the autistic person [24, 25]. This study is also a reflection of the neural plasticity that is inherent among all participants. There has been improvement in all participants though not at the same pace and along the same skill parameter.

Parent empowerment, defined as the process by which parents gain access to resources, has been implicated as one factor influencing parent responses to challenges associated with parenting a child with ASD and is linked to positive outcomes including parent self-esteem and perceived control over the environment [26]. Parent coaching in early childhood is an interactive process between a clinician/special educator/psychologist and a parent that involves observation, reflection, and action to directly promote the parent's ability to support his or her child's participation in family and community activities [27]. In recent times research is based on several important innovations for the implementation of evidence-based treatment models for young children with ASD in community settings [28].

Conclusion

This study shows that intensive intervention for autistic individual that improvement is possible irrespective of the age of the child at the time of pre training. It is true that the lower the age the higher the probability of improvement along different developmental parameters. This is due to the neuroplasticity of the human brain. Research has established that the human brain is capable of learning throughout life. This parent and child training (PCT) is much

more than just parents learning the ways to support their child. It is a training that instills confidence among the parents themselves that they are capable of providing support for their autistic child. As the training is done as a group the parents understand that they are not alone in this journey. This paves the way for parent empowerment. Parental empowerment is an approach that helps parents and other caregivers develop the confidence and skills they need to care for children with disabilities. Empowered parents have a deep understanding of their children's health conditions or disabilities.

Since this Parent and Child Training (PCT) is fully free for all participants irrespective of their economic background this program is envisioned to be an 'enabling' program where intervention services can be provided to those who can reach the training centre regularly.

Limitations of the study

The results of the present study must be considered preliminary, as no control group was included in the design. The program had to be restricted to the training venue. The outcomes could have been different if it was conducted in community settings.

Informed Consent Statement:

Informed consent was obtained from all subjects involved in the study.

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