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Are Online Interventions Effective for My Child with ASD? A Review of Online Interventions for Pre-Primary and Primary Aged Children with ASD during the COVID-19 Pandemic

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Abstract: ***This pandemic has been hard on us all but particularly on our children with Autism. Children in India have been in home isolation and lockdown for over 15 months. They have had no access to their schools, play areas, public spaces or outings. Children with Autism have been affected significantly as they are unable to access therapy centres and schools. We also realised that the families were under inordinate amounts of pressure adding to the complexity of the situation. At CADDRE, we were intent on continuing to provide the best care possible during this time. We quickly realised that without ongoing support and care, the gains made thus far would be lost. The uncertainty of the lockdown period also meant that unless we improvised and started providing interventions through the online platform, we would be unable to support the families and children. A review of the literature that was emerging during this time highlighted the challenges that were being faced by the Autism community; however, there was very little being highlighted in terms of changing practices to suit the current need or any information on how interventions were being provided during the pandemic. At our centre, we tried different ways of implementing academic and therapeutic strategies. We were faced with many challenges but took these as opportunities to innovate and create new practices. We have attempted to document these and put it in the form of an article. We would like to share the interdisciplinary knowledge and insights we have gained with parent communities and clinicians who work with young children with ASD (Age- 2.5 to 9 years) with the hope that during the pandemic, clinicians and families will consider alternatives to face-to-face therapies and will consider online interventions as an effective way of intervention implementation.***

Keywords: Autism, Online interventions, Pre primary children, Primary aged children

Since March 2020 schools have been shut all across India. As young children were considered to be extremely vulnerable to contracting COVID-19, the state governments advised restricted movement of pre-primary and primary-aged children, placing them in a situation resembling home isolation. Along with schools, places frequented by children were also closed. This included centers that were providing therapeutic interventions for children with special needs.

Our center, CADRRE (Centre for Autism and other Disabilities, Rehabilitation, Research and Education) in Kerala, India which caters to the educational and therapeutic needs of 25 children (between the ages of 2.5 and 18 years) with Autism Spectrum Disorder (ASD), has also been closed to the children for over a year.

However, interventions were provided to the children without a break. To this effect, multiple changes in the mode of delivery were undertaken. This paper will take you through the challenges we faced and modifications we came up with to continue providing services to the children enrolled in the pre-primary and primary years program. While there continues to be uncertainty around the reopening of schools and therapeutic centers, adapting our ways to support children with special needs, through any means available, seemed to be the need of the hour.

We have chosen to share our learnings and findings with the hope that parents and centers around the globe will be able to implement similar delivery methods to ensure ongoing care and support during these very unusual and trying times. We also hope that families in areas that have no physical access to therapy centers but have adequate internet connection can access online services.

ASD is marked with a triad of difficulties i.e. difficulties with social communication, social interaction and restricted and repetitive interests (DSM-V). Children with ASD tend to show a preference for highly predictable environments (Collizzi, Sironi, Antonini, Ciceri, Bovo & Zoccante, 2020). Unpredictable, sudden and complex changes often result in anxiety and feelings of confusion. The outbreak of COVID-19 and ensuing lockdown brought with it several challenges including using protective gear like masks, face shields, gloves and sanitisers; loss of previously established routines and outings. Difficulties with comprehending the situation and the consequences of not following the safety precautions added to an already difficult situation (Siracusano, Segatori, Riccioni, Galloreti, Curatolo, Mazzone, 2021). The sudden, indefinite, and rapidly shifting social and health-related situation saw the challenges faced by children with ASD exacerbate greatly (Collizzi, et al., 202 0; Sirascusano et al., 2021; Chen, Shu- Dan, Xing- Kai & Ren, 2020). Studies reported an increase in behavioural problems and worsening

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of pre-existing disruptive behaviours (Collizi et al., 2020). An increase in stereotypies, aggression, hypersensitivity, sleep, and changes in appetite was also reported (Kojovic et al., 2019). A study by Mutluer et al., (2020) suggests that the symptoms children with ASD have been exhibiting during this period mimic that of post-traumatic stress disorder (PTSD). However, it is with caution that these results must be interpreted, as standardized quantitative tools were not administered to measure the actual behavioural outcomes (Siracussano et al., 2021). It does, though, highlight the significant impact that this period has had on children with ASD.

The exacerbation of difficulties in children with ASD has put a great deal of strain on the parents and caregivers. Parents have been facing a range of issues on the work front (e.g., loss of jobs, working from home, reduced work hours/ change in work hours and reduced income) to having the children at home with no access to schools and intervention programs. Studies suggest that there has been an increase in mental health challenges, with parents reporting a significant rise in anxiety (Wang, Zhang, Zhao, Zhang, Jiang, 2020; Woolf, Muscara, Anderson, McCarthy, 2016), stress, burnout, depression (Kucuk, Alemdar, 2018), sleep issues (Neece, Green, Baker, 2017) and marital discord (Hartley, Papp, Mihaila, Bussanich, Goetz & Hickey, 2017). Lack of social support and social interaction also exacerbated these concerns (Ekas, Lickenbrock, Whitman & Optimism, 2010; Hastings, Allen & McDermot, Still 2002). The degree of parental distress has been seen to be directly related to the challenges the child experiences (Chen et al., 2020).

Since the enforcement of lockdown, all the above-mentioned concerns were observed and reported by the families and children that attended our center. This required the teachers and therapists to innovate the mode of delivery of services so that the families and children felt supported, stimulated and engaged through this period.

Before the enforcement of lockdown, 14 children with ASD between the ages of 3.5 and 9 years (Pre-primary = 6 and primary = 8: Boys = 13; Girls = 1) were receiving daily interdisciplinary therapeutic and academic interventions. They attended school five days a week from 9:00 AM to 3:30 PM. Their day was structured based on a pre-planned timetable (please refer to diagram 1 below). Each child received academic input, speech therapy, occupational therapy, social skills and behaviour modification as per an Individualised Education Plan (IEP). The IEPs were revised monthly for academics and quarterly for therapeutic interventions. The progress of each child was documented on a daily basis. Their progress was shared with their parents on a quarterly basis and an annual progress report was also provided. Parents were also given an opportunity to meet with the child's academic teachers and therapists on a weekly basis.

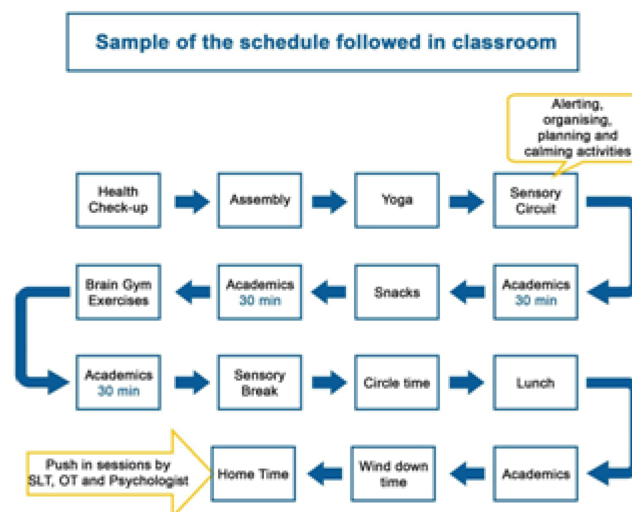

Diagram 1: Time table followed by children during a typical school day

Phase 1: Group sessions for parents via web-based interaction

Soon after the lockdown was enforced, it was decided that support to the parents would be provided through web-based sessions. These sessions were conducted in a group format (pre-primary and primary groups) and each discipline (speech therapy, psychology, occupational therapy and academic) took one session a week with the parents. The parents also had the opportunity to meet with the therapists and teachers on a weekly basis to discuss their concerns. Parents were taken through the rationale of each goal. They were sent lesson plans and resources that they could print and use with their child. The sessions were mainly aimed at strengthening the parents' understanding of their child's specific concerns and on training them to implement the interventions that were being provided at school previously. It however became evident that the parents were unable to provide a structured and predictable routine to the children. Also, the possibility of creating an environment at home similar to the one at school was proving to be a challenge. The children's concentration and attention were reported to be getting worse. Stereotypies and challenging behaviours were on the rise. Parents stated that while they were able to gain an insight into their children's challenges, they were finding it incredibly hard to implement the interventions. The lack of time and support made it harder to maintain regularity in doing the activities.

Phase 2: Pre-recorded video lessons Taking these concerns into consideration, it was decided to modify the means of delivery to pre-recorded lessons so that parents could watch the session as per their convenience. At this point, a detailed assessment of each area was undertaken, and an IEP was drawn up for each child. Based on the IEP goals, two videos from each discipline were sent every week. Weekly meetings with the parents were maintained to get feedback. But unfortunately, the feedback from a majority of parents suggested that they were not able to watch and conduct sessions with regularity and consistency. They reported gaining a deeper understanding of why particular goals and activities were taken. However, a large gap was noticed with the implementation. An increasing number of behavioural concerns like aggression (hitting, scratching or biting

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others), self-harm (hitting or biting self), destroying of property (throwing or breaking objects), pica (eating inedible objects), elopement (running away or wandering off from home), tantrums and vocalisations (ranging from persistent humming to screaming) were being reported. Many sensory concerns like mouthing and chewing on inedible objects, seeking vestibular sensations by running around in circles, flapping hands, cupping ears, pressing self against others and hugging others were also reported.

By this time, children had been in home isolation for almost 6 months. Their behavioural challenges and increase in sensory difficulties were understood as a means through which the children were communicating their frustration of being at home for this extended period. The indefinite time period that home isolation would be enforced meant that an alternate way to implement interventions was necessary. This intervention, in structure, content and efficacy needed to be as close to the face-to-face sessions as possible.

Phase 3: Individual online sessions

And so, after experimenting with online group parent sessions for 2 months and with pre-recorded video sessions for 3 months, in September 2020, an alternate system of providing individual online sessions of academic learning, and parent-mediated intervention guided by the therapist for each student along with weekly tele meetings with parents and caregivers was implemented. Group sessions with the teachers and students of the same age were facilitated as a morning assembly. The group sessions were put in place to help the children combat loneliness and isolation. Through this platform, they were able to meet their classmates and teachers and engage in some fun activities.

Please refer to diagram 2 for a detailed understanding of the structuring of the sessions

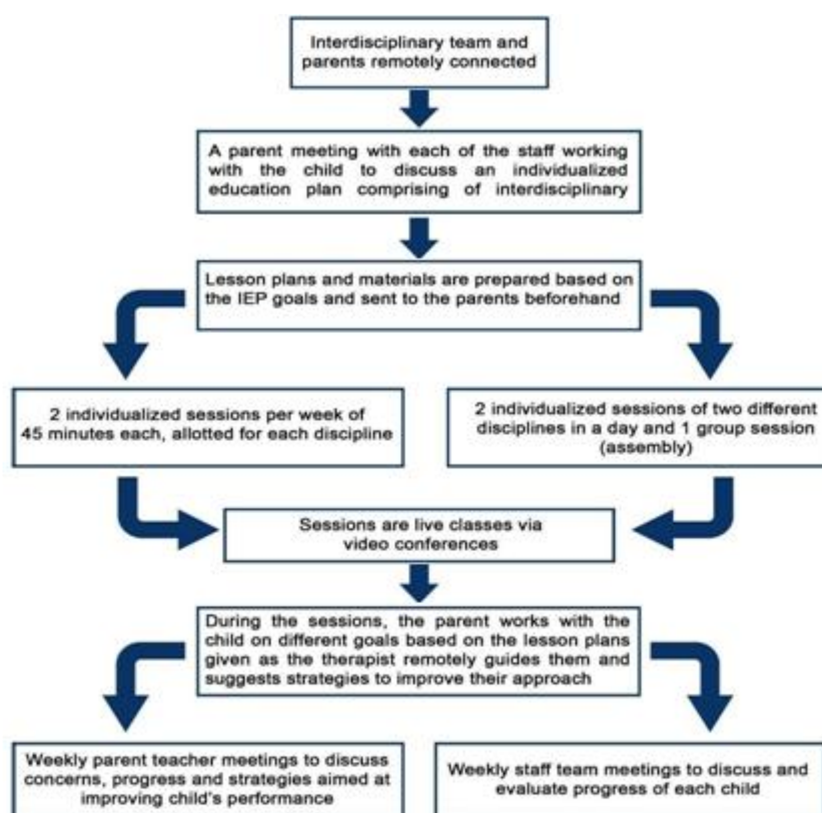

Diagram 2: Structure of the online classroom sessions

At the outset, many concerns regarding the plausibility and longevity of such sessions were brought up from both sides- parents as well as the therapists and teachers. The main concerns included the availability of technology and network, time constraints of parents, scheduling challenges, poor sitting tolerance and reduced attention span of the children, fascination with gadgets and its impact on their attention, lack of materials and resources, training of grandparents who were the primary caregivers in some cases, lack of awareness of ASD and ways of implementing the therapy.

In order to manage these challenges, the interdisciplinary team had to come up with innovative and extremely novel and flexible ways to ensure that the parents engaged in the sessions. The most important aspect of this entire process was the seamless functioning of the interdisciplinary team. To convince parents of the validity of this approach, the time spent with the children had to demonstrate efficient use of time, working on clear and concise goals and to facilitate notable changes in the child's experience of life. To this end, the team had weekly meetings where lesson plans for each discipline were discussed and planned to the minutest details. Each lesson plan was then put through a rigorous process of quality assessment by three members of the center. Each child's concerns and small achievements were shared amongst the team members. Every member was kept abreast of a recommendation made and it was ensured that suggestions made by one team member were reinforced by everyone on the interdisciplinary team. Planning,

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communication and consistency of information provided to parents was one of the most important factors that ensured success of this model.

Case study

Child A, 3 years of age, with a diagnosis of ASD joined CADRRE in 2019. He had significant difficulties with social interaction and communication. He was also experiencing sensory and behavioural difficulties. He lived with his mother while his father worked overseas. His mother preferred to keep him away from family get-togethers and discouraged him from playing with other children. She was hesitant to let him attend school outings. He had hardly visited any public places and his life revolved around his home and school. His mother was reserved and kept to herself. Discussions with the mother were limited to A's challenges at school. Any attempts to engage in a discussion beyond this were met with resistance.
The onset of the pandemic and related restrictions brought about a sudden halt to A's progress. The lack of social interaction and disruption of his daily routine to and from school weighed heavily on him.
opportunity to discuss matters in real-time. The parents appear to be better equipped at handling challenging situations and are able to work on the strengths of their children. The bond between the professionals and families has also deepened which helps in providing more holistic care.

It was also imperative to take into consideration that since lockdown many parents were working from home, thus each session for the child had to be scheduled in a manner that fit into his or her parent's work schedule. For some of the children, this meant sessions in the morning which were earlier than usual and/or in the evening which were later than a usual regular day at school. This change in schedule and timings meant that their sitting tolerance, attention and cooperation might be affected. Owing to an extended period of absence from school and an unstructured routine throughout the day, most children were found to be engaged with smartphones/tablets resulting in poor attention to structured activities. Due to the unfamiliarity of the online education system, children found it hard to cope and perform as they were expected to. With no access to the familiar set of reinforcements that were used for each child at school, therapists had to devise new ways to reinforce the children and keep them engaged in the sessions. Parallelly, behavioural management strategies of the parents that heavily relied on punishments had to be managed. New and positive ways of managing the behaviours had to be introduced and supported. Further, the online sessions had to be done at home without the luxury of most items required for the therapy and classes. Equipment had to be substituted with materials that were available at home and the therapist, parent and child had to work with objects at their disposal. Some of the preschool children were being taken care of by their grandparents, who lacked adequate knowledge of ASD and the ability to cope with present-day technology. This significantly affected the teaching. Lastly and most importantly, the children had limited to no means of communication with their caregivers. This seemed to be an important contributing factor to the behavioral and sensory challenge over the course of 9 months of online therapy, it has become apparent that what we already knew as best practices for children with ASD - interdisciplinary, collaborative therapeutic interventions need to be modified to suit the current times. Parents needed to be included and trained as co-therapists. Prior to lockdown, most parents preferred that their child was not introduced to picture-based communication or speech generating devices (SGDs). Most felt that the introduction of such methods would impede their child's speech development. Some raised concerns about the cultural appropriateness of using AACs. However, post lockdown and through the ongoing online sessions, these barriers to therapy have been greatly addressed. As parents were able to experience firsthand the process of working with their child, seeing what works and what does not, seeking guidance from the teachers and therapists in real-time and developing a far greater sense of trust and openness with the professionals, they were far more motivated to take up suggestions. Many families stated that they deeply wished for some sort of communication with their child so that they could understand what their child needed and wanted. Thus, online sessions began focussing on communication through the exchange of pictures, sign language and SGDs. As the parents were also part of the sessions, they experienced firsthand the way the child was responding. This prompted the parents to accept the methods too. Children started showing subtle but remarkable progress in communication. The progress of the child in using AAC was discussed with all the team members. All the team members, not just the speech-language pathologists, started using AAC to communicate with the child. This gave way for easy generalisation and learning for the child as well as the parent. Thus, the child's communicative intention increased far beyond where it was earlier. The recognition they got within the family and the intervention team also boosted their confidence. They also made appreciable changes in their Academic skills by the introduction of AAC as a means of expression. s that were being observed and reported. Please refer to the case study of child A to gain a detailed understanding of the implementation of the three phases described.

Exchange communications system (PECS), speech-generating devices (SGD) and communication boards were also introduced. Following this, there was a breakthrough in his speech, language and communication. He began to have more vocal utterances. His mother was taught a way to reduce her prompts, reduce her support so that she gave him an opportunity to learn and make mistakes, to use positive behaviour management strategies and implement his sensory diet. She has started to invest time in learning about Autism and implementing the suggested strategies. She began to slowly open up and started sharing her doubts and concerns. In due course, she became more comfortable with letting A be a part of group sessions and would actively encourage him to participate in co-curricular activities. She became far more open to new ideas and suggestions. Her resistance to using AAC with A greatly reduced. Her prior understanding of AACs being a barrier to the child's development of speech was challenged and she was able to understand and

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see for herself that the use of the AAC facilitated his speech and communication. The change in her attitude and acceptance of A brought about a sea change in him.

At the end of 11 months of online sessions, A has made remarkable progress. He is now able to sit for the entire duration of a class of 45 mins. He has begun to narrate simple stories. His ability to read and independently comprehend stories has greatly improved. He has shown an incredible ability to learn and repeat up to 10 digits from memory. Few sensory challenges remain and through the use of the AAC he is able to communicate and negotiate the activities he wants to do with his therapists and mother. The range of food that he is willing to try has improved greatly. He has also learnt to ride a bicycle and overall, seems to be happy and playful.

The case of A is an example of how online sessions can bring about great changes in a child and family. Many of the other families reported similar experiences. The experience of the online sessions has helped deepen the parents' understanding of their children's challenges and strengths. They have begun to view Autism as a part of who their child is rather than letting Autism define their child. They have learnt how to help and support their children. Through the one-on-one sessions with the teachers and therapists, they have the

This significant step brought about huge changes in the learning and understanding of the children. As there was a means to communicate, the therapists were able to involve the children as active members in their learning. The children were able to ask for breaks, change of activities, indicate discomfort, engage in conversations with their therapists and teachers independently.
Owing to the lack of sensory toys and resources at home which were readily available at school, parents were finding it difficult to manage behaviours that were a result of sensory overload or deprivation. These concerns were addressed by the therapist during the online sessions by the provision of home plans and sensory diets that were specific to each child's needs. Parents were taught how to administer and manage sensory concerns with resources that were available at home. They were also taught to make toys, obstacle courses and create an environment that mimicked what was provided for their child at school. Once parents were able to witness a change in their child's sensory-related behaviours in person, they felt encouraged to try different strategies at home.

The COVID-19 lockdown also brought about a disruption in everyday routines. Activities to promote independence in brushing, eating, dressing, etc which were being practiced regularly at school were not given the same importance at home because parents felt it was more convenient to quickly complete the child's routine and get into their work schedule for the day. This in turn made most children dependent on their parents and caregivers for their daily life activities. Keeping this concern in mind, parents were counselled in groups and during individual online sessions on the importance of each child being independent in their personal care routines. Activities like brushing and dressing were also tried during online sessions with appropriate measures for privacy being maintained.

Parents and grandparents (who were the primary caregivers) were also given a platform to share their concerns and mounting anxiety. They were offered individual and group sessions by the psychologists. As most mothers had taken on the role of being the co-therapist as well, they were provided with additional support. Fathers were provided with separate counselling sessions in which they were given an opportunity to share their concerns, and steps in which they could support their wives were discussed. As the children were confined in their homes for extended periods, many parents reported an increase in challenging behaviours like aggression, regression in previously acquired skills especially toileting, sleep disturbances, and trying to run away from the house. Individually tailored sessions were taken to address these challenges and close monitoring and follow-ups were maintained. In addition to this, domains like attention, memory, organisation and planning, social stories for age-appropriate behaviour, dressing- undressing, privacy, cosleeping, sitting tolerance were also worked upon in the online sessions.

While many would feel that online intervention will not be as effective as face-to-face interventions, it is our experience that they can be equally effective as face-to-face interventions and provide a good alternative till the children are able to assess face-to-face interventions again. The process that we undertook has been explained in such detail to highlight the challenges that may be faced by centers wishing to make similar modifications to their service delivery. It is also an attempt to highlight the flexibility needed and the detailed thought and willingness to persevere in the face of multiple obstacles.

The pandemic has brought about many challenges and while it is important to acknowledge the obstacles it has posed, it is far more important to figure out a way forward. As mentioned in the paper, the mode of delivery of the intervention does not matter as long as it is provided by an integrative team, who are committed to working closely with the family. While existing means of assessments, collecting data to inform the therapeutic goals, feedback, modifications to the IEPs need to be as relevant and must be adhered to strictly, expanding the therapeutic services to include more time training to empower the caregivers and providing them with psychological support is a must. Stretching ourselves beyond our conventional methods and styles of thinking to factor in the family, their challenges and vulnerabilities during this time is imperative. Considering providing individual and group counselling for the parents, establishing online parent communities to combat social isolation, setting up platforms to support the primary caregiver also have to be carefully considered.

With the uncertainty of when life will return to normal and whilst in-person therapies are inaccessible, it is important to consider online therapies as a means to access ongoing early intervention. It has been consistently demonstrated that early intervention helps children make significant gains in functioning; so providing ongoing therapy will ensure that young children do not lose out on that window of opportunity. Once the pandemic is over, online therapy can

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be a parallel means of providing services to children missing out due to long waiting lists. Children living in areas where therapies are inaccessible due to their geographical location will also greatly benefit from online services.

To conclude, though our online therapy evolved as a response to the current situation that the pandemic posed; it may also be considered as a beneficial add-on to the traditional approaches of early intervention.

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