

The Virtual Shift

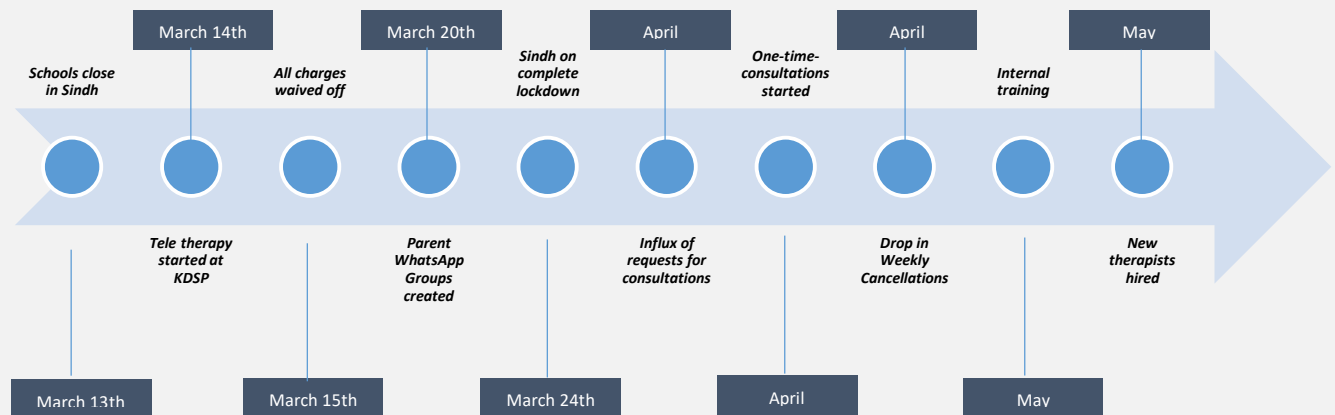
A Report on Karachi Down Syndrome Program's (KDSP) Early Intervention Response to the Pandemic and Its Initial Impact

Innovating Through the Pandemic

Pakistan fell prey to the coronavirus pandemic in the month of February and by March major cities went into lockdown. As the wake of the virus spread in Karachi, KDSP¹ decided to close all physical operations and serve the children with Down syndrome and their families from a distance. This meant shifting our services to the virtual realm.

One of KDSP's 6 areas of service focuses on early intervention and the necessary Occupational, Physical and Speech-Language therapy crucial for the development of a child with Down syndrome. The following case, will be detailing the initiatives, events, outcomes and results of KDSP's early intervention virtual, digital and tele therapy efforts during the pandemic for sustained growth and development of children with Down syndrome.

A Timeline of Events



¹ The Karachi Down Syndrome Program (KDSP), a non-profit organization, was launched in March 2014 by a group of affected parents and passionate individuals who, due to limited support and resources available locally, realized a need for a platform of those affected by Down syndrome. KDSP was formed with the mission to advocate for the value, acceptance and inclusion of people with Down syndrome living in Karachi and to provide them with the opportunity to lead fulfilling lives. Since its inception, KDSP has been involved in organizing workshops and trainings with international speakers and experts, running city-wide awareness campaigns, holding monthly support groups, printing regular newsletters, establishing guidance and support channels for parents, partnering with educational institutions to promote inclusive education, creating access to specialized quality healthcare with major hospitals, skills training and providing early intervention therapy for children with Down syndrome.

Tele Therapy

The first years of life are a critical time in a child's development. All young children go through the most rapid and developmentally significant changes during this time. During these early years, they achieve the basic physical, cognitive, language, social and self-help skills that lay the foundation for future progress, and these abilities are attained according to predictable developmental patterns.

Since children with Down syndrome typically face delays in certain areas of development, early intervention helps make sure those delays aren't prolonged so the first step was to make sure that the children enrolled with us continue to receive regular therapy. This was achieved by adopting a tele therapy practice, conducting one-on-one sessions online via WhatsApp video and audio calls with 170+ children with Down syndrome enrolled in the ECI clinics. These calls were made based on pre-set schedules and each one lasted for a minimum of 20 minutes, while the maximum went on for above 45 minutes. Therapists would divide their time engaging directly with the children and counseling parents/caregivers, training them to follow along the therapist's instructions.

Therapists set up resources online and used engaging techniques to make children as well their parents/caregivers comfortable with the new mode of therapy. It was also decided to waive the charges for all therapy sessions until June so that the parents/caregivers could ease through the process of adapting to the new normal.

Since 14th March (the day when the lockdown was imposed and operations moved online) , an average of 238 tele therapy sessions were successfully conducted weekly leading to a total of 3800+ tele therapy sessions conducted digitally since the lockdown (until June 30th, 2020), with children showing signs of progress as they receive regular support from the therapist as well as their parents/caregivers.

Case in Point

Narrated by: Maha Khan, Occupational Therapist

My client Mustafa Kashif is 2 years old and has shown progress while taking tele therapy. Initially it was challenging to figure out the best way to engage with him and his mother and we went through a trial and error period.

We started off with video calls, but saw that Mustafa was distracted very easily by the phone and the mother had to keep him at bay which did not help with my goals. We switched to audio calls with the mother only, but soon observed that there was no progress in Mustafa. Finally we agreed to use both the audio and video features and divide the time of the session effectively into 3 parts-I dedicated the first 10mins to speak to the mother on audio call where I shared my plans with her, explained the activity, the sitting arrangement needed for it and the delivery techniques to be used, as well as the possible hindrances that could arise during the activity. The next 25-30mins were spent on video call where the camera was hidden from Mustafa and I would only observe the mother carrying out the activity with him without passing on any instructions to her or taking any questions from her. In the 3rd part, I would get on audio call with the mother again for the last 5-7mins and give her feedback according to my notes and address her questions. This proved to be a very effective strategy and we were able to see progress in Mustafa as he was able to focus on the work being done and slowly became used to the phone being near him without getting distracted by it.

We also had to find our way through the challenge of not having any therapy and activity material at home. What we did was that we used household items like cardboard, kitchen supplies, toys, colors, etc. to prepare activity material for Mustafa-I used pictures and videos to show the mother what she had to make and then spoke to her in detail over the phone as she prepared the material (see pictures below).

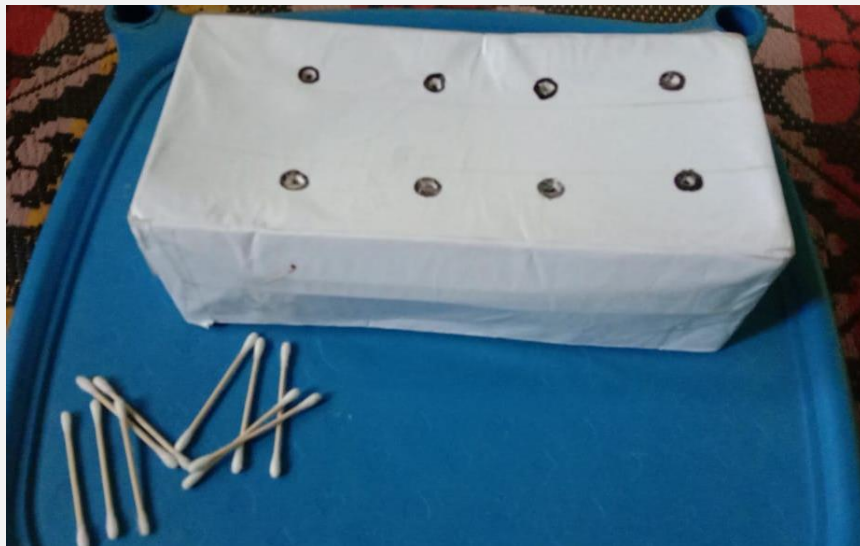
Overall, our combined efforts helped Mustafa tremendously and we observed an improvement in his fine motor skills. His sitting tolerance also increased from close to 1 minute when we started to Mustafa being able to sit and work for 20-25minutes at a stretch now.

We also got a great opportunity to work on his toilet training. This was not possible earlier (pre-virtual shift) because both the mother would be busy and Mustafa would be engaged in other activities during the day. Now that the mother found more time during quarantine she was able to dedicate time to train Mustafa and the results came in soon!

Mustafa's progress can be attributed not only to the fact that the mother has more time now, but also to her new-found sense of responsibility. Previously when Mustafa used to come to KDSP, I would give the mother home plans, but she would not be able follow them, however now after she has had the opportunity to physically engage with Mustafa herself and see the results hard work can bring in, she has become quite proactive and is always sending me videos

and pictures of her working with Mustafa, asking how to improve what she is doing. It is indeed quite beautiful to witness this!

And such progress is not just limited to Mustafa, but several other clients as well. There is an overall shift in the sense of responsibility that parents are now carrying towards their children and with our support they are able to channel the same to achieve the best outcomes for their children.



A small peg board made out of a shoe box and ear buds for pegs



A set of lacing beads made from bottle caps and shoe laces

Staying Connected

In an attempt to connect with the parent community and offer support in the wake of unsettling times, personalized phone calls were made to families of children enrolled in the Early Childhood Intervention (ECI) clinics. As a result, while some parents got a chance to express their concerns and share their changing needs, others took the opportunity to pass on their gratitude to the organization for going the extra mile for their children.

Furthermore, dedicated WhatsApp groups were set up with parents/caregivers for each therapy faculty i.e. Occupational Therapy (OT), Physical Therapy (PT) and Speech Therapy (ST). These groups served as platforms to help stay connected with the parent community and to share resources that would help them engage their children meaningfully in activities and exercises while staying at home. These groups continue to be active today and several resources are shared on a weekly basis with the parent community.

Internal Training

In order to share resources further, this time internally within the organization, a virtual training experience was launched. Each therapy department developed and conducted a workshop on their area of expertise and trained their colleagues as well as team members from across various departments in the organization on the basics of Occupational, Physical and Speech therapy. To date four such experiences have been organized and attended by a total of 50 participants.

Tele-health Support

Simultaneously, healthcare services such as the Development Pediatrics² Clinic, led by Dr. Sidra Kaleem³, was also brought online. Clients-children and teenagers with Down syndrome registered with KDSP, who secured appointments were provided tele-consultations via WhatsApp video call and they were able address their most urgent concerns. To date 18 tele-consultations have been provided and the tele-clinics are operational on alternate Saturdays.

Another immediate need that arose as result of the pandemic was access to affordable healthcare services for KDSP's family network. Children with Down syndrome often need regular medical attention and with the lockdown in place in addition to most OPDs and clinics in the city being shut or dedicated to COVID-19 response efforts, families were quite concerned.

² Developmental pediatricians focus on developmental, behavioral and learning issues your child faces from infancy through young adulthood. They are able to evaluate your child's overall development, provide a diagnosis, and recommend specific treatment plans.

³ Dr. Sidra graduated from Dow University in 2009, and later, she completed her residency in Pediatrics, followed by a fellowship in Pediatric Neurology from the Aga Khan University Hospital. She has recently completed her clinical fellowship in Developmental Pediatrics at McMaster University, Canada. She has been associated with KDSP since 2018.

As a result, a partnership was secured with Sehat Kahani⁴, an app based tele-medicine provider and a pioneer in the field, to offer free of cost primary healthcare consultations to children with Down syndrome registered with KDSP. Through the Sehat Kahani application, families could consult with general physicians, pediatricians and specialists, through their mobile phone, from the comfort of their homes, at any time of the day. Furthermore, in order to facilitate the team of doctors at Sehat Kahani and familiarize them with Down syndrome, a special training program was organized by KDSP's Awareness and Healthcare Department, in collaboration with a special team from The Agha University Hospital, before the service was officially launched to the family network towards the end of April. To date 4 families have signed up and have benefited from a total of 9 consultations on the Sehat Kahani app.

Performance at a Glance



⁴ <https://sehatkahani.com/>

Success Stories

Need based interventions

Each intervention planned and executed in response to the pandemic since March, has been a need based one which means that it is drawn from insights collected and concerns identified from among the Family Network⁵. This enabled the team to keep their energies focused and offer support to the family network in ways that proved to be meaningful for both. For example, the decision to move therapy services online and temporarily waive off all charges was taken to ensure that children enrolled in the ECI clinics do not lose out on any progress and so that their parents, who reported being stressed due to loss of work opportunities and having been restricted to their homes, can continue to focus on the needs of the child instead of worrying about finances.

Similarly, hearing concerns from the family network about not being able to access healthcare facilities, the team decided to introduce tele-clinics to host KDSP's in-house Developmental Pediatrics Clinic in addition to partnering with Sehat Kahani to provide free of cost tele-medicine support to children with Down syndrome and their families.

Increased parental involvement

One evident success that has come to the surface as a result of going virtual with therapies for children enrolled in the ECI clinics is that parents have been pulled into action, more aggressively than ever before. This change has come in because while the therapist is now at a distance, passing on instructions to the child through a video, the parents are the ones who are involved with the child physically, assisting him/her follow through and later taking notes from the therapist on what exercises to carry on at home and how. The team finds this change particularly exciting because over time it could bring in positive results in the child's progress. Ms. Najma Adam, Head of Occupational Therapy at KDSP, believes that a direct result of parents getting more involved with therapy has been that children's toilet training has picked up pace and their performance on ADLs⁶ (Activities of Daily Living) for example brushing teeth, changing clothes and cleaning around the house, has improved.

Additionally, the team has also seen the relationship between the therapist and the parents grow stronger as result of greater involvement. What is also quite exciting is that even the parents who used to be involved only passively during physical sessions or would not accompany their child into the therapy room, are now taking on a more active role.

⁵ Family Network is a term used to describe all the families of children and individuals with Down syndrome who are registered with KDSP and avail one or more of the services provided by the organization.

⁶ ADLs are basic self-care tasks that we expect all individuals to master: like getting dressed and undressed, feeding yourself, brushing your teeth, taking a shower and going to the bathroom.

Innovations introduced

While the team of therapists involved with the ECI clinics have had to stretch their strengths and capabilities to adapt immediately to tele therapy and maintain the highest quality of service, they have found innovative strategies to keep the children and their parents engaged. For example a number of therapists began to use dolls to demonstrate exercises and a few even went to the extent of using their own toddlers for the same. Similarly, a number of therapists brought in digital games and used the support of other applications like Zoom to make the interaction more entertaining for their clients.

Majority of the therapists have set up functional workspaces for themselves in their homes and have resourced various tools, material and equipment to facilitate their practice. They have also gone the extra mile to support parents and caregivers in creating resources and tools needed for therapy with material available at home. For example, using tape to mark lines on the floor for the child to follow and practice their walk, utilizing a stool in place of a walker, creating a parallel bar set up at home using PVC pipes and other innovative and cost effective ideas.

Additionally, many therapists have started encouraging parents and caregivers to record videos and take pictures of their children while performing assigned tasks and exercises. While this has helped the therapists keep a better track (visually) of the child's progress and identify areas of concern, it has also allowed for parents to become more active as they regularly send videos and pictures to their child's therapist. Furthermore it has provided the therapists with fresh resources in the form of videos and pictures that they are then able to share (with consent) with other parents who have to follow similar routines. These become a source of learning as well as inspiration for other parents.

In Speech Therapy particularly, the team has incorporated play into their practice and are encouraging parents and caregivers to use the same while training them on how to do so. This has proved to be beneficial in allowing the parents to establish stronger connections with their children and thereby see visible progress in their communication. For example one of the clients enrolled in Speech Therapy, Mohammad Mehdi has reported to have developed new vocabulary recently as a result of constant attention by the parent and the therapist.

Drop in Cancellations

Since taking therapy sessions virtually did not require parents to commute to the clinics and they could benefit from the service from the comfort of their homes and setup convenient schedules for themselves, there were fewer cancellations recorded from March onwards, as compared to the previous (pre-pandemic) months. More elaborately, when comparing average

weekly cancellation⁷ records from November 2019 to February 2020 (pre-pandemic) and March 2020 to June 2020 (during pandemic), a 28% drop was recorded.

Reach Beyond Karachi

Another positive that came as a result of the virtual shift was that it allowed the department to extend its reach far beyond Karachi as physical barriers such as commute, in-person interactions and payments were removed. A large number of families of children with Down syndrome who lived in other cities of Pakistan, especially rural Sindh and Punjab, as well as a few from outside the country, began requesting for tele therapy services as soon as these were introduced and they were slowly enrolled in the therapy clinics as soon as spaces opened up. Additionally, as the message spread further, families of children with Down syndrome even above the age of 7 years sent in requests for consultations and the Head of Departments from all three therapy faculties were engaged to address the incoming needs through one-time-consultations⁸ via audio/video calls-they heard the parents' concerns, assessed the individual's developmental needs and provided the parents with a basic plan on how to work on the same while at home. Since March, a total of 21 one-time-consultations including those from areas outside of Karachi.

⁷ A cancellation is recorded when a scheduled therapy session does not take place because the parents are not able to attend the session at the allotted time or the therapist is not able to attend to them at the allotted time or due to unforeseen circumstances the session cannot take place.

⁸ One-time-consultation refers to an audio/video call consultation that is provided once to a family, over a period of 3-6months, with the aim to address their most urgent questions regarding their child's development and to provide a basic therapy plan for them to follow with their child at home.

Challenges

Navigating Through a New Space

One immediate challenge that the team faced after going virtual was that time boundaries became blurry. For one, the therapists took some time in adjusting to new schedules and secondly parents found themselves reaching out to their therapists at odd hours or at unscheduled times because either they had missed their designated time slot and were eager to connect with the therapist to address their pressing concerns and questions. This was because both the therapists and the parents were setting up to navigate through a new space and its associated challenges as well as the emotional stress that comes along with those. Fortunately, by establishing firm time boundaries and adjusting schedules for those parents who were not able to meet their previous commitments, this challenge was overcome to a great extent and the additional pressure for the therapists was removed so that they could focus wholeheartedly on their clients and take care of themselves as well.

Connectivity issues

Since a number of families associated with KDSP come from humble backgrounds and from areas that are far off, they do not have access to reliable internet services and thus connectivity has come up as a challenge as the team has moved forward with the virtual shift. In order to overcome this however the team has been able to identify those families with no or very poor internet access or those that do not own a smart phone and has offered them therapy services via regular phone calls. This way, although the therapist is not able to see and interact with the child directly, they are able to connect with the parents and guide them on how to work with the child, while asking for regular updates and staying connected through text messaging. At KDSP, no one is left behind.

Additionally, connectivity issues also paly in at times during otherwise smooth interactions via WhatsApp video calls. Electricity outages, no data or simply weak connections often cause calls to break and as a result children lose attention and at times parents tend to become agitated as well. This is a difficult challenge to overcome fully, however therapists make up by giving extra time to the client in the next session or reconnecting with the parent again at a different time during the day.

Parents under-resourced for therapy practice at home

Since the country-wide lockdown was imposed almost overnight and operations moved online, families did not get a chance to fully equip themselves to practice therapy at home. Additionally a number of families could not afford to invest in basic therapy material and equipment like gym balls, parallel bars, flashcards, functional objects, etc. This meant that their children's therapy could be hindered, however the team of therapists at KDSP supported families in helping them learn how to use items easily found at home to practice therapy with their children for example plastic cups and saucers, dolls, stools, etc. Some families were even taught

how to build their own resources, for example the parents of a child enrolled in Physical Therapy who was required to practice his walk regularly, were trained to set up a parallel bar system in their house using PVC pipes and duct tape which was both cost-effective and ingenious. Similarly a number of families were trained to build their own equipment and make the best use of all resources readily available at home in order to ensure that their children continue to receive support.

Stretching Internal Capacity

With an influx of requests coming in for tele therapy and one-time-consultations from within and outside of Karachi, in addition to serving the existing clientele coupled with the constant need of learning from and adapting to a changing environment, staying constantly connected with families, training them extensively and supporting them emotionally as well, the team of therapists found themselves stretched for time and energy, putting in their fullest every day. In order to avoid burn-outs and enhance capacity, support was brought to the team in the form of close supervision and guidance from the Head of Departments, training opportunities in how to maneuver through the online realm and efficient scheduling to ensure that all therapists get a break during their otherwise packed day. Additionally, (2) new therapists were also hired during this time to enhance the department's internal capacity and cater to the clients waiting for their turn to begin tele therapy.

Beneficiary Quotes

Ms. Arshia Ahmed, the proud parent of a very active client, Sarah Ahmed, reached out the management soon after the virtual shift took place and shared how she was grateful for the support extended to her and her daughter. She wrote, "I can never thank you enough for the wonderful phone calls to Sarah. At a time like this, these phone calls are like a breath of fresh air for me!"

While commenting on how they stay connected with their child's therapist, Ruhaab Fatima's parents were quite excited to share:

"We send new videos to the therapist regularly for feedback and her response is very helpful".

When being asked about her experience with the virtual shift, Mustafa Kashif's mother shared that she is satisfied with the quality of the service and is grateful for the effort put in by the team as "they go out of their way for Mustafa". She added, "I am grateful that KDSP has stuck by us".

While talking about the most helpful interventions introduced during recent times to support parents, Anabia Rehman's father immediately mentioned the dedicated WhatsApp groups created for parents to stay connected with the team of therapists from each department. He added, "This is brilliant because it lets us see different activities and then practice the same with Anabia...we would like more activities to be shared on there, along with more local examples".

Ayra Haris's mother, shared how she finds the video calls very "helpful". She mentioned that she is able to follow the therapist's guidelines clearly and if she has any questions those are promptly and sufficiently addressed by the therapist.

The Way Forward

Although the virtual shift has brought in its set of unique challenges, it has also opened up several new opportunities for innovation and progress. The team is quite excited looking at increased parental involvement and deeper connections forming between parents and therapists, among other initial successes, imagining that these would over the next few months bring in positive results in form of progress among children continuing to take therapy virtually.

Moving forward, the team is planning to introduce a new and improve existing systems to support the family network for example, offering temporary financial aid to families who are adversely effected by the pandemic, creating a digital guidebook containing a vast array of activities and exercises parents can use with their children at home, introducing capacity building programs for therapists, as well as parents/caregivers, and enhancing e-health services available for children with Down syndrome.

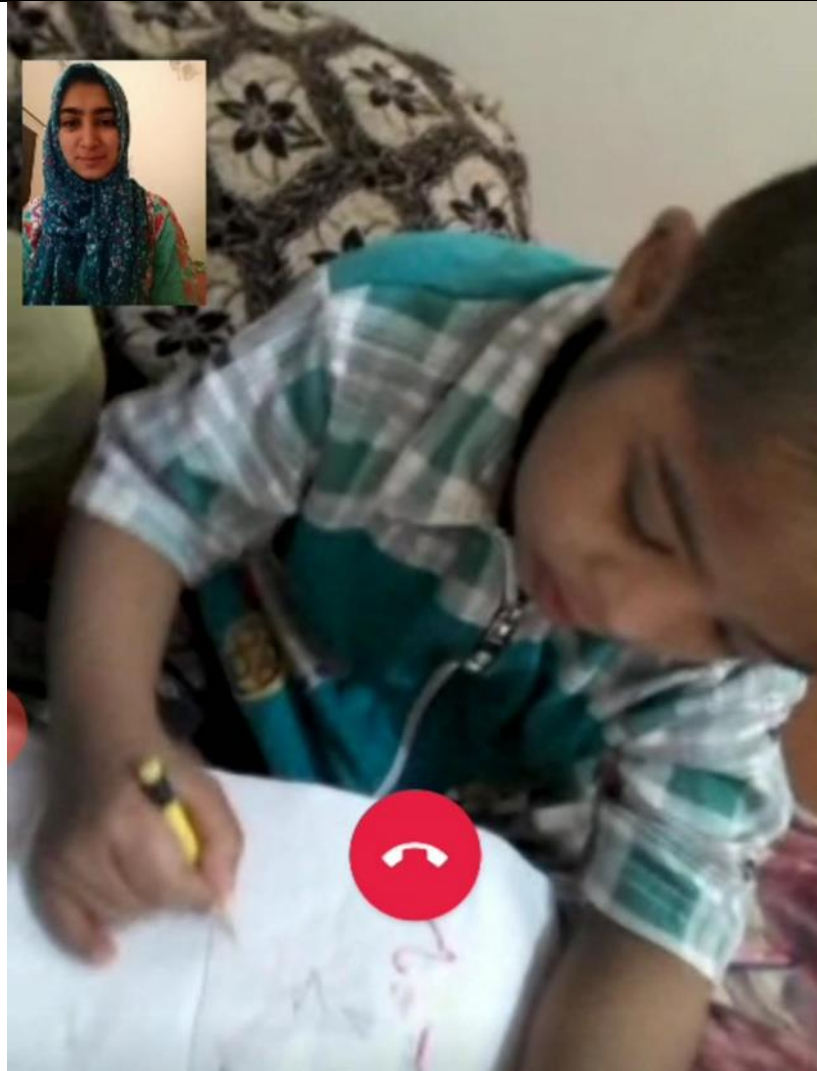
Pictures



Caption 1: A tele therapy session in action with a client and his therapist



Caption 2: Tele-therapy sessions in progress with clients via WhatsApp Video Call



Caption 3: A tele-therapy session taking place for Occupational Therapy



Caption 4: A set of shape cards made by a parent using chart paper



Caption 5: A parent working with her son at home helping him put a pencil through a hole in a tin can



karachidownsyndromeprogram



Caption 6: A glimpse from the virtual MOU Signing Ceremony between KDSP & Sehat Kahani