The Extra Mile KDSP'S COVID-19 RESPONSE

March 2020 to August 2020



COVID-19: First Step of Risk Aversion

At KDSP, ensuring good health and well-being of all individuals with Down syndrome is an utmost priority. Since some children with Down syndrome also have certain underlying health conditions – including respiratory concerns – the outbreak of COVID-19 in Karachi made it imperative for KDSP to safeguard their health.

On March 14, 2020, KDSP became amongst the first organizations to halt its on-ground services and make a 100% shift to offering virtual services in the best interest of individuals with Down syndrome and their families, its employees and the larger community.

Adapting Services and Creating New Opportunities

The COVID-19 pandemic brought along a host of uncertainties. But, one thing was certain for KDSP: it was determined to continue lending support to individuals with Down syndrome and their families, which led KDSP to adapt all its services, along with creating new opportunities for increasing the scale and repertoire of services, for the new normal.



About KDSP

The Karachi Down Syndrome Program (KDSP), a non-profit organization, was launched in March 2014 by a group of concerned parents and passionate individuals who, due to limited support and resources available locally, realized a need for a platform for those with 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 independent and fulfilling lives.

KDSP seeks to empower and support individuals with Down syndrome such that feelings of helplessness and despondence amongst parents and families of individuals with Down syndrome are relieved. KDSP achieves this through the provision of quality services and reassurance.

From the moment a family with an individual with Down syndrome is introduced to KDSP, until they feel empowered, included and equal members of society, KDSP embarks on a journey with them. In this journey, KDSP serves as a KASHTI through its 6 core areas of services:

Areas of Service



Empowering parents and caregivers through informational, emotional and financial support to become best advocates for their loved one with Down syndrome.



Raising awareness about Down syndrome through digital media campaigns, distribution of awareness material in schools and hospitals, public events such as the all-inclusive annual carnival and partnering with relevant stakeholders in the community.



Facilitating individuals with Down syndrome through access to affordable, high quality healthcare services by partnering with leading healthcare organizations such as the Aga Khan University Hospital (AKUH).



Organizing vocational skills training, social, physical and intellectual development programs to cater to children and adults with Down syndrome as well as their families.



Providing children with Down syndrome access to mainstream educational system by inculcating school readiness skills in children with Down syndrome, developing sustainable partnerships with mainstream schools and hosting trainings and workshops for teachers, allied professionals and parents.



Providing a comprehensive program of speech therapy, occupational therapy, and physical therapy for children with Down syndrome to help achieve their developmental milestones timely and pave the way for their independent living.

Family Support

Khandani Sahara

Adapting Services

Virtual Family Support Group Sessions

Informational support regarding all aspects of Down syndrome continued via weekly Facebook live sessions.





Initial guidance counseling and registration support offered to all families continued over phone calls.

Weekly Yoga and Wellness Sessions

Mothers of individuals with Down syndrome continued to enhance their physical and emotional wellness via Zoom.





Annual Family Network Survey

100 families participated in a phone call survey to share their feedback and experience with KDSP's services, enabling KDSP to improve service quality even further.

Humrahi Selection and Training

A group of parent peer counselors (Humrahis) were trained via Zoom over 8 weeks. The training equipped Humrahis with basic counseling skills and imparted a detailed understanding on Down syndrome, so they could lend informational and emotional support to other parents and caregivers.



Our Impact

New families registered through tele Family First Contact Meetings

400+

Parents and caregivers provided informational support across 17 weekly virtual Family Support Group sessions

Humrahis fully trained with a 60% change in perception of support they will offer to other parents and caregivers in KDSP's Family Network.



Family Support

Khandani Sahara

New Opportunities

Wider Reach

With geographical boundaries becoming blurred due to the introduction of virtual services, a greater number of individuals with Down syndrome and their families residing outside of Karachi registered with KDSP to benefit from services.





Monthly Grocery Packages and Cash Disbursement

To provide relief to families impacted financially due to COVID-19, KDSP arranged for monthly grocery packages and cash transfers through Easypaisa from April 2020.

IRD's Mental Health Counseling Helpline

To help parents and caregivers get through uncertain times, KDSP collaborated with the Interactive Research and Development (IRD Pakistan) in April 2020 to extend IRD's Pursukoon Zindagi initiative's free mental health tele-counseling service.



Our Impact

76% Increase in number of families registering with KDSP from

outside of Karachi

180+ Households benefited

through the monthly grocery distribution and cash transfers.



Awareness

Agaahi

Adapting Services

COVID-19 Sensitive Communication

Internal and external communications were adapted for COVID-19 sensitivity, with safety instructions shared and reinforced across all virtual platforms such as email, social media, and official WhatsApp groups for KDSP's Family Network.

Virtual Awareness Sessions and Collaborations

• Digital Baithak

In March 2020 KDSP collaborated with NOWPDP to host a live Digital Baithak which aimed to address questions about COVID-19.

In August 2020, Ms. Samar Naqvi, KDSP's COO was invited to speak about "Mental Health of Children with Disabilities" in a Digital Baithak hosted by AKUH and NOWPDP.

Sensitization Sessions

Awareness sessions were adapted for the virtual space and offered via Zoom to several schools and organizations, such as; Nixor College,Sehat Kahani, NED University, Adal aur Sehat and Interactive Research and Development (IRD).

UNAP MOU Signing

In April 2020 an MOU was signed with IBA's Chapter of United Nations Association of Pakistan (UNAP x IBA) to promote Down syndrome awareness initiatives.

• Frequently Asked Questions about COVID-19

In September 2020 with AKUH's collaboration, an informative video was released for the Family Network in which Dr. Sidra Kaleem and Dr. Salman Kirmani addressed COVID-19 related concerns specific to individuals with Down syndrome.

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160+

Individuals sensitized about Down syndrome through virtual sessions

Healthcare

Sehat

Adapting Services

Developmental Pediatric Tele-Clinics

The Developmental Pediatric Clinics by Dr. Sidra Kaleem provided consultations via WhatsApp video calls to individuals with Down Syndrome.

AKUH Tele-Consulting Clinics

Consulting clinic at the Aga Khan University Hospital (AKUH) became virtual and KDSP facilitated the Family Network with tele-clinics, April onwards.

Sponsored Hospitalizations and Medical Procedures

KDSP continued to sponsor hospitalizations and medical procedures at its partner healthcare organizations of individuals with Down syndrome with varying healthcare needs.

New Opportunity

Collaboration with Sehat Kahani

With the lockdown in place and most clinics in the city being shut or dedicated to COVID-19 response efforts, families were quite concerned. As a result, in April KDSP collaborated with Sehat Kahani, an app based tele-medicine provider to offer free of cost and quality primary healthcare consultations to individuals with Down syndrome registered with KDSP.



Our Impact





Healthcare facilitations via Developmental Pediatric Clinics, AKUH Tele-consultation and Sehat Kahani

10 Medical procedures

Enrichment and Skills Development

Hunar

Adapting Services

Adult Enrichment

Arts and Crafts, Paper Crafts, Block Printing and Yoga resumed after a brief pause through weekly pre-recorded video tutorials or Zoom sessions with the help of dedicated instructors. Craft kits were delivered to participants at home with all the tools they required to hand-craft master pieces.



Child Enrichment

Music and Movement was re-launched as 'Tele-Rhythm and Movement', and continued to enhance children's physical fitness and creative expression via Zoom sessions. In May, live virtual story time sessions were launched in collaboration with Nazia Kashif from Mommies and Muffins.

New Opportunities

Fit 5 Module

A physical fitness module for adults with Down syndrome was launched in April 2020 in collaboration with Special Olympics Pakistan (SOP). The SOP coaches shared detailed weekly dietary and exercise plans through engaging videos and infographics.

Exploring Art Sessions

The sessions, led by Sana Asad, were launched in July 2020 to teach sketching and painting techniques as a form of self-expression to reconnect with themselves and seek relaxation.

Our Impact

50%. Increased effort by instructors towards imparting skills

Adults and children engaged in skills development activities

5



Cooking and Baking Classes

Virtual classes began in July 2020 in collaboration with Sugaries Bakery where Ms. Mahwish Aziz and the enthusiastic chefs-in-training with Down syndrome enjoyed making delicious desserts.



Education

Taleem

Adapting Services

Early Preschool Experience Program (EPEP)

Parents received regular feedback and support from the preschool teachers to ensure learning continued through virtual means.

Program for Inclusive Education (PIE)

Facilitations for teachers and students with Down syndrome for virtual classes continued. Mainstream school admissions coordination for the new academic year was also simultaneously started off.

Tailored Assistance Program (TAP)

Parents were provided with after-school home learning packs and received regular feedback and support from the TAP teachers.



Inclusive Education Toolkit Workshop Series

The workshop series was launched in June for training teachers and parents on best practices of inclusive academic interventions. Professionals, teachers and parents participated in interactive sessions conducted by experienced professionals and experts in the field.

New Opportunity

Remote Education and Learning for Youth (RELY)

This new program was launched in April 2020 to equip caregivers with the information and online resources to create an ad-hoc education plan for their children with Down syndrome at home. The Education continues to provide guidance on how to cultivate an environment at home that is conducive to the learning of a child.

Our Impact

Children benefited

from preschool home plans and achieved overall 27% improvement in their academic outcomes

26

Participants benefited from Inclusive Education Workshop Series with reporting a 40% increase in their learning

21



Children benefited from home-based learning and completed 60% of the assigned activities with the help of parental involvement

6

local and international experts engaged for developing an educational plan during COVID-19.

Early Childhood Intervention

Ibtidayi Bunyaad

Adapting Services

Virtual Therapies

Speech, physical and occupational therapy sessions were offered via audio and video calls to ensure therapies continued as per schedule.



New Opportunities

Increased Parental Empowerment

Virtual therapies led to a palpable increase in parental involvement. A language of love, 'physical touch' was expressed and received by the child, through the parent, as parents practiced and followed therapists' instructions. Parents became more actively engaged as they regularly sent videos and pictures of child's progress to the therapists.

Innovations at Home

Therapists and parents arrived at innovative and cost-effective solutions to continue the child's developmental progress at home. For example, tape was used to mark lines on the floor for the child to practice walking, a stool was used in place of a walker and a parallel was set up at home using PVC pipes.

Efficient Channels of Communication

Dedicated WhatsApp groups were set up with parents/caregivers for speech therapy, physical therapy and occupational therapy. These groups served as platforms to help stay connected with the parent community and benefit from informational resources

shared by therapists.

Knowledge and Skills Enhancement

Internally within the organization, each therapy department developed and conducted a virtual workshop on their area of expertise for their colleagues on the basics of Occupational, Physical and Speech therapy.



Our Impact

320 Virtual therapy sessions scheduled weekly

50%

Increase in number of therapy sessions conducted

55%



Therapy sessions conducted via video calls

55%

of the parents felt empowered to practice therapy with their child

42%

6

Parents felt virtual therapy sessions have contributed to their child's developmental progress

13%

Increase in attendance and punctuality by Therapists'

0

Hear from the Beneficiaries

"My family availed monthly ration bag distribution service for about five months. Ration was provided to us at our doorstep. We were treated very well, with much respect."

> - Muhammad Hanif, Father of Khadija Hanif

"It's very unfortunate that due to the lockdown, children were unable to attend classes physically, but it's great that the teachers continued to facilitate us as best as they could virtually."

> - Fehmina Rizwan, Mother of Rumaisa Rizwan

"Even though the skills development sessions have shifted to a virtual platform, I still ensure Fatimeh follows the same routine for attending them as she did previously for in-person classes. Fatimeh loves Yoga with Ms. Dhanak, Music and Movement classes with Sir Faizan and Arts and Crafts with Ms. Mahtab and Ms. Sadia. I have seen outstanding improvement in her skills. I witness her do wonders when I give her my time, sit with her and guide her when she makes a mistake."

> - Mahroo Khanum, Mother of Fatimeh Shirazi

"I am glad I decided to attend virtual yoga sessions for mothers during lockdown days. Yoga helped me relax physically and mentally. These one-hour weekly sessions are something I really look forward to after a very tiring week."

> - Naghma Jamshed, Mother of Abdullah Hasnian

"KDSP is doing wonders right now. Hasan has been taking part in the arts and crafts class as well as painting and cooking classes. He always has an excellent time."

> - Ayesha Patel, Mother of Hasan Patel

"I consulted with Dr. Sidra virtually and was provided with detailed guidance. She evaluated my child's development thoroughly and recommended some medical tests he needed. Since I don't even reside in Karachi, I am happy I had the option of availing this consultation from the comfort of my home."

> - Amna Sundas, Mother of Muhammad Wali

While talking about the most helpful interventions introduced during recent times to support parents, Anabia Rehman's father immediately mentioned the dedicated WhatsApp groups. 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 there, along with more local examples"

> - Abdul Rehman, Father of Anabia Rehman

Acknowledgement

KDSP's COVID-19 Response was made possible through the gracious support of various individuals and organizations. A heartfelt thank you to the following organizations for going an extra mile for individuals with Down Syndrome and their families:









Danish Aman and his Saturday Welfare Group Team

The Way Forward

KDSP intends to continue its virtual services to ensure greater accessibility of its services for individuals with Down syndrome and its families. At the same time, KDSP is gradually, yet cautiously, planning to resume its on-ground services in the best interest of the overall development and wellbeing of individuals with Down syndrome. We can't wait to welcome our families back once all COVID-19 safety measures are in place at the premises!



Your Support keeps our Kashti Going!

KDSP's promise to provide high quality subsidized cost services has been elevated further to ensure no individual with Down syndrome is left behind during this challenging period of COVID-19. Your unwavering support has, and will continue to, support these brave hearts and intelligent minds.

Please consider donating generously to any of the following areas:

General Donation	Zakat	
Specific Donation		
Family Support (Khandani Sahara)	Education (Taleem)	
Awareness (Agaahi)	Early Childhood Intervention (Ibtidayi Bunyaad)	
Healthcare (Sehat)	Financial Aid	
Enrichment and Skills Development (Hunar)		

You may make your Donations and Zakat contribution in any of the following ways:

Cash or Cash Cheque	Direct Bank Transfer
Give your contributions by hand to our Fundraising	Transfer your contributions to the relevant KDSP
representative at the KDSP office.	Bank Accounts.
Crossed Cheque	Online Transfer
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"Karachi Down Syndrome Program" and dispatched	or Mastercard) using the HBL Secure Payment Portal.
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- For Bank and Online Transfer, once your transaction is complete, please notify the Fundraising Team by sending a screenshot via WhatsApp to 0315-3300033 or e-mailing at fundraising@kdsp.org.pk

Contact us

021-34395377 | 021-34315377 0334-3355377

5th Floor, Jason Trade Centre Shahra-e-Faisal, Karachi - Pakistan

info@kdsp.org.pk www.kdsp.org.pk





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