



OUR PROFILE



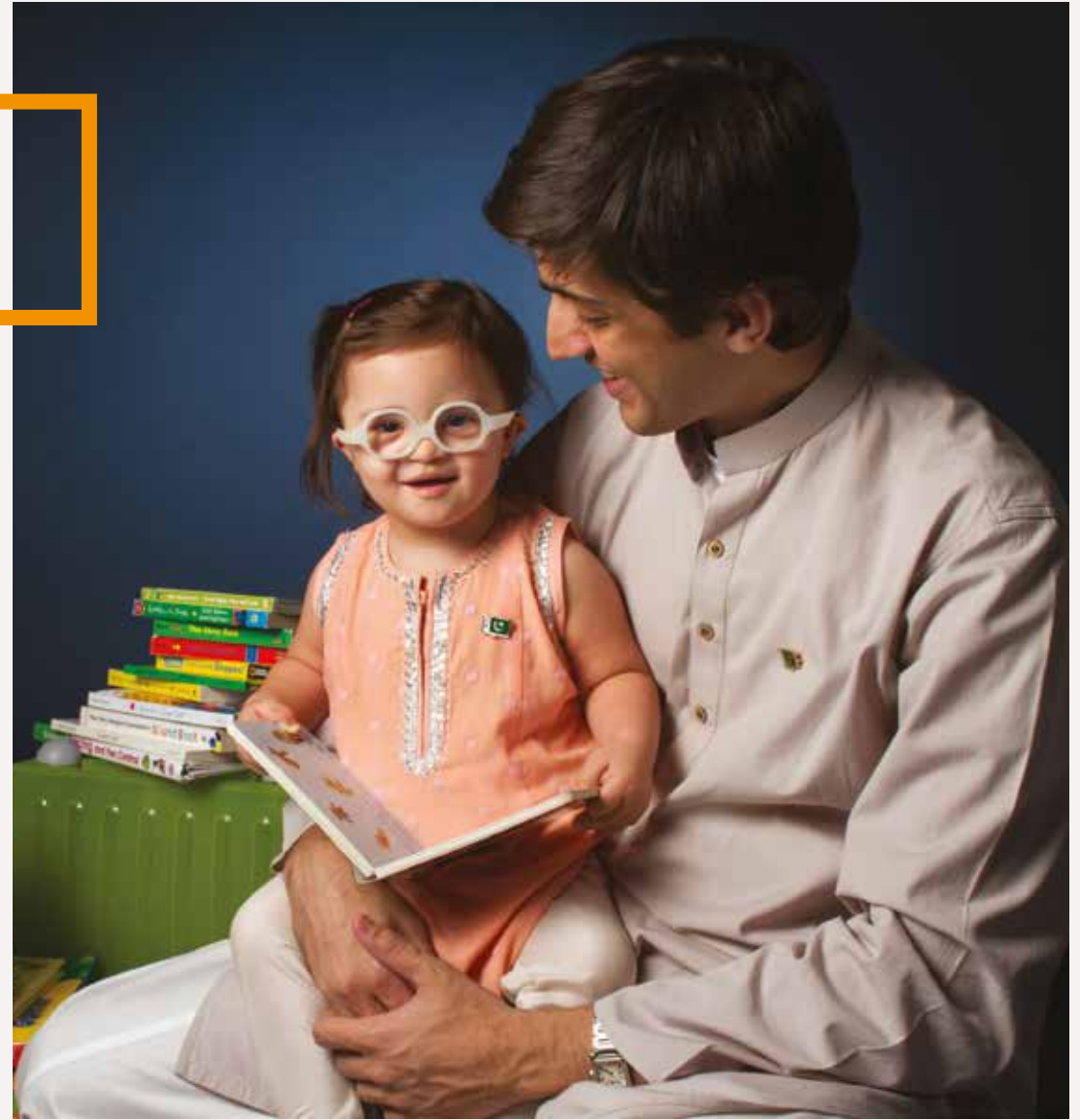
Karachi Down Syndrome Program



RECOGNISE  
THE POSSIBILITIES

# Our Story

“ If you ask any parent of a child with special needs, they will tell you that having them changes you in ways you could never have imagined. ”



**I**t is an overwhelming thought. The fact that what seemed like our darkest days more than seven years ago, led to the creation of something that has been a source of ease and support for hundreds of others. Truly, there are forces that are working beyond our control, planning things for us that we cannot even fathom. Truly, Allah is the best of planners.

On January 12, 2011, we were gifted with a baby girl, Alaiyah. We learnt of her diagnosis of Down syndrome after her birth. Down syndrome is the most common chromosomal conditions with approximately 1 out of every 700 children being born with it. It is important to understand that Down syndrome is not a disease. It occurs when the cells in the human body contain a full or partial extra copy of chromosome 21.

Alaiyah had a cardiac arrest a few hours after she was born, had to be resuscitated and was put on a ventilator. Countless complications and blood transfusions later, she finally managed to pull through. We held her for the first time exactly twenty days after she was born. We brought her home after she spent a month in the NICU. While we thought we would be leaving behind all the trauma following her birth once we left the hospital, little did we know the real ordeal was awaiting us. Intending to find out everything about Down syndrome and the ways in which we could help our daughter grow and progress, we were unable to find a single institution that was equipped to help and guide us. Leave alone providing the services that she needed, we were unable to even find accurate and relevant guidance.

If you ask any parent of a child with special needs, they will tell you that having them changes you in ways you could never have imagined. You start looking at the world through a different lens. There are many joys and many rewards. There are so many more challenges too. But when you love someone so desperately who is part of a marginalized group, you do learn to overcome. You learn to rise above all the unsolicited advice, unkind comments, curious stares, and moments of complete and utter frustration.

And if you are really lucky, if all the forces in the universe are conspiring in your favour, you are given the opportunity to start a ripple in the water. In early 2014, we along with a group of other motivated parents and family members of children with Down syndrome, set up the Karachi Down Syndrome Program – the only organization in the country exclusively advocating for the acceptance and inclusion of people with Down syndrome. The motivation behind setting up KDSP was to change the experience of all those who were to become future parents of children with Down syndrome. We didn't want others to go through what we had to go through.

KDSP envisions a world in which all people with Down syndrome are respected, accepted, included and are given the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. We strive to achieve this through advocacy at various forums and more importantly, by providing day-to-day services essential for the development and well being of individuals with Down syndrome and their families.

It is our hope that you will be able to join our cause in the capacity of a benefactor, donor, volunteer, collaborator or simply a well-wisher, and help us drive our mission forward of creating a loving and inclusive society.

**Farzeen Ali and Ali Allawala**

# Board of Directors



**Ali Allawala**  
Director and CEO

- BBA, Institute of Business Administration, Karachi
- MSc, London School of Economics and Political Science
- LL.M, Kings College, London
- Currently works as a Director at Tecno Pack Industries Pvt. Ltd.



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- Currently works as a CEO at Elahi Group of Companies



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Director

- MBBS, Dow Medical College
- Residency & Fellowship, Mayo School of Graduate Medical Education, Mayo Clinic, USA.
- Certified by the American Boards of Pediatrics, Medical Genetics and Pediatrics Endocrinology.
- Currently works as a Chairman at the Aga Khan University Hospital, Department of Pediatrics & Child Health, since September 2014.



**Farzeen Ali**  
Director and Deputy CEO

- BBA, Institute of Business Administration, Karachi
- MSc Finance and Accounting, Brunel University, London



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Director

- BA, PECHS College
- AMI Certificate, Montessori Teacher's Training
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- Currently works as a Sales Director at Unilever Pakistan Limited



**Javeria Siddiqui**  
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- MBA, Institute of Business Administration, Karachi
- Currently works as a Category Manager, Chocolates at Mondelez Pakistan Pvt. Ltd.

# Areas of Service



Karachi Down Syndrome Program

## AWARENESS

Awareness raising activities are conducted through various means, including hosting awareness sessions in educational institutions across the city, organizing an all-inclusive annual **carnival**, publishing bi-annual **newsletters**, developing **awareness videos**, launching **outdoor media campaigns**, and publishing a **children's book on inclusion**.



## EARLY CHILDHOOD INTERVENTION

Early Childhood Intervention refers to a program of physical, speech and occupational therapy designed for a child's specific needs. Currently, more than **300** Early Childhood Intervention therapy sessions are held weekly.





## FAMILY SUPPORT GROUP

Family Support Group sessions are held monthly to bring together families of individuals with Down syndrome and educate them on various aspects of the condition. Over 60 Family Support Group sessions have been hosted by KDSP for over **860** families in the Family Network.



## ENRICHMENT PROGRAMS

KDSP holds a range of programs to cater to individuals with Down syndrome of varying age groups and their families. **Arts & crafts** and **yoga classes for adults**, whereas **storytime** sessions, **Young Athletes** program, **Gymboree on the go**, **clay and art therapy sessions**, and **summer camp** for children with Down syndrome.



## EDUCATION AND TRAINING

KDSP's Education & Training programs are intended to successfully integrate children with Down syndrome into the mainstream educational system in Karachi. KDSP has **15** partner schools and 41 children under its Program for Inclusive Education (PIE) and 39 children benefiting from its Early Preschool Experience Program (EPEP).



## HEALTHCARE

KDSP collaborated with **Aga Khan University Hospital (AKUH)** in April 2017 to introduce a first of its kind **one-stop health solution** to facilitate children with Down syndrome and their families. With the launch of Down Syndrome Clinic at AKUH, parents can bring their children to see different health specialists in one clinic.



# Awareness

“ One of KDSP's primary mission is to raise awareness about Down syndrome amongst the masses to transform their mindsets. The aim is to create an inclusive society where people with Down syndrome are welcomed, recognized for their abilities and provide access to equal opportunities. ”



A vast majority of our society harbours outdated stereotypes for people with special needs, including those with Down syndrome. The same stereotypes are reflected in some parents in the form of shame and fear when they have a child with Down syndrome. They fear whether their child would be able to live amongst others and become a contributing member of the society. Inevitably, the mindset of the larger society and of the parents prevent those with Down syndrome from achieving their full potential.

One of KDSP's primary mission is to raise awareness about Down syndrome amongst the masses to transform their mindsets. The aim is to create an inclusive society where people with Down syndrome are welcomed, recognized for their abilities and provided access to equal opportunities.

KDSP launched its first awareness campaign ahead of World Down Syndrome Day on March 21, 2015 to introduce the public to its mission. A billboard campaign was developed to highlight the abilities of children with Down syndrome. It was a struggle to find families to participate in the photo shoot for the billboard campaign. Nonetheless, this one-of-its kind billboard campaign was well received. The families were overjoyed to witness the public welcoming such an initiative.

KDSP also organized a carnival on World Down Syndrome Day 2015 to celebrate individuals with Down syndrome. More than 1500 people came together to celebrate the day, proving that an inclusive society is truly possible. Families of people with Down syndrome, their friends, volunteers, celebrities and friends of KDSP came together for an evening full of fun, games, dance, delicious food – and best of all, the most heart warming smiles!

The first campaign and carnival started a ripple of change! Since then, KDSP's annual campaigns and carnivals have won the hearts of thousands of people. It is encouraging to see an increasing number of people join the World Down Syndrome Carnival each year, making it possible for us to cater to an audience of over 5500 people in KDSP's most recent carnival. It is an honour for KDSP to have collaborated with celebrities and other like-minded individuals to launch campaigns and release awareness videos to reach out to a wider audience. Their

support enabled a viewership of over 46,000 people for KDSP's awareness video released in 2020.



KDSP's Family Network database has grown to include over 860 registered families of individuals with Down syndrome as more people have found out about KDSP. Now, numerous families in the Family Network database request for their child to be featured in the annual awareness photo shoot. From having to convince families to feature their child, to unfortunately having to turn down interested families due to limited spots, KDSP has created an enduring impact along the way: The families themselves are now more accepting of their children and have realized that Down syndrome is a condition that is nothing to be ashamed about. Stereotypes are being dismantled. A truly inclusive society finally feels within reach.

Other than the annual awareness campaign around World Down syndrome Day, KDSP has held awareness sessions in educational institutions across Karachi, published a children's story book on inclusion called Aiza Alina in collaboration with Bookgroup, held an interschool competition to inculcate the importance of inclusion in school-going children, and has participated in morning shows to talk about its work.

# Early Childhood Intervention

“ Early Childhood Intervention refers to a comprehensive program of physical therapy, speech therapy, and occupational therapy to meet the developmental needs of a child. Children with Down syndrome may experience delays in achieving their developmental milestones. ”



**S**ilah is a little girl who came to KDSP when she was a few weeks old. Knowing that the first 1000 days of a child's life are extremely crucial for their development, she was immediately enrolled in KDSP's Early Childhood Intervention (ECI) Program. As a parent, one eagerly looks forward to their child's key milestones. There is no greater joy for a parent than witnessing the first time their child rolls over, their first smile, the first time they sit up without support, or the first baby step they take. Silah's mother is no different, she eagerly waits for Silah to achieve all her developmental milestones.

Early Childhood Intervention refers to a comprehensive program of physical therapy, speech therapy and occupational therapy to meet the developmental needs of a child. Children with Down syndrome may experience delays in achieving their developmental milestones. Care and guidance in the form of Early Childhood Intervention enhances their chance at achieving key developmental milestones in a timely manner.



Unfortunately, Karachi faces a serious dearth of quality Early Childhood Intervention care suited to the needs of children with Down syndrome. Lack of best practices in the field left many parents disappointed and longing for a facility where quality Early Childhood Intervention services were offered at an affordable cost.

Recognizing this gap in services and pressing demand from the parents, KDSP launched highly subsidized Early Childhood Intervention clinics in 2015 for children between 0 to 7 years. KDSP's Physical Therapy Department is run under the expert guidance of Dr. Zehra Habib, the only physical therapist in the country with a PhD, whereas Ms. Amina Siddiqui from Ziauddin University guides KDSP's Speech Therapy clinics.

Currently, more than 300 Early Childhood Intervention therapy sessions are held weekly, benefiting many like Silah. With consistent support through physical therapy, Silah started sitting without support at 6 months. The joy of Silah's mother and her therapist knew no bounds when they witnessed her achieving this milestone! Citing Silah's example and her mother's unwavering commitment for her daughter, KDSP encourages parents to begin Early Childhood Intervention early to maximize their child's potential.

A distinguishing feature of the ECI Program is its focus on research. KDSP's Physical Therapy Department conducted the first research of its kind on "The Effect of Early Intervention Physical Therapy using the Parent Empowerment Program for Pakistani children with Down Syndrome." The research was accepted for a poster presentation at the annual Combined Sections Meeting (CSM) by the American Physical Therapy Association (APTA) held on February 23, 2018 at New Orleans. The research poster also won KDSP the Global Health SIG award for Social Responsibility.

# Family Support

A young girl with Down syndrome and her mother are smiling and embracing each other outdoors. The girl is wearing a light purple t-shirt with a heart design and has a pink hair clip. The mother is wearing a white lace top with floral patterns. The background is a soft-focus green and yellow, suggesting a park or garden setting.

“ The sessions function as a forum where parents and caregivers can discuss new information, share ideas, navigate the challenges of raising a child with Down syndrome together, and offer emotional support to each other. ”

Discovering that one's baby has Down syndrome can be very overwhelming. Families and caregivers are met with countless questions, uncertainties and often feel alienated. During this time, the single most important source of relief can be someone who has gone through the same experiences.

Family Support Group sessions have been a regular feature of our Family Enrichment Program since our inception. Each monthly session brings together 35-45 parents and caregivers to facilitate better understanding of Down syndrome and associated conditions, enhance coping skills, and empower them to become advocates for their child. The sessions function as a forum where parents and caregivers can discuss new information, share ideas, navigate the challenges of raising a child with Down syndrome together, and offer emotional support to each other to develop a sense a belonging to a community. An expert is also invited in each session to discuss various issues pertaining to education, healthcare, development, and emotional well-being.



# Enrichment Programs

A young boy with short dark hair, wearing a red, white, and blue plaid button-down shirt, is smiling warmly at the camera. He is standing outdoors in front of a background of lush green plants and foliage. The lighting is bright and natural, suggesting a sunny day.

“ KDSP runs several enrichment programs designed to identify and hone skills and talents that an individual may possess. ”



**T** rue to its vision of helping people with Down syndrome lead fulfilling lives and in light of the nearly negligible opportunities available to them, KDSP runs several enrichment programs designed to identify and hone skills and talents that an individual may possess. Enrichment Programs are divided into children and adult enrichment programs and they are offered at a subsidized rate.

Our child enrichment programs go hand in hand with our Early Childhood Intervention program and aim to cater to children across all age groups beginning from birth. Programs such as Gymboree (in collaboration with Gymboree Pakistan) and Story Time (in collaboration with Hiba Masood from Drama Mama) contribute to children's intellectual, social and gross motor development, whereas Music and Movement sessions reinforce physical and social skills through musical and play based activities.

Adult enrichment programs comprise of weekly morning yoga sessions, and a skill-based Art and Craft program. The sessions are conducted by Mrs. Mahtab Pirzada who is a home-based craft entrepreneur and a former creative consultant for the Sindh Rural Support Organization. Under her mentorship, the adults hone their fine motor skills by learning how to cut, sew, weave and embroider. They learn to make handicrafts such as cushions, rugs, phone covers, bags, key chains and stuffed toys. The products are then sold through different avenues and full proceeds of the sales are returned to the participants to give them a sense of financial empowerment as well as to encourage a passion for entrepreneurship.

KDSP takes great pride in all the crafters who have, over the years, diligently developed their skills through these Art and Craft classes. Rabiya is no exception. She has been attending our Art and Craft program since its launch in 2015. Her aesthetic sense and love for crafts is palpable in the handicrafts she makes. Rabia dreams of owning her own car one day. She has dedicated herself to enhancing her crafting skills to make and sell more products. Rabia couldn't contain her happiness upon receiving the first earnings of her handicrafts sale. The twinkle of excitement in her eyes while receiving the envelope of cash from her mentor made everyone smile. She knew she had made it a step closer to her dream.



# Education & Training

“ KDSP decided to take on another challenge: Finding mainstream schools which would offer admissions to children with Down syndrome in an inclusive learning environment. ”



When the children who were receiving Early Childhood Intervention at KDSP clinics reached a school going age, their parents started enquiring about their child's educational prospects. "My other typical daughter started going to school at this age, would she also be able to go to school? Would schools accept her? Would she study with typical children or with children with special needs?"

Research confirms that children with Down syndrome learn best in a mainstream environment with typically-developing peers. Inclusive education not only benefits the child who has extra learning needs, but also inculcates in typical children the important values of empathy, compassion and kindness. Upon learning about the possibility of inclusive education, one relieved parent said "Everyone told me my child would have to study in a special school. You know, he isn't too different from his typically developing siblings. I want him to go to a mainstream school. And I will do everything to make that happen!"

But with only a handful of inclusive schools in Karachi, KDSP realized the challenges faced by parents of children with Down syndrome in having them admitted in these mainstream schools. KDSP decided to take on another challenge: Finding mainstream schools which would offer admissions to children with Down syndrome in an inclusive learning environment. Various schools were contacted. Some were adamant on not reforming the educational system they had been running for decades, while others were willing to welcome children with Down syndrome in their school but didn't have trained teachers. The latter became KDSP's partners for the Program for Inclusive Education (PIE).

PIE was initiated in 2016 for children between 2.5 to 3.5 years. The aim of this program is to partner with mainstream educational schools, provide them with best practices of inclusive education, and help these schools to successfully admit, educate and include children with Down syndrome while providing a conducive environment for the child's ideal personal, physical, social, and intellectual development. Our Education & Training department offers free of cost consultation, training and resources to our partner schools and parents of PIE. Initially the program started with 4 partner schools and 5 children. There are 41 children and 15 geographically dispersed partner schools under PIE.

PIE is run in collaboration with Down Syndrome Education International (DSE). Professor Sue Buckley, the CEO of DSE has over 30 years of experience in inclusive education specifically for children with Down syndrome and has conducted several trainings for our partner school teachers.



Guided by the learnings at the end of the first year of PIE, KDSP launched an Early Preschool Experience Program (EPEP) in August 2017 for toddlers with Down syndrome. This one-year school-readiness program aims to prepare a child with Down syndrome and their parents for a confident, productive, and smooth transition and settlement in an inclusive school environment in later years. Today, 39 children have benefited from the Early Preschool Experience Program (EPEP).

# Healthcare

“KDSP formed a collaboration with the Aga Khan University Hospital (AKUH) to introduce a first of its kind Down Syndrome Clinic – a one stop health-care solution for children with Down syndrome.”



“When I take my child to a neighbourhood doctor each time he falls ill, the doctor says he will remain unwell as he has Down syndrome and there is no need to bring him to me every time he is ill. I was hurt when I heard that. Should my child remain unwell and be denied medical attention just because he has Down syndrome?”

This dilemma was not only faced by this one mother who came to KDSP. In a city like Karachi, which has a mere handful of properly qualified medical professionals, it was rare for parents and caregivers to find a doctor who was trained and experienced enough to address the healthcare challenges faced by individuals with Down syndrome. More so, parents and caregivers struggled to find the right healthcare professionals all under one roof – they would oscillate from one hospital to another, one doctor to another. This resulted in parents and caregivers exhausting their energy and financial resources, while delaying the medical attention needed for the child.

In April 2017, KDSP stepped up to alleviate the struggles faced by individuals with Down syndrome and their families. KDSP formed a collaboration with the Aga Khan University Hospital (AKUH) to introduce a first of its kind Down Syndrome Clinic – a one stop health-care solution for children with Down syndrome. The clinic consists of multiple qualified paediatric specialists, and members registered in KDSP’s Family Network can access hassle-free medical consultation at a discount. More than 302 individuals have benefited from quality healthcare services at an affordable cost.



# Affiliations and Collaborations

KDSP has developed affiliations with several organisations in order to share learning opportunities, experiences and professional expertise.





#### **DOWN SYNDROME ASSOCIATION HOUSTON (DSA-H)**

KDSP collaborated with DSAH in 2014 facilitate exchange of knowledge and information related to Down syndrome.



#### **REACH PEDIATRIC THERAPY CENTRE**

KDSP collaborated with Reach Paediatric Therapy Centre in 2015 to provide professional networking opportunities for therapists working with children in Down syndrome in Pakistan and to offer online informational sessions for parents of children with Down syndrome.



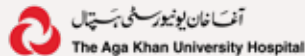
#### **DOWN SYNDROME EDUCATION INTERNATIONAL (DSE)**

KDSP collaborated with DSE in 2016 to benefit from the knowledge and expertise of professionals at DSE in order to expand the scope of Project for Inclusive Education. DSE also trained master trainers at KDSP to equip them to meet educational needs of children with Down syndrome.



#### **ZIAUDDIN UNIVERSITY - COLLEGE OF SPEECH LANGUAGE AND HEARING SCIENCES (ZU-CSLHS)**

KDSP collaborated with CSLHS in 2017 to benefit from the expertise and supervision of trained therapists for its regular Speech Therapy Clinics as well as to provide an opportunity to CSLHS therapists to further enhance their skill sets.



#### **AGA KHAN UNIVERSITY HOSPITAL (AKUH)**

KDSP collaborated with AKUH in 2017 to launch a Down Syndrome Clinic specializing in arena evaluations for children with Down Syndrome.



#### **GYMBOREE PLAY & MUSIC PAKISTAN**

KDSP collaborated with Gymboree Play & Music Pakistan in 2017 to conduct monthly music and activity sessions for children with Down syndrome at KDSP.

# Our Supporters

KDSP is honoured to have a diverse pool of supporters who help us sustain our mission of improving the lives of people we serve.





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Instagram: [karachidownsyndromeprogram](https://www.instagram.com/karachidownsyndromeprogram)





Inclusion is the foundation  
of a strengthened society.

Karachi Down Syndrome Program