



CONCEPT NOTE:



Kids with Down's Syndrome "MAKING CHOICES & LIVING UPTO POTENTIAL"

"My youngest sister, Cindy, has Down syndrome, and I remember my mother spending hours and hours with her, teaching her to tie her shoelaces on her own, drilling multiplication tables with Cindy, practicing piano every day with her. No one expected Cindy to get a Ph.D.! But my mom wanted her to be the best she could be, within her limits". Amy Chua

Essentially, they are in no hurry. "It takes him longer to reach milestones, but we celebrate them so much more because they are such an achievement for him," a mother said. Ironically, the human-race often accepts differences and exceptionality with high regards everywhere, except in its own clan. The preference for stereotyped features, intellectualities and resembling aspirations creates the conflict with those who are born with the difference and are destined to have a different growth chart and learning curve!

The medical literature on Down syndrome presents a bucket full of anomalies, ranging from benign dysmorphism to those abnormalities which cast doubt on longevity (e.g. cardiac anomalies) or those challenging the quality of the life (e.g. neurodevelopmental disorders). Historically, DS has evolved from being a mere phenotype to the finer details of genetic foundations due to the availability of increasingly sophisticated tests and treatments. Eventually today, goals of management of kids with the Down's Syndrome are clearly transformed. The Down's Syndrome is not a 'Disease' but a different arrangement of the

genetic material, known as trisomy 21. This understanding started as early as 1973, when National Down Syndrome Congress was founded in the United States by Kathryn McGee and others followed by the National Down Syndrome Society, founded in 1979. 21 March (Chromosome '21' X3) was declared as world DS day on 2006 and was recognised by UNGS in 2011.

All these historical developments created advocacy groups who worked day in and out, to segregate DS from mental disorders needing mental asylum, and enabled the current trends of normalization and deinstitutionalization of these patients.

Statistically, 23,000-29,000 children born in India, every year have trisomy 21. Barring the metro cities, antenatal and neonatal diagnosis of DS is suboptimal. Social stigma plays a role and a denial for any active intervention prevails or advocated. It is usual to find these kids unattended even when free medical facilities were available, due to the despondency on the part of families and pediatricians thinking that it is a waste of time and resources.

Down's Syndrome federation of India under the guidance of Dr Rekha Ramachandran has uniquely kindled the hope amongst the parents and encourage formation of the down syndrome parents society (DSPS) Delhi which is working for betterment of the children. DSPS has been working selflessly and have been engaging the new parents of kids with DS in a constructive way.

Needless to say, that these children have a long life and majority of them have capacity to get trained, educated and earn livelihood if given attention in the first year of life. They need love, trust and special effort of parents to reach upto the zenith of their potential.

Indian Academy of Paediatrics is an organization of more than 25000, pediatricians across the India. IAP Delhi is its state branch and along with its city branches strives to create a dialogue between advocacy groups and pediatricians by working together and by addressing the barriers related to the diagnosis, medical cost and by aligning the experts with the families. By downsizing the social stigma IAP Delhi state in collaboration with the North

Delhi city branch, would support the efforts of DSFI & DSPS Delhi, Down Syndrome Parents Society Delhi (DSPS).

It is imperative to heighten the confidence of the parents, particularly the mother, if she is the primary caretaker, so that she can be a resource person in her own city and can pass-on relevant information to the needy parents.

Ananya, the model for IAP Delhi “DS Day 2020 greetings” is one of such inspirational examples who stirred her mother to become active member of this group and to start guiding others in the city of Agra, UP. Ananya underwent an open-heart surgery at the age of 9 months for the AVSD. The program DOWN’S SYNDROME “MAKING CHOICES AND LIVING UPTO POTENTIAL!” was planned for the 21st March 2020, but could not be convened due to onset of COVID 19 pandemic.

Now it is being convened on 21st November in association with DSFI- Delhi Group.

It’s our privilege and honour to invite Dr Rekha Ramachandran-co-founder and President of DSFI and Mr TD Dhariyal - Chief Commissioner for Persons with Disability to inaugurate the program! Both have helped in revolutionised the social standing of children with special needs.



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