

Celebrating Simple Joys



MUSKaaN
Spreading smiles among the differently abled

Volume:31

INDRADHANUSH

E-Newsletter (July- September 2021)



From Director's Desk



We revived ourselves from the bruises of second wave and started working near to normal with some students joining back on campus. We were happy to have some students on campus as they brought back life to the whole place. The teachers continued with blended programs with guidance & support of their mentors. Our team started preparations for Annual Diwali Utsav though at very low scale due to unpredictability of situations to come with scare of third wave.

It was heart-warming to see the initiative by our Executive Committee members to show their gratitude towards our teachers on Teacher's Day. Few of them visited the campus and interacted with all team members while following safety guidelines.

Muskaan has been a member of PARIVAAR, a federation of Parents associations for persons with intellectual disabilities, PAN INDIA. In this issue we bring you a report on some advocacy initiatives taken by Parivaar with Ministry of Social Justice and empowerment. All of you are welcome to share your views on these which can be shared by muskaan with PARIVAAR for future action.

Muskaan

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Highlight of the quarter: Muskaan Second Satellite Center started operating in Gurgaon from July



Intellectual Disability + Associated Condition (Autism/Cerebral Palsy/ADHD/Low Vision/Hearing Impairment/Motor Disorder/Communication Disorder/etc.)

Parivaar NCPO Recommendations to MSJE on
National Policy for Empowerment of Persons with Disabilities

■ Parivaar Annual Report 2020-2021

We much appreciate your initiative to form the National Policy for the Persons with Disabilities. PARIVAAR has been closely associated with policy drafting for states and providing views on the special needs of PwDs to other GOI ministries. Earlier Parivaar had articulated its views to Min. of Education and MOHFW, towards empowerment of PwDs, when respective ministries were forming their policy. Our views were accepted and incorporated in the policies.

A national Policy is a framework that goes beyond the past & present legislations, rules, schemes, international charters & obligations, and sets course for the future while incorporating the present. The National Education Policy (NEP) is the best example; being (1) Transformative to the point of disruptive (positively) (2) Identifying systemic policy gaps & addressing them (3) Adapting emerging (proven) concepts & technologies (4) Building on Classical wisdom (5) Collaborating with other departments'/ ministries on their strengths & needs.

We are sure DEPWD team is aware of the above and drafting the policy which will prove to be a landmark for the empowerment of our wards with disabilities. Some transformative points from Parivaar's parents are enumerated below for inclusion in the National Policy:

1. **Transformational change in Early Detection & Intervention** in collaboration with RBSK/ MOHFW forming a traction among UDID, RBSK, RKSK schemes. **A longitudinal health record (0 – 18 years) of a child with Global Developmental Delays (GDD) linked to UDID and updated regularly by scheme workers thru easy mobile apps with biometric security.** This shall provide invaluable tool for providing timely early intervention and gap identification & timely intervention. In addition, it would provide both demand and supply data to planners from GOI to Panchayat level. From this transformational change will flow policy proposals utilizing existing schemes of DDRS, DEICs, DRCs, DISHA as well as respective components of NIRAMAYA.

The recent lockdown period has shown the way of providing homebound early intervention services by parents/ CBR workers thru instructions by remote located therapists. **If distance Early Intervention therapy is fine-tuned with mix of GUI technology and grass root process it would benefit millions of children with delayed milestones or developmental disabilities.** It requires to be detailed in National Policy for the inter department stakeholders to implement in remote areas. It may be worthwhile to devote a chapter on Early Intervention and elaborate on above two initiatives to get official sanctity and priority.

2. **Convergence of National Policy for Empowerment of Divyangjan with National Education Policy will be a Game-changer for Persons with disabilities** for education empowerment of children with special needs (CWSN). The U-DISE data referred by NEP shows CWSN have alarming school dropout rate; 50.9% in primary level and 88.8% in secondary school. This large gap should be addressed in the National Policy by follow-up on the enabling provisions for CWSN in NEP, such as:
 - a. Early Childhood Care & Education – design of sub-framework for 3-8 years
 - b. National curricular and pedagogical framework to suit special needs
 - c. DIKSHA for Increasing attention span, self-learning, learning to learn, and exploring the world 'own way' in 'own time & at 'own liking'.
 - d. Vocational crafts & training introduced at age 12 onwards; transformative for students with intellectual disabilities [ID & ASD]
 - e. Mentoring involving community and alumni; Life skill training can be introduced
 - f. **Integrating Special schools in the format of School Complexes and enable effective cross-disability**

training in the classrooms.

g. **Over the time as a national policy the education of CWSN (including Special schools) to be passed on to Ministry of Education.**

h. **Adult Education: Over 50% of PwD adults are illiterate and NEP has made special provision for literacy of all.**

There are many more provisions of overlapping interest and a chapter in the National Policy on this paradigm shift of educating CWSN & adult literacy of PwDs will do justice.

3. **Community Based Inclusive Development (CBID)** for Persons with disability has huge potential and has been duly recognized by DEPWD. The CBID is the way forward for developing soft-skills and job-skills among PwDs living in rural areas. These are much required for developing micro entrepreneurship, employment, and livelihood for PwDs. A chapter in the National policy on CBID is a must and should dwell on:

a. **Developing soft skills for adapting to work environment**

b. **Developing job skills based on demand-supply paradigm of local rural areas**

c. **Development of livelihood opportunities availing NRLM/ SRLM via Self-help groups and other schemes**

d. **Participation in MGNREGA and poverty alleviation schemes**

4. **Transforming Disability Statistics to reflect ground reality:** Till date the emphasis of disability statistics is on either disability at birth or acquired at younger or during working age. As per 2019 WHO statistics, the life span of Indian population is 70.8 years^{WHO/UNDP (2019)} but by the age of 60 years only 13.2%^{WHO (2019)} Indians remain hale & hearty. This is going by ICF (international classification of functions) methodology. Conversely, we will have 86.8% of population between age of 60 to 71 years having ailment or functional disability. This population with functional disability will not require early intervention, education, or employment but other special needs of PwDs such as health, accessibility, reasonable accommodation, high support needs will be similar or more.

This ground reality should be reflected in the policy to enable future endeavour to adopt UW Survey methodologies for planning, as adopted by WHO and developed nations. We may not attempt it in Census, but the National Policy should elucidate it whereby the surveys can get initiated by NSO.

5. **Lob sided Supply Demand Gap of Professionals in Disability sector:** On one side there is a dearth of grass-root professionals and service providers in both rural and urban areas, on the other side the qualified professionals and service providers remain under or un-employed. This is apparent from falling level of admissions in the national institutes and courses getting ceased. For example, the key professional for early intervention services is Occupational Therapist. But Occupation Therapist training vacancies are the last one to fill in the colleges. The other key professionals for Early Intervention is Speech & Audiologist. Here most of them opt to work as audiologist in private firms selling hearing aids. This results in our children being deprived of speech therapist and lose out on communication skills for life. The service providers are not available for residential homes for persons with intellectual (autism included) disabilities. Same case with CBR workers in rural areas, while the courses go without adequate number of admissions. We have spelled the issue which is surmountable by policy framework to catalyze RCI. **The systemic policy initiatives, addressing the nuances, be included in the Policy document after interaction with professionals and user of their services (parents & PwDs).**

6. **Intellectual Disabilities require innovative solutions:** The Intellectual disabilities consists of Autism/ ASD, Intellectual disability, Specific learning disabilities, ADHD. Their number is going to explode in the future. Autism/ ASD is likely to form 1.12%^{AIMS study} of newly born children. The Specific Learning disabilities in US children is 9.7%^{Pediatrics US 2007} and number in Indian students is likely to be of similar order as derived from international data. **The use of artificial intelligence in tracking learning outcomes and supporting lifelong learning thru continuous learning and assessment are the emerging tools.** In addition, the persons with Intellectual disabilities **require Soft Skill (self-advocacy) training to adapt to social and working environment.** These adults are prone to mental health issues as much as 4 to 5 times than mainstream

population. Till date there is no policy to fulfill special requirements of persons with intellectual disabilities as brought out in The National Trust Act and RPwD Act 2016. **Their special needs for Residential centers/ assisted living, supported decision making, Promoting Livelihood workshops/ SHGs initiated by parents, are unique from other disabilities. A separate chapter on policy to consider the special needs of this group is a critical requirement.**

7. **Awareness Generation & Media policy:** The UNCRPD principles for empowerment; inherent dignity, non-discrimination, inclusion, acceptance as human diversity, equality of opportunity, respect for the rights of women & children with disabilities etc. will remain on paper till a well thought of policy on creating general awareness is spelled in the National Policy. This would give required direction and authority to the executive to undertake this critical function on their own at National level and thru NGOs at grass-root level. But a policy direction is essential.
8. **Enabling measures to garner funds from CSR for disability sector:** CSR funding is an emerging opportunity and there are many sectors vying for the limited kitty. **How the National Policy will enable NGOs to receive larger share of CSR funds by promoting excellence, standardization, impact assessment etc. needs to be spelled out.** It would provide comfort to potential international and national donors also.

There are many emergent government schemes/ policies such as Amenabar which must have been appropriately linked with disability sector requirements to manufacture prosthesis, orthotics, hearing implants/ aids, intelligent learning kits etc. and included in the National Policy. So we are not dwelling on these.

Parivaar is ever willing to make presentation on any/ all the above points to enable inclusion in the National Policy.

प्रेरणा से प्रेरणा

■ सुश्री मीनाक्षी

हेलो दोस्तों ! मिलिए प्रेरणा से जो 25 वर्ष की हंसमुख और जिन्दा दिल लड़की है । प्रेरणा हर हाल से खुश रहती है। उसे मिल कर आप को अपने जीवन की सभी परेशानियां छोटी लगने लगेगी । प्रेरणा अपने नाम की तरह ही सब के लिए एक प्रेरणा है। वह मुस्कान से 2016 से जुडी है। उसके लिए मुस्कान केवल उसका ट्रेनिंग सेण्टर ही नहीं उसके जीवन का अहम हिस्सा है। वह मुस्कान में होने वाली सभी गतिविधियों में पुरे उत्साह और लगन से भाग लेती है तथा इसे पूरा करती है। उसकी मम्मी सभी काम में पूरी तरह उसका साथ निभाती हैं । प्रेरणा को मुस्कान आना बहुत पसंद है , एक भी दिन छुट्टी का उसे पसंद नहीं, उसे मुस्कान के सभी काम चाहे वह दीया पेंटिंग हो या जूट से कोई समान बनाना हो या कोई भी और काम हो वह बहुत ही लगन और मेहनत से पूरा करती है और यही नहीं वो इसे बहुत अच्छे से करने की कोशिश करती है। प्रेरणा को सभी प्रोग्राम जैसे नृत्य, अभिनय, और खेल में भाग लेना भी बहुत पसंद है, वह खुद से अपना नाम देती है । डांस तो जैसे उसके राग राग में शामिल है। उसे अच्छा खाना भी बहुत पसंद है। वह एक बहुत अच्छी स्टूडेंट है तथा वह मुस्कान के सभी नियमों का पालन करती है। अपने शिक्षिका की सभी बात भी मानती है कभी-कभी थोड़ा समझाना पड़ता है पर वह जल्दी ही समझ कर फिर से खुश हो जाती है और टीचर के साथ मिल कर काम करती है। इस महामारी के समय में भी उसने



मुस्कान का भरपूर साथ दिया है। इस दौरान प्रेरणा का स्वास्थ्य अचानक बिगड़ने लगा और टेस्ट करवाने पर पता चला की उसके लिवर में इन्फेक्शन है, प्रेरणा को लिवर ट्रांसप्लांट के लिए कहा है। डॉक्टर का कहना है कि वो अब ज्यादा फिजिकल काम नहीं कर पायेगी। प्रेरणा पहले से ही शुगर और थाइरोइड का सामना कर रही है, ऐसे में डॉक्टर की रिपोर्ट उसकी फैमली के लिए बहुत निराशाजनक थी। वह बहुत परेशान हो गए। उसकी माँ बहुत परेशान हो गई, कई बार उनसे मैंने बात की उनको समझाया कि हम सब आपके साथ हैं इससे भी बाहर निकाल आएंगे, आप ज्यादा परेशान न हो।

बीमारी के बावजूद भी प्रेरणा के उत्साह में कमी नहीं आयी, प्रेरणा ने अभी तक कोई भी ऑनलाइन सेशन मिस नहीं किया, टीचर से बात करना हो या अपना काम करना हो या काम की फोटो टीचर भेजनी हो, सभी काम उसने उसी जोश से किये जैसे वह पहले करती थी। सभी प्रोग्राम में पार्टिसिपेट भी वह उसी जोश करना चाहती है परन्तु उसके स्वास्थ्य के कारण हमने उसे के लिए लिमिट्स तय किया जैसे आप अब बैठ कर ही आसानी से होने वाले कार्य करोगे, आप डांस करना चाहते हो तो वो भी आप बैठ कर, कर सकते हो और उसने टीचर की बात मान कर, उसने होने वाले सभी प्रोग्राम्स को अच्छे से एन्जॉय किया। अपनी क्लास के लिए हॉस्पिटल में भी परेशान थी कि अब मैं अपनी क्लास कैसे अटेन्ड करूंगी, मीनाक्षी मैडम से कैसे बात करूंगी। तब उसकी माँ ने मुझे फोन किया और मैंने प्रेरणा से थोड़ी देर वीडियो कॉल पर बात की जिससे वह खुश हुई और उसे तसल्ली हुई। उसके बाद से वो रोज मुझसे से बात करती और मेरा बताया हुआ काम बहुत माँ लगा कर पूरा करती। कोई भी फेस्टिवल आने पर वह सब से पहले वो मुझे और अपने मुस्कान के सभी दोस्तों को विश करना चाहती है, जो उसे बहुत खुशी देता है।

प्रेरणा ने हम सब को हर हाल में खुश रहने की प्रेरणा दी है। इस जिन्दा दिल लड़की से हमें जीवन की सच्ची प्रेरणा मिलती है। जीवन कैसा भी हो, जीवन में कई उतर चढ़ाव आते हैं और यह जीवन हमें कभी खुशी, तो कभी गम के पल दे जाता है, परन्तु प्रेरणा की तरह हमें गम से हार नहीं मारनी चाहिए। हमेशा खुशी और उत्साह से अपने काम करते रहने चाहिए।

A Touching Lesson

■ Courtesy WhatsApp (forwarded story)

Unlike today, staffing was never a real problem, but I was searching for a someone to work three hours a day only at lunch. I went thru all my applications, and most were all looking for full time or at least 20 hours per week. I found one however, buried at the bottom of a four-inch stack that was only looking for lunch part-time. His name was Nicky.

Hadn't met him but thought I would give him a call and see if he could stop by for an interview. When I called, he wasn't in, but his mom said she would make sure he would be there.

At the accorded time, Nicky walked in. One of those moments when my heart went in my throat. Nicky had Downs Syndrome. His physical appearance was a giveaway, and his speech only reinforced the obvious. I was young and sheltered. Had never interacted on a professional level with a developmentally disabled person. I had no clue what to do, so I went ahead and interviewed him

He was a wonderful young man.

Great outlook.

Task focused.

Excited to be alive.

For reasons only God knew at that time, I hired him. 3 hours a day, 3 days a week to run a grill. I let the staff know what to expect. Predictably, the crew made sure I got the message, "no one wants to work with a retard."

To this day I find that word offensive. We had a crew meeting, cleared the air, and prepared for his arrival. Nicky showed up for work right on time.

He was so excited to be working. He stood at the time clock literally shaking with anticipation. He clocked in and started his training. Couldn't multitask but was a machine on the grill. Now for the fascinating part.

Back in that day, there were no computer screens to work from. Every order was called by the cashier.

It required a great deal of concentration on the part of all production staff to get the order right.

While Nicky was training during his first shift, the sandwich maker next to him asked the grill man/trainer what was on the next sandwich.

Nicky replied, "single, no pickle no onion." A few minutes later it happened again. It was then that we discovered Nicky had a hidden and valuable skill.

He memorized everything he heard! Photographic hearing? WHAT A SKILL! It took 3 days and every sandwich maker requested to work with Nicky. He immediately was accepted by the entire crew. After his shift he would join the rest of his crew family, drinking Coke like it was water!

It was then that they discovered another Rainman-esque trait.

Nicky was a walking/talking perpetual calendar! With a perpetual calendar as a reference, they would sit for hours asking him what day of the week December 22, 1847, was, or some more. He never missed. This uncanny trait mesmerized the crew. His mom would come in at 2 to pick him up. More times than not, the crew would be back there with him hamming it up. As I went to get him from the back, his mom said something I will never forget. "Let him stay there as long as he wants."

*He has never been accepted anywhere like he has been here." I excused myself and dried my eyes, humbled and broken-hearted at the lesson I just learned. *

Nicky had a profound impact on that store. His presence changed a lot of people. Today I believe with every fibre of my body that Nicky's hiring was no accident. God's Timing and Will is Perfect.

This New year, I hope we all understand what we are celebrating.

We are all like Nicky. We each have our shortcomings. We each have our strong points. But we are all of value. God made us that way and God doesn't make mistakes.

*Nicky certainly wasn't a mistake. *

He was a valuable gift that I am forever grateful for.

God doesn't care if you are rich or poor, republican or democrat, black or white.
He doesn't care if your chromosome structure is perfect.

He doesn't care what level of education you have attained.

So, this New year, let's check our hearts.

*There is a little bit of Nicky in all of us and I suspect there is a Nicky somewhere in your life that is looking for the chance to be embraced. *

FACT SHEET ON INTELLECTUAL DISABILITIES

■ Compiled by Ms. Prakriti Chawla,

What are Neurodevelopmental Disorders?

Neurodevelopmental disorders are a group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. The range of developmental deficits varies from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence. The neurodevelopmental disorders frequently co-occur; for example, individuals with autism spectrum disorder often have intellectual disability (intellectual developmental disorder), and many children with attention-deficit/hyperactivity disorder (ADHD) also have a specific learning disorder. For some disorders, the clinical presentation includes symptoms of the excess as well as deficits and delays in achieving expected milestones. For example, autism spectrum disorder is diagnosed only when the characteristic deficits of social communication are accompanied by excessively repetitive behaviours, restricted interests, and insistence on sameness.

Source: <https://dsm.psychiatryonline.org/doi/abs/10.1176/appi.books.9780890425596.dsm01>

What is Intellectual Disability?

Intellectual disability is a term used when there are limits to a person's ability to learn at an expected level and function in daily life. Levels of intellectual disability vary greatly in children. Children with intellectual disabilities might have a hard time letting others know their wants and needs, and taking care of themselves. An intellectual disability could cause a child to learn and develop more slowly than other children of the same age. It could take longer for a child with an intellectual disability to learn to speak, walk, dress or eat without help, and they could have trouble learning in school.

Intellectual disability can be caused by a problem that starts any time before a child turns 18 years old – even before birth. It can be caused by injury, disease, or a problem in the brain. For many children, the cause of their intellectual disability is not known. Some of the most common known causes of intellectual disability – like Down syndrome, fetal alcohol syndrome, fragile X syndrome, genetic conditions, birth defects, and infections – happen before birth. Others happen while a baby is being born or soon after birth. Still, other causes of intellectual disability do not occur until a child is older; these might include serious head injury, stroke, or certain infections.

Source: <https://caracentre.ie/wp-content/uploads/2019/02/Intellectual-Disability-Fact-Sheet.pdf>

Signs of Intellectual Disability

Usually, the more severe the degree of intellectual disability, the earlier the signs can be noticed. However, it might still be hard to tell how young children will be affected later in life.

There are many signs of intellectual disability. For example, children with intellectual disabilities may:

- sit up, crawl, or walk later than other children
- learn to talk later, or have trouble speaking
- find it hard to remember things
- have trouble understanding social rules
- have trouble seeing the results of their actions
- have trouble solving problems

Source: <https://caracentre.ie/wp-content/uploads/2019/02/Intellectual-Disability-Fact-Sheet.pdf>

Diagnosing Intellectual Disability

Intellectual disability is identified by problems in both intellectual and adaptive functioning. Intellectual functioning is assessed with an exam by a doctor and through standardized testing. While a specific full-scale IQ test score is no longer required for diagnosis, standardized testing is used as part of diagnosing the condition. A full-scale IQ score of around 70 to 75 indicates a significant limitation in intellectual functioning. However, the IQ score must be interpreted in the context of the person's difficulties in general mental abilities. Moreover, scores on subtests can vary considerably so that the full-scale IQ score may not accurately reflect overall intellectual functioning. Adaptive functioning is assessed through standardized measures with the individual and interviews with others, such as family members, teachers and caregivers. Three areas of adaptive functioning are considered:

Conceptual – language, reading, writing, math, reasoning, knowledge, memory

Social – empathy, social judgment, communication skills, the ability to follow rules and the ability to make and keep friendships

Practical – independence in areas such as personal care, job responsibilities, managing money, recreation and organizing school and work tasks

Intellectual disability is identified as mild (most people with intellectual disability are in this category), moderate or severe. The symptoms of intellectual disability begin during childhood or adolescence. Delays in language or motor skills may be seen by age two. However, mild levels of intellectual disability may not be identified until school-age when a child may have difficulty with academics.

Source: <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>

Causes of Intellectual Disability

There are many different causes of intellectual disability. It can be associated with a genetic syndrome, such as Down syndrome and Fragile X syndrome. It may develop following an illness such as meningitis, whooping cough or measles; may result from head trauma during childhood, or may result from exposure to toxins such as lead or mercury. Other factors that may contribute to intellectual disability include brain malformation, maternal disease and environmental influences (alcohol, drugs or other toxins). A variety of labour- and delivery-related events, infection during pregnancy and problems at birth, such as not getting enough oxygen, can also contribute.

Source: <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>

Related and Co-occurring Conditions

Some mental health, neurodevelopmental, medical and physical conditions frequently co-occur in individuals with intellectual disability, including cerebral palsy, epilepsy, ADHD, autism spectrum disorder and depression and anxiety disorders. Identifying and diagnosing co-occurring conditions can be challenging, for example recognizing depression in an individual with limited verbal ability. However, accurate diagnosis and treatment are important for a healthy and fulfilling life for any individual.

Source: <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>

Types of ID

Intellectual Disability (Cause Unknown)

Down Syndrome

Down syndrome is a condition in which a person has an extra chromosome. Chromosomes are small "packages" of genes in the body. They determine how a baby's body forms and functions as it grows during

pregnancy and after birth. Typically, a baby is born with 46 chromosomes. Babies with Down syndrome have an extra copy of one of these chromosomes, chromosome 21. A medical term for having an extra copy of a chromosome is 'trisomy.' Down syndrome is also referred to as Trisomy 21. This extra copy changes how the baby's body and brain develop, which can cause both mental and physical challenges for the baby. Even though people with Down syndrome might act and look similar, each person has different abilities. People with Down syndrome usually have an IQ (a measure of intelligence) in the mildly-to-moderately low range and are slower to speak than other children. Some common physical features of Down syndrome include:

- A flattened face, especially the bridge of the nose
- Almond-shaped eyes that slant up
- A short neck
- Small ears
- A tongue that tends to stick out of the mouth
- Tiny white spots on the iris (coloured part) of the eye
- Small hands and feet
- A single line across the palm of the hand (palmar crease)
- Small pinky fingers that sometimes curve toward the thumb
- Poor muscle tone or loose joints
- Shorter in height as children and adults

Source: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>

Prader-Willi Syndrome Prader-Willi syndrome is a complex genetic condition that affects many parts of the body. In infancy, this condition is characterized by weak muscle tone (hypotonia), feeding difficulties, poor growth, and delayed development. Beginning in childhood, affected individuals develop an insatiable appetite, which leads to chronic overeating (hyperphagia) and obesity. Some people with Prader-Willi syndrome, particularly those with obesity, also develop type 2 diabetes (the most common form of diabetes).

People with Prader-Willi syndrome typically have mild to moderate intellectual impairment and learning disabilities. Behavioural problems are common, including temper outbursts, stubbornness, and compulsive behaviour such as picking at the skin. Sleep abnormalities can also occur. Additional features of this condition include distinctive facial features such as a narrow forehead, almond-shaped eyes, and a triangular mouth; short stature; and small hands and feet. Some people with Prader-Willi syndrome have unusually fair skin and light-coloured hair. Both affected males and affected females have underdeveloped genitals. Puberty is delayed or incomplete, and most affected individuals are unable to have children (infertile).

Source: <https://medlineplus.gov/genetics/condition/prader-willi-syndrome/#causes>

Developmental Delay

A developmental delay refers to a child who has not gained the developmental skills expected of him or her, compared to others of the same age. Delays may occur in the areas of motor function, speech and language, cognitive, play, and social skills. Global developmental delay means a young child has significant delays in two or more of these areas of development. There is no one cause for delays in development. Factors that may contribute can occur before a child is born, during the birth process, and after birth. These could include:

- Genetic or hereditary conditions like Down syndrome
- Metabolic disorders like phenylketonuria (PKU)
- Trauma to the brain, such as shaken baby syndrome
- Severe psychosocial trauma, such as post-traumatic stress disorder
- Exposure to certain toxic substances like prenatal alcohol exposure or lead poisoning
- Some very serious infections
- Deprivation of food or environment

- In some cases, it may not be possible to find the cause of the developmental delay.

Source: <https://www.ssmhealth.com/cardinal-glennon/developmental-pediatrics/developmental-delay>

Fatal Alcohol Spectrum Disorder

Fatal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical problems and problems with behaviour and learning. Often, a person with an FASD has a mix of these problems. FASDs refer to a collection of diagnoses that represent the range of effects that can happen to a person whose mother drank alcohol during pregnancy. These conditions can affect each person in different ways and can range from mild to severe.

A person with an FASD might have:

- low body weight
- Poor coordination
- Hyperactive behaviour
- Difficulty with attention
- Poor memory
- Difficulty in school (especially with math)
- Learning disabilities
- Speech and language delays
- Intellectual disability or low IQ
- Poor reasoning and judgment skills
- Sleep and sucking problems as a baby
- Vision or hearing problems
- Problems with the heart, kidneys, or bones
- Shorter-than-average height
- Small head size
- Abnormal facial features, such as a smooth ridge between the nose and upper lip (this ridge is called the philtrum)

Source: <https://www.cdc.gov/ncbddd/fasd/facts.html>

Fragile X Syndrome

Fragile X syndrome (FXS) is a genetic disorder. FXS is caused by changes in a gene that scientists called the fragile X mental retardation 1 (FMR1) gene when it was first discovered. The FMR1 gene usually makes a protein called fragile X mental retardation protein (FMRP). FMRP is needed for normal brain development. People who have FXS do not make this protein. People who have other fragile X-associated disorders have changes in their FMR1 gene but usually make some of the protein.

FXS affects both males and females. However, females often have milder symptoms than males. The exact number of people who have FXS is unknown, but a review of research studies estimated that about 1 in 7,000 males and about 1 in 11,000 females have been diagnosed with FXS. Signs that a child might have FXS include:

- Developmental delays (not sitting, walking, or talking at the same time as other children the same age);
- Learning disabilities (trouble learning new skills); and
- Social and behaviour problems (such as not making eye contact, anxiety, trouble paying attention, hand flapping, acting and speaking without thinking, and being very active).

Males who have FXS usually have some degree of intellectual disability that can range from mild to severe. Females with FXS can have normal intelligence or some degree of intellectual disability. Autism spectrum disorder (ASD) also occurs more frequently in people with FXS.

Source: <https://www.cdc.gov/ncbddd/fxs/facts.html>

Slow Learner

A “slow learner” is not a diagnostic category, it is a term people use to describe a student who has the ability to learn necessary academic skills but at a rate and depth below average same-age peers. In order to grasp new concepts, a slow learner needs more time, more repetition, and often more resources from teachers to be successful. Reasoning skills are typically delayed, which makes new concepts difficult to learn. A slow learner has traditionally been identified as anyone with a Full-Scale IQ one standard deviation below the mean but not as low as two standard deviations below the mean. If a cognitive assessment (IQ test) has a mean (average) of 100, we expect most students will fall within one standard deviation of 100. That means that most students have an IQ of 85 to 115. Those who fall two standard deviations below the mean are often identified as having an Intellectual Disability (IQ below 70). A slow learner does not meet the criteria for an Intellectual Disability (previously called mental retardation). However, she learns slower than average students and will need additional help to succeed.

Source: <https://schoolpsychologistfiles.com/slowlearnerfaq/>

My journey with Mukul Andley, a Down's Syndrome child

■ Ms. Kamini Andley

When my son Mukul with Down's Syndrome was born, I hit a brick wall. His big, broad life on my mind with his delayed milestones. when will he walk? when will he talk? As a parent of a special child these questions always sucked me. Having a child with special needs has given me permission to act more in the moment and less within the confines of the status quo. Although it felt that as if I hit a brick wall on his birth, but my soul searched and discovered a great new world with hidden benefits.



Here are the secrets I have discovered in my 29 years journey as a parent of a down' syndrome.

1. There is humour to be found --- My son makes me laugh. He pays little attention to the rational world. He dances, laughs, and finds delight in what I often think as trivial or bothersome.
2. The ego doesn't get in the way of living. His ego isn't there like mine. If he wants something, he wants it with no agenda tacked on.
3. Sports can be enjoyed without competition. They get to enjoy the sports with no goals in mind other than the pure joy of it.
4. There is true happiness. Yes! They can be happy in the elevator, the grocery store and school no matter what place, things etc
5. It's OK to quit--- If an activity doesn't jive with my son he quits. He competes with only himself.

I really enjoy and learn from the beauty of above benefits.

Initially we found it difficult to understand him as he was not expressive. It was a tough task for us. When he was 3 years old, we took him to "early intervention programme" for special children. Then he joined a special school. Each down's syndrome child has different ability, none of them are similar. We kept on working for him but were not sure about his goal. Time kept passing without a goal in sight. Then in the year 2019, we came to know about 'Muskaan'. It came as a silver lining, with a ray of hope for us. A project for 'Lemon Pickle Associate' was about to start, and we got him enrolled for it.

I think everyone learns best in his own specific ways. Some are visual learners while others are auditory learners. This is the same for children with down's syndrome. Each child on the planet has his/her own set of skills, talent, abilities, and downfalls.

By identifying each of these, we enhance their happiness, success in learning and success in life.

The down's syndromes require repetitive learning practices. The need to hear information multiple times and in different ways to store this information in their long-time memory.

Hats-off to teachers in Muskaan who could do this with repetition, routine, and patience. Covid 19 restrictions made this year's project a bit tougher, but teachers worked hard and managed to prepare them for the qualifying exam by taking on-line classes to complete the curriculum. Now we can see a light at the end of the dark tunnel.

We extend our sincere gratitude to all the teachers and supporting staff who made this project a success.

Comprehensive Disability Inclusive Guidelines for protection and safety of persons with disabilities (Divyangjan) during COVID 19.

- Courtesy Department of Empowerment of persons with intellectual Disabilities
<https://www.disabilityaffairs.gov.in/>

In view of the pandemic situation due to the outbreak and rapid spread of COVID19 across the world, the public health has been endangered both nationally and internationally, necessitating urgent measures on the part of both the Central and State Governments, aimed at containing the spread of the disease. The Government of India has declared the situation arising out of COVID 19 as a National Disaster and necessary guidelines have been issued under the National Disaster Management Act, 2005.

2. The Ministry of Health and Family Welfare, Government of India being the nodal Central Ministry on health issues has issued guidelines for public as well as health workers to contain the spread of the disease. These are available on their website (www.mohfw.gov.in) which *inter-alia* contains: -

- Awareness material (both in Hindi and English) for citizens and frontline workers.
- Advisory on mass gatherings and social distancing.
- Guidelines and procedure to be followed by hospitals including telemedicine practices for patient care.
- Common Helpline Numbers: 1075, 011-23978046, 9013151515
- Frequently Asked Questions

3. While COVID 19 is impacting the entire population, persons with disabilities are more vulnerable to the disease due to their physical, sensory, and cognitive limitations. As such, there is a need to understand their disability specific requirements, daily living activities and take appropriate and timely measures to ensure their protection and safety during situations of risk.

4. Section 8 of the Rights of Persons with Disabilities Act, 2016 guarantees equal protection and safety for persons with disabilities in these situations. It also mandates Disaster Management Authorities at District/State/National levels to take measures to include persons with disabilities in disaster management activities and to keep them duly informed about these. These authorities are mandatorily required to involve the concerned State Commissioner for Persons with Disabilities during disaster management. In September 2019, National Disaster Management Authority, Union Ministry of Home Affairs issued National Disaster Management Guidelines on Disability Inclusive Disaster Risk Reduction (DiDRR) in line with the above provisions. Further, recently on 24th March 2020, Ministry of Home Affairs has issued guidelines for various authorities to prevent spread of COVID 19 for a period of 21 days starting from 25.3.2020.

5. While the guidelines issued by the Ministry of Health and Family Welfare and Ministry of Home Affairs are applicable to all citizens, the following measures are suggested which need to be acted upon by various State/District authorities to give focused attention to protection and safety of persons with disabilities during COVID 19.

6. General action points

- All information about COVID 19, services offered and precautions to be taken should be available in simple and local language in accessible formats, i.e. in Braille and audible tapes for persons with visual impairment, video-graphic material with sub-titles and sign language interpretation for persons with hearing impairment and through accessible web sites.
- Sign language interpreters who work in emergency and health settings should be given the same health and safety protection as other health care workers dealing with COVID19.
- All persons responsible for handling emergency response services should be trained on the rights of persons with disabilities, and on risks associated with additional problems for persons having specific impairments.
- Relevant information on support to persons with disabilities should be a part of all awareness campaigns
- During quarantine, essential support services, personal assistance, and physical and communication accessibility should be ensured e.g. blind persons, persons with intellectual/ mental disability (psycho-social) are dependent on care giver support. Similarly, persons with disabilities may seek assistance for rectification of fault in their wheelchair and other assistive devices.
- Caregivers of persons with disabilities should be allowed to reach Persons with disabilities by exempting them from restrictions during lockdown or providing passes in a simplified manner on priority.
- To ensure continuation of support services for persons with disabilities with minimum human contact, due publicity needs to be given to ensuring personal protective equipment's for caregivers.
- The Resident Welfare Associations should be sensitized about the need of persons with disabilities so as to allow entry of maid, caregiver and other support providers to their residence after following due sanitizing procedure.
- Persons with disabilities should be given access to essential food, water, medicine, and, to the extent possible, such items should be delivered at their residence or place where they have been quarantined.
- The States/UTs may consider reserving specific opening hours in retail provision stores including supermarkets for persons with disabilities and older persons for ensuring easy availability of their daily requirements.
- Peer-support networks may be set up to facilitate support during quarantine for PwDs ;

- Additional protective measures should be taken for persons with disabilities based on their impairment who need to be given travel pass during the emergency period and should also be sensitized for their personal safety and protection.
- Persons with disabilities should be given priority in treatment, instead they should be given priority. Special care should be taken in respect of children and women with disabilities.
- Employees with blindness and other severe disabilities in both public and private sector should be exempted from essential services work during the period as they can be easily catch infection.
- On-line counselling mechanism should be developed to de-stress persons with disabilities as well as their families to cope with the quarantine period.
- 24X7 Helpline Number at State Level be set up exclusively for Divyangjan with facilities of sign language interpretation and video calling.
- The States/UTs may consider involving Organization of Persons with Disabilities in preparation and dissemination of information material on COVID 19 for use of PwDs.

7.Mechanism to resolve disability specific issues during the period

(a) State Commissioner for PwDs

- The State Commissioners for PwDs should be declared as the State Nodal authority in respect of persons with disabilities.
- They should be the overall in-charge to resolve disability specific issues during the crisis period.
- They will coordinate with State Disaster Management Authority, Health, Police, and other line Departments as well as District Collectors and district level officers dealing with persons with disabilities.
- They will be responsible to ensure that all information about COVID 19, public restriction plans, services offered are available in local language in accessible formats.

(b)District Officer dealing with empowerment of PwDs

- The District Officer dealing with empowerment of PwDs should be declared as the District Nodal authority in respect of persons with disabilities.
- He should have a list of PwDs in the District and monitor their requirements periodically and should have a separate list of persons with severe disabilities who need high support in the locality.
- He will be responsible for resolving the issue within the resources available and if necessary, may take the help of Non-Governmental Organizations and Civil Society Organizations/Resident Welfare Associations.

Trying Times of Muskaan

■ **Mr. Rakesh Dewan**

When Covid shook the entire planet and for Muskaan too it was an unparallel crisis.

Stable sources of income suddenly turned uncertain. Construction activity and arrival of wards from Dera only added to the challenge!

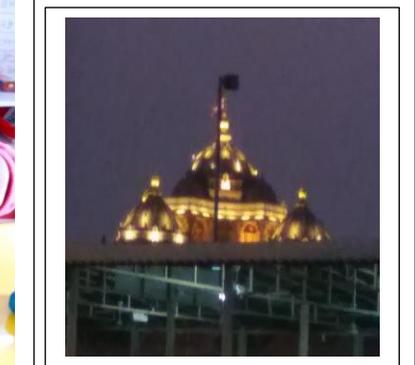
Muskaan quickly moved to reinvent itself to adopt to the new situation. Showed flexibility in it as there was no precedent to rely on!

Despite initial doubts about some parents being tech savvy & also effectiveness of the online classes and meetings, it seems these helped our wards to discover new abilities that they were not aware of!

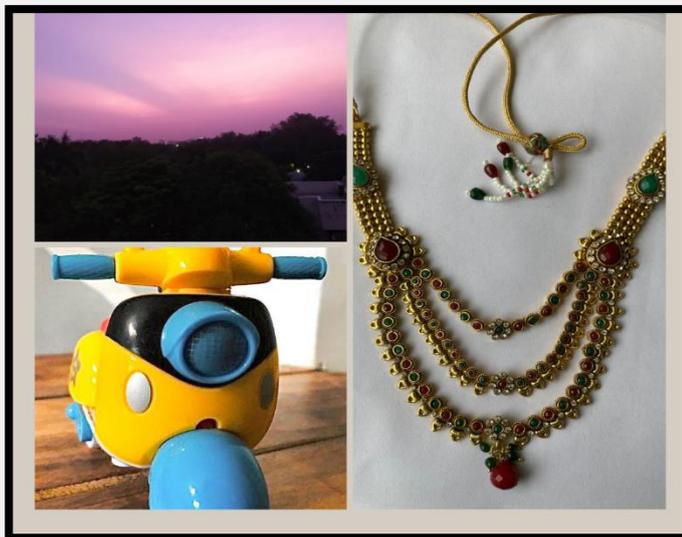
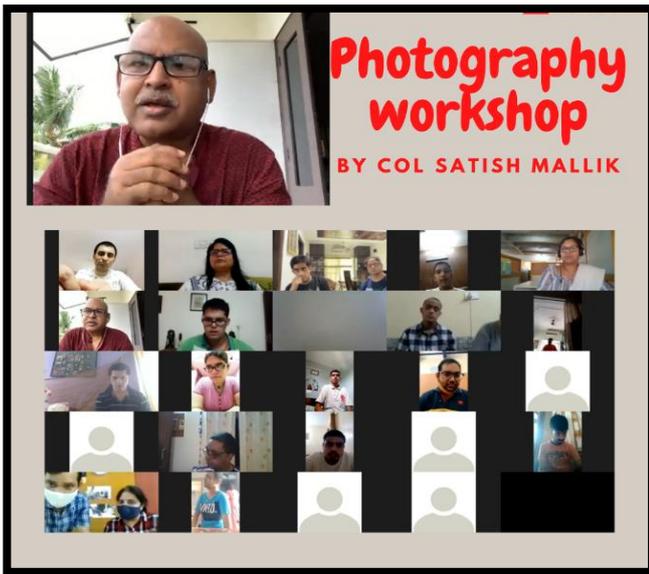
As a parent I clap for the Muskaan team as it took the challenge head on even at a personal risk!

मुस्कान में आकर यह अहसास हुआ, इस से जुड़ कर हर इनसान खास हुआ !

Friends Corner



खोल दे पंख मेरा कहता है परिंदा; अभी तो उड़ान बाकी है । जमी नहीं है मंजिल हमारी अभी तो आसमां बाकी है ॥



Donate to Muskaan:

Your donations go a long way in supporting our training programs as well as our advocacy and awareness efforts. You can donate through website also on this link <https://www.muskaan-paepid.org/>
Donation to Muskaan is tax exempted under section 80G of Income Tax Act

Support us:

Whether it is by raising awareness online or helping to raise funds, there are many ways you can help the cause!

Contact us: Email address: muskaan@muskaan-paepid.org & muskaan32@gmail.com

Address: Head Quarter: Plot no-3, Sector-B, Pocket-2, Vasant Kunj, New Delhi- 110070 Contact no- 91-11-41761873/41761874

East Delhi Office Flat No 245, Pocket D, Phase 2, Mayur Vihar, New Delhi, 110091 Contact No: 91-11- 43590600
Gurugram Office 4056 / 23A, Near North Cap University, Gurugram, Haryana, 122017

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