

Volume-30

Indradhanush

E Newsletter (April-June 2021)



Kaun Banega Karorepati played by residents on 16th April 2021

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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/>

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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- 91-11-41761873/4171874

East Delhi Office (Satellite Centre) Flat No 245, Pocket D, Phase 2, Mayur Vihar, New Delhi, 110091

Contact No: 91-11- 43590600

Gurugram Office (Satellite Centre) 4056 / 23A, Near North Cap University, Gurugram, Haryana, 122017

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From Director's Desk



The new normal in last 12 months had been pushing all to develop new strategies for survival. To top it with new challenges, arrived the second wave of Covid in early April 2021 and brought an unimaginable stress with it. This was the worst phase of pandemic as not even a single family was left untouched of its impact. Muskaan had to change its' way of functioning once again as the leadership decided to give one month vacation to all students & teachers during May 2021 since many families were fighting with survival issues due to pandemic. The focus of this period was to create support systems as per the need of each family. This included collecting, verifying and sharing information on medical facilities & supplies, organizing supplies, providing nutritional & emotional support. The saddest part was losing some of the members in this journey.

Muskaan's senior leadership also reached out to authorities for vaccination of persons with intellectual disabilities on priority basis due to their high vulnerability. Simultaneously the teachers started motivating the families to get the vaccination done for themselves & their wards as and when available in their nearest centres/ hospitals. Information about the vaccination centres was collected & shared with families. Muskaan leadership also connected with medical team in these centres and sensitized them for needs of PwIDs.

In June we opened our online sessions with a two weeklong "Summer Fest" with an idea of destressing everyone thro' some fun activities. This was highly appreciated by all participants including students, teachers and families. Regular Online learning program was restarted after that for all students.

Though this was the toughest period, we could sail together with each other's support and strengthened the bond between Muskaan and families.

Few things in the world are more powerful than a positive push. A smile. A world of optimism and hope. A "you can do it" when things are tough. -Richard M. DeVos

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About Unique Disability ID: (Link → <https://www.swavlambancard.gov.in/>)

"Unique ID for Persons with Disabilities" project is being implemented with a view of creating a National Database for PwIDs, and to issue a Unique Disability Identity Card to each person with disabilities. The project will not only encourage transparency, efficiency and ease of delivering the government benefits to the person with disabilities, but also ensure uniformity. The project will also help in stream-lining the tracking of physical and financial progress of beneficiary at all levels of hierarchy of implementation – from village level, block level, District level, State level and National level.

Second Wave: The Pandemic and its impact on families

Covid 19 was the most unfortunate phase that came into the world. It was contagious and spreading vastly. Every house was affected with the disease. The pandemic was spreading so fast that it was difficult to keep us apart. Unfortunately, we were also fallen in that situation, but the love and support of all family members helped us to go through this virus. It was the test time for our family when my girls took charge of home. They dealt with the situation very responsibly. With their care & support we became fit & fine. They have taken care of each and every medical & personal needs. Their prayer & health care helped us to get well soon.

- Mrs. Katari (Ekas's Mother)

I am sharing experience of our family members inflicted by COVID during 1st phase. We total are six members of family including my parents & one sister lives jointly. Five of us were infected asymmetric. My wife suffered fever for ten to twelve days without any major complications. Regarding Dhruv first two days he felt Sad then very quickly he adjusted himself & was very supportive to all & took special care to his mother.

We received full support from our neighbours, friends & relatives. We also followed COVID protocol. We are thankful to God.

- Mr. M S Ahuja (Dhruv's Father)

The 2nd phase of Covid during April & May 21, it was at its peak at Delhi. Myself, my wife Kawaljit & Ricky all three of us were diagnosed Covid positive on 29th April. We started treatment for the same. It was a critical battle which continued almost a fortnight. We were alone and Ricky being a specially able child it was very difficult for us to deal with. Communication was the main issue in high temperature and with low oxygen levels, but we were in dilemma how to hospitalise him alone.

However, we stayed at home. With online medical guidance from doctors & God's grace, we could come out the critical phase by end of May21.

I would like to thank and narrate here the names from whom we got the laudable support from the during this period.

1. My daughter Ramneek, from Ahmedabad, coordinated with doctors, arranged online medicines, oximeters, other gadgets. Food items at doorstep since we were not in a position to cook. Although she herself, husband and son were also attacked by Covid.
2. In this difficult time the emotional boosters provided by Muskaan Team, Specially Surinder ji & Aradhana Mam along with other staff members of Lemon tree Hotel by video calls made us to gain strength to come out of it successfully. It seems like rebirth of Ricky. He could sail through it despite low oxygen levels with everyone's support.
3. Special thanks to Happy Friends & parents during the crisis.
4. Special mention for support by relatives and neighbours.

THANKS TO ALMIGHTY ALSO FOR DIVINE BLESSINGS ON US.

- Mr. T. S. Anand (Ricky's Papa)

Keep yourself and others safe: Do it all!

- Get vaccinated as soon as it's your turn and follow local guidance on vaccination.
- Keep physical distance of at least 1 metre from others, even if they don't appear to be sick. Avoid crowds and close contact.
- Wear a properly fitted mask when physical distancing is not possible and in poorly ventilated settings.
- Clean your hands frequently with alcohol-based hand rub or soap and water.
- Cover your mouth and nose with a bent elbow or tissue when you cough or sneeze. Dispose of used tissues immediately and clean hands regularly.
- If you develop symptoms or test positive for COVID-19, **self-isolate until you recover.**

First Step to Muskaan: Training & Orientation Unit



The training and orientation unit is the first unit for the students who joins Muskaan.

We start the program with assessment and induction of the students. Initially we work with the students as well as the parents and families. In orientation, they get to know about Muskaan, teachers, infrastructure, peers, rules to be followed, timetable. Once they are oriented in the program the preparation of vocational training starts. We work on all the areas of the personality development of the students. It includes training in life skills, fine motor development, cognition, social skill, communication, and work behavior. Adulthood issues, Extra- curricular activities, public speaking, and safety in all the areas are integral part of the training.

The students need to understand the process of work. Doing work is important but taking responsibility of the work is more important. They are being taught how to take responsibility, how to follow structure of the work, how to follow instruction of the teachers, being regular and punctual for the program. These understandings help them in future training, and it helps them to get integrated in the programs they are placed in.

Their timetable includes morning orientation, discussion of previous days sessions, taking attendance, life skill training sessions, physical activity, work related projects, training in art related activities, sports music, and dance. We organize lot of events and festivals to enrich their lives and give them the opportunity to live a full life.

The aim of the training is to prepare the students for future vocational training and placement in any program.



Summer Fest: A new venture (31st May to 11th June)

In the month of May 2021, the corona cases were at the peak and almost all the families of staff and students were affected with it. Emotionally also it was a very hard time for the each of the members of Muskaan. To ease it out Muskaan declared the summer break in the month of May so that things should be easy and less demanding for everyone. Towards end of the May things started getting settled down and covid cases also started slowing down. so, to give the students a good start and boost their motivation we planned summer fest for them. it was a two-week program where we planned some inhouse activities and some workshops to be conducted by Resource persons from outside. Teachers planned the activities with care and enthusiasm and made elaborate plan, developed the videos, listed down the required material. the elaborate plan was sent to the parents so that they can be prepared for the activities.

Simultaneously three track of program was planned to cater all the students.

12 DIY activities and two workshop were conducted during this for all the three units: Training & orientation, Art & Activity Centre & Work Unit.

the activities included: fun games, games to enhance fine motor skills and coordination, paper craft, culinary art, fun with clay, art and craft and fun with colour.

two workshops were also planned and taken up by resource persons from outside - one was growing micro greens, and another was clay designing, both the workshops were not only enjoyed by the students and the family members it gave a new perspective too.

It was a good change after a long traumatic period of Covid and gave a good start to the program. Students became more enthusiastic and motivated to start online programs again.



Disability and Health

Key facts

- **Over 1 billion people live with some form of disability.**
- **The number of people with disability are dramatically increasing. This is due to demographic trends and increases in chronic health conditions, among other causes.**
- **Almost everyone is likely to experience some form of disability – temporary or permanent – at some point in life.**
- **People with disability are disproportionately affected during the COVID-19 pandemic.**
- **When people with disability access health care, they often experience stigma and discrimination, and receive poor quality services.**
- **There is an urgent need to scale up disability inclusion in all levels of the health system, particularly primary health care.**

Overview

Disability refers to the interaction between individuals with a health condition (e.g., cerebral palsy, Down syndrome, and depression) and personal and environmental factors (e.g., negative attitudes, inaccessible transportation and public buildings, and limited social supports). Over 1 billion people are estimated to experience disability. This corresponds to about 15% of the world's population, with up to 190 million (3.8%) people aged 15 years and older having significant difficulties in functioning, often requiring health care services. The number of people experiencing disability is increasing due to a rise in chronic health conditions and population ageing. Disability is a human rights issue, with people with disability being subject to multiple violations of their rights, including acts of violence, abuse, prejudice and disrespect because of their disability, which intersects with other forms of discrimination based on age and gender, among other factors. People with disability also face barriers, stigmatization and discrimination when accessing health and health-related services and strategies. Disability is a development priority because of its higher prevalence in lower-income countries and because disability and poverty reinforce and perpetuate one another.

Disability is extremely diverse. While some health conditions associated with disability result in poor health and extensive health care needs, others do not. However, all people with disability have the same general health care needs as everyone else, and therefore need access to mainstream health care services. [Article 25 of the UN Convention on the Rights of Persons with Disabilities \(CRPD\)](#) reinforces the right of persons with disability to attain the highest standard of health, without discrimination. However, the reality is that few countries provide adequate quality services for people with disability.

Barriers to healthcare

People with disability encounter a range of barriers when they attempt to access health care including:

Attitudinal barriers

People with disability commonly report experiences of prejudice, stigma and discrimination by health service providers and other staff at health facilities.

- Many service providers have limited knowledge and understanding of the rights of people with disability and their health needs and have inadequate training and professional development about disability.
- Many health services do not have policies in place to accommodate the needs of people with disability. Such policies could include allowing longer and flexible appointment times, providing outreach services and reducing costs for people with disability.
- Women with disability face particular barriers to sexual and reproductive health services and information. Health workers often make the inaccurate assumption that women with disability are asexual or are unfit to be mothers.
- People with disability are rarely asked for their opinion or involved in decision-making about the provision of health services to people with disability.

Physical barriers

Health services and activities are often located far away from where most people live or in an area not serviced by accessible transport options.

- Stairs at the entrance to buildings or services and activities located on floors which do not have elevator access are inaccessible.
- Inaccessible toilets, passages, doorways and rooms that do not accommodate wheelchair users, or are difficult to navigate for people with mobility impairments, are common.
- Fixed-height furniture, including examination beds and chairs, can be difficult for people with disability to use.
- Health facilities and other venues for activities are often poorly lit, do not have clear signage, or are laid out in a confusing way that makes it hard for people to find their way around.

Communication barriers

- A key barrier to health services for people who have a hearing impairment is the limited availability of written material or sign language interpreters at health services.
- Health information or prescriptions may not be provided in accessible formats, including Braille or large print, which presents a barrier for people with vision impairment.
- Health information may be presented in complicated ways or use a lot of jargon. Making health information available in easy-to-follow formats – including plain language and pictures or other visual cues – can make it easier for people with cognitive impairments to follow.

Financial barriers

- Over half of all people with disability in low-income countries cannot afford proper health care.
- Many people with disability also report being unable to afford the costs associated with travelling to a health service and paying for medicine, let alone the cost of paying to see a health service provider.

Disability inclusion in the health sector

Disability is often not perceived as a health issue. Therefore, action is not taken towards disability inclusion in the health sector, which is also often overlooked in national disability strategies and action plans to implement and monitor the CRPD.

Attaining the highest possible standard of health and well-being for all will only be possible if governments understand the need for a paradigm shift, recognizing that the global health goals can only be achieved when disability inclusion is intrinsic to health sector priorities, including:

- universal health coverage without financial hardship
- protection during health emergencies
- access to cross-sectorial public health interventions, such as water, sanitation and hygiene services.

Disability inclusion is critical to achieving universal health coverage without financial hardship, because persons with disabilities are:

- three times more likely to be denied health care
- four times more likely to be treated badly in the health care system
- 50% more likely to suffer catastrophic health expenditure.

Disability inclusion is critical to achieving better protection from health emergencies, because persons with disabilities are disproportionately affected by COVID-19, including:

- directly due to increased risk of infection and barriers in accessing healthcare
- indirectly due to restrictions to reduce spread of virus (e.g., disruptions in support services).

Disability inclusion is critical to achieving better health and well-being, because persons with disabilities are:

- 4–10 times more likely to experience violence
- at higher risk of nonfatal injury from road traffic crashes.

Children with disabilities are:

- three times more likely to experience sexual abuse
- two times more likely to be malnourished.

WHO response

To improve access to and coverage of health services for people with disability, WHO:

- guides and supports Member States to increase awareness of disability issues and promotes the inclusion of disability as a component in national and sub-national health programmes.
- facilitates collection and dissemination of disability-related data and information.
- develops normative tools, including guidelines to strengthen disability inclusion within health care services.
- builds capacity among health policymakers and service providers.
- promotes strategies to ensure that people with disability are knowledgeable about their own health conditions, and that health care personnel support and protect the rights and dignity of persons with disability.
- contributes to the United Nations Disability Inclusion Strategy (UNDIS) to promote “sustainable and transformative progress on disability inclusion through all pillars of work of the United Nations”; and
- provides Member States and development partners with updated evidence, analysis and recommendations related to disability inclusion in the health sector.


Courtesy WHO World Health Organization

Friends Corner: Budding talents



Aditya's Mandal Art



**Khushboo with sprout
Salad**



**Kulhad painted by
Shagun**



**Divya's delicious fruit
chat**



Photo clicked by Ritesh



Shivang' Diya painting



Radha's Painting



Puneet's colouring



Creation by Harleen Kaur



Painting by Nimmi



Understanding money concept



Biker of clay made by Ronit



Beautiful bags with cross stich made by Bindu



Trainees from East Delhi centre making Chaat



Trainees from Gurgaon with handmade pen stand



Marking to follow social distancing



At the time of 2nd phase when the conditions got worst, we, the team Muskaan tried to extend our support to the families in need. We arranged two oxygen cylinders, concentrators, and other equipment's to help families. Tried to facilitate in hospitalization. Planned for vaccination of our friends & staff who had some issues in reaching out for it. Apart from that we also provided continuous emotional support which was needed the most at the difficult time of Pandemic



Internship at Muskaan

Chavi Ilwadhi, Rashmi Chakravarthy, Prateek Debnath from TISS

We really appreciate your willingness to let us explore all the units within the organization. We were extremely satisfied with our learning exposure and how we could correlate our classroom pedagogy with the functioning and perspective of an esteemed organization like Muskaan.

Intellectual and developmental disability was the new arena for all three of us to explore pertaining to livelihoods. But, through the vision of Muskaan, we could gauge how disability can be embraced as diversity and how we can advocate in bringing the marginalized intellectually disabled population to the mainstream from the realm of the periphery.

We were fortunate enough to get an opportunity to interact with our **friends at Muskaan** through online classes despite the barriers of the pandemic. It was an extremely overwhelming experience to share space with them, to know them better and to be a part of unalloyed joys spread by them.

Furthermore, the entire staff of Muskaan has been extremely approachable. We didn't realize that we were connected in the online mode. The regular interactions that we had with all of you in the last couple of weeks made us feel as if we are also an indispensable part of the organization. We were amazed to witness the kind of camaraderie each one of you shared with all three of us that made us feel as if we are home.

We are also grateful for having met each one of you through the online and offline orientations, how we're encouraged to sit for the internal meetings, were allowed to see how a non-profit works, from the ground up. We have gained skills in research, writing content, product marketing and liaisons that would definitely be useful for our career.

Within such a short period, we were able to align ourselves with the ethos of Muskaan and could appreciate the journey it has embarked so far. All this is just a short elucidation of our learnings and reflections but, the experience is extremely memorable that will be cherished always.

We are extremely grateful to you all for such incredible learning exposure.



Different, but not Less: Our Abilities are Limitless!