

Volume:32

Indradhanush

E-NEWSLETTER (OCTOBER- DECEMBER 2021)



Diwali Utsav was the highlight of this quarter as we were able to organize our Diwali Utsav on campus with full enthusiasm like every year (except last one). The team was happy to be in full action for decorating the place, putting up the stalls, sending out invitations and backing it all with adequate production. Our regular customers also supported us by either visiting or ordering online through' Vyapaar app. We were happy to pack some bulk orders for gift Hampers once again for some existing & few new customers. The moment of pride came when we received orders from two Government agencies and came to know that our products will reach the high officials in Government thro' these hampers. It meant a lot to us since reaching out to the policy makers was a big achievement for us as the quality products made our students have been the biggest mode of creating awareness about their capacities.



In this issue we bring you one more report on advocacy efforts of PARIVAAR in the direction of creation of e-content for children & adults with intellectual disabilities. Muskaan has played an active role in this initiative and contributed to the guidelines for preparation of E-leaning content.

(N. Hawla)



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Diwali Utsav 2021

■ Ms. Mridula Sakle

At Muskaan we have been successful in extending our services virtually in the present circumstances. We were able to continue with sale of products since the month of July 2020 through our online store. Products were made by students with help of Teacher's Associates, during the time they were able to come to Muskaan. We started with receiving orders from nearby areas and home delivery of the products with SOP for packing and delivery. This helped us in reviving our contacts with the customers who have supported us in our journey of making our Supported work Centre a reality.

Diwali is one of the very important times for Muskaan as we reach to around 10,000 people with our products and are able to create awareness regarding capabilities and capacities of our persons with ID. This year also we wanted to reach as many people as possible and as the Covid situation was under control. Production of Food products was done at Muskaan following all FSSAI and hygiene rules. Few students came to work at Muskaan to make Mathris, pickle etc. Other products like gift paper bags, brown paper bags; Diya painting was done in the respective units by students very enthusiastically. They were given targets for everyday as there was a short period for doing production. Happiness and enthusiasm were palpable in the atmosphere as everyone was busy and looking forward to having a great Diwali sale. Our Diwali Bazaar was inaugurated by Mr Ahluwalia on.....26th October 2021. This was attended by few executive members and few parents as we followed the Covid guidelines. Few students came to Muskaan for Diya lighting and Ganesh Vandana with our teacher Ms. Rashmi Garg. These students also explained about products kept for sale and invited everyone to buy products made by them. Friends of Muskaan and different groups who have been supporting Muskaan were invited on different days for their shopping.

Sale of products on online store was started on Vyapaar App. Link was sent to all the customers of our data base. This included schools, colleges, corporate, donors, friends of Muskaan and customers who visited us during previous Diwali. We had a very good response, 8200 people visited the store and we received 140 orders online in a period of 8 days. We were able to reach approximately 10,000 households. We had a good response from our bulk buyers this year. In previous year we got only 4 bulk orders but this year we had 16 bulk orders. We also set up Diwali bazaar at Muskaan during Diwali and here also we got a very good response. Lot of our local customers from Vasant Kunj were happy to come to Muskaan for their purchases and gift orders. Workers working during these times were paid their stipend and bonus for their hard work.



My journey with Muskaan-PAEPID

■ Ms. Dhwani Jain

A counselor by profession & a sibling to a 21-year-old with socio-emotional challenges, I joined muskaan-PAEPID in 2021 to grow as a professional in the disability sector. It's been almost a year of my association and I have been lucky enough to find out their secret of successfully existing for almost 4 decades and revolutionizing perspectives on the capabilities of persons with intellectual disability. The secret is none other than acknowledging parents as an important resource in every aspect of their functioning. It is not really a secret that muskaan is a "parent association for the empowerment of persons with intellectual disability" however to understand the functioning of a parent led association is what I truly discovered.

Admission process is one of the initial contact points where parents share their experiences, challenges, and vision for their ward. Sharing such crucial and sensitive information doesn't come easy, however the kind of listening ears the staff here has, make the parents comfortable enough. I know many of the special educators, managers, leaders and support staff in the organization who have experienced similar challenges and hence are able to give an authentic relatability to the new parents. I have felt the contentment and hope on the face of the new families who become a part of this small community of like-minded people.

We are all sailing in this world-wide health crisis, and it became worst during the second wave. I vividly remember the team's effort to stay connected to the families and ready to help in whichever ways possible. We lost few of our students to corona and the organization genuinely felt immense grief.

I have no count of those conversations where the team came together and talked like a proud parent of one or the other student of muskaan. Remembering so much about them, knowing their strengths, knowing about their challenges etc. all of this comes so effortlessly to the team. This can only happen when you collectively understand and connect with the student's journey. I wonder if that really happens in other organizations.

Another hit event of muskaan is Diwali mela. i have been hearing about it from the team members since I joined. Stories of how it is not the same anymore after covid. I got to experience it this time. I was placed at the stalls with



the students. The customers who came in were parents, funders, people from the neighborhood, relatives of the staff etc. I never expected to hear more than the typical consumer behavior of just being interested in knowing the prices of the products, but I was surprised. I heard parents going to that specific stall first where their ward's work unit products were kept. There were parents who shared that they volunteered number of times, and they were observant enough to identify which product is not available this time. Few parents were keen to know me since I was new to their eyes. We had fewer products from the art n activity center this time and I felt it especially when people especially came to pick them only. I vividly remember parents picking up that one specific masala which was a hit for them or because of which they got compliments from friends and family. there were instances where people were video calling their relatives to tell them about the grandness of the setup and offering to buy stuff for them as well. I specifically liked how this event also became a platform to celebrate the contribution of various parents and other people. The acknowledgment of all this support by the leadership ship team was truly heartfelt. I also observed how this event was giving a platform to our students to demonstrate their acquired skills. Not just in creating those products but also to be on the forefront and helping out in managing this event which otherwise is a job of professional event planners. To conclude, this event is the best example of how a parent led organization looks like.



4IN.001 Global Impact of Non-communicable Diseases Data Blitz Presentations

Neuro- Developmental Disorders in India- An INCLEN Study (INA-2.001)

■ Donald Silberberg¹, Narendra Arora², Vinod Bhutani³, Maureen Durkin⁴ and Shefali Gulati⁵

Shared from Parivaar Annual Report 2020-2021

¹ Neurology University of Pennsylvania Philadelphia PA

² Executive Director INCLEN New Delhi India

³ Paediatrics Stanford University Palo Alto CA

⁴ Population Health Sciences Waisman Centre Madison WI

⁵ Paediatrics All India Institute for Medical Sciences New Delhi India

OBJECTIVE: The objectives of our research are: 1) estimate the prevalence of NDDs among children aged 2-9 years in India; 2) gather information on risk factors; 3) develop and disseminate methodology that may be useful in other low-income countries.

BACKGROUND: The domains studied were; Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorders, Intellectual Disability, Epilepsy, Learning Disability, Neuromuscular Disorders including cerebral palsy, Speech and Language Disorders, and Hearing and Vision Impairment.

DESIGN/METHODS: A 39 question NDST was developed in English and Hindi, translated into 8 regional languages, and validated among 593 subjects in 9 regions of India. The test-retest and inter-rater reliability of the NDST was assessed at two centres in New Delhi, and at the Child Development Centre in Thiruvananthapuram, testing 192 children. The test re-test reliability coefficient was above 0.8 for 35 of the 39 questions (89.7%) among both doctors and research assistants. The inter-rater reliability correlation co-efficient was above 0.8 for 21 questions (53.8%). The content validity of the refined tool was then validated in four different strata: rural, urban, hilly areas and tribal areas at five field sites. Conventional clinical diagnostic methods, including expert opinion were used to establish or rule out the presence of NDD's. A total of 593 subjects participated in this piloting.

RESULTS: A total of 4,000 households in 6 regions of India were sampled.

CONCLUSIONS: Subject to extensive ongoing analysis, it appears that 7.5% to 18.5% of children ages 2-9 years suffer from one or more NDD, including those who exhibited more than one NDD. If one excludes isolated hearing impairment, the overall prevalence of NDD's seems to be from 4.7 to 13.7%.

Supported by: NIH (USA) Grant R21 HD53057, MKC Nair (PI), J. Pinto-Martin and D. Silberberg (Co-PI's), S Gulati, Network Coordinator; Autism Speaks (USA); The National Trust (Government of India) and INCLEN.

Disclosure: Dr. Silberberg has nothing to disclose. Dr. Arora has nothing to disclose. Dr. Bhutani has nothing to disclose. Dr. Durkin has nothing to disclose. Dr. Gulati has nothing to disclose.

To know about schemes, visit the site --- <https://disabilityaffairs.gov.in/content/page/national-policy.php>

Government of India
Ministry of Social Justice & Empowerment
**Department of Empowerment of Persons
with Disabilities (Divyangjan)**

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National Fund Under PwDs	DDRS	Scholarship
ADIP	District Disability Rehabilitation Centres (DDRC)	State Spinal Injury Center
	SIPDA	Indian Spinal Injuries Center (ISIC)
	Accessible India Campaign	Others
	Awareness Generations	Financial assistance for deaf Colleges
	Incentive to Private Employer	
	Research & Development	
	In Service Training	
	Barrier free	
	TEST	
	Braille Press Scheme	
	Unique Disability ID (UDID)	
	Skill Development of PwDs	

Parivaar NCPO Recommendations to Ministry of Education & NCERT

On Special Needs of Students with Intellectual & Developmental Disabilities

Shared from Parivaar Annual Report 2020-2021

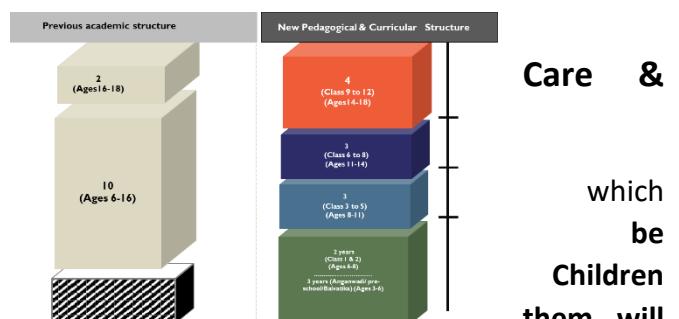
We thank Ministry of Education for organizing the meeting of Working Committee on 5th March 21 to discuss the recently formed guidelines for the development of E-Contents for the children with special; needs (CWSN).

Parivaar Parents also thank Prof Anupam Ahuja and sub-committee members for their dedication and efforts towards developing guidelines that will go a long way to implement NEP for CWSN, utilizing the potential of digital medium. Parivaar being representative of over 60,000 parents of children with ID would request you to consider the following:

We would very much like our children to be part of mainstream and use mainstream contents to develop their potential, as planned by NEP.

Prioritize Development of Early Childhood Education Contents

The NEP envisages experiential learning at this stage suits Children with intellectual disabilities. The contents developed in a manner suitable for the needs of with intellectual disabilities considering that most of use it for extended age.



The stipulation by NEP is to “**focus during ECCE on developing social capacities, sensitivity, good behavior, courtesy, ethics, personal and public cleanliness, teamwork, and cooperation completely**”.

NEP Introduce Vocational Crafts & Community based Mentoring at Age 12 onwards

As per NEP “**age 12 onwards every student will take a fun course, that gives a hands-on experience of a sampling of important vocational crafts, such as carpentry, electric work, metal work, gardening, pottery making, etc**”. The requirement of CwIDs coincides with NEP envisaged deviation (for CwSN) that these children might not pursue the formal school grades and will concentrate on Life Skill & Vocational development.

The special requirements of Children with intellectual disabilities will be taken care to a large extent by above, if the contents for students, teachers & parents follow the guidelines worked out by the sub-committee.



New Orders Regarding Family Pension for PWDs on 19th Jan 2022

Payment of family pension in respect of a child suffering from a disorder or disability of mind through the person nominated by the Government servant/pensioner/family pensioner

1/4/2021-P&PW(E)-Part I

भारत सरकार

कार्मिक, लोक शिकायत तथा पेंशन मंत्रालय

पेंशन और पेंशनभोगी कल्याण विभाग

(डेस्क - इं)

तीसरा तल, लोक नायक भवन

खान मार्केट, नई दिल्ली-110003

दिनांक-जनवरी 19, 2022

To

CMDs of All Pensions Disbursing Banks

(Through E-mail)

Sub: Payment of family pension in respect of a child suffering from a disorder or disability of mind through the person nominated by the Government servant/pensioner/family pensioner

I am directed to say that in accordance with the Central Civil Services (Pension)

Rules, family pension is payable for life, subject to certain conditions, to a child of a deceased Government servant/pensioner, who is suffering from any disorder or disability of mind or is physically disabled so as to render him or her unable to earn a living even after attaining the age of twenty-five years

2. As per Rule 50(9)(h)(iv) of the Central Civil Services (Pension) Rules, 2021 (earlier clause (iii) of second proviso to Rule 54(6) of the Central Civil Services (Pension) Rules, 1972), family pension shall be paid to a son or daughter, who is suffering from any disorder or disability of mind including the mentally retarded, through the guardian as if he or she were a minor.

3. Rule 50(9)(h)(vii) of the CCS (Pension) Rules, 2021 (earlier clause (vi) of second proviso to Rule 54(6) of the CCS (Pension) Rules, 1972), however, provides that in the case of a mentally retarded son or daughter, the family pension can be paid to a person nominated by the Government servant or the pensioner, as the case may be, and in case no such nomination has been furnished to the Head of Office by such Government servant or pensioner during his lifetime, to the person nominated by the spouse of such Government servant or family pensioner, as the case may be, later on. The Guardianship Certificate issued under section 14 of the National Trust Act,1999 (44 of 1999), by a local level Committee, shall also be accepted for nomination or appointment of guardian for grant of family pension in respect of the person suffering from Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities as indicated in the said Act.

Also Read: PCDA Circular 656: Alternate provision in Lifetime Arrear (LTA) certificate for grant of family pension

4. It has been brought to the notice of this Department that in some cases, the Pension Disbursing Banks are not allowing family pension in respect of a mentally retarded child through the person nominated by the pensioner or his/her spouse in accordance with Rule 50(9)(h)(vii) of the CCS (Pension) Rules, 2021 (earlier clause (vi) of second proviso to Rule 54(6) of the CCS (Pension) Rules, 1972) in spite of the fact that such nomination has been duly incorporated in the Pension Payment Order issued to the mentally retarded child. These banks insist for payment of family pension through a person having a guardianship certificate issued by a court of law.

5. Clause (vii) in the Rule 54(9)(h) of the CCS (Pension) Rules, 2021 is intended to avoid any hassles to the child suffering from a mental disability in obtaining the guardianship certificate from the court and in claiming family pension after the death of his/her parents. As per this rule, a government servant/pensioner or his/her spouse can nominate a person to receive family pension payable to a mentally retarded child. In cases where such nomination is

submitted by a government servant/pensioner/family pensioner, a guardianship certificate issued by a court of law is not necessary.

6. Accordingly, in cases where a nomination made by the Government servant/pensioner/family pensioner has been incorporated in the Pension Payment Order issued to child suffering from a mental disability, it is incumbent on the Pension Disbursing Banks to disburse the family pension in respect such child through the person so nominated. Insisting for a guardianship certificate by the Banks in such cases would defeat the very purpose of such nomination and would also amount to violation of the statutory provisions of the CCS (Pension) Rules, 2021.

7. It is requested that suitable instructions may be issued to the CPPCs/Pension Paying Branches of your Bank for payment of family pension in respect of a mentally retarded child through the person nominated by the Government servant / pensioner/family pensioner in accordance with the statutory provisions of CCS (Pension) Rules and not to insist for a guardianship certificate issued by a court of law in such cases. All Pension disbursing branches also be asked to acknowledge receipt of these instructions.

8. This issues with the approval of Competent Authority.

भवदीय

(संजय शंकर)

भारत सरकार के उप सचिव

टेलीफोन-24635979

Copy to:

CGA,
CPAO

CPPCs of all Pension Disbursing Banks
Secretary, Department of Financial Services for information

Bani Magoo



She is 24 years old young adults with Down syndrome. I remember when I met her in Muskaan first time in 2013, she was very shy and introvert. Hardly she was speaking or interacting with others. But in the other side regarding work, she was always keen to learn new task and always fully involved in the class activity. She was a keen observer and doing the things with full perfection.

In 2015 we have selected her for Lemon Tree Hotel Gurgaon under mainstream employment. As we believed that she has the potential to adjust and cope up with outside world demand and manage well. We were right she finished her eight months intensive on the job training and successfully placed in Lemon Tree hotel Gurgaon Sec- 29 in their Food & Beverage department.

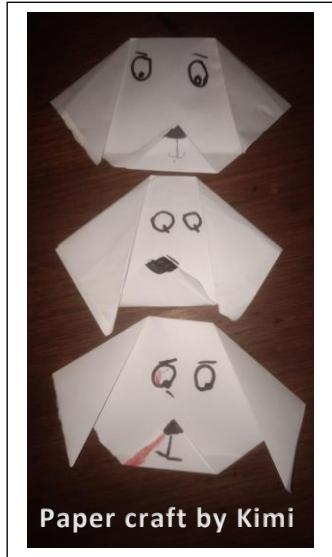
Initially she learnt all the task of coffee shop, but she was liking doing work in back area with minimum interface with people. After continuous dialogue and counselling she started working inside the coffee shop and start enjoying work with her teammates.

Entire family members were very cooperative and supportive during the entire journey. They were always keen to know about her training and ready to extend support wherever required.

During the pandemic everything got disrupted so eagerly waiting for Lemon Tree Hotel to open.....



Friends Corner



We Celebrate: Events of the Quarter a glance



Celebration means to make moment / occasions rememberable. So that whenever we think about that, multiple pictures and stories of that day come to our mind and give good and happy feeling to our heart. These little-little celebrations make our life easier and joyful. So, we celebrate every moment of life to give reason to ourselves to be happy ever. Celebrating as a team also helps build and deepen relationships among team members. Firstly, it naturally bonds people through a shared positive experience. Secondly, this time where team members can talk and get to know one another can help develop their relationships which in turn will improve team functioning. As

people get to know about hidden talent and get to know one another on a more personal level, this will help them work together more effectively on a professional level.

Throughout the year, we come together to celebrate various types of occasions & festivals differently and every day of the calendar in last quarter is full of festivals like Dussehra, Diwali, Disability Day, Christmas along with the birthday celebrations. What we celebrate and how we celebrate may vary but our appreciation of the importance of celebration is nearly universal.





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 are 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

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