



Director's Desk

**Festivals promote diversity, they bring neighbours into dialogue,
 they increase creativity, they offer opportunities for civic pride,
 they improve our general psychological well-being.
 In short, they make cities better places to live.**

-David Binder

Festivities were all around in the past quarter with Durga puja, Dussehra, Diwali, Guru Nanak Jayanti, Christmas and many more festivals. Though the normal hustle bustle of these festivities was missing as our students were not physically present in Muskaan Campus yet our team ensured that the spirit of festivities should not be dampened at any cost. Various online events were created around these festivals in small groups and large groups. A lot of activities were planned for students and parents too. We were amazed at the enthusiasm shown by both our students and families in response to creative initiatives taken by teachers & Program leaders.

Our Production and marketing team also left no stone unturned to reach out to its customers- retail & bulk, and fulfil their requirements. An online store was created with pictures and specifications of products so that customers can order from the comfort of their homes only and our delivery team delivered at their doorstep. Along with that a Diwali Utsav was also organised on campus though the inaugural function was held online. We received an amazing response to our online store and were able to sell our limited stocks with everyone's support.

The work for construction of additional block was in full swing during this period as we planned to shift our residents to Vasant Kunj in the new year. Majority of residents were living in our residential facility though some parents were waiting for the new block to be ready and send them directly to Vasant Kunj. Along with residents, caretaking staff was also living on campus to ensure the safety of everyone. We salute them for their commitment as they had to stay away from their families to fulfil their duties for a long period.

Sometimes I wonder about the general happenings in our world which are highlighted by our media and majority of these are negative in nature. Though when I look around myself – my colleagues in Muskaan- I always find a positive thinking which leads to solutions to any challenge that comes their way even if it's not an easy ride. I thank almighty and pray to him to keep blessing this team and may their enthusiasm and motivation never get dampened and they keep soaring high.

Mhanta

We Celebrate

Celebration means to make particular moment / occasions memorable. 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 Teacher's day, 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.

Teachers Day:
Cultural event held in their respective groups

Disability Day: To mark World Disability Day cultural events were organised in all units separately so that all student gets the chance to showcase their hidden talent. Along with that to spread awareness to a larger population we started to podcast a series of radio program on Disability on our you tube channel also shared the link on other social media. We also marked the day on our social media through specific post.
<https://youtu.be/HV-aaUVLrXc>

Diwali: Diwali has a different importance in Muskaan, with all adverse situations (Spread of Pandemic & lockdown) we somehow sail through and got prepared for "Annual Diwali Utsav". For the first time-ever we successfully organised a huge function online on zoom platform for inaugural on 5th November 2020. Chief Guest for the event was Mr. Ravinder Singh, CEO, Skill Council for Persons with Disabilities and Guest of Honour was Mr. Anup Srivastava, Former CEO, Skill Council for Persons with Disabilities. This was attended by our parents, students and friends of Muskaan. 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.

After that we also celebrated our Diwali celebration online with all trainees & an offline celebration with staff.

<https://youtu.be/WSXD6MurpP0>

Christmas: For Christmas we had two major events online, one on 24th December in which all the trainees participated. Where they saw a small movie on Christmas, sang Christmas carols, danced on the tune and had party. Another was on 25th December where parents & sibling of our friends performed and every one enjoyed thoroughly.

<https://youtu.be/FnXlrslDww>



Finding Ways: Marketing a new challenge during pandemic

■ 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 as production in the supported work centre is according to targets set for each month. Initially the products sold were made by the students before the lock down in March,2020. 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. Production was started for Diwali by Teacher's Associates with few students at Muskaan and some students were given work at home. Production of Food products was done at Muskaan following all FSSAI and hygiene rules. Few students came to work at Muskaan to make Mathi, pickle etc. Other products as making gift paper bags, brown paper bags; Diya painting was distributed to workers at home. All workers were encouraged to set up a small place at home for their work and work at specific time every day. They were given targets for everyday and asked to report regarding their work in online sessions with teachers. All the workers were very happy with this structure of work as they were also WFH as their other family members.

For sale of products an online store was started on Vyapar 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; 5400 people visited the store and we received 140 orders online in a period of 8 days. We were able to reach approximately 7000 households. We also set up sale of products in Muskaan during Diwali in open area and here also we got a very good response. Workers working during these times were paid their stipend also.

We will continue with online store and extend services for WFH to more students.

Link for Vyapar App: <https://vyaparapp.in/store/MuskaanPAEPID202022>

Digital Resource library: Adapting & accommodating the new changed environment

■ Ms. Rashmi Gerg

Creating and evolving teaching learning materials has to be an integral part of education. In Muskaan it is a continuous process and the teachers have created ample resource material considering the situation and need of their students. For the ease of access to teachers the need was felt to compile all the materials in a more structured and consolidated manner. Technology was the only answer to it.

Our plan of Digitization started in 2018 ... Digitalization in education refers to the use of digital technology - use of desktop computers, mobile devices, the Internet, software applications, and other types of digital technology to teach students. Digitalisation has many advantages such as accessibility to information, easy and immediate communication and ability to share information. Technology has become an important part of majority of people in their daily lives. Living in techno-savvy era where Smartphones, laptops and tablets have become common words, our students should not to be confined to simple learning. In Muskaan tablets were bought and use of computers and tablets became common and desirable both for teachers and students.

Pandemic gave a big push to this process. During Pandemic all sessions and interactions had to be moved online. At this time more sessions and more learning materials was needed for students' all-round development to ensure undisrupted training. A seventeen-members team was made to do thorough examination and continuous research of existing content for how to fill the gaps and make it user-friendly also to upgrade it, also identify and include more learning materials to the resource bank – **A digital resource library.**

A digital library is a collection of wide variety of digitally formatted resources such as flash cards, stories, photographs, worksheets, videos, apps and external links – organized in an electronic format. New and more advanced materials were added on topics like Health & Hygiene, nutrition, Safety, etc. Our digital support is an IT expert who procured Google workplace platform(G-Suite). The term 'digital learning resource' is used here to refer to materials included in the context of a course that support the learner's achievement of his desired learning goals. Email Ids of everyone at Muskaan including all the students were created. All the sessions are now conducted on Google meet using the training materials from the resource library. It has played a big role in changing the way our students learn life skills, get entertained, get physically fit, how they interact and how they behave in society.

Special Feature- Both Hindi & English language used

Final Goal is to Connect all TLM to our Curriculum



INTELLECTUAL DISABILITY

Medical reference < Intellectual disability

<https://www.statpearls.com/ArticleLibrary/viewarticle/23579>

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Continuing Education Activity

Individuals with an intellectual disability have neurodevelopmental deficits characterized by limitations in intellectual functioning and adaptive behaviour. This activity reviews the evaluation and management of intellectual disability, including the genetic and environmental aetiologies of intellectual disability, various disease manifestations, and appropriate evaluation strategies. This activity also highlights the needs of individuals with intellectual disabilities and suggests an interprofessional approach to the management of intellectual disability and recognizes the interprofessional team element in managing these cases.

Objectives:

- Summarize the epidemiology of intellectual disability.
- Outline the etiology of intellectual disability.
- Explain the treatment considerations for patients with intellectual disabilities.
- Review the importance of improving care coordination amongst the interprofessional team to enhance the delivery of care for patients affected by intellectual disability.

Introduction

Individuals with an intellectual disability have neurodevelopmental deficits characterized by limitations in *intellectual functioning* and *adaptive behaviour*. These disabilities originate and manifest before the age of 18 and can be associated with a considerable number of related and co-occurring problems including mental health (e.g., depression, and anxiety), neurodevelopmental (e.g., autism spectrum disorders, and attention deficit hyperactivity disorder), as well as neurological (e.g., infantile cerebral palsy) and medical conditions (e.g., meningitis).

Intellectual functioning

Intellectual functioning is generally called intelligence and includes a wide range of mental activities such as the ability of logical reasoning and practical intelligence (problem-solving), ability in learning, verbal skills, and so on. It manifests and expresses itself through a numerous set of capabilities, behaviours, thoughts, and emotions. In other words, intellectual functioning is definable as the global ability that allows the individual to understand reality and interact with it. Intellectual functioning is commonly measured by the intelligence quotient (IQ), which represents a total score obtained from standardized tests (IQ tests) developed for evaluating human intelligence. IQ test score has a median of 100 and a standard deviation of 15. A score of 70 or below (two standard deviations below the median) indicates intellectual limitations.

Adaptive behaviour

These disabilities express as lacking competence in social, conceptual, and practical skills. Social skills include interpersonal skills, social responsibility, self-esteem, gullibility, naivety, resolution of social problems, and the ability to follow the rules of the society and to obey the laws. Conceptual skills include the ability to understand time, finance, and language. Practical skills include the ability to use tools, carry out activities of daily living, and interact with other people. All these skills are learned throughout development and performed in response to common problems and simple/complex tasks as well as expectations from our community and society. Obviously, these behavioural responses become progressively more complex with age. Several validated tools are useful for assessing limitations in adaptive behaviour.

Etiology

While many causes of intellectual disability are not known, the etiology of intellectual disability mainly divides into genetic abnormalities and environmental exposure. Genetic abnormality can be a single gene mutation, copy number variation, or chromosomal abnormality that causes an inborn error of metabolism, neurodevelopmental defect, and neurodegeneration. Environment exposure can be maternal exposure to toxin/infectious agents, uncontrolled maternal medical conditions, delivery complications, and post-natal trauma and exposure to toxin/infectious agents. The most commonly known preventable or

environmental cause of intellectual disability is fetal alcohol syndrome, the most common chromosomal cause is Down syndrome, and the most common genetic cause is Fragile X syndrome.

Genetic

The genetic abnormality may cause an inborn error of metabolism neurodevelopmental defect, or neurodegeneration. An inborn error of metabolism, toxic by-products accumulate, causing intellectual disability and other behavioural problems. Phenylketonuria (PKU) is one of the inborn errors of metabolism that occurs in approximately 0.01% of the new born. PKU most commonly results from phenylalanine hydroxylase defect inherited in an autosomal recessive fashion. The defect disables the liver from converting phenylalanine to para-tyrosine. The consequent accumulation of phenylalanine is the culprit of intellectual disability. Neurological damage from PKU is irreversible but preventable. Therefore, new born screening of PKU is mandatory in the U.S. and other countries. Early screening followed by prompt initiation of a low phenylalanine diet before the age of 3 may prevent intellectual disability. Recently, different rare types of hyperphenylalaninemia were described, including the deficiency of the enzyme dihydroxyphenylpyruvate reductase and a deficiency of a cofactor, bipterin.

Lesch-Nyhan syndrome is an X-linked inborn error of metabolism caused by purine metabolism enzyme deficiency. This condition results from a mutation in HGPRT. This mutation leads to a build-up of uric acid, which causes severe self-mutilating behaviour of biting mouth and finger as well as intellectual disability. Other known inborn errors of metabolism that result in intellectual disability are Niemann-Pick disease, Hunter disease, Hurler disease, maple syrup urine disease, Hartnup disease, homocystinuria, and galactosemia.

A neurodevelopmental defect presents in Fragile X syndrome, a leading genetic cause of intellectual disability. It results from a single gene mutation in FMR1 (Xq27.3) gene. In most cases, CGG repeat of the FMR1 gene expands to over 200 times. The expansion leads to a phosphorylated CG pattern, causing methylation imprinting of the gene, thereby silencing FMR1 gene expression. FMR1 is a transcription factor of hundreds of genes expressed in the central nervous system, and its disruption causes intellectual disability as well as behavioural disturbance, and seizure. Neurodevelopment defect also presents in neurofibromatosis type 1, also known as von Recklinghausen syndrome, an autosomal dominant condition, caused by mutations of NF1. Its characteristic presentation is abnormal neural cell migration leading to cafe au lait spot, movement disorder, and intellectual disability.

Neurodegeneration leading to intellectual disability presents in Rett syndrome (RS), an X-linked dominant degenerative condition only seen in female secondary to mutation of the MeCP2 gene. In patients with RS, cerebral atrophy occurs at substantia nigra, causing defects in the dopaminergic nigrostriatal pathway, starting at 6 to 18 months of age.

IQ alterations can also occur as part of a clinical picture in other genetic syndromes. In many cases, the intellectual deficit appears to be limited and can occur at different stages of neurodevelopment, also in terms of cognitive decline. For example, in chromosome 22q11.2 deletion syndrome, or DiGeorge syndrome, or velocardiofacial syndrome, which is one of the most common multiple anomaly syndromes in humans, it is usually described a cognitive decline rather than an early onset intellectual disability.

Environment

Environmental exposure during pregnancy may lead to intellectual disability, which can be caused by maternal exposure to a toxin, infectious agent, uncontrolled maternal condition, and birth complications.

One common toxic substance that leads to an intellectual disability during pregnancy includes alcohol. Alcohol exposure, indeed, commonly causes intellectual disability along with other developmental abnormalities, in a condition known as fetal alcohol syndrome. Fetal exposure to alcohol inhibits the production of retinoic acid, which is an essential signalling molecule for the development of the nervous system. Even a small amount of alcohol at any trimester of pregnancy may cause fetal alcohol syndrome. Exposure to opioids, cocaine, and teratogenic medications may also lead to intellectual disability.

Common, well-known infectious agent that causes intellectual disability are rubella and HIV. Maternal rubella infection in the initial trimester of pregnancy leads to intellectual disability approximately 10 to 15% of the time; it can rise to above 50% with infection during the first month. Immunization may prevent the mother from rubella infection. HIV may be transferred vertically from mother to infant. Infants with HIV may develop encephalopathy, seizures, and intellectual disability within the first year of life secondary to microcephaly, immunosuppression, and *Pneumocystis jirovecii pneumonitis* (PCP) infection. Excessive neuro-inflammation causes overstimulation of the N-methyl-D-aspartate type receptor (NMDAR) system that leads to neuronal injury. Antiretroviral therapy to mother and prophylactic treatment with zidovudine to new born exposed to HIV has significantly reduced the transmission. Other known infectious exposures to mothers that may cause intellectual disability of the new born are cytomegalic inclusion disease, syphilis, and toxoplasmosis.

Uncontrolled maternal medical conditions may lead to intellectual disability. Pregnancy hypertension, asthma, urinary tract infection, pre-pregnancy obesity, and pre-gestational diabetes were shown to increase the risk significantly. Furthermore, uncontrolled

maternal diabetes, malnutrition, and obstetrical complications causing anoxia (placenta previa, placenta abruption, and umbilical cord prolapse) may also cause intellectual disability.

An intellectual disability is acquirable during early childhood. Causes include infection (notably encephalitis and meningitis), head trauma, asphyxia, intracranial tumor (either directly or indirectly through seizure, surgery, and chemotherapy), malnutrition, and exposure to toxic substances.

Epidemiology

The prevalence of intellectual disability in developing countries is estimated to range from 10 to 15 per 1000 children of those about 85% have a mild intellectual disability. From 1 to 3% of the Western population is estimated to have an intellectual disability. Incidence is challenging to accurately calculate as mild disabilities may be under-recognized until later in childhood. The intellectual disability is reported to peak at the ages of 10 to 14 years and is 1.5 times more prevalent in males than females.

History and Physical

Keeping up with daily functions is often challenging for individuals with a different degree of intellectual disability. They may have difficulty feeding themselves, going to the bathroom, and dressing. They also may have difficulty getting along with their family and friends because of a problem with communication as well as poor impulse control. They may have trouble excelling academically and socially at school.

Concerning clinical history, symptoms of intellectual disability usually begin during childhood or adolescence. Moreover, delays in language or motor skills may be observed by age two. Nevertheless, a significant number of children with mild levels of intellectual disability may not get identified until school-age.

A comprehensive history of patients with intellectual disability must include the following:

- Information about the mother's pregnancy, labour, and delivery
- Mother's use of substance or medications during pregnancy
- Mother suffered any uncontrolled medical condition
- Was delivery pre-term?
- Was there any issue with delivery?
- Patient's sensory, social, language, and motor developments to detect any developmental delay
- Patient's exposure to infection, trauma, and toxin
- Patient's medical conditions
- Patient's psychiatric conditions
- Medications that the patient is taking
- Patient's family history of psychiatric and medical conditions
- Patient's living situation, caretaker
- Patient's behaviour toward caretaker, parents, and siblings
- Patient's academic performance at school
- Patient's behavioural disturbance reported at school

Physical examination is vital to differentiate intellectual disorders from other conditions. A full neurological exam should be performed to identify any deficit that may mimic intellectual disability and comorbid symptoms. Visual and hearing tests are particularly important as abnormal vision or hearing causes difficulty with communication, leading to delay in developing language and social skills, closely mimicking intellectual disability. Motor dysfunctions such as spasticity, hypotonia, hyperreflexia, and involuntary movements commonly present in individuals with intellectual disabilities.

Some physical characteristics are closely associated with a specific diagnosis as following:

- Down syndrome: slanted eyes, flat nasal bridge, protruding tongue, small chin, and single crease palm
- Fragile X syndrome: long and narrow face, prominent forehead and jaw, large ears, and large testicles in male
- Fatal alcohol syndrome: smooth philtrum, thin vermilion, and small palpebral fissures
- Prader-Willi: obesity secondary to compulsive eating behaviour, hypogonadism, small hands, and feet

- Cat's cry (Cri-du-chat) syndrome: microcephaly, hypertelorism, low-set ears, and micrognathia
- Phenylketonuria: bizarre movements such as twisting hand mannerisms, poor motor coordination, and perceptual difficulties

Evaluation

According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), the diagnosis of intellectual disability requires deficits in intellectual function, deficits in adaptive function, and onset before the age of 18. The IQ test is widely used to assess the intellectual function of individuals. IQ test derives from Stanford-Binet Intelligence Scales, used for school placement in France. Lewis Terman adapted the test to measure general intelligence. Scores were reported as "mental age" divided by chronological age, multiplied by 100. The current version of the IQ test is standardized, and two standard deviations below the test taker's group calculate as IQ of 70. An IQ of 70 or below suggests intellectual disability diagnosis. Based on the IQ score, the severity grading appears below.

- IQ 50 to 70: mild intellectual disability (85% of cases)
- IQ 35 to 50: moderate intellectual disability (10% of cases)
- IQ 20 to 35: severe intellectual disability (4% of cases)
- IQ below 20: Profound intellectual disability (1% of cases)

However, it is no longer a standard to classify intellectual disability by IQ score alone. For instance, if an individual has IQ below 70, but has a good adaptive function, the subject does not have an intellectual disability. On the other side, individuals with a normal, or even higher than normal IQ, may manifest severe deficits in adaptive functions and are, therefore, classified as having an intellectual disability. In turn, the current diagnosis of intellectual disability also considers a person's adaptive function. The Adaptive Behaviour Assessment System can measure adaptive function. It encompasses the social and practical domain. Adaptive function measure's ability in communication, social participation, and independent living.

The DSM-5 also has "Unspecified Intellectual Disability" (Intellectual Developmental Disorder) to describe individuals over the age of 5 suspected of having an intellectual disability who has difficulty completing required tests, usually because of limitations resulting from blindness, deafness, or concurrent mental illness.

Chromosomal analysis, urine and blood tests, and neuroimaging techniques have been used to elucidate the etiology of intellectual disability.

Traditionally, chromosomal analysis has been done by parents' choice before the birth of a child via amniocentesis (performed at 15 weeks of gestation) or chorionic villi sampling (8 to 10 weeks of gestation). It is a highly specific test for Down syndrome, and early detection of chromosomal abnormalities allow a decision to terminate the pregnancy. Recently, a cell-free fetal DNA test has appeared as a non-invasive prenatal test for Down syndrome. It has demonstrated a higher detection rate, positive predictive value, and false-positive rate. Another current technique of chromosomal analysis is fluorescent in situ hybridization (FISH), which is useful to identify the microscopic deletion of the chromosome.

Urine and blood analysis allow the evaluation of enzyme activities and detection of inborn errors of metabolism, including PKU, Lesch-Nyhan syndrome, galactosemia, and Hurler syndrome with the help of advanced techniques such as tandem mass spectroscopy and gas chromatography.

As for neuroimaging techniques, computerized tomography (CT) or magnetic resonance imaging (MRI) has been useful to identify microcephaly, cerebral developmental delay, and cerebral palsy. Functional MRI and diffusion tensor imaging are being researched to identify abnormalities in neural circuit pathways. For example, Fragile X syndrome with aberrant frontal-striatal pathways has been found associated with ADHD symptoms. Electroencephalography (EEG) is used to detect seizures that often accompany intellectual disability; though findings do not direct to specific diagnoses.

Treatment / Management

Management of intellectual disability must begin promptly with the goals to prevent further worsening, minimize the symptoms of disability, and improve the quality of everyday life. When initiating therapy, a healthcare provider must be aware of the various avenues of treating intellectual disability to orchestrate a multidisciplinary and individually tailored treatment appropriately. This section will discuss some examples of the multiple interventions available.

Educational support is a crucial component of intellectual disability management. Upon diagnosis of intellectual disability in children, healthcare providers must contact the school promptly to set up special education arrangements. What special education entails may vary slightly among schools, but it typically aids comprehensively with providing academic modifications as well as transition planning from childhood to adulthood with a focus on promoting self-sufficiency. It also teaches them how to seek assistance, behavioural skills, vocational skills, communication skills, functional living skills, and social skills based on individual needs in the least restrictive

environment. Creating the least restrictive environment for students with an intellectual disability means to place them in general classrooms as much as tolerated. While segregated classrooms for special needs may be helpful for those who need it, implementing the least restrictive environment policy has been shown to improve student outcomes. It is important to monitor the patients' progress in school because education solely from classroom settings may not be sufficient. If an individual with intellectual disability requires assistance beyond what is available at school, the family can meet the need at home through family education or other outside resources. For example, a disabled student who needs extra attention with social skills may be referred to participate in the Special Olympics programs that have been shown to improve social competence in intellectual disability subjects. Lastly, other causes of learning difficulties need to be ruled out, and appropriate hearing and vision screenings are necessary for individuals with intellectual disabilities.

Behavioural intervention is another important aspect of intellectual disability management, and it can occur in a few different ways. Behavioural therapy aims to encourage positive behaviours while discouraging undesirable behaviours. Providing positive reinforcement and benign punishments (e.g., time-outs) is an effective method of behavioural training. Other supplemental methods may include avoiding triggers of negative demeanour, shunning misconduct, and redirecting to prevent or curtail any troublesome behaviour. Cognitive therapy is another mode of behavioural training that has been effective for eligible intellectual disability patients. Cognitive therapy has its basis on a principle that one's behaviour, emotions, and cognitions are connected, and it aims to correct one's negative behaviours by identifying and adjusting negative thoughts and emotional stress. Although many other approaches to behavioural intervention exist, the implementation of behavioural therapy, cognitive therapy, or a combination of the two is the most widely used method that has shown to be an effective mean of behavioural intervention for intellectual disability patients.

Vocational training helps teenagers and young adults to obtain the necessary skills to enter the labour market. In vocational training, patients carry out pre-scheduled activities under the supervision of a multi-disciplinary team consisting of a social worker, occupational therapist, teacher, counsellor, and psychologist. Patients learn to keep themselves clean, wear appropriate clothes, and carry out their responsibilities. A study has shown that patients who underwent vocational training had reduced support requirements compared to their peers.

Family education is an essential service provided by healthcare providers for family members of intellectually disabled patients. The first part of this is assisting the family members in understanding intellectual disability: definition, management, and prognosis. Then, healthcare providers can help the family through placement decisions, refer them to appropriate services and equipment, and provide caregiver training. In addition to preparing the family for the patient, physicians must recognize that family members also often bear a significant amount of stress as well. The medical team must support the whole family through psychosocial problems such as the need for respect, feeling helpless, depression, and anxiety. There are also outside resources to which the family can obtain a referral. American Association on Intellectual and Developmental Disabilities (AAIDD), The Arc of the United States, and Family-to-family Health Information and Education Centres are some of the nationally available resources, and social workers can help with connecting the families with local resources. Establishing strong support for the family, in turn, creates a caring home environment for the patient.

Government resources are available for patients with intellectual disabilities and their families. Patients with intellectual disabilities are eligible to benefit from social security income. Patients also may benefit from various community services that provide housing and food delivery. The government also provides education and employment opportunities as outlined under "Disability Resources" section of the US Department of Labour website.

Psychopharmacologic interventions may not be the main component of intellectual disability treatment, but they play a significant role in treating behavioural abnormalities associated with intellectual disorder and comorbid conditions. Aggressive behaviour is not uncommon among individuals with intellectual disabilities and causes admission to institutional settings. Risperidone is well-documented to treat disruptive, aggressive, and self-injurious behaviours in children with intellectual disability with good safety and tolerability profile. Risperidone is an atypical antipsychotic that is less likely to cause tardive dyskinesia, which commonly results in a typical antipsychotic. Aripiprazole is another atypical antipsychotic that is used to manage aggression. Treatment of comorbid conditions is an important aspect of adequate therapy. Attention-deficit/hyperactivity disorder (ADHD), depression, and movement disorders are some of the comorbid conditions accompanying intellectual disability that require evaluation and treatment. Methylphenidate, clonidine, atomoxetine are shown in randomized control trials to reduce ADHD symptoms. Methylphenidate significantly improved the maintenance of attention to complete a task; however, there was no long-term improvement in learning and social skills.

Depressive symptoms can be easily overlooked in individuals with intellectual disabilities when other behavioural problems are prominent; thus, requires careful evaluation. Selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine, paroxetine, and sertraline were shown in multiple studies to help with depressive symptoms in this patient population.

Involuntary movements, repetitive self-stimulatory behaviours, and obsessive-compulsive symptoms may be harmful to the patients. Antipsychotic medications have been anecdotally reported to diminish these symptoms, although there was no observation of improvement in adaptive behaviour. SSRIs are useful in treating obsessive-compulsive symptoms and stereotyped motor movements. Studies have shown that patients with intellectual disabilities are at risk for polypharmacy, and providers should be cautious when prescribing medications as some patients may be at a higher risk of side effects and may need lower dosages.

Differential Diagnosis

Several diseases or conditions can be mistaken for intellectual disability:

- Child abuse: childhood abuse may cause developmental delays in language and socialization, causing a defect in adaptive function. The child may have difficulty communicating her needs and develop trust and social responsibility. Unlike intellectual disability, symptoms are often reversible when the environment improves.
- Debilitating medical disease: Individuals with normal intelligence may experience depression and delay in the development of chronic, debilitating medical illness.
- Cerebral palsy: poor muscle coordination, problems with vision, hearing, and speaking may imitate symptoms of intellectual disability.
- Sensory disability: deafness or blindness may lead to a flaw in diagnostic testing, causing a false-positive diagnosis of intellectual disability.
- Speech disorder: expressive and receptive aphasia may be mistaken for intellectual disability.
- Prognosis

The cognitive deficit of intellectual disability is permanent damage; thus, the prognosis of intellectual disability depends on the severity of cognitive impairment and the supportive environment provided. If provided adequate support, individuals with mild intellectual disabilities may achieve adequate language and social competency to live independently and raise their own families. Individuals with moderate intellectual disabilities are not likely to achieve academic level greater than second grade; however, they may acquire language and communicate their needs. They may be able to get a job under supervision. Individuals with a severe intellectual disability usually have difficulty acquiring language. They may be able to develop alternative communication skills and recognize words that are critical to functioning. Adults with a severe intellectual disability usually require supervised living situations, such as group homes, and supervision to perform any work-related tasks. Individuals with profound intellectual disabilities have significant difficulty with communication and social functioning.

Complications

Most of the individuals with intellectual disability have comorbid psychiatric conditions. Individuals are at higher risk of developing depression because they are prone to developing negative self-images as they have difficulty interacting with others and meet social expectations. Other psychiatric comorbid symptoms frequently observed in these individuals are hyperactivity, self-injurious behaviours, and repetitive stereotypical behaviours. Management of complications is discussed above in the "Treatment" section.

Deterrence and Patient Education

Among the most challenging aspects of intellectual disability is the patient's sense of social skill deficit and social isolation. Educating family for support to improve social competence and self-esteem is critical. Special Olympics International program is an example program that helps with improving social interactions, friendships, and self-esteem. Individuals with a disability need to be continuously encouraged to learn and interact with other people. The family of individuals with intellectual disabilities should understand that they are more prone to experience failures and rejections and make sure to provide a supportive environment that is not discouraging. Family therapy can help with resolving any feeling of guilt, despair, anger that may occur in the family relationship.

Enhancing Healthcare Team Outcomes

The management of patients with an intellectual disability is best with an interprofessional team. When treating individuals with intellectual disabilities, a healthcare provider may find communication with the patients difficult and may coerce the treatments. It is important to act professionally and make sure that patients do not get excluded from fundamental rights, and they are not coerced to specific therapies, as emphasized in the United Nations Convention for Intellectual Disability. Healthcare providers must carefully listen to the patients' needs and provide treatments that are in the patients' best interest. To serve the patients' best interest, an interprofessional, an interprofessional approach is essential; it has been shown to reduce the healthcare cost by decreasing the number of tests for the diagnosis of intellectual disability and the frequency of hospitalization. Core members of the an interprofessional team are primary care physicians, psychiatrists, psychologists, neurologists, speech pathologists, special nurse educators, social workers, and pharmacists. To maintain the best collaborative care, communication among the members of the team be effective. Each healthcare provider must promptly and accurately document diagnosis, assessment, services provided, and follow-up plans. In the current healthcare system, it is efficient and effective for primary care physicians and nurse practitioners to refer to the specialists based on the patient's needs, collect the evaluations and reports, and coordinate the care.

The array of treating physicians will manage the overall case, but they must rely on the input of other team members. Specialty-trained mental health nurses can provide a great deal of valuable information as they engage with the patient. They are also excellent

resources for verifying medication and other therapeutic intervention compliance, which can be challenging in such cases, as well as evaluating the effectiveness of the current regimen. Pharmacists must weigh in with medication reconciliation, assisting in agent selection for comorbidities, and verifying dosing. Pharmacists can also educate the patient and/or their family regarding the medications used. Medication adverse events should be reported to the treating physician promptly from either the pharmacist or nursing staff. Thus, an interprofessional approach is the optimal means by which to address patients with intellectual disabilities.

List of common genetic disorders

Contributed by Lee Keun, MD

Genetic disorders	Genetic defects	Pathogenesis	Diagnostic strategies
Phenylketonuria	Phenylalanine hydroxylase; autosomal recessive	Inborn error of metabolism; accumulation of phenylalanine	Birth screen blood test for concentration of phenylalanine
Lesch-Nyhan syndrome	HGPRT; x-linked	Inborn error of metabolism; accumulation of uric acid	Elevated level of urate to creatinine ratio. Molecular genetic test for confirmation.
Fragile X syndrome	FMR1; x-linked	Neurodevelopmental defects; Gene silencing of transcription factor for CNS development.	PCR to assess CGG repeat. Prenatal testing is available.
Neurofibromatosis 1	NF1; autosomal dominant	Abnormal neural cell migration	Presence of café-au-lait spot, neurologic deficits, optic glioma. Molecular genetic test for confirmation.
Rett syndrome	MeCP2; x-linked dominant (only affects female)	Neurodegeneration at substantia nigra starting at 6-18 months of age	Loss of acquired speech, motor skills. Presence of stereotypic hand movement. Diagnosis is clinical.

Table 1: List of genetic disorders that can cause intellectual disability aligned with associated genetic defects, pathogenesis, and diagnostic strategies.

Ways of facilitating development in various areas.....

■ Dr Shanti Auluck

Promote your child's independence and self-reliance

- Understand the preparedness of the child for training independence in various areas of his/her life
- See the interest of the child and choose relevant areas which will give him a sense of competence and mastery in a given activity.
- Make it an interesting and exciting activity
- Encourage by recognizing and appreciating every small step in doing an activity
- Support tacitly not making it obvious so that the child feels he/she has done it

Provide active learning experiences

- Exploring environment that is relevant to life of the child according to his current functioning level
- Clarity of learning goals keeping capacity building in mind in various areas of development
- Designing activities that invoke application of learnt knowledge and skills and building new skills, e.g. teaching relationships in a family through pictures, stories, real life observations.
- Deepening the understanding of various objects, situations, emotions through real life observations

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On Going Students Programs: A Glance

■ Ms. Abha Karn and Ms. Mridula Sakle

In this quarter Teachers spent a lot of time reorienting and diversifying the program and activities. The objective was to make it more participative and give an opportunity to students to showcase their learnt skills. It helped to inculcate a sense of accountability in the students as well as the parents/ families. They took the sessions very seriously and helped their wards to be prepared for online assessments and presentations. The online sessions continued with the following goal and objectives:

Goal: To provide emotional, social and educational support to the students and their families during Covid 19

Objectives;

1. To give awareness about the changing situation and how to deal with its demands by training in life skills.
2. To sustain a meaningful routine for every student in his home so that he/she works like a productive/contributing member at home.
3. To provide the scope of self-expression through various creative activities.
4. To help students to stay physically fit.
5. To create opportunities to learn/practice vocational skills.

Activities: (for Life skills, Prevocational skills, Physical fitness & Recreation)

- a. Awareness building through' discussions, demonstrations, videos and stories
- b. Building Cognitive skills through' real objects, flash cards, worksheets and games
- c. Training for vocational skills with use of training materials
- d. Maintaining Physical fitness thro' live online sessions
- e. Physiotherapy thro' live online sessions
- f. Recreation through fun activities

Number of sessions:

Every day sessions by unit in charge continued for the quarter and the focus was to prepare the students for the new placements and assess their learning. Physical fitness program days have increased from two to four days a week for all the students. Teacher of the unit also joined the physical activity sessions as the group is little bigger now. They are facilitating the students while the sports teacher is demonstrating the activity. Total **687** online sessions have been conducted in this quarter. There are 3-5 students in each group session and in sports and extracurricular activity there are more than 15-20 students depending on the nature of the activity. Some of the sessions are still being conducted one on one, based on the attention span of students. Assessment and induction of 8 new students is complete and they are ready to join the regular program from the month of January 2021

S. No.	Objective of the session	Learning Outcomes	Methodology	Outcome achieved
1.	To Build Awareness regarding changing situation	Maintain enthusiasm to continue learning online by starting online assessments (as situation in Delhi & NCR was again deteriorating)	Discussions/ PPT presentation/ by conducting simple sessions. Online assessments, live performances of work related activities, art activities, dance and music sessions	Students were confident while attending the assessment, doing any presentation, engaged in peer learning/ tutoring. There was a sense of competition to present what they learnt.
2.	To sustain a meaningful routine	Engage in production related work at home and continue their engagement at home in day-to-day routine		Students continued to be a support to families by taking simple responsibilities when parents had to move out for work
3.	To create opportunities for self-expression	Be confident and present their talents/learnt hobbies in different forums		Students were engaged in performances in bigger forums e.g., Diwali celebration, disability day celebration and Christmas celebrations. They were engaged with some of the corporate who had employed the students of Muskaan in online celebration and earned praise from the viewers.
4.	To promote physical fitness	Remain physically fit and active Participate in a multi-unit group/ 10-20 persons group and follow the online activity.		Students are happy to see their peers of different units and continue following the activity. Their sense of discipline had increased and they had become more patient.
5.	To continue providing Vocational training	Participate in work from home or onsite work to complete the orders for Diwali and other upcoming orders.		A system of providing work at home and organizing onsite work was established. Orders were completed and students earned their stipend.

Review of training Program:

To make the students confident about their learning a shift in the program was brought and we made it performance based. Online assessment was designed and conducted which students were able to comprehend and complete. Life skill training was diversified

and students started practicing the learned concepts in their extracurricular activities. The outcome was very encouraging. Students had shown their true colours in different forums. Leadership team also held monthly review meetings with the team to help them in making online sessions more effective and bring novelty in it.

Few Parents' Remarks;

Lockdown due to Corona would have been very demoralizing for Punchika, but for the Untiring efforts of Teachers and staff of Muskaan. The manner in which the online classes have been conducted by Muskaan is truly praise worthy. The best part is that there has been a continuous effort to improve, whether in terms of expanding the scope of online activities or connecting to students through a better online platform. Punchika is very happy with online classes and is eagerly awaiting the resumption of the same.

- Gaurav Kumar (Brother of Punchika)

As a Parent I also am most impressed with how the teachers and others in Muskaan have reinvented themselves in troubling times to remain them meaningful engaged with our friends!

-Mr Rakesh Diwan (Father of Vineet Diwan)

The program was good and Surjo enjoyed it very much. It is this enjoyment and the glitter in their eyes which is most important for a meaningful life, no formal education is equivalent to it. As a parent, our prime motto is to give our children that meaningful involvement, irrespective of their abilities, since all of us have limitations to our abilities with some or other aspects in life. We are sure Muskaan will continue to grow to give such evocative rendezvous to more and more pure heart mankind 🙏

- Santanu Patatunda – Surjo's father after Disability day celebration

Today's event was excellent rather superb
It's proved the talents, willingness n determination of our young friends. . .
Hats off to them 🙏
It also depicted the hard work and perseverance that you so tirelessly carry out for all your students...
so thankful to you all at Muskaan 🙏
And last but not least, gratitude and appreciation to all parents 🙏👍🙏

--- Zarin Singh, Mother of Vasudev Sharan after Diwali celebration

To mitigate the challenges, we had realigned our staff training, planning and thinking about the work for the students, production and sale.

We had realigned the focus of the staff training and worked very closely with them to create and efficiently use the online content. A series of training and meetings was organized to make them familiar with the online system and use it in their sessions. They were trained to work with the student's so that they can use the assessment formats/ questionnaires, and the flash cards. The teachers were trained to conduct online assessment, facilitating the students to do the presentation. This has helped the teachers as well as the students and families to maintain the motivation towards learning.

Work for Students, establishing production structure and re-establishing Market for products

Our students of Supported work centre look forward to Diwali as it is a celebration of their work and creates awareness regarding their capabilities and capacities. They were encouraged to do production at home and were supported by online sessions. Material for production was sent to them with targets for every day. Quality guidelines were discussed every day during online sessions. This gave a big boost to their motivation and they started doing their work with enthusiasm. At the same time some of the students started coming to Muskaan in small batches and contribute to production of items. 8-9 students started coming in two batches and started working twice a week. Our team had maintained a contact with clients (institutional and individuals) thro' out lock down period. Now we were able to give them awaited products through home delivery system and opening our retail store with safety guidelines for public. To reach our customers during Diwali, online store was launched and link was sent to all parents, donors and customers.

Link: <https://vyaparapp.in/store/MuskaanPAEPID202022>

Impact of these initiatives:

1. We were successful in uplifting the motivation levels of students, teachers and families. Students were excited about Diwali and they started production with enthusiasm. Teachers also executed the program with fresh enthusiasm. Families were

satisfied to see their wards more meaningfully engaged and being productive and also reported that they were also looking forward to festivities with eagerness.

2. Our client base was contacted and revived gradually with the efforts of the team. Online store made contactless shopping possible. Regular customers were happy to get Muskaan products. All orders through online store were delivered at homes. We had 5600 views on store and 140 orders within a week.
3. Diwali Utsav was organised in Muskaan as is done every year. Inauguration was done online; we had a very good participation. Diwali Bazaar was set up at Muskaan with all safety guidelines. Most of the regular customers from nearby areas preferred to come for Diwali shopping to Muskaan.
4. Some (13) students earned their stipend rs1000/- each and 40 students got Diwali gift for their contribution in work and active participation in the program.

We; at Muskaan work tirelessly to ensure the development of our students and try to harness their skill sets thro' available resources. Thank you all for being with us, we are committed to deliver our best with your support.

Employee Engagement Program

■ Mr. Surender Singh

It defines and articulates strategies for effective engagement of employees from corporate sectors in social initiatives. We promote culture of volunteering and commitment of leadership. This service includes training for volunteers, frequent communication, recognition and evaluating the impact. There are wide range of volunteering activities in which companies and their employees can participate

- ✚ Introductory event.
- ✚ Team building activities.
- ✚ Short term projects in the community that utilise core skills of employees
- ✚ Quick turnaround projects.

Volunteering is offered depending on the interest and policy of the company. Some of the activities through which we engage employees: Art & Craft, Interesting Fun Games, Vocational activities, Awareness events etc. This year due to pandemic it was little different all the activities happened online.

Last quarter of 2020 ended with lots of learning with fun and making new friends from corporate sector. During this our trainees came forward with lots of new talent. In this quarter our both Partners Team AIG & Team Macquarie coming forward with full of enthusiasm. In initial stage both companies were apprehensive & also little bit concerned about how they can involve with Team Muskaan. But after conducting first virtual cultural event, their concern and doubt was sorted out. During this quarter the most interesting thing was that both companies were eagerly waiting for the engagement programs and their entire team came forward with new ideas. And they all are shared that they always get a very strong positive vibes during interaction.

In this quarter we organized two events for AIG and two events with Macquarie during Dussehra, Diwali and Children's day (Quiz competition) and we also invited them to attend our virtual Diwali Inauguration program and World disability day event. Team AIG was also played interesting fun games (twice) with Muskaan staff also.

While organizing our virtual World disability day program our other employer partner Lemon tree Hotel, CBRE, Country Inn Hotel, Microsoft also joined and they all were very happy to see & meet our friends. Apart from this our employer partners also take interest and join in ongoing online training sessions and mostly during birthday celebrations.



Reflection: A journey with East Delhi Centre

■ Ms Madhu Jain

Muskaan established an extension centre at Sahibabad (Distt. Ghaziabad) with an aim to provide services to persons with intellectual disabilities in that area. With 8 students and 2 special educators it was just the beginning. In the last one year the centre has seen lots of changes and faced many challenges, but in spite of all this it has stood the test of time and moved ahead.

I joined the centre as a program co-ordinator in mid-February 2020. I had barely taken over, when the spread of coronavirus started in India. So, before I knew it the centre was physically closed down within a month of my joining, due to Covid 19 lockdown. What was I supposed to do? There was barely any time to shoulder my responsibilities and know my colleagues. There was this huge task of building a centre in terms of infrastructure, admissions, training programs and other activities.

However, after 2 weeks of inactivity, we as a team realised that this situation is not going to go away soon, so we had to start planning for a long-term solution as we could not let our students sit idle at home.

The first challenge that we faced was how to conduct sessions so that we keep in touch with the students, give support to parents in this unusual situation, and bring various activities to the doorstep of the students. So, a decision was taken to hold online classes to address some of these issues. The classes using what's app video chat were started in mid-April. Initially, there were fewer classes but as we gained confidence the students were engaged every day of the week with some activity or the other. It was a great learning experience for all, students, teachers and the parents. Over a period of time with training in more advanced technology like Google Meet, zoom etc. these sessions have become very interactive and effective tool of teaching.

Along with the above activities, the planning for infrastructure, admissions and making individual programs was also being put in place. It was like an orchestra being played with players at different locations!

As we were settling down, another challenge came our way which unsettled us again. One of our special educators left leaving only one special educator out of two. This tested our capacity to work, as one person had to take the responsibility for all the sessions. This created a huge workload on her and it required constant support and team work. Time tables had to be reset, and larger groups formed. Here technology played a significant role as we could hold sessions with bigger groups. We enhanced online learning by offering a greater number of sessions per day as resource teachers offered regular sessions for physical fitness and extracurricular activities daily. So, reduced teaching staff that came as a challenge turned into larger exposure for our students. Events like birthdays, festivals and other celebrations are held with great enthusiasm.

A young centre like East Delhi Centre has shown that whatever challenges may come, but if there is team work, determination, dedication and desire to move ahead, there is always a way. Of course, in its journey there has been a constant support from the senior leadership, and a very close coordination amongst the team members. A very special thanks to the parents who supported us throughout and became a part of our team. Without their participation and commitment nothing of this would have been possible.



Learning never stops: Capacity building Program

■ Ms. Seema Chadha

'If I believe that I can do it, I shall surely acquire the skills to do it even if I may not have it at the beginning '
by Mahatma Gandhi.

At Muskaan we believe on creating opportunities for growth of our employees through discussions, holding or attending webinars and discovering avenues of learning. We all have high dreams but little do we realise that crown will come to us on its own the day we are ready for it. So, our team has grown its capacities even in the challenging times of COVID pandemic and become technology equipped to provide services to our students, workers and families. We present to you it in brief.

Month	Internal sessions	details	External sessions	Details	Total Sessions
October'20	21	meetings with parents on extra curriculum , new time table for trainees, pickle making students assessments and 1 staff training on Social stories	7	SCPWD and UKIERI, UK.	28
November'20	11	curriculum design meetings, discussion and planning for Diwali Mela and 3rd world disability Day.	1	webinar on introduction to LinkedIn	12
December'20	4	open discussions on World Disability day , Curriculum design, New admission and social media	4	Diversity and inclusion by Microsoft. National Seminar on Workplace Inclusion of Persons with Disabilities: Policies and Incentives by CII	8

Article from Economic & Political Weekly
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Disability during COVID-19 Increasing Vulnerability and Neglect

- Srei Chanda & T V Sekher

COVID-19 and the resultant lockdowns have severely curtailed the mobility of persons with disabilities, restricted their ability to seek basic necessities, healthcare, and assistance. Uncertainty on the disbursement of financial protection schemes meant for persons with disabilities have exacerbated their existing financial precarity. At this juncture, obstacles in accessing healthcare should be identified, facilities should be made affordable, and financial support should be exclusively planned for persons with disabilities to save them from the dreadful risk of the coronavirus and its aftermath.

The COVID-19 pandemic is an unprecedented public health crisis, and the attendant infections and fatality are concentrated in the lower strata of society in developing countries. It has also devastated developed countries, including the United States, Italy and United Kingdom. Poor health and socio-economic conditions widen the spread and susceptibility of COVID-19 in India. Increasingly, public medical facilities are getting overcrowded and failing to meet the massive demands of intensive care. Persons with disabilities (PWDs) is one of the segments of the population who face compounded vulnerability to contagious diseases and lack of access to necessary facilities. Globally, it is estimated that a billion people have one or more types of disability (WHO 2011). In India, 26.8 million people have one or more forms of disability (GoI 2011). The difficulties faced by PWDs in India are multidimensional in nature and their poor socio-economic conditions increase the risk and vulnerability from the pandemic and prolonged lockdowns.

COVID-19 is intensifying the inequalities experienced by PWDs around the world. Often, information on disability is gathered remotely, rarely highlighting emergency preparedness during a disaster. Despite provisions made to ensure equal rights and responsibilities towards PWDs, they are neglected. Looking at their conditions amid COVID-19, the United Nations (UN) and the World Health Organization (WHO) have come up with a framework, and guidelines for protecting PWDs by ensuring possible measures to protect them from distressful economic conditions (WHO 2020; UN 2020a). The guidelines mention the role of healthcare institutions and healthcare professionals in maintaining compliance for the inclusive development of PWDs (Armitage and Nellums 2020). Detection, assessment, treatment, escalation and recovery are the main steps that have been evoked to tackle COVID-19, and during the assessment phase, the strategy of test, isolate and treat has been followed in the current approach to mitigate COVID-19 in the West (Watkins 2020). The role of local governments to cater to the needs of PWDs has been emphasised in view of the pandemic by the UN (2020b). An online survey undertaken on PWDs across India by the National Centre for Promotion of Employment for Disabled People (NCPEDP) highlights the difficulties faced during the COVID-19 crisis, including problems in accessing essential items, medicines and pension.

**Important Links- For online Unique ID, Disability Certificate: <http://www.swavlambancard.gov.in/>
For Legal Guardianship & Niramaya: <http://www.thenationaltrust.gov.in/content/>
For Disability Pension: https://online.ndmc.gov.in/wpension/apply_pension.aspx**



An online assessment, theory & practical were completed successfully by the trainees from Pickle Making training group a pilot project by SCPWD & DFID.



Diwali 2020

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