



COMHAD NEWS LETTER



COMMONWEALTH ASSOCIATION FOR HEALTH & DISABILITY

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“Covid Pandemic - Its Impact on Persons with Special Needs : April 2021”

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MESSAGE

COVID-19 STIGMA AND DISCRIMINATION

Few months ago, in a newspaper story of a retired civil servant unfortunately succumbing to Covid-19, the author narrated that the officer could not get a final farewell. It was the municipal corporation authorities who did it. The couple had a 25-year-old child of Down's Syndrome who was unable to comprehend the ground reality of Covid-19.

Indians have been meticulously following Covid appropriate behavior for the past one year, with 2 meters social distancing, mask and repeated hand washing, barring few exceptions during marriages, festivities etc. The fear of the disease has not diminished. Man has become the enemy of man. This has led to difficult situations particularly in social context. It is time that we ponder over this social scenario, more obvious in big cities.

People who developed Covid-19 have been describing their woes of stigma and discrimination. Most patients, as they develop symptoms, go for Covid testing rather reluctantly. Once the test is positive, the saga begins. Ideally the patient with mild illness should stay isolated at home in one room having separate toilet facilities and family members attending to their relative following all Covid appropriate protocol. This makes the patient so comfortable, his anxiety lessens and recovery is faster. As against this, the real picture is different. The patient has to go to Covid care center all alone with no one around and stare at the walls in utter anxiety and depression. The result is not facilitative for recovery. If the patient is serious and needs admission to ICU, wherein there are scary health care staff in PPE suits, doing their duty. The fright and fear makes the condition of the patient worse. One ward boy from a tertiary hospital described that patients have died of fear at both places, patient in hospital and relative if single at home. The stress is so enormous that people have had myocardial infarction and cardiac arrests. If the patient is a specially challenged person, a divyang, the scenario worsens. Over all, patients have to manage on their own.

On discharge, when the patient comes home, the neighbors behave so rudely much the way lepers were treated 60 years back. This has to stop. The patient is well and non infective. But the discrimination continues. We should make all attempts to educate our population to overcome the stigma and not discriminate the patient. As one consultant said, “The patient has to go to hospital alone, get treated alone and die alone or survive alone if lucky.”

The message that we wish to propagate is Covid or no Covid, treat Covid-19 patients with empathy, care and with humanely attitude. We suggest that all hospitals should allow relatives wearing PPE suits following Covid appropriate behaviour and be involved in care of their patients.

Good attitude of doctors, health care staff will set an example.

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Vaccine Hesitancy - 'To be or not to be'

Dispel the myths. (An opinion)

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Covid-19 pandemic has created havoc in the world. Man has become the enemy of man. Year has gone by and the world sees light at the end of the tunnel now. Yes. They are the vaccines against Covid-19 and many countries have vaccinated more than several lakhs of people by now hoping to end the pandemic at the earliest. In Hamlet, the classic soliloquy by Shakespeare, 'to be or not to be' the dilemma 'to live or not to live', was described. Today, the medical fraternity is posed with this question day in and day out. One wonders if we are in the middle of devil and the deep sea. The answer today is very positive. Take the vaccine and survive, as also mitigate the pandemic.

We wish to dispel the myths of a common citizen in India about Covid-19 vaccine.

It was interesting to note the reaction of an elite educated senior citizen in context of vaccination. She said, "If there is a 94 % chance that I will recover from Covid and the vaccine efficacy is 95 % .So I have just a 1% chance of mortality. Doctor, should I then take the vaccine?" Her argument made us think. We wish to put before our learned readers, the importance of vaccinating against Covid and minimize anxiety.

What is vaccine hesitancy?

In 2015, the World Health Organization (WHO) Strategic Advisory Group of Experts on Immunization defined vaccine hesitancy as a 'delay in acceptance or refusal of vaccination despite availability of vaccination services'. Hesitancy is seen in many countries including India. Some surveys showed that 70% people in urban slums of Mumbai said that they would take Covid-19 vaccine, while some surveys showed much less acceptance. China gave the highest proportion of positive responses (631 of 712 respondents, 88.6%) and the lowest proportion of negative responses (5 of 712, 0.7%) when asked if they would take a 'proven, safe and effective vaccine'.

Respondents from Poland reported the highest proportion of negative responses (182 of 666, 27.3%), whereas Russian respondents gave the low proportion of positive responses (373 of 680, 54.9%). USA, UK have already begun vaccination and the response is good.

India as a country has a long history of childhood vaccinations both via public and private sectors. The success of our universal immunization program for children is around 76%. Now, we would be undertaking adult vaccination against Covid-19. Dry runs have begun; storage facility arrangements are in place. But are the people ready? This is a question that needs attention.

People want a vaccine that is safe, effective, affordable and acceptable,

There are many reasons that people think for not being vaccine ready. Coercion is certainly not the answer. Success will come by confidence building of general community and medical community by putting large information in public domain.

Is the Covid-19 vaccine safe?

Common man thinks that any vaccine brought out in so much of a hurry may compromise quality. But scientists have explained that previous platforms that were ready and used in SARS cov1 etc are used now. Also the clinical trials on Covid-19 vaccine have not compromised on anything. Whenever a clinical trial is undertaken, it is mandatory that there is a 'Data safety monitoring board' (DSMB), comprising of members who have no fiduciary or other interests in the vaccine. Any adverse event has to be reported to DSMB, to manufacturers and

regulators within 48 hours. All the vaccine trials done anywhere have to follow this protocol. It is not mandatory for the Principal Investigator of the clinical trial to inform to lay public or media about the adverse events. However, such a transparency by the manufacturers boosts the confidence.

In the Oxford trial, all serious adverse events were communicated through media by the manufacturers. If the same procedure is followed in India it would boost consumer confidence in the vaccine. Besides the transparency maintained by vaccine manufacturers, a press release and official stand of the regulatory bodies of the Govt. should be informed at the earliest.

So, when there is guarantee on the safety of the vaccine with least adverse events then confidence and vaccine uptake will improve. All vaccine strategists must see that correct information is released very quickly and transparently. All the Covid-19 vaccines that are likely to be licensed in India have gone through this procedure. It therefore stands to reason that people should not be afraid of adverse events or side effects. Or think that vaccines are brought out in a hurry. All the safety protocols are followed.

Current evidence is suggestive of good safety profile of approved vaccines.

Do these vaccines affect fertility?

Pregnant mothers and lactating women should not receive the vaccine as data is not available.

However, there has been a common fear expressed by some groups that vaccine may contain sex hormones, HCG etc which may make them infertile individuals. This fear was expressed during polio camps and it resulted in severe setback to the program. It was a total misconception propagated by various media. It took years to remove it. It is important here to know that none of the Covid-19 vaccines contain any hormones and the question of altering fertility or making any one lose his potency is totally baseless. Some notions that the vaccines contain pork gelatin are incorrect. Therefore there is no fear of harming religious sentiments of any groups.

Can I get an allergic reaction to vaccine?

Vaccine is an antigen, a foreign protein and when injected can rarely produce an allergic reaction known as anaphylaxis. This is like some people being allergic to sea foods, prawns, crabs, some to nuts and some to drugs like penicillin, neomycin, sulphas etc. Such people should tell their history of allergy to their doctor. Such people should not take the vaccine.

Recently CDC of USA has issued guidance that adults of any age with underlying medical conditions should be aware of the limited safety data. People with HIV were included in clinical trials on vaccines but Safety data specific to this group are not available at this time. People with autoimmune conditions were included in clinical trials but safety data is yet to be made available. Some vaccine candidates developed facial palsy though now it is known not to be related to the vaccine. People with history of GBS or facial palsy may receive the vaccine and no cases of GBS were reported with mRNA vaccine.

Can vaccine be given to Divyang children?

Covid vaccine can be given to children with disabilities only when trials of these vaccines on children are completed. At present most vaccines are tried in persons above 18 years of age. Some clinical trials for use of Covid-19 vaccine in children below 18 years are being done even in India.

Role of various media platforms.

It is important that social media can give some wrong information which can spread like wild fire. On one of the news channels some morphed pictures of people eating each other like cannibals were shown. This was blamed on the chimps adeno virus. It is important that such wrong ideas are immediately corrected by scientific community. News media, social platforms, WhatsApp and Instagram play a major role. All information should be provided through scientific journals, peer review process and through them to common citizen.

Do we need to take vaccine as Indians may have got herd immunity by now?

This is a very common statement made even by medical community. Many surveys in India, by ICMR showed that seropositivity was 1% in initial months; and in the last month's survey, it was found to be 10 %. It was only some pockets like few slums that showed 70% seropositivity for Covid-19 antibodies.

We know that if the R_0 (reproduction number meaning the number of people, one patient can give the virus and infect) of the virus is 3, we need at least 66 % seropositivity in the community to have herd immunity. One can thus realize that India is still far away from reaching the target to get herd immunity. The only answer therefore is to take the vaccine.

Do I need the vaccine if I have recovered from Covid?

Current available data suggests that few people who got Covid in May-June, still got re-infection and got Covid in November–December. Evidence suggests that immunity after natural infection i.e. Covid disease may not give full protection against second attack and immunity may wane after three to four months. It therefore would be desirable to take the vaccine after having got Covid once, with a gap of 12 weeks after the person has recovered from Covid disease. Clinical trials are going on to find out if only one dose of vaccine would be sufficient for them.

The next question that arises is, ‘will I get more severe reaction to vaccine if I have had Covid?’

Both the disease and vaccine are evolving. But in the vaccine trials, some patients who had Covid-19 disease were also included and given the vaccine. No special difference was found between them and other persons. Whether these people will mount higher antibody response or otherwise is not known. Yet, such individuals should take two doses similar to others.

Should vaccines be made compulsory?

No country can ever be successful in any strategy if the people do not accept it. The same is true for vaccination against Covid-19. Govt., Scientists, medical fraternity should make attempts to give the information first, and offer the best vaccine available without compulsion. It should be given both by public and private sector and in a cafeteria approach which means people will have the choice to take whichever vaccine they wish to.

Of course, one has to remember that the advantages of taking the vaccine far outweigh the risks of side effects. As time goes by, our knowledge will improve for better care.

Needless to say, mask, social distancing and hand washing cannot be compromised at anytime,

A good vaccine is your immunity and health passport!

So friends, come forward and take the vaccine!

Home - Based Intervention-An Occupational Therapy Perspective

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Services in the home supports the social and emotional well-being of the young children and their families. Home based therapy facilitates child's development, provides opportunity for enhanced decision making and parent empowerment.

Occupational Therapists must assess the impact of the child's disability on the family dynamics when opting for home -bound intervention. In the home the therapist can be more sensitive to family issues and to the psycho-social aspects of child's development which gives a better understanding of the family's interaction with the child and the effect of the environment on the child's performance. Education and emotional support of the parents along with one-on-one therapy to the child forms the services provided for home -based intervention. Explanation of therapy activities helps family members understand the rationale for the child's goals.

Families of children with sensory processing disorders, need help to understand the child's behaviors for example the family may experience frustration in dealing with the child's high activity level and inability to pay attention. Therefore the Occupational Therapist explains the sensory problems that affect a child's arousal, attention and behavior. Thus the therapist can develop an individualized sensory -motor/integration program and establish a sensory diet tailored to the child and family preferences. Accommodations made to the sensory environment at home, can help the child modulate and organize his or her sensory responses. When infants achieve *homeostasis* (i.e an optimal level of alertness and arousal), and when young children are comfortable in their environment, positive parent-child interactions naturally results.

Sensory Diet Activities

What is a sensory diet?

Just as your child needs food throughout the course of the day, the need for sensory input must also be met. A “sensory diet” (coined by OT Patricia Wilbarger) is a carefully designed, personalized activity plan that provides the sensory input a person needs to stay focused and organized throughout the day. Children need to engage in

stabilizing, focusing activities too. Infants, young children, teens, and adults with mild to severe sensory issues can all benefit from a personalized sensory diet. Each child has a unique set of sensory needs. Generally, a child whose nervous system is overaroused and too wired needs more calming input, while the child who is more underaroused and too tired needs more alerting input. A qualified occupational therapist can use her or his advanced training and evaluation skills to develop a strong sensory diet for your child—or you—but it's up to you and your child to implement it throughout the day.

The great news is that the effects of a sensory diet, combined with professional intervention, are usually immediate AND cumulative. Activities that perk up your child or calm him down are not only effective in the moment; they actually help to change your child's nervous system over time so that he or she is better able to :

tolerate sensations and situations that are challenging regulate emotions, alertness and increase attention span reduce unwanted sensory seeking and sensory avoiding behaviors handle transitions with less stress.

How can you tell if a child would benefit from a sensory diet?

If child has sensory processing dysfunction which requires management by a sensory diet this might be demonstrated by the child :

- Being very physically active (to the point they cannot settle to a task) or
- Looking tired and lethargic, or vague and day-dream
- Becoming 'wound up' with physical activity
- Being unable to settle after being in busy environments
- Having difficulty controlling impulses
- Has trouble modulating the tone of voice used
- Being restless at group time or in crowds
- Being too rough in play
- Failing to understand personal space (invading others inappropriately)
- Having difficulty sleeping

Creating a Sensory Diet : The Ingredients

It is strongly recommended that you work with an occupational therapist who has a solid understanding of sensory processing issues. One of the trickiest aspects of sensory difficulty is recognizing when a child is *over* reactive or *under* reactive in any given moment, and then calibrating sensory input to meet him where he is and provide a "just right challenge" to help him move forward into a "just right" state of being. That's why it's so important to partner up with knowledgeable help. You'll need to modify them depending on your child's age, arousal level (does she to rev up or relax?), whether she is in school, at home, or away, and whether or not you have special equipment available.

Proprioception

Proprioceptive input (sensations from joints, muscles and connective tissues that underlie body awareness) can be obtained by lifting, pushing, and pulling heavy objects, including one's own weight. A child can also stimulate the proprioceptive sense by engaging in activities that push joints together like pushing something heavy or pull joints apart like hanging from monkey bars.

Toddlers and Preschoolers

Make a "burrito" or "sandwich." Firmly press on your child's arms legs and back with pillows or make a "burrito" by rolling her up in a blanket.



Push and pull. She can push her own stroller, and a stronger child can push a stroller or cart filled with weighted objects such as groceries.

Carry that weight. Your child can wear a backpack or fanny pack filled with toys (not too heavy!).

School-age Kids

Jump! Have your child jump on a mini-trampoline or rebounder or play hopscotch.

Push and pull. Have him vacuum, carry books from one room to another, help wash windows or a tabletop, and transfer wet laundry from the washing machine to the dryer.



Teenagers and Adults

Heavy lifting. Without straining, teens and adults can shovel snow or lift free weights.

Push, pull, and carry. Rake leaves, push heavy objects like firewood in a wheelbarrow, do push-ups against the wall, wear a heavy knapsack (not too heavy!) or pull a luggage cart-style backpack, or mow the lawn with a push mower.

Reassuring pressure. Get a firm massage, use a weighted vest or lap pad from a therapy catalog, or place light weights in the pockets of a fishing, athletic or regular type of vest.

Vestibular

Vestibular input (the sense of movement, centered in the inner ear). Any type of movement will stimulate the vestibular receptors, but spinning, swinging, and hanging upside down provide the most intense, longest lasting input. If your child has vestibular (movement) sensitivities, please work closely with a sensory smart OT who can help you recognize and prevent signs of nervous system overload.



Toddlers and Preschoolers

Swing. Encourage her to swing on playground swings, trying various types of swings and movements, such as front to back and side to side.

Spin. Have him spin using a office chair. Let her run in circles, and ride a carousel. Hold your child's arm and spin in a circle as he lifts off the ground, or play airplane by holding one of his arms and the leg on the same side of his body as you spin in place (only if he does not have low muscle tone).

School-age kids

Get upside down. Have him hang upside down from playground equipment, do somersaults, or ride a loop-de-loop roller coaster.

Swing and roll. Encourage her to use playground swings and roll down a grassy or snowy hill (which good proprioceptive input as well).

Spin. Encourage her to go on amusement park rides that spin.

Teenagers and Adults

Swing and spin. Swing on a hammock, use playground swings or merry-go-round (you're never too old!).

Move that body! Do cartwheels, swim (doing flip turns and somersaults in the water), do jumping jacks, and dance.

Tactile

The tactile sense detects light touch, deep pressure, texture, temperature, vibration, and pain. This includes both the skin covering your body and the skin lining the inside of your mouth. Oral tactile issues can contribute to picky eating and feeding difficulties.

Toddlers and Preschoolers

Food and drink. Let your child drink plain seltzer or carbonated mineral water to experience bubbles in her mouth (you can flavor it with a little juice or with lemon, lime, etc.).

Messy play with textures. Have her play with foamy soap or shaving cream, and add sand for extra texture. Have her fingerpaint, play with glitter glue, mix cookie dough and cake batter, and so on. Let your child use the playground sandbox or create your own at home, filling a bin with dry beans and rice or other materials and small toys. Cover and store the bin for future use.

Use child-friendly modeling material such as Play-Doh, Model Magic, and Sculpey (the classic Play-Doh Fun Factory provides excellent proprioceptive input as well). Never force a child who is unwilling to touch "yucky" substances. Let him use a paintbrush, stick, or even a toy for cautious exploration.

Dress up. Dress up in fun costumes to get used to the feel of unfamiliar clothing,

School-age kids

Food and drink. Provide your child with frozen foods (popsicles, frozen fruit or vegetables) and mixed temperature foods (hot fudge sundae, hot taco with cold toppings, etc.).

Get in touch with nature. Encourage him to walk barefoot in the grass (avoiding pesticide applications), sand, or dirt. Have him garden and repot indoor plants.

Play dress-ups. Encourage play with make-up, face painting, and costumes, putting on a play or making a mini movie with a video camera.

Teenagers and Adults

Tactile hobbies. Sculpt, sew, weave, crochet or knit. Create a scrapbook (which involves lots of pasting and working with different textures). Use sandpaper to smooth a woodworking project. Make things out of clay, and try using a potter's wheel.

Auditory

Auditory input refers to both what we hear and how we listen, and is physiologically connected with the vestibular sense. In addition to various types of recorded and live music, here are some ways kids and adults can get calming and organizing auditory input.

Get outside and listen. Go to the beach or sit still and listen to the rain, thunder, and so on. If you hear birds singing, try to identify what direction a given bird is calling from.

Listen to natural sound recordings. There are many recordings of rain falling, ocean waves, bird songs, and so on. Sometimes natural sound recordings also feature light instrumentation with flutes, keyboards, etc. Some children and adults find they sleep better if they play such music.

Play a listening game. You and your child sit very quietly and try to identify the sounds you hear (traffic, the hum of the refrigerator, a door shutting, etc.) and where it's coming from.

Find calming, focusing music. Listen to music specially engineered to promote calm, focus, energy, or creativity. Keep in mind, of course, that musical preference is highly idiosyncratic, so this will take some experimentation. The music you love may distress your child, while the music he finds so soothing may drive you up the wall.

Encourage musicianship. Provide your child with a musical instrument and encourage him to play and even take lessons.

Give him some control. For a child with auditory sensitivity, predicting and controlling sounds can be very helpful. Encourage him to turn on the vacuum cleaner, help him pop the balloons after a birthday party, anticipating the noise. Try [Sound Eaze](#) and [School Eaze](#) CDs that desensitize children to everyday sounds such as flushing toilets, thunder, barking dogs, alarms, and other sounds many kids find distressing.

Create pleasant sounds. Get a white noise machine, tabletop rocks-and-water fountain, or aquarium.

Visual

Visual input can often be overstimulating for a child with sensory issues. Think about ways you can simplify the visual field at home or school for a calming, organizing effect. Alternately, if the child seems "tuned out" and doesn't respond easily to visual stimulation, add brightly colored objects to encourage visual attention. For example, a child who has trouble getting aroused for play may be attracted by a brightly painted toy chest filled with toys in appealing colors. A child who seems unable to watch a ball as it rolls may be able to watch it if the ball lights up or makes noise as it moves.

Avoid excess visuals. Hide clutter in bins or boxes or behind curtains or doors—a simple, solid-color curtain hung over a bookshelf instantly reduces visual clutter. In rooms where the child spends a lot of time, try to use solid colored rugs instead of patterned ones. Solid-colored walls in neutral or soft colors are less stimulating than patterned wallpaper in bold colors.

Seat him elsewhere. Have your child sit at the front of a classroom where there is less distraction. He may also need to sit away from the window to avoid distraction from outdoors. Some children do best sitting in the back of the room so they can monitor what other kids are doing without constantly turning around. Work with the teacher and an OT to see which seat placement works best.

Be color-sensitive. Avoid toys, clothes, towels, etc., in colors that your child find distressing.

Smell

Olfactory input (sense of smell) comes through the nose and goes straight to the most primitive, emotional part of the brain. So if your child is upset by something being stinky, it's no wonder. Certain odors can stimulate, calm, or send him into sensory overload.

Smell stuff! Explore scents with your child to find ones that work best to meet your

goal (to soothe him or to wake him up). Everyone has different preferences, but vanilla and rose scents are generally calming. Peppermint and citrus are usually alerting. Avoid synthetic scents.

Caution : Some kids, teens, and adults do not tolerate strong scents well. For them, use unscented laundry detergent and shampoos, and other unscented products.

Scent play. Play a smelling game with your child. Have her close her eyes or wear a blindfold and try to identify smells such as citrus fruit, flowers, spices such as cinnamon, and so on.



Taste

Taste input is perceived by our tongue but how we interpret or experience it is strongly influenced by our sense of smell. As an experiment, chew some gum until the flavor is gone, then hold a lemon under your nose; the gum will taste like lemon. Help your child with to broaden the tastes he tolerates or likes, and use strong tastes he enjoys to help arouse his sluggish system.

Give strong-tasting foods before introducing new ones. Strong tastes can stimulate the mouth of an under sensitive child and make him more willing to try new foods. Before presenting new foods, let the child have one peppermint, sour gummy bear, or other strong-flavored food.

Play a taste game. If your child does not have a strong negative reaction to refined sugar (becomes very “hyper” or sleepy), get an assortment of flavored jellybeans. Eat one at a time, and have her guess which flavor it is. If you wish to avoid sugar (and artificial color and flavor in most candies), you can play this game with slices of fruit, or another healthier snack.

Involve him in food preparation. Children are more likely to taste something if they help make it. Let your child help you grow fruit, vegetables, and herbs, and plan dinner and shop. Give him a sense of control: let him choose between chicken or fish, string beans or sugar snaps, potato or rice. Then let your child put the meat in the baking pan, break off vegetable tips and dump in water, and so on. Let him help you arrange food on each plate so it looks nice.

Play with your food. A so-called picky eater may be more willing to eat “rocks and trees” than meatballs and broccoli. Fun arrangements such as some vegetable sticks and grape tomatoes placed in a smiley face pattern on a plate encourage kids to taste something new.

If left untreated what can, difficulties with an inadequate sensory diet lead to?

When child has an inadequate sensory diet they might also have difficulties with :

Learning and demonstrating this learning in an academic environment.

Poor self regulation of physical activity, attention, emotion, or thought.

Ongoing sleep difficulties that can impact on their ability to learn in general.

Difficulties coping in busy social settings, thus affecting social interactions.

Anxiety and poor self-esteem issues.

Social isolation because they find it hard to cope in group situations.

What are the benefits of taking a guided (team) journey to wonderful with a therapist?

Well targeted and efficiently delivered therapy can help children to :

Remove the frustration from daily life and common situations.

Develop skills, where there was previously just deficit and difficulty.

Increase Self Esteem and confidence making life feel easier (even if some of the challenges still persist).

Socially engage with their peers and siblings.

Learn new skills (be that academic, physical, play, self-care or social).

COVID-19 - Birth of a New Dawn

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COVID-19 spread like a wild fire across the globe after initial cases in Wuhan, China. It soon flew in to India and triggered a tsunami of fear psychosis as the road ahead was dark and full of uncertainty.

We, at New Horizons Child Development Centre (NHCCDC), were also engulfed by this pandemic as we watched in bewilderment the dwindling numbers of patients at our physical centers. This scare did not spare our multidisciplinary clinical team members with many of them reporting absences due to the concerns related to safety while travelling to the centers.

The deserted centers with occasional patients and few brave clinicians were a virtual nightmare in broad daylight. What came next was a nation-wide lockdown completely paralyzing our clinical services. As clinical services for special needs children are not considered life-saving; wait and watch approach was the default option for patients and our clinical services.



As we were grappling with our own pain; the mayhem in the life of special needs children was expanding in leaps and bounds. The crippling disruption to social life and daily routines led to a sudden brake on the clinical improvement of these children.

These children usually do spend a sizable chunk of their time on smart devices and it was no surprise that the screen time ballooned significantly beyond the recommended. Erratic sleep and wake cycle, lack of outdoor activities, minimal play and disturbed dietary habits aggravated the psychosocial challenges and physical health of these children.

Parents were busy and lost in their own battle with the onslaught of work from home, daily chores at home and struggle to find meaningful time for kids. Some of them were not spared even from job losses aggravating their financial pain to access online services.

In this doom and gloom scenario what emerged was a ray of hope which crystallized and zoomed in to an online intervention services served directly to the patients in the comfort of their home. The roller coaster bumpy ride continued as challenges for patients and our clinicians in terms of tech savviness and internet connectivity were overtly impacting the online services.

To help parents, teachers and adolescents overcome these difficult times, New Horizons came up with an A.R.C.H Intervention model to help parents overcome the psychosocial challenges for their children.

A.R.C.H is an acronym for Adapt and Attempt, Resilience, Collaboration with Care and Humor and Humility. The four ingredients of A.R.C.H helped parents cook a perfect recipe to reduce the psychosocial burden of their children.

It has been a year since COVID-19 touched our lives and it has made all the stakeholders resilient, collaborative and innovative in their care for special needs children. It has also been a blessing in disguise for families from remote parts of India with limited or scarce developmental pediatric services as they are now able to access and gain from the online intervention services.

The multiple challenges in the saga from pre-COVID era to the COVID-19 time and the probable future new normal has helped unlock several hidden jewels to support special needs children. This once in a life time experience has triggered and accelerated a new revolution in the adoption of new intervention models which will go a long way in improving access and benefits of online intervention. We are seeing this all over the country and this will only increase the access for intervention and help to many more children.

Thus, there was a paradigm shift in our physical NHDP (New Horizons Development Program) intervention services as it spun into a full-fledged online clinical coaching model empowering the parents to implement our individualized NHDP program for their kids. The intense trial-and-error efforts finally clicked and what emerged was a full-fledged seamless online intervention service (NH E-nable) available across the length and breadth of the country.

For quite a few resourceful families COVID-19 times was a blessing in disguise as parents became the 24-hour therapist at home for their children under the guidance of our NH E-nable developmental pediatricians and clinical coaches.

We hope everyone across India will continue with this spirit of innovation and “never give up” attitude, because the challenges in providing happiness, independence and contentment to the children and families with neuro developmental conditions will need all our innovation, cooperation and commitment. We salute the distinct presence of COMHAD as the platform that helps us all achieve this dream!

Missing Therapy/Early Intervention during Pandemic for Special Children

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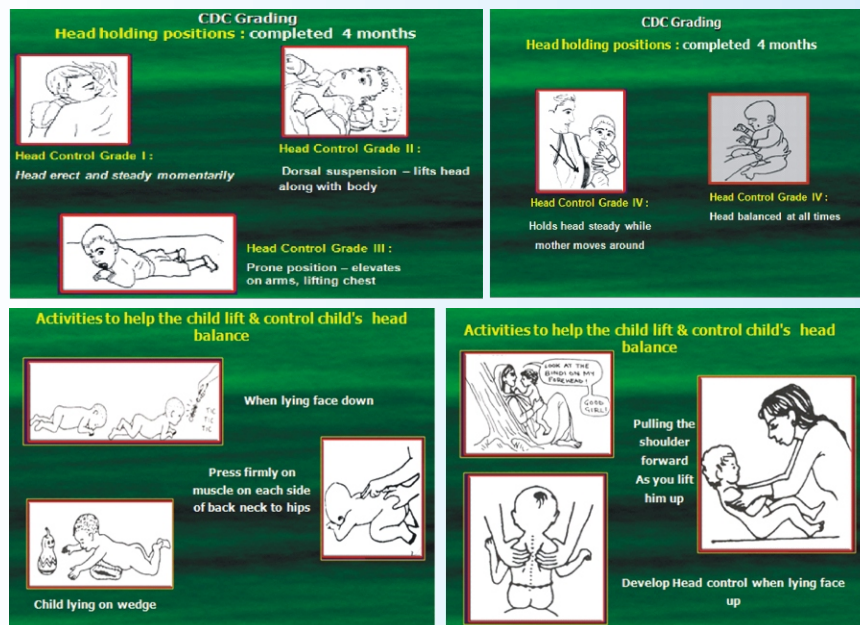
During the pandemic special children with Developmental Delay had problem to attend the Child Development Center. They were advised Stimulation Programs according to their mental and motor milestones. The list of toys was given to the parents and how to play was also explained. Follow up was done on WhatsApp video call.

We used Trivendrum Scale by Dr. M. K. C. Nair for screening; we also used Developmental Observation Card as a screening test. The milestones observed were social smile at 2 months, neck holding at 4 months,

sitting at 8 months, standing at 12 months. We have to confirm that child obeys command, listen, hear and speak 2-3 words at 12 months.

Following pictorial therapies with checklist were given to parents with instructions.

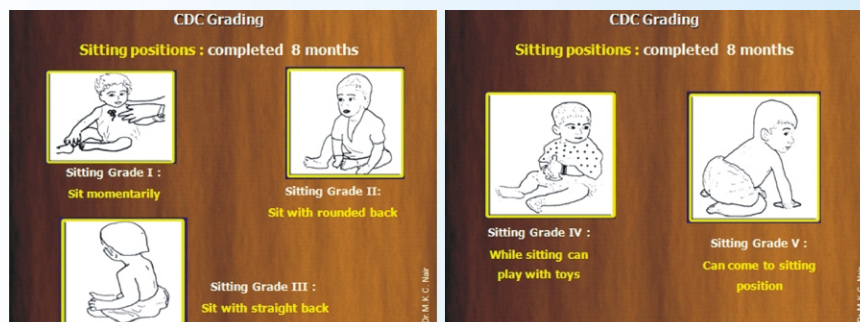
1. Neck Holding



E.I. for Head Control

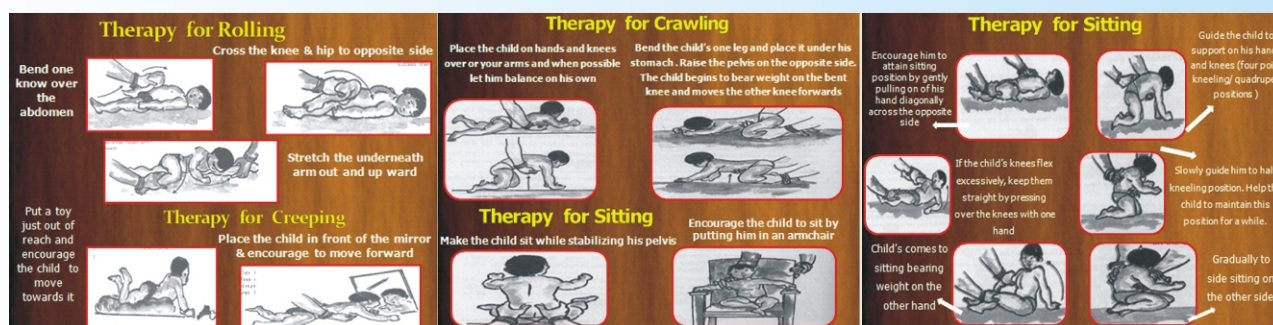
- Carry the child in upright position.
- The child is made to lie on stomach, a role is placed under chest encourage the child to lift & hold his head by showing colorful toy.
- Slowly lift the child from lying down position holding axilla, to sitting position & then slowly put him back to lying position there by stimulating to lift & hold head. (5 minutes x 4 times / day)*
- If child do not lift his head, gently stroke downwards over the neck muscle.

1. Sitting

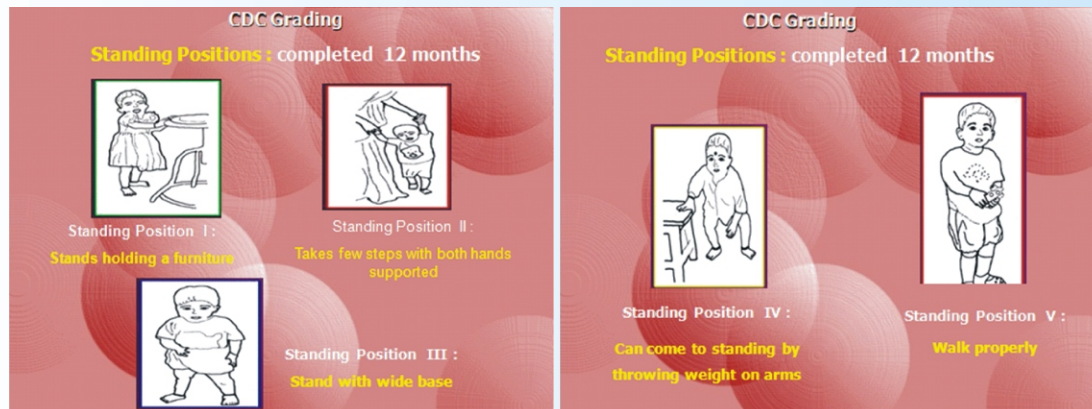


E.I. for Sitting

- Make the baby lie on the back holding at the axilla make her come to sitting position, hold her in this position and then make her lie down. (5minutes x 4 times a day)*.
- Make the child sit across his mother's knee, just tilt the child forward and sideways, so that he outstretches the hand. This helps in development of righting reflex.
- Make the mother raise her knees up and down so he has to balance on his own.
- Make the child sit provide support and toys, slowly reduces support.

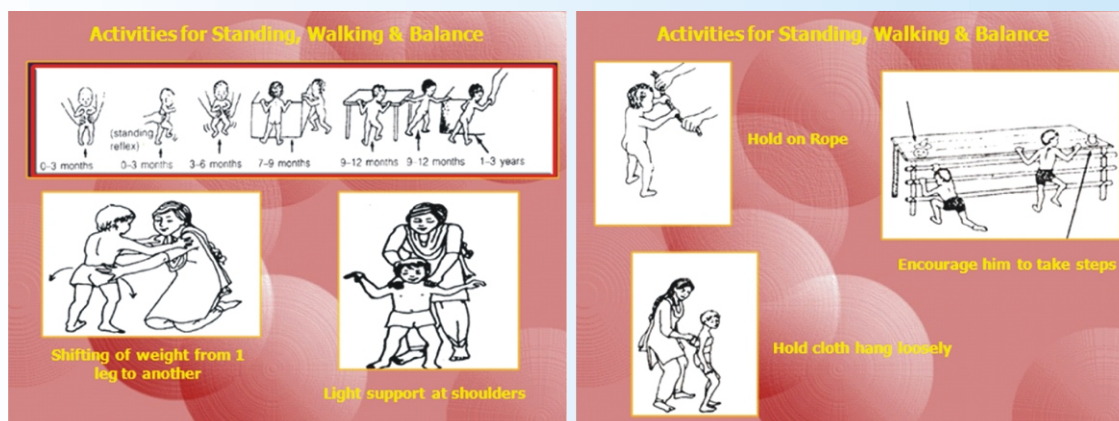


3. Standing



E.I. for Standing

- Place the child on his back gently pull one of his shoulders diagonally across to the opposite side, the child comes to the sitting position bearing weight on the other hand. This helps in coming to sitting position on his own
- Make the child stand leaning against the wall
- Make him come to standing position holding a stool put toys
- Help him to balance on an inclined surface
- Help him to walk with support using both hands and later with one



Conclusion

Simple methods for screening and therapies at home helped parents in achieving milestones.

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- Alfred L. Early Diagnosis & Intervention Therapy in C.P. Pediatric habilitation vol. 2. pg. 124
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Covid Pandemic and Barriers for Persons with Disability – (PWD)

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As the world is facing THE COVID PANDEMIC and now getting ready to LIVE WITH CORONA, all are expected to follow certain preventive protocols. While adjusting to this NEW NORMAL, we all are supposed to change our lifestyle, adopt certain good habits and help in prevention of corona spread.

While we all are making these effort, there are certain vulnerable groups in the society, where extra focus needs to be given like; senior citizens, immunocompromised individuals or persons with disability (PWD). There is

definite need to identify and make special efforts to make these vulnerable group adjust to “new normal”.

Let us consider the “barriers” faced by PWDs while following these preventive measures. The focus is being given on “SMS”

S..for Sanitization

M...use of mask

S..social (physical) distancing

Following are some of the difficulties faced by PWDs :

Persons with physical handicap, may not be able to use sanitizer appropriately or sanitizer bottle may not be accessible easily, due to limitation in movement or use of hands or legs.

Similarly, it may not be very safe to keep the bottle of sanitizer easily accessible near the children with intellectual disability or autism , for the fear of accidental ingestion. Thus extra training and help from caretaker is essential to promote proper use of sanitizer.

Masks are heavily recommended for prevention of covid. Use of mask for children with disability may not be very easy and more perseverance may be needed on the part of caretaker to motivate these children to use mask. Individuals with autism may not be very comfortable with the material of mask, due to touch sensitivity, similarly, children with CP will need extra help to use mask. PWD s with ID may need training to use mask consistently.

For students with HI, who are dependant on observing lip movements (lip reading), it will be difficult for them to understand the messages from the sender. Thus masks can be a barrier in effective communication for HI.

Social distancing is recommended as one of the effective ways to prevent spread of corona. Many PWDs need help of caretaker / parent or are in contact with therapist, which can create hindrance in maintaining distance. Some may need assistance in use of assistive devices or wheelchair, as well need close contact during ADL. Caretakers need to be very careful in such situations.

In the same way, isolation / quarantine / hospitalization / testing can pose certain problems in case of PWDs or their family members. Keeping children in care of others, sanitization of assistive devices, irregular therapies or E- learning are some of the challenges these families may face.

Conclusion : PWDs and their families need extra support and training to adjust in “new normal”. Society needs to be more sensitive towards them and extend helping hand as and when possible

Parents and Parenting in Covid Times

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Being a ‘Parent’ is the most beautiful and blessed feeling in an individual’s life. With the greatest joy comes a huge sense of responsibility towards this new life. Every father and mother has different roles to play in this angel’s life. Currently, with the Covid 19 Pandemic spreading rapidly throughout the world, the daily life of every parent has become very challenging.



Managing a child with behavioural issues, physical disabilities, hyperactive, visually deficit, hearing loss, etc has been extremely difficult in a home environment due to limited or no socializing. No break time for parents with special needs has led to psychological stress and depression. Child having no or limited friends to interact or to play has delayed their Developmental Milestones. These children have lost Developmental Social Skills which was developing through the interaction to their teachers and friends in school, park or beach. Parents have very little time to interact with their children due to extra burden of household chores and disrupted schedules. This had led to no quality time with kids. Children are still waiting for their Special Sundays when parents take kids for movies, restaurants, parks or beaches.

Parents should release their stress by taking out 'ME TIME' by listening to music, light jokes, standup comedy on youtube or do relaxation through meditation for atleast 30 mins for everyday. It is extremely important for parents to keep their 'mind calm' to help their child. Parents need to make sure that their child does simple exercises like jumping, running, sit ups and deep breathing or even yoga should be a part of routine for 10 mins everyday. Talking to a friend or grandparents or a cousin once in 2 days should be must to be able to connect with other people's feelings. Learning something valuable each day like reading a book, draw a picture, typing on computer, writing a story, building a creative lego etc. should be the goal. Having a goal for everyday is very necessary for these developing minds, so they can wake up with a zeal and enthusiasm.

Make smart use of Internet for limited time for productive activities, various online classes or continuing treatment or therapies relating to learning something new. Definitely, 'Online' is the new normal and everyone has to get used to this to sustain.

Kids have tremendous energy and happiness. Gluing them on TV and computers for maximum an hour is more than enough. Encourage self-care activities like having own baths, keeping toys organized, folding their own clothes, placing their dishes in the kitchen sink etc. Making them independent for future, no one knows how long will the pandemic last? Teach your child to be 'Self Motivated and Independent'. Take time to teach your children to live happy, healthy and successful life and encourage constant learning. Enjoy Parenting and love your children.

Build bridges - Transform lives - A Multisectoral Approach

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Covid 19 and the unprecedented lockdown and restrictions have overturned lifestyles and impacted human relationships in different ways. While all of us have experienced certain levels of frustration and loneliness, the plight of the differently abled or of those who were dependent on others for their daily activities it has been even more distressing. With institutions for the specially abled shut during the lockdown, their days were gloomy and even depressing. While some had the support of family and friends there were those others who were left to irresponsible caretakers or to fend for themselves. A teacher at a center for the specially challenged children said "There has been a setback in the progress of training, behavioral outcome and compliance to instructions and it will be a long time to get the children back to their performance levels pre lockdown".



Some studies have shown that the effects on this special category of people range from increased depression, anxiety symptoms, non compliance to any therapy or training, anger and even behavioral changes attributed to boredom. It has also been reported that there has been a setback in their progress in terms of training to be independent. In some cases destructive behaviour and tantrums have also been reported. The prolonged lockdown has taken its toll on the caregivers and parents too. The lack of coordination between institutions, caregivers, parents and guardians and the need for connecting these key players has been revealed in the background of these findings too. Multidisciplinary and multisectoral approaches in the care of the differently abled children and adults is perhaps the need of the hour. There is a need for developing specialised programmes, modules of care and therapy and this requires the pooling of resourceful persons from various



Photos of the members of the Rotary Bangalore abilities - RBA in action

categories of experts. It is therefore imperative to have a comprehensive approach to meet the needs of this category of children and individuals. Civil societies and Policy makers need to explore the CSR support of organisations to pool in resources that are necessary to meet the growing socioeconomic needs of this special group of people. Setting up of funds specifically for those in the low socio economic category, and forging partnerships with various agencies to develop innovative responses that suit local needs, and to enhance community support is of utmost importance. Pooling of ideas from all involved in the care and support of differently abled persons and developing acceptable policies that involve community participation is the key.

The care and support of the specially abled children and individuals should aim at making them self reliant and able to merge with the mainstream. There are several examples of Civil society organisations contributing to the cause of the specially abled. It was in this direction that the Rotary Club of Bangalore set up an exclusive Club called the Rotary Bangalore Abilities - RBA that is exclusive to the differently abled. This Club has members who are differently abled and have come together to use each other's strengths to contribute in their own ways to make life easier for the less privileged. It is amazing to see how members complement each other and support one another and are able to think and deliver beyond their limitations in terms of research, social and economic and psychological support. It is astonishing to note that their contributions as an organisation range from research and publications in national and international journals, arts and crafts, providing scholarship to needy children, to individuals and organisations that support the specially abled, providing gainful employment, providing counselling and family support services and have been carried out successfully. Their enthusiasm has captured the interest of several other NGOs and CSR partners who are now devoting exclusive funds for their impressive range of activities. The professionalism with which they are able to conduct their meetings and express their intent has inspired us to go all out and encourage them to merge with the mainstream in society. The members of the RBA are all gainfully employed too.

Another example of CSR partnerships and NGOs is the set up of an Occupational Therapy Center for the differently abled at the Home of Hope in Doddagubbi near Bangalore. The Home of Hope is an organisation that provides shelter to the destitute and those rejected by society. The residents in this Home are picked up from the streets and provided food, shelter and basic amenities. Several among them are disabled, handicapped and have been rejected by families to avoid the burden of having to care for them. This Home shelters seven hundred

people including children and adults. Having noticed a significant number of disabled persons including children, we decided to set up an Occupational therapy center for the residents along with like minded CSR partners and individuals who came forward willingly to contribute funds to realise this dream project. Built at a cost of over one and half crores this center has facilities for training in pottery, tailoring, welding, carpentry and basic health assistance training for the residents. An exclusive facility for counselling is also a part of the center which sees a footfall of an average of 200 to 250 residents each day being trained in different batches at this facility. This training has created a feeling of self worth and satisfaction. Being productive has improved their attitude and created a positive outlook in the trainees. Occupational therapy for the differently abled has certainly increased their strength and endurance and helps those residents with physical, sensory and cognitive problems. This Center was recently inaugurated and is fully functional. The successful set up of this center is an example of linking organisations, encouraging partnerships with civil society, policy makers and NGOs.

Photos of the Occupational Therapy Center (sent by separate mail)

Such initiatives justify the need to connect partners and organisations from all walks of life with similar objectives to have impactful interventions and facilities for the care of specially abled people and to make their lives meaningful thereby achieving the objectives of such organisations as the COMHAD. It is the Alliance of stakeholders like Governments, Political organisations, civil societies, business sectors and philanthropists that can combine their diverse resources and expertise to jointly achieve much more than one can do in isolated groups. Multisectoral approaches have proved to be far more effective in providing comprehensive care and have miraculously changed lives for the specially abled in remarkable ways. It is only when research studies, data and policy making and discussions in Boardrooms translate into actions at the grassroots that miracles happen in society.

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