Monthly e-Newsletter of IAP Chapter of Neurodevelopmental Pediatrics

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Dear Friends,

Hope you all are doing well and keeping yourselves safe from this Pandemic. We have been in lockdown since last 5 weeks. All of us have got time to introspect, change certain aspects of our lives, become better human beings, adopt more environment friendly habits and learn some innovative style of practicing our skill. We have to make wise choices every day in what we consume and how we live.

Most viruses only get to know their original host animal. Many exist entirely in the humid understory of a remote rain forest. Viruses are kept in check by healthy environments with diverse and abundant wildlife. But by ripping forests apart and capturing billions of animals to feed our insatiable appetite and false cures, we bring viruses out of their natural quarantines. So, if this Pandemic opens our eyes to a deeper sickness in our shared planet, it will be to all our benefit. By protecting nature in all its wild and wonderful forms, we protect ourselves. As the Earth stops to take a collective deep breath, we have a rare opportunity to reimagine and redefine a new future.

Most of us are practicing Telemedicine with professionally approved guidelines successfully. Doing assessments and giving therapies on Videoconferencing platforms such as Zoom, Skype etc. will empower parents to give therapies to their ASD child under professional guidance, although it can't replace therapies done by professionals. However, the flip side is kids are being subjected to increased screen time because all schools including play schools are taking online classes. In addition, ASD kids spend another 1.5 to 2 hours due to the therapies online. So, for them the screen time becomes 4-5 hours /day which I fear may mitigate the benefits of therapy.
April 2nd is Autism awareness day and due to lockdown, all of us couldn’t do the activities we have been doing for many years now but the administration of therapies on Videoconferencing apps will probably go down as a historical landmark. It mitigates at least one factor of access that comes between many ASD children and treatment that they would benefit from. The distance factor such that even post the lockdown, if any patients are not able to make it for certain appointments due to time or travel constraints they can conference in and ensure their child’s continued progress!

This edition has very interesting articles focusing on the impact of Covid19 in our lives and that of kids with special needs especially ASD kids. It’s interesting and heartening to me, as a person that has dedicated her life to this caregiving profession, to see the shift in the image of doctors as warriors against the rising tide of an invisible enemy.

There is a beautiful writeup called the musings of a Developmental Pediatrician during Corona times and in the end, she asks, “Do you want to save the changes?” I guess if I were to answer that question, a lot of us might say yes we would like to save the changes that have come in our lifestyle and attitude and while that may be small in the face of such mass death and fear, I like to look upon it as a small ray of hope and change, testament to the spirit of resilience humans carry no matter how tough the times.

“We shall overcome, we shall overcome one day!”

Jai Hind! Salute to our warriors!

Dr. Lata Bhat
Chief Editor
Dear Readers,

Welcome to the spring issue of the DPT Newsletter. As the air is warming up and colours blooming, cheering us through the COVID19 lockdown, we are beginning to understand the impact of this pandemic. There are silver linings of family bonding, and opportunities of interaction with children. On the other hand, there are news of greater incidence of abuse for not being able to cope with stress and strain of life. And the community with special needs is getting worried as their services are getting compromised. This is a great opportunity for finding innovative ideas and utilising a family-centered approach and parent empowerment programmes for assistance and support of these children; moreso, for being self-reliant.

E-learning and dissemination of information through IAP portal are being actively held and DPT Newsletter is another forum advocating continuity of services for development of this group of children and upholding child rights at all times.

April 2 was Autism Awareness Day and was the 13th year of relentless commitment to creating an inclusive world. This year it is all the more important where survival of mankind is at stake and lockdown has forced the services for the children out of gear.

I am very thankful to the members of the Neurodevelopment Pediatric Chapter for their continuous efforts toward meeting these goals. While doing so it is advisable to work with the health authorities to understand the transmission of the disease in your area and the necessary monitoring thereof.

Stay Safe, Stay Healthy, Stay Concerned.

Long live IAP!

Dr. Shabina Ahmed MD, FIAP
National Chairperson
Neurodevelopmental Pediatrics Chapter of IAP
Dear seniors and friends,

Hope this issue of newsletter find you all and your families in good health. April month has proven to be a real testing period for almost all of us and with the lockdown getting extending to 03 May, there is more pain left in the days to come is the predominant view coming from most experts. On the brighter side of the things, we have been able to spend more time with our families that was earlier not possible due to the hectic life and make wonderful memories which will last a lifetime as I really don't want to see another pandemic/lockdown in my lifetime. Most of all, it has taught us the value of time and small things/emotions in life that we were earlier neglecting or ignoring while chasing our dreams. My take of the COVID-19 situation in India is that we seem to have done well and that we should remain patient and maintain our composure towards the end of the lockdown as it is the last mile of the journey that is most important yet the most difficult!!

The month has seen a digital tsunami in all spheres of our lives - kids are having their classes online, people are working from home, doctors are providing tele consultations, etc. All the earlier guidelines on screen time regulations have been tested in this period and parents and doctors are both finding it difficult. We need to unlearn and relearn new ways of managing screen time for kids as these times are likely to last for few months. The parents have had to learn to take charge of the therapies for children at their homes under the telenguideance/consultations and I think this will help parents become more confident and capable while taking decision for their wards when consulting with doctors in future. Central IAP too has taken a digital avatar in the form of dIAP to reach and teach the pediatricians all over the country using new age technology, an initiative which will benefit one and all in the days to come and transform the way we conduct our educational and outreach activities.

02 April is World Autism Awareness day and this will be the first year since 2007 that we haven't celebrated the day like earlier years as the whole country and the rest of the world is in the midst of Corona Pandemic. This year, the theme for the day is “The transition to Adulthood” which is the need of the hour as more and more cases are being diagnosed early these days and multidisciplinary therapy initiated early. The ultimate aim of all therapies is to bring all autistic cases to mainstream society which needs excellent care, coordination and understanding between doctors, parents and society. Studies have shown that there are multiple factors causing poor adulthood transition in autism: uncertainty of parental roles, poor person-environment fit, lack of integrated services, etc to name a few. There is a need for collaboration between government, society, businesses, parents and doctors to identify the barriers to successful transition in India and add these to the multidisciplinary management of autism. This will help all involved parties to start working early in life of the child towards overcoming these barriers and help autistic children become useful members of the society.

In this issue of newsletter, we have brought you a mix of articles on some of the issues/personal experiences faced by doctors, therapists and parents and lessons learnt from the lockdown times in addition to an interesting article on the ‘Impact of COVID-19 situation on children with Autism’ by our chairperson.

‘Autism is not a disability, it’s a different ability.’

Jai Hind!

Wg Cdr (Dr) KS Multani
National Secretary
IAP Chapter of Neurodevelopmental Paediatrics

‘Life is not about waiting for the storm to pass, it is about learning to dance in the rain.’

- Vivian Green
Impact of COVID 19 on Children with Autism

Dr Shabina Ahmed  MD, FIAP
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National Chairperson, Neurodevelopmental Pediatrics, Indian Academy of Pediatrics

April 2 was adopted as World Autism Awareness Day (WAAD) by United Nations General Assembly resolution number 62/139 on 18th December 2007. It is one of the only seven official health specific United Nations days. WAAD highlights the need to help improve the quality of life of those with autism so they can lead full and meaningful lives as an integral part of society.

Autism is a developmental disorder which affects the social, emotional and language development of a child leading to maladjustment in the society and inability to fit in the prevailing education system.

The incidence of autism has increased manifold over the last decade. The population-based estimate from the USA is 14.6 per thousand children (1 in 68). The pooled estimate of autism in India varies from 14/10,000 to 12/10,000 in both urban and rural regions. There are approximately 2 million children with this disorder in our country, reflecting a loss to the country’s human resource and Government exchequer.

This day has been celebrated every year over the past 13 years throughout the world with various activities, but this year the day comes knocking with hard realities of the corona virus pandemic. The prevailing scenario is a life and death concern with recommendations for social distancing, strict hand hygiene dictated by the law of forces of nature and worldwide attempts for lockdown of surface communication for containment of the problem. Within all this, there is a group of children with disabilities who are being thrown out of gear.

A lockdown means a sudden change of routine for children who are comfortable with structured routine schedules in therapy centres. The current situation finds them in difficulty to adjust to the change. As a result of anxiety and inability of expressing their needs due to communication difficulties, they are prone to tantrums and unmanageable behaviours posing challenge to parenting. When the need for social proximation is the answer to the problems, now we have social distancing leading to reverting to their cocoons and increasing loneliness which may disrupt the learning curve.

Face-to-face sessions are very necessary to keep them engaged, but the situation is such that both parties need to wear masks augmenting further distancing leading to loss of connectivity.

We must keep in mind that many of the disabled children cannot do simple tasks like washing hands, cannot move or reach to operate soap dispensers. This increases dependency on others and lowers frustration thresholds, contrary to our efforts to increase independence.

As a logical solution to containment, the educational institutions and youth programs
have been closed but this has added the burden of care to the parents who had a large chunk of their time being handled by caregivers, hence jeopardising continuity of care.

On the other hand, caregivers and professionals could be major agents of transmission of Covid19, as child proximity cannot be avoided. Furthermore, these children have added medical risks of low immunity and chronic illness.

We are certainly in a dilemma and the present solution has been to close down therapy centres. Unfortunately, there is a great concern within the disability community that they may be forced to go without care, and could lead to disruptions and collapse of the service systems.

So once again questions arise: are disability rights still important in times of global crisis? Will the present dynamics of society trigger a social exclusion on the face of society’s own survivality?

All these problems may appear insurmountable but with human resilience, certainly it is solvable. People have taken recourse to digital media for connectivity and continuity of learning. The question is will that work for these children?

The theme of WAAD in 2019 was Assistive Technology and Active participation. This indeed has become very relevant this year too because online and virtual instructions through teletherapy seem to be the way out. However screen time is a double-edged sword. Too much may precipitate inhibition of learning and therefore has to be judiciously used while increasing face to face interactive periods.

This is the time to propagate naturalistic teaching strategies using multiple incidental teaching sessions where parents and siblings get involved. They must impart education in a flexible, fun-filled natural way while assessing the amount of generalisation of his previous teaching.

Naturalistic teaching strategies emerged out of need to facilitate speech acquisition and promote generalisation in natural environments such as home, school and community. It incorporates three vital elements. These are motivation-enhancing techniques, functional relationship and, finally, other variables that facilitate generalisation. These include delivery through free play within the home environment, serving as a motivating tool. Evidence shows that such methods do give good results.

We all should take this great opportunity for family bonding. Avoid meltdown of the children by compensatory services. All is not lost; there is always two sides of the coin.

Much of the behavioural problems are from cognitive rigidity, fixed routines and restricted interests. The rigidity-minimising strategy is to prevent abrupt and multiple changes concurrently. So, it is good to maintain a schedule that eases into a transition, maintaining normal daily routines, but preventing strict routines being formed. Gradually broaden their interests and prevent children doing repetitive activities by reinforcing it. Always insinuate gently, but ascertain that some new input has been given either through visual support or clear communication. Provide praise when transitions are handled well. Remember the calmer you are, the smarter you are. Clear overbearing situations by walks, dance and music.

These actions may not address all the needs and rights that the people with disabilities face, but it will be a good start and good contingency plan on this World Autism Awareness Day 2020.
It was not a long time ago. Around 13th March, I was rushing around to do a long clinic and seemed chronically short of time. It seemed like there were too many balls in the air to juggle. Apart from the busy clinics, a recent personal tragedy and in midst my son’s board exams! It seemed that just when one got adept at juggling 6 balls adroitly, a 7th got added without your knowledge throwing everything out of tandem!

And then, suddenly things changed dramatically. There was this new threat of a virus infection, COVID 19 that seemed to be slowly spreading its tentacles all over the world. And to prevent COVID affecting a humungous number of people that could potentially overwhelm our medical services, there was a lockdown. The first striking casualty for me was that my son’s exams were postponed indefinitely. With 4 papers still to go for him and my elder son returning back from his university hostel campus, neither he nor we knew whether to chill or strain in this vacation that was thrust upon us. Bitter-sweet!

And just like that, all the balls that were being juggled disappeared into thin air.

There was only one, albeit a pretty heavy one at that, now left. Taking care of house with no household help. Sounds simple when you have managed to juggle seven balls but the sheer repetitiveness of the same job having to be done over and over and over can add enormous weight to ball. Though everyone in the family contributing can make it a bit lighter, the fact remains that it is a non-glamorous heavy ball that finds very few takers!!

The first few days seemed a welcome break from the hectic schedule that was being followed before realising that it had been replaced by a different set of regular activities that needed done at home that were being taken for granted for so long. So, the state of mind was akin to a child going on a summer vacation but realising that though the location was exotic, the vacation was actually a summer camp with loads of discipline!

Is this how children with behavioural issues feel when they are thrown into uncomfortable situations when they were promised something a lot different? Whoa! Inconsistent responses to such children in terms of their actions fuel their irrational outbursts. I seemed to understand that with practical clarity as things did not happen in perfect harmony in domestic setting as opposed to the professional setting where one was used to it! A tap dripping, clogged up basins, broken sofa legs, lizards creeping through a 90% shut window, each one of them had the ability to send the day’s routine into a tailspin and the mind into stratosphere with the fuming! Skills to counter this come only with acceptance of certain facts along with a consistent schedule and response, which is exactly what we advise in the clinic. To see first-hand how these things help surely reinforced faith in our therapy programmes.
In a few days, one started missing the daily routine that had been so set over the years. The morning newspaper with the tea, the ability to start the day according to the clinic timings, driving down to the clinic many a times enjoying the drive on the way with either music or plain contemplation, the ability to put a smile on the parents face were the elixir that seemed to make one look forward to the next day. The absence of these aspects made one confused, irritable and feel incomplete. That must be the same feeling that children with Autism spectrum disorder get when they are disturbed from their schedule! Again, a practical lesson to understand what these children and their parents are coping with! If we, considered to be socially ‘normal’ can feel so disoriented after missing a simple daily schedule, how difficult it must for someone who craves the same schedule daily and sometimes cannot find it. Gentle desensitization is what I ordered for myself! So, the physical newspaper became a PDF on the phone, clinic visits were changed to online consultations in a designated room in the house, music became part of a daily schedule of exercise. Thus, adapting to the changes in a slow manner seemed to make it easier to accept them. Just as we do with the children with Autism spectrum disorder in our clinics!

Also while we all decry the excessive use of the mobile phone and social media ( and we should in no uncertain terms), a thought that crossed my mind is that if the way forward is less or no social interaction, guess who is best suited to be involved mainly with objects and gadgets and prefers less social interaction! So, we may have to learn from them! In this time of social distancing, there is no doubt that social media has helped in emotional bonding too! We are spending too much time in front of the screens (webinars not withstanding!) and will we have to redefine the optimum amount of time spent in front of the screen?!

As the lockdown progressed without any signs of abating, simple things started getting exciting. The doorbell ringing or a request to see an elderly person not feeling well (no fever or cough) in the society or a video/audio call from a friend or family member made one drop whatever they were doing and run to the ‘more exciting’ thing! Yup, you guessed right! Just like our children with ADHD. They cannot seem to settle down as they always find the next thing more exciting. Having been deprived of the usual things that we take for granted; this message hit home in a surreptitious manner! And just as behavioural therapy and schedules help these children immensely, making a regular activity schedule helped us to get our things done and at the same time, carry out the exciting things. Like scheduling a regular phone call with friends and family, making a time table of activities that needed to be done in the day so that one is not flitting from one job to the other and at the same time not being tied down by the monotony of the same job for a long time!

While one realised that things would not suddenly go back to normal, there seemed to be no light at the end of the tunnel. It was slowly being learnt that we had to take one day at a time and not think too much into the future. There was a seeping recognition of this fact rather than a hallelujah or Eureka type of enlightenment. And again, you are right. This is similar to what the children who have academic difficulties feel. Things are learnt far more slowly than the speed at which others learn. And yet we are judging them by the absoluteness of time and the ability to learn things that are considered ‘important’ which now seemed to be rapidly becoming irrelevant! Just as we all got there by realising
what lay in store for us by the ever pervading knowledge of what was happening around us and the repetitive messages from personalities like our Prime Minister; these children also reach their final goal given time, repetitive messages and addressing their issues in an ongoing steady manner. Again, a lesson that all of us can carry!

Thus, over the last month most of us, have gone through the stages we so often talk about. Once we heard about the Novel corona virus in March it started with a bit of shock and a lot of denial! Protocols to help continue seeing patients for consultations and therapy with precautions like sanitisers, handwashing, masks etc were quickly drawn up, as the idea of just stopping seemed ridiculous and was not going to happen! Then came the anger, irritation, anxious stage. What will the families do if we suddenly stop therapy, how will it affect our patients, how will we manage the waiting list?!

But this settled quite quickly, and most of us fortunately skipped the stage of depression or feeling low as acceptance stage started, where new ways and options like tele consultations were initiated. Reaching out to parents and making sure they felt supported. The therapy team started posting activities for individual patients as needed and the counsellors started helping parents with scheduling of the day with their children.

We realised that for some of our patients and families this period was a welcome pleasant drizzle where they got some time for the family and were able to do the therapy activities and behavioural handling in a much efficient way, while for some it was a hurricane where being cooped up in the house worsened the behaviour of the child and threw the entire schedule of the day out of gear.

To conclude, I have always wondered whether we were hamsters on a wheel and kept going faster and faster without reaching anywhere. In the last few weeks, what has changed? Lots of changes for sure. Some are striking, some are insidious! Re-evaluation of what is important has crossed the mind many times. Irritation and annoyance at anyone for simple misdemeanours seems misplaced. To many of us this lockdown has taught patience, family bonding, interesting new skills, and in general slowing down to stand and stare at the marvels of nature.

Thus, I can honestly say that ‘my development’ has shown an exponential growth in the lockdown period!!

And yet, when the lockdown is relaxed and we slowly go back to our ‘normal’ lives, we will all have to answer this question for ourselves – “Do you want to save the changes?!”
Role of camel milk in autism spectrum disorder

Dr. Puja Kapoor
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The importance of camel milk in autism spectrum disorder was highlighted after a mother of 3.5 years old child suffering from autism and severe food allergies tagged Prime Minister Narendra Modi in a tweet. She underscored her son’s plight of not getting camel milk supply due to the country wide lockdown in order to prevent the spread of Covid 19.

This news reopened the Pandora box of various complementary and alternative medicine (CAM) options for ASD. There were parents calling to find any recent research/development in this field which they had missed, as a treatment for their autistic children.

This article reviews the literature to find the role of camel milk in treatment of autism spectrum disorder.

The use of camel milk in autism is based on two hypothesis, which are considered as etiopathogenesis of autism:

1. Oxidative stress theory: Oxidative stress occurs when reactive oxygen species (ROS) levels exceed the antioxidant capacity of a cell. It acts as a mediator in brain injury, strokes, and neurodegenerative diseases; thus, the control of ROS production is necessary for physiologic cell function. The ROS within the cells are neutralized by antioxidant defence mechanisms, including superoxide dismutase (SOD), catalase, and glutathione peroxidise (GSH-Px) enzymes. The increased production of ROS both centrally (in the brain) and peripherally (in the plasma) may result in the reduction of brain cell number leading to autism pathology and apoptosis. The oxidative stress could be increased by casein present in cow, buffalo, goat milk and other environmental factors.

2. Autoimmunity to CNS: It is speculated that an autoimmune reaction to neurons might be triggered by some cross reacting antigens in the environment resulting in the release of neuronal antigens. These neuronal antigens may result in induction of autoimmune reactions through the activation of the inflammatory cells in genetically susceptible individuals. The environmental antigens may include food allergies to certain peptides such as gliadin, cow’s milk protein and soy.

Camel milk is considered to have potential therapeutic effects in many diseases such as food allergy, autism, and other autoimmune diseases because of unique composition that differs from other ruminants’ milk. It contains no beta lactoglobulin and beta casein which are the main causative of allergy in cow’s milk. Furthermore, camel milk contains various protective proteins, mainly enzymes which exert antibacterial, antiviral, and immunological properties; these include immunoglobulins, lysozymes, lactoferrin, lactoperoxidase, N-acetyl-$\beta$-glucosaminidase (NAGase), and peptidoglycan recognition protein (PGRP), which are crucial in preventing food allergy and rehabilitating the immune system. Camel milk proved its potential effect in the treatment of food allergies, due to its inflammation-inhibiting proteins, and
hypoallergenic properties, in addition to its smaller size nanobodies, which are different than those found in human. Camel milk nanobodies, as a single domain, show many promising and therapeutic potencies in infection and immunity. After review of literature, there were multiple case reports, 3 double blinded, Randomised Control Trials, which are discussed below. The case reports were self reporting of parents, with subjective improvement in social interaction and speech, after giving camel milk to their autistic children, and hence not discussed here.

The 1st RCT is a 2-week randomized controlled trial examined the efficacy of camel milk in 45 children, aged 2 to 12 years, with autism. The study showed improvements in the Childhood Autism Rating Scale (CARS) scores in the raw camel milk group, compared to non-significant changes in the boiled camel milk and placebo (cow milk) groups (1). Irritability and stomach discomfort were mentioned as adverse effects, though there was no mention of whether there was a significant difference observed between treatment groups in reported adverse effects. (1) The 2nd RCT is a 2-week randomized controlled trial including 60 children (aged 2 to 12 years) with autism showed improvement in CARS scores in the camel milk groups (both raw and boiled) versus placebo. (2) The 3rd RCT is a 2-week study examined the efficacy of camel milk in 65 children (aged 2–12) with autism, and showed improvement in CARS scores and Social Responsiveness Scale (SRS) scores in the camel milk group, but no significant difference in the Autism Treatment Evaluation Checklist (ATEC) scores between the camel milk and placebo groups (3). There are certain limitations in the above stated RCT’s:

1. The hypothesis of use of camel milk in autism (autoimmune phenomenon and oxidative phenomenon) is still not proven. There are no studies which could exactly delineate the exact causative agent. Infact, MMR vaccine which was once considered as an inciting factor has been ruled out as a cause in multiple studies. So the use of camel milk as a hypoallergic agent and antioxidant agent is questionable.

2. The sample size is too small for a confirmatory result. 3. The quantity of camel milk was slowly increased in small children so as to prevent adverse effects like nausea etc. The titration of the milk amount is not defined. This puts a question mark on the quantity of milk used in each child to produce the results. 4. Though the studies examining the efficacy of camel milk report on the similarity of appearance of the milk between the three groups, there was no report on the flavor of the milk and if it was indistinguishable between the groups, which affects the efficacy of the blinding. 5. In 1 RCT both raw milk and boiled milk produces significant CARS score difference in children (2), but in the other RCT (1), only children given raw milk showed improvement in CARS. The number is too small to come to a conclusion. We need more studies to prove the effect of raw milk versus boiled camel milk. 6. The current studies were done by the same group, and findings have yet to be replicated by other researchers till date.

A Paradigm Shift In The Doctor Image Perception

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The times are changing and so are the perceptions, but how soon and how rapidly they take a full 360 degree turn is what teaches us that nothing is static or forever. I do not forget to recall how the medical professionals were considered the most heartless and irresponsible professionals by the community. Till few months back we were reading practically everyday a case of violence and aggression against the doctors in some part of the country or the other. The most disheartening fact was that almost all doctors had forgotten the respect and gratitude the profession gives them. Their believes in their own professional entities were challenged making them fill their hearts with guilt of choosing this profession.

Where a soldier in army fighting the enemy at the boarder was the most brave of all humans, how did we forget that it takes the same or maybe even more courage to face an invisible enemy.

In these times of COVID-19 viral attack, suddenly all the efforts are directed towards reducing the spread and preventing mortality. The doctors are called as “GOD”. The health care professionals especially the doctors who were always taught the same lesson of ethics since ages to save and serve their patient first, of choosing their patients above all other needs continue to exist the same way. Without any fuss or denial the doctors are tirelessly continuing to do their duties, which is most commendable. It thereby also proves the point that dedication and responsibility towards their profession had never diluted. In this time of Global Crisis, where the whole country is in a state of “lockdown”, the doctors are going out there, to work, to attend to their patients, take care of the ones diagnosed with COVID-19 and at times still facing resentment by the people in the society where they live, the doctor continues with their spirit, mind and body to work towards the mankind.

It has been proven time and again that it is indeed the most honored profession, where we are not fighting for a piece or land, for a religion, for some political, and financial interest but we are fighting to save mankind and humanity beyond all odds and diversities.

The sudden change in the perspective of the people, journalists, politicians and most importantly our patients towards medical profession is observed in the times. Doctor are once again called “Bhagwan Ka Roop” It has been proven well that the authenticity of profession and the dedication of the medical professionals towards serving mankind is above all their priorities.
That reminds me of a small story that I was told as a child, it was this story of a king who instructed his wise men to inscribe a ring for him with words which would be true in every situation and bring him comfort whenever he is in difficulty. After many weeks the wise men presented him with a ring on which these words were inscribed “THIS TOO SHALL PASS”. I hadn’t realized in my dreams that after reaching the nadir of my medical professional career, I shall be experiencing a period of lockdown because of a viral threat. This story reminds me that these tryst times too shall pass. While passing, this time leaves us all some goodness, like humans are still capable to fight and exist against all odds, a clean air to breath in, gives us time to acknowledge once again that nature around us is beautiful, the sky is blue and mornings are filled with chirping of birds. The most important lesson for us all to learn is we fight for land, religion, power, money everyday but its the humanity which is at stake and we need to work very hard to save it beyond all diversities.

Hopefully this passing time shall also leave the society and community with respect and gratitude towards doctors and medical profession which each one of us dreams to earn the most while choosing this profession.

Lastly I shall congratulate and pay my gratitude all my colleagues who have been working tirelessly towards saving the mankind and remind us all to be once again proud of the profession that they have chosen and that it still for ages to come will be the most gifted profession to be in.
Pandemic COVID 19: Experience dealing with special needs children

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CONTINUA KIDS

India reported its first COVID 19 case on 30th January 2020. Ever since then, our knowledge and vocabulary about COVID 19 started burgeoning. Every day, new words like social distancing, home quarantine, doomsscrolling etc, were introduced by social media, newspaper, news channels. But still, life had a momentum, although with a tint of fear and suspicion.

And then suddenly, lockdown was announced on 25th March, 2020, to flatten the curve, to prevent the spread of COVID 19. As there was no vaccine or medication to treat or prevent this highly contagious virus, lockdown was the only solution to curb the dissemination of the virus.

This was an unprecedented move, none of us living, had ever experienced this type of situation/ pandemic and were naive to these new circumstances. The sequence of events following the lockdown led to altogether different situation which no one was accustomed to.

We were suddenly confined into the limits of our houses, connected to the outside world virtually through screen and newspaper. The daily routine of children going to school or day care, working adults going out for work, special needs children going for therapy, retired elderly enjoying their daily strolls was hampered. Everything came to a standstill.

Then there were channels which were showing something inexplicable to the naive audience. The newspapers had suddenly concentrated their news on corona. It appeared as there was nothing else happening in the world except the virus.

So, on the first hand there was lockdown which was altogether a new phenomenon and then there was all pessimistic and gloomy news all around.

The first reaction to all this was surprise. It took a period of 2 to 5 days to let this new lifestyle sink in. Everyone was taken by surprise, still trying to understand as to what is this lockdown and what would be the consequences of this. During the first week there was a lot of reading, watching, understanding, talking of the new terminology. There was a lot to be done in the initial week, so everyone enjoyed this new lifestyle with surprise.

As a pediatric neurologist, also incharge of therapy centre for special needs children, we closed our units in compliance to maintain social distancing. We started with online teleconsultation as approved by Medical Council of India. During the first week, there were no calls for advice nor for any therapy sessions.

The real problem started with the start of second week. Everything was monotonous and there
was nothing new now. Also, there was a lot, and lot of work. For all those who were working from home, there was added household chores, as there was no outside domestic help. There was an added responsibility of keeping the special children engaged as there were no ongoing therapy sessions. The second week gave rise to anger and frustration.

It started with ever increasing phone calls from the panicked parents. The new unstructured, normal was unacceptable to both parents and more so to special needs children. Now, during the second week, there were special needs parents calling for help. Due to lack of therapies, the behavioural concerns of the children had increased exponentially; there were panic attacks at both parents and childrens’ end, the extra energy was giving way to conduct disorders. Children started becoming disruptive due to lack of structure, lack of instruction, lack of sensory diet.

The second week saw an increase in number of online consultation both for myself and other team members. We started with online consultation for diagnosis, and for treatment. Technology was used for the same. As there were online school sessions for typical children, so we started with structured online therapy sessions for our children.

Parents were given notes, on the day before the session, on the goals to be worked on, in the particular session. The significance of the particular exercise was written. The alternative material used for the session was informed in advance. During the session the therapist demonstrated the concept of the exercise and asked the parents to do the same on the child. Even though this was done previously at our centre, for out of station children, but not to such an extend.

So the major goal was to educate the parents so as they become the therapists of their children. The other goal was to provide psychological support as emotions like anger, anxiety, frustration was seeping in the parents. For that we roped in our psychologist, started multiple session on councelling. Multiple videos were posted on youtube as “How to destress yourself from the infodemic” etc.

Now as the third week of lockdown started, parents got used to the new concept of teleconsultation, accepted the new online way of teaching, diagnosing, and treating. Everyday new technological tools were used uniquely, to cater to the needs of our unique children. We started having regular meeting with our parents through apps like zoom, microsoft teams, google hangout, etc to answer their queries and providing help wherever required. We had our CONTINUA app too, through which we provided regular tips for general concerns. These tips were based on questions put up by the parents through the app.

The fourth week is calmer and smoother as it is more structured. Every alternate day new plans are shared with the parents. The parents are educated about the application of the same. Parents are feeling more confident in dealing with their children. I think talking to them regularly is also giving them the psychological support that they are not alone in this difficult time.

We don’t know what the future holds for us, but let’s be hopeful in this unpredictable world.

Let’s hope everyone is safe and doing their bit to cater to the needs of our special needs children through whatever means and resources they have.
Tele-consultation trial at AsterKIND during COVID-19

Dr. Maria Grace Treasa
Speech-Language Pathologist, AsterKIND
Aster Medcity, Kochi

The world is facing an unprecedented challenge to tackle the COVID-19. Salute to the corona warriors who are fighting this battle bravely while the community in large is remaining in lockdown. Hats off to our dear children with special needs and their warrior parents too, who are experiencing difficulty in managing their child particularly during this crisis time. No school, no outings, no shopping, no stepping out of the house! So most of the children resort to excessive screen time which negatively impacts child’s communication and behavior. It would be nice if screen time is restricted as it does not simulate two-way human interaction and social communication development. Some parents are themselves obsessed with social media exploring solution for their child’s problems or seeking a comfort zone for their minds.

This lockdown period turns out to be a blessing for certain families of kids with special needs when the entire family is at home for an extended period although fear is all around! These days can be used to facilitate spending quality time in parent-child interaction, communication, play, singing and doing household activities together with the child. A routine could be planned and executed together meaningfully. Although there are innumerable resources in this digital era, many parents experience information overload and are confused and depressed at the end of the day. The need for professional guidance is vital in this long journey of emerging speech and social skills and behavior management. This led to the planning of tele-consultation facility and exploring ways to help these families.

After the free trial of speech-language intervention which we had over Skype at AsterKIND, Aster Medcity Hospital, Kochi, these observations were noted:

1. Parents can be guided through phone or online call on how to implement specific goals of therapy or schedule the daily activities to facilitate learning for their child at home. They appreciated the guidance and noted down the suggestions given during trial tele-therapy, although direct therapy with the child was not possible.

2. Parents found it hard to control the child or make the child to sit in front of computer for online therapy or interaction of child with therapist through video call for more than 5 to 10 minutes.

3. Although we got strong internet connectivity and webcam facility fixed (thanks to management), it was observed that the video call over Skype was getting disconnected frequently and audio call wasn’t clear due to poor connectivity at the parent’s end.
Then we shifted to guiding parents over phone (audio call) which was clear and smoother. Any pictures or links for therapy materials were shared through Skype with the parent for better understanding.

Due to the current COVID situation, tele-consultations will be helpful. For new patients, informal assessments can be done on the basis of parent interview, case history and watching child’s videos before tele-consultation. Parents can upload their child’s brief videos (of communication and interaction) to Google drive and share the link through the hospital tele-health webportal for the clinician to be prepared. While we await for formal assessment post-lockdown through direct observation of the child, we can guide parents through tele-health by providing practical strategies and individualized program to manage their child and promote speech development. This will help the child to capitalize on the benefits of their critical age of learning with proper guidance.

Our suggestions after trial tele-therapy for those who have already been under our intervention services prior to COVID situation at AsterKIND are as follows:

1. We can have tele-consultation through the hospital web-portal for guiding parents regarding specific goals or activities, behavior management, modifying the environmental barriers for communication, providing language stimulation etc. Subsequently, the parents can work on implementing those goals/activities with their child. They can clarify their queries regarding the difficulties experienced in implementation of goals or any other related issues during the next follow-up appointment.

Conference call or zoom can be used, if required to involve both parents/family members in counseling. After the tele-consultation, the therapy plan/ progress/ recommendations will be documented by the clinician on the webportal.

2. Payment gateway needs to be created and charges decided. Appropriate reduction of charges should be considered, as the clinician will not be able to work with the child directly for both assessment and intervention.

Post-informal assessment, usually frequency of sessions suggested is either once a week or once in a fortnight for an individual child’s therapy. We should have option to offer free tele-consultation or counseling for those patients who are having financial difficulties.

3. Duration of each session can be set as 45 mins. It could be inclusive of 30 mins of tele-consultation, 10 mins for documentation and sharing of resources for intervention and 5 mins for technical delays.

4. Once the details are finalized, would be nice if we have a brochure highlighting details of tele-services to inform parent groups, or our regular client cohort.

Once situation returns to normalcy, we can resume typical formal assessment, counseling and intervention sessions.

Through tele-health, let us support these families to live without fear as true warriors!
Autism Spectrum Disorder – Overview

P. Krishnakumar
Director, IMHANS, Kozhikode
Month in Pics

Early markers of developmental delay - 4th April
Month in Pics

Join us for a lively discussion with,

Dr. Swati Bhave
Adolescent Pediatrician,
President IAP 2000

Mrs. Priya Dutt
Ex Member of
Parliament

Mrs. Sharmila Lele
Headmistress,
Cathedral School, Mumbai

Moderators

Dr. Samir Dalwai
Dr. Shekhar Dabhadkar

8pm - 25th April
Join on YouTube Live:

Haath me haath bahuchon ki haat
Free Live webinar on Autism spectrum disorder was conducted on 26 Apr from 2-4.30 pm

Month in Pics
Dr. Lata Bhat gave therapies to Kids with ASD on Zoom along with her team. The experience taught a lot to her team. It’s not easy, since we have to get activities done through the parents. Kids who have been coming to the centre for a while and are familiar with the team, are the ones who comply with our commands. Many parents do not have the patience to get the activities done by their child. We have to give them list of items that they have to keep ready for the session in advance so that time is not wasted during the session, still it takes more time than sessions done at the therapy centre. However, it is still worthwhile trying at least with kids and parents who comply with our commands.
Help Children Adjust To Sensory Challenges In Classroom
For Better Learning & Positive Behaviours

SENSORY CHALLENGES IN CLASSROOM

VISION
Hearing
Smell
Taste
Touch
Vestibular
Proprioception

To interpret the sensory information from environment, these areas in the brain must work in association and in rhythm.

<table>
<thead>
<tr>
<th>Somesthetic association area in parietal lobe</th>
<th>Visual association area</th>
<th>Auditory association area in the temporal lobe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps the position of Limbs, Location of Touch or Pain, Shape, Weight and Texture of an object</td>
<td>Occipital Lobe helps to identify things as we see; faces recognized in Temporal Lobe</td>
<td>Helps to recall the name of a piece of music or identify a person by his voice</td>
</tr>
</tbody>
</table>

Sensory Processing Challenges can influence how a child responds to his/her environment.
Sensory Processing Disorders can affect mood (anxiety and depression), social skills, motor dexterity, behavioral breakdowns, and learning.

HOW TO RECOGNIZE THE SENSORY TYPE OF ANY CHILD

UNDER-RESPONDER STUDENT
POOR AWARENESS, MISSES ENVIRONMENTAL CUES, RESPONSES TO INSTRUCTION SLOWLY
ACTS AS IF IT DOES NOT HEAR

OVERWHELMED STUDENT
HEIGHTENED AWARENESS, LACKS ACTIVE RESPONSE, CAN BECOME EASILY OVERWHELMED, COMPLAINS OF THINGS "BOtherING", ANXIOUS/UPSET, OVERREACTS TO SMALL CHANGES IN THE ENVIRONMENT

ACTIVE AVOIDER
HIGH AWARENESS, WITH ACTIVE RESPONSES, WILL ACTIVELY AVOID (SEARCHING OUT ESCAPE AREAS, COVERS EARS/YES, EXPRESSES AGRRESSION TO "PROTECT SELF"

SEEKER
HEIGHTENED AWARENESS WITH LOW SENSITIVITY TO STIMULATION, WILL SEEK OUT INPUT (FREQUENTLY AND INTENSIVELY MOVING, JUMPING, SPINNING, TOUCHING)

WAY TO FUNCTIONAL INDEPENDENCE FOR EVERY CHILD
SCHOOL TEACHERS CAN HELP IN ENVIRONMENTAL MODIFICATIONS TO DECREASE THE STRESS ON THE FRAGILE SENSORY SYSTEM OF THE CHILD

WHAT CAN TRIGGER AN UNWANTED NEGATIVE BEHAVIOUR IN A CHILD

- Biological issues: Hunger, tiredness, illness
- Sensory issues: Noise, light, touch, over stimulations, under stimulation
- Lack of structure: Visual Support
- Challenging situations: Having to wait, not get what one wants, disappointments
- Threats to self-esteem: Losing, mistakes, criticism, unmet wishes for attention and when being ignored
- Withholding recess/play / break period based on the child's behavior or inability to complete work. Movement and activity may be the input the child needs in order to maintain behavior, concentrate and learn!

ENVIRONMENTAL, VISUAL & ORGANIZATIONAL SUPPORTS

- Firm supportive seating
- Place to rest feet on floor
- Desk and chair that fit snugly
- Safety precautions & remove pointed sharp edges
- Railings on stairs
- Space to move and add pace and stretch in the class
- Or
- Items kept within comfortable reach in the work area
- Colour coding of areas / rooms / spaces / cubicles
- Timers / watches
- Written directions
- Written rule reminders

POSITIVE ENCOURAGING ENVIRONMENT WITH FIRM AND ASSERTIVE DISCIPLINE

STRATEGIES TO TEACH

- Structural learning
- Work on eye contact, listening skills & sitting behaviour
- Help improve instruction following
- Teach with numbers, shapes, alphabets and picture books
- Sequential learning

- Using token reward system and behaviour charts
- Use social stories
- Developing peer sensitivity - lunch buddy, academic buddy, extracurricular buddy
- Parent counselling - coping strategy & power struggle
- Evaluating outcomes every 6 months

ASHA, CENTER FOR AUTISM & INTELLECTUAL DEVELOPMENTAL DISORDERS
Clinic: SCO 809, FIRST FLOOR, MAC MANI MAJRA, HOUSING BOARD CHOWN, NEAR MPRIRIAS DIAGNOSTICS CENTRE, CHANDIGARH | PHONE: 0172-4189999
On the occasion of 2nd April World Autism Awareness Week, Dr. Chhaya Prasad shared a presentation on the Early Intervention Models for Children with Autism and a Poster that she created which depicts Sensory Challenges experienced by children with Developmental Disorders; how we can Identify the Sensory Type of each child and strategies to help these children adjust in the classroom environment for better learning.
Dear Members,

Greetings from IAP!

Join us for a very enriching discussion on Academic Under Achievers, School Readiness Skills And Learning Disabilities.

Dr Samir Hassan Dalwai in discussion with our esteemed panel of experts—Dr Geeta Patil, Dr Chhaya Sambharya Prasad & Dr Chitra Sankar

This webcast is brought to you under dIAP, an initiative of IAP to facilitate e-learning in all spheres of pediatrics. Live webcast of the webinar discussions, on-line clinics and their subsequent archiving is one of the activities under this banner.

With warm regards

DR BAKUL JAYANT PAREKH
DR GV BASAVARAJ

Date: Thursday, April 30
Time: 1.30 PM to 3.30 PM

Go to diapindia.org/event-calendar or click the link below
LOCKDOWN LAUGHS  

**YOU’VE PUT ON WEIGHT EVER SINCE YOU STOPPED CHASING CARS!**

LOCKDOWN LAUGHS  

**I HAD THE WORST NIGHTMARE! I DREAMT I GET KISSED BY A PRINCESS WHO TESTED POSITIVE!**

LOCKDOWN LAUGHS  

**HAVEN’T SEEN ANY PLANES LATELY. DO YOU THINK THEY’VE MIGRATED?**

LOCKDOWN LAUGHS  

**DON’T EVEN THINK ABOUT IT! I HEARD HIM COUGHING LAST NIGHT!**

LOCKDOWN LAUGHS  

**FOOLISH HUMANS! JUST WHEN THE AIR BEGINS TO GET CLEAN, THEY START WEARING MASKS!**
Blind men and COVID 19

Necessity is the mother of invention.

The curve is flattening. We can stop social distancing!

The parachute has slowed my fall. I can take it off now!

MOBILE NOT ALLOWED IN SCHOOL

COMING TO SCHOOL NOT ALLOWED. USE MOBILE
## A to Z Corona Instructions

### Always remember A to Z

<table>
<thead>
<tr>
<th>A</th>
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<tbody>
<tr>
<td>AVOID CROWD</td>
<td>BEWARE OF FAKE NEWS</td>
<td>CLEAN YOUR HANDS</td>
<td>DON'T GO OUT</td>
<td>EMPTY THE STREETS</td>
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<td>GATHERING IS BAD</td>
<td>HAND SANITIZING</td>
<td>INSIDE THE HOME</td>
<td>JOIN FIGHT AGAINST CORONA</td>
<td>KIND TO THE NEEDY</td>
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<td>LOVE YOUR FAMILY</td>
<td>MEDITATE DAILY</td>
<td>NO TO HANDSHAKES</td>
<td>OFFER HELP TO EACH OTHER</td>
<td>PRACTICE YOUR PASSION</td>
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<td>QUARANTINE YOURSELF</td>
<td>REGULAR EXERCISING</td>
<td>SOCIAL DISTANCING</td>
<td>TRAVELING IS DANGEROUS</td>
<td>USE MASKS</td>
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<tr>
<td>VISIT YOUR DOCTOR ONLINE</td>
<td>WEAPONIZED IMMUNE SYSTEM</td>
<td>XTRA PRECAUTIONS FOR ELDERS</td>
<td>YOUR AWARENESS IS A PREVENTION</td>
<td>ZERO FACE TOUCHING</td>
</tr>
</tbody>
</table>
DEAR MEMBERS,

GREETINGS FROM IAP!

Join us for a very enriching discussion on Pediatrists Role In ADHD management.

Dr Samir Hassan Dalwai & Dr Leena Deshpande in discussion with our esteemed panel of experts-
Dr. Shabina Ahmed, Dr. Jeeson Unni, Dr. Leena Srivastava, Dr. Jyoti Bhatia, Dr. Shambhavi Seth & Dr. Kawaljit Singh Multani

This webinar is brought to you under dIAP, an initiative of IAP to facilitate e-learning in all spheres of pediatrics. Live webinar of the webinar discussions, on-line clinics and their subsequent archiving is one of the activities under this banner.

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With warm regards
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DR GV BASAVARAJ

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