



Life in the Times of Covid 19

A GUIDE FOR
PARENTS OF
CHILDREN WITH
DISABILITIES



United Nations
Educational, Scientific and
Cultural Organization

New Delhi Office
Cluster Office for Bangladesh,
Bhutan, India, Maldives,
Nepal and Sri Lanka



CDMRP
COMMUNITY DISABILITY MANAGEMENT
AND REHABILITATION PROGRAMME



**SOCIAL JUSTICE
DEPARTMENT**
care, protection & empowerment

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• UNESCO Chair
• on Community-based
• Disability Management
• and Rehabilitation Studies
• University of Calicut, Kerala, India



Foreword

The 2019–20 coronavirus pandemic has affected educational systems worldwide, leading to the widespread closure of schools and universities. As of April 2020, over 1.5 billion learners were out of school due to closure of educational institutions in response to COVID-19. In India, over 320 million learners have been affected due to Covid-19.

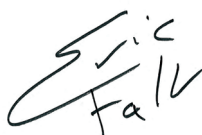
Amongst all learners, children with special needs can find it very difficult to stay in confined spaces without any social exposure, which often leads to them being easily frustrated, showing regular fidgeting, aggressive behaviour etc. As a consequence, their parents are going through tough times. This is further enhanced by the fact that their children's stress, which was earlier shared between parents, schools and vocational training centres, has to be now dealt with by the parents or guardians alone. During such a time, it becomes increasingly important to support the children with special needs as well as their parents who take care of them.

UNESCO is committed to promote and ensure equitable access to quality education for all. Inclusive education comes out of a vision of the world based on equity, justice and fairness. In this regard, UNESCO New Delhi office launched, **'N FOR NOSE - State of the Education Report for India 2019:**

Children with Disabilities', in July 2019. It aims to articulate a vision of education for children with disabilities for 2030 as set out in national and international policy documents and legislative frameworks and has been widely shared across the country.

With the vision of providing further support to children with disabilities and their communities, UNESCO New Delhi and the UNESCO Chair in Community Management of Disabilities (University of Calicut) have jointly developed guidelines for parents of specially-abled children to combat this difficult phase of Covid-19.

The guidelines are action-oriented and would help serve all families with special needs in dealing with the extreme crisis of COVID-19. We would like to thank the efforts put in by the Department of Psychology, University of Calicut and the Social Justice Department, Government of Kerala, that have continued to help create an inclusive approach in raising awareness through their joint initiative, the Community Disability Management and Rehabilitation Programme (CDMRP).



Eric Falt
Director and
UNESCO Representative to India

Preface

The COVID-19 pandemic is continuing to perpetuate an intense and catastrophic impact upon the people in India and across the world over the last few months. In these dire times, it is important to highlight the fact that certain people are facing an additional crisis of understanding and dealing with the present challenges brought about by the pandemic. Children with disabilities and other special needs, as well as their Parents/ Caregivers, comprise one such group that is undergoing a hard time. Needless to reiterate the point, but supporting children with disabilities at home during the nationwide lockdown does require extraordinary effort and patience.

The radical changes and ensuing stress brought about by COVID-19 and the lockdown may also result in different sorts of difficulties among these children. Hence, parents and caregivers of such children must know how to manage and guide their children during this pandemic.

This guideline explains the different aspects that a parent/ caregiver must take into account while taking care of children with special needs. This guideline also addresses the need to maintain the mental health of the parent/ caregiver of children with special needs. The eleven sections in this guideline explain the duties and responsibilities that parents/ caregiver must follow. The sub-sections of the article include children's cleanliness, food habits and health, emotional and psychological wellbeing, physical

exercises, medicines, entertainment, responsibilities, training, and behavioural issues. Apart from these, the last sub-section of the article explains the psychological wellbeing of parent/ caregiver.

Like any other children of similar age, children with disabilities meet and interact with different people every day. Among the people whom these children interact with everyday are therapists who treat the children with special needs and, thus, play an important part. Most of the children with special needs, who are undergoing regular sessions for Physiotherapy, Occupational Therapy, Psychotherapy, Psychiatry, Special Education, Speech Therapy, etc. are supposed to continue with these therapy sessions. Skipping even one session of their regular therapy could lead to a decline in the child's therapy progress. This may even lead to opposite effects in the child's behaviour.

In this period of COVID-19 pandemic, when accessibility to therapy sessions is not possible, this article will serve as a guideline for parents. Also, this guideline will help to reduce the adversities of not continuing therapy sessions of children with special needs.



Professor K. Manikandan
Director, UNESCO Chair on Community Based Disability Management and Rehabilitation Studies, Calicut University

Managing the Stress of Lockdown, Taking Care of Children with Disabilities



How to manage the stress of an unexpectedly long and continuous stay at home is a question that all of us are struggling to answer today. Apart from the other times when we are compelled to stay at home for extended periods, the on-going Coronavirus (COVID-19) crisis is far more serious and has further complicated the matter. It is without doubt that all of us are enduring high stress under these circumstances. In the midst of this crisis, a person with disabilities, someone undergoing a serious health issue or an elderly person in our home can become a major contributor to our mental distress. People who take care of children with developmental disabilities and emotional and behavioural issues are certainly going through a hard time. After all, under normal circumstances their burden would have been shared by care centres, inclusive schools, vocational training centres and other spaces.

Being in a confined space without social exposure for a long period of time may intensify existing problematic behaviours or even lead to development of novel ones in these children. Some of the developmental and behavioural disorders commonly seen in children these days are Attention-Deficit/Hyperactivity Disorder (ADHD), Learning Disability (LD), Intellectual Disability (ID), and Autism Spectrum Disorder (ASD). Most commonly seen symptoms of such disorders and disabilities are fidgeting, lack of attention, temper tantrums, aggressive behaviour, being easily frustrated, etc. Under the present circumstances created by Covid-19, the big responsibility of managing these behaviours at home will most certainly fall upon the parents. So, knowing more about how this responsibility can be properly taken up is what all parents with children with disabilities should learn.

Managing Children with Special Needs with Special Care and Love

The parents of children with disabilities and disorders must realise one crucial aspect of handling their wards. Over and above all the medical, psychological and scientific means of treating them,

such children respond most noticeably to warmth of love, caring and patience. Keeping these aspects in mind, given below are some areas of concern and how you could possibly manage them without getting stressed out yourself.

1 | CLEANLINESS OF CHILDREN

Since the outbreak of the COVID-19 pandemic; constant sanitisation of one's hands, by washing with soap and water or by rubbing with alcohol-based solvents, has become the norm. Although sanitisation sounds easy, it seldom is an easy task, especially for children with developmental disabilities or behavioural issues. The innate tendency of children to touch surfaces and handle things without any concern for hygiene underscores the importance of this aspect. Therefore, it is very important that they should be trained

to sanitize their hands properly and frequently. This training should follow the procedure for washing hands as per government recommendations i.e. washing with soap and water for about 30 seconds.

The fact that children with disabilities tend to have a weak immune system raises the risk many folds and makes them more susceptible to various infections. Therefore, extra care should be taken to keep their bodies clean. During the months of hot weather, children tend to sweat a lot. This leads to accumulation of dirt in the scalp. So, their hair should be washed regularly with soap or shampoo.

Children should also be taught the basic habit of covering their nose and mouth with a clean towel while sneezing and coughing. Parents should keep the children away from strangers or people who have come from abroad. Since the corona virus spreads from human to human, it is wise to teach children to keep a distance of at least 1 meter from any person they may interact with. This will, in turn, prevent the spread of the virus through droplets that may be released when a person coughs or sneezes.





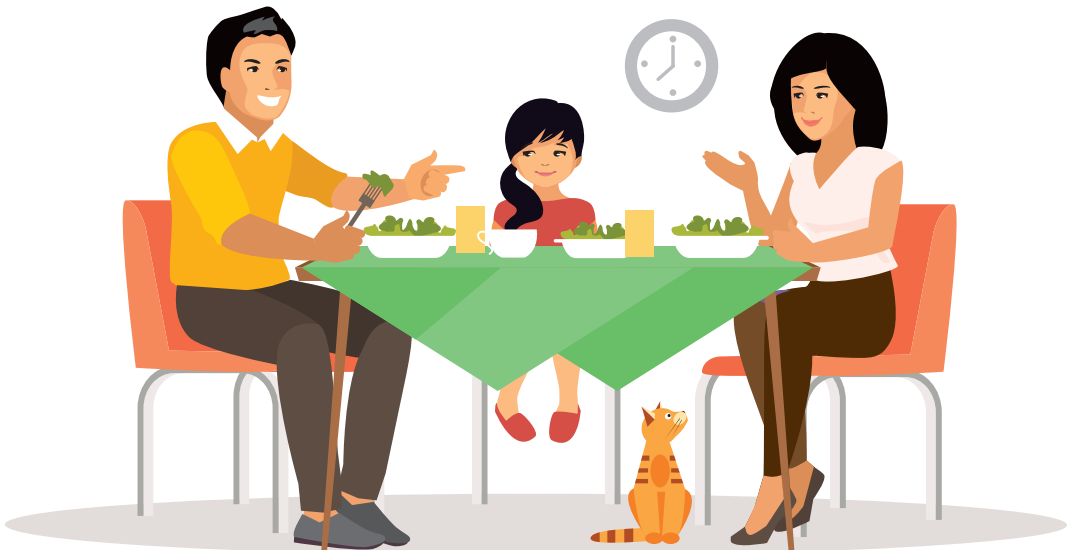
Most children with disabilities have difficulty in following instructions and learning from experiences. As most children are good at imitation, appropriate behaviour may be shown by their caregivers and the children should be invited to repeat this.

Caregivers must always keep in mind that their instructions may have to be repeated many times. They may even have to reintroduce the instructions through various techniques for the child to understand and follow.

2 EATING HABITS AND HEALTH OF CHILDREN

There is a need to inculcate healthy eating habits in children to ensure they get appropriate vitamins, minerals and proteins for their proper growth and sustenance. Fruits, pulses, grains and leafy vegetables should be included in their daily diet. Giving them lime juice regularly during the day may help tackle the dehydration caused by hot weather. Make sure your child drinks enough water. Avoid processed foods as

these are usually rich in fat and sugar. Fresh and fully cooked fish or meat could be consumed in limited quantity. Curd, vegetables and salads are recommended for lunch. Food allergies should be looked at carefully before planning meals. It should also be noted that meals should be consumed at appropriate times. Being late in having food, especially dinner, is not advisable as it may lead to health problems.



3 CHILDREN'S EXERCISE ROUTINE



Under these difficult circumstances, where we are locked down in our houses for many weeks, daily activities have become confined to eating and

cleaning. This sudden and profound lack of exercise can have detrimental effects on our health. For children with disabilities, this lack of exercise can lead to sudden gain in body mass and loss of pre-acquired skills. The World Health Organization (WHO) has recommended that children must do at least one hour of exercise every day. It could be any kind of exercise, such as playing games, yoga, walking up and down the stairs, etc. Children's exercises should be adapted to their physical limitations. Parents must consult physiotherapists before introducing their wards to new exercises and techniques.

Remember, the habit of exercising paves the path to a healthy body and an energetic mind.

4 SLEEP



Adequate amount of sleep is very essential for children. That's why we need to control and check the use of mobile phones by children especially at night. Children should be woken up at the usual time as in the normal days,

which could be done by using an alarm clock. If this routine is not set properly, then after the reopening of schools or vocational teaching centres it would be difficult and take lots of time for children with intellectual disabilities to re-adjust to the routine.

5 MEDICINES

Medical conditions such as thyroid and epilepsy accompanying intellectual disabilities, congenital disabilities, and congenital heart diseases are common conditions. For this, consultation should be taken from primary health centres or general medicines can be bought from the nearest medical shops. It is also important for parents to stockpile enough medicines during the lockdown. For disorders such as schizophrenia and mood disorders, it is necessary



to take medicines without a break. Breaking the course of medicines without doctor's advice may lead to further difficulties.

6 LEARNING NEW SKILLS



This lockdown and the ample time that it has left at our disposal should be viewed as a chance of acquiring new skills. Each day could be used to learn new skills. For example, brushing, combing, wearing shoes and tying shoe laces, colouring, gardening, washing of hands and legs could be taught to children by devoting enough time. Contact with the therapist needs to be maintained if the child is being trained by a behaviour therapist, physiotherapist, occupational therapist, speech therapist or special educator. Material available on the Internet could also be used to train the children.



7 RESPONSIBILITIES / DUTIES

Some people may think that children with disabilities should not be given charge of supporting house chores. Yet, it is important to note that the duties you entrust to them and the

work they take up can contribute in moulding them and helping them develop identities of their own. Initially, small responsibilities and tasks can be assigned to them. For example, collecting the newspaper in the morning and placing it in the appropriate place; arranging the newspapers, folding clothes and watering the plants; keeping their things safe, secure and clean, and cleaning the dining tables after having dinner, can be assigned as responsible tasks. This would help them develop a sense of responsibility. Small roles could be given to children in each of the tasks performed by elders, as this would increase the confidence level of the child and help in the formation of identity.



8 ENTERTAINMENT

The lockdown could also be looked upon as a period for having fun. Hearing stories, watching videos are good.

Television, mobile games, you tube videos have gained a place in the routine of disabled population too. For this, a schedule can be made by assigning a period of one hour to watch these. Continuous screening would affect negatively by reducing the cognitive skills acquired till then.

When the child is exhibiting some maladaptive behaviour patterns, he or she should not be encouraged.



9 | BEHAVIOURAL PROBLEMS

In a situation where there is a need to isolate oneself, everyone could eventually become disturbed and angry. This could be of more intensity in the case of children with disabilities. So, in order to address this we have to concentrate more on the activities and tasks to do. Children can be encouraged when they perform desired activities, and it could be video recorded and shown to them afterwards. Likewise, they would understand



what the desired behaviours are and confidence could be built up using it. One should make sure that they are not provoked unnecessarily.

10 | EMOTIONAL PROBLEMS



Children with intellectual disabilities can sometimes lack some emotional intelligence-related skills. Even though they have difficulty in understanding their own and others' abilities, emotions and behaviours appropriately, yet they have the ability to imitate. So, they could be trained and many of the necessary skills acquired through it. Children with learning disabilities or difficulties may have associated emotional problems and thus their talents need to be identified and encouraged appropriately. Chances of depression and anxiety are high for children who lack emotional intelligence. In order to reduce it, chances of them being left alone need to be reduced and chances of them mingling with family members need to be increased. In these uncertain times, anxiety and fear levels are soaring. If the lockdown situation gets worse and the child starts to show different problems, then online services and tele-counselling can be availed.

11 PSYCHOLOGICAL, PHYSIOLOGICAL AND EMOTIONAL WELLBEING OF CAREGIVERS

Studies point to the fact that in many homes, primary care for children with disabilities is provided by their mother/motherly figure. Ideally, this responsibility should be shared by all responsible adults in the household. The support of the family always has a positive impact upon the development of children. The primary caregivers should take care of their families, but they need not disregard their own well-being and happiness. Caregivers should engage in activities for their own well-being and relaxation, such as listening to music, or reading a book, or even some physical activities or indoor sports. If negative feelings are overwhelming, it is important to consider consulting a mental health professional in the nearest centre or through online services. Patterns of sleep need to be checked and a routine should be established and maintained.

It is important to reiterate here that information available via social media is not always true and, thus, should not be automatically believed.

Follow instructions and take precautionary measures as prescribed by the government officials and professional health practitioners.

When we are quarantined for a long period of time, it is quite likely that we will get physiological and psychological distress. This is a good time to connect with yourself and your family and work on enriching yourself and your relationships. Take this time to engage with your family, to appreciate the beauty of nature through electronic means, to tell night time stories to your children, sing the forgotten lullabies. All these activities would provide some good memories to reminisce over.

Together, we can overcome this.



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