



# IMPACT OF COVID-19 ON ONLINE SCHOOLING IN CHILDREN WITH TRISOMY- 21: PERSPECTIVES OF PARENTS AND TEACHERS

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## Abstract

Trisomy 21/Down Syndrome is the most common genetic chromosomal disorder caused due to abnormal division of cells resulting in an extra, full or partial copy of chromosome 21. It leads to learning disabilities in children due to developmental delays. Most children with Down syndrome have mild to moderate cognitive impairment, delayed language ability in addition to problems in both short and long-term memory (<https://www.mayoclinic.org/diseases-conditions/down-syndrome/symptoms-causes/syc-20355977>). The Covid-19 pandemic brought about a huge shift in the way day to day affairs were conducted. Children with Down syndrome and their parents who already face comparatively more challenges had a new challenge- 'online schooling'. The present study is an attempt to study the perceptions of parents and teachers regarding the impact and challenges faced by the children with Trisomy 21 due to online schooling during the Covid-19 pandemic and provide suggestions and the strategies for the same.

Keywords: Trisomy-21, Covid -19, online schooling, Awareness, Challenges, Parenting and Teachers.

## Introduction

Down syndrome, the result of the trisomy of chromosome 21, is the most common genetic cause for intellectual disability. It is associated with specific co-occurring health conditions and immune dysfunction that may impact the clinical course and increase risk of life-threatening disease due to infection by the novel severe acute respiratory syndrome SARS-CoV-2. (<https://europepmc.org/article/ppr/ppr235181>). Though children are thought to be less likely to contract COVID-19, children with Down syndrome are a vulnerable group and are more likely to develop respiratory infections. In addition, children with Down syndrome are more likely to have concomitant diseases: immunodeficiency, heart disease (including diseases that require valve replacement), obesity and diabetes (Picchianti Diamanti, A. *et al.*, 2020; Ruan, Q. *et al.*, 2020; & Sullivan, K.D. *et al.*, 2016). The treatment for COVID-19 remains experimental. Various groups of drugs are used to prevent and correct complications: antiviral drugs anti-inflammatory drugs (chloroquine, azithromycin), anticoagulants (Tisoncik, J. R. *et al.*, 2012). Down syndrome patients are advised to follow standard precautions: social distancing, use of protective masks and gloves, frequent hand washing, and disinfection of hands and surfaces (Tuttle, K. D. *et al.*, 2020). Families raising children with Down syndrome face special

challenges during the pandemic. In about 40% of these families, a parent (or other family member) was not working at the time the pandemic began. Other family members continue to work and thus increase the risk of infection. The rhythm of life in the family is disrupted: social contacts are sharply reduced, children with Down syndrome are deprived of communication (they usually go to school with pleasure and love to communicate with older relatives) (Watts, R., & Vyas, H. 2013; Zhou, F. *et al.*, 2020; & Zhu, N. *et al.*, 2020) Formal education of these children is a difficult process because it needs different teaching strategies and they face many hurdles in their learning such as lack of required skills, low IQ level, memory issues, communication and behavioral problems, passivity, and distraction issues. (Humayoun, A., & Yaar, M. 2019) For the parents of 5-year-olds with Down syndrome, the major issue is their ability with regards to language and its functionality (Dolva, A., S *et al* 2004). Children with Down syndrome are more attentive towards gestural rather than vocal communication and thus caregivers can help increase these skills by interacting with them while they are playing with their favourite toys (Broadley, I., & MacDonald, J. 1993). Children and young adults between the ages of 4 to 21 with Down syndrome can handle the mouse while working on computers as compared to the keyboards, thus there is scope in computer related education and training so as to expand the career opportunities for individuals with Down syndrome (Feng, J. *et al* 2008). Issues such as the development of systematic psycho-social support systems that increase full participation and motivation of parents in distance education programs are important during extreme times such as the pandemic (Celik, S. *et al* 2022). It has been witnessed that the pandemic period, has negatively impacted the emotional state of children with disabilities contributing to parental stress. Thus, there should be an emphasis on adapting curricula and teaching plans to individual needs, necessitating professional development of teachers, and provision of services within the school and involvement and support of parents in the education of the child so as to improve the quality of education and inclusion opportunities for children with disabilities (OECD).

### Objectives of the Study

To ascertain from parents and teachers their perception regarding the

1. impact of online schooling
2. challenges experienced
3. suggestions/strategies

while dealing with online schooling in children having Trisomy 21/Down Syndrome during Covid-19 pandemic.

### Methodology

The research was an exploratory study, using purposive snow ball sampling with a sample size of 70 participants (50 parents and 20 teachers). A survey was conducted using Google form using self-constructed questionnaire for parents with 20 close-ended and 2 open-ended questions (<https://forms.gle/y4uDNYFK47CKs8su5>) and teachers with 16 closed ended and 6 open-ended questions (<https://forms.gle/Qk5Drcgxja6mNLB39>). Data was quantitatively analysed using frequency and percentages. Seven parents had more than one child suffering from Down syndrome. A large majority of the mothers (88%) had conceived this child between the ages of 20-30 years, whereas six of them were over 40 years of age when they conceived this child. More of the parents (60%) were ignorant about the condition of their child before the birth. Many of these (40.4%) children were dependent on caregivers for their daily chores. Substantial majority of teachers (95%) were specially trained for teaching children with special needs. Most teachers who responded belonged to schools that had extra-curricular activities like arts and craft, sports and music, etc. to help in cognitive and physical development of the children.

### Results and Discussion

#### Impact of Covid-19 on online schooling on children with Trisomy- 21

**Parents:** According to most of the parents, lack of professional guidance to provide support was the major challenge while bringing up their child. Finding a special school near their houses for their child was a major challenge for 72% of the parents and some of the parents did express some benefits which included, better food intake and health of the child and ability to give more attention to the child.

**Teachers:** Few teachers mentioned improvement in certain skills, as increased parent interaction was observed during the pandemic

## **Challenges experienced by parents during Covid-19 in relation to their children with Trisomy 21/Down Syndrome:**

**Parents:** Most of the parents (82%) rated that the transition from offline to online schooling from mildly difficult to very difficult, whereas the rest (18%) stated that the transition was not challenging. Lack of technological knowledge (34%) to access online schooling and lack of space at home (30%) were the major difficulties faced by parents. Little less than a quarter of them (22%) reported that there was no partner for the child during online schooling, as parents had to report for work. Issues regarding sitting in one place during classes, following instructions given by the teacher & attention deficiency were the crucial problems faced by the children. A majority of parents (60%) felt that the children faced anger issues, decreased social interaction and decreased physical activity.

**Teachers:** Majority of the teachers (70%) mentioned that they experienced challenges while interacting with the children even in offline mode and little less than half of them (45%) felt transition from offline to online schooling was thus very difficult. Most teachers also revealed some of the change in students during online schooling were problems in comprehension (50%), increased distraction (40%), low levels of interaction with teachers (30%), stubbornness (25%) and increase in weight (20%) due to decreases activity levels. The major challenge faced by teachers was lack of eye contact, temper tantrums by students, attention deficiency and speech problems, changed behaviour in students due to social isolation and limited interaction with the students due to the online medium. Some of them (50%) also expressed challenges were added due to network problem, device unavailability and technological ignorance of parents.

## **Strategies and suggestions provided in dealing with children having Trisomy 21/Down Syndrome in online schooling during Covid-19:**

**Parents:** Most parents were very happy with the manner in which teachers dealt with the challenges, only 1 parent recommended that teachers should be more patient with the students and give them less homework, as they find it difficult to complete it.

**Teachers:** Varied interesting strategies were suggested by teachers (35%) which included, more efforts put into digital transformation of these children by introduction of play and fun activities, like playing more interactive games, or through online worksheets and use of multimedia like music and videos and suggested that school management should train teachers to use of assistive technologies. In addition to this, few teachers (10%) suggested active participation of parents in the education of their wards.

## **Conclusion**

Screening of the expectant mother for congenital defects is not considered important, due to which many parents are unaware of the condition of the child till birth. People in general are not aware of the condition of Down syndrome and the challenges faced by these individuals. There is lack of affordable professional support for children having Down syndrome and their parents and there is a lot to be desired even in a metro city of Mumbai when it comes to access to special schools catering to children with special needs. The pandemic compelled everyone to use online education, however technology used for regular children cannot be used as effectively for those with special needs - technology cannot be 'one size fits all'. There is thus a need to have technology that can cater to different categories of special children. This can only happen if problems and challenges faced are known, so that effective solutions can be explored. Active involvement of parents in the schooling of their children having Down syndrome is extremely important for better development.

## **Contribution of the research**

Findings from this study can help intellectual disability administrators and parents as they continue to navigate through Covid-19 challenges, as well as prepare for future pandemics. As demonstrated in the findings, the Covid-19 pandemic has had a profound impact on the daily life of individuals with intellectual disabilities. During a pandemic or other unusual times, organizations can provide safe service settings that normalize the lives of individuals with intellectual disabilities to the greatest extent possible, such as by offering opportunities for skills development and socialization. Developing technology aids for remote learning accessible for individuals with intellectual disabilities of varying ability levels is an important step. Additionally, providing healthy, fresh foods, rather than defaulting to processed food options, and structuring safe, regular physical activities in indoor and outdoor settings for optimal wellness could help maintain wellness and provide a routine. For intellectual disability staff and parents, in addition to providing adequate mental health supports and stress management training, organizations must plan for safe work settings that

minimize risk and maximize benefits to staff, offer resources that may be helpful for intellectual disability organization administrators and parents to provide the safest, most enriching environments for individuals with intellectual disabilities and staff during challenging times.

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