Parental Involvement in Educating Children with Intellectual Disabilities in India During the COVID-19 Pandemic: A Comprehensive Review

Abstract:

The COVID-19 pandemic has drastically altered the educational landscape globally, with a particularly profound impact on children with intellectual disabilities (ID). In India, where educational infrastructure and support systems for children with ID are already strained, the pandemic exacerbated existing challenges. In India, the sudden shift to remote learning has placed a significant burden on parents, who have had to take on new roles as educators. Parents have had to step into roles traditionally held by educators, therapists, and support staff, making their involvement crucial. This research article explores the multifaceted role parents played in the education of children with intellectual disabilities during the COVID-19 pandemic in India, highlighting both the obstacles faced and the resilience demonstrated by families. This article also emphasized the role of parents in educating children with intellectual disabilities during the pandemic, through case studies and community efforts, highlighting both challenges and innovative solutions.

Key Word: Intellectual Disability (ID), COVID-19, Pandemic, Educational infrastructure, Parents, Special Educators, therapists, and Telepathy.

1. Introduction

The COVID-19 pandemic has brought unprecedented disruptions to educational systems worldwide, with significant repercussions for children with intellectual disabilities (ID). In India, where educational resources and support for children with ID were already limited, the pandemic further exacerbated these challenges[36,37,38]. The sudden shift to remote learning necessitated that parents assume a central role in their children's education, functioning as educators, therapists, and advocates. This introduction explores the critical role parents played during this period, the strategies they employed, and the broader implications for the education of children with ID in India.

The educational landscape for children with intellectual disabilities in India is characterized by a complex interplay of socio-economic, cultural, and infrastructural factors. Prior to the pandemic, these children often relied on specialized educational programs, in-person therapies, and tailored support systems to facilitate their learning and development (Pynadath et. al., 2021). The closure of schools and therapy centers during the COVID-19 lockdown disrupted these essential services, placing immense pressure on parents to fill the gap (Asbury et al., 2020; Jeste et al., 2020).

Parents of children with ID had to quickly adapt to new roles and responsibilities, often without prior training or support. As primary educators, they needed to develop and implement individualized lesson plans that catered to their children's unique learning needs (Irwin et al., 2022). This included breaking down complex concepts into manageable tasks, using multisensory teaching methods, and continuously monitoring progress (Zaagsma et al., 2020). The role of parents as educators was especially critical given the difficulties many children with ID face in engaging with conventional online learning platforms (Cerna, 2020).

Moreover, the role of parents extended beyond traditional educational duties. Many children with ID require consistent therapeutic interventions, such as speech, occupational, and physical therapies, to support their cognitive and motor development. With in-person sessions suspended, parents had to become therapists, guided by virtual consultations with professionals (Ellison et al., 2021). They incorporated therapeutic exercises into daily routines, striving to maintain their children's developmental progress despite the lack of direct professional oversight (Villani et al., 2020).

The advocacy role of parents also became more pronounced during the pandemic. Parents needed to navigate the educational system to secure necessary resources and accommodations for their children. This often involved engaging in regular communication with teachers and

school administrators to ensure that remote learning was tailored to their children's specific needs (Willner et al., 2020). Advocacy was crucial for addressing barriers such as the digital divide, which significantly impacted the ability of children with ID to access remote learning (United Nations, 2020).

Emotional support provided by parents was another vital aspect of their role. The pandemic-induced disruption of routines and the lack of social interaction caused heightened anxiety and stress among children with ID (Turk & McDermott, 2020). Parents had to provide constant emotional reassurance, helping their children cope with the uncertainty and changes brought about by the pandemic (Mutluer et al., 2020). Establishing and maintaining structured routines at home became a key strategy for providing stability and reducing anxiety (Zaagsma et al., 2020).

Despite the numerous challenges, parents demonstrated remarkable resilience and adaptability. They leveraged community resources, including online support groups and non-governmental organizations (NGOs), which offered educational materials and emotional support (Mathias et al., 2020). These networks facilitated the sharing of strategies and resources, helping parents manage the demands of home-based education (Perera et al., 2020). Additionally, technology played an indispensable role, with parents utilizing educational apps, online learning platforms, and teletherapy services to support their children's learning and development (Cochran, 2020, Nanda et al., 2023).

Case studies from various regions in India highlight the diverse strategies employed by parents. For instance, in rural Maharashtra, a family integrated practical life skills into educational activities, using community-provided materials. In urban Delhi, an online support network facilitated resource sharing and emotional support among parents. In Bangalore, a structured teletherapy approach enabled significant developmental gains for a child with ID (Mathias et al., 2020; Cochran, 2020; Pantsyr & Shvedovskiy, 2020).

In light of these experiences, several policy recommendations emerge to better support the education of children with intellectual disabilities in future crises. These include improving digital infrastructure to ensure equitable access to remote learning, providing training and resources for parents to equip them with the necessary skills, developing inclusive educational resources, and fostering collaborative frameworks between educators, therapists, and parents (Zaagsma et al., 2020; United Nations, 2020).

The COVID-19 pandemic has underscored the pivotal role of parents in the education of children with intellectual disabilities. While the challenges were significant, the resilience and adaptability demonstrated by parents highlight the need for systemic support and

resources to empower them. Addressing these systemic issues is crucial for ensuring equitable educational opportunities and preparing for future disruptions.

This research highlights the resilience and adaptability of parents in managing their children's education during the pandemic. This research article investigates the crucial role parents played in educating their children with ID during this period, highlighting their multifaceted roles as educators, therapists, advocates, and emotional supporters. Policy recommendations for future crises include enhancing digital infrastructure, providing training and resources for parents, developing inclusive educational materials, and fostering collaborative frameworks to support children with intellectual disabilities. Addressing these systemic issues is crucial to ensure equitable educational opportunities and better preparedness for any future disruptions.

2. The Impact of COVID-19 on Education for Children with Intellectual Disabilities

The COVID-19 pandemic has disrupted education systems worldwide, significantly affecting children with intellectual disabilities (ID). These children face unique challenges, and the shift to remote learning has exacerbated existing inequalities and created new obstacles. The challenges encountered and the adaptive strategies implemented by parents, educators, and communities in intellectual disabilities (ID) fraternity is highlighted below

A. Digital Divide and Accessibility

One of the most significant challenges faced by children with intellectual disabilities during the pandemic was the digital divide. Limited access to internet connectivity and digital devices prevented many children from participating in online learning. According to a study by UNICEF, only 24% of households in India have access to the internet, with rural areas being disproportionately affected (UNICEF, 2020). This digital divide made it difficult for parents to facilitate continuous learning at home (Xafis, 2020).

B. Lack of Specialized Resources and Training

Parents often found themselves unprepared to handle the specialized educational needs of their children. Special education requires tailored resources and teaching strategies that many parents were not equipped with. The sudden shift to home-based learning left many without the necessary training or resources to effectively support their children's education (Grills et al., 2022; Kumar et al., 2020).

C. Disruption of Routine and Structure

Children with intellectual disabilities often rely on consistent routines and structured environments for effective learning. The sudden closure of schools disrupted these routines, causing confusion and anxiety among these children (Asbury et al., 2020). The lack of a structured educational setting impacted their ability to focus and retain information (Irwin et al., 2022; Udayan Care, Miracle Foundation, 2022).

D. Access to Specialized Education and Therapies

Many children with ID require specialized educational programs and therapies that are difficult to deliver remotely. Speech, occupational, and physical therapies, typically provided in-person, were significantly disrupted, affecting the children's developmental progress (Jeste et al., 2020; Schiariti, 2020; Manjaly et al., 2023).

E. Parental Burden and Stress

The responsibility of facilitating home-based education largely fell on parents, who may not have the training or resources to effectively teach their children with intellectual disabilities. This added burden increased stress and anxiety levels among parents, impacting the overall well-being of the family (Mutluer et al., 2020).

3. Parental Roles during the COVID-19 pandemic for children with intellectual disabilities

During the COVID-19 pandemic, parents of children with intellectual disabilities had to step into multiple roles to facilitate their children's education. These roles included being educators, therapists, advocates, and emotional supporters.

A. Home-based Educational Interventions

Parents had to become the primary educators for their children as schools transitioned to remote learning. During the lockdown, parents took on the primary responsibility for their children's education. This involved creating structured routines and learning environments at home. This required them to engage in direct teaching, plan educational activities, and monitor their children's progress. Given the specialized needs of children with intellectual disabilities, parents often had to tailor lessons to suit their child's learning pace and style (Zaagsma et al., 2020; Cochran, 2020). Studies have shown that consistent routines and structured environments are beneficial for children with ID, helping them to maintain a sense of normalcy and reduce anxiety (Panchal et al., 2020).

B. Utilizing Online Resources and Support Networks

Many parents turned to online resources and support networks to fill the gap left by the closure of schools and therapy centers. Various NGOs and community organizations offered online workshops and training sessions for parents to help them understand how to use digital tools for their children's education (Ranjan et al., 2022). Additionally, social media platforms and online forums provided spaces for parents to share resources, strategies, and emotional support (Kumar et al., 2020).

C. Psychological and Emotional Support

The pandemic increased stress and anxiety levels among children with intellectual disabilities and their families. The psychological and emotional well-being of children with ID was a significant concern during the pandemic. Parents had to provide emotional support, helping their children cope with the changes in routine and the lack of social interaction with peers (Turk & McDermott, 2020). Parents played a crucial role in providing emotional support and managing the increased stress and anxiety that their children faced. Research indicates that children with ID are particularly vulnerable to changes in routine and social isolation, which can exacerbate behavioral issues and emotional distress (Willner et al., 2020). Parents employed various strategies such as mindfulness exercises, consistent communication, and involving children in household activities to mitigate these effects (Kumar et al., 2020; Kocchar et al., 2020).

D. **Advocates and Therapist**

Parents also had to advocate for their children's needs, ensuring they had access to necessary resources and support. This involved communicating with educators and school administrators to secure appropriate accommodations and modifications for remote learning (Willner et al., 2020).

Many children with intellectual disabilities rely on regular therapy sessions, such as speech, occupational, and physical therapy. With the closure of therapy centers, parents had to take on the role of therapists, implementing therapeutic exercises and activities at home based on guidance from professionals via telehealth services (Perera et al., 2020; Villani et al., 2020).

4. Adaptive Strategies Employed by Parents during the COVID-19 pandemic for children with intellectual disabilities

Despite these challenges, Parents employed various adaptive strategies to manage the challenges of educating their children with intellectual disabilities during the pandemic.

These strategies included utilizing community resources, implementing structured routines, innovative educational approaches, leveraging technology, leveraging available resources and engaging in collaborative efforts were key to overcoming obstacles and promoting resilience.

1. **Community Engagement and Support Networks**

   Community support played a vital role in helping parents navigate the challenges of home-based education. Online support groups and community networks provided a platform for parents to share experiences, resources, and coping strategies (Mathias et al., 2020). These networks offered emotional support and practical advice, helping parents feel less isolated and more capable of managing their children's education (PLOS ONE, 2020 and Stenhoff et al., 2020).

2. **Innovative Educational Approaches**

   Parents adopted creative approaches to facilitate learning at home. Many reported implementing structured routines and behavioral strategies that mirrored the school environment (Zaagsma et al., 2020). These routines helped maintain a sense of normalcy and provided children with a predictable structure, which is crucial for those with intellectual disabilities (Willner et al., 2020).

3. **Leveraging Online Resources and Teletherapy**

   Teletherapy and online educational resources became essential tools for parents. Educational websites, mobile applications, and virtual therapy sessions provided accessible learning materials and support (Cochran, 2020). While these resources could not fully replace in-person instruction, they offered valuable alternatives that helped bridge the gap during school closures (Villani et al., 2020; Gudlavalleti, 2018; Kumar et al., 2020; Manjaly et al., 2023).

5. Challenges Faced by Parents of children with intellectual disabilities during Covid-19 pandemic

Parents of children with intellectual disabilities encountered several challenges during the COVID-19 pandemic. The sudden shift to online education exposed the digital divide, particularly in rural areas where internet access and digital literacy are limited (Zaagsma et al., 2020; Mathias et al., 2020). Furthermore, the lack of specialized resources and training for parents made it difficult to provide the necessary support at home (Pantsyr & Shvedovskiy, 2020).

A. **Balancing Work and Caregiving Responsibilities**

   One of the most significant challenges was balancing work-from-home responsibilities with caregiving and educational duties. Many parents, especially

mothers, had to juggle professional commitments with the increased demands of home-schooling and caregiving, leading to heightened stress and burnout (Mathias et al., 2020). The lack of external support from schools and therapy centers intensified this burden.

The COVID-19 pandemic imposed significant burdens on families worldwide, but the impact was particularly profound on mothers of children with intellectual disabilities in India. As schools shut down and specialized educational resources became inaccessible, these mothers were thrust into the primary role of educators for their children, often while managing their own professional responsibilities and household duties.

Mothers had to adapt quickly to this new reality, employing a variety of strategies to support their children's education. Many utilized online resources and virtual learning platforms, despite the challenges of inconsistent internet access and a lack of familiarity with digital tools. They often had to modify educational content to suit their children's specific needs, creating personalized learning experiences that were both engaging and effective. This required a deep understanding of their children's abilities and learning styles, as well as significant patience and creativity.

The pandemic highlighted several gaps in the support systems available to families with children with intellectual disabilities. Many mothers reported a lack of access to professional guidance and specialized instructional materials. Additionally, the closure of therapy centers and special education schools deprived children of essential services, further complicating the mothers' tasks.

Despite these challenges, the resilience and dedication of these mothers were remarkable. They not only facilitated their children's academic learning but also provided emotional support to help them cope with the uncertainties of the pandemic. This dual role underscored the need for systemic changes to provide better support for families in similar situations.

The experiences of these mothers during the pandemic emphasize the critical need for more accessible and robust support systems. These include improved access to online educational resources, professional training for parents, and stronger community support networks. Such measures would help ensure that children with intellectual disabilities receive the education and care they need, irrespective of external circumstances.

B. Digital Divide and Technological Barriers

The transition to online learning was not smooth for many families. In India, internet penetration is uneven, with rural areas suffering from poor connectivity and a lack of digital devices (Willner et al., 2020). This digital divide disproportionately affected children with intellectual disabilities, who often require tailored educational tools and consistent support. Parents struggled to access online platforms, and many were not technologically equipped to facilitate their children's learning (Cochran, 2020).

Special educators and therapists often provide tailored interventions that are difficult for parents to replicate at home without professional training. The interruption of regular therapy sessions meant that many children missed out on essential developmental support, which parents struggled to compensate for (Pantsyr & Shvedovskiy, 2020).

C. Lack of Specialized Resources

Special education teachers play a crucial role in the education of children with intellectual disabilities. However, the pandemic forced a sudden shift to remote learning, leaving many parents without the support of these specialized educators (Perera et al., 2020). Parents had to quickly adapt to new roles as educators, often without the necessary training or resources to address their children's unique learning needs (Pantsyr & Shvedovskiy, 2020).

D. Psychological and Emotional Impact

The pandemic exacerbated stress and anxiety among families of children with intellectual disabilities. The disruption of routines, social isolation, and the absence of therapeutic services took a toll on both children and their caregivers (Villani et al., 2020). Parents reported increased behavioral issues and a decline in their children's mental health, which added to the challenges of managing home-based education (Turk & McDermott, 2020).

6. Outcomes and Observations of parents for children with intellectual disabilities during Covid-19 pandemic

The pandemic highlighted both the vulnerabilities and the resilience of families of children with intellectual disabilities. Despite significant challenges, many parents reported positive outcomes and developmental gains in their children, attributed to increased family time and tailored learning strategies.

1. **Resilience and Developmental Gains**

   Several parents observed that the slower pace of life during the lockdown allowed for more quality family time and individualized attention to their children's needs (PLOS Global Public Health, 2020). This period enabled some children to make developmental gains, as parents could implement personalized behavioral strategies and routines more consistently (Pantsyr & Shvedovskiy, 2020).

2. **Increased Parental Involvement**

   The pandemic underscored the critical role of parental involvement in the education of children with intellectual disabilities. Parents' active participation in their children's learning processes fostered a deeper understanding of their needs and strengthened the parent-child bond (Perera et al., 2020). This involvement is likely to have long-term positive effects on educational outcomes and family dynamics (Turk & McDermott, 2020).

7. Some Case Studies related to education of childrens with Persons with Disabilities and role of parents during COVID-19 pandemic

Case Study 1: Impact of the First Wave of COVID-19 and associated Lockdown Restrictions on Persons with Disabilities in 14 States of India

The study aimed to assess the impact of the COVID-19 pandemic and lockdown restrictions on PwDs in India. The objective of the study is to determine the level of disruption due to COVID-19 and the associated countrywide lockdown restrictions on PwD in India during the first wave. The study was conducted using a cross-sectional, mixed-methods approach and data were collected from a representative sample of 403 persons with disabilities in 14 states in India during the COVID-19 first wave at two different points in time (Lockdown and post-lockdown phase)(Tetali, S. et al., 2022).

The results from the qualitative study supported the quantitative findings. PWDs felt that the lockdown restrictions had negatively impacted their productivity, social participation, and overall engagement in everyday activities. Access to medicines and rehabilitation services was felt to be extremely difficult and detrimental to the therapeutic benefits that were gained by them during the pre-pandemic time. None of the pandemic mitigation plans and services was specific or inclusive of PWDs. The authors concluded that COVID-19 and the associated lockdown restrictions have negatively impacted persons with disabilities during the first wave in India. It is critical to mainstream disability within the agenda for health and development with pragmatic, context-specific strategies and programs in the country (Tetali, S. et al., 2022).

Case Study 2: The Impact Of COVID-19 Lockdown on Parents Handling Children with Disability in Chennai, India

The aim is to assess the Impact of covid-19 lockdown among parents handling disabled children, parenting stress, their concerns, and morbidity during the COVID-19 lockdown. The study was done among the parents of disabled children attending special schools in Chennai, India, using a cross-sectional study design. Parents with any recent trauma, mental disorders, or major diseases and undergoing treatment for themselves were excluded. After obtaining ethics approval, a semi-structured questionnaire was used to assess the Impact of the covid-19 lockdown. Collected data were analyzed using SPSS v.21. The study concluded that COVID-19 outbreak and lockdown significantly impacted the parents of disabled children. It is high time we give importance to these parents of children with special needs during this pandemic to help them during similar occasions in the future. (Palaniappan et al., 2023)

Case Study 3: A Strategic Analysis of Impact of COVID-19 on persons with disabilities in India

The report "A Strategic Analysis of Impact of COVID-19 on Persons with Disabilities in India," prepared by the Indian Institute of Public Health, Hyderabad, highlights the multifaceted challenges faced by persons with disabilities (PWDs) during the pandemic. It reveals that PWDs experienced heightened health risks and greater difficulties accessing healthcare due to pre-existing conditions and the restrictions imposed during lockdowns. Essential services such as rehabilitation and therapy were disrupted, exacerbating health and daily living challenges. Economically, PWDs were disproportionately affected, with many losing jobs and facing financial instability, particularly those in informal sectors. Educational disruptions were significant as students with disabilities struggled with the shift to online learning due to inadequate access to technology and tailored educational resources. Additionally, social isolation measures led to increased mental health issues, including stress, anxiety, and depressions, as support networks were disrupted. The report underscores the inadequacy of existing policies and emergency responses in addressing the needs of PWDs. Recommendations include enhancing healthcare accessibility, providing targeted economic and educational support, expanding mental health services, and ensuring that policy frameworks are inclusive. These measures aim to build a more resilient and equitable system for PWDs in future crises (Murthy GVS et. al., 2020).

8. Policy Implications and Recommendations

India is home to nearly 150 million people with some degree of disability. Nearly 25-30 million have severe disability. Most of them depend on a carer. This adds to another 25-30 million carers. So we are looking at nearly 50 million people who need special support. Special efforts need to be made by the Government, NGOs and the civil society to reach people with disabilities. They need to make efforts to convert prevention and care messages on Covid into an accessible format.

Key recommendations

In consultation with key stakeholders – students, parents, teachers, civil society organisations (CSOs) and government officials – and based on the findings of this study, the report provides actionable recommendations on the delivery of education, social security, coordination within government departments and coordination between government and CSOs in the disability space.

As mentioned above, recommendations include immediate responses to the challenge incurred due to the COVID-19 pandemic, and suggestions for addressing socio-economic vulnerabilities and inclusion in education in the long-term.

Recommendations are addressed primarily to the Ministries of Education (centre and state) and Ministries of Social Justice and Empowerment (MSJE) (centre and state), including disability commissioners, health, and social welfare departments (Nisha V, et al, 2020).

Education provisioning and greater inclusion for children with intellectual disability

1. **Identify needs of children with intellectual disability that require face-to-face interaction, and what can continue remotely, without compromising quality**

In consultation with parents, children with intellectual disabilities might be provided access to special schools and rehabilitation centres. However, children with chronic illness, low immunity, (possibly at higher risk of contracting the virus, and suffering more severely from it) and children below 5 years should not return to schools yet.

2. **Bring children with intellectual disability back to schools to ensure continued education and rehabilitation (where required)**.

Identify and track children at high risk of dropping-out, or who have discontinued education during the pandemic, and reopen hostels/ residential schools for older children with intellectual disability, following COVID-19 protocol**.** Further, prioritise transportation needs of children with restricted mobility due to disability, ensure schools have appropriate TLM

that is accessible to children with visual, hearing impairments, and install appropriate infrastructure to facilitate physical access for children with intellectual disability.

3. **Making digital modes of education inclusive and accessible**

These include using multiple modes of communication to be more inclusive, interactive and efficient, enabling two-way interaction between students and teachers, through home visits, follow-ups on calls or messaging applications, employing sign language interpreters, using pre-recorded videos or television lessons, and assessing the possibility of providing devices/ internet to vulnerable households where possible, among others.

4. **Address needs of children with intellectual disability more holistically, regardless of modes of instruction**

These include opening up vacancies for special educators in mainstream schools and as resource persons in underserved regions, reorienting pedagogical practices towards teaching children at their level rather than syllabus completion, and encouraging a holistic approach to a child's education, including mental socio-emotional, psychological well-being.

4. **Integrated Support Networks**

Establishing strong support networks that include educators, therapists, and community organizations to offer comprehensive support to families.

5. Mental Health Resources

Increasing the availability of mental health resources for both children and parents to address the psychological impact of crises.

Minimise disruptions in access to health, nutrition, other support schemes, and early intervention

Strengthen the following systems to support low-income households – these include ensuring access to medical care for CWDs, especially providing transport facilities for those with restricted mobility or in remote areas, creating a repository of commonly used, and essential medicines by children with chronic illnesses, and ensuring their local stock availability, improving service delivery by systemising coordination between government and CSOs as well as by developing a common application process for schemes with similar eligibility criteria.

9. Conclusion

The role of parents in educating children with intellectual disabilities during the COVID-19 pandemic in India has been pivotal. The COVID-19 pandemic has posed significant challenges to the education of children with intellectual disabilities in India, but it has also

underscored the resilience and adaptability of parents. Despite facing significant challenges, parents demonstrated resilience and adaptability, utilizing various strategies to support their children's education and well-being. By employing innovative strategies, leveraging community support, and utilizing available resources, parents have played a crucial role in ensuring the continuity of their children's education. This period has highlighted the importance of parental involvement and the need for robust support systems to ensure that children with ID continue to receive the education and care they need, even in times of crisis. Moving forward, it is essential to address the digital divide, provide specialized training for parents, and develop tailored educational resources to support the education of children with intellectual disabilities in any future crises. Future efforts must focus on addressing the gaps identified during the pandemic and strengthening the infrastructure to better support these children and their families.

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