



Theme : Disability and Covid-19 Pandemic: Challenges, Initiatives and Interventions

TISS JOURNAL OF DISABILITY STUDIES AND RESEARCH

Inaugural Issue • Half Yearly Journal

VOLUME-I • ISSUE-I • JUNE 2021

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Tata Institute
of
Social Sciences

Theme : Disability and Covid-19 Pandemic: Challenges, Initiatives and Interventions

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16th August, 2021

FOREWORD

I am delighted to know that "TISS Journal of Disability Studies and Research"(TJDSR) is being launched by the Centre for Disability Studies and Action, Tata Institute of Social Sciences, Mumbai. I congratulate the Institute and Dr. Vaishali Kolhe of the Centre for taking this academic initiative which will benefit the persons with disabilities in the country. As TISS is the first centre in India to start a course on two year Masters programme in Disability Studies and Action in Social Work, the Journal coming out from this Centre is an encouraging step for disability research.

TJDSR is expected to be peer reviewed of an international and multidisciplinary nature. The period of publication is half yearly (June, December). It will provide a fresh perspective across research, critically reflect, review the problems and perspectives on emerging issues faced by persons with disabilities with a quest for achieving an equitable society.

It's first issue of June 2021 has a central theme of 'Disability and Covid-19 Pandemic: Challenges, Initiatives and Interventions'. The Journal has called for manuscripts reporting original research, case comments, book reviews, empirical studies, educational innovations, disability social work practices and action work.

I understand that the Journal will deal holistically with issues of disability and inclusion with multidisciplinary lens to create an academic space and foundation in the subject of Disability Studies. This is a flagship project of the Centre which aims to establish an unique platform of multi-faceted discourse on disability in all forms, including epistemological research, evidence based practice, scientific analysis of people centered sustainable development, promote grassroot level work, provide voice to people with disabilities and promote rights based approach with UNCRPD framework in the academic spaces and disciplines.

I wish "TISS Journal of Disability Studies and Research" all success and I sincerely hope that it will contribute consistently to the body of knowledge in disability studies.

(K.V.S. Rao)

रामदास आठवले
RAMDAS ATHAWALE



सामाजिक न्याय और अधिकारिता राज्य मंत्री
भारत सरकार

MINISTER OF STATE FOR
SOCIAL JUSTICE & EMPOWERMENT
GOVERNMENT OF INDIA

Date : 14/02/2021

MESSAGE

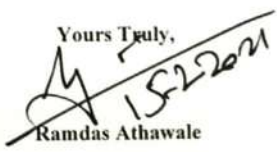
The total population of Persons with Disabilities in India is about 2.68 Crores as per census of India which is 2.21% of the total population. In the context of United Nations Convention for Rights of Persons with Disability (UNCRPD) which India is signatory and hence the laws and policies are required to be harmonised as per UNCRPD framework. The higher education laws and policies are also one of them which require strengthening and amendments as per RPWD Act 2016.

The centre for Disability Studies and Action, Tata Institute of Social Sciences has introduced the journal of its kind "TISS Journal of Disability Studies and Research". The journal determines to enrich the knowledge in the field of disability studies with multi-disciplinary approach. The editorial board comprises of distinguished scholars of Law, Social Sciences, Rehabilitation Sciences, Social Work and Research Methodology alongwith established practitioners aims to establish knowledge building process in the field of disability studies.

I congratulate the editor of the Journal from The Centre for Disability Studies and Actions, Tata Institute of Social Sciences to initiate this journal towards the dialogue among all disciplines on the subject of disability & inclusion. I also congratulate the Institute to start such pioneering work in the field of disability studies as significant contribution to the development of persons with disability in the country.

Thank you !

Yours Truly,


Ramdas Athawale



National Law University Odisha

(established by Odisha Act IV of 2008)

Accredited with grade 'A' by NAAC



Prof. (Dr.) Yogesh Pratap Singh
Vice-Chancellor(I/c)

Date: 03.03.2021

Note

On

TISS Journal for Disability Studies and Research (TJDSR)

The world Summit for Social Development, established the concept of social integration to create an inclusive society, "a society for all" as one of the key goals of social development. Following this, significant policy commitments were made in the Millennium Declaration (2000) which subsumes social integration in its synthesis of peace, security, development and human rights and further embodies social inclusion principles as well as the objectives and goals set out by international communities in previous UN Conferences. However, there can be no better illustration of the impassivity and inconsiderateness entrenched in the laws and policies than the fact that in a country that has the world's largest disabled population, the government had failed to institutionalize a vigorous process for efficiently recording the disabled population in the country. The generous interpretation given by the Supreme Court to the disability rights discourse not only demonstrated a progressive approach but also led to the enactment of a new legislation. New law "The Rights of Persons with Disabilities Act, 2016" intends to confirm India's international commitment towards United Nations Convention on Rights of People with Disabilities (UNCRPD). More rights have been conferred on the disabled persons and more categories have been added. In addition, access to justice, free education, role of local authorities, National fund and the State fund for persons with disabilities have been created. The 2016 Act outstandingly makes a paradigm shift in the perception and requires a march forward look with regard to the persons with disabilities and the role of the States, local authorities, educational institutions and the companies.

However, despite a robust disability legislation envisioned to increase the social and political participation of people with disabilities, there continues to be significant barriers in accessing all aspects of the policymaking process. Studies in United States recognizes the significance of direct participation of people with disabilities in all policy debates, and civic engagement. For people with disabilities, civic engagement can help to create self-efficacy, promote social integration, and develop personal interests. Research, publication, advocacy and technology are other critical tactics used by the disability community to advance the rights of people with disabilities. Further understanding of how these tactics and tools empower people with disabilities to connect with government is required. The Centre for Disability Studies and Action, Tata Institute of Social Sciences (TISS) and its peer reviewed Journal for Disability Studies and Research (TJDSR) is an attempt to provide a fresh perspective towards research, critical understanding and review of the problems, perspectives on emerging issues of the persons with disabilities and quest for developing an equitable society. The Journal epitomizes the full range of methods, epistemologies, perspectives, and content that the multidisciplinary field of disability studies embraces. It is committed to developing theoretical and evidence based practical knowledge about disability discourse and to promoting the full and equal participation of persons with disabilities in society.


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From

TISS Ex Director's Desk...



The Right of Persons with Disabilities Bill, 2014, passed by both the houses of Parliament in December 2016 complies with the UN Convention on Rights of Persons with Disabilities, increases the number of recognised disabilities from 7 to 21, including disability due to acid attacks, Thalassemia, Haemophilia, Muscular Dystrophy, Learning Disabilities and Parkinson's. According to the 2011 Census, the number of disabled in India stood at 26.8 million. With the passing of the Bill, the official count of disabled in India is set to rise and going by conservative estimates, the figure could be between 70-100 million.

Historically, the three big disability groups – the orthopedically disabled, the blind, and the deaf - have gained from the various entitlements. Crucially, the Bill provides for access of public buildings for the disabled, sorely needed in a country with an infamously inaccessible built environment. It sets the government a two-year deadline to ensure persons with disability get barrier-free access in physical infrastructure and transport systems. Additionally, it will hold the private sector accountable for creating an accessible environment. This includes educational institutions funded and recognised by the government such as privately owned engineering and management colleges. One of the path-breaking features of the Bill is raising the reservation in government jobs for the disabled from 3% to 4%. It also has a clause against places of employment discriminating against

people with disabilities. The Bill provides for imprisonment up to two years, along with a fine ranging between Rs 10,000 and Rs 5 lakh for those discriminating against the differently-abled. Special Courts that will look at the issues affecting the physically challenged, feature among the other proposals.

Social protection plays a key role in realizing the rights of persons with disabilities of all ages: providing them with an adequate standard of living, a basic level of income security; thus reducing levels of poverty and vulnerability. Moreover, mainstream and/or specific social protection schemes concerning persons with disabilities can have a major role in promoting their independence and inclusion by meeting their specific needs and supporting their social participation in a non-discriminatory manner. These social protection measures may include poverty reduction schemes, cash transfer programmes, social and health insurance, public work programmes, housing programmes, disability pensions and mobility grants.

It is in this context, the efforts of the Center for Disability Studies and Action of the School of Social Work to bring out a multidisciplinary 'Journal of Disability Studies and Policy Research' is a desirable move. The Journal aims at bring out emerging advances in research and action by analysing laws, policies, programs, interventions and lived experiences of persons with disability to provide evidence to create better condition for the people. This journal aims to add to the knowledge base on the PWD in order to bring together research output on how the new policy is being translated into action. It aims to set an avenue to other universities to initiate Disability Studies and policy action programs with an interdisciplinary perspective.

State and non-State organisations are engaged in providing quality services and support to persons with disability. Intervention

work is being carried out at the individual household and community level with facilitation by both government and non-government organizations. Most organisations are working on inclusive practices. However not all good efforts and new ways of addressing vulnerabilities are documented and disseminated. There is a need to develop these experiments into serious academic writings. There is need to facilitate this multi layered field practices documented in a systematic and scientific manner.

I hope this journal shall provide space to articulation the voices of persons with disabilities in their dynamic efforts leading to their independent living, full participation, and attainment of just and dignified life.

The faculty and students of the Centre for Disability Studies and Action are an amazingly talented and committed group continually aiming to educate, sensitise normal people and create new ways of addressing the problems faced by the PWDs. I fully support the efforts of this centre and wish the efforts placed by practitioners, legal experts, administrators and communities will contribute to empower persons with disability in improving their quality of life.

The Institute shall support this effort and produce quality publication at defined interval.

TISS, Ex. Director, Prof. S. Parasuraman

Editorial

The Centre for Disability Studies and Action, Tata Institute of Social Sciences is proud to introduce to you 'TISS Journal of Disability Studies and Research'. It is a Half yearly Journal (June & December). The June issue is focused on the central theme of *'Disability and Covid-19 Pandemic: Challenges, Initiatives and Interventions'*. The journey of the Journal started with the collaboration with National Law University, Odisha to develop academic knowledge in the field of disability sector. Hence, we are grateful to NLUO. TISS Journal of Disability Studies and Research has invited research papers, manuscripts reporting - original research, case comments, book reviews, empirical studies, grassroots level studies, development sector interventions, evidence based studies, educational innovations in relation to persons with disability, disability studies, social policies and law. The journal has been conceptualized to promote multidisciplinary lens to study the issues surrounding the persons with disabilities. It strives to create an interface between persons with disabilities issues and various academic disciplines such as law, social work, computer science technology, artificial intelligence, architecture, social sciences, and rehabilitation sciences to develop dialogues among disciplines to interrogate, create knowledge in the field of disability. The purpose is to develop holistic framework and critical enquiry into the epistemological questions around the lives of persons with disabilities. The Journal determines

to enrich the knowledge with scientific enquiry into problems of persons with disabilities through case study, qualitative and quantitative studies, case analysis and empirical research in the field of disability to broaden the scope of work in disability studies. The editorial board comprises the distinguished legal scholars, field based practioners, professionals from National Institutes of Disability, Psychiatric social work professionals and academicians to work on theme of disability. The editorial board is governed by independent quality control with the help of distinguished scholars, academicians and disability rehabilitation practitioners aiming to contribute to the disability studies. The June Issue, consist of nine Scholarly Articles which has been double blind peer reviewed articles with the central theme of ***'Disability and Covid-19 Pandemic: Challenges, Initiatives and Interventions'***. The thematic area aimed to understand the problems of persons with disabilities in Covid 19 scenario. The idea is to study the services, provisions of government, reviewing Supreme Court judgements, initiatives of NGOs sector to understand broader scope of interventions provided by institutions of significance for the persons with disability in pandemic situation in Indian context.

The four Sub themes of the central theme for the June 2021 Issue are as follows **1. COVID-19 Scenario and Disability, 2. Indian Judiciary, Laws and Disability 3. Inclusive Design and Accessibility 4. Disability, Poverty and Access to Resources.**

Sub-Theme 1. "COVID-19 Scenario and Disability" constitutes the following 3 articles. It also factors the persons with disabilities in Covid-19 senario to their access to basic needs, access to resources, vaccination facilities. It also looks at initiatives taken by various stakeholders for persons with disabilities to make their life better in the pandemic.

Article 1 Exploring the Barriers faced by People with Disabilities in Vaccination Drive amidst COVID-19 in Rural North 24 Parganas District: Care providers' Perspective

Authored by Deepshikha K Mishra, Master in Public health- Health Administration at School of Health System Studies, Tata Institute of Social Sciences, Mumbai, India, Dr. Paayal Bose, Master in Public health- Health Administration at School of Health System Studies, Tata Institute of Social Sciences, Mumbai, India. The study is an exploratory, descriptive approach and qualitative study. The study is based on health care providers incorporating Braun and Clarke's thematic analysis. Study findings suggests that the policy makers and health administrators mitigate the barriers for PWDs in vaccination drives. The study provides multiple insights towards making vaccination strategies inclusive for the entire population in India and other low middle income countries with special reference to persons with disability.

Article 2. Challenges in Accessing Healthcare for People with Disabilities during COVID-19: An Exploratory Study in West Bengal.

Authored by Mr. Smarak Prasanna Roy, Masters in Public Health (Health Administration) and Sayani Mandal, Masters in Public Health (Health Administration) Tata Institute of Social Sciences, Mumbai. The study is an exploratory qualitative design highlighting problems that the persons with disability faced ranges from the multiple vulnerability, unavailability of services, lack of transport, information gap, financial burden, fear of Covid-19, non-cooperation from society to affordability which is considered as a major barrier in treatments of Covid 19.

Article 3. Challenges and Implementation of Innovative Initiatives during COVID-19 for the Welfare of Children and Adolescents with Disabilities

Authored by Vinnarasi

Geetha Ernest¹ DGM (Rehabilitation) & Correspondent, School for Children with Speech & Hearing Challenges WORTH Trust, Katpadi Vellore District, Tamil Nadu and Aravendan Muthusamy¹ Professor-Design, Department of Leather Design, National Institute of Fashion Technology NIFT Campus, Taramani, Chennai Tamil Nadu. A case study approach is adopted to implement the initiatives in the Rehabilitation division of Worth Trust organization in the Vellore district of Tamil Nadu. The proposed initiatives are implemented and recorded with the feedback of the beneficiaries and stakeholders as the research outcome and deliverables as keeping the voices of people with disability to strengthen implementation of services in Covid 19

Sub Theme 2:- Indian Judiciary, Laws and Disability, It constitute one major article by eminent Professor Prof. Krishan Mahajan highlighting critical analysis of key judgements in relation to SC/ST and entitlements of PwD. The Hon. Supreme Court's landmark judgments are critically analysed that its meant to protect the human dignity of the persons with disability.

Article 4. SC's Comparative Suffering Approach: Division & Illusion Authored by *Dr. Krishan Mahajan (*Advocate Supreme Court of India; former Additional Registrar (Research) Supreme Court of India, former Dean and Professor NLUO Odisha. Dr. Krishan Mahajan is renowned professor worked at Centre for Research & Planning, Supreme Court of India, former Union Government Counsel at Supreme Court. The paper is critical analysis of the three judgments shows that the Supreme Court's approach involves more potential suffering for the disabled. The disability laws and inquires into judicial knowledge & highlights- the aspects of disability, This Article analyses the disability laws and government schemes to show how effective measures are lacking in the system despite the UN

Convention on the Rights of the Disabled, to which India is signatory and ratified to harmonise the laws.

Sub Theme 3. Inclusive Design and Accessibility highlights the factors affecting the learning loss during online education in the Covid 19 scenario and critical analysis of inclusion of children with disability in education system through a scientific review.

Article 5. Inclusive Education and Children with Disabilities in the Indian Landscape: A Review authored by Sumaira Khan, Perna Patra, Mansi Gohil*, Aishwarya Bhojkar* Tata Institute of Social Sciences, Mumbai, . The paper critically reviewed the online learning mode due to the COVID-19 pandemic and analysed bringing universal design perspective to disability action and inclusive education. The paper provides the scope for inquiry by special educators, disability rights activists, and rehabilitation policymakers for broadening discourse on Universal Design and inclusive education in India to harmonise the education in coherence with UNCRPD in context of Covid 19

Article 6 Beyond The Barriers Of Disability: Is Inclusion A Viable Alternative? Authored by **Dr. Amit Gautam** Assistant Professor *Dayalbagh Educational Institute, Dayalbagh, Agra, India.* **Anshula Dua**, *Junior Research Fellow, Dayalbagh Educational Institute*, The study is based on the secondary data and review of literature. The search strategy to study the content from various government official websites and organizations with content analysis. The result indicates that inclusion can work as a viable alternative if appropriate measures are facilitated by schools, teachers, society and government and all stakeholders to create an inclusive society.

Article 7. Factors Affecting Learning Loss due to COVID-19 for Students with Disabilities in India: A Secondary Data Analysis authored by Architect Navjit Gaurav; PhD Scholar at the School of Rehabilitation Therapy, Queen's University, Kingston, Canada. This study explores the factors affecting learning loss due to COVID-19 for SWDs in India. Secondary data analysis of various government reports provide the key findings that inform the educational institutions and practitioners on the relevance of providing equal access and strengthening the online learning platforms for SWDs in covid 19 pandemic in order to take steps towards equal accessibility in online learning platforms.

Sub Theme 4- Disability, Poverty and Access to Resources. The theme aims to understand disability and poverty as multidimensional phenomena and interrelated to each other and require immediate remedial measures for sustainable development of persons with disability.

Article 8. Non-Accessibility of Resources and Treatment Facilities for the People with Disabilities in Rural and Semi-Urban Areas and the Remedial Measures authored by Ms Sumathi Aravendan¹ from Unit Head, Worth Trust (Digitization Division), Selaiyur, Chennai- Tamil Nadu and NIFT Professor of Design, Prof. Aravendan Muthusamy² Department of Leather Design, National Institute of Fashion Technology, Taramani, Chennai. The study focuses on the issues and problems of the persons with disabilities in the rural and semi-urban areas and their core issues about the non-availability and non-accessibility of the resources and treatment facilities. The descriptive research with a detailed literature study is adapted. Then, the researchers applied the Survey and Case study research methods using the appropriate statistical tools to

recommend inclusive solutions and remedial measures in Covid 19 scenario.

Article 9. Experiences of Defence Servicemen with Spinal Cord Injuries serving in Indian Armed Forces: A Qualitative Study authored by **Shubhankar Apte** MPhil Scholar, School of Social Work, TISS, Mumbai, **Ragamala R Datta**, MPhil Scholar, School of Social Work, TISS Mumbai **and Shadma Ahmed** MPhil Scholar, School of Social Work, TISS, Mumbai. The study was based on a qualitative narrative design. The study highlights the existence of gaps in the services envisioned post completion of rehabilitation in tandem to the awareness related to those services among the defence servicemen. Further, it informs the policy makers and shares the scope of social work practice in context of defence services while including disability as a dynamic human phenomenon.

Vaishali Kolhe

TISS Journal of Disability Studies and Research

ISSN Number awaited

TISS Journal of Disability Studies and Research attempts to work on serious engagement of faculty, students, practitioners on scientific enquiry & critical questions about lives of Person with Disabilities. The aim is to initiate the knowledge building process through rigorous multidisciplinary enquiry towards encouraging them to develop knowledge on disability studies and action research. The Journal attempts to develop multidisciplinary subject knowledge to add to the body of existing knowledge. The Journal invites research papers, manuscripts, reporting of original research, case comments, ethnographic studies, book reviews, empirical studies, scientific innovations, disability studies, social work through needs assessment, survey analysis or action work related to disability. The social science, humanities, any discipline highlighting academic research on disability issues to create scientific knowledge, scientific engagement contributing to disability studies, research into social policies and law, special education. Selected papers will be published in the issue.

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TISS Journal of Disability Studies and Research is a Journal of multidisciplinary nature. It aims to transcend beyond the traditional boundaries of academic disciplines such as Social Work, Sociology, Psychology, Anthropology, law, Technology, Engineering, Media, Medical Sciences, Rehabilitation Sciences, Social sciences to facilitate and develop disability related knowledge, research and innovative practices from the multidisciplinary perspectives. It is peer reviewed/ referred journal of interest to Disability studies professionals, social workers, physiotherapists, occupational therapists, speech and hearing professionals, sociologists, special educators, teachers, legal experts, academia, psychologists, human rights professionals, health care experts, scholars in any discipline working in the disability sector, to contribute to the field of disability studies. This Journal attempts to address the contemporary and critical issues of persons with disability across the life span and epistemological questions. The social model conceptualises the social construction of disability, marginalisation, intersectionality. The Medical Model constitutes early intervention, therapeutic rehabilitation for mainstreaming disability for independent living with dignity. The Journal promotes indigenous work, evidence based practice, field based research, people centred work at grassroots that require scientific enquiry to develop disability studies with bottom up approach. Essentially to understand voices of persons with disability to contribute to the sector and identification of research gaps important for policy makers. Broader aspects are mainstreaming disability in education, livelihood, and work, family, community are important towards strengthening their sustainable development. The journal deals holistically with issue of disability studies and inclusion with

multidisciplinary lens to create an academic space in disciplines on the subject of disability to develop academic rigour and foundation of Disability Studies.

This is a flagship project of the Centre for Disability Studies and Action, TISS. Through this journal, TISS aims to establish a unique platform of multi-faceted discourse on disability in all forms, including epistemological research, evidence based practice, scientific analysis of people centered sustainable development, promote grass root level work, provide voices to people with disabilities and promote rights based approach with UNCRPD framework in the academic spaces and disciplines.

Aim To establish dialogue on multidisciplinary issues of disability and inclusion with an aim to create an evidence based knowledge and innovative practice to strengthen the field of disability studies and promote principles of the UNCRPD framework.

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Exploring the Barriers faced by People with Disabilities in Vaccination Drive amidst COVID-19 in Rural North 24 Parganas District: Care providers' Perspective

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Declaration by Authors :

The article submitted is original and belongs to the authors, and has not been published elsewhere. Both the authors are joint first authors of this work.

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Abstract

Through its world's largest vaccination drive (WHO, 2020; UNICEF, 2020), India has planned to immunize 1.38 billion population in a prioritized and phased manner. While the policymakers have acknowledged the risk of exposure among healthcare and front line workers in their vaccination priority list, people with Disabilities and their vulnerabilities have not

received their due considerations. Moreover, several physicals, infrastructural, social, and administrative barriers exist that further restrict the inclusion of People with Disabilities in vaccination programs. This study explores the Barriers for People with Disabilities in the vaccination program in the North 24 Parganas district of West Bengal. We used a qualitative study using semi-structured interviews. We adopted purposive and snowball sampling strategies to conduct telephone interviews of health care providers. The Braun and Clarke's thematic analysis framework informed our data analysis process. Following key themes emerged: prioritization and inclusion; attitudes and stigma associated with vaccination; issues of accessibility; and inadequate administrative support. Our findings add to the evidence base regarding the barriers experienced by persons with disabilities in accessing the COVID-19 vaccines. Furthermore, it provides opportunities for policymakers and health administrators to develop effective strategies to address the barriers and create an inclusive environment to increase the accessibility of the vaccination drive. Findings offer insights into making vaccination strategies inclusive for the entire population in India and other low-income countries.

Keywords: COVID-19, barriers, vaccination prioritization, disability, care providers, inclusion, qualitative study, EDQ approach, India.

Introduction

The World Health Organization (WHO) declared COVID-19 a pandemic due to the speed and scale of transmission. Pandemic had a substantial implications on health (more than 4 million worldwide and counting), socio and economic disruption are devastating: tens of millions of people are at risk of falling into extreme poverty (ILO, 2020), 6.7 million people are an addition

to 690 million already-existing malnourished population due to COVID-19 (UNICEF, 2020), and nearly half of the world's 3.3 billion global workforce are at a brink of losing their livelihoods (ILO, 2020). The WHO Declaration (2020) called for global action and a quick emergency response mechanism. Nations were urged to take necessary preventive and curative measures like social distancing, wearing face masks in public, ventilation and air-filtering, hand washing, disinfecting surfaces, and monitoring and self-isolation for people exposed or symptomatic to contain the spread of Coronavirus. Accordingly, the Indian government has taken urgent measures to expand the country's vaccine manufacturing capacity and launched the world's largest (WHO, 2021a) free vaccination drive on January 16, 2021, against COVID-19. As of June 1, while targeting a total population of 1.38 billion, 216 million people have been vaccinated. It has frontline workers, 270 million older adults aged over 50 years and people with comorbidities. COVID-19 has implications the population disproportionately, and while prioritizing the most vulnerable population, persons with disabilities have been left behind in consideration by policymakers.

Indian vaccination drive and people with disabilities

Disabled people are at greater risk of morbidity and mortality if they contract the virus, yet they are in danger of being deprioritized for care (Dave, 2021; Pandit, 2021; Williamson et al., 2021). People with disabilities already have underlying health conditions that require constant support and supervision even amidst the pandemic (Dave, 2021). The Indian authorities are organizing a special drive-through vaccination camp for people with disabilities to address low vaccination rates (Dave, 2021). These include people with disabilities and people sleeping on the streets, homeless, and deprived of society. For example, Organizers of the weekend campaign in Ahmedabad, the biggest

city in Gujarat state, aimed to vaccinate 500 disabled people, who often struggle to book slots and get access to vaccination centres (Dave, 2021).

Moreover, having the campaign to support people with disabilities to access vaccination is not serving the purpose. People with disabilities often face additional problems reaching vaccination sites due to a lack of transport or no ramps at the centres for easy access. Some people with disabilities have struggled to use a government-mandated smartphone app required to register for shots.

The Indian government has taken steps to mitigate these challenges by taking actionable measures like ‘near to home’ vaccination centres for the elderly and people with disabilities. The department of empowerment of people with disabilities (DEPwD) has sought prioritization and special provision for addressing the medical needs of people with disabilities (Pandit, 2021). This is in sync with the provision of the Rights of Persons with Disabilities Act 2016, which mandate “priority in attendance and treatment for people with disabilities” (RPWD ACT, 2016, article 25C). The government allowed registration for vaccination using the unique disability ID to ease out the process; the data highlights that as of June 7, 2021, the number of people with a disability holding a UDID card is 55.82 lakhs (Pandit, 2021) out of a total of 2.62 crores (Census of India, 2011). As per the 2011 Census, about 26.8 million people are ‘disabled’ in India, 2.21% of the total population. While West Bengal has 2.1 million of the total disabled population, 0.21 million live alone in the 24 North Pargana District.

Literature Review

As per the central policy, the Ministry of Health and family welfare (MoHFW) had declared vaccine administration to citizens above

60 years and those above 45 years with comorbidities (PTI, 2021). As per the MoHFW list of 20 comorbidities prioritized during vaccination, enlisted conditions like intellectual disabilities/ muscular dystrophy/ acid attack with respiratory system/ persons with disabilities having high support needs/ multiple disabilities including deaf-blindness (Rahman, 2021). Although coverage of some disabilities in phase-2 of the vaccination drive is welcomed from the inclusion point of view, it is still not enough. In the list of comorbidities, severe mental illnesses were missed. One of the fundamental flaws in the vaccination policy of India is disability being addressed as comorbidity instead of being called a high-risk group in the vaccine priority list.

A review of newspaper articles showed the MoHFW (Ministry of Health and Family Welfare) received requests from persons with disabilities, Disability Rights Alliance (DRA) and other disability rights groups to scrape off age bars for the disabled and include all categories of disabilities (Rahman, 2021). Time and again, the Indian judiciary had to intervene to ensure priority was given to persons with disabilities (“HC notice to Centre”, 2021). Tamil Nadu (“COVID-19 vaccination”, 2021) and Goa (“Vaccination for disabled”, 2021) came forth with vaccination centres specifically for persons with disabilities following notices from the State Commissioner for Persons with Disabilities (person with disabilities). In West Bengal, the metropolitan city of Kolkata had separate vaccination sites set up for persons with disabilities. MoHFW published guidelines for vaccines near homes for the elderly and persons with disabilities after almost four months of starting the vaccination drive (“Elderly and disabled”, 2021), but the implementation is taking considerable time.

Problem statement

People with disabilities face challenges in everyday life, but these challenges should not include access to life-saving services in the COVID-19 pandemic. There should be consideration given to the vulnerabilities, risks, and needs of persons with disabilities, who may have a greater risk of being hit by a pandemic in light of underlying societal, geopolitical, and biomedical factors (Dave, 2021). However, there is a dearth of information regarding access to such health care provisions by people with disabilities during vaccination drives. Often there lies a gap between the provisions, services delivery and access to those services by the people with disabilities. It would be insightful to understand the challenges in the service delivery through the working experiences of the care provider as this would offer a nuanced understanding about the provision to be made in service delivery for people with disabilities to make the vaccination drive further accessible.

Methodology

Research Design

This study involved an exploratory, descriptive qualitative (EDQ) method. EDQ has been identified as a suitable design to study areas within healthcare practice that have previously received little or no attention (Stebbin, 2001). Exploratory nature allows for understanding, rather than simply observing and recording the phenomenon in healthcare (Sehularo, Du Plessis and Scrooby 2012). The EDQ's descriptive nature allowed flexibility (Hunter, McCallum and Howes, 2019) to document and describe the phenomenon (Rossman and Rallis, 2016), for instance, the barriers faced by persons with disabilities in the vaccination process. The description of the phenomenon

provided a detailed account of its significance and described it from health care providers' perspectives (Holloway and Wheeler, 2010). This design is also appropriate as it allowed us to situate (Issacs, Duma and Mayers, 2013) our study in the context of 24 North Parganas.

Sample

The sample frame of this study included healthcare personnel in a rural setup, including CHO, ANM, BPHN, MO, Staff Nurse and health care activists, i.e. ASHA workers. Purposive (Tongco, 2007) and snowball sampling strategies (Etikan, Alkassim, & Abubakkar, 2015) were used to recruit participants. Purposive sampling was the most appropriate strategy for descriptive qualitative study and allowed the researcher to capture and describe the phenomena over various situations (Sandelowski, 2004). The snowball sampling technique helped maximize recruitment variation of similar participants from various sub-centres (Stebbin, 2001). Hindi speaking health care providers actively engaged in ongoing vaccination drives were included in the study.

Additionally, the participants must have at least 3-4 persons with disabilities in their service area. EDQ gives flexibility concerning sample size. Moreover, our sample selection was purposely based on the information power (Malterud, Siersma, & Guassora, 2016). Considering the study aim, sample specificity, theoretical background, quality of dialogue, and strategy for analysis determined whether sufficient information power will be obtained with fewer or more participants included in the sample. Being experts in their domain care providers, we interviewed 10 participants who could justify rationale with the potential to fulfil a specific function concerning the study aims (Cleary, Horsfall, & Hayter, 2014).

Data Collection

Field visits were conducted to build rapport with the participants prior to telephone interviews (Novick, 2008). Before the visits, a written permission letter to visit health facilities in North 24 Pargana district was sought from the Chief Medical Officer of the district health department. During visits, verbal permission to interview the caregivers, observation, and field notes of the facility was taken from the respective supervisors or the concerned authorities. Six COVID-19 vaccination sites functioning under the rural public healthcare delivery system were visited on six different days in the month. Observations were made with the help of an Observation checklist (Garousi et al., 2020) to conduct observations in a structured manner, important for novice researchers. The checklist included the process of vaccine registration for persons with disabilities, available infrastructure, care providers' activities and the services provisions for 4-6 hours each day. A list of codes and abbreviations were made based on the most commonly observed activities related to the study objectives. The observations were regularly transcribed and discussed among the researchers before moving to the following observation site. This process ensured the richness of the data collected. Comprehensive field notes were maintained, which helped conceptualize the study further and helped in the later phases of data analysis (Phillippi and Lauderdale 2017). Researchers jointly conducted a 30-40 minutes long, semi-structured telephone interview with the help of an Interview guide (Evans, 2017). A semi-structured interview ensured flexibility to the participants' responses (Leech 2002). The participants have given a short description of the study purpose (Leech 2002) at the beginning of the interview. We scheduled the interview at the participant's preferred time, as we hoped that this would reduce the potential researcher-participant

power imbalance (Parnis, Du Mont, & Gombay, 2005). Data were collected over 15 days. An interview guide (Table 1) with 20 open-ended questions was prepared after reviewing relevant literature and considering the observations and field notes. A pilot test was conducted for refining the questions to improve the quality of the data collected (Davies, 2014). Telephone interviews allowed participants to answer the questions freely and relaxed (Mitchell & Chaboyer 2010), considering their safety during a pandemic.

Table 1

Some of the critical questions of the Interview guide.

Questions
Could you tell me about the PWDs being served by your centre?
Could you tell about the level of support they get from their family and community?
Could you tell me about an experience of you working with any PWD?
What is the process of informing the PWDs about the COVID vaccination drive at your centre?
Suppose I am a PWD; how would I register for the COVID vaccination?

Data Analysis

Interviews were audio-recorded with participants’ consent and transcribed verbatim (Zhu, Duncan & Tucker, 2019) in the original language (Hindi) to avoid meaning loss, and the participation was voluntary. We employed reflective thematic analysis by Braun and Clarke (2014) was used. The authors were reflective and critical about each step during the data collection,

any decision made. The exploratory aspect of EDQ is concerned with discovering generalizations (Stebbins, 2001), and thematic analysis helps identify the core of the participant's experience (Holloway & Wheeler, 2001). Initially, both the researchers (re) read the transcripts several times to fully understand the data. Then, an initial list of codes was identified by both the researchers after going through each other's codes. This peer debriefing process helped researchers achieve reliability and ensured the richness of the data (Admiraal et al., 2011). The codes were compared for similarities and differences to identify ambiguities and overlaps. This step facilitated the identification of persistent similarities and differences within and across the codes. The codes were collated into themes at a broad level that exhibited the latent content in the context. Observations and field notes were referred to refine the themes by both the researchers. Quotes from the participants were used to substantiate the findings. Confidentiality was maintained by providing each participant with a pseudonym and participant number (Smith, 2005). As the quotes originally were in Hindi, they were translated into English and sent to bilingual researchers to ensure that the translation retained the actual meaning of the quotes (Chen & Boore, 2010). As this was a reflective analysis process, the authors ensured trustworthiness using peer-debriefing (Hadi & Closs, 2016) and maintaining audit trail (Carcary, 2009) of the entire process from collection to analysis.

Key Findings

Participants' characteristics

There were ten participants overall, as shown in Table 2, 1 BPHN and 1 SN from the highest level of the 3-tier rural health care system; 1 MO and 1 SN from the 2nd level and 6 participants from the lowest level of hierarchy for the study. The average age

of the participants was 46 years. 9 out of 10 participants were women.

Table 2

Characteristics of the study participants

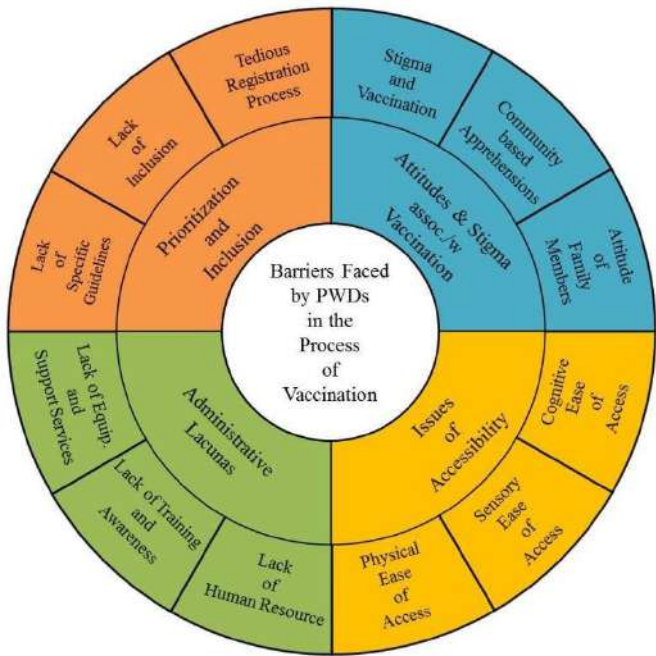
Characteristics	Value
Number of participants, (n)	10
Average age in years (range)	46 (42-56)
Sex (%)	Female, (90%)
BPHN ^{a*} (n)	1
SN ^b (n)	2
MO ^{c*} (n)	1
CHO ^d (n)	2
ANM ^e (n)	2
ASHA ^f (n)	2

^aBlock public health nurse; ^bStaff Nurse; ^cMedical Officer;
^dCommunity Health officer; ^eAuxiliary nurse-midwife;
^fAccredited social health activist. *decision-making authority

Four key categories were extracted including, a) Prioritization and inclusion; b) Attitudes and stigma associated with vaccination; c) Issues of accessibility for persons with disabilities. And d) Inadequate administrative support. Based on these categories and subsequent subcategories (refer to diagram 1), researchers discussed the barriers faced by persons with disabilities in getting vaccination in the following paragraphs.

Diagram 1

Barriers faced by a person with disabilities in a vaccination program



The key barriers highlighted in the implications of the graphics overall access to vaccination for persons with disabilities. These barriers cumulatively implications the healthcare provisions and their access for persons with disabilities in the 3-tiers system.

Prioritization and Inclusion

Prioritization of vaccines in the first phase depended upon the disease incidence and prevailing pandemic situation. Higher risk groups were prioritized in order to include vulnerable populations. Through this study, researchers identified a lack of acknowledgement towards the vulnerabilities of persons with disabilities.

Lack of specific guideline

Most of our participants revealed that they were unaware of any specific provisions and guidelines for vaccinating persons with Disabilities. A Person with disabilities undergoes the same vaccination process as any other person regardless of inconvenience caused by their disability. In a rural setup, the care providers cooperate with persons with disabilities and make necessary adjustments as required.

“There is not any specific instruction for dealing with a person with disabilities, but there should be one. When a person with disabilities arrived, we arranged for a room on the ground floor with a fan. Later our ANM went downstairs to vaccinate him.” (CHO 2)

Lack of inclusion

The first phase of COVID-19 vaccination marked no considerations for persons with disabilities. While health care providers and front line workers (medics, paramedics, police, and local administration personnel) were prioritized due to the higher risk of exposure to novel coronavirus, vulnerabilities of persons with disabilities were overlooked. Although certain groups with disabilities were included under the umbrella term of “comorbidities” in the second phase, the explicit inclusion of people with disabilities in the vaccination priority list was absent at the implementation level.

“We did not receive any instructions for giving priority to the persons with disabilities, but they should be given priority. They already are suffering in one way. If they get affected by the virus, treating them will be a complicated issue.” (ANM 2)

While there is a dearth of vaccines all over the country and the government has announced a priority-based vaccination drive,

political interference further implications the availability of vaccines. The care providers seldom came across the requests made by the local political leaders to give preference to their candidates. The care providers were obliged to do so. This also affects the number of persons getting registered and being vaccinated.

“Now the list is coming from the BDO office. There are times when one political leader adds 2-3 names of his family members. Because of this, people who are not staying under my region are getting the vaccines, and I miss out on people from my village even if they are a person with disabilities and have travelled from far” (ANM 2)

Tedious registration process

The Indian government developed a digital system to administer all the aspects of vaccination. While in many districts across states, people are told to book a date and time slot on the COWIN app or Arogya Setu mobile application, some districts like 24 North Parganas are practising in-person on the spot registration. Issues with the registration process have caused several challenges related to accessibility. For instance, rural populations are not equipped with technological access, while people with disabilities still struggle with an accessible format. On the other hand, in-person registration has other challenges like a dearth of vaccines at the centres, remoteness of vaccination sites and non-availability of public transport facilities.

“There is no specific provision for vaccinating a person with disabilities. Sometimes they come to the centre and go back without getting the dose because there are no more vaccines left. This causes much inconvenience.” (ANM 1)

Attitudes and stigma associated with vaccination

The findings of this study highlighted confusion, anxiety and fear among the rural population regarding COVID-19 vaccination. Unfortunately, these factors have led to negative stereotypes in society, and as a result, there is vaccine hesitancy from specific population groups.

Stigma around vaccination

Most of the participants have witnessed low numbers of people with disabilities getting vaccinated. They assume the main reason is the stigma around vaccination prevalent among people with disabilities, their families, and certain ethnic groups. To avoid discriminatory behaviours against a COVID-19 positive patient, people do not disclose their test results. Also, the care providers found the vaccination sites to be unsafe for persons with disabilities and other populations. (AlShurman, 2021)

“Our vaccination duty involves many risks. We do not know who is infected. It is so risky to have a person with disabilities here. Their family members are afraid they might get infected if they bring them to the vaccine sites.” (CHO 1)

Another stigma is around the credibility of vaccines. There has not been enough knowledge dissemination about the side effects of vaccines, especially in rural areas. One issue may be that there is a lack of inclusive communication materials from the governments. There is a common belief that getting a vaccine will make them fall sick. Awareness of benefits is also essential. Participants would then be able to make informed decisions to take up vaccination by weighing the benefits against the risks. Families of persons with disabilities become apprehensive of getting their disabled family member(s) vaccinated as they are more vulnerable to infection.

“Earlier when the 60 years and above population was being vaccinated, some had fever after taking the vaccine. People believed that vaccines are making them sick, and now no one in the village is ready to take the vaccine.” (ASHA 1)

Community-based apprehensions

Participants highlighted that some communities, due to limited awareness, show resistance towards getting vaccinated. Various religious viewpoints like the sacredness of the body should not be contaminated by chemicals or blood/tissues from animals and should be healed by God, or natural means further induce distrust and suspicion towards vaccines. In such scenarios, persons with disabilities of these families are far from getting vaccinated compared to other persons with disabilities, and the health care providers try to avoid such sensitive matters.

“Some communities are not at all willing to get vaccinated. They say, ‘I am doing fine, I am healthy, why to get vaccinated and fall sick. We have our GOD above us. We will not get COVID.’ It is a sensitive matter. We cannot force them.” (ASHA 2)

An attitude of family members

People with disabilities often are not the decision-makers, and most are dependent on their family members. On the other hand, the family is either too protective and sceptical about the safety of vaccines or too ignorant towards people with disabilities to keep procrastinating from getting their vaccinations.

“There is a person who cannot speak. His entire family took the vaccine after my motivation. Nevertheless, the family believed that being a person with disabilities has more chances of falling ill. Now it is up to them, and I tried motivating them if they want they will get him vaccinated” (ANM 2)

Issues of accessibility for person with disabilities

Physical or visible disability alone does not expose a person with disabilities to a higher risk for getting COVID-19 infection. A disabling environment contributes equally to their vulnerabilities. When the environment is disabling, it curbs people with disabilities' participation opportunities like equal access to healthcare provisions, having agency over their choices, and travelling to and fro vaccination sites.

Physical ease of access

Infrastructural barriers like lack of space and lack of built environment support pose challenges for persons with disabilities with limited mobility or those who use wheelchairs, walkers and other aids to move around. Persons with visual impairment need a clear and smooth path to navigate. Most of the time, they had to rely on their family members to accompany them to vaccination sites and a mode of transportation as none of the sites were near their homes.

"There are people who are bedridden due to spinal cord injuries or other issues. Such individuals will not be able to go out for vaccination, let alone registration. The government should consider the possibility of vaccinating these people at home. With mobility issues, it is not easy to reach vaccination sites located in far-flung areas." (BPHN)

"We have limited space, and it is difficult to maintain distance during vaccination. Even when the person with disabilities is waiting in the queue, they cannot maintain distance." (ASHA 1)

Sensory ease of access

Some people with disabilities are sensitive to lights, sounds, smells, or touch involved in the vaccination process. Limiting the waiting time is critical. Moreover, special training should be

given to the person involved in vaccination services to be patient and sensitive towards the needs of persons with disabilities.

“I feel better than asking the person with disabilities to go to the vaccination centre to get the vaccine, and they should be visited house to house and be vaccinated. As it is not easy for them and family members to stand in queues or wait like the general population.” (SN 1)

Cognitive ease of access

Each person and their individual needs are different. The information must be provided in different formats and understandable language; a visual or a graphical storyboard can help to improve the understanding. People with disabilities should be given enough time to understand and process the information. Health care providers involved in vaccination need to be patient and considerate that it might take a longer wait time for a response while testing, taking a swab or vaccinating a person with disabilities.

Administrative lacunas

Lack of equipment and support services

The vaccination sites lack basic support infrastructure. There was not enough space that facilitated vaccinations with enough physical distancing. There was no facility for a person with disabilities like waiting rooms, ramps, instructions written in braille etc. When questioned, the care providers highlighted the need for an official order from the government to provide essential equipment required during vaccination and support infrastructure for a person with disabilities beneficiary. One of the ANMs mentioned-

“We do not have an oxygen supply. Serious conditions may need oxygen after vaccination. They might develop shock and can even die. We refer people with disabilities to places with oxygen supplies. If there are any serious complications, we are not equipped enough to handle the situation.” (ANM 1)

Lack of training and awareness

Although the policy guidelines regarding eligibility criteria to access vaccines were updated in the second phase of vaccination, people with disabilities are included in the priority list due to their vulnerability to infection (under the umbrella of comorbidity). However, there have not been any up-gradation in human resources and skills of health care providers to understand the needs of the person with disabilities during vaccination. Besides making the population aware of the COVID-19 preventive and curative measures, health care providers also need to be aware of the existing provisions and guidelines regarding vulnerable populations. Most of the participants were unaware of “near to home vaccination centres” that MoFHW had issued.

Lack of human resource

Diagram 1:

Another major issue identified was the lack of health care providers for conducting the vaccination sessions. The existing care providers had to multitask and overwork tirelessly in order to achieve full coverage. The pandemic gave a chance to the government to increase the number of people involved in healthcare delivery. Instead, it conveniently burdened the existing cadre with more workload. In such situations, separate care for the person with disabilities cannot be expected at the vaccination sites.

“I need to register 200 people or vaccinate them. It becomes so tiring at times. Despite having a PHC nearby, the MO is not available. He is on duty at the airport for the COVID screening. Amidst this, if we have a person with disabilities, we treat him like any other beneficiary.” (CHO 1)

Analytical discussion

Our study findings shows that Govt. facilities of vaccination are not align with the UNCRPD guidelines (2021) and suggest policy recommendations to ensure accessible vaccination and healthcare support for people with disabilities amidst COVID-19 and emergencies of similar strata (refer to table 3).

Our study findings	UNCRPD guidelines	Implications
Prioritization and Inclusion ■ Lack of specific guidelines ■ Lack of inclusion ■ Tedious registration process	People with disabilities are being denied the right to receive critical public health information in alternative and appropriate formats, such as sign language interpretation, captioning, plain language and easy-read format, following articles 9 (Accessibility), 21 (Freedom of expression and opinion, and access to information) and 25 (Health) of the Convention. Health resources are being diverted to mitigate the	Our study findings could help policymakers address these barriers based on UNCRPD guidelines in making vaccination programs more inclusive of vulnerable populations.
Attitudes and stigma associated with vaccination ■ Stigma around vaccination ■ Community-based apprehensions		

- An attitude of family members

Issues of accessibility for person with disabilities

- Physical ease of access
- Sensory ease of access
- Cognitive ease of access

pandemic, and health workers are often unable to travel owing to preventative measures, leaving many persons with disabilities with unmet health needs. .
(Source-<https://undocs.org/CRPD/CSP/2021/2>)

Administrative lacunas

- Lack of equipment and support services

India Context of Implementing UNCRPD Article 25 –Health and Article-9 Accessibility with Inclusive measures for Disaster Risk reduction for PWD. COVID 19 Vaccination and Disaster Risk Reduction measures provided in the Indian context through the supreme court asked states about the provisions for vaccination for PWD. SC pronounced notice to centre on plea for door-to-door COVID-19 vaccination for people with disabilities to ensure equal access.

As highlighted, study findings could also help the administrators plan interventions

■ Lack of training and awareness ■ Lack of human resource	The State should make available quick and easy access to COVID-19 vaccine within the ‘Principle of Reasonable Accommodation’ under The RPWD Act, 2016. Other State High courts judgements also ensure vaccination facilities near to their homes. (September 20, The Hindu, 2021). As the COVID-19 pandemic devastates the world, persons with disabilities already living in overcrowded camps and urban locations or remote rural areas with poor water and sanitation facilities and limited access to health care find the situation “too much to bear” (26) as they are unable to implement any measures to mitigate the spread of COVID-19. In the Global Humanitarian Response Plan for COVID-19, which sets out the critical priorities for the humanitarian response to the pandemic, persons with disabilities were recognized among	to mitigate the challenges faced by persons with disabilities and minimize the gap in policy planning and implementation at the grassroots level. The study findings are relevant for low-middle income countries, as the study was conducted in a low resource setting.
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the most affected populations groups in 63 countries (27). In addition to the risk of infection and death, there are also the long term implications of isolation and the loss of socio-economic safety nets due to the pandemic. (Source-
<https://undocs.org/CRPD/CSP/2021/2>)

People with disabilities are being denied the right to receive critical public health information in alternative and appropriate formats, such as sign language interpretation, captioning, plain language and easy-read format, following articles 9 (Accessibility), 21 (Freedom of expression and opinion, and access to information) and 25 (Health) of the Convention. Health resources are being diverted to mitigate the pandemic, and health workers are often unable to travel owing to preventative measures, leaving many persons with disabilities with unmet health needs. (Source-
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The study findings are relevant for low-middle income countries, as the study was conducted in a low resource setting.

India followed an aggressive vaccination policy intending to cover the maximum number of people in minimum time and hence has prioritized the population more vulnerable to COVID infections. As the study findings highlighted, India needs to

revisit its definition of “Vulnerable population” and revise its priority list. There is an urgent need for more substantial administrative support from the government to strengthen our rural health care infrastructure. States like Kerala and Tamil Nadu have performed meticulously in tackling COVID cases during the second wave of the pandemic. As suggested by the findings of this study, it was done by prioritizing the most critical cases, including vulnerabilities due to disabilities and connecting patients to medical aid. Vaccinating the vulnerable populace like persons with disabilities can be achieved efficiently by creating a relevant and inclusive provision in the 3-tier system. This will enable persons with disabilities to have ease of access to preventive healthcare provisions like vaccination.

We conducted this study with rural health care service providers of different levels across 3-tier rural health care systems to gain their perspective on barriers for persons with disabilities in attaining COVID vaccination. This helped us understand the entire vaccination process from planning, including prioritization, vaccine distribution, and knowledge dissemination to lower levels of hierarchy to implementation level where the information is received, and the community is served accordingly. This study is unique because it uncovers the ground level realities and represents how the provisions that shine in government policy documents mark no or limited presence at an implementation level. For instance, health care providers are unaware of the provisions like “Near to home vaccination centres” (MoHFW, 2021) for persons with disabilities or if they even fall into any priority list (Rahman, 2021).

The study findings highlight the importance of prioritizing persons with disabilities as “high-risk groups” in vaccination policy and not merely counting disability as one of the comorbidities. Rahman (2021) also highlighted similar findings.

It is imperative to address the infrastructural barriers (Minnesota Department of Health, 2021) and build environmental support, including building ramps, audio-visual cues at vaccination sites and separate waiting spaces to facilitate persons with disabilities in getting vaccinated and make this process more inclusive of the vulnerable population. The study takes into consideration the socio-economic and cultural factors to further explore the barriers. For instance, lack of technological access, transport facility, and stigma around vaccination due to cultural beliefs contribute to keeping people with disabilities away from vaccination. There is a need for knowledge transfer through awareness camps to demystify myths and stigma around vaccination in an accessible format for rural and disabled populations with more visual and graphical representation to better engage with the community.

Study findings highlighted the gap between workload and human resources in the healthcare system_(Ghosh et al., 2021). The government needs to provide adequate administrative support by acquiring more health care providers and equipping them with the required skills and knowledge to engage with persons with disabilities. While discussing strategies for strengthening vaccination, Rahman (2021) highlighted government plans of geo-tagging COVID vaccination centres. Our study findings suggest that information related to compatible built environments like ramps and waiting areas, availability of information in accessible formats and other support services will make geo-tagging plans comprehensive and inclusive.

Limitation

The study findings may not be generalizable as we only explored the perspectives of women. In practice, however, men are also involved in the vaccination process, e.g. Gram Sabha

representative, Medical Health Officer. The study findings are limited as it only included service providers' perspectives to identify the barriers. The lived experiences of the persons with disabilities could have added more insights to their barriers. As COVID-19 vaccination drives have begun recently, not much literature was found on the barriers faced by persons with disabilities during COVID vaccinations. Keeping in mind the widespread pandemic, the method for data collection was chosen to be the telephonic conversation. In collecting data over the telephone, the duration was shorter and non-verbal communication was missed, which could be used for substantiating the data.

Conclusion

Access to healthcare services is the basic need for any individual, particularly in an emergency like COVID-19, who are vulnerable and could be subjected to multiple marginalizations. For instance, people with disabilities are often left out or considered at last in any health benefit schemes. Our study highlighted the challenges care providers face while providing healthcare benefits (vaccination) to people with disabilities amidst COVID-19. We can learn from these challenges and plan interventions to mitigate the challenges faced by persons with disabilities and create an efficient vaccination mechanism for them.

Scope

Based on the interviews with rural health care service providers, observation and field notes, it was evident that barriers faced by persons with disabilities in getting vaccination are more than their physical disabilities. This study provides some considerations for future research, for instance, how a rural health care setup

can be made more efficient and compatible for improved access for people with disabilities.

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Declaration of conflict of interest

The researchers declare no conflict of interest.

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Challenges in Accessing Healthcare for People with Disabilities during COVID-19: An Exploratory Study in West Bengal

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Abstract

The paper explores how the wake of the Covid-19 pandemic has further limited the already existing limitations to healthcare access for the world's largest minority population, persons with disabilities. The paper uses a general theoretical framework to examine the access and then applies the framework on research evidence to detect the challenges. The broad objective of the study is to understand the perception of healthcare accessibility issues among persons with disabilities during the Covid-19 pandemic. An exploratory qualitative study was carried out using Telephonic/face-to-face interviews with 10 participants. Eligible participants were Persons with disabilities and family members of persons with disabilities.

A purposive sampling technique was adopted. The major problems that the disabled faced were unavailability of services, lack of transport, information gap, financial burden, fear of

Covid-19, non-cooperation from society. Family members found affordability as a barrier as some of the treatments are expensive. Identifying the challenges faced by persons with disabilities may help the policymakers and healthcare service providers to mitigate the gap, adapt and improvise Disability-friendly methods, formulate tailored healthcare services to meet the needs of PWDs.

Keywords: Healthcare Accessibility; Persons with Disabilities; Covid-19; Pandemic; Challenges, Perception; Affordability.

Introduction

The wake of the COVID-19 pandemic has disrupted the regular living pattern of every individual across the globe. The rising cases unprecedentedly overwhelmed the entire healthcare system along with social and economic crises. The emergency, subsequent lockdown, and various remedies to curb the disease spread have impacted the lives of every individual and inflamed the already existing exclusion of persons with disabilities.

According to Census 2011, India is home to 2.68 million people with disabilities, 2.21%. Historically, access to healthcare services has been a major issue faced by them across the country. The WHO defines ‘accessibility’ as an element of the ‘AAAQ framework’ of ‘Right to Health,’ which includes physical, economic, and information accessibilities and non-discrimination (World Health Organisation, 2020). The ‘World report on disability’ reveals that 50% of people with disabilities face challenges in accessing healthcare. Apart from the standard healthcare needs, people with specific disabilities require regular medical assistance. A survey report by NCPEDP shows that 73% of interviewed PWDs faced severe challenges during the Covid-19 crisis, where 9% of them faced obstacles in accessing healthcare. The healthcare facilities also saw a drop in people

visiting them for diagnosis and treatment of diseases other than covid-19, primarily because of medical avoidance. Research suggests that avoiding emergency and routine care because of covid19 concern was highly prevalent among unpaid caregivers, especially persons with disabilities (Czeisler et al., 2020). When some studies pointed to the fear of nosocomial infection as a factor behind people refraining from seeking treatment during a pandemic (Makiyama et al., 2021), another study suggested the unavailability of accessible transport. These specified needs cannot be mitigated with teleconsultations, reduced communication in an accessible format as potential factors (Czeisler et al., 2020). One crucial aspect not covered in these studies is that healthcare utilization was avoided solely because of risk concerns or limited access to healthcare. Several kinds of literature captured the inequities in accessing healthcare faced by this vulnerable section from ages. When the pandemic posed a challenge in accessing healthcare for common people, it is pretty apparent that it stretched those existing inequities further. Although several newspapers reported incidents of challenges faced by people with disabilities, there has been a lack of in-depth study on the lived experience of these people. The study tries to address the gap by exploring the perception and lived experiences of the segment on healthcare accessibility during the pandemic crisis. To understand the issues faced by the disabled in their wake to receive treatment, we have outlined specific objectives that make the understanding of the subject clearer. The following objectives have been undertaken for the study, 1. the availability of healthcare services for people with disabilities during a pandemic in terms of perceived needs, 2. the affordability of healthcare during a pandemic, 3. barriers that influence the healthcare utilization of PWDs during covid19 pandemic,

4. How PWDs and their family members dealt with healthcare needs during the crisis. We have frequently used the word 'PWDs' in this study. The Convention on the Rights of Persons with Disabilities defines persons with disabilities as 'physical, mental, cognitive or sensory impairments which bar them from effective participation with society' (UNHCR, n.d.) (United Nations Enable, 2007).

Method

Research Design

A qualitative exploratory research design was used to conduct this study. The idea of the exploratory research is not to provide conclusive results but to identify potential issues focused on for future research. The qualitative nature of the study allowed the participants to express their lived experiences regarding the issues in an open-ended manner.

Study Participants

The inclusion criteria required the participants to have mobility, sensory and cognitive impairment, or their family member or caregiver if they could not speak for themselves. The participants for the study were chosen by the purposive sampling method. The motive behind choosing the respondents was under the criteria that they were in need to access healthcare facilities or assistance during the time of covid-19 from March 2020 to date. In order to gain information-rich cases and to have a greater understanding of the situation, and keep the time constraint and inclusion criteria into account, a small sample size was recorded. Accordingly, 18 participants were approached, and 10 participants among them gave consent for the study. The final study included four respondents who had disabilities but could look after their care, and six were taken as caregivers of persons

with disabilities. The caregivers were family members in these cases, father, mother, or spouse.

Data Collection

The study was carried out in June 2021 in various parts of West Bengal, mainly on a pre-decided and mutually agreed time. Due to covid-19 related restrictions, a telephonic interview was taken from most of the participants (6), rest (4) were face-to-face interviews. Voluntary participation was encouraged, and all people interviewed had provided verbal informed consent for the study. Consents for audio recording were taken separately. Participants with limited literacy were explained the entire process thoroughly.

Instruments

The interviews were carried out in Bengali and Hindi languages. Each interview lasted for (20-30) minutes, which included open-ended questions on the nature of the disability, their perception regarding the accessibility and affordability of healthcare services during the pandemic, and factors that influenced their healthcare utilization.

Data Analysis

The study used thematic analysis to interpret the realities of the issues faced by people with disabilities (Brown & Clarke, 2014). The data was audio-recorded, manually transcribed, and transported to QDA MINER 6.0 version software for coding.

The anonymity of the participants was maintained while transcribing the audio recordings. The themes were generated by categorizing all the data into groups identified by the codes. The authors repeatedly reviewed the transcripts and codes to

retain the diversity and congruence with the themes defined (Nowell et al., 2017).

Table 1

Respondent Profile

SL NO	RESPONDE NT	AGE	GENDER	NATURE OF DISABILITY	INTERVIEW GIVEN BY
1	A	29	M	Congenital disability(Autism)	Parent
2	B	46	M	Congenital disability (Down syndrome)	Parent
3	C	45	M	Locomotive (Leprosy leading to legamputation)	Patient
4	D	64	M	Visual (Epilepsy leading to blindness)	Spouse
5	E	36	M	Congenital disability (Epilepsy)	Patient
6	F	14	F	Congenital disability (Down syndrome)	Parent
7	G	36	M	Congenital disability (Down syndrome)	Parent
8	H	29	M	Visual disability	Patient
9	I	28	F	Locomotor disability	Patient
10	J	62	M	Locomotor Disability (deformed legs)	Patient

Results

We identified six broad patterns within the given framework by analyzing the data produced from the interview. They are Lack of

Transport, unavailability of services, information gap, financial burden, fear of Covid-19, and non-cooperation from society. The quotes of respondents were translated to English, keeping the closest resemblance to the original vernacular versions

Unavailability of Services

With the advent of covid-19, the nation came to a standstill. The situation became like a medical emergency within days, with covid-19 cases rising steadily. To make matters worse and contain the virus, the focus of health care solely shifted to covid-19 care, and other treatments were either halted or delayed. This was the same for people with disabilities too, who found it difficult to get appointments for checkups or at times find unavailability of OPD or IPD services in a hospital turned into a covid-care centre. The condition became such that covid was at top priority and rest was given less priority. This was also done to accommodate covid-19 facilities, which otherwise lacked in normal times.

“We have been visiting the doctor for last ten years at Fortis hospital, but since the lockdown, the doctor did not sit there, and so we could not go for a checkup,” said respondent A’s parents.

“The hospital we used to visit in Mukundapur was turned into a covid-care centre, and so we could not take our son for any checkup for months,” said the parent of respondent B.

“I needed to get some tests done, and the pathology that I used to get my tests done was solely doing covid-19 testing and so had to find other places”, said a respondent.

“I needed to get my cataract to checkup done as I was having vision difficulty, but due to lockdown, I could not visit the hospital, and my treatment got delayed,” said respondent E

Financial burden

With covid-19's onset in India, getting access to healthcare at the same spending became a problem. There was a lack of medicines, medical equipment, and treatment facilities, leading to an increase in cost and burdening the family of patients. As the income of people started to become less, the cost of healthcare grew, which posed many problems for the general public and especially the poor and middle class. The respondents of the study had similar situations.

"Before we used to travel by public transport which was cheap but due to lockdown, we had to book cabs and come for a visit and that cost a lot," said respondent E. Similar was the situation of respondent A, *"The cost of his medicines increases from time to time, and it has become difficult to deal with that, so we tend to look for cheaper medicines."* Respondent C had to go through a leg amputation surgery. He had his financial problems, "due to covid there was a delay in my operation and that even led to increase in the cost of operation later." The parent of respondent F said, *"My daughter has been suffering from down syndrome since birth. We tried for treatment for some years, but we are very poor, and with time, our money is burned out, now we do not go to the doctor as we cannot afford."*

Lack of Transport

The government adopted partial and total closure of the public transport system as a remedial measure to contain the spread of the virus. It is a matter of discourse if the step could serve the purpose, but it indeed negatively affected people with disabilities. People with no access to household vehicles and drivers suffered the most. The unavailability of vehicles, surged price of existing transport options often compelled people to refrain from seeking routine and non-emergency healthcare.

“The hospital is very far, and during the lockdown, there is no car or bus available, so we had to book one. Due to this, the doctor’s appointment used to get delayed many times,” said respondent A.

Another respondent stated how the distance between the hospital and residence incurs an enormous amount of travelling cost to them, *“We live in Garia area which is in south 24 Parganas, and the hospital is in North Kolkata, going that far without proper transport is not possible and booking car takes a high charge”.*

“My husband had cataract and vision issues and operation was needed to be done, but due to the lockdown we could not go for checkups, so the operation got delayed for 3months”, said another respondent.

Information gap

Most of our study respondents used television and mobile phones to get information from the government and other agencies. However, the study respondents with visual disabilities started having issues with the non-inclusive nature of such a mode of information.

“We do not get proper information about the covid situation and have to rely on others words” “Amra to thik thak kbabor e paina corona r bepar e, et je ja bole otai suni,” said respondent C, the spouse of respondent D, said, *“My husband cannot see properly, and we are not that educated, so if the authorities made audio announcements it would be better,”* respondent G said, *“Not only for us but for the people with hearing issues, there should be an audio guide while government announcements are made.”*

Fear of Covid-19

A disease for a human being is always to worry about as it includes medication, treatment, and the body getting weak. Covid-19 made it worse as it was suddenly taking lives, and there was no remedy, which made the situation very difficult. It was

more difficult as reports came that people with other illnesses and comorbidities were more susceptible to the virus, fearing the disabled. The underlying medical conditions of the disabled people make their immunity fragile, so they and their families lived in fear over time as to get affected by the virus. This often led to avoidance of routine and non-emergency healthcare utilization toppled with increased anxiety and worsening of treatable health conditions.

A respondent said, *"I work, and all the time I had this fear of getting the infection as i had to travel and this made me have high blood pressure later". "We try to keep him indoors always and still live in fear of covid, if anything happens we do not know how to tackle"* said a parent of respondent A. Parent of respondent B, who had to be admitted to hospital with pneumonia said, *"When he got sick, we got terrified and thought we might just lose him, thank god it was detected pneumonia and he was cured."* *"I have to workhouse to house, and others go out too. We live together and have the thought of getting infected by the virus. We feel petrified at times,"* said the spouse of respondent D. The fear of covid is still there, which has given rise to many other health issues.

Non-cooperation from society

A society becomes healthy by the people who reside in them. People, their behaviour, and their will to help can change a society and improve it by aiding those who need them. That is how a healthy society is formed. Nevertheless, often than not, we see people not helping each other in need. The disabled feel discriminated against many times as if they are different and tend to isolate themselves. This non-cooperation became more evident during covid-19, where many people with disabilities did not get help when needed from their neighbours. This was more because people perceive that they are sick beforehand and

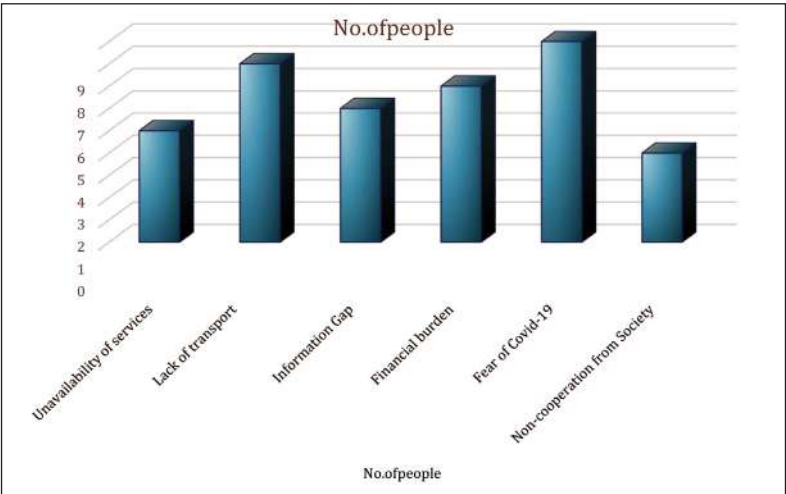
are more prone to the virus and can affect them. This, in turn, became a problem and hindrance for the disabled.

Respondent F's parents said, *“Otherwise, we have a friendly neighbourhood, but during covid when my son had a fever, we did not get any help as they thought he might have corona.”* The parents of respondent C said, *“We are poor and have faced discrimination from people while travelling in public transport, they think different of my son it seems,”* similar was an experience of respondents B and E.

We understand this that is not particular to covid, but as a whole, people with disabilities have faced discrimination from society.

Graph_1

FIG: Graphical analysis of Challenges faced by the Respondents of the study.



The figure is a graphical representation to understand the challenges that the respondents specifically face. Due to the onset of covid-19 in our society, the main fear is around that. 9 out of 10 respondents have said their fear of getting affected

had affected their daily lives. Other than that, lack of transport was a significant problem that they all faced. It was common for the general public and those with disabilities who needed public transport to travel to healthcare facilities due to the lockdown and covid-19 restrictions. 8 out of 10 respondents spoke about lack of transport as a hindrance for them. All these affected the respondents financially, and that affected their treatment. 3 out of the ten respondents were earning members themselves and they could afford medical treatment costs, but the rest said about facing financial problems as the cost of living rose, and they had difficulties coping with them. The other hindrances included lack of proper information and lack of services. Correct information was a must during this time of covid-19 as false news and wrong information were there, but 6 of the respondents said they did not receive accurate information, including information from their hospital or medical centres where they go for checkups. Due to covid-19, many facilities were shut, and thus services had to be halted, which caused hindrance to the respondents. Moreover, lastly, 4 respondents said about having less support from their neighbourhood or the society as a whole, which was not a problem due to covid-19 but increased during this time.

Discussions

The Indian healthcare system is overburdened, with the doctors to patient ratio being 1:1456 according to the Economic Survey of 2019-2020 and disproportioned with lack of facilities in rural areas where 65.53% of India's population lives. The high infectivity and unprecedented nature of the Covid-19 led to the prioritized allocation of scarce healthcare resources in Covid-19 specific cases and reduced routine and non-emergency healthcare services for non-infected patients. The idea of 'Health for all' to provide equitable access to the population was sidelined. In most cases, the people with disabilities voluntarily opted

out from seeking healthcare assistance due to the difficulties in accessing healthcare, added with fear of covid-19. Though teleconsultation services were made available, people with specific sensory disabilities could not get much help.

The country also saw frequent closure of the transport system, shutdown of economic activities, which disproportionately affected this vulnerable segment. A study by Wolfe et al.(2020) revealed how transportation barriers resulted in delayed care, missed appointments, and even medical avoidance, which might exacerbate potential health problems in the future. The respondents in our study reported how they were compelled to shell out a lot to afford transport to access healthcare. In the study, while interviewing many respondents had the issue of not being able to access the medical facilities due to lack of proper transport. For a person living 20kms away from a medical facility, it was nearly impossible to reach hospitals for checkups, and even if they tried, it would cost a lot. For some, the situation was more difficult as doctors for the general check were not sitting due to covid-19 treatment, and at times even doctors were affected by the virus leading to delay. One of the respondents interviewed had to delay his cataract operation, leading to a severe eye condition. And even though in later times when transport was allowed they were more minor in numbers did pose barriers for disabled and their treatment

The out-of-pocket expenditure of India is around 63% of total expenditure. According to the National Health Accounts (NHA) estimate for 2014-15, the Government Health Expenditure (GHE) per person per year is only Rs 1,108 that comes to Rs 3 per day. This is in contrast to the Out-of-Pocket Expenditure (OPE) of Rs 2,394 annually. Many of our study respondents used healthcare services from private facilities due to the rich customer experience and less waiting time. The unavailability of

services at public hospitals compelled the rest of the people to seek healthcare from private facilities. With scarce resources and high demand, the prices for regular services at private hospitals also went high, which was a challenge for those who require regular medical attention to keep going.

Reports have documented how the measures like social distancing added to the woes of the lives of people with disabilities, solely reliant on a caregiver for daily living((Narayanan, 2020). We live in a society that often discriminates against people with disability and show a lack of empathy. Due to covid-19 that increased where people were less helpful and poised barriers for disabled people.

Various information circulated regularly for common people for covid-19 related matters was devoid of inclusive structure for the disabled population. As a result, a large part of the vulnerable population stayed outside the ambit of accurate information. There was a lack of information which was needed more than any other time. A big problem that came through the interviews was this. The people with visual or hearing disabilities did not receive accurate information, and the awareness campaigns were significantly less. This lets fake information spread quickly. This was seen during the process of vaccination, too, where people had varied pieces of information about vaccination being not reliable or vaccines having severe side effects and led to people not wanting to take vaccinations. The actual reports or information that should come from the government lacked.

All this led to people gripping with fear during the time of covid-19. In usual times, people with disabilities face many daily challenges, which multiply due to covid-19. The especially abled are weaker and have various comorbidities, especially those suffering from nervous or congenital disabilities. They

tend to get sick more often, and as WHO and ICMR reported that the weak or less immune persons were more easily affected and vulnerable by covid-19, this fear transferred in them. The situation became more psychological for those with disabilities who travelled by public transport or lived in a populated area.

This fear was also in the parents and caregivers who used to go out in public for various reasons, and even after maintaining good hygiene and trying to maintain physical distancing, they always had the fear if their child or ward got affected due to this. This led to many people suffering from anxiety, depression and this became an added problem. Also, the physical distancing, which turned into social distancing, made the people with disabilities lonely at times and not get the help and support needed from society.

Conclusion

People with disabilities comprise a significant population in our country, and if their families who are directly involved with them are included, it becomes an enormous sizeable population. However, this population is too often forgotten in policymaking and governmental decisions. Through the study, this has been found that there are major challenges that the disabled face, more than an average person. The covid-19 pandemic has made that situation worse and also brought the situation in front of us. From accessibility to lack of service, from poor financial support to lack of help from society, the people with disabilities have to face barriers at every level and survive. The problems and challenges were explored to understand the situation. The issues that people with disabilities face should be included in future crisis strategies and response planning. The authorities should look into this and provide service and valuable information, the basic need for better treatment. As a society, we should stand up

for the people who need us the most. Help can be as emotional support, social support, and people with disabilities should not be looked down on or discriminated against as they are one of us and have equal rights as others.

Scopes and Limitations

The interviews and the study are starting to understand a broader aspect of the challenges people with disabilities face at every point of their daily survival.

This can be helpful for future researchers, doctors, and medical professionals. However, there were some limitations of the study as well. Due to time constraints, the number of respondents taken was less, so a broader perspective and view of the people was not taken.

Another limitation was the telephonic interviews that were taken. They are one-dimensional, and without face-to-face interviews, the respondent's emotion is not always understood or reciprocated properly. However, due to the pandemic and ongoing restrictions, a telephonic interview was the only way forward in many cases. Another restriction was the language barrier as most respondents spoke in their vernacular mother tongue, and their versions were translated. Sometimes the essence of what the speaker says is not entirely put on paper.

Implications

Results obtained from the study have highlighted challenges and difficulties faced by people with disabilities during the pandemic, from accessibility to service provided to financial drawbacks. It is imperative to have a better understanding.

The study also underlines the lack of research about the impacts of the COVID-19 pandemic on people with physical disabilities.

People with disabilities should be given more importance as they are a significant part of our society. Thus studies with the motive of exploring and understanding the impacts on people with disabilities should be conducted more if we want to act and respond better to the specific needs of the disabled.

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Challenges and Implementation of Innovative Initiatives during COVID-19 for the Welfare of Children and Adolescents with Disabilities

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Abstract

The spread of the COVID-19 pandemic has been affecting all sections of society, especially the children with disabilities in different parts of India who are severely affected by various challenges faced in their day-to-day lives. Engaging and providing support services to the children and adolescents with disabilities for the past two years, especially during the summer vacation during COVID-19 lockdown, are pretty challenging for the special schools, rehabilitation units, and the parents of the children with disability. The parents and teachers of children

are also facing many challenges in caring for and facilitating the children with disability due to lockdown, school closures, remote working, and physical distancing while following the COVID-19 protocols. With this background, this research work studies the various challenges faced by the children with disability, their parents, teachers, and rehabilitators of the special schools and rehabilitation units by reviewing the literature, implementing the Survey method, relevant research tools, and techniques for collecting and analyzing the primary data. Based on the analysis and interpretation, innovative initiatives/activities are worked out to facilitate, comfort, and engage the children with disability with appropriate life skills and developmental activities. A case study approach is adopted to implement the initiatives in the Rehabilitation division of Worth Trust organization in the Vellore district of Tamil Nadu. The proposed initiatives are implemented and recorded with the Feedback of the beneficiaries and stakeholders as the research outcome and deliverables.

Keywords : Autism Spectrum Disorder (ASD); COVID-19; Cerebral Palsy; Disabilities; Pandemic Lockdown; Rehabilitation; Children with disability; Speech & Hearing Impairments

Introduction

The COVID-19 pandemic and the lockdown conditions have disrupted the everyday life of the world population severely. The abnormal conditions and impacts have worsened the education systems for all children, learners, and educators at all levels in the academic community. Among them, the most affected are the school students and adolescents with different abilities. Though the legal structure and arrangements are safeguarding the fundamental rights for education for all the people, about 25% of the children and adolescents with disabilities from 5 to 19 years old, and 75% of the students at the age of 5 years are

not able to get admitted in any formal education as reported by UNESCO, 2019. As about 69% of India's disabled population live in rural areas, they are socioeconomically more backward and have poorer living conditions than the other non-disabled children.

In this context, engaging and providing education and training, adequate care, and support to the differently-abled students and adolescents are pretty challenging for the special schools, rehabilitation units, and the parents of the children with disability. The COVID-19 pandemic has been affecting all the segments of the population in the country, particularly the differently-abled children in different parts of India who are affected severely by various difficulties and challenges in their day-to-day life. The parents and teachers of children with disability are experiencing many challenges in taking adequate care, comforting, and facilitating the children with disability during the lockdown, school closures, remote working, and physical distancing while following the COVID-19 protocols. With this background, the researchers study the various challenges faced by the children with disability, their parents, teachers, and rehabilitators of the special schools and rehabilitation units, identify the various innovative activities, and propose by reviewing the literature, by surveying the parent stakeholders and also implement the proposed set of activities and finally document the Feedback of the beneficiaries.

Literature Review

The researchers surveyed the research papers published by the past researchers on the area of research during the COVID 19 pandemic period in the research journals at the national and international level. The reviews of the relevant research papers are presented as follows:

Duraku and Nagavci (2020) presented the factors influencing the level of inclusive education for children with disabilities before and during the COVID-19 crisis. The impacts of social distancing, online learning on day-to-day life routines, and the health conditions of the differently-abled children and the parents were determined. The researchers concluded that the COVID-19 factors like lockdown quarantines, restrictions in social interactions, altered routine activities, and the absence of support services have badly impacted the emotional status of the differently-abled kids and students and led to low inclusion in the online education and overloaded the parents with more stress. Fegert et al. (2020) presented the challenges and threats faced by the differently-abled children and their caring parents during COVID 19. The children were suffered due to isolation, contact restrictions, and reduced opportunities for stress reduction. The threats for the parents were more risks for their illness, increased intolerance leading to violence at home, and ill-treatment of children. Another most significant challenge was the psychiatric treatment for maintaining the cognitive balance of differently-abled students. Finally, the researchers concluded many threats to mental well-being due to the pandemic restrictions, which would badly affect the differently-abled students and adolescents already marginalized and living in poor conditions. They also proposed to have suitable policies to contain the pandemic impacts on the students' emotional and mental well-being and estimate the beneficiary measures taken to curtail the risks.

Amorim et al. (2020) researched the effect of the pandemic on kids with disabilities like autism disorder and analyzed the difficulties of the kids and parents when they were in lockdown and isolated at their homes. They found that the ASD children had more behavioral issues than the other children in the

study group. The majority of the parents of ASD children communicated emotional imbalances and issues, whereas the parents of the other kids communicated no such issues. Vernekar et al. (2020), in their research report, discussed the challenges of the pandemic and inaccessibility of learning in the schools for the students with different abilities during the COVID-19 lockdown period in the four states, Andhra Pradesh, Karnataka, Kerala, and Tamil Nadu of India. The researchers reported that the (i) families were impacted without jobs/income, shelter, borrowings, inadequate food, and health care, (ii) the educational systems and teaching mechanisms were inaccessible due to lack of online facilities at home, non-availability of study and instructional materials, inability to understand the assignments, visual and hearing impairments and lack of individual attention, and (iii) Academicians reported less teaching activities, more non-teaching activities, loss of jobs and poor salaries, and difficulties in handling the online methods of instructions to children with disabilities. Jackson and Browdon (2020) reported that the COVID-19 made the schools in the country close, leading to millions of children continuing their learning from home, which severely affected the differently-abled children. The lockdown also led to sudden shifts in the instruction and training methodology, support services, and management of the classes for the differently-abled children by the educators and thrown logistical and pedagogical challenges for the educational districts in serving with the differently-abled students. In their research, Spinelli et al. (2020) explored the effect of challenges and difficulties due to the COVID-19 pandemic lockdown experienced by the families of children with disability. Through an online survey analysis, the researchers reported the impacts of the pandemic on home environmental conditions, the stress-related issues between the parents and children, and the emotional and behavioral problems of the differently-abled children.

Bobo et al. (2020) studied and presented the experiences of the students and adolescents having ADHD confined in the period of the COVID-19 pandemic crisis. The result outcomes show that a majority of the children and adolescents experienced either better well-being or a stable psychological state as reported by their parents. Anxiety reduction is due to interruption in face-to-face schooling and a tailor-made pace of training. Some parents reported the abandonment of accommodation, problems due to the volume of tasks, behavioral and emotional difficulties due to the deterioration of the conditions of the differently-abled children.

Duraku and Hoxha (2020) explored and analyzed the impacts of the pandemic on teaching and learning, the wellness of teachers, students, and parents, and the difficulties faced due to the social isolation, perspectives of teachers and parents regarding the online or remote teaching. The researchers applied qualitative methods, case study research, and interview techniques. They found that the groups studied had common concerns with the students' evaluation, stress due to overload of assignments, and varied assessments due to incompatibility in learning. Researchers also reported the importance of the preparedness and self-motivation of the teachers for advancing the subject knowledge and technical skills and contributing to improving the quality of education. Chen et al. (2020) assessed parents' cognitive status and well-being of children with disabilities during the pandemic lockdown in China through a survey. Research outcomes reported that the parents or caregivers of children affected with ASD were facing mental health problems than those with intellectual difficulties, visual or hearing problems. Parenting distress was associated with the parents having a difficult child, children with ASD, and intellectual disability. Tiziana et al. (2021) presented the new e-mechanism for distance and online support for blind

and visually challenged children. The e-mechanism through the online process covers all the support involving audio-video calls, videos, and customized multi-sensory materials explicitly developed for every child. From the survey analysis, it is found that the parents and professionals indicated a high level of satisfaction with implementing this new mechanism. Mariene et al. (2021) presented their research on the emerging health challenges for differently-abled kids and their caregivers/parents during pandemic crises by applying an ECHO French survey. The researchers concluded that most of the kids surveyed had cerebral palsy(42%) and neuromuscular diseases (11%).

The lockdown and social distancing impacted the children negatively on their morale (44%), behavior (55%), and no contact with other children (55%). Many students stopped physical activities (44%), most of them were educated from home (76%). Only 22% maintained medical follow-up, 48% continued physiotherapy, and 27% continued occupational therapy. Parents performed the therapy for more than 60% of children and reported that their main concern was with rehabilitation services (72%), mental stress (50%), and the absence of assistance and support mechanisms (60%). Alicia et al. (2021) discussed the factors influencing the behavior of the differently-abled kids affected by ASD in the first wave of the COVID-19 pandemic. The researchers analyzed the predictors of behavior problem impairment of the children and presented the results. The parents reported the intensity or frequency of the behavioral difficulties of their children and the increased mental illness due to COVID-19 infections and overstressed in handling the children during the lockdown.

Pervin (2021) reported the challenges faced by the differently-abled children and their parents in Bangladesh during the Covid-19 pandemic while caring for children at their houses.

The researcher reported that the novel corona had effected unprecedented changes in the daily life of children and families of special needs, especially the children with autism spectrum disorder (ASD). Duraku and Nagavci (2021) explored the challenges faced by the children with disabilities and their parents during online teaching due to the Corona pandemic in Kosovo. The research outcomes revealed that the differently-abled children experienced many challenges during online learning, including irregular attendance, lack of access to Technology, inconvenience, trouble with the online format, and increased parents' stress levels. Faccioli et al. (2021) researched the experiences and difficulties faced by differently-abled adolescents and their parents during the pandemic lockdown in Italy. Parents expressed concerns regarding restrictions on meeting friends by the adolescents with disabilities, anxiety symptoms, fear of COVID-19 infections, and financial problems. They also expected remote support from educational institutions, health care professionals, technology assistance, and online or telephonic rehabilitation supports during the lockdown period. Life skills education is crucial for children and adolescents with disability to face the pandemic and day to day situation of covid 19.

Review Summary with Research Gaps:

From the literature review, it is observed from the research outcomes and reports of the past researchers that

- (i) COVID-19 more severely affected the children and adolescents with disability than the general or non disabled population, especially the school going differently-abled children due to the pandemic lockdown, self-isolation, non-inclusion in education and training, inaccessibility, and non-affordability of technological resources.

- (ii) The children and adolescents with disabilities are affected or experience challenges and difficulties in their emotional and mental behaviors, more stress than the average period, and overall physical and mental health deterioration.
- (iii) The parents of these special populations are also highly stressed both physically and mentally and could not cope with the good caring of their children and not able to manage the situation; felt very inconvenient without adequate support from the special schools, rehabilitation centers, and other supporting resources.
- (iv) Though many researchers suggested remedial measures, in general, to tackle the situation, adequate/concrete proposals are not found in the literature to educate, train, engage, and comfort, especially the school-going children and adolescents with disability, especially during the summer vacation and lockdown period due to COVID-19 pandemic.

Research Problem

COVID-19 has been affecting the people of all the countries across the world wide very severely and continuously. People across all the strata, especially in developing and underdeveloped countries, face many difficulties and challenges for saving their lives and livelihoods from the pandemic crisis. The children and adolescents with disabilities' conditions are further worsening due to the challenges faced due to the pandemic conditions and lockdowns in terms of lack of need based resources and lack of accessibility to resources in rural areas. The children and adolescents with disability studying in the schools, getting training and treatments in the rehabilitation centers are heavily affected due to the closure of the schools and rehabilitation centers. Their daily routine activities are highly disturbed, and the parents are

also stressed with their inability to handle the children at home as they are experiencing increased behavioral, emotional issues and deterioration of their physical and mental healths. In this context, the researchers identified the need for a thorough study and understanding of the various difficulties and challenges faced by the children and adolescents with disabilities at the schools and rehabilitation centers. The researchers researched, analyzed, and proposed various innovative activities to engage the differently-abled children according to their level and nature of disabilities during the COVID 19 closure/lockdown period, improving the overall emotional, physical, and mental well-being of the differently-abled children. Finally, the activities proposed are implemented through a case study approach and validated with the benefits gained by the differently-abled children and their parents with the recording of their Feedback.

Research Objectives

The main objectives of the research work are desired as follows:

- (i) To study the challenges and difficulties experienced by the parents, children, and adolescents with disabilities studying in the special schools and rehabilitation centers during the COVID 19 pandemic lockdown.
- (ii) To study and propose innovative activities for engaging and comforting the differently-abled children and adolescents during the vacation period for the well-being of the children and their parents.
- (iii) To implement the proposed innovative activities in a special school/rehabilitation center for the benefit of the stakeholders and real-time validation.

Research Methodology

The methodology adopted for the research consists of the following combination of research methods:

Descriptive Research Method:

This combines quantitative and qualitative research methods that focus mainly on discussing and explaining the nature and characteristics of a population segment by collecting both objective and subjective data from the population identified in demography. A thorough survey of the literature from the research journal publications, various reports from the government departments and NGOs, articles from the online magazines, websites, and other secondary sources was conducted to collect the secondary data and to understand the background of the research area, various problems dealt and research approaches adopted and reported by the past researchers. Then, the following two research methods were implemented to conduct the research.

Survey Method

This is a quantitative research method used to collect the primary data from a predefined population to get the information related to the area of research. The data are collected usually with the help of a questionnaire with either open-end or closed-end or both types of questions to ensure an unbiased answer from the respondents representing the population. In this research, parents of children and adolescents with disability in the northern part of Tamil Nadu, especially in Chennai, Kanchipuram, and Vellore districts, were surveyed by distributing a semi-structured questionnaire. The sampling technique applied here to collect the primary data is convenience sampling which was more feasible due to pandemic conditions. Responses from 152

parent respondents, both female and male parents, are collected, analyzed, and interpreted.

Case Study Method

The Case study method is a qualitative research method that involves in-depth research and data collection of a single entity or unit: a person, an organisation, a family, a cultural group, a market segment, or even the whole community. In this research, a case study was implemented to study, apply and validate the proposed innovative activities for engaging and facilitating the differently-abled children and their parents in a particular organization dealing with a disabled population. A special school affiliated to the rehabilitation division of Worth Trust at Katpadi, Vellore district, Tamil Nadu. A semi-structured questionnaire was circulated to the parents of the differently-abled children and adolescents studying in the Special schools, and the Feedback was collected.

Data Analysis & Interpretation

Survey Method

The survey was conducted by circulating the semi-structured questionnaire to the parents of the differently-abled children as per the sampling plan and technique discussed in section 5. (ii). The data collected are analyzed with represented using the statistical tools in Microsoft-Excel and presented as follows:

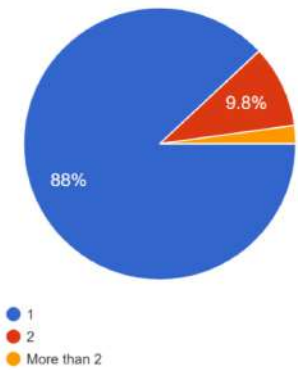
Data Analysis & Interpretation

All the data collected, segregated, and analyzed and the most important and very relevant information are interpreted as follows:

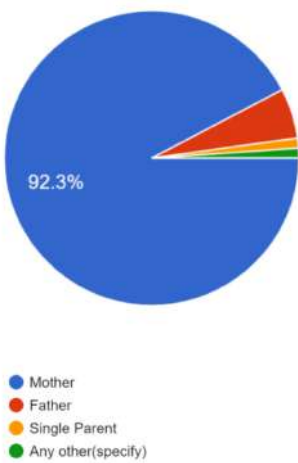
Out of the 152 samples collected, about 65.7 % are male children/ adolescents, and 34.3% are female children/adolescents.

From Chart C-1, it is observed that 88% of the family have a single child with a disability, 9.8% have two children with disabilities, and the remaining 2.2% have more than two children with disabilities.

C-1.No. of Children with Disability in the Family

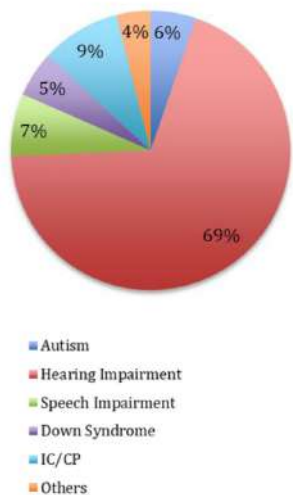


C-2.Care Taker of Child with disability in the Family

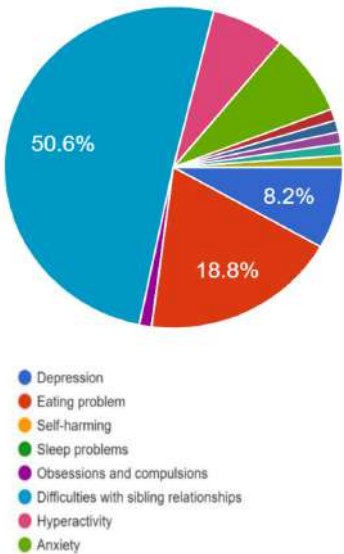


C.3. Type of Disability

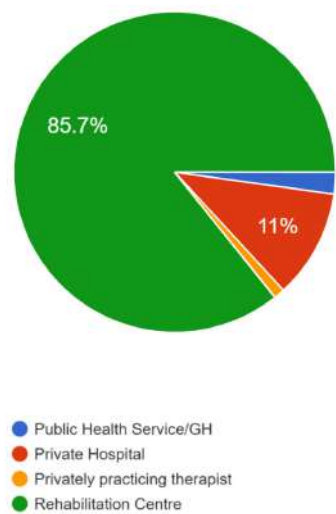
C.3. Type of Disability



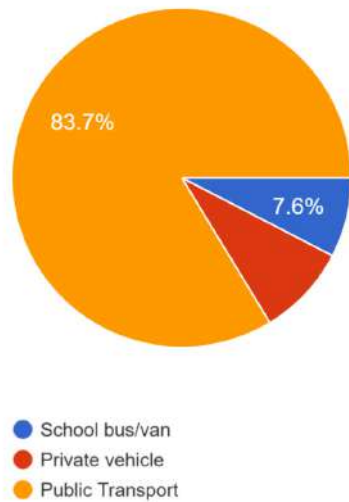
C.4. Problems faced by the Childre



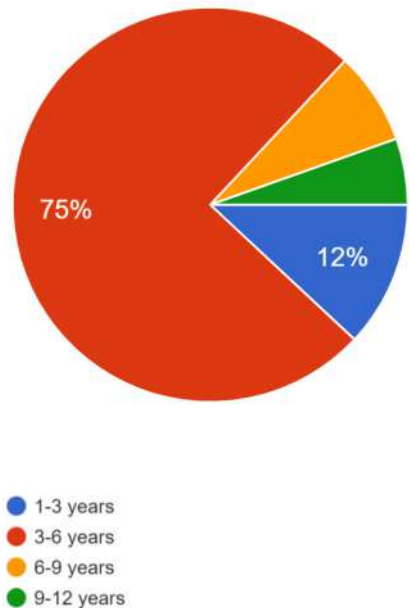
C-5. Places of availing services



C-6. Mode of Transport



C-7. Years of availing Training



C-8. Managing Children with disability during COVID-19

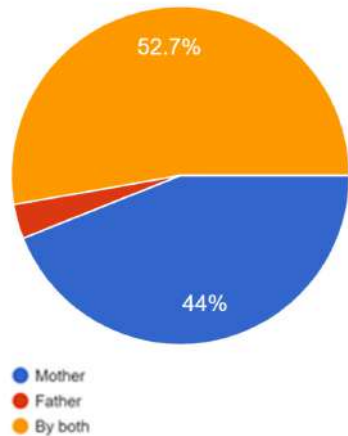


Chart C-2 represents that about 92.3% of the families, the mother is the permanent caretaker of the children with disability, in 5.5% of the families, the father is the permanent caretaker, and 1.1% of the families have only single parent others are 1.1%.

As per Chart C-3, 69% of the children have a hearing impairment, 9% have an intellectual challenge/cerebral palsy, 7% have a speech impairment, 6% have Autism, 5% have down syndrome, and 4% have other disabilities.

The various difficulties and challenges faced by the children with disability during the COVID-19 pandemic lockdown can be observed from chart C-4. It is found that about 50.6% of the children are facing difficulties with sibling relationships, 18.8% are having eating problems, 8.2% are in depression, 8.2% are in Anxiety, 7.1 % are with hyperactivity, 1.2% are in obsessions and compulsions, and the remaining children are suffering from loneliness and sleep problems.

The information regarding the place of the education, training and medical treatment services for the children with disability shall be found from the chart C-5, which represents that 85.7% of the children get their education and training in Rehabilitation Centre, 11% get their treatment done in private clinics/hospitals, 2.25 % in public health centers and about 1.1% only go to the private therapists.

The modes of transport used by the children with disability are given in C-6, where about 83.7% are using only public transport, 7.6% are using school van/bus, and the remaining 8.7% are using private vehicles.

Chart C-7 presents the number of years of special education/training/treatment service availed by the children with disability. 75% of the children are availing the services for 3-6 years, 12%

are availing for 1-3 years, 7.6% are availing for 6-9 years, and 5.4% are availing the services for 9-12 years.

Caring for and managing children with disability during the pandemic lockdown is the primary concern for the parents. Both the parents have equal responsibility in handling the situation, and the actual scenario is represented in C-8. According to this, 52.7% of the children are cared for by both the parents, 44% of the children are taken care of by only the mother, and only 3.35% of the children are taken care of only by their father.

Innovative Activities proposed

Based on the survey conducted, outcomes of the data analyzed, various difficulties and challenges faced by the Children and adolescents with disabilities, innovative activities are identified in consultation with the teachers, trainers, and the parents of the children and adolescents with disability as key stakeholders as nothing about us without us UNCRPD framework.

The innovative activities proposed by the researchers for implementing during the summer vacation of the COVID -19 pandemic period are presented below:

- i. Gardening Therapies,
- ii. Folding Techniques for clothes
- iii. Arts and Crafts Activities,
- iv. Speech Training by Oral-Aural method
- v. Inclusive Playing of Outdoor games
- vi. Purposeful Savings

Case Study Method

In this section, the Case study approach adapted for implementing the innovative activities proposed by the researchers as the

outcome of the survey research among the stakeholders. The details of the Case identified, innovative activities implemented, the summary of the training outcome with benefits for the beneficiaries as an of the feedback survey conducted are discussed and presented below.

Case study on “Worth Trust Rehabilitation Unit,” Katpadi, Tamil Nadu

Special School for Children with Speech and Hearing Impairment

WORTH Special School was started in 1999 with seven students and two teachers. It became a government-recognized special school in 2003. They were currently working well with 53 students and 9 Special Educators. Classes are conducted in the school from Pre-Primary to class 1 to 5th, and the subjects are taught as per the Tamil Nadu Government State Curriculum, and it is introduced from Class I onwards. Daily activities School starts with worship at 9 am. Before that, all the students will check and wear hearing aids. Before starting the daily classes, breathing exercises, babbling exercises, and speech training are given according to the class subject. All classes have daily calendar training. Pre- School classes include breathing exercises, speech training, primary language, Maths, Environmental Science, and writing. Each day is divided into eight sessions of 40 minutes, with a break between two sessions and training followed by a break after the meal and re-teaching of the games.

Day Activity Centre for Children with Intellectual Challenges (DAC):

This activity center was started in 2007 with a specialty to train the children by involving their parents or caretakers so that they can continue the training even at their homes. The Day Activity

Centre offers a specialized training program for children and adolescents with Cerebral Palsy(CP), Autism, Attention Deficit Hyperactive Disorder(ADHD), and Mental Challenges(MC). The Centre trains around 168 children, who get trained on Living Skills, Academic Education, Vocational Skills and Domestic skills and activities. The children regularly participate and excel in various sports, cultural, and other co-curricular activities also.

Regular Summer Activities for the children and adolescents with disabilities

- i. Handwriting practice to the students as per the class levels.
- ii. Exercises on vocabulary, consonant sequence words in language exercises with the support of parents.
- iii. Number writing practice of the numbers from 1 to 100, 100 to 1000, and 1000 to 10000 as per the class levels.
- iv. Encouraging the students to read newspapers and magazines with the support of parents.
- v. Creating shapes by connecting dots.
- vi. Detect the minor differences in identical images and select the correct image
- vii. Discovering complex puzzles.
- viii. Practicing an orderly system of daily cleanliness, physical exercises, self-cleanliness exercise, and food habits.
- ix. Knowing the relationship patterns at home.

Implementation of Innovative Activities

Since the children and adolescents with disability could not attend the school due to the lockdown, Worth trust felt that the students needed to stay motivated and healthy at home during the

pandemic. So, the students were kept engaged by implementing the proposed innovative activities through instructional and demonstrational videos online.

Innovative Initiatives/Activities implemented during the summer vacation of the COVID -19 pandemic period are presented below:

The main innovative indoor and outdoor activities proposed and implemented are:

- i. Gardening Therapies
- ii. Folding Techniques for Clothes
- iii. Arts and Crafts Practice
- iv. Speech Training by Oral-Aural method
- v. Inclusive Playing of Outdoor games
- vi. The practice of Purposeful Savings

These activities were implemented in May with a weekly schedule to learn and practice these special activities. The purpose and importance of training these activities were circulated in Tamil to the parents of the children and adolocents with disabilities in the Rehabilitation Unit for children for their better understanding with multisensory approach as scientific method of innovative training.

Gardening Therapies

Gardening therapy is very effective, and in this activity, all the Children and adolocents with disability and their parents were encouraged and instructed to grow as many plants as they can in their accessible outdoor or surroundings to keep themselves active and cheerful, especially during this COVID-19 pandemic. They were all given a project/assignment to grow plants that would give more oxygen, prevent air pollution, be helpful in

day-to-day life, etc., and choose whichever was possible and they liked.

Cognitive Benefits

The children and adolescents with disabilities learned about plants and gardening, how the plant grows, lives, and changes over a period. This approach led to the cognitive development of the differently-abled children by focusing their attention in a healthy natural environment which improved the concentration, memory, patience, and initiation, monitoring, and management of tasks with surroundings.

Physical Benefits

Gardening activities are efficient and feasible for children and adolescents with disabilities. Gardening activated the children's muscles very well when they performed stretching, bending, lifting, pushing, and pulling activities. The activation of the muscles made them stronger and enhanced stamina, coordination, balance, flexibility, and motor skills.

Social Benefits

The children and adolescents with disabilities got the opportunities to interact socially when gardening with parents, siblings, and neighborhood people in their home space and the surroundings. The children experienced problem-solving, were able to work with freedom, followed the directions and instructions of the parents, observed the happenings in the surroundings curiously. The outdoor activities also improved their communications with their peers and outsiders with improved socializing skills.

Sensory Benefits

The gardening activities facilitated the children and adolescents with disabilities to activate and explore their senses very

constructively with sensing of different plants, rustling sounds of the leaves, the smell of various flowers, touching of soils, etc. The children were involved in selecting plants with a sensory orientation by recognizing the color, smell, texture to encourage the interaction with the soothing elements of natural gardens.

Gardening for a Stress-free and Happy Life

The garden can be a private haven for relaxation. A breath of fresh air, the mild scent of the blooming flowers, and all the greens around actually have brought calmness for the mind and body of the children. The children posted their planting activities in WhatsApp groups and were excited to see each other's gardening activity, enjoyed and got motivated to engage and learn more through gardening.

Folding Techniques for Clothes

Dressing activities help children learn how to care for their clothes and help in other areas of development. Learning to fold and maintain different types of dresses and clothes is an art and an essential skill that requires good eye-hand coordination. It also enabled the students to learn geometric and simple mathematics.

Initially, children were taught and demonstrated step by step to fold simple clothes like a tea towel, T-Shirts, etc. Then, they were demonstrated with more categories of clothes that are used in their day-to-day life. Different folding techniques as per the size and design of the clothes were taught to maintain the clothes intact in fold conditions and save space in the almirah.

This activity encouraged teaching and learning through a playful method and ensured that all children had had the life skills needed to care for their dressing activities. The main areas of developments planned through this activity are:

Physical and Intellectual development

Practicing folding techniques of various clothes helped the children to improve their hand skills and free movements of their upper limbs. This also develops both creative and critical thinking abilities for the children.

Applied Mathematics and Understanding the forms and proportions

This activity helped the children develop the concepts of a quarter, half, and three by four proportions while practicing the folding techniques of different clothes. The students understood the profiles of the garments and sectional profiles of the panels/components and their proportions in the whole design of the clothes through the demonstrations.

Improves the Self Reliance and Responsibility to Assist Parents

Through exciting activities with innovative techniques, children enjoyed the newness in the folding activity, engaged themselves very actively, and became more responsible for assisting their parents in organizing the clothes and almirah to maintain things tidy and hygienic. They also gained self-confidence and learned to be more independent.

Arts and Crafts Activity

Arts and crafts play a vital role in building various skills for physical and cognitive development. So the researchers, in consultation with the educators, designed various arts and crafts as per the levels of the classes. The special educators implemented the activities with the support of the parents. The importance and advantages of the Arts and Crafts activities for

the children with disabilities are paramount, and some of the benefits are discussed below:

Improvement of Fine Motor Skills and Coordination

The activities enabled the children with disabilities to use their fingers to handle and manipulate arts and crafts materials, thereby developing their fine motor skills by activating their forehands' small muscles and joints. The Children began to understand complex ideas like relationships, shapes, and numbers by developing eye-hand coordination and fine motor skills. Drawing dots and lines, painting with different mediums, colors, shapes, brushes, and cutting with scissors have improved dexterity and fine motor skills, and the children enjoyed performing the activities.

Enhances Literacy and Communication Skills

The arts and crafts activities developed the communication skills of both verbal and non-verbal nature. The children answered the questions by the parents and teachers for the reasons behind choosing a particular color, paint, or a tool and learned new vocabulary and terminologies from parents and teachers.

Develops Math Concepts

Arts and crafts developed mathematical skills in children with disabilities . Children learned about and have recognized various forms, shapes, counts, managed to arrange the art and craft materials. They were able to measure the materials to the lengths and different sizes.

Promotes Problem Solving Ability

Art and creativity helped improve the sense of analysis, solving the problems that are critical skills required for success in life.

By engaging in artistic activities and explorations, children developed confidence in their abilities and learned to think with reasoning. The arts encouraged risk-free exploration with a freedom that has built confidence and problem-solving ability.

Improves Creativity

Art allowed children to develop their creativity and be more productive, which is essential throughout their lives. The children were able to express their feelings and new ideas and gained self-confidence. The variety of materials with different colors, shapes, sizes and handling activities enabled the children to experiment and make the crafts of their choice with a freedom that brought out the students' natural creativity. This may even help them later choose lucrative careers in creative fields like fashion design, product design, graphic design, etc.

Spending Quality time / Parent Bonding

The children with disability had to spend more time with their parents when they did the activities with the support of their parents. The parents also spent quality time and cared for their children with love and affection. During this constructive time, the children tend to talk about making the art and craftwork with their parents by sharing their ideas, getting suggestions from their parents, and freely expressing their different ideas.

Limited use of Technology

Engaging the children in arts and crafts by their parents diverted them from spending their whole time on technology-driven devices or looking just at a screen as many parents resort to Technology like mobile, computer, TV, etc., to keep their children engaged completely.

Enables free expressions

These activities enabled the children to freely express their feelings, emotions, and observations through the arts and crafts works they practiced. The children felt comfortable getting engaged in arts and crafts, shed their shyness and fears, and quickly expressed their emotions and thoughts through visual arts and craftworks.

Speech Training by Oral/ Aural Method

THE EDUCATORS ADAPTED the ORAL-AURAL training method and supported by the parents with different approaches for the children with speech and hearing disabilities. Appropriate methods were adapted by understanding the difficulty levels of the children to improve their speech, memory, and learning abilities. The educators and parents started to focus more on the Oral/Aural teaching method at home, especially for Children with Speech and Hearing disabilities from remote mode.

In this training, the children were taught to speak and communicate freely and precisely through various methods without applying sign language. Using different techniques, instructions were designed to accelerate the child's ability to acquire spoken language throughout the day.

The special educators and parents listened carefully during various activities to what the child said to help them speak better. The educators capitalized on the teachable moments to help children improve the child's language and speech quality.

Training activities to develop Auditory Skills

Activities that improve auditory skills were given due importance to observe and receive the amplification of sounds appropriately. Some of the activities practiced are discussed as follows:

Distinguishing Sound Sources and effects

In a natural environment, the children were guided to hear and differentiate sounds like footsteps, motorcycles, cars, autos, emergency vehicles, etc. The rhythmic tapping of footsteps, claps, pen tapping the table, music, bell, door opening, birds chirping, toilet flushing, etc., were also included as the sources of sound to hear and practice. The procedures of these exercises were instructed remotely to the parents to practice at home and nearby surroundings.

Recognizing Sound Shadows

In this activity, with a fixed sound source, learning children with disability could sit on the chair or stool when hearing the sound. When the children practiced it, large cardboard was placed between the children and the sound source. The children were asked to recognize the difference between the sounds in the presence and absence of the board. Then the parents walked with the cardboard such that the audio spread had more dynamic change until the student identified the obstruction passing between them and the sound source.

Recognizing Sound Masking

In this activity, students were guided to hear the sounds from two radios with two types of music or sound with the volume adjusted to make the sound level equal. The students/children with disabilities were advised to sit in a position or location to hear both radios equally. Then, the students were asked to raise the sound of one of the radios such that the sound overpowered the sound of the other radio.

Localizing Sounds

The parents were instructed to begin the activity in a silent space or a room where they could control the space or environment

to maintain their sound cue as the only source of the sound. Then the sound source was playing a fixed sound as the parents walked around the students in a larger circle. The students were made to sit to focus the sound source and were asked to track the parents as they circumnavigated the students while ultimately going around in both clockwise and anticlockwise directions.

Inclusive Playing of Outdoor Games

The special educators and the parents guided the children with disabilities to play games outdoor mingled with other children. Playing outdoor games in a natural environment brought out the best in every child and was more enjoyable and developmental for the differently-abled children than talk therapy.

Playing outdoor games nurtured developmental activities like healing, growing, exploring, and communicating emotions and feelings. The inclusive playing of games with the children of all abilities enabled the children with disabilities to learn “person-first language,” which honored the individual child before their disability. Play in the natural environment alleviated stress, reduced anxiety, improved mood, and boosted happiness and well-being. In an outdoor environment where social interactions occurred, they contributed to greater acceptance, breaking down barriers, and fostering friendships even among their siblings. It encouraged social development in children of all abilities. It helped to bridge the communication gap, promoted unity and inclusion while playing together.

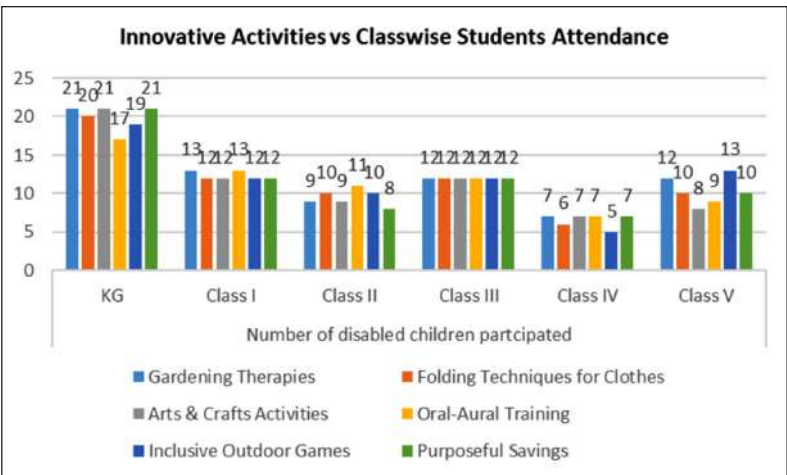
The practice of Purposeful Savings

The children were trained on savings, sharing, and spending with allowance for a meaningful purpose. Whether the allowances were to be tied to scores was an individual choice left with each family. One method that worked out well was to give kids a

flat allowance in exchange for the primary family responsibilities expected out of them (like maintaining their beds, folding clothes, feeding household pets, or doing any beneficial activity to support parents). The parents were instructed to deal with the allowances by emphasizing that saving and sharing were just as important as spending.

Some children saved in separate piggy banks or envelopes, and some elder children and adolescents saved in bank accounts by setting aside a portion of their allowances for their future spending. The most successful outcome of this activity was the contribution of these savings for COVID-19. The children with Speech and Hearing Disability, Intellectual Disability, Autism Spectrum Disorders, their parents, and the respective class educators jointly contributed Rs.41500/- as a donation for COVID-19.

In a nutshell, all the innovative programs planned and implemented during the COVID-19 lockdown period were well received and supported by the parents of the children with



C-9. Class wise students (Children with Disability) distribution in the Innovative Activities

disability and well-executed by the special educators and school management. The number of students who participated with enthusiasm and commitment in all the six programs, class-wise are illustrated below in C-9:

The children have participated in these activities mixedly; the number and composition varied in each activity. Some children have participated in all the activities, some in many and some in few activities.

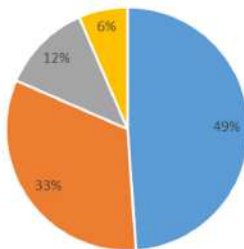
Feedback of the Beneficiaries

At the end of the training activities, the parents were instructed by the researchers and special educators to continue practicing all the activities as applicable for the various levels of the students at their home as the rehabilitation unit, the special school, and the daily activity center were closed due to pandemic lockdown as per the Government order.

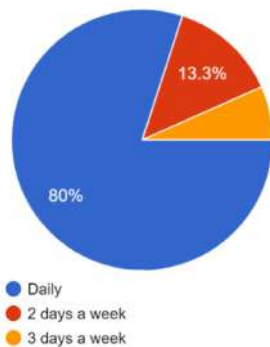
The parents were able to train the students at their homes with the remote guidance given by the special educators. Then, a semi-structured feedback survey was conducted with the parents of the children with disabilities, undergone training on the innovative activities with the supervision of the special educators for assessing the outcome/impact of these remote training activities.

About 85 parents have responded to the survey questionnaire distributed online with the guidance of the teachers. The Feedback given by the parents on the training provided was very positive, and the parents have reported excellent improvements in their physical and cognitive behaviors. The benefits gained by the children and the parents and the developments that happened to the differently-abled children due to the training are presented as follows:

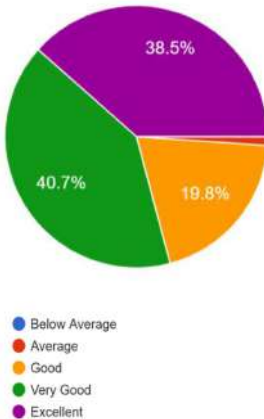
C-10 Gender wise distribution of Trainees



C-11. Frequency of training given remotely



C-12. Overall Feedback by the parent on the innovative training given



As found in chart C-10, out of the total students who participated in the special training and the follow-up practice remotely at their respective places, 49% belong to children-male, 33% belong to Children-Female, 12% belong to Adolescents-Male, and the remaining 6% belong to Adolescents-Female.

The frequency of the follow-up training and practice with the support of parents and the remote guidance of special educators is given in the chart C-11, which presents that 80% of the children undergone training every day, 13.3% undergone training two days a week, and the remaining 6.7% have taken the training three days a week.

The parents were delighted with the outcome of the training programs, and the overall assessment of the training programs is represented in C-12, which states that 38.5 % says Excellent, 40.7% says Very Good, 19.8% says Good, and the remaining 1 % says average.

Some of the significant benefits gained by the children and improvements reported by their parents as the impacts of the special training activities given are:

- Improvements in behavior, attention, listening skills, and speech level.
- Cooperating better with parents and assisting parents in house works.
- Watering the plants every day and spending time in gardening works
- Produce voice much better, improved vocalization
- They were becoming more regular, waking up early in the morning/on time, doing exercises, and maintaining the routine works independently.

- Started doing small savings, becoming more sensible in spending
- Improved socializing with friends and better relationships with siblings
- Developed speech with regular practice, better auditory skills, and asking more questions
- Reduced behavioral problems and better handling of emotions
- Improved drawing, painting, and artistic skills and developed simple crafts from the available materials.

Research Outcome

The outcome of the research work carried out thoroughly complies with the main objectives of the research. The problem identified and formulated was approached meticulously with appropriate research methods.

The researchers thoroughly understood the difficulties and challenges faced by children and adolescents with disabilities, especially those studying in special schools and rehabilitation centers and then suffering due to the COVID-19 pandemic lockdown conditions.

As the outcome of the research study through the survey conducted, the researchers proposed innovative activities for engaging and comforting the children and adolescents with disabilities during the vacation period for the well-being of the children and their parents.

The proposed innovative activities were successfully implemented in a special school/rehabilitation center belonging to Worth Trust, Katpadi, for the benefit of the stakeholders and real-time validation.

The parents and children benefited greatly from the special training programs offered remotely during the COVID-19 pandemic lockdown period. The concrete benefits gained by the children with disability and the improvements in their physical, emotional, cognitive, sensory developments and social behaviors due to the training given are reported in section 6.

Due to the specialised training activities conducted, the parents were relieved of the stress and pressure they experienced while caring for and managing the children and adolescents with disabilities during the pandemic lockdown.

Conclusion

The researchers strongly feel that the entire research work would be beneficial to one of the vulnerable communities of the society, i.e., the school going children and adolescents with disabilities who are vulnerable and deprived with the facilities, resources, and the benefits enjoyed by the non-disabled people in our society are lacking to the persons with disability. The problems, difficulties, and challenges become multi-folded during this crisis period like pandemic lockdown due to the absence of adequate resources and support mechanisms. In this context, the innovative activities proposed, implemented, and the outcomes achieved in this research work gain significance in addressing the critical challenges and difficulties faced by children with disabilities. Further, the scope of the research includes implementing innovative activities in a sustainable manner, even during the non covid period in the special schools, rehabilitation units, state and central government schools to rehabilitate and develop children with disabilities to their full potential towards building together the inclusive society.

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SC's Comparative Suffering Approach: Division & Illusion

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Abstract

The Supreme Court of India has adopted the comparative suffering approach in the disabled concerning transportation, government jobs, and admission to educational institutions. This has been done even when the legislation concerning the disabled does not require this. The approach has not brought any benefit to the disabled. Instead, it has splintered the disabled into each kind of disability or merged them with general poverty or the scheduled castes and scheduled tribes. This failure to judicially recognize the disabled as a separate legislative category carries the danger of division and rule. It puts the unity of the disabled movement as such in danger. It pits one disability against another, merges the disabled into the vast spectrum of poverty, and pits the disabled against the SC/ST for concessions, government jobs, and admission to educational institutions. Three Supreme Court judgments, Javed Abidi vs. Union of

India, National Federation of the Blind vs. Union of India, and Aryan Raj vs. Chandigarh Administration, are analyzed to exhibit how the judicial process of the highest court in India has sowed the seeds of division and illusion.

Key Words: Comparative suffering, Economic capacity, merger, poverty, SC/ST

Introduction

Three Supreme Court judgments have taken a comparative suffering approach in cases of the disabled under the Persons with Disabilities Act, 1995 (PWD Act, 1995). The thinking process remains valid for the Rights of Persons with Disabilities Act, 2016 (RPWD, 2016), after the repeal of the 1995 Act. An analysis of the three judgments shows that the Supreme Court's approach involves more potential suffering for the disabled. It is an approach of illusion and division for the disabled. It dissolves the disabled as a unified class.

Literature Review

Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (PWD Act, 1995), Rights of Persons with Disabilities Act, 2016 (RPWD Act, 2016).

Methodology

Doctrinal research based on Supreme Court of India's judgments.

Two judgments and one Order (Judgments: Javed Abidi vs. Union of India and Union of India vs. National Federation of the Blind. Order: Aryan Raj vs. Chandigarh Administration) of the Supreme Court of India have interpreted the Persons with Disabilities Act, 1995 (PWD Act, 1995) by referring to the suffering of one disability against other disabilities, to poverty and the facilities granted to the Scheduled Castes/Scheduled

Tribes. Under S.2(i) of the PwD Act disability means (i) blindness (ii) low vision (iii) leprosy cured (iv) hearing impairment (v) locomotor disability (vi) mental retardation (vii) mental illness. After India signed the 2006 UN Convention on the Rights of Persons with Disabilities, the 2016 Act rationalizes this list by introducing the ideas of impairment, full and effective equal participation in society, and a disabled with high support needs. The vital point remains for the disabled for being productive citizens eligible for jobs in government establishments wherein reservation stands increased to four percent from three under the 1995 Act.

Two Consequences: Illusion & Division

The first consequence of this implicit approach of comparative suffering is the creation of a judicial illusion in terms of its Art.32(2) (Art. 32(2) of the Constitution of India, COI, 1949) power to issue directions for enforcement of fundamental rights. The Supreme Court in the two judgments and the order has not laid down time limits, periodic reporting to it, and mandatory help from the relevant administration to ensure the rights of the disabled.

Worse, the second consequence is that it creates a fertile divisive ground by pitting the disabled against the legal, socio-economic and constitutional divisions of India's population, competing for reservations in transport, jobs, and education---- the three crucial areas for the disabled under the 1995 and the 2016 Acts. These three areas are the gateways for the disabled under the 1995 and the 2016 Acts, to the fundamental right of equal opportunity for public employment (Art. 14, 16 (1) of COI, 1949) and an inclusive life of dignity (Supreme Court in *Francis Coralie Mullin Vs. UT of Delhi*, 1981, 1 SCC 608 on Art. 21) with the abled.

The first Supreme Court judgment, *Javed Abidi vs. Union of India* ((1999)1SCC467), related to airfare concession only for the locomotor disabled. The second judgment, *Union of India vs. National Federation of the Blind* (*Union of India v. National Federation of the Blind*, (2013)10SCC772), related to government jobs. The third “Order” (July 8, 2020, in Civil Appeal 2718 of 2020) related to admission to an educational institution vis a vis the relaxed qualifying percentages for SC/ST.

The 1995 Act has been repealed and replaced by the 2016 Rights of Persons with Disabilities Act, 2016 (RPWD Act, 2016). However, this judicial thought process of comparative suffering promises to continue, as shown by the July 8, 2020 order of the Supreme Court in *Aryan Raj vs. Chandigarh Administration* under the 1995 Act. The 2016 Act has nothing to check this nil- evidence-based judicial approach, which only holds the promise of prolonged legal battles of one disability versus other disabilities, disabled poor versus able poor, disabled vs. SC/ST. The repeal makes no difference because the three gateways for the disabled to a life of dignity—transport, jobs, and education—remain the same under the 2016 Act to be interpreted by the same Supreme Court bound by the precedents of its thought process. This judicial recipe gives a handy tool to the political class for dividing and ruling the disabled. It has been made possible by these three judgments of doubtful legality and constitutionality concerning the identity of the disabled.

Who is More Disabled?

The first judgment concerns the Indian Airlines concessional fare for the blind in *Javed Abidi vs. Union of India* (Supreme Court Case, citation: (1999) 1 SCC 467). Mr. Abidi has a locomotor disability and, arguing in person, informed the court that the

concessional fare was already being granted to the blind disabled. He contended that “the orthopedically handicapped persons with a locomotor disability require the relief of concession for air travel more as it becomes an impossible task for them to travel from one corner of the country to the other corner of the country and there is no justification for the Airlines not to grant such concession to such people when the concession is made available to the blind people.” The argument legally fractured the disabled as a class. It divided the disabled into each legal category of disability recognized under the PwD Act, 1995. The issue that ought to have been presented before the court was whether Indian Airlines could deny equality of treatment in the matter of concessional airfare for all the disabilities under the 1995 Act except for the disability of blindness(already receiving the concession), with a request for data from the Union Government on the use of the Airlines by the disabled certified under the 1995 Act and the potential number of disabled with financial ability to pay even the concessional fare. The data could have been obtained through the Attorney General, who was the counsel for the Airlines. This would have kept the disabled as a class regardless of their particular disability and linked disability to poverty to pay the concessional fare. However, the trajectory of the legal discourse in the case had been set by the argument only for the locomotor disabled. It would have segregated the disabled with paying capacity from those without paying capacity.

The court’s response to Mr. Abidi’s argument was that of comparative suffering. It was expressed as: “When we consider the different types of disabilities mentioned in S.2(i) of the Act and examine the same about the difficulties one may face by traveling by train to far off places, say from Delhi to Trivandrum, those who are suffering from the locomotor disability would stand by a separate class itself because of their immobility and

the restriction of the limbs. It may not be difficult for a person with low vision or hearing impairment or mental retardation or a person suffering from leprosy to travel by train, even far-off places. In contrast, a person who has locomotor disability above a certain percentage of the same will find enormous difficulty in traveling by train or bus.” Hence, in concessional airfare by a State-owned Indian Airlines, subject to fundamental rights of all the legal categories of the disabled in the Act, locomotor disability was hived off from the other disabilities for the concessional fare. The loud and clear message was that for concessional airfare from a State-owned airline, each legal category of disability had to construct its case in terms of that particular disability and vis a vis another category of disabilities. This only added another legal hurdle for the disabled to those existing under the Act itself, without excluding the creamy layer of the disabled from appropriating the scarce resource of concessional airfare.

Other Disabilities—No Notice

The court did this without notice to those suffering from disabilities other than locomotor and blindness (Indian Airlines told the court that it was giving concessional fare to the blind even prior to the 1995 PwD Act). The opportunity for a hearing for the other disability categories, on the court’s comparative suffering basis for hiving off locomotor disability from other disabilities in terms of mobility and air travel, could have been given by a specific notice to the Union Ministry of Social Justice liable for implementing the Act under the Govt. of India’s Allocation of Business Rules, 1961. The notice could also have gone to NGOs, private and semi-government specialized institutions working for each of the disabilities under the Act. However, the court, in its wisdom, did not even consider doing this.

No Evidentiary Basis

This was done without any evidence from disability medical and psycho-social experts as to whether the mobility and travel suffering of the locomotor disabled is more than that of the other legal classes of disability under the Act.

For national and international data, the judges have court-paid law interns at their research homes and can issue notice to any government or non-government institution doing disabilities work. Nevertheless, the judgment has no indication even that the judges thought in this direction at all. Law is the reason, and reason comes from the scientific temperament. The hypothesis of comparative suffering laid down by the court was without relevant data, reason, and the scientific temperament (COI Art 51A(h)--- It shall be the duty of every citizen of India to develop the scientific temper, humanism, and the spirit of inquiry and reform) concerning the comparison of disabilities in the context of mobility for the disabled.

Role of the Attorney General

The probable reason for this was that the thought process pitch in the case had already been queered by the Attorney General of India appearing for Indian Airlines. The Attorney General focussed on the economic condition of Indian Airlines instead of how to facilitate the disabled. As the constitutionally recognized counsel for all Indians, the Attorney General could have led the court to put the entire issue in the framework of the fundamental right to movement under Art 19(1) (d) and the need to enable disabled citizens to enjoy this fundamental right through a concessional fare for all categories of legally recognized disability. The economic condition of Indian Airlines would then have been of no avail against the enforcement of the fundamental right of a disabled citizen. However, the Attorney

General chose to act like any other law officer of the Union Government and limited himself to defending his client, the Indian Airlines, instead of rising above his brief as the highest and only constitutional officer of the court, to press for the fundamental right of the disabled.

Accordingly, he advanced the argument that “the Act itself postulates for providing facilities to the disabled persons within the limits of economic capacity.” (Francis Coralie Mullin Vs. UT Delhi, (1981)1SCC608). He did not refer to Directive Principle, COI Art.41(The State shall within the limits of its economic capacity and development, make adequate provision for securing public assistance...)

This argument in itself was fallacious as the Act nowhere generally provides that any facility provided under it is limited to the economic capacity of the provider of the facility. The specific sections that refer to this limitation in providing the facilities under the Act were Section 46, non-discrimination in the built environment; S.47, non-discrimination in Government employment; S.66 on rehabilitation; S.67 on insurance; S.68 on unemployment allowance. Airports and air travel do not find a specific mention in the 1995 PwD Act.

Without examining the Act to locate the provision which says what the Attorney General was contending, the court declared that it agreed with the Attorney General that “the economic capacity is a germane consideration to decide the question as to whether all persons who have a disability as defined under S.2(i) of the Act, should be granted concession like blind persons for traveling by air....”

The Attorney General, confining himself to the role of an ordinary law officer bound by the State-owned Airlines instructions, did not state that if economic capacity were a

germane factor, then the examination of the lack of such capacity would also be germane. If a State-run institution puts its case on the lack of its economic capacity to abide by the fundamental rights of the disabled, then the question would be whether persistent mismanagement of State resources has resulted in such economic capacity. If so, then State-run Airlines cannot take advantage of their wrong to deny air concession facilities to the disabled under the Act. This issue was ignored by the Attorney General, mentioning neither any fundamental right nor any specific provision of the Act relating to economic capacity in this context.

Role of the Court

The court then tried to balance the “germane” economic capacity argument to the broad objectives of the Act. It simply limited the issue to air concession on the State-run Airlines for the locomotor disabled by using the hypothesis of comparative suffering of such disabled vis a vis other legal categories of the disabled under the Act. In short, the court created a separate class of the locomotor disabled vis a vis the airfare concession for air travel without any evidence of comparative suffering to deprive other legal categories of the disabled under the Act of this concession.

However, the court did not stop here. It then entered the legislative field of Parliament to lay down that even among the locomotor disabled, the entitlement to the concessional airfare would be only for those with locomotor disability of “80% and above”. The Act stipulated in S.2(t) only a minimum of “forty percent of any disability as certified by a medical authority.” The Court ensured the enforcement of its minimum of 80% locomotor disability by directing the District Medical Officers to issue certificates of locomotor disability for this purpose

only based on the minimum of 80%. The court's only reason for doing this was that "we think it appropriate to direct." No provision of the Constitution, no general principle of law, and no provision of the Act was mentioned. The concluding reference was again to the economic condition of Indian Airlines and the "broad objectives of the Act." The court arrogated to itself the power to customize a Parliamentary law to what "it thinks appropriate."

Consequences for the Disabled

The socio-legal damage caused by this approach of the Supreme Court was:

- i) It pitted the seven kinds of disability against each other and thereby made it possible to fragment the disability movement.
- ii) It enabled State-run enterprises to plead lack of economic capacity to deny even those facilities to the disabled which are not subject to the condition of the economic capacity of the provider under the Act.
- iii) It showed the path for the court to do what it wants with a Parliamentary Act without any evidence-based rule of reason. Hence, though the court found that air travel was necessary for the locomotor disabled, it arbitrarily raised the de minimis qualifying disability to 80 from the legally stipulated 40 percent. The court did this without calling for medical or any other evidence regarding the number of disabled who would get or be denied the relief of airfare concession.
- iv) It demonstrated how the Attorney General could remain unaccountable for the constitutional and legal rights of the disabled by acting like the Solicitor General or other law

officers of the Union Government, even though he is a constitutional appointment to a constitutional office.

Merger with Poverty

In the second case, *Union of India vs. National Federation of the Blind* (Union of India v. National Federation of the Blind, (2013) 10 SCC 772), the suffering of the disabled found itself merged with that of the poor in general, in the context of the mandatory minimum three percent job reservation in government establishments under S.33 of the Act. The court had to clarify that the minimum three percent job reservation for the disabled is to be calculated based on all the vacancies in the cadre strength of service under a Union Ministry, as shown in the mandatory roster of vacancies required to be kept by each cadre controlling authority or each Ministry of the Union Government. The court had to reiterate its 2010 judgment (*Govt Of India Th: Secy & Anr vs. Ravi Prakash Gupta & Anr on* (2010)7SCC626) that the vacancies for reservation of jobs for the disabled were just vacancies and not only those vacancies which the Union Government had identified as being fit for persons with specific disabilities. Further, this calculation method applied to all the posts in Group A, B, C, and D and had to be calculated from 1996, when the Act came into force. The disabled seem to have lost out on the backlog of vacancies so calculated, as the court did not pass any order for calculating and reporting these vacancies by a specific date.

Reliance on the Union Government to calculate and give the benefits of accumulated vacancies would be misplaced given that the disabled have had to litigate against successive government hurdles against their entitlement to reserved jobs under S 33, PwD Act, 1995. Thus, the disabled find themselves in the court against the UPSC's decade-old practice of announcing

“expected approximate vacancies” for the annual All India Civil Services Exam, instead of vacancies, as mandated by the PwD Act, 1995 and then the RPwD Act, 2016, the rules under these Acts, the Civil Service Exam Rules of the Union Govt. and the detailed administrative proformas (January 16, 2020, Office Memorandum No. 39011/02/2019-Estt (B) GOI Ministry of Personnel, Public Grievances and Pensions (Department of Personnel and Training) of the Union Govt. to inform the UPSC of the “vacancies” in each Ministry. The disabled do not have the economic and physical muscle to fight the Union Govt and the UPSC every year in the courts. The legality of this practice has been pending for over one year in the high court of Delhi, as public interest litigation, in *Sambhavana vs. Union of India*(CWP 5153/2020). S.25(c),(f), and (h) of the 2016 RPwD Act provide for screening, care of mother and child, and awareness. The 1995 Act had no such provision. However, the court could have referred to preventive care based on the Fundamental Right to health under COI Art.21(*Vincent Panikurlangara vs. UOI* (1987)2SCC165)

Reservation: Disabled a Separate Class

The judgment repelled the Union Government’s attempt to apply the fifty percent quota ceiling to such reservations based on the Supreme Court’s judgment in *Indra Sawhney vs. Union of India* (*Indra Sawhney v. Union of India*, 1992 *Supp 3 SCC 217*) concerning reservation in government jobs for SC/ST and OBCs. It did this by declaring the SC/ST/OBC reservation as a vertical reservation for the disabled as a horizontal reservation. In short, the suffering of the disabled was distinct from that of the SC/ST/OBC, and so the fifty percent reservation quota ceiling of the SC/ST/OBC was inapplicable to the reservation for the disabled. This seems to be seriously impacted by the

2020 Supreme Court's order, discussed below, in the *Aryan Raj vs. Chandigarh Administration* case.

However, in its conclusion, the court merged the disabled into the poverty class of Indians by pointing out that many disabled persons live in poverty because of the "social and practical barriers which prevent the disabled from being part of the workforce." The suffering of the disabled was the same as the suffering of the poor. A recognition that the disabled face social and practical barriers over and above or in addition to those of poverty only would have reinforced the concept of the disabled being a class by themselves among the poor. The courts do not take cognizance that non-implementation of the provisions to prevent disability results in more and more disabled. Nevertheless, when the disabled come to the court, they are not recognized as a separate class of citizens who are witnesses to the failure of the rule of law since their birth (*COI. Vincent Pani Kur Langara Vs. UOI* (1987) 2 SCC 165).

Court's Failure

Having declared a direct link between poverty and disability, it was legally expected that the court would ask the Union Government to identify the social and practical barriers and what it was doing to at least lessen such barriers. This was not ordered. The court did not ask the Union Government to point out any specific anti-poverty programs meant only for the disabled. There was no attempt to determine whether the poverty of the disabled and the barriers keeping them in poverty were caste-based and in which segment of poverty the disabled were located.

The implicit comparison of the suffering of the disabled as the poor did not yield any court order for viable steps to be taken by the Union Government for the disabled poor or for even being counted accurately and adequately in the Union Government's

labor surveys. Before making this declaration in its conclusion, the court did not seek any socio-economic, human geography, or psycho-social data about the disabled.

The merger with poverty brought no benefit to the disabled. It only diminished the legal recognition of the disabled in the Indian population of the able, leaving the disabled to fend for themselves in a hostile sea of the able. The Union Government escaped from any constitutional or legal accountability with a judicial lecture on its legal duty under the international law of human rights and Conventions to which it is a party. This was the logical result of the absence of relevant data to permit the legal construction of a minimal accountable framework concerning the poverty of the disabled. The absence of data happened despite the court having the legal power and the human research resources to secure this data. Nevertheless, the absence of data was not even recognized. It did not direct the National Legal Services Authority working directly under it to produce a Legal Plan of Action for the disabled.

The court's failure to act on the acknowledged poverty of the disabled left the disabled in an "as is where is" position under a constitution which does not mention anywhere in the Fundamental Rights, poverty, health, national resources, and territorial accountability of the legal managers of India----elected representatives and a non-elected administration and judiciary. The disabled were left only with the court's lamentations.

Judicial Elegies

The court lamented, "even though the Act was enacted way back in 1995, the disabled people have failed to get the required benefit until today," October 8, 2013, the date of the judgment. With this approach, as expected, the lament of the court in the cases of the disabled continued in 2014 and then

in 2016. In *Sunanda Bhandare Foundation vs. Union of India (NATIONAL INSURANCE CO. LTD. & ANR. v. KIRPAL, 2014)*, the court was writing the elegy: “More than 18 years have passed since the 1995 Act came to be passed and yet we are confronted with the problem of implementation of the 1995 Act in its letter and spirit by the Union, States, Union Territories and other establishments to which it is made applicable.” The judicial mourning continued in *Rajeev Kumar Gupta vs. Union of India (Rajeev Kumar Gupta & Ors vs. Union Of India & Ors on June 30, 2016)*: “It is disheartening to note that (admittedly) low numbers of PWD (much below three percent) are in government employment long years after the 1995 Act.” When the highest and proverbially the most powerful court in the world can only give endless elegies on the failure of the law to deliver to the disabled what is legally theirs, the disabled can only wring their hands in despair.

SC/ST & the Disabled

The third case is *Aryan Raj vs. Chandigarh Administration (Aryan Raj vs. Chandigarh Administration, July 8, 2020)*. Whether the disabled are entitled to the same relaxation of marks as given to the SC/ST candidates for admission to various courses. The case involved the aptitude test for a painting course. The Supreme Court gave a cryptic order holding that the disabled Aryan Raj before them was entitled to the same relaxation for qualifying the aptitude test as that given to the SC/ST candidates (35% pass marks instead of the normal 40% marks for candidates). There was no judgment. That is an order with reasons. Only an “Order” was passed. For passing this order, the court stated that it was “following the principle laid down in the Delhi High Court’s (*Anamol Bhandari (Minor) Through ... vs. Delhi Technological University on September 13, 2012*) judgment in *Anamol Bhandari (Minor)* through its father/Natural Guardian

vs. Delhi Technological University.” In the Delhi high court case, Anmol Bhandari had applied for the B.Tech Computer Science course as a duly certified disabled candidate. He was ranked in the All-India Engineering Entrance Exam conducted by the CBSE. However, he was denied admission as he did not fulfill the minimum eligibility of 55% marks in Physics, Chemistry, and Maths in the qualifying school exam, even after being given the five percent relaxation for disabled candidates. After the relaxation, he had only 52.66% marks. However, if he were given the ten percent relaxation meant for the SC/ST candidates, he would qualify because the eligibility marks would be only fifty percent after deducting ten percent from the sixty percent normal eligibility marks.

The high court, after examining the Union Govt's National Policy for Persons with Disabilities, a 2007 World Bank Study, National Sample Survey reports on school education of disabled children, the Census 2001, Article 21A of the Constitution, the education provisions in the PwD Act, 1995 and the National Policy on Education held as discriminatory the provision giving only five percent concession in marks to PwD candidates as against ten percent relaxation for SC/ST candidates. It was fortified in its conclusion by the Supreme Court's March 19, 2002 judgment in *All India Confederation of Blind vs. Union of India* and the Union Govt's reply that it agreed to extend the same benefit to visually handicapped persons as was enjoyed by SC/ST candidates. The high court concluded “all those mentioned above clinchingly demonstrates that the people suffering from disabilities are equally socially backward, if not more, like those belonging to SC/ST categories and therefore as per the constitutional mandates, they are entitled to at least the same benefit of relaxation as given to SC/ST candidates.” The Supreme Court in its order has stated that what the high court

has concluded is “correct.” It would follow the same principle as laid down by the Delhi high court. There was no evidence of the comparative suffering of the disabled vis a vis SC/ST in the high court judgment nor the Supreme Court order based on that judgment. The scientific temperament, a constitutional duty, was missing again.

Consequence

The order of the Supreme Court promises to push the disabled into prolonged litigation on a host of questions untouched and left unanswered by the order:

- i) If the disabled are entitled to the same legal facilities as are meant for SC/ST, then does the ceiling of fifty percent reservation in any facility apply to them. (See the discussion above on the second judgment, *National Federation of the Blind vs. Union of India*) As pointed out above, the Supreme Court had repelled the application of this ceiling to the disabled on the ground that reservation for the disabled is horizontal under Art.16(1) of the Constitution, whereas the reservation for SC/ST/OBC is vertical. This logic becomes tenuous after the Supreme Court order in the *Aryan Raj* case.
- ii) Under the *Aryan Raj* order, does the interlocking category of a disabled who is also SC/ST remain valid?
- iii) If all the disabled are entitled to the same facilities as those extended to SC/ST, then does it amount to effectively recognizing the disabled as SC/ST, and if so, can the list of SC/ST, issued by the President under Art.341(1) (Art. 341 (1) of COI. June 5, 2021) COI, be extended judicially because of Art.341(2) of the Constitution of India.

- iv) Whether the disabled, on being given the same relaxation as the SC/ST in qualifying marks or evaluation standards for reservation in matters of promotion, will be subject to Art.335 (Siddaraju vs. the State of Karnataka, 2020) COI?
- v) The issue before the Supreme Court involved the interpretation of Arts. 16(1), 341, and 335 of the Constitution, such issues are required by Art.145(3) (Art. 141 of COI, n.d.) COI, to be decided by a bench of at least five judges. Such an issue cannot be decided by a mere “order” and without issuing notice to the Union of India and at least to the Art.338 National Commission for Scheduled Castes. If so, then the per incuriam order in the Aryan case is not binding on anyone.

In short, the disabled seem to have lost out under the Supreme Court’s comparative suffering approach. Given the severe competition for government jobs and educational admissions in government establishments, the Supreme Court seems to have given the disabled further legal battles that will pit them against the Scheduled Castes. Furthermore, will the creamy layer doctrine laid down by the Supreme Court in Indra Sawhney apply to the reservations for the disabled? The Supreme Court order in the Aryan case seems to have a life of the disabled that much legally uncertain when what they are entitled to be legal certainty.

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Conflict of Interest

There is no conflict of interest whatsoever.

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- Art. 32(2) of COI (1949). “The Supreme Court shall have the power to issue directions ... for the enforcement of any of the rights conferred by this Part.”
- Art. 141 of COI. (n.d.). The minimum number of judges who are to sit for the purpose of deciding any case involving a substantial question of law as to the interpretation of this Constitution... under Art. One hundred forty-three shall be five.
- “Art.14. The State shall not deny to any person a quality before the law or the equal protection of the Laws within the

territory of India.” “Art. 16(1). There shall be equality of opportunity for all citizens in matters relating to the employment of appointment to any office under the State.” (June 15, 2021). *The Constitution of India*. (1949). <https://legislative.gov.in/sites/default/files/COI-updated.pdf>

COI. Vincent Pani Kur Langara Vs. UOI (1987) 2 SCC 165. S 25 (c), (f) and (h) of the 2016 RPwD Act 2016 provide for screening, care of mother and child and awareness. The 1995 Act had no such provision. However, the court could have referred to preventive care based on the Fundamental Right to health under Art 21.

Constitution of India. (June 10 2021). Art.51A(h) “It shall be the duty of every citizen of India to develop the scientific temper, humanism and the spirit of inquiry and reform.” *Constitution of India*. (1949). <https://legislative.gov.in/sites/default/files/COI-updated.pdf>

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Supreme Court in Francis Coralie Mullin Vs. UT of Delhi, (1981) 1 SCC 608 on Art. 21.

Supreme Court Judgments/Orders on Disability and Mental Health (1999) 1 SCC 467 Note: Supreme Court Judgments are Available at <http://www.judis.nic.in>

Supreme Court in Francis Coralie Mullin Vs. UT of Delhi. (1981). 1 SCC 608 on Art. 21 of COI.

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Inclusive Education and Children with Disabilities in the Indian Landscape: A Review

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Abstract

The turn of the 21st century has brought to light the discourses on inclusivity and accessibility for vulnerable communities. The education of children with disabilities (CWD) has been a

substantial part of this discussion. Universal Design (UD) is a concept derived primarily from architecture- and has increasingly been at the forefront of this discourse. This paper has focused on five critical aspects of UD for inclusive education through a comprehensive literature review. These include- inclusive school policy, inclusive infrastructure, inclusive curriculum, inclusive teaching methods, and inclusive evaluation methods. Our search revealed many evidence-based studies and approaches of UD application in educational settings. These are discussed systematically with special reference to the Indian context. We have also suggested future directions for inclusive education in India, considering the current shift in education to online learning due to the COVID-19 pandemic. Our review will support disability literature in India, bringing the vital universal design perspective to disability action and inclusive education. It will find scope for inquiry by special educators, disability rights activists, and rehabilitation policymakers for discourse on UD and inclusive education in India.

Keywords- Inclusive education, universal design, disability, COVID-19, India, assistive technology, special education

Introduction

Inclusive education is defined as a system of education that promotes inclusion and support to the learning of *all* students, irrespective of their abilities and requirements. This includes creating inclusivity enabling teaching curriculum and infrastructure that supports and fosters the learning of all children in the same school (UNICEF, 2017). The Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) both express the urgent need of guaranteeing quality education to all and the holistic support required to develop each child's potential, especially keeping in

consideration the most vulnerable and marginalized groups of children. Article 24 of the CRPD protects the rights of Persons with Disabilities (PwD) to inclusive education, highlighting the importance of non-discrimination, inclusion, and proclamation of the right to education for PwDs on a global scale (Beco, 2014) Requirements and (Remaining.

India is home to a population of 1.21 billion people, out of which 372.4 million are children in the age group of 0-14 years. This translates to 30.7 percent of the total population of India being entitled to receive a quality education as their fundamental right (Verma et al., 2016).

Free and compulsory education of all Indian children aged between 6-14 years is an established fundamental right, with the Right to Education (RTE) for PwD under 18 laid down under separate legislation ensuring inclusivity (Ministry of Education, 2021). However, the Indian education system is essentially exclusive of children with disabilities (CWD) (Grills et al., 2019).

26.8 million or 2.21% of the Indian population suffers from a disability, out of which 7.8 million are estimated to be children. Over 2 million of these estimates fall in the age category of 0-6 years (Verma et al., 2016). Only 44.8 percent of PwDs are literate, with only 62.9 percent of those between 3-35 years enrolled in a regular school. Progression from the primary school level is complex, with only 9% of PwDs completing secondary education (Ministry of Statistics and Program Implementation, 2019). Along with this, the retention rate remains abysmally low, with only 23.1% of the enrolled children in the PwD category attending schools. Further, there is a cross concentration of disparities regarding access to education along with specific disability categories and gender, and female CWDs are less likely than male children to attend school (Ministry of Statistics

and Program Implementation, 2019). There are only 85,877 PwD enrolled students at the higher education level as of 2019, presenting with significant sex and caste differentials (Ministry of Education, 2020).

Lack of accessibility, availability of special instructors and quality of schools, and the unwillingness of families to invest in their child with disability remain critical reasons for poor indicators for PwD education in India. Since 74% of the PwD population of India resides in rural areas, awareness and advocacy for the rights of PwDs to a dignified life and education, skill training, and job opportunities remain largely inaccessible to the majority of the PwDs and their families (Verma et al., 2016). Moreover, although the latest education policy of India- the New Education Policy (NEP) 2020 refers back to the Rights of Persons with Disabilities Act (RPwD) of 2016 and declares barrier-free education for all CWD as an integral part of all teacher education programs, the implementation of RPwD itself to this day remains precarious (Press Trust of India, 2020).

In the above context, even though inclusive education for PwDs has been mentioned right from the advent of the RTE 2009 to NEP 2020, a gap in research exists concerning discourse and documentation of inclusive education approaches in India. Further, keeping with the gender, caste, and urban-rural divide, a discussion of inclusive education from the perspective of universal design is lacking, especially with relation to education for PwDs in the post- COVID-19 era (K. C. Deepika, 2020).

In this regard, our review has focused on the five critical approaches to inclusive education and universal design (UD), including- inclusive school policy, inclusive infrastructure, inclusive curriculum, inclusive teaching methods, and inclusive evaluation methods, along with a discussion on the education

of PwDs in the post-COVID era. Our review will support the disability literature in India, bringing to light the vital universal design perspective to disability action and inclusive education in India and find scope for inquiry by special educators, disability rights activists, and rehabilitation policymakers for discourse on UD and inclusive education in India.

Methods

Search strategy

A comprehensive literature search was carried out using different research databases such as Google Scholar, JSTOR, SAGE Journals, and EPW. A total of 40 studies were reviewed, and 15 government reports of India which mentioned PwDs and inclusivity were also referred. Relevant peer-reviewed literature and their reference sections were thoroughly examined, particularly in the Indian context. Studies published from 2010 onwards (last ten years), focusing on education for CWDs, and the inclusion of (but not limited to) the Indian context, were included. Studies published before 2010, not focusing on education for CWDs, or studies only focusing on inclusive education of adolescents or adults with disabilities were not included in the review. Government reports, policy papers, and grey literature relevant to inclusive education for CWDs in India were included to give a holistic picture of the issue.

Our search revealed many evidence-based studies and approaches of UD application in educational settings. The keywords used were “inclusive education,” “integrated education/integrated schools,” “education for persons/children with disabilities,” “universal design in education,” and “comprehensive education.” We also included recent news articles that capture inclusive education in India in the context of the COVID-19 pandemic.

We have suggested future directions for inclusive education in India, especially regarding the post- COVID-19 digital era and considering the intersectional marginalization of PwDs in India regarding gender, caste, class, and the urban-rural divide.

Key Aspects of Inclusive Education

Inclusive School Policy

When analyzing the literature on comprehensive education in India states that the words "children with special needs" and "children with disabilities" are often used interchangeably (Singal, 2005). The Sarva Shiksha Abhiyan (SSA) was founded to universalize elementary education by the year 2010. Access, enrollment, and preservation of all children aged 6 to 14 are three critical aspects of the universalization of elementary education. Under the SSA program, a zero-rejection policy has been implemented, ensuring that any child with special needs, regardless of the type, category, or degree of disability, receives meaningful and quality services (Press Information Bureau, 2018). Before the SSA, The Sargent Scheme of 1944 and the Kothari Commission of 1966. both produced nearly two decades apart illustrated several common concerns. Both reports acknowledged the plight of CWD and advised that a dual solution be used to address these children's educational needs (Naik, 1969). According to these findings, CWD need not be separated from their peers; instead, comprehensive schooling should be implemented. In India, Persons with Disabilities 1995, which was the country's primary disability legislation until the Right of Persons with Disabilities Act 2016, continued to promote integration and special schools while ignoring the concept of inclusion. The Kothari Commission 1966, the first National Policy on Education 1968, involved children with disabilities, but the language of comprehensive education had

been ambivalently used to keep the broader idea of integration at bay (Bhattacharya, 2010).

The issue of ‘how’ CWD should be included is rarely answered in school policy. (Johansson, 2014) in her study investigating policies and practices on inclusive education discovered that while proposals for the education of children with disabilities are positive, the arguments remain superficial and do not address how this will be accomplished in India. This ‘how’ refers to visible improvements such as providing suitable instructional materials, aids, and appliances, access to new means of communicating, a resource room with equipment, and the hiring of special educators/training instructors. Teachers’ pedagogical activities receive less attention; instead, particular input and planning for children with disabilities are prioritized.

Furthermore, while policies discuss sensitization, attitudinal improvement, and teacher instruction, it is unclear what these practices involve. However, there has been much debate on the “what” and “why” of inclusive education, the issue of “how” has remained unanswered. The current study should not include the whole school or the classroom to improve our comprehension of ‘how.’ This theme can also be seen in India’s scholarly debate on inclusive education. Due to extreme neglect in school policy and research, a contextualized interpretation of how inclusive education can be implemented in India is needed (Johansson, 2014). Further, Sawhney (2015), in her study on inclusive schools in Hyderabad, reported a dire situation when it came to inclusive schools in the city. Her initial appraisal of the school, which carried the “inclusive” tag, revealed only two schools- one government and one private to be inclusive with a diverse student population.

Moreover, while these schools had CWD students, these were children who did not require any special arrangements on the part of the school. Both schools made no changes regarding infrastructure, curricula, examination, and marking systems to accommodate a CWD. Inclusive education has turned out to be something of a gimmick to give the appearance of integration rather than a genuine attempt to pursue inclusive practices (Sawhney, 2015).

Although comprehensive education is a part of the Indian government's policy rhetoric, it is primarily based on providing education for CWD. Children with disabilities are not a homogeneous category. Other facets of their general personality, such as gender, economic class, race, and so on, maybe more closely associated with them. They are slightly more vulnerable if they belong to one or more of these groups. Disability should be seen as one of many problems of disparity and inequality, not as a stand-alone problem, and broader educational initiatives should consider the multidimensionality of those disparities (Miles & Singal, 2010).

Inclusive education entails a change in underlying principles and attitudes retained across the system, rather than only discussing feedback problems, such as access and procedures- teacher training (Singal, 2005). These principles and ideals are expressed in the policies and educational programs (Miles & Singal, 2010).

A study by Bhatnagar & Das (2014) on school teachers' attitudes in traditional schools towards inclusive schools discovered that inadequate facilities, financial pressures, and large class sizes were among the teachers' concerns. Furthermore, teachers' views of integration obstacles backed up their fears. A lack of an integration agenda, a lack of qualified teachers and paraprofessionals, and a fear of a decline in academic performance, among other factors,

hindered the successful adoption of inclusion in the schools of New Delhi. The need for a social inclusion program to empower all young people, particularly those with special needs, to attend school and effectively access education is one of the immediate priorities of Delhi's schools. The outcomes of this study warrant introspection from all Indian stakeholders involved in the introduction of inclusive education. To understand why these findings have arisen among Delhi teachers, it is essential to examine the results in depth.

Furthermore, a thorough examination is needed to fully comprehend the obstacles preventing teachers from effectively integrating children with disabilities into their classrooms. To overcome teacher issues and potential challenges, all parties must work together for a long time. Only then can India's genuine inclusion imperative become a reality. Responsible incorporation necessitates a change in current financial practices as well (Bhatnagar & Das, 2014). The recent National Education Policy (2020) emphasizes the importance of creating mechanisms to provide children with special needs (CWSN) with equal opportunities to achieve quality education as other children. It reiterates the importance of inclusive education in all schools, to be following the RPWD Act (2016) by providing resources to schools for integration of CWD, training for teachers, recruitment of special educators, establishing resource centers, building barrier-free access in schools, providing appropriate teaching learning-material and assistive devices. These facilities should be provided across all activities in the school.

Inclusive Infrastructure

The school building is the site for education. Thus, central to inclusive education is an inclusive infrastructure for the school building. An inclusive infrastructure refers to a barrier-free

environment based on the principles of Universal Design. According to the United Nations Convention on Rights of Persons with Disability, Universal Design means designing products, environments, programs, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design (United Nations, 2007). The definition of universal design as provided by the United Nations Convention on the Rights of Persons with Disabilities (2007) further notes that ‘universal design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed. Building disability-sensitive facilities is part of the Sustainable Development Goal of Quality Education outlined by the United Nations (United Nations, 2015). India officially ratified the Convention on Rights of Persons with Disability on October 1, 2007, signifying the 2030 Agenda for Sustainable Development Goals (RIS, 2016).

The school building and infrastructural facilities within it determine its accessibility. The aim of inclusive education is Barrier-Free Access to education. Barrier-free access refers to universal access for all children and adults within the space and is particularly relevant for CWD as they face many physical and social barriers. While the universal design approach in designing the school building deals with the physical barriers on the surface, increasing physical accessibility can also decrease social barriers (Kaur, 2014).

Elements of Inclusive Infrastructure

A background paper by (Agarwal 2020) prepared for the 2020 Global Education Monitoring Report, which focused on the state of school accessibility and universal design in school infrastructure in middle and low-income countries, has outlined the elements of accessible school infrastructure. According

to this report, the school building includes various internal and external components that determine its accessibility. The internal components include accessible entrances, ramps, elevators, accessible washroom facilities, desks, switchboards, chairs, canteens, etc. Some of the essential requirements in the design of internal components within a school include:

1. Doorways should be level, without any steps, and wide to ease use with mobility devices. Tactile indicators should mark them for the visually impaired.
2. Ramps must not be too steep and should be paved to avoid slips, with handrails on both sides at different levels to allow for ease of use by individuals of various heights.
3. Stairs should not be excessively steep and should be sufficiently comprehensive and level, with handrails on both sides at different levels and tactile indicators or anti-slip tapes on edges to avoid accidents.
4. Signs should be contrasted strongly from the background, must have braille, universal symbols, and large fonts for ease of understanding by all.
5. Optimum temperature and illumination must be maintained in classrooms with adequate space between aisles for ease of movement with mobility devices.
6. Flooring must be anti-skid, and tactile pathways should be present throughout the school for the visually impaired.
7. Wheelchair-friendly accessible toilet cubicles in washrooms.

India, following the ratification of the UNCRPD in 2007, has framed the National Building Code of India, 2016, and the Harmonized Guidelines and Space Standards for Barrier-Free Built Environment for Persons with Disability and Elderly

Persons, 2016). Both of these provide extensive guidelines regarding the requirements of buildings and built environments to be accessible for persons with disabilities. The latter includes an audit checklist and provides highly detailed information and guidelines for a barrier-free built environment. These guidelines should be referred to for new constructions and retrofitting old buildings, including schools to ensure the building is accessible for all (Agarwal, 2020; Bureau of Indian Standards., 2016; Ministry of Urban Development, 2016).

The Importance of Inclusive Infrastructure

The impact of the school infrastructure on students' quality of learning has been documented in some studies. Nepal (2016) analyzed the relation between school infrastructure, learning environment, and student outcomes in Nepal using a conceptual framework that hypothesized that a school's infrastructural facilities would impact students' learning outcomes both directly and indirectly through its impact on the learning environment. His analysis of the responses of students and teachers across 40 schools in Nepal concludes that the school's infrastructural facilities positively correlate with the learning environments and students' learning outcomes. Thus, the school's infrastructure has a direct and significant effect on students' learning outcomes.

Cheryan et al. (2014), in their study on classroom environment and its impact on students' achievement, found scientific evidence which shows that the physical classroom environment has profound effects on students' achievement. The classroom environment consists of two key aspects- the structural facilities that include appropriate lighting, noise, heating, etc., and the symbolic features of the classroom include the objects present within the classroom and its decor. Inadequate structural facilities

seem to have profound adverse effects on the performance and achievement of students.

While the school infrastructure directly impacts students' learning, it has also affected its more expansive growth and development. Bhattacharya (2020), in their study on the impact of building infrastructure on inclusive growth in India, found that infrastructural development in the education sector significantly bolsters economic growth and assists in poverty reduction. Based on these findings, it has been suggested that infrastructural investment has to be increased, especially public investment, since much of the infrastructural requirements are in rural and remote areas of the country, along with better planning and implementation of infrastructural development plans.

Accessible School Infrastructure in India

Access audits carried out in 500 schools across 15 states between 2011-2014 by Samarthyam with support from the Department of International Development, Government of United Kingdom, revealed that the majority of school infrastructure was barrier-filled and unsafe for children with a disability which hampered their use of school facilities such as washrooms, playground, classrooms, libraries, et cetera (UNICEF, 2016).

One of the most basic requirements in any building is accessible working and accessible toilets. Only about 22.44% of schools across India are equipped with disabled-friendly accessible washrooms, with the situation comparatively worse in rural areas where only 21.66 % of schools have accessible washrooms. In comparison, only 26,69% of schools have them (National Institute of Education Planning and Research, 2018).

Bandhopadhyay (2009), in her study on infrastructural facilities available across schools in India based on District Information System for Education, discovered private schools seemed to have better infrastructure, and their numbers seemed to be more significant with parents often preferring these schools over government schools. It was noted that due to various government initiatives, there had been some improvement in government schools, especially concerning having a proper school building, availability of toilets, drinking water, and classrooms. However, there still seems to be a lack of boundary walls, playgrounds, and electricity. Facilities such as computers and computer-aided learning are even harder to come across.

On a positive note, the education departments of most states in India, in partnership with UNICEF, have implemented sustainable WASH (Water, Sanitization, and Hygiene) projects across schools. The Orissa Primary Education Programme Authority (OPEPA) has installed drinking water and hand wash facilities at various heights accessible to all persons with and without disabilities. OPEPA, along with UNICEF and Samarthyam, has also trained approximately 350 engineers on access audits and universal design applications in schools, resulting in a significant number of state-run schools in urban and semi-urban areas being made accessible with state funds (Agarwal, 2020).

Inclusive Curriculum

The International Bureau of Education under UNESCO defines an inclusive curriculum as a curriculum that considers and caters to all learners' diverse needs, previous experiences, interests, and personal characteristics. It attempts to ensure that all students are part of the shared learning experiences of the classroom and that equal opportunities are provided regardless of learner differences.”

Thus, an inclusive curriculum aims to fulfill the right of all learners to a high-quality, equitable education that meets their basic learning needs and understands the diversity of backgrounds, contexts, and abilities as learning opportunities. It contributes to fostering an inclusive society feedback relationship.

Curriculum Adaptation- The Universal Design Approach

For an existing curriculum to be inclusive, the curriculum has to be adapted to the unique needs of each child. Curriculum adaptation is the dynamic process of adapting an existing prescribed curriculum to suit the learning requirements of children with special needs (Mishra et al., 2019).

For a curriculum to be effectively adapted and be inclusive for all, it should be developed based on the Universal Design approach. A universal design approach to curriculum development emphasizes the need for the curriculum to complement the learner's needs instead of requiring the learner to adapt themselves to the curriculum (Rose & Meyer, 2000).

Inclusive Curriculum in India

A significant challenge to inclusive education is the curriculum followed across India. The curriculum in India seems to be segregated between children with and without disabilities. Much of the general curriculum in Indian schools- Central Board for Secondary Education (CBSE), Council for the Indian School Certification Examinations, various state boards, etc., are all intensely competitive exam-oriented systems that put excess pressure on both students and teachers to perform well in examinations, resulting in a curriculum that fails to accommodate children with disabilities (Kohama, 2012).

The National Education Policy (2020) focuses on reorienting the curriculum by reducing the curriculum content and emphasizing essential learning and critical thinking. The curriculums are also supposed to be modified to provide students increased flexibility in the choice of subject with less rigid separation between curricular, co-curricular, and extra-curricular subjects and the different streams of subjects. On a positive note, the NEP states that curriculum changes will be made in consultation with national institutes under the Department of Empowerment of Persons with Disabilities. This will ensure that inclusion and accessibility will be kept in mind while developing the curriculum instead of being viewed as rectifications to be made later, such that children with disabilities will have to adjust to the curriculum instead of the other way around (Sarkar, 2020). However, no further information is available regarding how changes in the curriculum will be made to suit the needs of CWDs

The CBSE Handbook of Inclusive Education (2020) provides specific guidelines regarding curriculum adaptation by directing educators to plan the curriculum, keeping in mind the diverse needs of children. Some of the suggested methods for curriculum adaptation include: providing physical assistance and accommodating materials to adapt learning tasks that will suit the abilities of the CWD. Children with differing needs may work at different levels in the same subject area or follow an alternate curriculum with activities to reach the learning outcomes. Further, for CWD, CBSE has made the second language an optional component and reduced the attendance requirement.

A study on the good practices of inclusive education by certain schools in India revealed an effort to make the general curriculum appropriate for CWSN. Some of the efforts included

a school in Haryana making provisions to include children with intellectual disability, orthopedic, visual, and hearing impairments in a nature and adventure camp to be part of a curriculum activity on learning through experience. A school in Rajasthan provided training to children with visual impairment (VI) in using computers so that CWDs could gradually learn from an Information and Communication Technology (ICT) based curriculum. On completion of the program, laptops were provided with appropriate softwares; At the same time, another in Madhya Pradesh also provided training to children with VI in the use of various ICT technologies such as voice recorders and calculators, and other e-resources. On completion of training, the children were provided with smartphones as an ICT tool for learning and recorded classes. Academic outcomes for these children seemed to improve significantly compared to the previous academic year (Kaushik, 2020).

The WiSaLT Curriculum Appendix

The ‘WiSaLT Curriculum Appendix’ attempts to identify curriculum elements that may be challenging for CWD, offer recommendations for differentiating activities, and help individuals with communication challenges participate more successfully in classroom activities. The WiSaLT initiative in South Bristol, which began in April 1997, was financed equally by Avon Health Authority and the seven participating primary schools and offered a full-time equivalent speech and language therapist (SLT) for two years to work only in the participating schools. The Speech and Language Therapy Project will assist educators in delivering services, including providing speech-language therapy expertise and interventions in schools (Wren & Parkhouse, 1998).

The WiSaLT Curriculum Appendix could serve as an example of how the drawbacks of the current curriculum available in schools in India may be recognized, and appropriate changes can be brought about to suit the needs of CWD. The WiSaLT appendix may be adapted, or a similar method can be developed in India to fulfill the needs of CWD in India, keeping in mind the diversity of our population.

Inclusive Teaching Methods

Inclusive teaching methods would entail a democratic approach that includes a range of approaches to teaching that- consider the diverse needs and backgrounds of all students and create a learning environment where all students have equal access to learning and are equally valued. An online evidence-based teaching guide published as an academic paper emphasizes- teaching instructors developing self-awareness, cultivating empathy, cultivating student-teacher relationships and inclusive classroom climate, focusing on pedagogical choices on an individual basis, and basing classroom education on building relationships and dialogue (Dillenburger & Coyle, 2019)

(Baglieri & Knopf, 2004) suggest a model for differentiated learning that increases inclusivity in schools through teaching methods. Firstly- designing a curriculum based on where the students are in their learning curve and not where a graded curriculum wants them to be. Secondly- teachers select methods in which the students learn as deeply and as quickly as possible. The teachers should not reduce learning to its ordered parts which are more logical than the psychological approach of inclusive learning. Moreover, thirdly, the teacher-student learning relationship should be kept at the center of all learning sessions- and should be valued as an essential pillar of learning and knowledge growth.

Approaches to Inclusive Teaching

Some specific examples of inclusive teaching methods from published sources include-

TEACCH method for autistic students

The TEACCH method, which stands for Treatment and education of autistic and related communication disabled children, is a special education program designed to promote an integrated and practical approach to teaching children on the autism spectrum. The basic idea behind TEACCH is that autistic children are visual learners, and hence teaching should correspondingly be adapted to visual teaching methods and intervention strategies. A study conducted by D'Elia et al. (2014) found that a low-intensity home and school TEACCH program is beneficial to both the autistic child and their families as it helps to decrease parental stress and psychopathological comorbidity. Further, the study suggests that involvement of schools, teachers, professionals, families, and promotion of natural environments for the child with ASD -with peers functioning as co-therapists.

Sherborne Developmental Movement

The Sherborne Developmental Movement (SDM) relies on non-developmental movement experiences for body management, physical health enhancement, and social development of children of all ages and abilities. It is an inclusive method of teaching and working with the movement for children of all ages and abilities. A study conducted by Marsden et al. (2005) found SDM's innovative and inclusive approach to be a powerful tool in promoting children's motor development and body management along with social development and enhancement of concentration in studies.

Art therapy for inclusive education practice

Art therapy is a technique rooted in the idea that creative expression can foster healing and mental well-being. A study conducted in Ukraine states that art therapy should become an integral part of inclusive education for students with disabilities and students displaced through refugee crisis and migration. The application of “role play” in the art- therapy oriented inclusive education was suggested wherein the psychological and emotional barriers of the student can be broken down, and a relationship of empathy and frankness could be established between the student and the teacher, leading to better learning outcomes and self-actualization (Gonchar et al., 2019). Further, music therapy and social stories can also be a cost-effective inclusive education practice for CWD in LMIC countries like India (Chan & O'Reilly, 2008; Kern & Aldridge, 2006).

Conductive Education

Conductive education (CE) is an all-inclusive method to educate and rehabilitate a person with a motor handicap, whose impairment (dysfunction) is caused by central nervous system injury (CNS). The overarching aim of conductive education is to include assistive learning to develop maximized ortho-function (- which is the ability to conduct daily activities such as eating, dressing, and self-care) of children with neurological disabilities. The program also seeks to develop independence in the school setting, the community, and the workforce using minimal or no adaptive equipment, an approach that can be explored in the context of LMIC countries like India (Kozma, 1995).

Diagrams and drawings for visually impaired students

In India, Sharma & Chunawala (2015) revealed the benefits of using diagrams and models as teaching aids for visually impaired students. It was seen that collaborative learning

through diagrams and models was successful in evoking higher-order questions from students. Further, it was suggested that embossed (colored) diagrams and their integration into braille would be essential in raising students' critical thinking skills and higher-order thinking with visual impairments.

Inclusive teaching in India

An exploratory study (Srivastava et al., 2017) in Jaipur ascertained three critical factors in the Indian context necessary to prepare regular teachers for inclusive education- attitude, knowledge about disabilities, and knowledge about inclusive teaching methods. The study found that teachers had a neutral attitude towards inclusive education, attributing it to their possible lack of knowledge about recent changes in educational policies and laws regarding inclusive education in India. Further, even though teachers had CWD in their classrooms, they had minimal knowledge about the types of disabilities. Lastly, the knowledge of the teachers regarding inclusive teaching methods was of an acceptable positive level. Updating the teacher's education curriculum and training on inclusive education and knowledge of specific disabilities would increase the quality of their existing knowledge and practice in classrooms (Srivastava, 2016). Another study conducted in New Delhi found that pre-service teachers held positive attitudes towards inclusive education but lacked resources and essential knowledge about inclusive education.

Further, the study noted that pre-service teachers were keen on receiving training from foreign experts who are well-versed in implementing inclusive programs and had not witnessed indigenous functional, inclusive models of education and functional co-teaching models either (Das et al., 2013). Further, the lack of appropriate support structures in the teaching

pedagogy to facilitate inclusive education and the teacher's struggle to engage CWDs in the classroom is also reported in Indian literature. This invariably leads to teachers indulging in exclusionary practices, even though they realize the importance of education for all (Taneja-Johansson et al., 2021). Other studies highlight similar themes of – acceptance by the teachers of the inclusive education pedagogy, but the lack of proper training, knowledge and structures that provide a conducive environment to practice inclusivity in teaching are present in literature (Shah et al., 2016; Singal, 2014). Increasing the competency of teachers in inclusive education pedagogy, coupled with fostering positive attitude among teachers towards inclusive education, regular planning and proper execution of policies, the inclusion of assistive devices innovative digital education tools, and increasing awareness about the rights of education for CWDs among teachers, parents, and the community at large is essential (Bhat, 2017).

In the western context, a unanimous opinion exists on the factors that make inclusive education successful, including appropriate policy and leadership, adequate teacher training and adequate resource and support given to teachers and classrooms, and professional development opportunities (Philpott et al., 2010). Improving the quality of teacher training programs, expanding diploma courses and training to rural and low-income regions, and increasing the remuneration for inclusive teachers will help expand inclusive teaching and evaluation practice and enrolment of CWD to inclusive schools in India.

Inclusive Assessment

Assessment and learning are processes that are complexly related to each other. One of the main reasons is that – learning will not necessarily translate into performance. Hence, assessment

methods remain a subjective topic. This also raises questions about the quantifiability of assessment methods. Assessments have been carried out since time immemorial. However, the challenge of making them predictive, helpful, and inclusive remains. Educational assessment methods carry the power to occupy and promote certain students and deny opportunities to specific students. Hence, the same system of assessments should be questioned (Wiliam, 2017).

Universal Design for Learning

A Universal Design approach to Learning (UDL) encompasses the evaluation process. According to Villa et al. (2005), assessment should focus more on real-life demands, considered the primary educational outcome. Students can make portfolios that include conceptual ideas, rough drafts, self-edited papers, and final versions. It can include a variety of creative methods like letters, poems, research papers, or anything that the student wishes to portray. The goals set by the student are personal, and hence each student goes at their own pace (Villa et al., 2005).

Harlen (2013) gives the meanings, purposes, uses, and ways to implement two assessment forms into school systems: Summative and formative assessments. Summative assessment refers to the traditional evaluation done at the end of learning to test how much the student has learned. It is considered to be unavoidable in the formal schooling systems. However, this form of assessment does not seem to fulfill the objectives of learning thoroughly.

Formative assessment, unlike summative assessment, is done before introducing a concept and indicates how much the students know about the subject. The teacher might plan activities to introduce a concept and let students explore and investigate on their own. Their findings, their observations play

a part in planning what should be learned next. The students' role is participative in the learning process and in deciding what should be learned, how it should be learned, and how much the students get by self-discovery. Informative assessment, judgments about progress, and decisions about next steps take into account the circumstances, past learning, and effort of individual students and what they can do about the goals of the work at a particular time. Hence, the process of learning is individualized and does not apply the same standard to all students. Also, this process includes two-way feedback, which enhances learning as the students receive feedback from the information they can provide to the teacher (Harlen, 2013).

Worcell (2008) describes another innovative form of evaluation using instructional rubrics, which can be used instead of giving marks. They consist of written statements that tell the specific criteria to analyze a student's proficiency in a subject or an assignment. It offers more constructive feedback; students can self-evaluate and get an understanding of the teacher's expectations. Teachers can also administer tests made by them as they will be more individualized. The teachers will know best how a concept has been taught, how much time was spent on it, and hence they can make these tests keeping in mind all of these things. Students should also demonstrate their understanding using more creative and different modes, e.g., illustrating concepts through storybooks, orally explaining them, writing essays, making models, et cetera (Worrell, 2008).

Inclusive Assessment in India

With regards to assessment, the NEP 2020 proposes a shift in the aim of assessment 'from one that is summative and primarily tests rote memorization skills to one that is more regular and formative, is more competency-based, promotes

learning and development for our students, and tests higher-order skills, such as analysis, critical thinking, and, conceptual clarity.’ The policy further speaks of bringing about a change in the purpose of assessment to be solely for learning; and hopes it will help the teacher and student, and the entire schooling system continuously revises teaching-learning processes to optimize learning and development for all students. This has been defined as the underlying principle for assessment at all levels of education (Ministry of Education, 2020).

For CWD, the policy mentions that the proposed new National Assessment Centre, PARAKH, will formulate guidelines and recommend tools to conduct assessments at all stages of their education to ensure more equitable access and opportunities.

The SSA provides guidelines on evaluation techniques for CWSN, with some general guidelines including allotment of extra time, allowing the use of required assisted devices, technology, providing objective questions instead of essays, recording responses orally if needed, and flexibility in the allocated syllabus for testing. There are more specific guidelines on evaluation techniques for the specific needs of children with specific disabilities (Ministry of Education, 2020).

The CBSE Handbook for Teachers on Inclusive Education also outlines specific methods and concessions for CWD to make assessment more equitable. These include provisions such as providing readers/scribes, making an assessment room available on the ground floor, use of assistive devices if required, providing extra time, giving the exam on a computer, and substitution of practical exams for theory exams if appropriate (Central Board of Secondary Education, 2020).

To adapt evaluation methods for CWSN, it is imperative to assess the abilities of the child, avoid unfair comparison between

children in the classroom, adopt a criterion-referenced testing method, and that evaluation should be ongoing depending on multiple criteria instead of one or few (Madan & Sharma, 2013).

During our search for studies on inclusive evaluation or assessment practices in India, we were confronted with a lack of studies on how effective the guidelines on making evaluations more inclusive for CWD, framed by the government policies, are in practice. While there are many studies from India articulating the needs and barriers to inclusive education, solutions for inclusive education as well as critical analysis of the education policies and laws of India, with regards to assessment or evaluation, the majority of the studies recognize a need for inclusive practices and provide suggestions on approaches or practices that can be adopted.

Inclusive education in the COVID-19 era

In the COVID-19 pandemic, with education shifting to an online learning mode with no definite end in sight, inclusive education for PwD seems precarious. The government has issued a comprehensive disability-inclusive guideline for the protection and safety of persons with disabilities in COVID-19, with no mention of the digital education roadblock for PwDs as an issue to be resolved (Ministry of Social Justice and Empowerment, 2020).

A survey with 3,627 respondents conducted by Swabhiman, a community-based cross-disability organization working for the rights of persons with disabilities in India, revealed that 43.52 percent of students with disabilities were planning to drop out of online schooling in the pandemic. Forty-four percent of children complained of the absence of sign language interpreters in webinar sessions. Thirty-nine percent of visually impaired children found online lessons

incomprehensible, with other students talking simultaneously. Moreover, 86 percent of children with disabilities said that they did not know how to use technology, and 81 percent of teachers complained of inaccessible educational material provided to them for the education of PwDs (Mohapatra, 2020). In an exploratory study conducted among a cohort of children with disabilities in Karnataka, India, it was reported that 53% of the parents in the sample considered the online educational support being received as inadequate for their child's needs, with close to 14% reporting that they were not receiving any online educational support at all (Krishna & Rajaraman, 2020).

The critical challenges to inclusive online education for persons with disabilities in the pandemic remain- increased household responsibilities and stress on the caregivers resulting in lack of individual attention given to their child with a disability for online learning, disrupted routines due to mental health of children, disruption to government aid and support mechanisms for education (especially those with intellectual disabilities), lack of subtitles or sign language interpreters for students with visual impairments, lack of training given to teachers for the education of children with disabilities (except Kerala), the limited scope of two-way interaction in digital mode of education, et cetera (Vernekar et al., 2020).

A coordinated approach to inclusive education is required to meet the challenges of the online education COVID-era. From the conception of the curriculum for the school year to the teaching methodology and delivery of lectures and webinars, everything has to be designed from the perspective of inclusive education for PwDs, rather than its consideration as a futile supplementary exercise. Further, comprehensive government guidelines as a plan of action in all the states of India have to be drafted. These should be for educational institutions and regular,

inclusive, and special educators concerning the education of PwDs both for the COVID-19 era and the induction of PwDs back into the schooling setting in the post-COVID-19 era. Tracking the number of PwDs dropping out of schools during this time is essential to get well-acquainted with their specific difficulties, develop interventions, and induct them back into the education system.

Discussion

There is a lack of indigenous research which studies the impact of inclusive infrastructure on student learning outcomes. There is ample data available on the infrastructural facilities available in schools across India, most of which indicate that most schools in India are poorly designed, and few possess the facilities to meet the needs of children with disabilities (Singh, 2016).

While India has many policies and guidelines which ensure inclusive infrastructure for school buildings, they have not been successfully implemented (Singh, 2016). Some of the challenges to implementation of these policies include the lack of awareness regarding the need for accessibility and inclusion as well as the policies themselves, which hamper their implementation; inadequate funds available to the education sector, which will ensure retrofitting and constructing accessible school buildings and equipping the school with assistive devices; and lack of interdepartmental and ministerial planning and policies due to the concerns of inclusive education, disability rights, building guidelines all belonging to separate ministries (Agarwal, 2020). Further, the lack of trained personnel, availability of government and private inclusive schools, segregation of children with disabilities into separate sections within inclusive schools, and the lack of institutional bodies that can standardize and monitor the quality of inclusive schools across the country remain huge

gaping problems in the Indian education system (Barua et al., 2017).

The Ministry of Education (2020) has introduced multiple online learning platforms for primary, secondary, and higher secondary education. Some of these platforms are- Apps- Diksha, e-pathshala, Web portals- National Repository of Open Education Resources, Swayam, National Digital library, and Teacher training portal and app- Nishtha. The Government of India is also cognizant that there is considerable digital and technological inequality among the citizens, with many not having access to smartphones and computers, unable to purchase data packages or WIFI networks, or living in areas that might not have proper network coverage. Keeping these factors in mind, the Government of India has launched special educational TV programs through DTH networks and radio programs. Swayam Prabha includes 32 DTH channels with educational content for classes 1-12. These channels are free and can be accessed for free using the free DD set-top box and antenna. Private DTH service providers, too, will have these channels.

There is no doubt that efforts have been made with regards to fostering inclusive education in India from both the government front and through private institutions, with the latest effort being the New Education Policy (2020) of India declaring barrier-free education for all children with disabilities as an integral part of all teacher education programs. However, on the implementation level, collaborative effort is still required to integrate inclusion for children with disabilities into the functioning of the education system in India. Further, approaches to form scalable inclusive interventions that can traverse the barriers of- socioeconomic status, gender, caste, severity, type of disability, and specific challenges associated with different types of disabilities need to be further accounted for. In the current context of the COVID-19

pandemic, the most critical barrier to be traversed remains the exclusion of children with disabilities from the changing pattern of education from offline schooling to online schooling. This divide itself is an extension of the barriers of socioeconomic and demographic origin discussed above. Inclusive education is a broad topic that should be expanded to include the rights of persons with disabilities and all learners with impairments to get an education in their educational setting. It is frequently challenging to put policies in place in developing countries to promote inclusive education, and their expectations may be unreasonable if they are based only on international creeds. Lastly, India's education for children with disabilities cannot be enhanced without working on other essential child determinants, such as health, poverty, nutrition, and early intervention.

Future Directions

Based on our literature review of both global and national studies along with government reports on education in India, we have suggested the following future directions for inclusive education in India-

Multi-sector engagement and advocacy to implement inclusive education in India

The public health sector, the education sector, the IT sector, educators, researchers, and practitioners from psychology and psychiatry, early intervention, and special education should work together to make educational platforms inclusive for persons with disabilities. Adequate funding through government and advocacy for disability inclusion in multiple sectors would foster this multi-sector engagement for disability inclusion in India. For inclusive and barrier-free infrastructure, India has comprehensive policies and guidelines in place. For successful implementation of the policies and guidelines, it is first essential to increase

awareness regarding disability rights, the need for accessibility in school infrastructure, and the policies and provisions regarding accessible infrastructure that are in place. Generating awareness for disabilities in all significant sectors should rely on- disability acceptance through governmental policy changes, collaborative research, and cross-disciplinary disability inclusion initiatives. Coupled with this, community outreach, disability rights and inclusion in school and college curriculum, and societal support are necessary to foster awareness and acceptance for persons with disabilities in India.

Intersectional approaches to designing policies and interventions for inclusive education

In the context of India, evidence-based studies from an intersectional perspective are required to target the most vulnerable groups among PwDs, for instance- the severity of a disability, gender, caste, socioeconomic status, and location of residence (urban or rural) work to create severe disabling conditions for groups of persons with disabilities. Identification of PwD groups oppressed by these intersectional forces, and further research to generate accurate statistics on indicators such as- school drop-out rate, enrolment rate, spending on education by family, availability, proximity, and quality of inclusive schools, et cetera would give us clear target groups among PwDs based on their level of vulnerability and lack of access to education. The intersectional determinants can then inform education policies and disability-inclusive interventions of lack of inclusivity and accessibility for the PwD community.

Increased government engagement

Accessibility in education requires significant engagement from local governments. Private players, such as NGOs like

Samarthyam, which conducts access audits and has conducted access audits in collaboration with the government and provides training regarding accessible infrastructure, have to build accessible school buildings.

The community's needs around a particular school have to be mapped out, and accordingly, the school has to be renovated and retrofitted to match the needs of the students in the school. An increase in government funding to public institutions and inclusive and special educational set-ups and an increase in the pay of special educators would work to enhance the quality of education for CWDs. Further, the provision of scholarships and decreased cost of life skills training and vocational opportunities for the PwD youth cohort would prove beneficial from an inclusive education standpoint.

Equitable digital technology as assistive learning techniques

Along with making the present digital platforms for education inclusive to CWDs through increasing opportunities of two-way interactions, blended mode of learning, home-visits, changes to evaluation methods, and the design of need-based approaches to cater to individual cases of students with disabilities, research must be expended in the direction of digital technology interventions for the severe and low-functioning CWD cohorts. For instance, the use of gamification techniques, social robotics-virtual reality and augmented reality for children with autism spectrum disorders has proved beneficial in educational teaching methods to improve their practical skills and social skills (Subin et al., 2017; Taheri et al., 2019; Valencia et al., 2019) Furthermore, it is of paramount importance that the development of digital technologies as assistive learning techniques is equitable and scalable in the context of India where the rich-poor and rural-

urban divide is extensive, with the majority of CWD residing in rural areas (Verma et al., 2016).

Needs-based approach to training and education

The premise of a needs-based approach lies in accepting that each individual has different needs. Education should be relevant, and the ownership of the education should be with children. Understanding the children's perspective will result in the satisfaction of their needs, and education will be meaningful to them. Fitting CWD into existing mainstream education systems will only widen the gap between them and their peers. Teacher training should also be approached from need-based inclusivity and not bulk inclusivity of all CWD.

Conclusion

There is an acute lack of research and policy implementation in India focused on inclusive education approaches for children with disabilities in India. The issue has become more pronounced in COVID-19 when education has shifted to the online mode. Intersectional disabling forces work to disempower the CWD community in India, leading to low school enrollment rates and absenteeism and drop-out rates. Our review suggests inclusive design approaches taken from global and national studies and recommendations for policy action in India to increase the accessibility and inclusion of children with disabilities to the education system. A multi-sector and multifaceted engagement and collaborative effort from the government, institutional bodies, and research organizations are needed to enhance inclusive education for children with disabilities in India.

Scope and Limitations

The scope of the literature review finds relevance in the domain of inclusive education for children with disabilities in India.

Our review has focused on five key aspects of universal design for inclusive education through a comprehensive literature review. These include- inclusive curriculum, inclusive school policy, inclusive infrastructure, inclusive teaching methods, and inclusive evaluation methods. Our review will support the disability literature in India, bringing to light the vital universal design perspective to disability action and inclusive education literature in India. This review finds scope for further inquiry by special educators, disability rights activists, and rehabilitation policymakers into the universal design and inclusive education approach for children with disabilities in India.

The limitations of the literature remain largely methodology-based as follows - the chosen studies could not be critically appraised for their quality as that is beyond the scope of a narrative review and is part of a systematic review and meta-analysis approach. Further, although this review brings to light the need for dialogue on inclusive design and accessibility to inclusive education in India and is comprehensive in its inquiry and approach of summarizing literature, conclusions from the review should be extracted with caution because of its narrative nature.

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Conflict of Interest

The authors declare that there is no conflict of interest

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Beyond The Barriers Of Disability: Is Inclusion A Viable Alternative?

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Abstract

In the present decade, we have seen a shift among children with disabilities (CWD). Now they are also attending the same school that the non-disabled do. As per MHRD Statistics, cited by World Bank, approximately 30 million children are out of school in India due to the marginalization of poverty, caste, and other factors like disability and gender. The concept of inclusive education arose in 1944 when the particular term need was emerging. It says that the school should fulfill the educational needs of each child irrespective of their disabilities. 'That some people support and some do, we have seen that inclusive education is a controversial theme that some people support and' do not do. Sometimes people perceive the concept of inclusive education

in a different way. Today, how can a teacher meet the needs of CWD? How can the CWD be provided with quality education? The present study is based on secondary data, including a review of related literature and data collected from various government official websites and organizations. Further, the research tool used for the analysis of data is content analysis. The result indicates that inclusion can be a viable alternative if proper measures are taken up by schools, teachers, society, and our nation's G.

Keywords: CWD, World Bank, Marginalized, Inclusive Education, Special Needs, Quality Education, Inclusion, Alternative

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Introduction

The literal meaning of the word 'inclusion' is 'to include.' Thus also to include the children with diverse needs and includes children with disabilities to their maximum potential. The concept of inclusive education has aroused from Salamanca's statement, 'Framework for Action on Special Needs Education, '1994'. Inclusive education involves modification in structural organization, philosophy, teaching strategy, and curriculum. It is very well said that inclusive education is a part of creating an inclusive society. Inclusive education is an education where every child is taught under one roof, whether disabled or non-disabled. Inclusive education can be said as education that is not only for disabled people but also for all children. In the context of inclusive education, special planning is required to bring the

students into mainstream education, such as special curriculum, specially designed classes, and special infrastructure. Inclusive education means when schools, colleges, and educational institutions are open for students with diverse backgrounds such as underachievers, intellectually disabled children, gifted children, delinquent children, backward children, and slow learners. Therefore, teachers, schools, and systems must bring the students with diverse needs under one roof. Inclusive education involves three things: presence, participation, and achievement (Ainscow, 2005, Engelbrecht and Green, 2007). It means including CWD in those regular classrooms designed for children without disabilities (Kugelmass, 2004). Regardless of the ‘student’s physical, emotional, learning, or intellectual disability, equal education opportunities must be given to all children (Loreman et al., 2005). It is said to be an endeavor where recognition is needed to be given to the sameness of learners; on the other hand, regard must be given to differences and diversity among individuals (Norwich, 1996). According to Lipsky and Gartner (1997), inclusive education is not a reform of special education. Inclusive education aims to remove exclusion within and outside the school through modification of policies and legislation to promote reorganization of the educational systems and accept the students irrespective of their differences (Rustemier, 2002, Rieser, 2009).

The emergence of the term ‘inclusion’

Until the 18th century, children with special needs (CWSN) were not receiving attention worldwide. According to Chadda (2003), Political reformers in medicine and education were energized by political reformers of France and America so that attention could be paid towards the educational needs of CWD with liberty, fraternity, and equality. As per UNESCO, inclusion involves a) philosophy which is based on a belief that each person is equal

and should be valued b) “ unending set of processes “ where people with disabilities will be provided with equal opportunity to participate in community activities which are provided to non-disabled one. As the world made efforts for the success of placing CWD in regular school. During the last five decades, the Government of India (GoI) has made significant efforts towards providing services to children with comprehensive disabilities. Therefore a program was included in Integrated Education (IE) by the planning commission of India. The Government of India launched a scheme in December 1974 named Integrated Education for Disabled Children (IEDC). IEDC is a centrally sponsored scheme introduced to provide equal opportunities to CWD in public schools and facilitate their intention. The efforts of the Government of India can be traced through the National Education Policy, 1986, which focused on integrating the CWD with the general student community to prepare them for average growth and provide them help and support in facing life with fearlessness. In 1990, the world declaration on education for all was adopted, which fostered the ongoing effort. A training program was initiated by the Rehabilitation Council of India Act, 1992, to develop professional teachers who will respond to the needs of CWD. The National Policy attempted Persons with Disability, 2006 to clarify the framework where state and private sectors must work to ensure that a person with disabilities must have a dignified life. According to Abbott & Mcconkey (2006), social inclusion involves four aspects that are opportunities, being accepted by others, usage of various facilities provided by society, and talking to people. The students who are with or without disabilities were engaged in positive social interaction but infrequently.

Review of related literature

In this section, we document researches published mainly between 2015-2021.

Beaton et al. (2021) suggested a need to adopt a new approach in the context of professional learning to inclusion, which will be effective, sustainable, and adaptable to professional learning and societal changes. San Martin et al. (2021) found a significant relationship between ‘teacher’s attitudes towards two variables: self-efficacy and inclusion. In their study, Terese Wilhelmsen et al. (2021) concluded that one could improve the pedagogy and inclusion of CWD in physical education by better understanding variables such as parental satisfaction, parental attitude, and pedagogical inclusion. Prediger and Buro (2021) found various ways to work with students of diverse disabilities, such as differentiated learning goals during curricular adaptations, emphasis on joint learning settings and compensating practices, and different priorities for different abilities. Kiat Bong & Chen (2021) conducted a systematic review in the context of increasing ‘faculty’s competency in digital accessibility for inclusion and found that most of the courses focus on topics that provide an inclusive environment through digital learning and ways to produce digital learning material, disability, and accessibility. The courses do not provide objective data about the courses because it uses survey and instrument method. Therefore, there is a need to research establishing a standardized instrument that measures training outcomes. Rose et al. (2021) conducted a research where a comparison was made between a metropolitan city and a rural district of Telangana state based on provision and access to inclusive education, and it was found that services provided by the Government of India currently fall short in comparison to the required one to achieve more significant inclusion in the education system. Ainscow (2020) has discussed inclusion and

equity in education. He concluded that if the proper emphasis is given on two aspects that are inclusion and equity, then there is a chance of improvement in the quality of education for citizens within an education system. Kefallinou et al. (2020) indicated that if inclusive education is implemented successfully, it can ensure quality education, lead to social inclusion, and improve learning outcomes. Crispel & Kasperski (2019) have found that interviewees have experienced a change in their attitude after completing the course in special education, and further, there is a change in the ability to implement inclusion in the classroom. Keppens et al. (2019) have found that adequate training is to be provided by teacher education programs with the aim of training pupil teachers for the inclusive classroom.

Sharma (2018) suggested that proper planning is to be done in inclusive education by keeping in mind the research done in this area as it will respond to citizens as individuals and recognize individuality. Hasan et al. (2018) concluded in their study that inclusive education acts as a strategy for achieving education for all as inclusive education is a constant process that ensures that education for all works for all. Professional development is a critical factor that requires attention for leading towards a healthy society. Walsh (2018) suggested that for a successful inclusive classroom, the teacher must brainstorm with fellow mates about new strategies and promote collaboration among all students. According to Lawrence (2017), SWIFT, a Schoolwide Integrated Framework for Transformation, is a model adopted in school for MTSS that is a Multi-Tiered System of Support for all students. By adopting this inclusion approach, we can create schools where students with different needs are supported, valued, and engaged in learning. Kumar Singh (2017) concluded that the educational needs of CWD cannot be advanced in isolation; therefore, “education for all “shall be ensured for the

effective implementation of inclusive education regardless of barriers. Buli-Holmerg and Jeyaprabhan (2016) conducted a study. They found that general teachers lack expertise in delivering lectures in an inclusive classroom, and there is a need to develop competencies of the general teachers by providing them training so that they can quickly adapt to all types of inclusive classrooms. Morgado (2016) suggested a specific proposal is needed, including processes, strategies, programs, and policies that will lead to the success of inclusion. Suleymanov (2015) there are certain aspects in inclusive education such as classroom arrangement, universal design of learning, academic achievement, sociocultural activities, cooperative learning, participation and engagement, inclusive assessment, the role of a classroom teacher, role of a teacher assistant, curriculum adaptation, individual education plan. Educational responses to CWSN should be considered a priority compared to uncritical inclusion (Anastasiou et al., 2015).

Objectives of the study

Following are the objectives of the research paper:

1. To analyze and interpret the data related to disability.
2. To briefly explain the initiatives at the global and national level regarding inclusion.
3. To analyze how inclusive education is different from special education?
4. To find out the factors concerned with inclusion and whether they are viable alternatives?

Methodology

In methodology, we presented how the data and studies were collected, analyzed, and interpreted. To find out the research

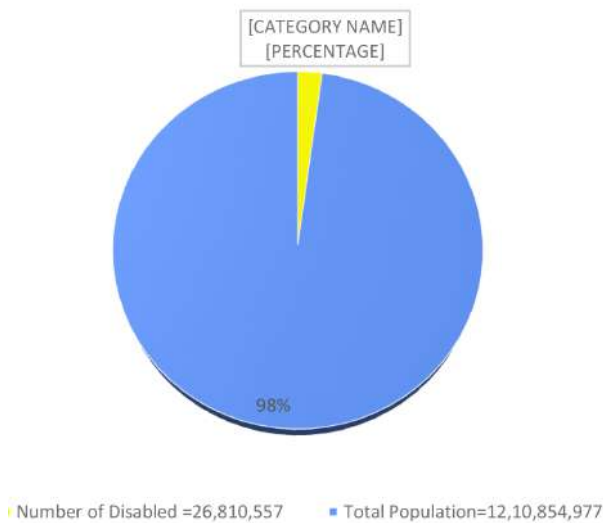
gaps and pieces of evidence, we documented the researches published between 2015-21 among the following areas a) training of pupil teachers for inclusive education, b) professional learning for inclusion, c) pedagogy adopted in inclusive setup, d) aspects in inclusive education, by using the internet as a source. We collected the literature which was relevant to our field of research. We kept our search limited to 2015-21, and further, with the exception, we mentioned significant studies too. Since the paper will serve the needs of teachers, students, policymakers, and ‘ NGOs, we included various studies conducted by researchers in inclusion. To finalize the studies, we considered systematic, review studies, quasi-experimental studies, and case studies. The following terms were searched: inclusion, inclusive setup, inclusive education, inclusive classroom, inclusive school, and strategies to adopt for inclusion.

Further, a literature review term was added to find out the studies, and the search was initially focused at the national level and then at the international level. The quantitative data was collected from various government ministries, organizations and their websites, and international organizations, such as the Census Survey of India, UNESCO, UNICEF, etc. We have interpreted the collected data by visualizing the dataset (bar graphs, tables, and pie charts) and descriptive statistics (percentage). Lastly, each country has a different education setup. Therefore, we can see the variance in the adoption of strategies and setup.

Disabled population in India

A census is an enumeration of people (Britannica,n.d.). The 15th Indian Census was conducted in the year 2011. Following are the data of Disabled Population in India:

Disabled population – Census 2011



Graph 1. Depicting Disabled Population as per Census of India, 2011

Source: C-Series, Table C-20, Census of India 2011

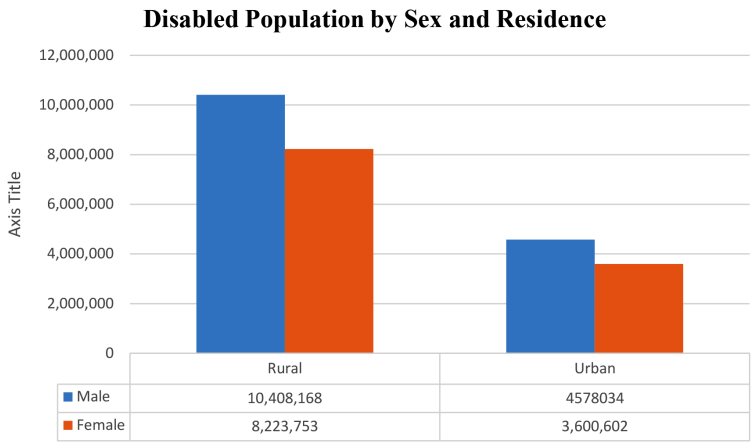
As per the Census of India, 2011, out of the 121 Crore population, 2.68 Crore persons are disabled that is 2% of the total population. Nevertheless, in comparison to the disabled population, services are not provided adequately.

Table 1

Disabled Population by Sex and Residence as per Census of India, 2011

Disabled Population by Sex and Residence India, 2011			
Residence	Persons	Males	Females
Total	26,810,557	14,986,202	11,824,355
Rural	18,631,921	10,408,168	8,223,753
Urban	8,178,636	4,578,034	3,600,602

Source: C-Series, Table C-20, Census of India 2011



Graph 2. *Depicting Disabled Population by Sex and Residence as per Census of India, 2011*

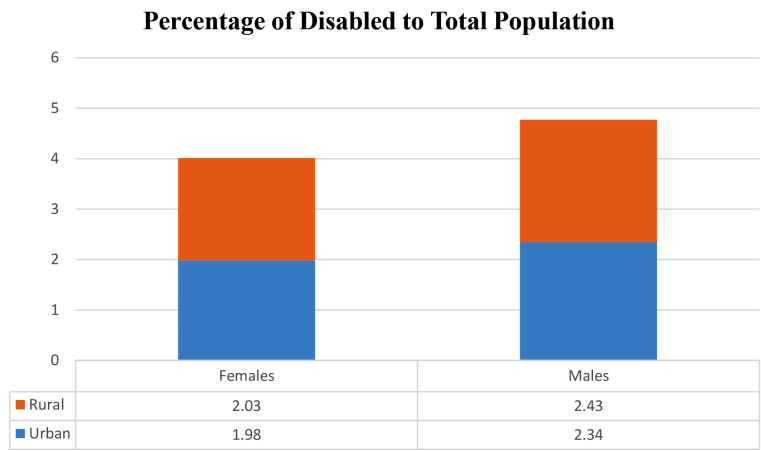
As per census 2011, 26 million is the total population of disabled ones, out of which 56% are males, and 44% are females. Further, we can interpret that 70% of the disabled population is from rural areas while 30% is from urban areas. Hence, it can be said that the majority of the disabled population is living in rural areas; therefore, GoI needs to take some significant steps to provide education and services in rural areas.

Table 2

Percentage of Disabled to Total Population as per Census of India, 2011

Residence	Persons	Males	Females
Total	2.21	2.41	2.01
Rural	2.24	2.43	2.03
Urban	2.17	2.34	1.98

Source: C-Series, Table C-20, Census of India 2011



Graph 3. Depicting Percentage of Disabled to Total Population as per Census of India, 2011

As per the census of India, 2011, 2.21% of the total population is disabled, out of which 2.24% belongs to the rural area while 2.17% of the disabled population lives in an urban area. Hence, from Tables 1 & 2, we can interpret that the maximum population of disabled people lives in rural areas, which indicates that policies need to be formed by considering rural areas as the priority as top schools work in urban areas with infrastructure facilities for disabled people ones. Hence, the Government of India needs to focus on rural areas as well.

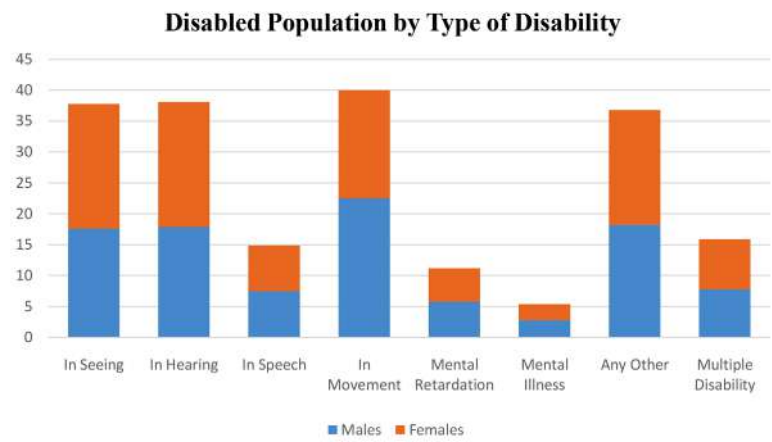
Table 3

Proportion of Disabled Population by Type of Disability as per Census of India, 2011 (%)

Type of Disability	Persons	Males	Females
Total	100.0	100.0	100.0
In Seeing	18.8	17.6	20.2
In Hearing	18.9	17.9	20.2
In Speech	7.5	7.5	7.4

In Movement	20.3	22.5	17.5
Mental Retardation	5.6	5.8	5.4
Mental Illness	2.7	2.8	2.6
Any Other	18.4	18.2	18.6
Multiple Disability	7.9	7.8	8.1

Source: C-Series, Table C-20, Census of India 2011



Graph 4. Depicting Proportion of Disabled Population by Type of Disability as per Census of India, 2011 (%)

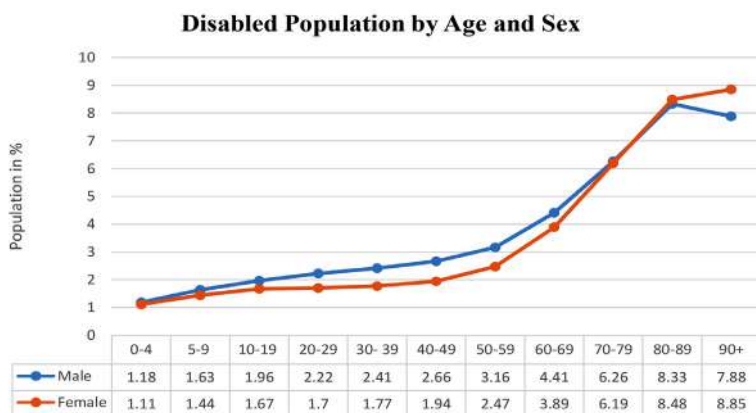
The table-3 shows the distribution of the disabled population as per their type, and from graph-4, it can be seen that there are three significant types of disability: movement, hearing, and seeing with 20.3%, 18.9%, and 18.8%, respectively. The Government of India and schools shall use the data for providing equipment, infrastructure, and instructional material as per the disability. The Government should expand its resources as per the needs of disabled ones.

Table 4

The proportion of Disabled Population in the Respective Age Groups as per Census of India, 2011 (%)

Age Group	Males	Females
All Ages	2.41	2.01
0-4	1.18	1.11
5-9	1.63	1.44
10-19	1.96	1.67
20-29	2.22	1.70
30-39	2.41	1.77
40-49	2.66	1.94
50-59	3.16	2.47
60-69	4.41	3.89
70-79	6.26	6.19
80-89	8.33	8.48
90+	7.88	8.85
Age Not Stated	3.21	2.91

Source: C-Series, Table C-20, Census of India 2011



Graph 5. Depicting Proportion of Disabled Population in the Respective Age Groups as per Census of India, 2011 (%)

Table 5

Percentage distribution of Disabled Population by Literacy status and Educational level in India (2001 and 2011)

Literacy status and Educational Level among disabled population	2001			2011			Progress between 2001 & 2011		
	Total	Male	Female	Total	Male	Female	Total	Male	Female
Illiterate	50.7	41.9	62.7	45.5	37.6	55.4	-5.2	-4.3	-7.3
Literate	49.3	58.1	37.3	54.5	62.4	44.6	5.2	4.3	7.3
Percentage to Literates							0	0	0
Literate but below primary	26.5	25	29.9	19.4	18.5	21.5	-7.1	-6.5	-8.4
Primary but below middle	26.4	25.6	28.1	24.3	23.5	25.8	-2.1	-2.1	-2.3
Middle but below matric. secondary	16.4	16.6	14.8	16.7	17.3	15.8	0.3	0.7	1
Matric/Secondary but below graduate	20	21.5	16.9	23.6	24.9	21.2	3.6	3.4	4.3
Graduate and above	6	6.6	4.6	8.5	9	7.7	2.5	2.4	3.1

Source: Registrar General of India, Ministry of Home Affairs, Govt. Of India, July 2016

Table 6

Educational status of Disabled population in India (2001 and 2011)

Below primary			Below middle			Below metric/secondary		
Sl. No.	Top Ten States	Percentage	Sl. No.	Top Ten States	Percentage	Sl. No.	Top Ten States	Percentage
1	Mizoram	43.87	1	Odisha	31.88	1	Jammu & Kashmir	26.58
2	Meghalaya	39.53	2	Rajasthan	30.35	2	Manipur	25.56
3	Sikkim	36.31	3	Himachal Pradesh	30.02	3	Uttar Pradesh	22.01
4	Tripura	30.75	4	Andhra Pradesh	29.59	4	Assam	21.87
5	West Bengal	29.57	5	Madhya Pradesh	29.27	5	Nagaland	21.63
6	Assam	28.55	6	Jharkhand	28.98	6	Uttarakhand	21.59
7	Chhattisgarh	27.85	7	Nagaland	28.78	7	Tripura	20.95
8	Odisha	27.23	8	Chhattisgarh	27.57	8	Madhya Pradesh	20.55
9	Nagaland	25.95	9	Bihar	27.11	9	Rajasthan	20.48
10	Kerala	24.76	10		27.11	10	Chhattisgarh	20.31

Bottom Ten States			Bottom Ten States			Bottom Ten States		
1	Uttar Pradesh	17.10	1	Meghalaya	25.05	1	Himachal Pradesh	17.11
2	Andhra Pradesh	15.89	2	Tripura	24.83	2	Bihar	17.10
3	Himachal Pradesh	15.53	3	Mizoram	24.59	3	Meghalaya	17.04
4	Uttarakhand	15.11	4	Assam	24.52	4	Gujarat	15.99
5	Haryana	15.11	5	West Bengal	23.39	5	Chandigarh	15.84
6	Jammu & Kashmir	12.92	6	Maharashtra	21.74	6	Maharashtra	15.76
7	Manipur	12.46	7	Jammu & Kashmir	20.96	7	Goa	15.19
8	Punjab	11.62	8	Goa	19.96	8	Sikkim	14.12
9	Chandigarh	11.58	9	Chandigarh	19.51	9	Karnataka	13.03
10	Tamil Nadu	11.20	10	Manipur	17.91	10	Andhra Pradesh	10.94

Source: *Lakshmana & Maruthi (2018)*

As per the census of India, 2011, if we combine the figures of age groups 5-9 and 10-19, we can say 3.36% of the disabled population falls under the studying/school-age group. Therefore, it indicates that schools' arrangement needs to be made for 3.36% of the disabled population. The schools must have assistive devices and technology which will help the disabled in learning.

As is evident from the table above, over a while, the percentage of literates (both male and female) among the disabled population has increased during 2001-2011. Also, the percent of disabled both male and female, having attained higher levels of education such as secondary, graduation, and above has increased over time.

Table 7

Number of Special Schools (State-wise)

State	Number of Special Schools
Andhra Pradesh	84
Bihar	13
Delhi	144
Gujarat	14
Haryana	11
Jammu & Kashmir	1
Karnataka	37
Kerala	49
Madhya Pradesh	17
Maharashtra	53
Manipur	14
Meghalaya	2
Nagaland	1

Orissa	11
Rajasthan	43
Tamil Nadu	43
Tripura	2
Uttar Pradesh	56
West Bengal	42

Source: *Punarbhava-National interactive web portal on disability (2021)*

Hence, from the above table, it can be interpreted that there is a limited number of special schools in some of the states while the majority of schools are in Delhi. Therefore, as per keeping in mind the disabled population, more special schools must be constructed.

Initiatives at the global level

Following are the initiatives that are taken at a global level in the context of disability:

Report of United Nations Educational, Scientific and Cultural Organization (UNESCO)

UNESCO has released a report in the year 2019 titled “ State of the Education Report for India: Children with Disabilities. “ “This report throws light on accomplishments and challenges in the context of the right to education of children with disabilities (CWDs). The report indicates that the number of children already enrolled in school is dropping out with each successive class or level of schooling. Many CWDs are enrolled in the National Institute of Open Schooling rather than regular schools. Among all disabled categories, children with intellectual disability, intellectual illnesses, and multiple disabilities are the least one attending school.

Sustainable Development Goal (SDG), 2030

Sustainable development goal, 2030 comprises of 17 goals out of which SDG, 4 aims to “ensure inclusive and equitable quality education and promote lifelong learning opportunities for all”. Target 4.5 of SDG, 4 focuses on building and upgrading facilities that are disability sensitive.

Global Action of Disability (GLAD)

Due to Covid-19, UNESCO joined its partners in the GLAD network to create awareness regarding the strategies to be adopted so that closure of schools does not impact learners with disabilities.

Article 24 of the Convention on the Rights of Persons with Disabilities (CRPD)

Article 24 of the Convention on the Rights of Persons with Disabilities (CRPD) aims that CWDs should not be discriminated against but participate in the education system. Further, Article 24(1) requires states parties to guarantee inclusive education and inclusive lifelong learning to all persons with disabilities.

Initiatives at the national level

In the Constitution of India, 1949, it is clearly stated that each person has the right to equality, stating that each person has the right to equality in terms of opportunity. Even Article 41 of Directive Principles of the Indian Constitution states that the Right to Education must be provided even if disabled. Following are the initiative taken at the national level:-

Integrated Education of Disabled Children (IEDC), 1974

This scheme was enacted in the year 1974 by the Ministry of Welfare. The objective of this scheme was to provide financial assistance for uniforms, books, ‘equipment, etc., while later on Government realized that not only financial assistance but the structural change of school is needed to be done. Further, the scheme had certain limitations: lack of special ‘types of equipment and trained teachers.

Rehabilitation Council of India Act, 1992

The Rehabilitation Council of Indian Act, 1992 focused on providing training to teachers, which was named special education teachers. Hence, the quality of training was emphasized under this Act.

A person with Disabilities Act (Equal Opportunities, Protection of rights And Full Participation), 1995

The person with Disability Act, 1995 emphasized the right to education to CWD up to 18 years in a free and friendly environment. This Act covered various aspects such as providing training to teachers, supplying free books, transportation facilities, scholarships, etc.

National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act, 1999

The trust was formed to provide financial assistance to CWD and bring changes in the attitude of the Government, policymaker, and CWD.

Zero Rejection Policy of Sarv Shiksha Abhiyan, 2000

Sarv Shiksha Abhiyan was launched in the year 2000 to achieve the universalization of Elementary education. Here, the Zero Rejection Policy implies that children with special needs are ensured to have quality education irrespective of their type of disability. It involves various aspects such as removing architectural barriers, providing training to teachers, resource room, etc.

Action plans for Inclusion in Education of Children and Youth with Disabilities (IECYD), 2005

The objective of this action plan was to make sure that the CWD would have access to mainstream education. Further, for achieving the objective Government of India (GoI) collaborated with the Rehabilitation Council of India (RCI) and National Council for Teacher Education (NCTE) to ensure that a sufficient number of teachers are trained for inclusive education.

National Policy for People with Disability, 2006

The policy aims to create more number of District Disability and Rehabilitation Centres (DDRCs), which will bridge the gap between rural and urban areas, and it will also provide information regarding the availability of aids.

Inclusive Education of the Disabled at Secondary Stage (IEDSS), 2008

The Integrated Education for Disabled Children Scheme (IEDC) of 1974 was reformed in 2008 and named Inclusive Education of the Disabled at Secondary Stage (IEDSS). Earlier, the objective of IEDC was to provide resources to CWD in the age group of 6-14 under the SSA scheme, while the objective of

IEDSS is to ensure that CWD who have already completed their elementary education are now enrolled in the secondary stage of inclusive school. Here, IEDSS funded the inclusive School where CWD between the age group of 14 – 18 is studying with rupees 3000 annually. The objective of the funding is to provide necessary items which will ensure inclusion.

***Rashtriya Madhyamik Shiksha Abhiyan (RMSA)
in collaboration with Inclusive Education for the
Disabled at Secondary Stage (IEDSS), 2009***

It ensures that the needs of the special children at the secondary level of education will be identified, and accordingly, services will be provided to them, such as assistive devices.

Right of Persons with Disabilities Act, 2016

The Act has replaced the existing Persons with Disabilities (Equal Opportunity, Protection of Rights and Full Participation) Act, 1995. The present Act involves 21 types of disability which were 7 in the previous Act. The Act aims to provide the right of education to disabled children between 6 to 18. Further, the Act provides reservation in different sectors, such as 5% in higher education.

National Sample Survey (NSS)

National Statistical Office (NSO), a wing of the Ministry of Statistical Programme Implementation, has surveyed from July 2018 to December 2018. This survey was related to persons with disabilities. Hence it was a part of the 76th round of NSS. Following data was collected:

Table 8

Data as per National Sample Survey (NSS), 2018

Survey Covered Population of 1.18 lakh		
Literate	Above seven years	52.2%
Gained Secondary Education and above	Above seven years	19.3%
Pre-school Intervention Programme	3-35 years	10.1%
Enrolled in Ordinary School	3-35 years	62.9%
Living alone		3.7%
Living with the caregiver		62.1%
Received aid from Government		21.8%
Received aid from organizations other than Government		1.8%

Source: *National Sample Survey (NSS) Report 2018*

Factors concerned with inclusion:

The factors that are concerned with inclusion are (Kumar, 2019):-

Finance-related factors- The factor that plays a vital role in finance involves resources and income availability.

NGO-related factors - They can provide resources to CWD as well as to educational institutions for providing support.

Family-related factors - It involves the socio-economic condition of parents, awareness about rights, and their attitude towards CWD and education.

Government-related factors - The Government can modify policies and provide legal provisions to CWD.

How is inclusive education different from special education?

S.No.	Basis	Inclusive Education	Special Education
1	Definition	According to UNESCO (1994), inclusive education is seen as “a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion from education and from within education”	Special education is the process by which students with special needs receive education via the process of addressing their differences while integrating them as much as possible in the typical educational environment of their peers (Benitez Ojeda & Carugno, 2021)
2	Concept	Inclusion provides students with disabilities access to regular classrooms irrespective of race, caste, language, class, geographical location, and disability equitable and quality education that responds to their needs as learners. The concept facilitates heterogeneous grouping and zero rejection (SCERT, 2007).	It is a term that refers to educational provisions for children with special needs that emerge due to physical, mental, and emotional challenges. Therefore, they have Special Educational Needs (SEN). Thus, Special Education means specially designed instruction for a learner with the challenges as mentioned

earlier in all settings such as classroom, home, workplace, public places, and rehabilitation homes, etc. (NCERT, 2007)

The first group that advocated for special education was parents whose children were marginalized as far back as 1933. The majority of these family associations began making waves in the 1950s when their lobbying encouraged the passage of laws that provided training for teachers who worked with deaf, hard-of-hearing, and intellectually disabled students.

In the 1960s, multiple laws were passed, granting funds for special education students (National Council on Disability, 2000).

The concept of inclusion first gained more recognition in Canada and the USA than in the UK. (UK Essays, 2018). In 1994, the Salamanca statement was promulgated by UNESCO, which called for countries to promote inclusive settings in schools and colleges (UNESCO, 1994). Ninety-two countries adopted this statement, and 25 organizations and movements towards inclusion were raised globally (UNESCO, 1994).

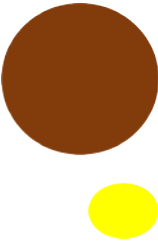
In India:

The Government of India is constitutionally committed to ensuring the right of each child to primary education.

3 Foundation

4	Trajectory The Government of India has created various policies around special education since the ‘country’s independence in 1947. One of the earliest formal initiatives undertaken by the GOI was the Integrated Education for Disabled Children (IEDC) scheme of 1974 (NCERT, 2011).	In India: Initiatives to educate people with disabilities began in 1883 when a Christian missionary started the first school for the blind (John Antony, 2013). However, only by 1918, a formal school for children with intellectual disabilities was established in Kurseong in the eastern part of India.
	Some of the essential milestones in the field of inclusive education are written below:	Some of the essential milestones in the field of special education are written below:
	Integrated Education of Disabled Children (IEDC), 1974	Rehabilitation Council of India Act, 1992
	Zero Rejection Policy of Sarv Shiksha Abhiyan, 2000	The person with Disabilities Act (Equal Opportunities, Protection of rights And Full Participation), 1995

5	Ministry of Education looks upon inclusive education	Action plans for Inclusion in Education of Children and Youth with Disabilities (IECYD), 2005 Inclusive Education of the Disabled at Secondary Stage (IEDSS), 2008 Rashtriya Madhyamik Shiksha Abhiyan (RMSA) in collaboration with Inclusive Education for the Disabled at Secondary Stage (IEDSS), 2009	National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act, 1999 Rehabilitation Council of India Act, 1992 The person with Disabilities Act (Equal Opportunities, Protection of rights And Full Participation), 1995 National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act, 1999 National Policy for Persons with Disabilities, 2006 Right of Persons with Disabilities Act, 2016 Ministry of Social Justice looks upon special education

6	Laws	Integrated Education for Special Disabled Children (IEDC) Scheme, 1974	The Persons with Disabilities Act (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 Right of Persons with Disabilities (RPWD) Act, 2016 Individuals with Disabilities Education Act (IDEA), 1997 Mata Bhagwati Chadha Niketan, Noida The Gateway School, Mumbai
7	Example	Lady Andal School, Chennai Kindle Care High School, Hyderabad	
8	Diagrammatic presentation		An integral part of the general system Source: https://www.special-education-degree.net/what-are-inclusive-special-education-programs/ A part of the general system Source: https://www.special-education-degree.net/what-are-inclusive-special-education-programs/

Sociocultural related factors - This factor involves language, caste, and gender, which determines inclusion.

Teacher-related factors - It involves proficiency and readiness of teacher and curriculum modification.

Geographic related factors - It means the closeness of learner to attend the school.

Learner-related factors – To identify what the attitude of a learner is? That means early identification of CWD and intervention must be provided accordingly.

School-related factors - It indicates school policies, infrastructure, availability of resources, and evaluation criteria.

Recent development in inclusive education (NCERT, 2021):

1. NCERT (a National Institute of Ministry of Education) has signed a Memorandum of Understanding (MoU) with Indian Sign Language Research and Training Center-ISLRTC (a National Institute of Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment) to convert books into Indian Sign Language.
2. NCERT releases CWD guidelines for children with disabilities in collaboration with expert
3. Online Learning of Children with Disabilities -Diksha portal to be made accessible, and all academic resources have to be made accessible for children with disabilities/PWD

Is inclusion a viable alternative?

Integration itself indicates that segregated students are accommodated in school and classroom. It also indicates

that schools are forced or requested to set up their school for the disabled. Placing exceptional children with non-disabled children without a proper school arrangement can lead to a significant disaster. The setup for inclusive education demands various things such as man, material, resources, curriculum flexibilities, programs, activities, and other support services. With its vast population of exceptional children, India cannot achieve its target of providing free and compulsory education to all children up to the age of 14. Sometimes inclusion is criticized as well. Nevertheless, with proper planning and execution, the CWD can provide a non-disabled one in the least restricted environment and maximum reach. Through the following ways, inclusion can be made better:-

1. The full inclusion model can be accepted so that all children can be taught in Government and aided schools.
2. Special schools will be considered for the specific type of students. However, NGOs and Government shall provide incentives to the schools that are supporting inclusion.
3. Essential services like special education teachers, resources, aids, and ‘types of equipment must be provided per the need of the CWD.
4. Since classrooms become heterogeneous because of inclusive education, the emphasis must be on designing a suitable individualized curriculum instead of standard instruction.
5. The teacher must practice teaching techniques in an inclusive setup such as collaborative team approach, data-based instruction, activity-based learning, and creative problem-solving. These strategies can be applied to non-exceptional children as well.

6. The teacher should not expect the same learning outcomes from the students of an inclusive classroom.
7. Additional services such as individualized guidance, resource room facilities, and support from a particular teacher can be arranged for exceptional children.
8. The responsibility is to help the exceptional children in leading their adult and community life. They must be helped out in adjusting to their physical and social environment.

Where does India stand now in inclusive education?

According to estimates of the UNESCO Institute for Statistics (UIS), there were 110 million children out of school, which went down to 73 million children in 2010. As per data of MHRD, 2009, there are 8 million children out of school in India, where they are marginalized by various dimensions such as gender, poverty, disability, and gender. According to Deepa (2006), though the word inclusion may exist in education policy, we see the difference between law and its implementation. Most schools do not have special educators for the CWD; even the Rehabilitation Council of India Act, 1992 indicates that CWD has the right to be taught by exceptional teachers (Deepa, 2006).

The constitution of India is dominated by the sentiment of equity and social justice (Chatterjee, 2003). The parental community is also seen to be resistant to inclusive education (Chatterjee, 2003). Several reasons, such as lack of sensitiveness, awareness, and education of inclusive education among the parents, have negatively impacted inclusive education even though the number of research is done in inclusive education and the development of methodologies. However, the inclusive educationist says that these things must comply with the culturally appropriate practices and precepts (CAPP) (Chatterjee, 2003).

NEP 2020: Making education more inclusive

The National Education Policy, 2020 has discussed the structural change in the education system, aiming to make India the global knowledge superpower by ensuring equity and inclusion. The aim of equity and inclusion is now one of the goals of the new NEP. In higher and school education, inclusion involves restructuring the whole education system to ensure a wide range of educational opportunities; this includes curriculum, pedagogy, infrastructure, teaching-learning, recreational opportunities, etc. The policy is designed to avoid segregation and isolation of ethnic and linguistic minorities, those with disabilities, and those who face learning difficulties due to language barriers and are at risk of educational exclusion (Anuja, 2020).

Analytical discussion

1. Adaptation in School

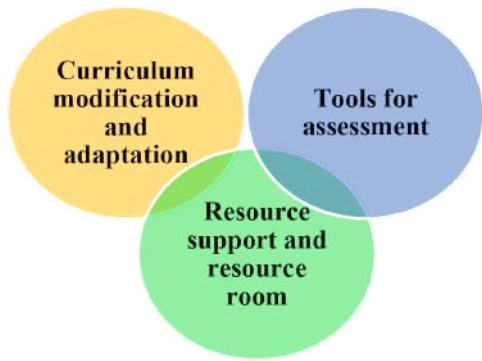


Figure 1. Depicting points to be considered for adaptation in school

Curriculum modification and adaptation

The curriculum is the center point that connects students as well as teachers. The curriculum can be adapted in time,

children's needs, rules, regulation, pedagogy, content, etc. When it is said "curriculum for all" that indicates three major points that are child centeredness, flexibility, and participation.

Tools for assessment

Assessment is a concern for teachers as they need to lower the standard because of CWD as there is not much provision of CWD in the regular classroom. Therefore, an alternative system of examination can be adopted for CWDs. This will help the CWDs to showcase their abilities.

Resource room facility

Resource teachers with different disabilities can be appointed in schools to work with regular teachers and support CWDs. Further, resource rooms shall be constructed in schools, such as ICT, academic lab, soundproof, etc.

2. Adaptation in Society

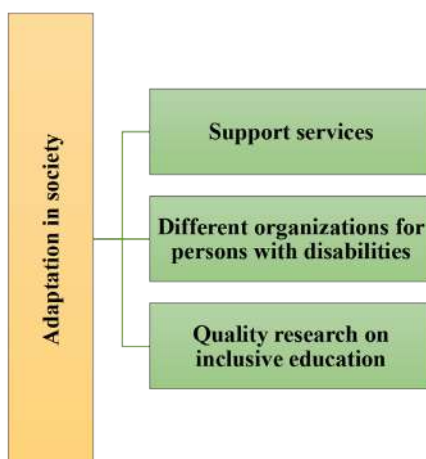


Figure 2. Depicting points to be considered for adaptation in society

Support services

Support services must be provided as per the needs of the child. Here, support services indicate availability and up-gradation of aids or assistive devices as per the various parameters such as technical support and individual needs. In the context of India, either there is no installation of devices, or there is no accessibility to these devices. In other countries, there are IT-enabled customized communication tools that help the disabled to enjoy their independence. Hence, an IT-enabled approach is the need of the hour.

Different organizations for persons with disabilities

Topics related to disability such as peer sensitization, parental awareness, and community mobilization are key to work. Different organizations such as NGOs and self-help groups can work collectively to work for CWD. Hence, sharing of information and resources can be done.

Quality research on inclusive education

Giffard-Lindsay (2007) said that it is essential to conduct quantitative and qualitative research to implement inclusion continuously. Further, there must be an evaluation of ‘stakeholder’s perspectives such as CWD.

Key findings

Following measures can be adopted for the implementation of inclusive education in India in a better way:-

1. Right to Education (RTE) must apply to all citizens of our nation.
2. In the Indian education system, a policy of inclusion is needed to be implemented.

3. The teacher needs to be trained for special education in rural areas as per the program's aim.
4. The flexibility of inclusive education must be reflected through methods and materials which are used for teaching.
5. A support team must be provided to the teacher as a resource.
6. The support team should also develop strategies for the school to fulfill the needs of CWD.
7. The school must provide education structures and methodologies to meet the different needs of all children.
8. Parents must be taken into consideration for decision-making concerns to the child.
9. The school must make an adjustment in advance regarding transport and architectural facility.
10. The school must provide Student-oriented services per the students' needs—for instance, uniforms, transport allowance, books, etc.
11. Rather than seeing the CWD with sympathy, they must be treated equally as the non-disabled children. They must be recognized based on their talent.
12. The modification must be made in the examination system as per the requirement.
13. Toward the educational system, a good attitude of teachers must be formed for good practices.
14. In-service training programs must be provided to general as well as special educators with all disabilities.
15. For 'teacher's preparation, planning must be done in periodic evaluation of the training programs.

16. Parallel work must be done in terms of curriculum reform and the training of teachers. The expert group should develop the curriculum in which the practice of special teachers must be included.

Conclusion

The approach to be adapted in inclusive education must be inter-sect, comprehensive, and holistic. Every citizen of a country has the right to education. In broad terms, the school system of our nation must effectively work to fulfill individual needs. Education must be provided without considering caste, religion, race, and ethnicity. Hence, human beings are assets of our nations that are appreciated, not depreciated. Therefore, just because of deformity, children must not be ignored. With proper ‘teacher’s training and infrastructure, one can provide education to the disabled. Even at the societal level, society needs to change its attitude towards the disabled.

Further, Government shall focus on the data related to the disabled and must plan and execute as per it. It is said that the success of inclusive education depends upon multiple factors such as teacher, infrastructure facility, curriculum, etc. Therefore, issues related to the abovementioned factors, such as curriculum modification and infrastructural facility, must be addressed. Inclusion will yield results when adequate preparation is done. Community involvement is required for the capacity building of inclusive education.

Scope and limitation

The present study will benefit stakeholders such as teachers, learners, society, and the nation. Further, this study can be used as a base for forming new policies or making amendments to existing policies related to disability.

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Factors Affecting Learning Loss due to COVID-19 for Students with Disabilities in India: A Secondary Data Analysis

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Abstract

The education sector has suffered a significant hit due to COVID-19. UNESCO estimates about 65% drop out in school-going children, and among them, students with disabilities (from now on referred to as SWDs) are disproportionately represented. Globally, SWDs are at higher risk of dropping out of school, college and being unable to complete their education. The situation is similar in India, where SWDs cannot cope with online learning and risk dropping out of school. The learning loss due to COVID-19 for SWDs is less explored and needs immediate attention. This study explores the factors affecting learning loss due to COVID-19 for SWDs in India. Secondary data analysis employed analysis of various government reports and articles. Unprepared teacher/student, home-schooling, social isolation, school closure, and reduced employment opportunities significantly affected learning loss for SWDs. The study findings can inform the educational institutions and practitioners about the relevance of providing equal access

and strengthening the online learning platforms for SWDs. The study findings can enable policymakers and educational administrators to make informed decisions and plan actionable strategies to ensure continued access to learning opportunities for SWDs.

Keywords (6-8): Students with disabilities, learning loss, COVID-19, access, learning opportunities, e-learning, India.

Introduction

Education is crucial for an individual's overall growth and development as it empowers them to make an informed decision and have access to independent living opportunities. Education imparts learning that engenders awareness about resources and societal acceptance and can make an individual a productive member of their society. Additionally, education impacts health, psycho-social well-being, livelihood opportunities, and open avenues for an individual to learn and grow. Education for all is a global concern (UNICEF, 2013), and efforts are made to ensure globally no one is left behind (UNDP, 2019). Inaccessibility and limited or no access to education is a human rights issue (UNDP, 2019). The United Nations (UN) Sustainable Development Goal 4 (SDG 4) aims to provide- "inclusive and equitable quality education and promote lifelong learning opportunities for all by 2030" (Desa, 2016, p. 21). However, achieving this goal seems challenging as with the onset of the COVID-19 pandemic, all the sectors concerning education and development have experienced a cascading effect.

Global impact on education

Globally, the education sector has been affected severely by the COVID-19 pandemic, as 1.53 billion learners are out of school in 184 countries due to preventive measures like school closure

(UNESCO, 2021). A nationwide closure in 153 countries monitored by UNICEF and local closure in 24 countries would affect 98.6 percent of students worldwide. UNESCO estimates about 65 percent drop out in school-going children, and SWDs are disproportionately represented (UNESCO, 2020b). Globally, SWDs are at higher risk of dropping out of school, college and being unable to complete their education (UNESCO, 2020b).

Impact in India

The situation is similar in India, where 320 million students have been affected by school closure (UNESCO, 2020a), and only 37.6 million children across 16 states continue education through various education initiatives such as online classrooms and radio programs (UNICEF, 2020a). The SWDs are unable to cope with online learning (Krishna & Rajaraman, 2020), struggles and attend classes irregularly (Swabhimani, 2020), are at risk of dropping out of school, and are unable to complete their education. Unable to complete education puts SWDs and girls in the most vulnerable groups at risk of having compromised future opportunities. According to Ranjan (2020), about 77% of SWDs who cannot access distance learning methods felt they would fall behind in learning. Additionally, SWDs who lack access to the technologies and are forced to attend home-based learning have limited means to continue their education (PTI, 2021). Consequently, many SWDs may face the risk of never returning to school, undoing years of progress made in education leading to limited or no access to future opportunities for employment and growth.

Literature Review

Factors affecting education during COVID-19

COVID-19 had a multi-faceted influence on students' access to educational opportunities, particularly SWDs in low-resource environments. For instance, in India, where most of the population either live in the rural part of the country or low resource environments (informal settlements¹) of urban space. Researchers highlight multiple factors affecting the education of SWDs during the COVID-19 across various literature. Some of them include unprepared teachers/students for online education (Jena, 2020); home-schooling with increased parents' responsibility to teach their wards (Krishna & Rajaraman, 2020; Jena, 2020). The majority of the literature highlights that particularly underprivileged students cannot explore online learning opportunities due to limited access to the technologies and digital world (Jena, 2020; Menon & Unni, 2020).

The paradigm shift to online learning methods may exuberate the rural-urban divide (Kundu, 2020; Jena, 2020). There have been significant challenges in adaptation to new-age modern education approaches in rural India and urban low-resource environments (Kundu, 2020; Chowdhuri & Rohtagi, 2021). For instance, daily waged workers and often uneducated parents find it challenging to look after their children's home-schooling (Menon & Unni, 2020). This lack of parental guidance demotivates the child to continue their learning further due to no support at home. All the factors mentioned above collectively limit the learning opportunity and curb the SWDs for such subjective experiences.

1 Informal settlements are those settlements which are in urban spaces with limited basic facilities.

What is learning loss?

Researchers have used the term ‘educational loss’ and ‘learning loss’ interchangeably; however, there is a stark difference between these two terms. As suggested by (Surabhi 2021; Exley, 2021), education is a process of receiving and providing knowledge through systematic instruction, for example- school education. In comparison, learning is a life-long process (Exley, 2021). It involves an intellectual process of acquiring new skills and knowledge, through experience, social involvement, study, or teaching (Surabhi, 2021), for example- value-based learning. Learning involves students’ personal and environmental (physiological, psychological, and social) interaction (Kiswanto, 2017; Jarvela et al., 2019; Surabhi, 2021) to create opportunities to regulate their future actions and develop new knowledge (Surabhi, 2021). It is an organic or natural process (Surabhi, 2021; Jarvela et al., 2019) driven by the intrinsic motivation (Achiam & Sastry, 2017) of the students and can take place through day-to-day activities (Schlesinger et al., 2020), community life (Chambers, 2019), and interactions (Probine, 2021).

Most studies focus on educational loss and fail to cater to the need to explore learning loss which is crucial and embedded in the social environment and learning experience of the SWDs. Understanding the learning loss could provide insights into the psycho-social challenges SWDs are facing on a day-to-day basis staying inside their home in isolation. The factors affecting learning loss due to COVID-19 for SWDs are sporadically explored across studies and need immediate attention to bridge the learning gap and facilitate an advanced learning environment for them. Hence the core focus of this study is to explore the learning loss.

Problem statement

Access to education is a human right issue (McCowen, 2013); it empowers individuals to undertake informed decisions (Rieckman, 2018), has agency over choices/voice (Donnini, 2015), and independent living (Borntrager, 2006). Multiple factors can influence access to education (UNICEF, 2020). For instance, with the dearth of infrastructural facilities (Fagbohunka, 2017), limited trained teaching staff (Bajaj, 2011), inaccessible curriculum, and pedagogy (Menon & Unni, 2020) to access online education, it is anticipated that these factors will affect the learning and outcomes of many children in low-resource settings (UNICEF, 2020) like India. The SWDs are anticipated to be the worst affected by this online shift as they face challenges in understanding the instructions digitally due to limited acquaintance with this mode of learning (Krishna & Rajaraman, 2020). Learning loss is much more than just access to education as it influences the physio-psycho-social development of SWDs (Kumar, 2018) and is associated with their subjective experiences (Morgan et al., 2019; Spinelli, Lionetti, Pastore, & Fasolo, 2020). They understood the factors affecting learning loss due to COVID-19 and the relevance of an actionable approach to mitigate these so that SWDs could have a better future. Hence this secondary data analysis proposes to explore the factors affecting learning loss due to COVID-19 for SWDs in India.

Research Questions

- What are the factors that affect learning loss for SWDs in India due to COVID-19?
- How do these factors influence SWDs' learning loss?

Research Methodology

Method

This study employed a secondary data analysis method primarily been used in educational and evaluation research (McArt & McDoughal, 1985). This process allowed the researcher to examine the data more closely for latent content that reflects the detailed meaning of the responses (Rew et al., 2000) related to the study's objective. This approach was selected, as secondary data analysis is an efficient and cost-effective research method (McArt & McDoughal, 1985) for novice researchers and students (Smith, 2008). The method provided a time-saving opportunity to understand factors affecting learning loss due to COVID using the same empirical data with a different perspective (Koziol & Arthur, 2011).

Search Strategy

I performed an in-depth literature search for secondary data using the keywords- education loss, COVID-19, students with disabilities, learning opportunities, challenges, e-learning, access, strategies by government, India. I also included some phrases after the initial search, to explore further, these phrases included- 'education during COVID-19', 'education in India during COVID-19', 'education for students with disabilities amidst COVID-19', 'impact of COVID-19 on education', and 'Online learning during COVID in India.' I looked for the literature in the following databases: Google, Google Scholar, SCOPUS, Indian government websites like- Ministry of Education, Ministry of Social Justice and Empowerment, NGO websites for reports.

Inclusion and exclusion criteria for articles

The secondary data included the research papers published over the last ten years (focusing on the last two years) and

government and non-government reports of the past 4-5 years. Secondary data also included steps undertaken by various local and government bodies to mitigate the challenges associated with online learning. The analysis of several mitigation strategies employed by the authorities helped understand how the steps taken either bridge the gap or lead to a further digital divide for SWDs and their families. All the articles and reports dates before 2010 were excluded from the study. The articles not based on Indian contexts were also excluded. The author did a title and abstract screening for 20 documents (16articles + 4 reports) which were initially selected and excluded 12 as they did not relate to the education loss; the last eight documents (6 articles + 2 reports) were screened full text by the author and three documents were further excluded as they did not meet the study objective and were not related to the research question. Finally, the author ended up at the five related and suitable articles to answer the research question. Table 1 shows some of the critical articles and reports that somehow highlight the learning loss. All this existing empirical evidence highlights the potential shift in the Indian education system and how the learning loss has further intensified due to COVID-19.

Data Analysis

The analysis followed content analysis, and the researcher looked for contents across literature and government reports exploring the factors that affect learning loss and its impact on the physical and mental health, social life, and self-identity of SWDs. The initial analysis provided qualitative and quantitative results about the association among crucial factors and concepts affecting SWDs' learning loss due to online education patterns amidst COVID-19.

Later these findings were summarized and substantiated with the evidence-based findings from similar studies. A secondary analysis of the qualitative responses led to a more in-depth description (Johnston, 2017) of how the various factors coupled together can create further barriers related to the physio-psycho-social development of the SWDs.

Findings

Based on the literature reviewed, the researcher identified that there had been significant learning loss, and there are factors that affect the learning loss. The researcher proposes that “educational loss” should be considered as an objective approach to gauge unidirectional influences of socio-physical structure (people and institutions) on SWDs, whereas “learning loss” is the subjective experience of SWDs that accounts for the missed opportunities of experiential learning from the person-environment interaction, including places, peer-to-peer learning, activities, people, and objects. The predominance of learning loss for SWDs is anticipated to be higher than non-disabled students (Krishna & Rajaraman. Multiple factors might lead to significant learning loss (Jena, 2020), and these can be mitigated through an actionable approach to ensure inclusive access to learning for SWDs (refer to table 1. column four: bridge the gap strategies).

The factors highlighted initially that affect the educational loss, on a broader aspect, likely leads to significant learning loss to SWDs in India. The learning loss is associated with SWDs’ subjective experience while performing a task, participating in societal events in and out of home, and social interactions. The SWDs develop meaning for each of these experiences and imbibe the learning for their emotional and cognitive growth. For instance, the meaning could be an agency to participate, develop

Table 1

Factors affecting learning loss of Students with Disabilities during the COVID-19 period and E-Learning Resources

Title and Author	Factors affecting the learning of students with disabilities	Secondary data analysis & findings	E-Learning Resources during COVID-19	Bridge the gap strategies
Impact of pandemic covid-19 on education in India. (Jena, 2020)	Unprepared teachers/students for online education.	We have reduced global employment opportunities.	Secondary education: Diksha portal, e-Pathshala, National Repository of Open Educational Resources (NROER) STEM-based games.	Accessible features in Diksha Portal, e-Pathshala, NROER with Sign Language accessibility, Colour Contrast, and Deaf-Blind Student accessibility features to be added. Low vision features to be added.
	Increased responsibility of parents to educate their wards.	Some may lose their jobs in other countries.		
	Access to the digital world.	Passing out students may not get their job outside India due to restrictions.	Higher Education Swayam Swayam Prabha e-PG Pathshala	Accessibility Features for all 21 types of disability-specific and common features to be added in All Higher Education portals like Swayam portal, E-PG Pathshala,
	Underprivileged students are unable to explore online learning.	Loss of nutrition due to school closure and impact on health.		

The Paradigm Shift in the Indian Education System during COVID19: Impact, Opportunities, and Trends (Menon & Unni, 2020)	Parents (daily wagers) face difficulty managing children's studies at home.	There is a high peak in violence and exploitation.	e-PG Pathshala	UGC guidelines with the inclusion of accessibility features on all universities' websites all university websites shall comply with the W-3 guidelines of global accessibility standards. Accessible features with Sign Language accessibility, Colour Contrast, and Deaf-Blind Student accessibility features to be added. Low vision features to be added. Deploying E-learning methods can also assist special educators in reaching many children simultaneously. All of
	Digital divide, with embedded gender and class divides.	Anticipated trends in the post-COVID world.	CEC-UGC YouTube channel	
			National Digital Library (NDL)	
		Fewer children will go back to school when schools reopen or will go out of town to study.	National Academic Depository (NAD)	

	Social distancing, little or no sports.	National Knowledge Network (NKN)	this is possible only when the government takes an active interest in building technologies and capacities to make education truly inclusive and universal.
Impact of COVID-19 on School Education in India:	Engagement in economic activities and participation in household chores.	PM e-Vidya.	
What is the Budgetary?	The quality of	The state takes initiatives	Accessible features with Sign Language accessibility, Colour Contrast, and Deaf-Blind Student accessibility features to be added. Low vision features to be added.
Implications? (Kundu, 2020)	The electricity supply is impoverished, especially in rural India.	Governments: i. Andhra Pradesh: Abhyasa ii. Kerala: Digitalisation of all school textbooks iii. West Bengal: TV Channels, WhatsApp,	The term ‘inclusive education’ needs to be defined under the RTE Act. The Act should be amended and brought
	While 24 percent of Indians own a smartphone.		

Only 24 percent of Indian households have an internet facility.	A recent survey in West Bengal- child labor among school-going children has increased by 105 percent during the pandemic. Only 37.6 million children across 16 states are continuing education through online classrooms and radio.	and phone calls for doubt clearing sessions iv. Rajasthan: SMILE (Social Media Interface for Learning Engagement) v. Haryana: Ghar Se Padhao Abhiyan vi. Bihar: Unnayan- 'Mera Mobile Mera Vidyalaya' National Council for Educational Research and Training (NCERT), inclusive online education.	in line with the RPWD Act to update norms and standards to become inclusive, and guidelines should be issued under it for student and parent preparedness.
Impact of COVID -19 on Inclusive Education in India	Inaccessibility to Information and Communication Technologies.	Change in daily routines, lack of socialization, lack of emotional support, and change in means of learning have impacted the emotional state of children with disabilities.	Video content: Indian sign language and captioning, audio description of the video content not conveyed in the dialogue.

An Exploratory Research Proposal (Krishna & Rajaraman, 2020)	Ineffectiveness of television-based lessons. High dependence on parents. Challenges in-home visitations by a teacher. Challenges faced by teachers in acclimatizing to the online mode of education.	NGO involvement to provide individualized support. Inaccessibility of disability-related benefits, nutritional supplements, and rehabilitation put the CWD at a higher risk than neurotypical children.	National Council for Educational Research and Training (NCERT), student's learning enhancement guidelines 2020-21 The Ministry of Social Justice Furthermore, Welfare issued guidelines for the protection and safety of PWDs. Provision of Compensatory Education.	Audiobooks: Indian sign language and captioning, effective navigation and browsing as per DAISY standards, caption to read along. Image/picture or visual explanation of concepts: Textual description of the image, non-cluttered images, color contrast, and low vision features to be added. Multi-sensory+ Indian sign language+ closed captioning +audio to be considered
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The New Normal of the Education System: Issues of Rights and Sustainability in Pandemic Trapped India.	UNESCO (2020c) data, 100 countries have not yet announced a date for schools to reopen; 65 have plans for partial or complete reopening.	School closure raises a range of ethical and social issues. Underprivileged families- disproportionately affected.	Digital reach of education- categorized into three groups: ● online ● partially online ● offline mode	Learning Enhancement Programmes and Models need to take into cognizance following challenges and concerns of learning during the COVID-19 period: ● For students not in school for a longer duration, there would be a visible gap in the learning level of students. ● Students have parents at risk due to their jobs. ● Children of migrant workers.
(Chowdhuri & Rohatgi, 2021)	Digital access- rural internet density is 25.3, while the urban internet density is 97.9.	Transitioning to online learning is a challenging and highly complex undertaking. Adverse impact on learning outcomes and the social and behavioral development of children and young people.	Digital access- rural internet density is 25.3, while the urban internet density is 97.9. 75% of SWDs never attend school.	In the pandemic period, with an uncertain future facing all while planning any model for learning enhancement, the social-emotional aspects of learning need to be kept in view.

The use of mobile phones, television, and the internet in India is mainly for leisure and entertainment.	The digital divide will widen existing gaps in inequality concerning education.	Of the 6,572,999 children in the 5-19 age group, only 61.18 percent (4,021,301) have attended any educational institution. This was well below the national average of 70.97 percent for children in all categories.	Accessibility of devices, ICTs, resources, building infrastructure, Affordability of the devices and resources to the larger population in remote and rural areas.
Children with internet problems walk 10 kilometers in the village in-network access zone and develop leg pain, acute fatigue, and discontinuing education due to regular school attendance.	The citizens in the 'offline' category will suffer the most in the changing and challenging times.	Some 26.68 percent (1,753,737) have never attended any educational institute compared to the national average of 17.21 percent.	Capacity building of teachers and caregivers.
	This 'faceless' classroom-exhaust the participants.	About 12.14 percent (797,961) attended one but dropped out later.	Promoting home-based schooling as an acceptable feature under RTE.
			Mapping the curriculum, reducing contents, and creating refreshers programs for the learning loss of students with disabilities.

social bonds, interact with friends and peers, and contribute to society's development. The subsequent paragraphs talk about the factors affecting learning loss from a psycho-social lens.

Learning loss due to unprepared teachers/students

Online learning leads to compromised learning experiences for the SWDs as they have poor access to resources, ICTs, internet, and even if they have access to these resources, the online interface is not disabled-friendly. This is further aggravated as the teachers have limited accessible tools for online instructions (Krishna & Rajaraman, 2020), and most of them are not adequately trained (Jena, 2020) to conduct need-based online learning sessions for SWDs. As SWDs could not comprehend the online instructions comprehensively, they failed to accept this online mode (Jena, 2020). When they are dependent on someone (people as environment) for their learning, they find it challenging to navigate and get frustrated. The imitation of E-learning is its unfriendly user interface (Kundu, 2020), making it difficult for the SWDs to comprehend the learning materials, maintain their attention, retain what they see on online platforms, and simultaneously assimilate the learnings (Ranjan, 2020). The SWDs develop fatigue, stress, anxiety, and it hampers their cycle of learning- attention, sensory process, analysis, memory, retention, assimilation, etc., which was possible in the offline mode of learning with the continued support of peers, teacher, and caregivers.

Learning loss with home-schooling

Due to the shift to online learning, SWDs and their parents either do not have access to advanced technology (Jena, 2020) or, if they do, they are not accustomed to using these efficiently. They lack the understanding of even operating technological

devices and have difficulty using these applications. As a result, the parental involvement, guidance, and support that could lead to the reinforcement of a positive approach toward learning are missed (Menon & Unni, 2020), affecting SWDs' psycho-social growth. Also, the SWDs with limited digital literacy, understanding regarding the use of the internet, devices, understanding of online platforms, social media, other media platforms to learn, participate, and contribute miss the opportunity and have a negative experience from online learning and due to that they refrain attending the class regularly (Kundu, 2020). In most cases, parents cannot afford such devices (Krishna & Rajaraman, 2020), and with no device to access online learning (Chaudari & Rohatgi, 2021), SWDs are left behind to drop out of class then continue for nothing.

This process of unfamiliar home-schooling and learning loss is diverting children into loneliness (Chowdhuri & Rohatgi, 2021), lack of social play (Menon & Unni, 2020), a sense of low self-esteem (Krishna & Rajaraman, 2020), and they are unable to follow the learning routine of online learning (Chowdhuri & Rohatgi, 2021). Also, Children with poor network and access to the internet walk 10 kilometers in the village on network access zone and develop leg pain, acute fatigue, and discontinue education as they cannot maintain regularity in school. These adverse experiences are internalized so much that SWDs can take years of effort to overcome with continued irregularity. These adverse experiences are internalized so much that SWDs can take years of effort to overcome with continued irregularity.

Learning loss due to school closure

Studies highlight that the change in daily routines, engaging in home chores, lack of socialization, lack of emotional support, and change in means of learning had affected the emotional

state of SWDs (Kundu, 2020). In addition, with school closure, the in-person connection is missing. SWDs miss opportunities to retain and make social connections engage in personal conversation with their friends and peers. During this time, SWDs' social environment includes people, places, and objects that do not facilitate conducive learning opportunities to inculcate their emotional and cognitive development. School closure impacts mental and physical health as well, as there is a lack of outdoor physical activities that make them prone to various health disorders (Chowdhuri & Rohatgi, 2021).

Learning loss due to social isolation

Missing the in-person connection due to lockdown leads to inadequate learning opportunities and social isolation. Social isolation refers to staying inside the home with no social support and fear of getting affected by COVID-19 if they socialize. Although, with the prevailing societal stigma around disability, SWDs have been living in isolation for so long (Agrawal, 2020). However, the COVID-19 pandemic was triggered further, and those who could have recovered from this isolation in everyday life are further pushed back. All the efforts to promote the learning experience with an inclusive education philosophy (Lindsey, 2007), where inclusion means that children are physically present and socially included (Bhan & Rodricks, 2013), are gone in vain.

Social isolation is likely to lead to aggressive behavioral change in SWDs. Frustration, anxiety, anger, and irritation become habitual behavior for them (Rajan, 2020). The entire experience of being in a homely environment, staying close to family, and support, go in vain, and the SWDs are at higher risk of experiencing traumatic episodes and could hurt themselves in isolation.

Learning loss due to reduced employment opportunities

With the onset of COVID-19 induced lockdown, significant job losses and reduced employment opportunities (Deshpande & Ramachandran, 2020). A report by United Nations Human Rights (2020) highlights that individuals with disabilities who are employed or self-employed (United Nations, 2019) “ may be prevented from working from home due to the absence of equipment and support which are available in the workplace and face increased risks of losing their income and job” (p. 5). The qualified SWDs may not get their job within India due to restrictions caused by COVID-19 (Jena, 2020) and unprecedented recessions in the employment sector (Raman et al., 2021). Data from the survey by the National Centre for Promotion of Employment for Disabled People of 1067 individuals with disabilities (approx. 73% male and 27% female) shows that about 57% of individuals with disabilities, including students, are facing a financial crisis and job loss (NCPEDP, 2020, p.13). The situations are even worse when it comes to female SWDs (NCPEDP, 2020). The opportunity that the SWDs might have for life-long learning (Jena, 2020) and experience that could help them develop the skill required for working in the industry, social capital (Rai, 2020), psychological and emotional contentment (Seevers & Lopez, 2021) through on-the-job placement (Garg, 2017) is curbed due to COVID-19.

Discussion

This study is unique in its approach as it explores the learning loss concerning the subjective experience of SWDs (Carvalho et al., 2020), which they obtain while interacting with their physio-psycho-social environment (Jena, 2020). Moreover, looking at the subjective experience from a psycho-social lens could enable

us to explore the extent of emotional and cognitive growth of SWDs that the COVID-19 pandemic has impacted (Chowdhuri & Rohatgi, 2010). The study is noble as it emphasizes experiential learning of SWDs, rather than traditional learning, and contributes to building discussion around the experiential learning loss that leads to negative consequences on their mental and physical health (Krishna & Rajaraman, 2020). These analytical findings also resonate with India's National Education Policy (NEP, 2020) philosophy that attempts to transition from the traditional education model to more experiential learning approaches by including vocational training, skill development, and instruction in the local language to promote inclusion and diversity. National Education Policy intended to promote skill-based learning and develop scientific temper from a young age to improve the quality of higher educational institutes and bring them at par with the global standards (Panditrao & Panditrao, 2020). However, pandemic-induced lockdown and restrictions have compromised the ambitions of National Education Policy which looked promising and in the right direction. Moreover, COVID-19 has pushed us way behind even thinking about such experiential learning provisions when the population is fighting to survive and thrive (Menon & Unni, 2020).

This study highlighted the factors affecting learning loss due to the online mode of education and its effect on the emotional, social, physical, and cognitive growth of SWDs. These findings resonate with the World Bank (2021), recognizing that the transition to online learning at scale is challenging and highly complex for education systems.

Consequences of school closure

There is a high peak at violence and exploitation (Menon & Unni, 2020). Evidence-based literature highlights that

when schools are shut down, early marriages increase, sexual exploitation of girls and young women rises, teenage pregnancies become more common, and child labor grows (Kundu, 2020). Exploiting the SWDs with no support at home is so common. SWDs undergoing such violence and exploitation are at increased risk of mental or physical stress that could have a long-lasting impression (Chaudhari & Rohatgi, 2021). With the dearth of child counseling opportunities, the mental well-being of SWDs is at stake, further making them vulnerable to violence.

Government initiatives and way forward

The initiatives so far are not enough and inclusive to cater to disability-related needs of SWDs and could lead to inevitable and irreparable learning loss if not addressed with relevant, actionable measures. Several government initiatives have been to bridge the digital divide and promote better learning experiences to the learners (Diksha portal, e-PG pathshala, etc.) (refer to table 1). However, they knowingly or unknowingly missed the opportunity to facilitate comprehensive, inclusive, and accessible learning. Since the larger population is not digitally aware and informed to use these online portals, there is limited acceptability of these platforms by the caregivers and SWDs. In addition to that, the availability of resources to the SWDs is access, and if there is a certain amount of investment required, then the affordability of these resources further leads to loss of learning. So, considering the Indian population size and limitation of resources and infrastructure, collaborating with NGOs can help to extend the learning benefit of online mode transition during the pandemic to children. Through their community outreach, NGOs can provide individualized support to the SWDs and create a healthy home-schooling learning environment for both SWDs and families. The government could also provide the

families with activity kits and create awareness around using household materials as a medium of experiential learning and craft activities. The Play way method with hands-on experience with different materials is likely to inculcate a better learning experience and provide opportunities to SWDs that their friends might have (Kiswanto, 2017).

In addition, government and local organizations could collectively provide basic digital literacy to the caregivers and teachers and adapt the pedagogy using a universal design of learning (UDL). UDL allows for creating facilities that are not only accessible (objective) but also usable (subjective); usability is the effective, efficient, comfortable, convenient and engaging way (Iwarsson & Stahl, 2003) to provide a learning experience to the children. Moreover, the usability of the facilities is assessed using field experience (Imrie & Hall, 2003), and this is where the NGOs can play an active part. Also, usability has an activity component (Iwarsson & Stahl, 2003), making the provisions more experiential for the users (SWDs in this case), and they can learn a lot from these experiences.

Current pedagogy focuses mainly on educational gain. However, after the COVID-19 pandemic is over, we can build on the study findings related to the concept of learning loss and create an infrastructure that provides opportunities for comprehensive learning experiences. There has been a significant gap in online education highlighted in the paragraphs above, and there is a need for a future road map with equal accessibility measures and provision in E-Learning resources and online learning provision in school education in coherence with UNCRPD.

Conclusion

Each situation has its pros and cons and affects individuals differently. The present pandemic situation and its effect on

the education sector cannot be overlooked in India. We need to develop innovative strategies to ensure the learning and development of the learners are not affected further (refer to table 1). Adapting to a digital literacy strategy could be one such step. Also, the facilities and opportunities should be created on an equal basis for all irrespective of caste, class, gender, ability, language, rural/urban background. The strategies should adhere to three As strategies- Affordable, Accessible, and Acceptable. One such strategy would be to adopt a universal design strategy to maximize the use of the services and provide a better learning experience. Responsible authorities need to collaboratively work to deal with the poor access to education for all. Also, focusing on what resources we have and how we can adapt to them and broaden the access using those resources can be an effective strategy. These strategies are likely to create an enabling environment that can nurture meaningful participation and learning experience for SWDs. There are high chances that fewer SWDs will go back to school when the school reopens (Menon & Unni, 2020; Sholas, Apkon and Houtrow, 2021), considering the internalized incapability of the learning pedagogy to engage them in the experiential learning process (American Academy of Paediatrics, 2021). It is anticipated that the effect of COVID-19 induced lockdowns and social distancing might lead to many SWDs getting socially distant (Carvalho et al., 2020).

Scope of the study

The scope of this study focused on the learning loss of SWDs due to the COVID-19 pandemic and provided insights into the implication of these research findings. For instance, the study findings can inform the educational institutions and practitioners about the relevance of providing equal access and strengthening the online learning platforms for SWDs. Additionally, the study

findings can enable policymakers and educational administrators to make informed decisions and plan actionable strategies to ensure continued access to learning opportunities for SWDs. Considering the learning loss as an essential aspect of SWDs' psycho-social growth. Future research could consider exploring the learning loss and its immediate effect on the SWDs. Further research can also investigate the family-school partnerships or parent-teacher partnerships to provide insights for adapting an experiential learning pedagogy. Researchers could also explore the impact of SWDs' learning loss on the mental health of families and caregivers.

Study limitations

The study provides comprehensive insights into the importance of learning loss; however, this analysis has limitations. The analysis did not look thoroughly into the psychological literature, which is embedded in the subjective experience, social interactions, activities in and out of the home. Moreover, this study is limited as it does not provide detailed insights into the effect of learning loss for the post-COVID world.

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Declaration of conflict of interest

Since it is sole authorship, so there was no conflict of interest. Moreover, all the reports and articles cited are given due credits.

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Non-Accessibility of Resources and Treatment Facilities for the People with Disabilities in Rural and Semi-Urban Areas and the Remedial Measures

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Abstract

Over the past 10 to 15 years, there has been a growing awareness about treatment options for people with disabilities. Statistics show that 69% of the disabled people in our country are from rural areas and 31% from urban areas. Though institutions are established and run by the private, state, and union governments in the cities of a few states, it is tough for the people in the rural and semi-urban areas to avail themselves of the services. People

who live in the urban areas have more awareness of disability, resources, treatment facilities, and better funding opportunities than those in the rural and semi-urban areas due to the active NGOs, Special Schools, private clinical services, and privately practicing therapists. In this context, this study focuses on the issues and problems of the persons with disability in the rural and semi-urban areas and their core issues about the non-availability and non-accessibility of the resources and treatment facilities. Descriptive research with a detailed literature review is adapted for this study. Then, the researchers applied the Survey and Case study research methods. The data collected are analyzed using the appropriate statistical tools, and the results are presented in diagrammes. Appropriate solutions and remedial measures are proposed as the research outcome for stakeholders working in the disability sector.

Keywords: **Persons with Disability,** Therapy, Multiple Disabilities, Rural, Poor, Primary Health Centre, Non-Accessibility

Introduction

Disability/disability has always been a word that hurts our minds. It is the duty of all stakeholders including academicians, researchers, social workers, NGOs, and charities to stop feeling pity for them, to explore their daily problems and try to find solutions to them, to explore ways of their livelihood, and to implement them with the help of the Government. Awareness about this has been increasing in our community for the last 15 years. In addition, the work of many private and non-governmental organizations, while somewhat beneficial to the welfare programs of the Union and State Governments for the Disabled, we are still lagging in obtaining medical and training and treatment methods for children and adults with

disabilities. While we analyze the key factors, we can understand that poverty and difficulties in accessing the resources are the major issues the PWDs and Parents of children with special needs suffer a lot. On the one side, PWDs face challenges in terms of accessibility to resources, education, transportation, employment opportunities, health and medical facilities, accessibility to places; on the other, the parents of children with special needs, particularly the mothers who are the permanent caretakers of the child, face innumerable difficulties. In this present context, this research paperwork presents the study on the scarcity/paucity of resources required by the Persons with Disabilities (PWDs) in the rural and semi-urban areas of our country and treatment facilities. The researchers discuss the literature survey by reviewing the works on struggles and challenges faced by persons with disabilities, disability in rural areas, issues related to persons with disabilities, opportunities and trials, factors associated with the employment of persons with disabilities, persons with disabilities, and the labor market, disability, and rural livelihoods approach, in section 2. Section 3 is presented with a statement of the problem and the need for the research. Section 4 is presented with the research objectives, and in Section 5, the methodology adopted for carrying out the research work. In section 6, the researchers present the data collection, analysis, and interpretations in detail. Then the researchers discuss the research findings in section 7 and conclude the research work in section 8.

Literature Review

The literature review of past research papers surveyed from the various offline research journals/databases and online publications very relevant to the area of research is presented in this section. Jonckheere (2020) researched the perceptions of disabled people in rural areas. He reported that 15% of

disabled people live in developed countries and face significant challenges like negative attitudes, stigma, discrimination, and lack of accessibility to physical and virtual environments. The researcher also reported that a significant proportion of disabled people are consistently poorer than non-disabled people. Many people in developing countries struggle to have an optimum level of households and suffer without adequate food to eat. Divyakirti (2020) presented the issues of people with disabilities as impairments, activity limitations, and participation restrictions and brought these three under the term Disabilities and explained each of them. The author also analyzed the percentage of the disabled population as 2.21% of the total population of 121 crores as per Census 2011 in India. A majority of the differently-abled people, about 69%, resided in rural India.

Narayan Seva Sansthan (2020) discussed the ten significant problems faced by disabled people in our country, viz. accessibility, education, health care, myths, and stereotypes, feeling of being ignored, lack of employment, feeling of being incompetent, teased and abused, being patronized and relationships. The author discussed how people with disabilities deal with these issues and suggested that the rest of the people, as responsible citizens of this country and the society, should support and inclusively develop them for a better life. Jha (2017) discussed that to combat challenges faced by persons with disabilities, India has to have a plan for the long term. The researcher also presented that about 2.21% of India's total population constitutes the disabled population, more than the total population of many countries in the world. Disabled people are leading a challenging life in India irrespective of their significant strength, and their disability is misunderstood for their inability by the rest of the population of India. He also reported that disabled people are denied employment opportunities, face

discrimination, harassment, and get isolated by most people due to their misconceptions about disabled people.

Narahariseti and Castio (2016) researched the factors associated with people with disability employment in India and poverty alleviation approaches offered to people with disabilities, including employment programs. The researcher followed a longitudinal analytic approach to find employment associates among persons with disabilities in India, and the models stratified by rural and urban areas were also measured. The research ends with Poverty alleviation programs designed for persons with disabilities in India should reason for differences in employment by types of disability and should be spatially targeted. Since persons with disabilities in rural and urban areas have different factors contributing to their employment, the Government and planning organizations need to justify these differences when forming programs aimed at livelihood development.

Uromi and Mazagwa (2014) analyzed the challenges faced by people with disabilities and the possible solutions in Tanzania. Referring to the first world report jointly created by WHO and World Bank on disability, which submits that more than a billion people in the world experience disability at present, which is about 10 percent of the world's population. Researchers also found that 80 percent of PWDs live in developing countries. Referring to the reports 2007 of WHO and ILO about Tanzania, more than 3 million people in Tanzania have a disability. The research also addressed the status of education of the PWDs of Tanzania. Konadath et al. (2013) presented their work on the prevalence of communication disorders among India's rural population. The researchers assessed the prevalence of communication disorders between gender and across age groups, producing results. The conclusions of the study/survey presented as audiological and ontological disorders

were more prevalent in the selected population; males showed a higher frequency of communication disorders than females. The frequency of severe and moderately severe hearing loss was higher than other degrees of hearing loss. Child language disorders and reading/writing difficulties also were the most persistent problems among speech and language disorders.

Mohapatra (2012) researched the opportunities and challenges for people with disabilities in the rural village Haraspada, Puri district of Odisha, India. The author presented his viewpoints on the social model of disability and sustainable rural livelihoods. The author surveyed the employment, education and training, self-employment, and social security, which are the critical features of livelihoods, using qualitative interviews and quantitative data from secondary sources. Based on the response from the contributors, the research proposes that availability of work, access to training, credit, raw materials, marketing facilities, treatment, and increased awareness by stakeholders can enhance the livelihood options for people with disabilities in the village. So, the specific policies for rural areas should be reinforced by good funds and strenuous monitoring. Shenoy (2011) studied the challenges and opportunities concerning persons with disabilities and the Indian labor market. Summarizing the significant challenges and issues faced by the persons with disabilities in Indian labor markets, providing an outline and about the services of the key organizations and institutions working for persons with disability in India, identifying considered prospects to increase the participation of PWDs in Indian labor markets and recommend necessary interventions that the ILO in India could pursue are presented in the research work. The World Bank Report prepared by O'Keefe et al. (2009) explores the social and economic situation of the people with disabilities in India. It reported that the implementation of policy commitments by the

governments in many areas remains unfulfilled for developing disabled people. The policy commitments of governments in several areas remain in large part unfulfilled. It also covers relative neglect of the people with disabilities in weak institutions due to poor accountability mechanisms, lack of awareness among the service providers, communities, and people with disabilities of their rights, and failure to involve the NGO sector intensively. The report also reveals a steeper fall in the employment opportunities for the people with disabilities than that of the rest of the population, leading to further deepening of poverty and social marginalization. It is also reported that curtailing or slowing down the employment opportunities for these marginalized people in India severely affects the people with disabilities first, then the society and the economy at large in terms of underdeveloped human capital and impacts on households and communities.

Seeley (2001) presented her research on recognizing India's diversity and disability & rural livelihoods approaches. In this research, the author analyzed that there are near, 90 million disabled people in India. Hence, beyond the welfare initiatives, there is a strong need for action in policymaking and practice to make sure that PWDs can participate and benefit from mainstream rural development programs. In their research, Agarwal and Goel (1978) examined and proposed reducing the number of disabled people by increasing the rehabilitation mechanisms and procedures. They reported that the city-based rehabilitation centers are witnessing/enrolling with a poor attendance of the disabled people as most of the population under poverty and residing in rural India are not aware of the facilities available in the cities, socioeconomically very backward, fears of city life and lack of proper transportation facilities.

Summary and Research Gaps

- i. The main observations and research gaps found from the literature review are as follows:
- ii. The majority of the people with disabilities (about 65%-70%) live in rural India and poverty.
- iii. The problems, challenges, and difficulties faced by people with disabilities are always persisting irrespective of the legislature enacted and schemes introduced for the welfare of the PWDs.
- iv. The people without disabilities or the normal people always have misconceptions and preconceived notions about the capabilities and performance of the PWDs though they are adequately qualified and experienced.
- v. Though the past researchers identified the common difficulties and challenges faced by the PWDs in general, enough attention was not given to identifying the real problems and difficulties/challenges experienced by the people with disabilities living in rural India.
- vi. Also, the negligence of the support services at the Primary Health Centres and the absence/ inadequate treatment facilities in PHCs and GHs for the PWDs in the rural and semi-urban areas are not given due attention and coverage.
- vii. The mechanisms for ensuring the inclusion of the PWDs in the mainstream society without any discrimination and the measures to be taken for the educational, economical, socio-cultural inclusive growth and development are the need of the hour as these issues were not resolved even after having the legislations and the schemes for many decades due to inadequate/poor implementations, especially in rural areas.

Statement of Research Problem

For several decades after the independence, the differently-abled people have been facing many challenges, difficulties for optimum living conditions, getting education, training and employment opportunities, and the treatment facilities for their health care. The conditions of this population are worsening in the rural and semi-urban areas compared with those in the urban areas in India. People who live in the urban areas have more awareness of disability, resources, treatment facilities, and better funding opportunities than those in the rural and semi-urban areas due to the active NGOs, Special Schools, private clinical services, and privately practicing therapists. In this context, this study focuses on the issues and problems of the persons with disability in the rural and semi-urban areas and their core issues about the non-availability and non-accessibility of the resources and treatment facilities. The researchers also propose a set of remedial measures to eradicate the challenges and difficulties faced by the PWDs in the rural and semi-urban areas after thorough research and analysis through a survey among the stakeholders and discussing the real-time cases.

Research Objectives

The researchers formulated the main objectives of this research work as follows:

- i. To study and understand the issues and challenges experienced by people with disabilities living in India's rural and semi-urban areas.
- ii. To study and analyze the availability and accessibility of the resources, support services, and facilitating institutions for the PWDs in the rural and semi-urban areas and the

problems faced by the PWDs due to the absence of these facilities and systems.

- iii. To study and diagnose the real-time cases of PWDs suffered/under suffering due to the lack of resources due to poverty and the inaccessibility of the facilities and institutions.
- iv. To suggest or propose the appropriate remedies and measures to be taken by the state and union governments in India to alleviate poverty and eradicate the challenges and difficulties faced by the PWDs due to lack of facilities and resources.

Research Methodology

The research methods followed for implementing this research work are briefed as follows:

1. Descriptive Research Method

Secondary data are collected, and a literature review is done to understand the background of the research area in focus. The living conditions, issues, challenges, and concerns of people with disabilities are studied by referring to various articles in magazines, national and international reports, research papers published in offline and online research journals. Then, the descriptive research method, which combines both quantitative and qualitative research methods, is applied in this research work.

ii. Survey Method

Survey research is conducted to collect the primary data from the stakeholders to understand their present conditions, challenges, difficulties, their perceptions on various related issues concerning their lives in society. A semi-structured survey questionnaire has been circulated to the people with disabilities in Chennai,

Chengalpattu, Kanchipuram, Villupuram, Tiruvallur, and Vellore districts of Tamil Nadu, for collecting the data through a convenience sampling technique.

Case Study Method

The case study approach is adapted to diagnose the real-time cases in the research area, validate the survey method's research outcomes, and emphasize the significance of the proposed remedial measures.

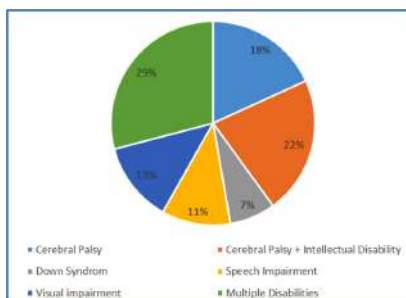
Data Analysis & Interpretation

The data collected, analyzed, and interpreted in survey and case study approaches are presented in this section.

Survey Method

The collected from about 115 people with disabilities (79 are males and 36 females), especially from the rural and semi-urban areas of Chennai, Chengalpattu, Kanchipuram, Villupuram, Tiruvallur, and Vellore districts are analyzed and represented through the graphical representation charts as follows:

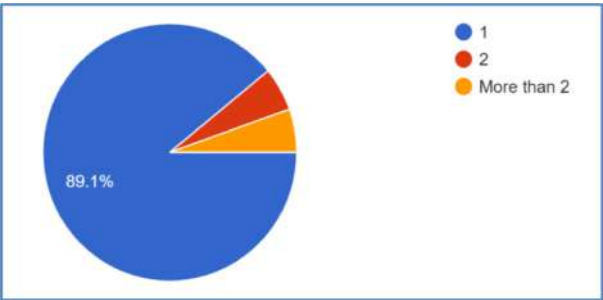
A-1: Type of Disability



From this representation, it is noted that 29% have multiple disabilities, 22% of the PWDs have cerebral palsy with

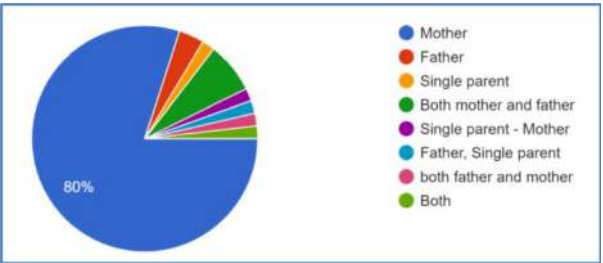
intellectual disability, 18% have cerebral palsy, 13% are visually impaired, 11% have a speech impairment, and 7% are with down syndrome.

A-2: No. of differently-abled people in the family



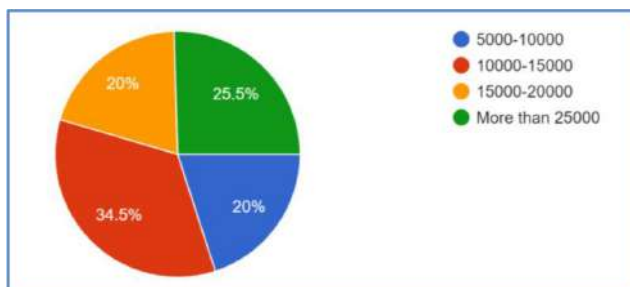
About 89.1% of the families have 1 PWD in their family, 5.5 % have 2 PWDs, and another 5.5% have more than 2 PWDs.

A-3: Permanent Caretaker of the Special Child in the Family



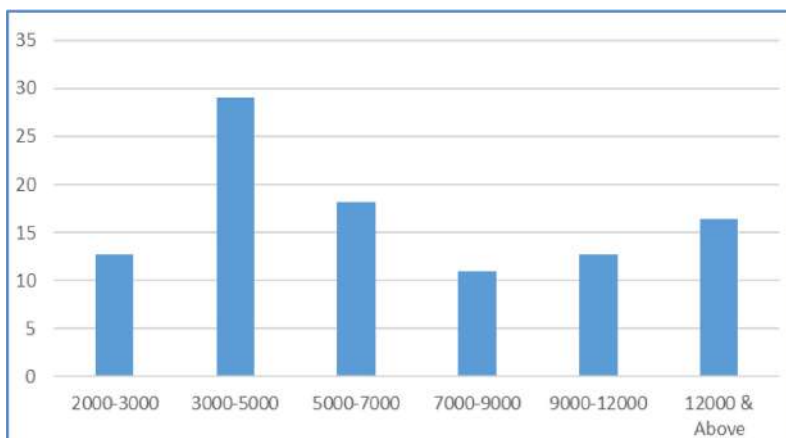
The permanent care take of the Pods in the family is represented as follows in A-3: For 80% of the PWDs, the mother is the permanent caretaker, the father takes care of 5.4 % of the PWDs, 9.1% are taken care of by both mother and father.

A-4: Monthly Income of the Family



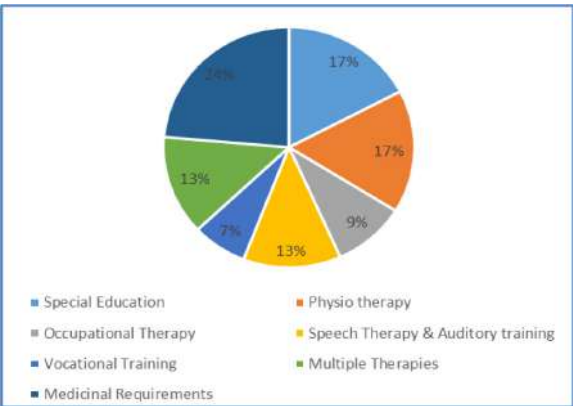
The family's monthly income is as follows: 20 % earn about Rs.5000-10000, 34.5% earn from Rs.10000-15000, 20% have an income from Rs.15000-20000 25.5% earn more than 25000.

A-5: Monthly Expenses incurred for caring for the Children with disability



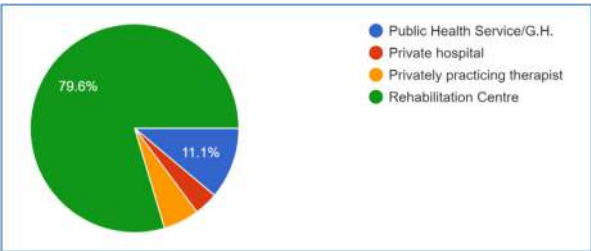
From A-5, for taking care of the PWDs, it is found that 12.7% spend Rs.2000-3000, 29.1% spend Rs.3000-5000, 18.9% spend Rs.5000-7000, 10.9% incur Rs.7000-9000, 12.7% incur Rs.9000-12000 and Rs.12000 & above is incurred by 16.4% of the families.

A-6: Treatments/Services required for caring for the PWDs



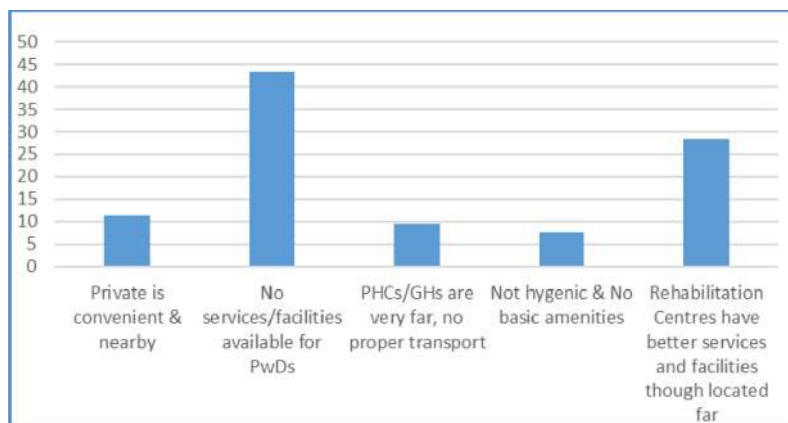
From the responses received and represented in A-6 on the types of services required, the researchers found that the PWDs from the rural and semi-urban areas need many essential treatments, training, and educational services. About 24% are medicinal requirements, 17% seek special education, 17% need physiotherapy, 13% require multiple therapies, 13% need speech therapy with auditory training, 9% need occupational therapy, and 7% need vocational training. For some people, all the therapies are required lifelong, and many people need daily routine training and therapies to be done regularly to maintain physical fitness.

A-7: Places from where the services are availed



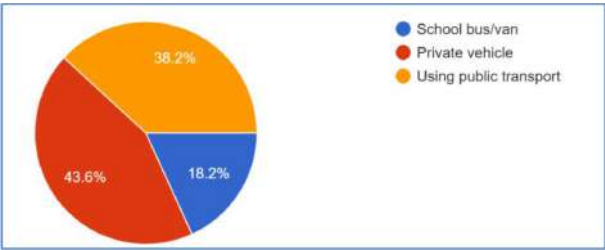
About 79.6% of the PWDs avail the treatment services from Rehabilitation Centre, 11.1% avail from public health service, 5.6% avail from a private therapist, and about 3.7% are taken care of in private hospitals.

A-8: Reasons for not availing of the services in PHCs/GHs



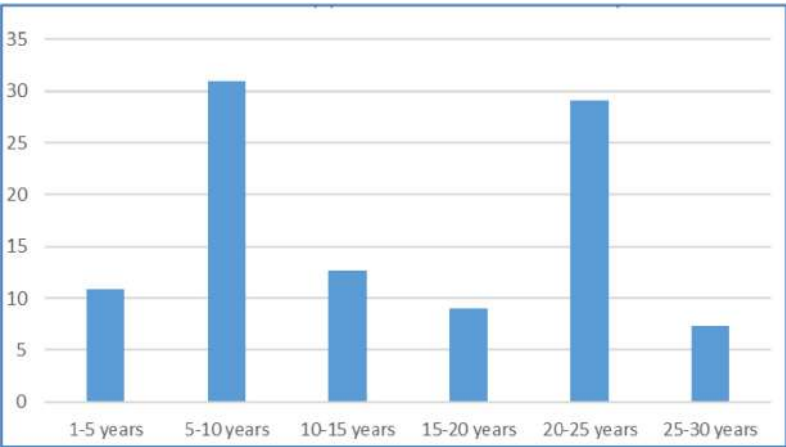
From A-8, when the reasons for not availing the services/facilities by the PWDs from the PHCs and GHs are analyzed, 11.3% says privately is more convenient and nearby, 43.4% says there are no services or facilities in PHCs/GHs to take care of PWDs nearby their locality, 9.4% reports PHCs/GHs are farther and no proper transport facilities are available, 7.6% says PHCs/GHs are not hygienic and without basic amenities like water, clean toilets, etc. and 28.3% reports that the rehabilitation Centres have better services and treatment facilities even though they are also far from their localities.

A-9: Mode of Transport used by the special child for going to the school



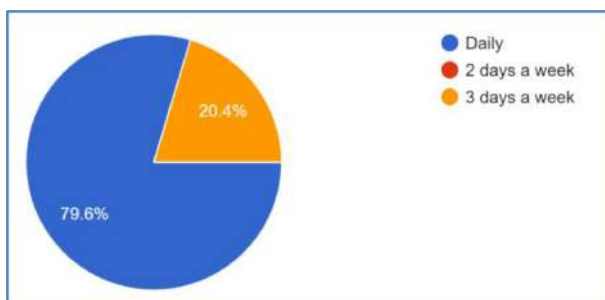
From A-9, it is observed that about 18.2% of the PWDs use a school bus/private van, 43.6% of the PWDs use a private vehicle, and about 38.2% use public transport.

A-10: Duration of the support services availed by the PWDs



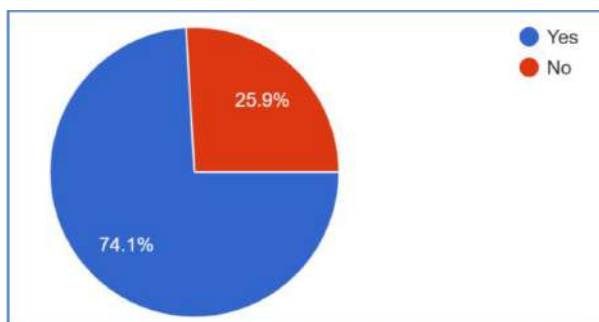
From the above chart, it is understood that about 10.9% avail the services for 1-5 years, 30.9% avail for 5-10 years, 12.7% avail the services for 10-15 years, 9.1% avail for 15-20 years, 29.1% avail the services for 20-25 years and 7.3% avail for 25-30 years.

A-11: Frequency of service required for service



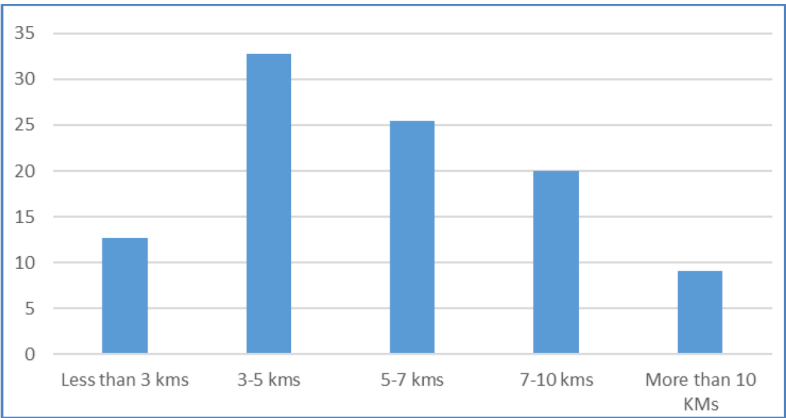
When the frequency of the services required for the PWDs is studied from A-11, it is found that about 79.6% of the PWDs require the services daily, 20.4% of the PWDs need the service three days a week.

A-12: Availability of Primary Health Centre in your Locality



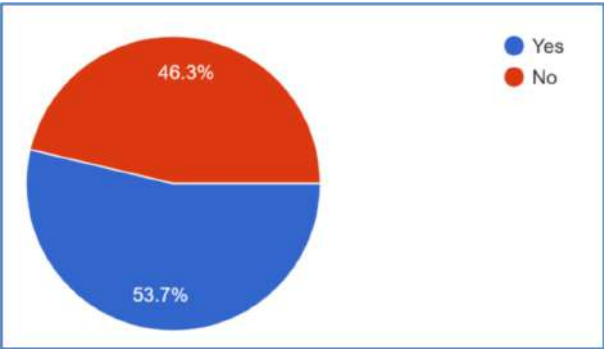
From A-12, it is found that about 74.1% of the PWDs have primary health centers in their locality, and 25.9% of the PWDs do not have PHCs in their locality.

A-13: The distance of the PHC from the residence of PWDs



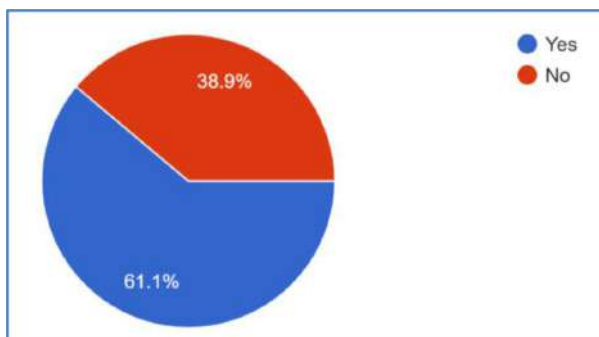
From the above chart, it is observed that 12.7% of the PWDs have their PHCs located within a distance of 3 km, 32.7% have the PHCs located within 3-5 km, 25.5% have the PHCs in 5-7 km, 20% of the PWDs have the PHCs located within 7-10 km, and 9.1% have their PHCs located more than 10 km.

A-14: Availability of Special Schools in your locality



From the above chart, it is observed that 53.7% of the people have special schools in their locality and 46.3% have no special schools in their locality.

A-15: Livelihood support from any organization



A-15 reveals that about 61.1% of the families get their livelihood support from some organizations, and 38.9% are not getting livelihood support from any organizations.

Case Studies

In this section, about 4 cases of the PWDs, two cases from Villupuram district, one case from Karaikkal, Puducherry, and one case from Chennai, have been identified by the researchers, and a thorough study was done by the researchers on their profile, problems, and challenges faced by the PWDs. The names of the PWD cases are replaced with dummy names to ensure confidentiality and research ethics. The case studies with the suitable remedies for the problems of the cases identified are presented as follows:

Case Study I: 14 years old Boy, Karaikkal, Puducherry

Case Profile

14-year-old boy Satish has been affected with Cerebral Palsy and Gross-motor Disability from childhood. He lives with his mother, younger sister, and grandmother at Karaikkal (around 300 kilometers from Chennai) as his mother is the only caretaker

who takes him for all the required therapies. Satish is studying the seventh standard at Govt. School and he is good in studies. He uses a wheelchair for mobility and needs mobility aids like a caliper and knee brace to practice walking, as advised by the Ortho specialist.

Problems identified

The challenge for his mother was to find out the place where the required supportive device/mobility aid would be provided and at a lower cost. While the researcher met her in a government rehabilitation center (RC) at Chennai, in the Prosthetics and Orthotics Dept. (P&O), she was telling the purpose of her visit to the RC after one year, to the staff in that Dept., availability and cost of the required equipment for her son. As the person who took the measurement was on leave on that day, she was asked by the staff to come on the next day. As she came from the outstation, she said she could not come on the next day and wanted to know the cost of the caliper if purchased from outside. The staff told her that the cost would be Rs.10,000/- approx. The mother shed tears on the spot as she could not pay/buy the cost of the equipment. She is one of the thousands of victims who suffer from a disability, poverty, and non-accessibility of resources. We immediately contacted the organization's Social Worker and the P & O Dept. HOD and arranged the client's stay in the RC cottage. Due to the prompt intervention and timely action of the P&O HOD, necessary/required equipment was provided to the client the next day.

Remedies suggested

District Differently Abled Welfare Office (DDAWO) may conduct regular and periodical camps in every division or every town panchayat level with proper prior public notification to

know and understand the needs of people with disabilities and take steps to provide the necessary assistive devices to them. Also, organizing awareness camps about types of disabilities, availability of treatment facilities, and necessary guidance to reach out to the right place to avail the required support services.

Case Study II: 10 years old Girl, Villupuram District, Tamil Nadu

Case Profile

10-year-old Vinodha's parents are from a village in Villupuram District. They stayed in a rented house in Chennai, and her father worked in a bakery for a lower salary. Vinodha has two siblings, a brother, and a sister. Both are younger to her. For baby Vinodha, her mother is the caregiver even her father is supportive, but he is the only bread-winner of the family. He does not always accompany her to avail the services.

Problems identified

Vinodha is affected with Developmental Delay, MR, and Attention Deficit Hypertension Disorder (ADHD). She also has specific speech issues as she can only speak one or two words. Vinodha needs Physio Therapy, Speech Therapy, and Occupational Therapy daily. When her mother sought support from a Government Rehabilitation Centre in Chennai, she was initially sent for physical medicine and a complete IQ assessment. After visiting all the required departments, the mother was advised to bring the child for therapies three times a week. The mother has to travel in public transportation with the child for almost 36 km. Three days a week to avail the therapies. Though the child needs therapies daily due to a large number of beneficiaries and the inability to provide adequate time for the required services to all the parents daily by the organization, almost all the parents are advised to come two or three times a

week to avail the services for their children and practice at home on other days. The situation became worst due to the covid pandemic crisis. Most of the parents who were settled now in cities, mainly for availing therapy services for their child, shifted to their native places, resulting in a complete regress/lapse in the overall development of the special child.

Remedies suggested

Early Intervention Centers, Physio, and Occupational Therapy services are to be made available in the Primary Health Centers (PHCs) and Sub Centers (SC) established by the Government. Establishing special schools at the primary level depending on the percentage of the PWD population in every division.

Case Study III: 9 years old Boy, Villupuram District, Tamil Nadu

Case Profile

9-year-old boy Senthil is from an interior village of Villupuram District. His parents are not educated, and he has two siblings.

Problems identified

Senthil met with an accident at home when he was seven years old (Collapse of the house wall), injured his spine, and could not walk. Senthil was having delayed milestones though he was attending the normal school before the accident. After undergoing the complete physical check-up, it was found that there was a sensory loss in locomotor – particularly in the D5-D7 area due to the spine affected by accident. After consulting with the necessary departments, it was advised that regular physiotherapy is needed, and this should be with the support of a Hip-Knee-Ankle-Foot-Ortho (HKAFO) device, either Dynamic or Static. They were directed to the Prosthetics and

Orthotics (P&O) department, and the device was not available there. So, the P&O took measurements to make a new one and asked the needy to come after their intimation.

Remedies suggested

Organizations that provide special services may have the necessary staff in all departments as there should not be any delay/lapse in providing the services due to the absence of staff. They may appoint more than one staff for every service, keeping in mind the need of special parents as most of them are taking so much pain to avail the services, including transportation. Their difficulties and their time spent for their children have to be taken into account and considered.

Case Study IV: 5 years old boy, a native of Bihar, settled in Chennai, Tamil Nadu

Case Profile

5-year-old Narendar's parents are from Bihar, and they settled in Chennai three years ago. His father is the only earning person in the family, and the source of income is selling Pani-poori. Narendra has two siblings, and both are younger him.

Problem identified

Before moving to Chennai, the parents have found and understood that the boy needed some special care. The boy is affected with Cerebral Palsy, Speech impairment, and seizures at times. So, after coming to Chennai, the father had taken the boy for some therapies in private centers. However, due to financial constraints, he was unable to continue the therapies for the boy. As per the doctor's prescription and advice, the father is getting medicine for the boy for seizures at Kilpauk Govt. hospital.

The researcher had coordinated with the parents and arranged to have an assessment for the child with a psychologist at ICSW. With the initial assessment, it was understood that the child is affected with cerebral palsy. He is unable to stand. As per the parents' understanding, the hearing and vision of the child are normal. Nevertheless, it is advisable to go for a medical evaluation to check the hearing and vision ability of the child. Also, the child is unable to communicate verbally and expresses his needs by gestures. Last year before the pandemic, the parents had tried to take admission from a special school located in their area, near ICSW.

Nevertheless, it was understood from the parents that they need to pay an initial fee of Rs.2000/- and Rs.1000/- to be paid (every month) as a monthly fee. As they could not meet the school fee expenses, the parents did not proceed with admission to the school. The parents are not educated, and no one there around them to guide them with suitable suggestions.

Remedies suggested

Children affected with Cerebral Palsy or any disability should be taken care of with necessary therapies and treatment daily. Early intervention is essential for babies and children to provide proper treatment at the early stage itself, which will help significantly develop the child and reduce the overall percentage of disability. Proper awareness programs throughout the districts may be periodically conducted.

Research Findings and Recommendations

The findings/outcomes of the research work conducted through Survey method and Case Study Analysis with suitable recommendations/remedies to resolve the challenges and

difficulties being experienced by the People with Disabilities are summarised and presented hereunder:

Main Inferences from the Survey analysis

- 29% of the PWDs surveyed have multiple disabilities, and 22% of the PWDs have cerebral palsy with intellectual disability.
- About 89.1% of the families have only one PWD in their family
- For 80% of the PWDs, the mother is the permanent caretaker
- About 54.5% of the families have their monthly income less than Rs.15000
- About 40% of the families incur more than Rs.7000 per month for caring for the PWDs.
- About 79.6% of the PWDs are available for treatment services from Rehabilitation Centre, and only 11.1% are available from public health centers.
- 43.4% of the PWDs surveyed report that there are no services or facilities in PHCs/GHs to take care of PWDs, nearby their localities.
- 30.9% avail the support services for 5-10 years, and 29.1% avail the services for 20-25 years.
- About 79.6% of the PWDs require support services daily.
- About 74.1% of the PWDs have primary health centers in their locality but without the treatment facilities for PWDs, and 25.9% of the PWDs do not have PHCs in their locality.
- 25.5% have the PHCs in 5-7 km, 20% of the PWDs have the PHCs located within 7-10 km

- 53.7% of the people have special schools in their locality, and 46.3% have no special schools.

Main Inferences from the analysis of the Case Studies

- The major difficulty faced by the PWD cases discussed is the absence of treatment facilities in the PHCs/GHs in their districts. The rehabilitation centers are located in far-away places that lead to transportation difficulties and time constraints.
- If the parents of children with special needs are not educated, they have no consistency in availing the therapies and treatments for the child due to poverty, poor livelihood, non-availability of resources, and lack of awareness.
- Parents of children with special needs have worries about safeguarding their jobs for the survival of their families and the financial burden of availing of the special services for their children.
- Though few government organizations provide necessary services and assistive devices, there is a significant delay (almost six months to 1 year) in providing the service, therapies, manufacturing, and delivering the required devices to the needy.
- This delay leads to frustrations among parents and completely paralyzes the treatments for children with disabilities for months together.

Recommendations and Remedies

- The researchers suggest the following recommendations and remedies for resolving the challenges and difficulties faced by the people with difficulties in the rural and semi-urban areas:

- Adequate awareness and training programs shall be organized for educating the parents and caretakers of the PWDs by the government departments through the Special schools, Rehabilitation centers, District Disability Welfare Offices, and NGOs working for PWDs, at the district levels.
- All the Primary Health Centres/Government Hospitals at the Taluks/Division level shall be set up with a special section with adequate staff and medical facilities, early intervention units, treatments to treat and care for the PWDs.
- Ambulance and other transport facilities shall be organized for the PWDs in rural and semi-urban areas to reach rehabilitation centers and hospitals on time for their emergency needs and regular/routine treatments.
- The legislations and developmental schemes created/introduced for the welfare of the PWDs and their families shall be implemented adequately without further delays at all the levels, prioritizing the rural and semi-urban areas where more lapses are observed.
- Livelihood training programs and special employment drives shall be organized for the parents and caretakers of the PWDs to provide adequate livelihood/employment opportunities for eradicating their financial crisis and alleviating their poverty.

Conclusion

The research provided a clear understanding of the issues and challenges experienced by people with disabilities living in India's rural and semi-urban areas. The necessity to create more awareness on the treatment facilities among the public

and the parents of children with special needs in rural areas, education, and implementation of welfare measures for PWDs are emphasized. Analyses on the availability and accessibility of the resources, support services, and facilitating institutions for the PWDs in the rural and semi-urban areas indicate the necessity and importance of establishing therapy units and early intervention units at the Primary Health Centres and GHs. The scope of the research includes a more extensive survey and analysis across India's rural and semi-urban areas to propose an inclusive mechanism and remedial measures for the welfare of the PWDs in the country.

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Experiences of Defence Servicemen with Spinal Cord Injuries Serving in Indian Armed Forces: A Qualitative Study

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Abstract

This paper aims to explore and study the experiences of defence servicemen who survived spinal cord injuries (SCI) with the objectives of capturing the experiences related to the SCI and the rehabilitation services provided post-injury; to understand the challenges faced by defence servicemen post-injury on the personal, social, and economic fronts; and to create knowledge on the rehabilitation provided to the defence servicemen post-injury. The study was based on a qualitative narrative design, and data was collected through in-depth interviews with 14 participants. Findings: It was found that the repercussion of the injury upon an individual's health was based on the nature of the

injury and the individual's socio-cultural background. Though the servicemen were shielded by their salaries and pensions, concerns were expressed regarding the bearing of financial expenses for services after rehabilitation. Some servicemen aspired to pursue higher education or skill development courses to build upon future career prospects. The servicemen expressed that their familial relationships are structured and dynamic.. However, a decline in relationships was reported with friends and colleagues with whom they were deployed. On the rehabilitation front, they participated in rehabilitation processes customized according to the injury sustained. The study also highlights gaps in the services envisioned post-completion of rehabilitation and the awareness of those services among the defence servicemen.

Keywords - Experiences, Spinal cord injury, Rehabilitation, Defence servicemen, Narratives

Introduction

Spinal Cord Injury (SCI) is defined as damage to the spinal cord caused by trauma or disease, resulting in partial or total paralysis (Alhoseini & Movaghar, 2014). SCIs are often considered a traumatic event for all affected individuals. However, it is particularly crushing for soldiers who have performed at superior mental toughness and physical ability (Apte, 2019). Even after the rehabilitation process, the relationship of SCI-affected soldiers gets affected psychologically, socially, and physically with their peer and familial counterparts (Kumar & Gupta, 2016). Keleher et.al. (2003) point out that falls from height, gunshot wounds, and motor vehicle accidents are the most common incidents that result in SCI. SCIs pose considerable challenges in an individual's life when it comes to coping with trauma and rehabilitation. SCI may cause quadriplegia, which according to Friden & Gohritz (2015), refers to “profound impairment of

mobility manifesting as a paralysis of all four extremities owing to cervical spinal cord injury” or paraplegia which, according to Nas et. al. (2015), refers to “impairment or loss of motor and sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to damage of neural elements within the spinal canal.” The functioning of organs, limbs, trunk, pelvic organs, bowel, bladder, and sexual functions may depend on injury (Kumar & Gupta, 2016). Although numerous activities may remain permanently affected, including assisted walking with support, micturition by supra-pubic pressure, etc. (Somers, 2001), some individuals recover from SCIs to perform certain daily activities with the help of rehabilitation processes. With the aftermath of SCI, the absence of function leads to significant changes making routine vocational, social, sexual, and recreational activities difficult. Paralysis of upper and lower extremities, loss of ability to walk, loss of bowel and bladder control, and loss of sexual function can be mentioned among the shattering consequences of SCI, according to Kathleen (2004). Offering plausible findings on traumatic SCIs, Joseph et. al. (2016) provides that injury may lead to alteration in body functioning, changes in social interaction, and unprecedented change in an individual’s perception of self. Sudden requirement of careful planning and prearrangement becomes necessary to perform tasks that require little cognitive demand and effort earlier. Numerous research studies have been conducted worldwide on SCIs among the civilian population. These studies have ranged from quantitative studies assessing the epidemiology of SCI to the Quality of Life of SCI-affected individuals. Studies have mostly sought to capture the lived experiences post-injury in the civilian population in the qualitative domain.

In the Indian context, quantitative studies are more prevalent than qualitative studies. As research in the military community of India remains scarcely accessible, there are not enough studies conducted with individuals (especially servicemen) affected by SCI. Although a study had been conducted to assess the quality of life of Ex-servicemen with SCI, given its quantitative nature, it has not been able to capture the experiences of these ex-servicemen concerning SCIs. A research was conducted with the retired servicemen by Kumar and Gupta (2016). However, given its quantitative nature, it could not capture the lived experiences of the ex-servicemen.

This research paper seeks to bring to light the lived experiences of serving defence service men concerning the injury and the subsequent multipronged changes in their lives. The paper also highlights the state's policies and provisions for rehabilitation and reintegration of Defence servicemen post SCI, thus contributing to the available knowledge base.

Literature Review

Rehabilitation in Defence Services

While the literature on defence rehabilitation is scarce and not restricted to SCIs, one can always look at the progression of defence rehabilitation in different nations.

American physician Harvey Cushing reports that there were no successful treatment methods for SCI during World War I. As a result, 80% of the infected servicemen died of bedsores and catheterization in the first few weeks. However, Canada became one of the first countries to provide a wide range of funding, services, and programs to re-establish veterans, including those with disabilities in civilian life, towards the culmination of World War II. These interventions drastically reduced SCI-related

mortality rates from over 80% in World War I to below 10% by 1946. A similar trend of declining mortality rates was witnessed in the United States and England based on their rehabilitation programs (Tremblay, 1996).

A research study conducted in New Zealand documented repatriation measures taken in the 1920s and 1930s for the servicemen who returned with disabilities from the Great War (1914 - 1918). Walker (2013) provides that the primary motive behind these measures was to restore the wounded soldiers as wage earners and responsible citizens. Providing medical treatment, consisting of curative and vocational therapy to assist the soldiers to return to military service was the first measure taken as part of repatriation. If otherwise, measures (including pensions, acquiring suitable employment, educational/vocational classes, etc.) were taken to restore them to civilian life.

Another study conducted in Australia sought to document the rehabilitation of servicemen with disabilities after the culmination of the Great War. 'Restoring the spirit' was the focal point of rehabilitation as investigated by the study. They were encouraged to overcome the impairment via their own "will" and eventually attain independence and self-reliance by drawing out their inner potential. Components such as musical concerts, vocational training, education, social gatherings, and curative workshops were incorporated into the rehabilitation process for enhanced social integration. Depending on their disability, instructions were provided to the soldiers in various trades and crafts to become independent and productive. The soldiers regained their productive capacity via employment and practical recovery achievements like gaining physical strength (Larsson, 2004).

Quality of Life of Persons With SCI

Jahan et al. (2016) studied the Quality of Life (QOL) post-SCI. The study reflected upon the implications of SCI on physical and mental health. To enhance the Quality of Life, the study highlighted the requirement of a slew of measures to better Individual's physical and emotional condition.

Several studies have also been conducted to determine the QOL of defence servicemen with SCIs. Using the Health-Related QOL (HRQOL) questionnaire, a study was conducted by Smith et.al. (2008) in the US with defence servicemen as participants and pointed out that in comparison to the general population with SCI, a higher percentage of veterans reported poor or general health conditions. According to the study, veterans with SCI experienced more significant depressive symptoms and frequent mental and physical distress.

A notable QOL study conducted in India with ex-servicemen with SCIs showed that a significant influence over the quality of life was put upon by factors like injury, medical co-morbidities, and level of education (Kumar & Gupta, 2016).

Lived Experiences of Persons With SCI

According to Joseph et.al. (2016), people with SCI are confronted with a diverse set of challenges while seeking to reclaim full participation in society. People with SCI seek to reconstruct the meaning of living in a society designated for and dominated by able-bodied people who may not accept people with disabilities. Negotiating barriers along the path of recovery and living with the injury became imperative to get re-involved in activities and roles prior to the injury. Research aiming to study the efforts and strategies applied by people with SCI to sustain long-term resilience and wellbeing was conducted in Norway and found

that to maintain health and wellbeing - which included positive attitude and staying active, diverse and not linear strategies were applied. Balancing autonomy and dependence were pointed out as the keystone in staying emotionally stable (Geard et al., 2018).

Perceiving themselves as “normal” in everyday relationships and circumstances was studied to be most imperative for the health and wellbeing of persons living with SCI in research conducted in Sweden. The normalization process involved averting embarrassing situations by acting “behind the scenes” or in a “covert world.” Despite substantial disability performing specific tasks covertly enabled the person to interact smoothly with others and be perceived as usual (Suarez et al., 2015).

Seeking to capture the experiences of men living with long-term SCI and to understand how they constructed their life post-injury, a research study conducted in Japan found that they had constructed collective identities of persons with acquired disabilities through their relationship with other men living with SCI. Involving in fostering interpersonal relationships like other able-bodied people and investing in leisure activities like playing sports were strategies used to attain the objectives mentioned above. Involvement in social activities enabled some participants to gain confidence to consequentially overcome the burdens of life and associated stigmas to the disability. Successful employment enabled the participants to operate as full-grown men alongside able-bodied people (Tagaki, 2015).

Epidemiology of SCI

To decipher the patterns of SCIs and the management of such injuries in tertiary care hospitals, a study conducted in Pakistan showed that predominantly the community most prone to SCI was the males in their third decade of life. Gunshot wounds,

road accidents, falls from heights, followed by carrying weight, were the most common cause of injury (Masood et al., 2008).

Another study initiated in the Armed Forces Institute of Rehabilitation Medicine, Pakistan, recommended the introduction of regional units for the treatment of SCI along with the development of medical first aid system and emergency evacuation protocol while parallelly highlighting the scarcity of knowledge about spinal trauma evacuation protocol among paramedic staff and doctors (Rathore et al., 2003).

In India, research conducted in Haryana India also reflected the lack of trained medical personnel, basic infrastructure, and scarcity of knowledge on primary mobilization and transportation of these patients, leading to excessive preventable damage until the hospitalization of injured persons (Singh et al., 2003).

In their study, Pandey et. al. (2007) suggested developing infrastructure of government hospitals and management of SCI patients and enhancing awareness among the general diaspora regarding the traffic safety measures to bring down the incidence of SCI in India. The study also highlighted the need for social legislation to enable SCI patients' reintegration and upgrade the specialized spinal trauma units with further accessibility to poorer sections.

Research Method

Study Design

To understand and explore the experiences of defence servicemen with SCI, the research was based upon qualitative narrative design. Being a low-inference method (Sandelowski, 2000) qualitative description enables the necessary thick description of the phenomenon by gathering facts from people

living in the natural setting. Further, narrative inquiry enables the study of respondents' experiences over time and in an in-depth and intimate context (Candelin& Caine, 2008). Authors further utilized this approach to understanding the participants' constituted, enacted, shaped, and expressed experiences by capturing their cultural, institutional, and social narratives (Clandinin&Rosiek, 2007).

Study Setting

This study was conducted at the Spinal Cord Injury Centre in Military Hospital, Khadki. Permissions were obtained from the Commandant of the institution beforehand.

Participants and their Recruitment

Purposive sampling was utilized for the study. Participants for the study were selected based upon the two-criterion listed as follows:

- a. The participant sustained the injury when serving in the Indian Armed Forces.
- b. The participant was undergoing rehabilitation at the SCI center.

A total of 14 participants agreed to be a part of the study. The participants represented all branches of the Indian Armed Forces. Of the total participants, two had quadriplegia, while twelve had paraplegia.

Data Collection

The semi-structured interview schedule was used to conduct face-to-face interviews with the participants of the study. According to DiCicco-Bloom and Crabtree (2006), the semi-structured interview can be defined as “organized around a set of predetermined open-ended questions, with other

questions emerging from the dialogue between interviewer and interviewee/s.”The prime purpose of a semi-structured interview is to gather essential information from the informants about beliefs, attitudes, perceptions, and personal experiences in coherence with the subject of interest.

The interviews were conducted without interfering with the rehabilitation schedules of the participants and were audio-recorded for a detailed study with the prior consent of participants.

Data Analysis

The interviews were audio-recorded and transcribed later by the researcher for the study. Multiple readings of the interviews were made to pinpoint the emerging themes from the data collated.

Key Findings

Table 1

Profile of Participants of Defence Servicemen with Spinal Cord Injuries serving in Indian Armed Forces

Participant No.	Age of injury (years)	Type of injury	Cause of injury	Services
Participant 1	27	Paraplegia; D4-D9	Sports injury	Army
Participant 2	23	Quadriplegia; C5, C6	Fall from building	Army
Participant 3	39	Paraplegia; LV1, LV2	Hit from snowstone in avalanche	Army
Participant 4	35	Paraplegia; C7, D1	Road Accident	Army

Participant 5	35	Paraplegia; D5, D6	Road Accident	Army
Participant 6	35	Paraplegia; C6, Vertebra	Sports Injury	Army
Participant 7	28	Paraplegia; L3, L4, L5,	Bullet Injury	Army
Participant 8	27	Paraplegia; D9, D10	Spinal Cord TB	Navy
Participant 9	26	Paraplegia; L1	Road Accident	Air Force
Participant 10	33	Paraplegia; DV 12	Road Accident	Army
Participant 11	38	Paraplegia; D3, D4	Road Accident	Air Force
Participant 12	31	Paraplegia; L1, L2, L3	Splinter injury in IED blast	Army
Participant 13	22	Quadriplegia; C4, C5	Accident while lifting	Army
Participant 14	42	Paraplegia; D9, D10	Road Accident	Army

Reasons of SCI

Of the 14 participants who survived SCI, 6 sustained SCI due to Road Accidents, 2 participants had combat injuries, 2 participants had sports injuries while remaining 4 sustained SCI due to snow stone hit in the avalanche, Spinal Cord Tuberculosis, fall from height and during lifting of heavy equipment each respectively.

Key narratives of injuries

Sports Injuries

“It was a swimming accident. I was immediately taken to the hospital. I probably had some hairline fractures in my vertebrae. So that is why my injury is complicated, as it starts from the c4 level and goes up till c7. The spinal injury per se is only at the c6 level. That is why I can use my hands. Otherwise, my vertebrae were all damaged up till c7. So, when I dived, it probably jerked my neck and broke the c6 vertebra and thus, the spinal cord.”

Combat Injury

“It was a gunshot wound. On 4th June 2015, I was traveling in a convoy. 4-5 vehicles were carrying 40-50 soldiers. The militants were hiding in the forests of the mountains and ambushed our vehicles. Thus, I was also hit by bullets in the attack. The bullet hit the spinal cord leading to paralysis... I immediately realized that I was injured in the ambush. So I told the fellow soldiers that bullets hit me. They saw it and carried me on a stretcher behind some cover as the firing continued. They removed my shirt to have a look at the wound and did first-aid to stop the bleeding...I was taken in one of those vehicles to the base, where the nursing assistant gave me a painkiller and injection to reduce the pain. After that, I was airlifted in the helicopter and taken to the military hospital where the treatment began.”

Spinal Cord Tuberculosis

“As per the doctors, I might have caught this disease six months back. Thus this disease incubated in my body for six months and did not show any visible symptoms. Furthermore, suddenly it started coming out as a mild backache which lasted around one month...Then, suddenly, the pain got severe one evening, and when I tried to get up and sit, I suddenly got a kind of electric shock throughout my body, and my lower half started getting paralyzed... there was no prior indication. So by the time they took me to the hospital, my entire lower half was paralyzed.”

Avalanche Hit

“I got this injury when I was on duty. An avalanche hit me. I had gone out based on some intelligence input. While coming back after finishing the task, I was hit by an ice stone that came down in the avalanche. The ice stone hit me in the waist, and I got injured.”

Initial Medical Treatment Post-SCI

Of the 14 participants, 11 received their initial medical treatment at armed forces establishments located in various places, while the other three were admitted/ accessed private medical facilities. Subsequently, all of the participants were transferred to MH, Khadki, for rehabilitation. Participant 3, who got treated within the defence medicine establishment from inception, expressed that,

“So, when I got injured, the nursing assistant reached me within half an hour. They treated me with whatever material was available with them. After the injury, I got transferred to (number not disclosed) base hospital by air. This is where my rehabilitation started. The area where I had got injured was in a remote location. It did not have resources for treatment. Thus, my accident was reported to the base, and I was evacuated by air. From there, I was taken to the base hospital, from there. I was sent to R&R hospital Delhi. I was operated on 6th, and after 15-16 days post, I was transferred to Military Hospital, Khadki.”

Implications of SCI's on Defence Servicemen

Implications on Physical Health

SCIs have a considerable fall out on how an individual's body functions and its mobility, thereby posing several challenges in the lives of defence servicemen. The participants also reported numerous difficulties in bladder and bowel functioning and weakness in the body. Participant 14 expressed that,

“Yes, I am having problems. I feel that the stool is there in the rectum, but it does not come out. With regards to urine, unless I apply enough pressure, it will not come out. So I have to put in the extra effort.”

Other health-related challenges included problems with sneezing and coughing, digestion problems, and bedsores. Participant 4 informed that,

“I have got bedsores. It happens due to continuous bed rest after the operation. If you do not take precautions or keep changing positions, then it can happen. They remained for one and half years.”

Implications on Personality of defence servicemen

While at service, the defence servicemen are prepared through rigorous training to work and survive in extreme and arduous conditions. Shifting to a phase where a helping hand is required to perform daily tasks severely implications on self-perception. While several participants were informed of no change in their personality post-injury, other participants expressed diverse opinions regarding changes in the personality oneself. A considerable section of participants expressed the feeling of dependence. Participant 4 suggested that,

“...Earlier I was mobile. I would do all my work by myself. Now, this injury has put me in a situation where I have to depend on others. All the work like bathing, feeding will have to be done by my family members... I feel dependent. The injury that has happened is a horrible one. In such an injury, the person cannot do anything. My whole life is destroyed... So I feel sad because, at such a young age, I have got such an injury. Now I feel useless.”

In addition, short periods of depression were mentioned by three participants. The injuries can be a life-altering event in the lives of defense service members as they can leave a person feeling helpless and failing to manage the unanticipated challenges

posed before them, leading them to depression. Participant 11 informed,

“Initially, I got very depressed when doctors told me that I could not walk and sit. This happened for about two months. After that, I felt that I could do it. So now I am sitting and walking with the help of a walker, doing exercises, swimming and playing basketball. It hardly affects, but it is the perception of mind about how you think and come to terms with life.”

However, some participants also mentioned cultivating a positive outlook to life post-SCI.

Implications on Economic Life

A defense serviceman's physical and mental strength are essential parameters in the defence Services, which get affected by SCI. After the rehabilitation process, the continuation of services depends on the extent of recovery and thus influences their further economic prospects. The economic condition of the defence servicemen is severely affected if they are boarded out. 7 of 14 participants opined that they would look for alternate employment opportunities after their service gets over. In case of getting boarded out of defence service, participant 9 said,

“As an alternative, I have thought of appearing for competitive exams. So I will try to find a job. I will try not to be dependent on my pension and sit idle at home. So I will prepare accordingly after going back home.”

SCIs lead to a rise in expenditures to provide for the needs of Defence service members after the injury, thereby adding to their economic burden. 4 out of 14 participants also expressed concerns regarding added expenditures after the duration of rehabilitation. Participant 7 said,

“The economic condition will be altered to a great extent... had I been physically fit then I could take a cheaper means of transport like bus or share rickshaw. Now I will have to hire a separate vehicle to travel, and

I will also need some person along with me. Now rather than investing 10,20 or 50 rupees, I will have to spend 500 rupees. So, there will be many problems economically.”

To counter the perilous implications on the economic life of servicemen with SCIs, facilities for pursuing vocational training have been created near the location of data collection. 3 out of 14 participants were undergoing/had undergone vocational training during rehabilitation. Participant 8 informed,

“...I have done a one-year computer course in QMTI. It helped me learn many things. So I know about net banking, and it is also useful for the job of clerk. So I can now apply for the post of clerk in some school or college after returning. Thus, I got much information regarding computers. So it has helped me a lot, and I have a certificate of completion of the course. Thus, if there is a job offer near my house, then I can start working there.”

Being central government employees, the servicemen with SCIs will be eligible for a pension from the government. They will also be eligible to get several financial incentives in addition to the disability pension. Thus, participants also expressed that SCI's economic repercussions would further get diluted given that they would receive pensions and other financial benefits post-retirement. Participant 7 suggested that,

“...Everything has been taken care of. I will get a pension. I will get my gratuity when I go out of service. Also, I had saved enough, so I do not think there will be much of a problem.”

Implication upon the Social life of defence service men

The study sought to understand whether the injury has changed relationships with family, friends, and colleagues. Almost all participants suggested a strengthened bond with families or no changes in family relationships, respectively. Participant 14 informed that,

“The whole family is supportive. Whenever my brother gets to leave, he first comes to me. First 5-6 months (post-injury), he stayed with me only after taking permission from his CO (Commanding Officer). My jijaji(brother-in-law) also comes to meet. He will come again next month. My mother has been supportive too. She would take care of me when I was admitted to Delhi. As the weather does not suit her, she has not come yet but will come soon to meet me.”

Regarding relationships with friends, 10 participants suggested no changes in the relationship with friends, while three others now felt ignored. Suggesting no changes in the relationship, Participant 5 said,

“...no change at all. When I was at home, everyone would come and meet me. Now since I am away, I keep in touch with them using the phone.”

On the other hand, participant 2 suggested,

“There has been many changes in relationships with friends. Many friends ignored me when I got injured. Now I ignore such people. I speak to all those people who made an effort to talk to me or came and met me after the injury.”

On the relationship front with colleagues, most participants suggested that colleagues had been supportive and relationships remained unaffected. However, in some cases, regular communication had reduced. Participant 13 said,

“My contact is intact with them. Whenever they get time, they talk to me. They boost my morale and tell me about what is going on in the unit... There is much attachment with them as we completed the training together.”

Implications on Activities of Daily Living

Several restrictions are imposed on the physical condition incorporating loss of sensation around the location of an injury and lower extremities in tandem with other health comorbidities. Resultantly, the ability of the servicemen to take care

of their hygiene and perform everyday tasks is compromised. The majority of participants faced challenges related to bowel and bladder management, bathing, and clothing management. Challenges with grooming and sitting upright were mentioned by some participants, especially those with quadriplegia.

Rehabilitation Services provided after SCI

Chhabra (n.d.) highlighted that rehabilitation is the keystone to the management of SCI. The prime objective of rehabilitation is to enable the person to become independent and resume the everyday lifestyle. Physical rehabilitation in sync with psychological counseling makes the crucial aspects of rehabilitation. SCI has a psychological ramification not only on the person concerned but also on his/her family. However, the services to counter psychological implications remain in a nascent state in India. In addition, the objective of rehabilitation exists unaccomplished unless the individual is enabled to become economically productive.

Further, home modifications remain imperative for the rehabilitation of individuals. These services are not well developed in India. However, the past two decades have witnessed progress in SCI management in India. In addition to Indian Spinal Cord Injuries centers, some regional centers also have sprung up. However, there remains enormous scope for reaching out in the community, implementing preventive measures, and encouraging research and development. (para change) In contrast to above, the study revealed numerous facilities extended to defence servicemen as part of their rehabilitation and included the following:

Physiotherapy: Along with preventing secondary complications and reducing physical health complications, the goals of

physiotherapy also focus upon activities like using upper limbs, transferring, walking, and pushing a wheelchair (Harvey, 2016).

14 out of 14 participants said that they are undergoing physiotherapy as part of rehabilitation. Participant 12 stated,

“Physiotherapy is useful as it helps in relaxation of nerves, muscles and also reduces the spasm. Physiotherapy gives movement to those parts of the body which are immobile currently. It also helps in increasing blood circulation and in reducing pain. It also leads to relaxation in the body and helps me sleep better.”

Occupational Therapy

Law (2002) states that *“occupational therapy focuses on enabling individuals and groups to participate in everyday occupations that are meaningful to them, provide fulfillment, and engage them in everyday life with others.”* Occupational therapy enables the individual to reach the most significant degree of physical and psychological independence regarding injury in home, and work environment.

It is even more critical for those with tetraplegia as restricted arms function creates hindrances in performing activities of daily living (Henshaw et al., 1986). The majority of participants received occupational therapy. Informing about the experience with occupational therapy, participant 2 expressed the following respectively,

“It involves picking and keeping small objects from one place to another. It is also about the movement of hands. It involves making an individual able to do small tasks. As I am a quadriplegic, I will not be able to perform much, but it is useful for people with paraplegia.”

While participant 9 added that,

“For any person with spinal cord injury, the biggest problem is bed sores. Mat exercise (as part of occupational therapy) enhances flexibility in the

body. So you are instructed about how to turn your body when required. Also, exercises related to stretching of legs using the ball are done in the mat section. This helps increase flexibility and decreases the chances of getting bedsores as you can change body positions. It (computerized cycling) is a mechanical paddling machine. That is it. The paddles move by themselves when the equipment is started; you have to keep your feet on the paddles. This gives movement to the leg muscles.”

Vocational Training

Obtaining gainful employment is a primary indicator of effective rehabilitation, and low employment rates can become a reason for worry (Ottomanelli & Lind, 2009). Vocational rehabilitation provides a spectrum of skill development courses that can be used to earn a livelihood or gain employment after the duration of rehabilitation for defence service members with SCI reaches its culmination. The servicemen opting for vocational training attend classes in Queen Mary's Technical Institute (QMTI), near Military Hospital, Khadki (Apte, 2019). 3 out of 14 participants were informed about attending/ attended vocational training courses. Participant 2 stated,

“There is a course called COPA. It stands for Computer Operating and Programme Assistance. In the course, I have been learning about accounts and English also. That is it. It can be useful as I am now able to operate computers. Also, as I am learning to account, if I start a business of my own in my hometown then, the subject can be useful to me.”

Assistive Devices provided as part of rehabilitation

Effective rehabilitation includes using assistive devices as an essential component. To realize effective independence, in varied aspects of life, including social engagement and personal hygiene, assistive devices become crucial for persons with SCI (Florio et al., 2015).

Participants mentioned the use of the following assistive devices:

- a. Electric Wheelchair
- b. Bathroom Chairs
- c. Waist Harness
- d. Knee Callipers
- e. Foot Drop Holders
- f. Alpha Mattress

Further, participants were informed that they could be replaced anytime regarding the maintenance and replacement of assistive devices. However, devices like wheelchairs have a warranty of one year, as informed by six participants. After the warranty period gets over, the expenditures for maintenance have to be taken care of by the individual. However, electric wheelchairs are reissued every seven years. Participants 3 and 6 respectively expressed that,

“...There is a life to these devices. For example, the wheelchair is reissued after every seven years.”

“This wheelchair is of the Ottobock company. It has a one-year warranty. If it is under warranty, then the company will repair the damages for free. If out of warranty, then I will have to bear the expense of getting it repaired.”

Provisions for Rehabilitation post-SCI and associated policies

Out of 14 participants only three had knowledge about policies which were to be availed after the rehabilitation course got over. The participants mentioned receiving financial assistance for modification of their houses to make wheelchairs accessible in addition to modified two-wheelers. Participant 8 informed that,

“Soldiers who have got disabled are provided with a modified two-wheeler. I received one. It is a vehicle with four wheels. The two wheels are for balancing

the vehicle. We also get an amount of 40,000 for the modification of the bathroom at our homes. So there are some formalities to be completed, and the sum amount is given to you. I will get the benefit of this scheme after my documents are prepared.”

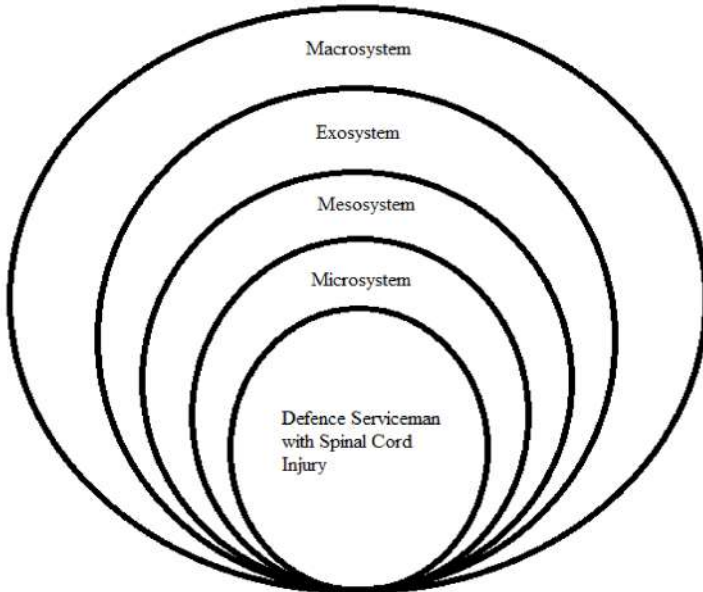
This study also attempted to visit the secondary data to collate information on the policies which could be availed. Guide Book (2011) envisages numerous policies implemented by the Kendriya Sainik Board and other organizations under the Ministry of Defence.

Scope for Social Work Practice

Compartmentalized away from the generalized practice with the civilian population, military social work is a niche area wherein personnel, their families, and veterans work and receive social benefits and healthcare within a structured military organization consisting of a peculiar socio-political and hierarchical environment. Occupational hazards, high-performance demands, organizational culture, personal demands, and standard order and discipline differing from civilian occupation makes social work within military a specialised field of practice. (Wooten, 2015). Awareness of cultural and organizational differences in the military and their derivative stimulus on sync between military and civil organizations and the effects on adherence and access to care is essential for practicing social work within the military/ defence context. Inhabiting in the micro-macro continuum, social work practice in the military context requires information that is multifaceted and complex

The environmental system immensely influences human development, as is explained by Urie Bronfenbrenner in his ecological systems theory. The surrounding environments interact in complexities within the individual for the development to occur (Ettekal & Mahoney, 2017). Macrosystem,

Exosystem, Mesosystem, and Microsystem were the categories of the environment for human interaction, according to Bronfenbrenner (Landon et al., 2019). In the context of this area of research and study, the following scope for social work intervention can be visualized:



Scope of Social Work Practice with Defence Servicemen with Spinal Cord Injuries using Ecosystem Model:

Microsystem: Microsystem: (Working with individuals and families, significant others)

Direct contact by the participant with primary social networks, including family and friends, mirrors the microsystem (Landon et al., 2019).

Components in the microsystem:

- Healthcare services
- Spouse
- Other family members
- Friends
- Neighbors
- Colleagues
- Other Servicemen with Spinal Cord Injuries
- Career prospects
- Kendriya Sainik Board (KSB)

Social Work Method:

Social Case Work - Parmar (2014) states that “Social casework may be defined as the art of doing different things for and with different people by cooperating with them to achieve at the same time their own and society’s betterment”.

1. Individual counseling sessions for serviceman and related family members, friends, neighbors, and colleagues to provide detailed information about the injury, rehabilitative practices, and their importance
2. Counselling sessions for service members regarding future career prospects in case of boarding out of defence services.
3. Networking with designated KSBs in districts of residence of service members with SCI for needs assessment and availing of required schemes by them and their Next of Kin (NOK) for comprehensive rehabilitation post-retirement/ board out of service.

Mesosystem (Working with community and stakeholders): Interaction among numerous microsystems creates a social layer that indicates the presence of mesosystem.

Components in the system related to area of study: Need-based interactions between healthcare service provider and spouse, friends and spouse, family members and spouse, and neighbours and family members.

Social Work Method:

Social Group Work- Reid (1997) provides that alleviating personal suffering and enhancing the wellbeing of members is the prime purpose of social group work. Encouraging democratic participation, social and emotional support can be extended to individuals via group work.

A group is assumed to have the strength to restore and maintain the social functioning of individuals and further the solution-deriving capacities.

Potential Social Work Practice:

1. Conducting Focussed Group Discussions with family members, friends, and colleagues to chart out their role in supporting the rehabilitation process of service members with SCI.
2. Usage of tech-based interventions for enabling collaboration between KSBs, Healthcare facilities, and family members to extend benefits of policies and provisions designated for in-service and post-retirement rehabilitation.
3. Arranging Interactive sessions with other service members with spinal cord injuries to share their experiences about SCI and dynamic rehabilitation practices and prospects.

Exosystem: Participation is influenced at the national, state, and local levels without the client's direct involvement.

Components of Exosystem:

- Social media
- In-service rehabilitation policies
- Post-retirement welfare provisions
- Local, state, and national level action plans for an independent accessibility

Social Work Method:

Social Action - A calibrated initiative to mobilize and organize people of the community to improve and amend the social institutions (Cherian & Thomas, 2018).

This can be achieved based on research based-democratically evolved action plans.

Potential Social Work Practice:

1. Creating user-friendly manuals in lucid languages to create awareness regarding schemes and provisions for sociopscho-eco-political rehabilitation.
2. Amending defence policies at the national level to provide jobs within defence establishments in line with functional abilities of service members with spinal cord injury post-rehabilitation
3. Enabling direct representations of service members with spinal cord injuries in designing, monitoring, and implementing committees responsible for creating accessible environments in public spaces and armed forces establishments

Macrosystem (Working with larger systems - Laws, policies, broader systems of society): Values, customs, attitudes, and beliefs of the cosmic culture in which the individual inhabit are reflected by the macrosystem (Bronfenbrenner, 1977).

Components of Macrosystem:

- Perception associated with disability
- The stigmatization of disability.
- Misconception regarding spinal cord injuries.

Social Work Method:

Community Organisation - For Gangrade (2001), community organization initiates adaptation and synthesis via social systems within the community.

Potential Social Work Practice:

1. Advocacy campaigns led by servicemen with spinal cord injuries for eliminating misconceptions associated with spinal cord injuries.
2. Campaigning to ensure representation of persons with disabilities in curriculum designing thus, attempting to de-stigmatize disability via the pursuit of educational awareness.

Conclusion

Aligning with the available literature, this study showed how SCI could significantly change an individual's personal, social, and economic life. Depending upon the level and type of injury, the defence servicemen underwent various changes in their emotional and physical health on the personal front. The defence servicemen reported feelings of depression and

dependence in terms of Implications on Personality, while many others suggested adopting the path of acceptance to create a positive perspective about life.

On the economic front, diverse intensities of economic implications were reported by defence servicemen. While numerous service members were concerned about rising expenses over healthcare due to SCI, many others expressed their plans to search for alternative employment opportunities rather than solely rely upon the pension and disability pension they would get post-retirement.

There was no significant change reported by the participants in terms of social interaction. Participants stated that their families were supportive, and no negative fallout was seen post-SCI. However, the participants reported a positive change where they mentioned how to post the injury their bond with their families strengthened. Some participants reported that they felt ignored by their friends, whereas, in some cases, their relationships remained unaffected. On the front of relationships with colleagues, most participants felt that they were being empathetic to their condition and were constantly supported by their colleagues as they were aware of the conditions in which the SCI had happened. Regarding the challenges faced in daily activities, participants reported various difficulties such as the absence of mobility, loss of sensation in the lower extremities, pain due to SCI, and other health-related issues. Defence servicemen also reported challenges in personal hygiene, including grooming oneself and sitting upright while carrying out activities related to bladder management, bathing, and bowel.

Defence servicemen who got injured on duty received their treatment quickly compared to those who sustained SCI while

off-duty. Assistive services also played a significant role in enhancing the rehabilitation process.

Policies are designed so that even after their retirement, a defence serviceman will be able to access certain services such as military hospitals and other organizations like Kendriya Sainik Boards to avail and repair costly devices like electric wheelchairs.

Apart from the policies related to assistive devices, defence services and the government have introduced policies that defence servicemen can utilize for comprehensive social and economic reintegration in society.

Scope

Firstly, quantitative studies can be conducted towards the completion of rehabilitation duration to understand the level of awareness about the policies and provisions extended by the government for their welfare. In addition, interventions and modules can be created to inform servicemen about these provisions and access them. Thus, bridging the knowledge gap and reducing the rift between policy formulation and implementation.

Secondly, to create a comprehensive rehabilitation environment for defence servicemen with SCI, further studies can be conducted in capturing the experiences of caregivers of defence servicemen to understand the multidimensional challenges faced by them in the process of caregiving, thus, attempting to create customized intervention processes for the betterment of the quality of life of injured service members and their caregivers.

Thirdly, comparative studies can be conducted in rehabilitation services provided in military hospitals, government hospitals, and private healthcare institutions to persons with SCI, thus creating a scope to adopt the best practices from these institutions for

better rehabilitation of Defence servicemen and their civilian counterparts

Limitation

The study had its limitation profoundly concerning the implications of the injury on relationships with family given the fact that most participants were undergoing rehabilitation at locations different from where their families were located.

Secondly, it would be challenging to generalize the study findings in the civilian population given the military culture in which the servicemen are trained, operate, and rehabilitate, thus creating the possibility of differential experiences related to injury, its implications and rehabilitation processes.

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