

# Innovations

## Working with Families for Improved Functional Outcomes in Teenager Group with Developmental Delays

Aarti Nair<sup>1</sup>, Dr Ajeet Saharan<sup>1</sup> (Ph.D Scholar), Dr Shantanu Sharma<sup>1</sup>,  
Dr Anuja Chaudhary<sup>1</sup>, Dr Manoj Mathur<sup>1</sup>, Diya Nair<sup>2</sup>

<sup>1</sup> NIMS College of Physiotherapy and Occupational Therapy, Jaipur, Rajasthan,  
India

<sup>2</sup>University of Western Ontario, London, On, Canada

---

**Abstract:** This study reviews the importance of working with families for improved functional outcomes in teenager group with developmental delays. Collaboration with families of children with developmental delays, by providing information about prognosis and long term improvements, encouragement and optimism effects functional outcomes for their wards. Employment and independence for their child is the ultimate goal for every parent. By using a systematic format of periodic assessment and focusing on individuals strengths and job matching, it is possible to achieve this ultimate goal. Addressing the challenges faced and making it the main focus for improved functional outcomes is the step towards long term goal of successful inclusion. Data on persons with disabilities are hard to come by in almost every country. Specific data on their functional outcomes are even harder to find. Yet persons with disabilities face the same predicament everywhere. The data for this study is culled from assessments and from reports, provide an anecdotal picture of the current situation. While teenagers with disabilities can make valuable contributions in community work places, they typically experience challenges in low rates of paid employments on being included in same social and ability parameters. **Objective:** A retrospective study to examine the importance of working with families can lead to improved long-term outcomes for teenagers with developmental delays. The study is aimed to examine challenges faced by teenagers so as to improve their functional outcomes by collaborating with families. **Design:** A qualitative research design utilizing observations and in-depth interviews and evaluations was conducted with teenagers in the age group of 13-19 years, using the Functional Assessment Checklist for Programming (FACP) tool. **Conclusion:** This study represents a concerted effort to better meet the needs of youth with disabilities as they transition towards employment and successful inclusion. Teenagers with disabilities can contribute, they need understanding, support, opportunities not charity or misplaced sense of compassion.

**Keywords:** Developmental Delays; Teenagers with disabilities; Family's Intervention;  
Functional outcomes; Inclusion.

---

### **Introduction:**

Inclusion of teenagers with disabilities in the community has become a pressing issue in modern society. Participation of families is critical for ensuring the services are aligned to family needs and the needs of the individuals. Parents have been found to be good advocates for their dependents, when they are provided with encouragement, optimism and information. In developing countries, 80% to 90% of teenagers with disabilities of working age are not included, whereas in industrialized countries the figure is between 50% and 70%(1). Even though people with disability constitute a significant 5-6% of India's population, their employment needs remain unmet. Studies conducted reveal that in spite of People with Disability Act in India which reserves for them 3% of Government jobs of the 70 million people with disabilities in India, only about 100,000 have succeeded in obtaining employment in the industry(2).

Work is a crucial issue in everyone's lives including people with delayed development for personal identity, independence and improved quality of life. Despite various national and state policies promoting and supporting employment for adults with delayed development or intellectual disabilities, stigma still persists. Policies and laws that are supportive of youth with developmental concerns are often not understood or utilised due to poor regulatory mechanisms. The opportunity to leverage these services can be easily missed as cultural beliefs and society stigma often force families to look for "fixes" and cures for their children(3). It is frequently viewed that youth with disabilities will not be able to perform and accommodations will be required which may not be viable economically for employers.

In this respect a brief model is studied to describe and account for the factors that caregivers can influence. Collaboration with family members leads to changes in attitudes of community and work place towards the long term goal of improved functional outcomes and successful employment.

### **Background:**

Services for families and children with disabilities infrequently consider psychosocial factors and their influence on the youth or their family. Low caregiver literacy limits access to information and they are misinformed in about their child's disability. Stone and Colella's model (1996) (Nota2013 (1), suggested that the more visible the disability the more probability of the person not being desirable in the community(4). This was a critical factor characterising peoples' attitude. It was observed that people with intellectual disability experienced more discrimination for inclusion as compared to those with sensory processing disorders.

Persons with disabilities are frequently not considered potential members of the workforce. Perception, fear, myth and prejudice continue to limit understanding and acceptance of disability in workplaces everywhere. Myths abound, including that persons with disabilities are unable to work and that accommodating a person with a disability in the workplace is expensive. Some studies measure attitudes of co workers and the corelation to the type of disability and presentation of disability. The current study has researched areas that families of teenagers can work on so these challenges can be addressed and teenagers are accepted in the workplace. Young people with disabilities can perform and give quality work output if training and instructions are given in a manner they understand. Importance of family-professional collaboration

In any household the family spends most time with their children and they are the actual constant in the child's life. Involving parents and other family members in the intervention process is more powerful than focusing exclusively on the youth. When families are involved, trained and supported, youth get more opportunities to revive interventions when professionals are not present. Encouraging caregivers to choose their level of involvement in program planning, decision making and service delivery benefits both the individual and family. This also helps the service provider to be effective(5).

Basic effective, interpersonal skills, such as building trust and following through plans, actively showing attention are courtesies viewed as critical to successful collaboration from parents point of view. Parent-professional collaboration is essential for meaningful outcomes for the individuals with disabilities. Non-judgemental reactions to families cultural views and beliefs is essential for building a rapport. One way of achieving this is using family priority for establishing the goals and using multiple techniques to engage family members in discussions about how to develop their child's functional skills during the daily skills. Positive capacity building and positive help giving encourages and empowers the family and uses new strengths as they emerge(6).

### **Methodology:**

#### **Participants**

We recruited 10 employees working in a Not-for-Profit Organization in Dehradun for evaluation and assessment of teenagers followed by mentoring and supporting families. These employees were well versed with using the Functional assessment checklist for programming (FACP tool). The checklist was used for 113 students, age group-13-19 years, who were admitted in the vocational centre of Latika Roy foundation, Dehradun during the years 2019-2022. Out of the 113 students, 45 were short listed for the study. In this group, 9 were girls, constituting to 20% of the total and 36 were boys, (80%), as illustrated on figure 1.

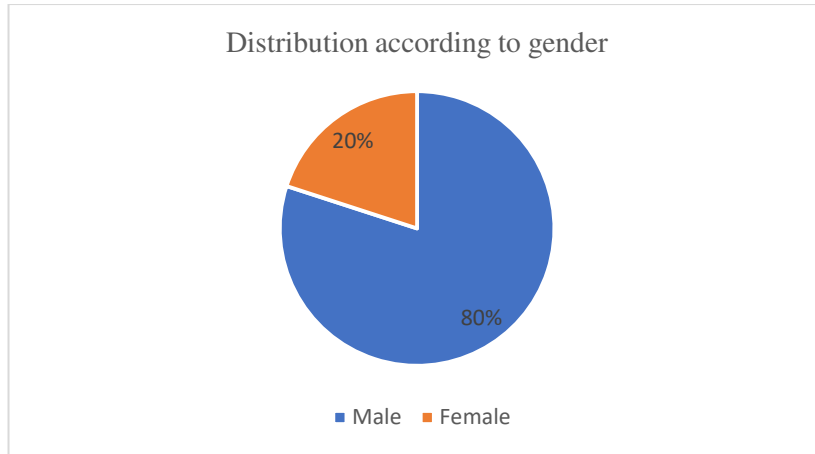


figure 1

The age group of the teenagers were, 13-19 years. Maximum number belonged to 15 year age group. figure 2. There was one child who was 13 years of age and 2 in the age group of 14 years. There were 11 children each in the age group of 17 and 18 years. A total of 45 teenagers were part of this study.

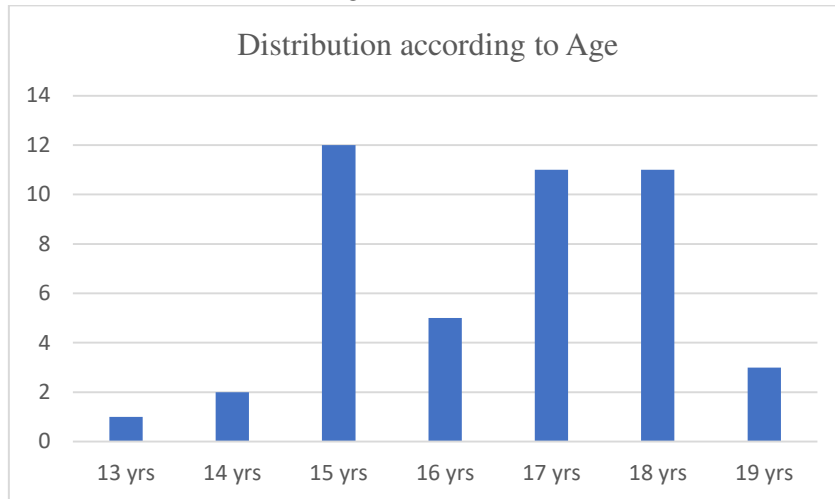


figure 2

table 1- Description of families

| Categories         | Demographics                                      |                                      |
|--------------------|---|--------------------------------------|
| Location           | Rural 13(31%)                                     | Urban 32(69%)                        |
| Family Structure   | 40(87%) Two-parent families                       | 5(13%) single parent family          |
| Mother tongue      | 43(97%) Hindi speaking                            | 2(3%) other languages                |
| Mothers' Education | 30(63%) Mothers educated to high school and more. | 15(37%) Mother less than high school |
| Fathers' Education | 39(81%) Father educated to high school and above  | 6(19%) Father less than high school  |

**Tool Used:**

The instrument used in this study was a questionnaire, Functional Assessment Checklist for Participation (FACP)(7).It starts with a Generic Skill assessment checklist- Phase 1, which checks prerequisite skills for vocational training (figure 3). The assessment helped to select and match the job based on generic skill achievement score and the specific skill needed for specific job as per the job analysis. This tool was coupled with a semi-structured interview where initially the interviewee was told to give their sociodemographic data (name, age, gender, qualifications, type of disability, and number of months/years of training). The questionnaire was filled in-person and to reduce social desirability bias the interviewee was told that there were no correct/incorrect answers and it was based only on survey views.

In Phase 2, community assessment and job analysis is undertaken. The job analysis format is based on an individualised curriculum and evaluation procedure. It requires a periodical evaluation and has 5 categories marked as, I- Independent, M-Modelling, V- verbal prompting, P- Physical prompting, D- Totally dependent.

The Work Behaviour assessment data is also a periodical assessment in 5 areas namely, 1. Physical appearance, 2. Personal Interaction, 3. Regularity and punctuality, 4. Communication and Social manners, 5. Quality and Quantity aspects of work. The data collected was scored on a Likert scale of 0-3 where 0 signifies, 'never' and 3 stands for, 'always'.



figure 3

Job placement is an outcome of the assessment. Based on the strength of the individual they may start with supported employment and progress to open employment or work on their own. Some individuals may continue in sheltered employment.

#### Functional Assessment Checklist for Programming (FACP)

FACP is an assessment tool that helps in finding the current level of performance of an individual with profound intellectual disability and planning a suitable educational program. FACP is developed as part of a research project which is useful in development and planning of educational programs for youth with intellectual disabilities. The generic assessments and specific assessments, (figure 3) are part of each checklist in FACP(8).

Depending on the age group different checklists are used. The 6 checklists that are part of the FACP are: 1. Primary II Checklist- age group 9-14 years.

2. Secondary Checklist- age group 11-14 years.

3. Non Vocational Checklist –(Care Group)

4. Pre-vocational I Checklist- (15-18 years).

5. Pre-vocational II Checklist-(Over 18 years).

This tool help to assess the strengths and skills of the individuals and based on skills and interest job matching is done for job placements.(figure 3).

#### **Project Overview:**

Various project partners (special educators and counsellors working in the vocational centre of Latika Roy Foundation), provided a variety of services to the youth with developmental concerns as indicated in figure4. Project partners assumed different roles in project implementation. This transition services project was designed in collaboration with the families of teenagers who were part of Latika Roy Foundation during the year 2019-2022. Families and teenagers worked along with the professionals to determine best job profile depending on interests and strengths. They provided the youth with mentoring services, coordinated training and conducted the assessments. Internally, the staff at Latika worked alongside the families to improve functional outcomes for teenagers and externally worked with employers and families for identifying suitable employment activities thereby providing community based work experiences, job try-outs, mentoring and internships.

**Project Overview**

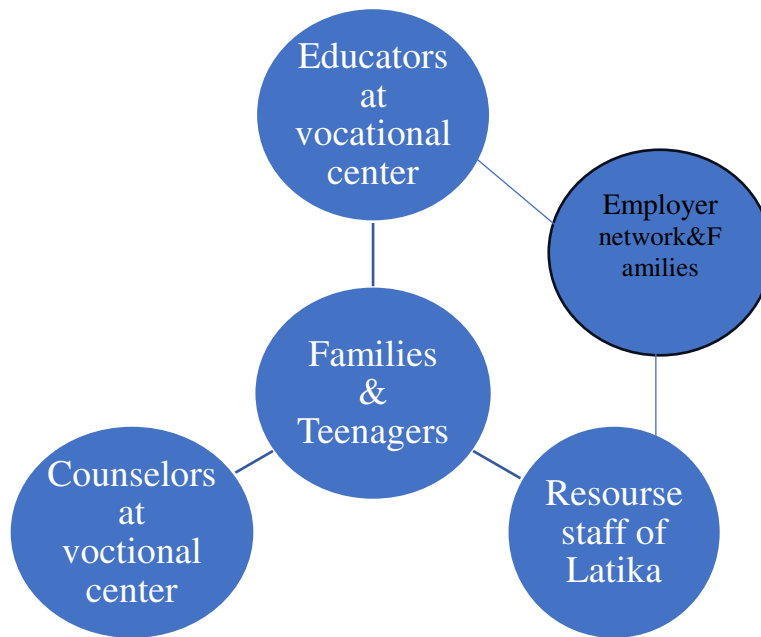


figure 4.

The employer network that was set up were also part of this project. Potential employers were made aware of various disability profile for job try-outs and job shadowing opportunities. Paid and un-paid work experiences were set up. The project was centred around the teenagers and their families while the professional of Latika worked alongside internally and with external agencies like the employers of business who were open to recruiting trainees., (figure 4). The trainees who were part of the study had varied disabilities, namely Downs Syndrome, Cerebral Palsy, Autism and Intellectual disabilities. (figure 5). There were 9 trainees who had Downs Syndrome, 7 with cerebral palsy. 14 teenagers had Autism and Intellectual disabilities.

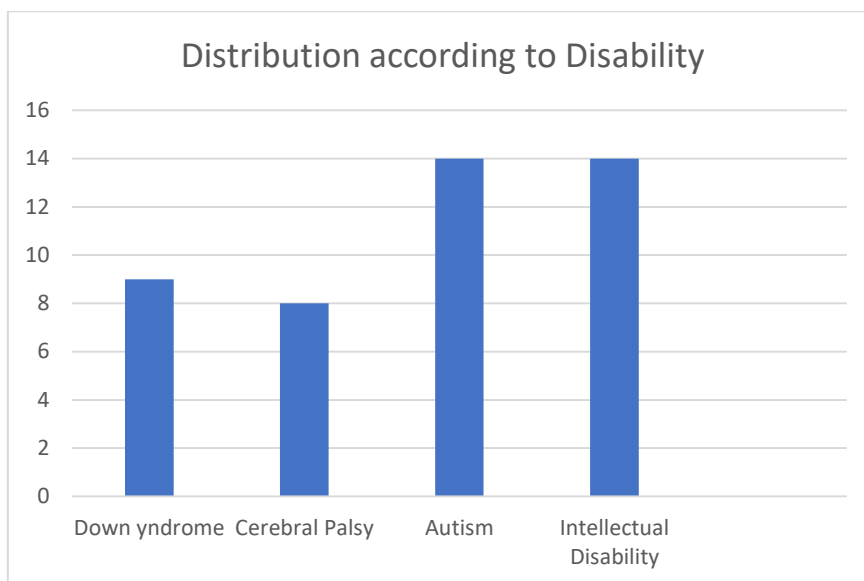


figure 5

### Strategies for supporting families

Support groups were set up for group and individual counselling. Mentoring and training for families on weekly basis for 8 weeks followed by 4 group sessions at an interval of 4 weeks. Brain storming sessions with parents and support staff of Resource centre of Latika Roy Foundation were also organised. Family outcomes were the priority and multiple techniques were used for engaging family members and positive capacity-building.

### Soft Skills

Family members and caregivers were involved in many different aspects of the teenagers program. After the decision about the areas of interest and possible job placement ventures their child would like to peruse. A routine was set up for the parents to ensure regularity and punctuality of their ward. Providing nourished food and ensuring clean and healthy appearance. Being closely involved with implementation of the programme, through regular meetings with the educator and counsellor. Discussions with the employer and the direct supervisor once the job matching was done and internship began.

### Academic Support

Academic assessment tools ideally lead to appropriate programming for the child. The periodic assessments have the provision of qualitative and quantitative measurement of child's progress. Besides monitoring progress it also has the provision of modifying the program. Eventually a brief teaching plan of activities s written down for every child after detailed discussion with parents for each term (at every quarter).

### Career Exploration

Through the evaluation process educators had greater awareness of the adult services that were available to the teenagers with disabilities, exiting the vocational centre that would lead to enhancing the transition outcomes. Parent involvement in planning job accommodations, modifications and training assistance lead to more success in employment opportunities, work try-outs, situational assessments and internships. While there were some variations across with regard to how families and their wards were connected, in most cases teenagers interests and strengths were identified using the evaluation tool prior to matching them with local businesses.

Network with potential employers were organised with the help of individual families who had existing partnerships. Employers who had a special interest in disabilities were approached and invited to be part of the support group.



### Project Outcomes

Using a family-centered approach for improving functional outcomes for teenagers is a unique approach. The daily routine being interconnected with activities of each member affecting all others as a whole has great benefits.

This relationship based approach lead to actively developing strong family-professional and professional-to-professional collaborations. Participation of families increased and sharing of experiences lead to positive outcomes for themselves and heir children. Family members experienced different reactions and shared ways of coping with challenges that their children were facing. They were able to share creative techniques that worked for them and felt empowered in the process.

The assessment was done periodically using FACP (figure 3), 14 children were in the developmental category of primary level, 9 of them were 15 years of age, 2 were in the age group of 14 years and 1 was 13 years old. 4 children reached the secondary level, 3 of them were 15 years old and 1 was 17 years of age. The non vocational group comprised of 8 youth, 7 were in the age group of 15 and 3 were 18 years of age. 5 teenagers were in Prevocational 1, age group 16 and 17 years. The prevocational 2 level was achieved by 14 teenagers, from the age group of 18 and 19 years. As the candidates improved in the set levels and their score went over 80% they were shifted to the next corresponding level. The teenagers in the non-vocational group comprised of profound disabilities and continued in care group. Families of this group were trained to continue with regular sustainability training.

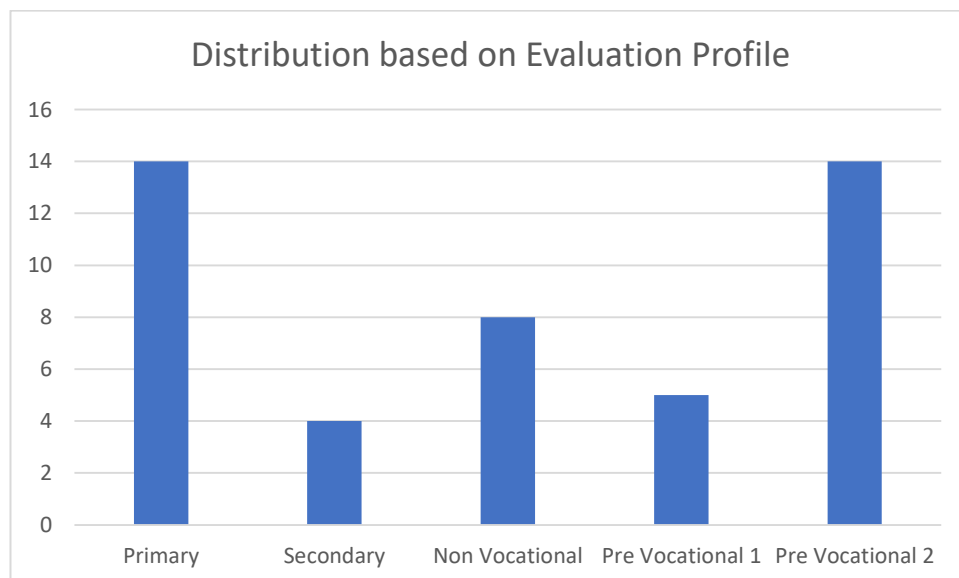


figure 6

There was testimony from employers about the achievements of trainees. Contrary to these notions, many found that persons with disabilities are more than capable. When the instructions were clearly give they were able to complete the

task as did the colleagues. Taken together, these findings suggest that potential employers receiving information on applicants' strengths and abilities to perform specific functions and positive behaviours tend to show more welcoming attitudes towards these candidates(9).

**Systematic Barriers to transition for youth with disabilities.**

Most youth with developmental delays and disabilities at these projects lacked the skills and support necessary to maintain employment, including lack of work history, poor social skills, lack of knowledge on employers expectations, workplace etiquette as well as information benefits.

Another intervening perception is the potential to be disruptive or dangerous and assumptions of people with disabilities will likely find it difficult to comply with regular norms, perform poorly and cause tension or unease and uncertainty in social interactions.(10). Studies show that employers are more concerned with work performance and social behaviours of people with intellectual disability as compared with those with physical disability.

There was an inherent focus on disability and not on strength. While typical individuals working in the same areas also depicted certain behaviour trends, it was assumed that the behaviour was a result of the disability of the individual. This lead to the individual getting less latitude of adjustment.

Myths about accommodations was another predominant factor. Most employers felt that the accommodations required would not be affordable for them. Families revealed that attitudes of coworkers had significant effects on their children to maintain a job in the workplace. Some teenagers found colleagues to be unfriendly and unable to share jokes with them as they did with others.

### **Conclusion:**

This study represents a concerted effort to better meet the needs of youth with disabilities as they transition towards employment and successful inclusion. Teenagers with disabilities can contribute, they need understanding, support and opportunities not charity or misplaced sense of compassion(11). Taking into consideration that this is a subject of limited knowledge and new for most people, it is possible to create an insight into the subject for persons with developmental delays themselves, also for employers and colleagues, since broadening knowledge will be beneficial for both. This preliminary study is to support families and practice shift from managing individual behaviours within a limited scope to pragmatically collaborating with youth and caregivers to support youth to sustain employment and be independent and successful. What is important is for families and employers is to embrace and operationalize principles into practice, and keep an open mind

towards employment of people with cognitive delays and other developmental delays.

This study does not have the capacity to verify the accuracy of each individual's reporting of their improvement activities and/or their outcome data. It is possible that greater strides in improvement have been made or that challenges have been experienced in individual cases or programs since reporting their improvements and/or their data to staff at LRF; what was reported in 2022 may no longer reflect current program practices or outcomes.

The present study acknowledges that such programs are complex to implement and requires a fine understanding of diverse needs of individuals with developmental delays across different contexts. Many organisations across India have made considerable progress in terms of putting in place a robust framework and a range of programs and schemes that have improved employability of people with disabilities Implementation can be improved through better provider training, positive feedback and monitoring mechanisms(12).

Moreover, unless persisting structural challenges are addressed, implementation of regulations will not be effective. Capacity building is the only way to achieve lasting progress for youth with developmental concerns. And, while there is still much work to be done to develop, implement and evaluate best practices, youth and families across the state served by staff, families and community are experiencing improved outcomes when this work is done well.

**Acknowledgements:**

I would like to extend my sincere thanks to all the participants. Most importantly, I would extend my sincere gratitude to Dr Ajeet Saharan. This study would not have been possible had it not been for his guidance as a mentor. His expert knowledge, patience and guidance through the research work and writing has deeply inspired me.

I would like to extend a special thanks to Diya Nair who worked tirelessly during the collection of data and for patiently reading through research material. The field work of this study was made possible through staff of Latika Roy Foundation. I would like to thank all the 10 staff members who were actively involved in the functioning and gathering the data for evaluating the program. And working with the families. Especially because they continued to work during the ever changing and extremely challenging time of Covid 19 Pandemic. Secondly, I wish to thank the families who agreed to be part of this study from the District of Dehradun. I would like to express my deep and sincere gratitude to all of them.

Once again I am thankful to Dr Ajeet Saharan and Dr Anuja Chaudhary for helping in this publication and always encouraging and positive attitude.

I would also like to thank Sandeep Khanna, Senior Physiotherapist, Project Head and Direct Services, Latika Roy Foundation, who was ever ready to help. Thank you to my family and friends. Thank you to my parents who have encouraged me and provided all the support while I completed my work.

**References:**

1. Kumar SG, Roy G, Kar SS. *Disability and rehabilitation services in India: Issues and challenges. Journal of Family Medicine and Primary Care. 2012 Jan 1;1(1):69-73.*
2. McVeigh J, MacLachlan M, Ferri D, Mannan H. *Strengthening the participation of organisations of persons with disabilities National Government and the United Nations: Further analyses of the international disability alliance global survey. Disabilities. 2021 Aug 3;1(3):202-17.*
3. Awasthi A, Pandey CM, Dubey M, Rastogi S. *Trends, prospects and deprivation index of disability in India: Evidences from census 2001 and 2011. Disability and health journal. 2017 Apr 1;10(2):247-56.*
4. Chaurasia A, Singh AP. *Assistive Support Through Technologies for Persons with Disabilities in Libraries. DESIDOC Journal of Library & Information Technology. 2022 Mar 1;42(2).*
5. Coleman E, Arcelus J. *Standards of Care for the Health of Transgender and Gender Diverse People, Version 8. Int J Transgend Health. 2022 Sep 6;23(Suppl 1):S1-S259.*
6. McVeigh J, MacLachlan et.al. *Strengthening the participation of organisations of persons with disabilities in the decision-making of National Government and the United Nations: Further analyses of the international disability alliance global survey. Disabilities. 2021 Aug 3;1(3):202-17.*
7. Muthumbi JW. *Enhancing transition outcomes for youth with disabilities: The partnerships for youth initiative. Journal of Vocational Rehabilitation. 2008 Jan 1;29(2):93-103.*
8. Nair A, Nair D, Girdhar M. *Optimizing developmental outcomes by setting smart goals individualized home program for children with disabilities during COVID-19. Int. J. Physiother. Res. 2021;9:4028-34.*
9. Poli M, Malagas K, Nomikos S, Papapostolou A, Vlassas G. *The Interaction of People with Disabilities with the Intelligent Packaging. In Novel & Intelligent Digital Systems Conferences 2023 Sep 23 (pp. 9-20). Cham: Springer Nature Switzerland.*
10. Ramanujam N, Caivano N. *Centering economic inclusion in policy for realizing disability rights in India. Disability & Society. 2023 Apr 8:1-24.*

11. Roy B. *Understanding the disability divides in india: a spatio-temporal analysis with district-level datasets. Regional Development Planning and Practice: Contemporary Issues in South Asia. 2022:233-53.*
12. Srinivasan R, Kulkarni V, Smriti S, Teplicky R, Anaby D. *Cross-Cultural Adaptation and Evaluation of the Participation and Environment Measure for Children and Youth to the Indian Context-A Mixed-Methods Study. Int J Environ Res Public Health. 2021 Feb 5;18(4):1514.*
13. Suresh V, Dyaram L. *Job matching for Persons with Disabilities: An Exploratory Study. Employee Responsibilities and Rights Journal. 2023 Dec;35(4):475-92.*
14. Yee W, Ross S. *Communicating with parents of high-risk infants in neonatal intensive care. Paediatric Child Health. 2006 May;11(5):291-4. PMID: 19030293; PMCID: PMC2518680.*