A Systematic Review of Status of Persons with Intellectual Disabilities

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ABSTRACT

Purpose: The purpose of the review of the literature was to identify the awareness of Intellectual Disabilities in the community and to systematically review the way forward in aspects such as personal life, work life, social life, early intervention and training for people with intellectual disabilities

Design: The related information on the topic was sourced from various secondary sources and 102 articles were reviewed on areas such as the early intervention of intellectual disability, the status of interventions, parents' involvement, pre-vocational and employment for persons with neurodiversity. The researcher used a descriptive research design by identifying articles from sources such as Research Scholar, ERIC, PubMed, and PsychNet through identified keywords and reference list searches.

Findings: The review reveals that there is a scope for a further breakdown of bringing awareness about building eco-system of persons with intellectual disability. Further research must focus on a sustainable approach to involve parents, society, and companies towards equity.

Originality Value: The statistical data on the prevalence of Disability is studied by many but it is important to bring to the notice of training and bring awareness about Intellectual disability in the community.

Paper type: Systematic literature review-based analysis.

Keywords: Intellectual disability, special educators, Pre-vocational skills, Parents of Persons with Intellectual disability, ABCD analysis.

1. INTRODUCTION:

About 31 million persons have intellectual Disability in India out of which about 35.29% belong to the age group of children [1]. The terminology shift from mental retardation to intellectual disability was first supported by mutual acceptance by the America Association on Intellectual and Developmental Disabilities (AAIDD), International Association for the Scientific Study of Intellectual Disabilities (IASSID), and President's Committee for People with Intellectual Disabilities [2]. Most of them are debarred from actively participating within their families, and communities due to their disability. Many laws and policies were drawn for the betterment of Persons with Disabilities such as the Persons with Disabilities Act of 1995. Although this law has been a benefit to many but not to the rural communities. Persons with Disabilities living in rural India face challenges to live a dignified and determined life and be able to equally participate at home and in society. It emphasizes factors such as socio-environmental, personal for these challenges. Often they are encountered with a negative attitude from the community which then draws them into the vicious circle of worthlessness. Suggestions include seeing a person before their disability and including them at home and then in society, which increases their self-esteem [3]. The recent trends and advancement in education for Pwds in India concerning different policies, perspectives, and educational practices and struggles in implementation of it [4]. Children with intellectual disabilities are observant and learn job skills that is mostly practiced by that area or community which is not taken into consideration in school system. To provide education in rural areas by teachers with technological development requires focus on vocation training which will make

education more impactful [5]. The present study reviews 50 articles about intellectual disability in rural communities.

2. OBJECTIVES:

- (1) To understand the socio-demographic, and socio-economic aspects of people with intellectual disabilities in Rural Settings.
- (2) To identify the research gap between the existing and desired awareness about intellectual disabilities in rural communities based on a literature review.
- (3) To choose a research agenda for further research based on priority.
- (4) To conduct an ABCD analysis to bring out the effectiveness of the paper.
- (5) To suggest further research on inclusive schools in rural areas.

3. METHODOLOGY:

The researcher used descriptive method of study. The review process included gathering and analyzing secondary sources from various sources. These secondary sources include published literature from various scholarly journals searched through Google Scholar, ERIC, PubMed, and PsychNet by means to identify keywords and references. Inclusion criteria for this review are: Studies published in peer-reviewed journals and outcomes associated with Intellectual disability in rural settings. The research work related to the above is summarized to understand the evolution of disability and its existence in rural settings.

4. RELATED WORK /REVIEW OF LITERATURE-BASED ANALYSIS:

The below tables consists of various research articles and studies that highlights the prevalence of disability from early 90s to 2022. It summarizes the key areas such the importance of pre-vocational training, vocational training, building eco- system of supports, social role valorization from sources such as google scholar, pubmed, ERIC, etc, (1990 to 2022).

Table 1: Review of various studies from 1994 to 2022 specifically about the growth of status of intellectual disability

S. No.	Focus	Contribution	References
1	Model of disability - medical model	As per the medical model, People with patients are termed as patient or require treatment clinically.	Simon, (2007). [6]
2	Models of disability - Religious model	Various labels such as sin to the family, being impure, weak, and needing to be healed has its roots from religious model.	Clapton, & Fitzgerald, (2015). [7]
3	Models of disability - Cultural model	The roots of present myths and facts also relate with cultural model.	Conyers, (2003). [8]
4	Models of disability - Social model	By contrast, the social model defined disability as a social context.	Deborah Marks, (1997). [9]
5	Models of disability - Human Rights model	When disability is viewed in context to society whereas the human rights model places the person in the center with dignity in all stages of decisions and views the main challenge or outside of the person.	Anna & Angharad, (2021). [10]
6	Measuring disability in the Indian context	A person's ability or inability to function properly depends on their socio-physical set up.	Jeffery & Singal, (2008). [11]

7	Indian disability rights movement	Although the movement and its presence are still trying to reach the public to the fullest. Contrary to this, it did impact many people with disabilities to access disabled-friendly environment.	Mehrota, (2011). [12]
8	Rural India and meals program in schools	A study conducted by the author found the effect of providing monthly grains to the school children and providing daily meals to school children from rural India.	Afridi, (2011). [13]
9	Community intervention for untreated schizophrenia.	The author concluded by suggesting that there needs to be more efforts to implement community-based care which can bring in more sustainable up-liftments.	Srinivasa et al., (2005). [14]
10	Disability status in the Indian context	Challenges include educating them and accessing resources. In a developing country, there is positive growth in the special school that provides valuable life skills and training for children with disabilities	Byrd, (2010).[15]
11	Using the Indian disability evaluation assessment scale.	Using the scale it was found that there was high prevalence of mental disability among females than males.	Kumar et al., (2008). [16]
12	Need for action for discrimination against differently-abled children in rural communities in India.	Community-based rehabilitation is facing a growing impact and contributes toward the self-sustainability of the disabled.	Janardhana et al., (2015). [17]
13	A summary of access to Primary Health Care Among Persons With Disabilities in Rural Areas.	Specialized expertise plays a crucial role here. Innovations in these areas could be encouraged and thus remove the barrier.	1
14	Disability, Intersectionality and Deprivation: An Excluded Agenda	- A large number of PwIDs face difficulties in lead a normal life due to social reproach, disregard, and strongly religious, sociocultural conditions also lead to such social labels.	Pal, (2011). [19]
15	Community inclusion work for PwIDs	India ratified partner, integrating PwIDs in society has attracted a lot of attention.	Vanmala et al., (2014) [20]
16	Results of patients with psychotic disorders in a rural India community-	Success and best practice is through community based rehabilitation.	Chatterjee, et al., (2009). [21]

	based rehabilitation programme.		
17	Issues and Challenges in India's Disability and Rehabilitation Services	The committees need to build each other by supporting them for various research and interventions to address the issues faced by people with disabilities.	Kumar et al., (2012). [22]
18	Students' Classroom Behaviors in Rural Mainstreamed Settings: A Comparison of Normative Peers and Students with Disabilities	In terms of instructional engagement with the teacher, disabled pupils did not appear to differ much from their peers.	Butera, et al., (1994). [23]
19	The WHO's significance Ten Questions Screen for Disability Detection in a Rural Community: The North Indian Experience	The study showed a significant identification of disabilities in kids between 2 to 9 years. This is by crosscultural study.	Singhi, et al., (2007). [24]
20	ACross-Sectional Study on the Quality of Life of People with Physical Disabilities in Udupi Taluk	The scale showed lower under the psychological domain reflecting on negative feelings, bodily image, appearance, spirituality, and self-esteem of respondents.	Kunal et, al., (2015). [25]
21	Need for microfinance self- help organizations among rural Indian women who care for people with mental disabilities	The interview produced information about the financial requirements, caregiver's capacity, community resources, the need for microfinance self-help groups, informational needs, social support, burnout, and stigma.	Nair, et al., (2018). [26]
22	The prevalence of disability in elderly in India.	Study shows that one in every twenty Indian citizens aged 60 years and above falls under physical or mental disability.	Velayutham et al., (2016). [27]
23	.Rural south Indian community and disability.	In rural south India, women are more likely to be disabled due to factors like early marriage, starvation, poor nutrition, arthritis, gastrointestinal problems, and undetected dementia.	Duba, et al., (2012). [28]

24	Adult prevalence of disability.	According to studies, there is a high rate of impairment among people over 70. There is an immediate need to mitigate this prevalence and improve public health.	Ramachandra, et al., (2016). [29]
25	Strategies for inclusion in the writing of disability histories in India	The disability is one of the human characteristics of living being such as ethnicity, gender, etc.	Buckingham, (2011). [30]
26	Disability and stigmatization in India	In Rural India, this is still being followed as per the religious model. Only through education and awareness the stigmatization could be eliminated.	Kayama, et al., (2019). [31]
27	Global Report on Disability	By engaging people with disabilities at all levels of the program such as developing and delivering the services and conducting research processes the effectiveness of the program can be met.	McLeod, et al., (2014). [32]
28	Sexual and Heath concerns of PwIDs	Women with disabilities may face difficulties with regard to their sexual needs and reproduction, particularly in India.	Sharma & Sivakami, (2019). [33]
29	Disability in India: Trends, Prospects, and Deprivation Index	The population of People with Disabilities in India has increased significantly,	Ashish et al., (2017). [34]
30	Disability training and placement firms in India engage in talent management	Creating jobs in various sectors like IT, Housekeeping, Hospitality, self- employment nd sheltered employment leads to empowering Persons with disabilities and their families.	Kulkarni & Hugh, (2015). [35]
31	India's rural communities housing disabled people	Persons with Disabilities face the hurdle of living a dignified life in their community.	Gupta, et al., (2021). [36]
32	Aging, Disability, and Disabled senior citizens in India	Due to inappropriate interventions and timely attending of the issues nearly 4 million people are prone to mental challenges and problems in India.	Indira, (2003). [37]
33	Differences in Older Adults' Gender and Disability in North and South India:	Marriage plays an important factor as it associates with impairments.	Sengupta et al, (2002). [38]

34	Community based follow up	Rehabilitation services and follow up with social interaction helps with reducing the loneliness faced by People with Disabilities	Nagarkar & Kashikar, (2017). [39]
35	Strategies of inclusion	The study argues the strategy of mainstream schooling requires inclusion	Llyod, (2008). [40]
36	Approaches to intellectual disabilities	To work with Persons with Intellectual Disabilities requires extensive support from parents, caregivers, and other stakeholders.	Kanesalingavelan, et. al., (2016). [41]
37	Working for Persons with disabilities	it is necessary to engage with humane elements like empathy and positivity when interacting with people who have intellectual disabilities.	Hazarika & Choudhury, (2021). [42]
38	Special educators and training	Although they needed additional training, teachers shown a moderate level of concern for implementing inclusive education in the classroom.	Bhatnar et al., (2013). [43]
39	Tools to measure vision- health quality of life	With the findings of the study the paper suggested to use more appropriate tool for assessment of vision-related quality of life in children with ID.	Cui, et. al., (2010). [44]
40	Post School success	Challenges post schooling include finding the right job or even for higher education, accessibility in public spaces.	Buck, (2013). [45]
41	Health services and Rural India	Health professionals and practices reaching rural India are still a challenge.	Odiyoor & Jaydeokar, (2020). [46]
42	Disability and future path	Eliminating stigma from family, society, and the community can be a supporting factor to bring up persons with Intellectual disabilities towards inclusion.	Werner. et al., (2012). [47]
43	Practices towards inclusion	Changing the mindsets of people about Disability and Persons with Intellectual Disability can bring dignity and help them lead their life to the fullest.	Scior, (2011). [48]
44	National governing bodies	This plan will guide people with disabilities, disability practitioners and researchers and policy makers.	Menon, (2019). [49]
45	Livelihood	People with intellectual disabilities could become independent and change their mindsets by receiving training in life skills and daily living techniques.	Chandra, (2019). [50]

46	Theoritical study to disability	The choice of attitude towards people with disabilities mark a significant factor in the personal and social relationships.	Stepanova, et al., (2019). [51]
47	History and the disability	Inclusive schools are the most holistic approach toward welcoming community.	McLeskey, et al., (2014). [52]
48	Entrepreneurial education	Entrepreneurial education and framework brings in a value added ecosystem for persons with intellectual disabilities.	Krüger & David, (2020). [53]
49	Exclusion	They are largely excluded from the human resource market	Garrels, & Sigstad, (2021). [54]
50	Right of person with intellectual disabilities	People with previous work experience has better scope for working with them as they understand how to work better.	Elahdi, & Alnahdi, (2022). [55]
51	Competitive employment	For inclusive employment in competitive sector, working closely with government, corporates, other stakeholders is important	Lysaght, et al., (2012). [56]
52	Parents and social networks towards employment	There are limited opportunities that fit for persons with neurodiversity in the indian society. The employment needs to be tailored as per the strengths of the person and mapped to the available opportunities.	Petner-Arrey, et al., (2016). [57]
53	Competitive integrated employment	These employment pathways helps persons with intellectual disabilities be more productive as they are asked to the task that they enjoy and retain the job at the workplace.	Wehman, et al., (2018). [58]
54	Supportive measures towards employing persons with neurodiversity	Psychiatrists working with people with neurodiversity suggests psychotropic medications to deal with behavioral issues and emotional support for the families.	Courtenay, (2020). [59]
55	Psycho-social wellbeing of persons with neurodiversity	Working and providing psycho-social support such as counselling, therapies, relaxing work life balance activities can help them overcome the barriers.	Kåhlin, & Haglund, (2009). [60]

Table 02: Review of related research publications on special educators for persons with intellectual disabilities from the year 1990 to 2017

S.	No.	Area	Findings	References
1		Retention of Special educators	A special educator plays multi-role in the organization such as administrations, conducting induction program, mentoring programs, etc	Vittek, (2015). [61]

2	Job stress of special educators	Training persons with intellectual disabilities could be challenging as there will be lot of training in terms of behaviour modification, counselling etc involved. Hence the special educators tend to go through lot of physical, mental stress.	Dedrick, (1990). [62]
3	Job retention among special educators	In this study it was analysed that one of the negative factor was stress due to the job design as it is.	Keating, et al., (2001). [63]
4	Special educator's work	The researcher founded that the special educators tend to work better with better administrator support as their external support at work.	Bozonelos, (2008). [64]
5	Career by choice	This study shows that the sample respondents with a positive employment from the district.	Fish, (2010). [65]
6	Importance of research based in special education	There should be more of research based practice in the special education sector for effective implementation	Billingsley, (2004). [66]
7	Implications for special educators	Some major factors that holds strong implication for educator's retention are historical, environmental and external factors.	Brownell, & Smith, (1993). [67]
8	Motivational factors for special educators towards their retention	Continuous staff recognition was a major factor that affected the retention of the special educators	Battitori, (2010). [68]
9	Paraeducators and their work status	Some schools still find it difficult to retain some paraeductors due to reasons such as unable to meet the expected salary.	Tillery, (2003). [69]
10	Mediational model	One demographic variable is also age that affects the employment retention of special educators	Conley, (2017). [70]

Table 03: Review of Related Research Publications on parents of persons with intellectual disabilities from the year 1997 to 2020

S. No.	Area	Contribution	References
1	Health and well-being of parents with intellectual disabilities	Parents with poor economic background tend to have poor mental well being	

2	Stress among parents	The stress is often colides with the meaning they see towards their child who are kept at home and seen as a burden to the family.	Flores, et al., (2020). [72]
3	Persons with disabilities as Parents	Parent who are persons with disabilities are often discriminated and considered as not enough good parents which needs to be changed in this society.	Reinders, (2008). [73]
4	Parenthood and disabilities	Parenting or bearing a child is problematic and hence being avoided by persons with disabilities	Areschoug, (2005). [74]
5	Parenting style	Parent's parenting lies often is neglected in terms of psychological support rather than physical support	Feldman, (1998). [75]
6	Carers and parents of persons with intellectual disabilities	Parents in the journey of taking care of their child or adult they tend to spend more time with the carers to provide necessary	McConkey, (2005). [76]
7	Support from grandparents	Maternal depression was caused due to the age factor being young mothers and less emotional support from grandparents while raising a child with intellectual disabilities	Heller, et al., (2000). [77]
8	Family quality of life for persons with neurodiversity	A study was conducted with Person with intellectual disabilities about family quality of life. The results shows that family support is one of the major aspect they look up to while they grow up.	Correia, et al., (2017). [78]
9	Individual quality of life and family quality of life for persons with intellectual disabilities	The studies shows that there is a correlation between the three aspects such as financial wellbeing, wellbeing of their family and support service.	Bertelli, et al., (2011). [79]
10	Family to be addressed	Studies to analyze the family quality of life of persons with intellectual disabilities is emerging in the recent trend as it supports family wellbeing and togetherness	Brown et al., (2006). [80]
11	Family inclusion for Persons with Intellectual disabilities	Studies found out that inclusion in the family in terms of involving them in decision making is the first step to prepare them for the outside work	Ahmad et al. (2022). [81]

12	Community and social inclusion	The paper highlights the research conducted an ecological approach in terms of interviewing children with and without disabilities on the barriers to social and community inclusion.	Barnwell, et al. (1998). [82]
13	Parents as caregivers	The larger social context stresses on how parents due to various reasons also take on the responsibility of caregivers for persons with intellectual disabilities.	Seltzer, & Heller, (1997). [83]
14	Factors associated with inclusion from parents context	Faith communities and their support towards persons with intellectual disabilities plays a key factor	Ault, et al., (2013). [84]
15	Family centric approach	This paper highlights the key points on how if parents and family is included in working with persons with intellectual disabilities, there could open up many unconscious bias, mindsets, and opportunities	Bailey et al., (1998). [85]

Table 04: Review of Related Research Publications on pre-vocational skills for persons with intellectual disabilities from the year 1992 to 2018.

S. No.	Area	Contribution	References
1	Pre- vocational plan	This studies shows the findings of the Assessment of Basic Learning Abilities with persons with neurodiversity which will help support in planning the prevocational training.	Vause, et al., (2007). [86]
2	Transition from school to vocational training	This study highlights the importance of pre-vocational training as there is gap after schooling and before joining the vocational training.	Gebhardt et al., (2011). [87]
3	Challenges in pre- vocational planning	This study highlights the challenges faced while planning the prevocational training in terms of customization as each individual is different and the support will be different	Cobigo, (2007). [88]
4	Competitive employment	For a clear competitive employment for persons with neurodiversity its linked to their pre-vocational skills especially functional skills as its the foundation on which they will build their career	Friedman et al., (2018). [89]

5	Structure for pre- vocational skills	In this study, 13 experts with 5-25 years of special education practitioners were part of this study to pool expertise knowledge and structure the training for prevocational. This study highlights the implications of the curriculum	Valaikiene et al., (2016). [90]	
6	Pre- vocational trainers	This study comprises the need for building skills for pre-vocational trainers in terms of delivering and planning the training	Grbich, & Sykes, (1992). [91]	
7	Training methods for prevocational training	Using picture based activity showed positive improvement such as self-management, ability to complete the task and improved self-determination.	Duttlinger, et al., (2013). [92]	
8	Pre-vocational training and supported employment	Study indicated that with training in functional and foundational skills, the supported employment shows a better result as the adults learn fine and gross motor skills required for the job role	Nazarov, et al., (2012). [93]	
9	Work skills as part of pre-vocational training	This study indicates the adaptive behaviori for work setting and its implications for persons with neurodiversity. The work skills and training works effectively when they get exposed during the pre- vocational training	Gomes, et. al., (2016). [94]	
10	Employment outcomes	The statistics shows better results and employment outcomes when they undergo a customized prevocational training that is customized to their strengths and possibilities	Barnett, & Crippen, (2014). [95]	

Education and its system implies a platform to transform an individual's values and ethics. It is the root of every individual and inclusive practices open up many opportunities for every individual. The New Education Policy sets a framework for inclusive education and training; it is yet to be implemented in many rural sectors to measure the impact of inclusive education. The way forward for persons with neurodiversity is to improve the research in new aspects to this [96]. The pre-vocational training also guides the persons with intellectual disabilities with self-control, self-regulation and problem solving [97].

5. DISCUSSION AND NEW RELATED ISSUES:

Many types of research and studies must be conducted with an empirical approach and create open educational resources for all disability practitioners and professionals for inclusive education. A timely review of the practice or policy is suggested to get the credibility of the program. Inclusive education is the root of the development of People with Neurodiversity. In an Urban setting, with advancements in technology and resources there is a higher possibility for promoting and advocating inclusiveness

whereas in a rural setting, due to a lack of resources and professional expertise, there is still a gap in implementation as we need to consider all aspects such as the culture, beliefs, practices, rituals, norms, etc. towards disability. Some developed countries provide facilities such as accommodation, better pension, medical aids, schemes and intervention for betterment of persons with neurodiversity and their families [98].

6. IDEAL SOLUTIONS DESIRED STATUS & IMPROVEMENTS REQUIRED:

The desired ideal solution is to work on a workable employment plan that is tailored to the strengths of the employment interests of persons with neurodiversity. This tailored pathway must cater to working with all stakeholders to achieve success and effectiveness.

7. RESEARCH GAP:

This review of the literature search revealed that there is comparatively or no study on the work life balance of people with neurodiversity as it signifies their eco-system. The current reviews don't explain the usage of standardized tools to assess the knowledge of different intellectual disabilities.

8. RESEARCH AGENDAS BASED ON RESEARCH GAP:

Hence, the future study aims to build eco-system by understanding their work-life balance using an assessment with various constructs to cater to the lives of people with neurodiversity.

9. ANALYSIS OF RESEARCH AGENDAS: (For importance & viability)

The group sessions will be conducted to bring in possible opportunities for persons with intellectual disabilities as it leads to a whole lot of change in mindsets and social role valorization. These sessions will then be helpful to guide the participants towards inclusive work life balance.

10. FINAL RESEARCH PROPOSAL/PROBLEM IN CHOSEN TOPIC:

Parents and community act as a support structure for people with neurodiversity. They need to work together to empower people with neurodiversity. It breaks mindsets and opens up lot of opportunities for them in the society toward dignity of life, equal work opportunities, rights and responsibilities and impacting the society as a contributing member.

11. ABCD ANALYSIS:

ABCD analysis is the process of understanding the advantages, benefits, constraints and disadvantages of a factor for the study purpose [99]. This is a framework of tools to identify the most important attributes for the study. [100]. It a new model developed by Aithal et. al., to identify the theory and hypothesis [101]. This model acts as a pyramid method to analyze the factors affecting the respective research [102].

Table 05: ABCD analysis of the determinant issues relevant to special education and vocational training

S. No.	Determinant issues	Advantages	Benefits	Constraints	Disadvantages
1	Early intervention	Diagnosis at early stage of a child with neurodiversity plays a crucial role as it has implications in future behaviour.	The early intervention will guide the parents about disability and this will provide a dignified life.	Due to lack of resource and policy implementation, there are many children with disabilities especially in rural sector who are kept at home and excluded.	These children and persons with neurodiversity are often treated as patients and a sin in rural sector.

2	Vocational training	Vocational training helps build employable skills among persons with intellectual training.	The trained adults will find a suitable job and be productive thus being a contributing member in the family.	The vocational training at often restricted to fit the requirement in the society. It is not tailored to the strengths of the person with neurodiversity.	When the adults with neurodiversity are trained because of lack of continued support, the retention of the adults are low.
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12. SUGGESTION TO IMPLEMENT RESEARCH ACTIVITIES ACCORDING TO THE PROPOSAL:

One of the suggestions is to do a comparative study of different employment opportunities for persons with intellectual disabilities in the Indian context and analyze the effectiveness of tailoring a process for the same.

13. LIMITATION:

One major limitation was the studies, particularly with regard to persons with neurodiversity and their employment pathway lacking in Indian context. This review paper is limited to 102 papers and more papers could be studied further.

14. CONCLUSION:

Communities are aware of physical disability but not neurodiversity, or intellectual disabilities, which is why it is essential to sensitize the community about Neurodiversity and its parameters. It is simpler to engage with persons with intellectual impairments and increase their capacity for independence when the community is aware of these disabilities and how to work with each one of them. Every person with intellectual disability is given the same chance to live their life in society with respect and dignity. Working with persons with intellectual disabilities will be effective with support from their parents and community.

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