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Challenges of Parents of Children with Intellectual Disabilities: Psychological, Social, Economic, and Educational Perspectives

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Abstract

Parents of children with intellectual disabilities (ID) experience a wide range of challenges that affect their psychological well-being, social relationships, economic stability, and overall quality of life. Intellectual disability is a lifelong developmental condition requiring continuous care, supervision, specialized education, and rehabilitation services. Although advances in medicine, education, and disability legislation have improved opportunities for persons with disabilities, parents remain the primary caregivers and continue to shoulder substantial responsibilities. These responsibilities frequently lead to chronic stress, anxiety, depression, financial hardship, social isolation, and uncertainty regarding the future of their children.

The present paper examines the multidimensional challenges encountered by parents of children with intellectual disabilities through an extensive review of existing literature and policy documents. The study adopts a descriptive research design based entirely on secondary data collected from books, peer-reviewed journals, government publications, reports of international organizations, and disability-related legislation. The review highlights the influence of stigma, discrimination, inadequate healthcare services, limited educational opportunities, insufficient rehabilitation facilities, and poor implementation of welfare schemes on the lives of caregivers. Particular attention is given to the Indian context, where cultural beliefs, limited awareness, and unequal access to services continue to create barriers to inclusion.

The paper further discusses the role of inclusive education, community participation, family-centred rehabilitation, counselling services, governmental initiatives, and non-governmental organizations in improving the quality of life of both parents and children with intellectual disabilities. It emphasizes that disability should be viewed from a rights-based and social inclusion perspective rather than solely through the traditional medical model. Strengthening social support systems, increasing public awareness, expanding rehabilitation services, and ensuring effective implementation of disability policies are essential for reducing caregiver burden and promoting social justice.

The paper concludes that collaborative efforts involving families, educators, healthcare professionals, policymakers, and civil society are indispensable for creating an inclusive society where children with intellectual disabilities and their families can live with dignity and equal opportunities.

Keywords: Intellectual disability, parents, caregiver burden, parental stress, social stigma, inclusive education, rehabilitation, disability policies.

1. Introduction:

Intellectual disability (ID) is a neurodevelopmental condition characterized by significant limitations in intellectual functioning and adaptive behaviour that originate during the developmental period. These limitations affect conceptual, social, and practical skills required for independent living and participation in society. Children with intellectual disabilities often require lifelong support in education, communication, self-care, employment, and community living. Consequently, parents become the primary caregivers and play a central role in meeting the developmental, educational, emotional, and healthcare needs of their children.

The birth of a child with intellectual disability represents a life-changing event for parents and families. While the birth of every child is generally associated with hopes and aspirations, the diagnosis of intellectual disability frequently brings uncertainty, emotional distress, and major adjustments in family life. Parents must adapt to continuous caregiving responsibilities, frequent medical consultations, therapeutic interventions, educational planning, and long-term financial commitments. In many cases, they also experience grief arising from the discrepancy between their expectations for the child and the developmental realities associated with intellectual disability.

Globally, intellectual disability affects millions of individuals and constitutes an important public health and social welfare concern. Advances in neonatal care, early diagnosis, special education, rehabilitation, and assistive technologies have considerably improved survival rates and developmental outcomes. Nevertheless, families continue to face significant obstacles in obtaining equitable healthcare, educational opportunities, and social acceptance. These challenges are often more pronounced in developing countries where specialized services remain inadequate or inaccessible.

In India, caregiving responsibilities are predominantly family-centred. Unlike many developed countries where institutional and community-based support systems are well established, Indian families largely depend upon their own financial, emotional, and social resources for the upbringing of children with disabilities. Cultural values emphasizing family responsibility encourage parents to provide lifelong care, yet this expectation often places considerable emotional and economic pressure on caregivers.

Parents of children with intellectual disabilities commonly report elevated levels of psychological stress compared with parents of typically developing children. Continuous supervision, behavioral difficulties, communication problems, concerns regarding education, social participation, and uncertainty about future independence contribute to chronic caregiver burden. Mothers, in particular, frequently assume primary caregiving responsibilities, leading to reduced employment opportunities, diminished social interaction, and increased susceptibility to anxiety and depression. Fathers also experience considerable stress associated with financial responsibilities and future planning, although their emotional difficulties may be expressed differently.

Social stigma remains one of the most pervasive challenges faced by families of children with intellectual disabilities. Disability is still surrounded by misconceptions, myths, and prejudicial attitudes in many communities. Families may experience blame, pity, social rejection, or exclusion from community activities. Such experiences negatively affect parental self-esteem, increase social isolation, and discourage families from seeking available support services. Stigma not only affects the child but also extends to parents and siblings, influencing family relationships and community participation.

Economic challenges further compound the difficulties experienced by caregivers. Children with intellectual disabilities often require repeated medical evaluations, psychological assessments, speech therapy, occupational therapy, physiotherapy, behavioural interventions, special education, transportation, and assistive devices. These recurring expenditures impose substantial financial burdens, especially on families with limited income. In many households, one parent—most commonly the mother—reduces or leaves employment to provide full-time care, thereby decreasing household earnings while simultaneously increasing expenditure.

Educational opportunities continue to remain unequal despite growing emphasis on inclusive education. Many schools lack trained special educators, accessible infrastructure, individualized educational planning, and adequate learning resources. Parents frequently struggle to identify appropriate schools willing to accommodate children with intellectual disabilities. In rural regions, these challenges become even more severe due to limited availability of specialized institutions and rehabilitation services.

Healthcare access also remains uneven across geographical regions. Delayed diagnosis, shortage of developmental paediatricians, psychologists, psychiatrists, speech-language pathologists, occupational therapists, and rehabilitation professionals often result in delayed intervention. Early intervention is widely recognized as critical for maximizing developmental outcomes, yet many families are unable to access timely services because of geographical distance, financial constraints, or lack of awareness.

Recent disability policies have increasingly shifted from the traditional medical model toward a rights-based approach that recognizes persons with disabilities as equal members of society entitled to dignity, education, healthcare, employment, and social participation. In India, legislative measures such as the Rights of Persons with Disabilities Act, 2016, along with inclusive education initiatives and welfare programmes, have strengthened legal protections for persons with disabilities. However, implementation remains inconsistent across different states and districts, limiting the practical benefits available to many families.

The present paper seeks to examine these multidimensional challenges comprehensively by reviewing available literature and policy frameworks. It highlights the psychological, social, educational, healthcare, and economic difficulties experienced by parents while emphasizing the need for coordinated interventions involving healthcare professionals, educators, policymakers, community organizations, and families. A holistic understanding of these challenges is essential for developing evidence-based policies and family-centred support systems that enhance the quality of life of both children with intellectual disabilities and their caregivers.

Need and Significance of the Study:

Understanding the experiences of parents of children with intellectual disabilities is essential because parental well-being directly influences child development, rehabilitation outcomes, educational achievement, and social inclusion. The existing paper identifies stigma, financial hardship, inadequate healthcare, and limited educational opportunities as key concerns affecting families.

Domain	Key challenges identified	Priority response
Psychological	Chronic stress, anxiety, depression, guilt, emotional exhaustion, burnout and sleep disturbance.	Counselling, stress-management and family-support services.

Social	Stigma, discrimination, social rejection, isolation and reduced community participation.	Awareness programmes, peer support and inclusive community participation.
Economic	Therapy, healthcare, education, transport and assistive-device costs; employment disruption.	Financial assistance, insurance, subsidies and accessible local services.
Educational	Limited inclusive schools, trained staff, IEPs, assistive technology and accessible infrastructure.	Special educators, adapted materials, IEP implementation and school–family collaboration.
Healthcare & rehabilitation	Delayed diagnosis, shortage of specialists, uneven rehabilitation access and travel burden.	Early intervention, multidisciplinary care and community-based rehabilitation.
Future & family	Concerns about independence, employment, guardianship, long-term care and family adjustment.	Vocational pathways, supported living, guardianship mechanisms and family counselling.

Table 1. Multidimensional challenges and support priorities

An expanded examination is significant because:

- It provides a comprehensive understanding of caregiver burden within psychological, social, educational, and economic contexts.
- It supports policymakers in strengthening disability welfare schemes and improving implementation.
- It assists counselling psychologists, special educators, rehabilitation professionals, and social workers in designing family-centred interventions.
- It contributes to the promotion of inclusive education and community-based rehabilitation.
- It encourages greater public awareness to reduce stigma and discrimination.
- It identifies areas where future empirical research can improve services and policy outcomes.

Ultimately, improving the well-being of parents enhances the developmental opportunities and quality of life of children with intellectual disabilities, thereby contributing to a more inclusive and equitable society.

2. Review of Literature:

Previous studies have consistently demonstrated that caregiving for a child with intellectual disability is associated with increased psychological stress, financial burden, social isolation, and reduced quality of life. While considerable progress has been made in disability rights and inclusive education, research indicates that parents continue to encounter numerous barriers in accessing healthcare, education, rehabilitation services, and community support.

2.1 Conceptual Background

Intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behavior that originate during the developmental period. Adaptive behavior encompasses conceptual, social, and practical skills required for everyday functioning. Children with intellectual disabilities require varying degrees of support depending on the severity of their condition. Consequently,

parents become lifelong caregivers responsible for educational planning, healthcare management, emotional support, behavioral interventions, and social integration.

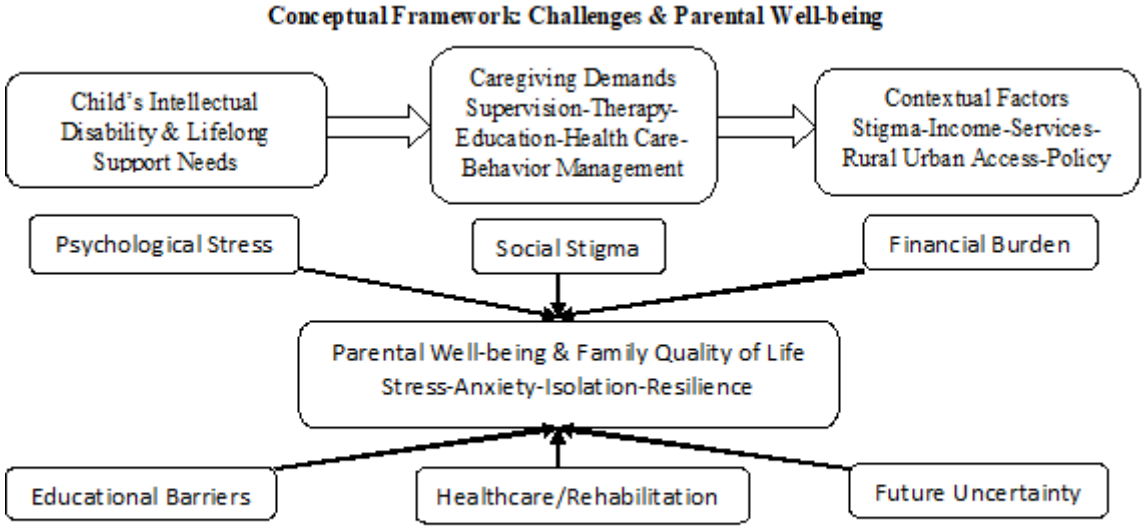


Figure 1: Conceptual Framework linking intellectual disability, caregiving demands, contextual barriers, major challenge domains and parental well-being

Earlier research primarily focused on the medical aspects of intellectual disability. However, contemporary studies increasingly adopt ecological, family systems, and rights-based perspectives, recognizing that parental well-being is strongly influenced by environmental factors such as community attitudes, accessibility of services, governmental support, and social inclusion.

2.2 International Literature

International research consistently demonstrates that parents of children with intellectual disabilities experience substantially higher levels of stress than parents of typically developing children.

Emerson (2003) reported that caregivers frequently experience psychological distress, poor mental health, reduced social participation, and economic disadvantage. The study concluded that caregiving demands significantly affect parental quality of life, particularly among mothers who provide the majority of daily care.

Goffman's (1963) theory of stigma remains one of the most influential explanations of the social experiences of families affected by disability. According to Goffman, stigma extends beyond the individual with disability and affects family members through "courtesy stigma," whereby parents experience discrimination, social rejection, and negative societal attitudes. These experiences frequently discourage families from participating in community activities and seeking professional assistance.

Lazarus and Folkman's (1984) Transactional Model of Stress and Coping provides an important theoretical framework for understanding parental stress. The model suggests that stress results from the interaction between environmental demands and an individual's perceived coping resources. Parents of children with intellectual disabilities continually appraise caregiving challenges, and the availability of social support, financial resources, and coping strategies influences their psychological adjustment.

Recent international research has increasingly focused on family resilience rather than pathology. Studies indicate that positive family functioning, social support networks, adaptive coping strategies, and community participation significantly reduce caregiver stress. Families receiving multidisciplinary

rehabilitation services generally demonstrate better psychological outcomes than those lacking access to comprehensive support.

Research also highlights gender differences in caregiving experiences. Mothers consistently report higher emotional burden, anxiety, depression, and caregiver fatigue because they spend more time providing direct care. Fathers primarily report concerns related to financial responsibilities and long-term security of the child. Nevertheless, both parents experience considerable psychological strain.

2.3 Indian Literature

Indian studies reveal that parental experiences are influenced not only by disability-related factors but also by cultural beliefs, family structures, socioeconomic conditions, and availability of rehabilitation services.

Gupta and Singhal (2004) observed that Indian parents often experience emotional distress immediately after diagnosis, followed by gradual adjustment through acceptance and positive adaptation. Their work emphasized that despite numerous challenges, many parents develop resilience and derive personal growth through caregiving experiences.

Dalal (2006) examined social attitudes toward disability in India and reported that misconceptions, superstition, and discrimination continue to influence community perceptions. Many families experience blame, pity, or social exclusion because disability is frequently interpreted through religious or cultural beliefs rather than scientific understanding. These attitudes create barriers to education, employment, and community participation for both children and their parents.

Studies conducted in various Indian states have shown that access to rehabilitation services remains uneven. Urban families generally benefit from better availability of developmental pediatricians, psychologists, speech therapists, occupational therapists, and special educators, whereas rural families often travel long distances to receive specialized care. Such disparities increase financial burden and delay intervention.

Indian literature also emphasizes the important role of extended family systems. Grandparents, siblings, and relatives frequently provide emotional and practical support to caregivers. However, family support varies considerably across socioeconomic groups and geographical regions.

Source/theme	Main finding represented in the paper	Implication
Gupta & Singhal (2004)	Emotional distress after diagnosis can be followed by adjustment, acceptance and positive adaptation.	Need for resilience-oriented, family-centred support rather than deficit-only approaches.
Dalal (2006)	Misconceptions, superstition and discriminatory attitudes influence community perceptions of disability.	Public awareness and anti-stigma interventions remain important.
Indian literature synthesized	Urban families generally have better access to specialists; rural families may travel long distances for services.	Rural–urban service disparities require targeted research and service planning.
Family-system evidence synthesized	Extended family can provide emotional and practical support, but support varies by socioeconomic and geographic context.	Interventions should strengthen family and community support networks.

Policy-related evidence synthesized	Awareness and administrative access to welfare schemes remain uneven.	Simplify procedures and improve outreach/counselling about schemes.

Table 2. Synthesis of Indian literature and implications for practice.

Research further indicates that awareness regarding governmental welfare schemes remains inadequate. Although disability pensions, educational support, rehabilitation programmes, and legal protections are available, many eligible families either remain unaware of these benefits or encounter administrative difficulties in accessing them.

2.4 Various Challenges Identified in Previous Studies

2.4.1 Psychological Challenges: Psychological stress remains the most extensively investigated issue among parents of children with intellectual disabilities. Common psychological difficulties reported include chronic stress, anxiety, depression, feelings of guilt, emotional exhaustion, caregiver burnout, sleep disturbances and reduced life satisfaction. Several studies suggest that psychological distress increases when behavioral problems accompany intellectual disability. Parents often report concerns regarding aggression, communication deficits, self-injurious behaviors, and dependence in activities of daily living. The uncertainty surrounding future care arrangements also contributes significantly to parental anxiety. Questions concerning independent living, vocational opportunities, financial security, and guardianship remain major sources of lifelong concern

2.4.2 Social Challenges: Social stigma continues to be one of the most persistent barriers faced by families. Researchers have identified several forms of stigma like public stigma, self-stigma, courtesy stigma affecting family members and Institutional discrimination Negative social attitudes often discourage parents from participating in religious, educational, recreational, and community events. Many families report social isolation due to insensitive comments, ridicule, or exclusion.

2.4.3 Economic Challenges: Numerous studies identify financial burden as one of the strongest predictors of caregiver stress. Major sources of expenditure include medical consultations, diagnostic assessments, speech & occupational therapy, physiotherapy, behavioral interventions, special education, transportation, assistive devices and residential care where necessary. Many mothers discontinue employment to provide full-time care, thereby reducing household income while simultaneously increasing expenditure. Low-income families are disproportionately affected because they possess limited financial reserves and restricted access to insurance or governmental assistance.

2.4.4 Educational Challenges: Research consistently demonstrates that parents encounter substantial difficulties in securing appropriate educational opportunities. Common educational barriers include limited availability of inclusive schools, inadequately trained teachers, lack of individualized educational planning, insufficient learning materials, poor accessibility and negative attitudes among school personnel

2.4.5 Healthcare Challenges: Healthcare services remain unevenly distributed. Delayed diagnosis, shortage of specialists, inadequate rehabilitation centers, and geographical inequalities contribute to delayed intervention and poorer developmental outcomes. Rural families experience greater challenges because specialized facilities are concentrated in urban centers.

2.5 Research Gap

Despite substantial research on intellectual disability, several important gaps remain:

1. Most studies examine parental stress in general without integrating psychological, social, economic, educational, and policy perspectives into a comprehensive framework.
2. Many investigations focus predominantly on mothers, whereas fathers' caregiving experiences remain comparatively underexplored.
3. Limited research has examined differences between rural and urban caregivers regarding access to healthcare, rehabilitation, and educational services.
4. Few studies evaluate the long-term effectiveness of governmental welfare programmes and disability policies from the perspective of parents.
5. There is insufficient evidence regarding culturally appropriate counselling interventions, family-centred rehabilitation programmes and community-based support systems in diverse Indian settings.
6. Longitudinal studies examining changes in caregiver burden across the lifespan of children with intellectual disabilities are relatively scarce.

Gap area	Identified Evidence/gap	Direction for future research
Integration gap	Psychological, social, economic, educational and policy dimensions are often studied separately.	Use a multidimensional framework integrating these domains.
Gender gap	Research frequently emphasizes mothers; fathers are comparatively underexplored.	Include both mothers and fathers in future empirical work.
Geographical gap	Rural–urban differences in access to healthcare, rehabilitation and education remain limited.	Conduct rural–urban comparative studies.
Policy evaluation gap	Long-term effectiveness of welfare programmes is insufficiently evaluated from parents' perspectives.	Assess awareness, accessibility, utilization and outcomes of schemes.
Intervention gap	Limited evidence on culturally appropriate counselling, family-centred rehabilitation and community support.	Develop and evaluate context-sensitive interventions.
Longitudinal gap	Long-term changes in caregiver burden across the child's lifespan are relatively scarce.	Use longitudinal designs across developmental stages.

Table 3. Research-gap matrix

These gaps indicate the need for multidisciplinary research that integrates psychological, educational, social, and policy perspectives to better understand the experiences of families and to develop evidence-based interventions.

3. Research Methodology

The present study adopts a **descriptive and analytical research design** based on **secondary sources of data**. The methodology is intended to provide a comprehensive understanding of the multidimensional challenges experienced by parents of children with intellectual disabilities by synthesizing findings from existing literature, policy documents, and institutional reports.

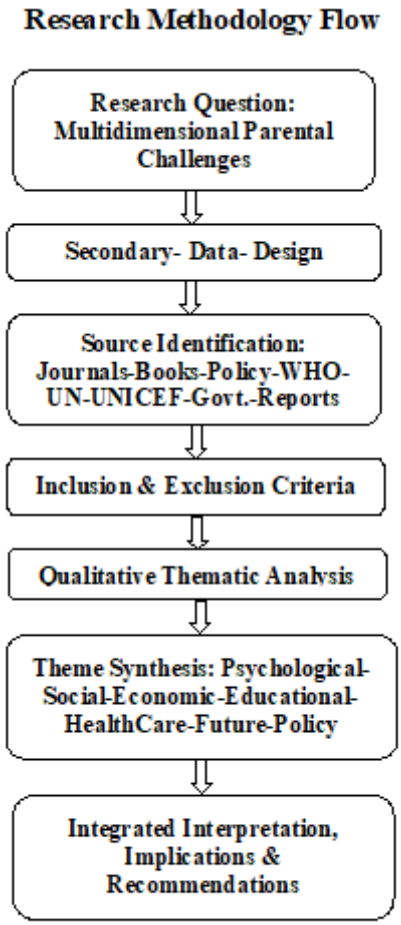


Figure 2. Methodological flow of the secondary-data review.

3.1 Research Design: A descriptive research design was considered appropriate because the study aims to examine and interpret the psychological, social, educational, healthcare, and economic challenges encountered by parents rather than to establish causal relationships. This approach enables the researcher to integrate findings from diverse studies and identify recurring themes related to caregiver burden and family well-being.

3.2 Sources of Data: The study is entirely based on **secondary data** collected from credible academic and institutional sources. These include Peer-reviewed national and international journals, Books on intellectual disability and special education, Government publications and policy documents, Reports published by the World Health Organization (WHO), United Nations (UN) publications, UNICEF reports, Publications of the Department of Empowerment of Persons with Disabilities, Government of India, Research reports published by universities and rehabilitation organizations

3.3 Inclusion Criteria: The literature included in this review met the following criteria:

- Studies focusing on parents or primary caregivers of children with intellectual disabilities.
- Research examining psychological, social, educational, healthcare, or economic issues.
- Peer-reviewed articles and authoritative reports.
- Policy documents related to disability rights, rehabilitation, and inclusive education.
- Classical theoretical works relevant to caregiver stress and disability.

3.4 Exclusion Criteria: The following sources were excluded:

- Studies unrelated to intellectual disability.
- Publications lacking sufficient methodological information.
- Opinion pieces without empirical or theoretical support.
- Duplicate publications.

3.5 Method of Analysis: The collected literature was analyzed using a qualitative thematic approach. Similar findings reported across different studies were grouped into major themes such as psychological challenges, social stigma, financial burden, educational barriers, healthcare issues, future concerns and government support systems.

Component	Description	Interpretive note
Research design	Descriptive and analytical review based on secondary sources.	Integrates recurring findings without causal inference.
Data sources	Peer-reviewed journals; books; government documents; WHO, UN and UNICEF reports; rehabilitation/university reports.	Provides multiple perspectives across policy and research literature.
Inclusion criteria	Parents/caregivers of children with ID; psychological, social, educational, healthcare or economic issues; authoritative sources.	Keeps the review aligned with the paper's central topic.
Exclusion criteria	Unrelated disability studies; insufficient methods; unsupported opinion pieces; duplicates.	Reduces irrelevant or weak evidence.
Analysis	Qualitative thematic analysis.	Themes: psychological, social, financial, educational, healthcare, future concerns and government support.
Ethics & limitations	Accurate attribution; no human participants; secondary-data limitations.	Interpret findings cautiously and acknowledge gaps in available evidence.

Table 4. Methodological summary

This thematic organization facilitates a holistic understanding of parental experiences and identifies common patterns across different research contexts.

3.6 Ethical Considerations: Since the present paper relies exclusively on published secondary sources, no human participants were directly involved. Ethical responsibility was maintained by accurately acknowledging original authors, appropriately interpreting published findings, and avoiding plagiarism through proper academic citation practices.

3.7 Limitations of the Study: The study has certain limitations.

- It relies solely on secondary data.
- No primary data were collected from parents.
- Findings depend upon the quality of previously published research.
- Regional variations within India may not be fully represented.
- The review cannot establish causal relationships because no empirical investigation was undertaken.

4. Major Challenges Faced by Parents of Children with Intellectual Disabilities:

Parents of children with intellectual disabilities encounter numerous interrelated challenges that influence nearly every aspect of family life. These challenges extend beyond caregiving responsibilities and affect psychological health, social relationships, employment, financial security, and overall quality of life.

Challenge domain	Examples identified	Likely family-level impact
Psychological stress	Chronic stress, anxiety, depression, fatigue, burnout and sleep problems.	Reduced psychological well-being; risk of caregiver exhaustion.
Social stigma	Blame, pity, discrimination, rejection and reduced community participation.	Isolation and reduced social support.
Financial burden	Recurring healthcare, therapy, education, transport and assistive-device costs.	Reduced income and increased economic vulnerability.
Educational barriers	Limited trained staff, IEPs, accessibility, materials and assistive technology.	Difficulty securing meaningful inclusive education.
Healthcare/rehabilitation	Delayed diagnosis, specialist shortages and unequal service distribution.	Delayed intervention and increased travel/time burden.
Family/employment/future	Marital strain, sibling concerns, career disruption and long-term uncertainty.	Effects on family functioning, financial security and quality of life.

Table 5. Major challenge domains, consequences and family-level impact

4.1 Psychological Stress and Caregiver Burden: Psychological stress is one of the most frequently reported consequences of raising a child with intellectual disability. Parents often experience emotional reactions beginning immediately after diagnosis. Initial responses may include shock, denial, sadness,

guilt, anger, confusion, and helplessness. Although many parents gradually adjust to the situation, the caregiving responsibilities continue throughout the child's life.
Daily caregiving involves assisting with personal hygiene, feeding, mobility, communication, educational activities, behavioral management, and medical appointments. Continuous supervision often results in physical exhaustion and emotional fatigue.

4.2 Social Stigma and Discrimination: Social stigma remains one of the most significant barriers affecting families of children with intellectual disabilities. In many communities, disability continues to be misunderstood and is frequently associated with myths, superstitions, or misconceptions. Parents may encounter insensitive remarks, social rejection, pity, blame, or discrimination. Such experiences reduce family participation in social, religious, and cultural activities. Social isolation reduces emotional support, increases loneliness, and contributes to psychological distress. Courtesy stigma also affects siblings and extended family members..

4.3 Financial Burden: Children with intellectual disabilities often require continuous expenditure on medical consultations, psychological assessment, speech therapy, occupational therapy, Physiotherapy, behavior therapy, special education, transportation, assistive devices and nutritional support. These recurring expenses significantly affect family finances. Families from economically weaker sections face even greater hardship because specialized services are often available only in urban centers and private institutions. Although disability pensions and governmental assistance schemes provide some relief, awareness and accessibility remain limited in many regions.

4.4 Educational Challenges: Education represents one of the most important concerns for parents.
Despite national policies promoting inclusive education, many schools continue to lack qualified special educators, Individualized Education Programmes (IEPs), accessible classrooms, appropriate teaching-learning materials, assistive technologies and behavioral support services. Parents frequently struggle to identify schools willing to admit children with intellectual disabilities. Even when admission is granted, inadequate teacher training may hinder meaningful inclusion.

4.5 Healthcare and Rehabilitation Challenges: Access to healthcare remains uneven across many regions. Parents often encounter delayed diagnosis, shortage of developmental pediatricians, limited availability of psychologists, insufficient speech therapists, lack of occupational therapists, and inadequate rehabilitation facilities. Rural families encounter additional barriers due to the limited availability of specialized educational institutions and rehabilitation centers. Early diagnosis and intervention are essential for maximizing developmental outcomes. However, geographical distance, financial limitations, and insufficient awareness frequently delay access to appropriate services. Regular follow-up appointments require considerable time and financial resources, further increasing caregiver burden.

4.6 Family Relationships and Marital Adjustment: The presence of a child with intellectual disability influences relationships within the family. Couples may experience increased stress due to disagreements regarding caregiving responsibilities, financial management, and future planning. Limited opportunities for leisure, social interaction, and personal time may reduce marital satisfaction. At the same time, many families demonstrate remarkable resilience. Mutual support, effective communication, and shared caregiving responsibilities strengthen family relationships and promote adaptive coping.

4.7 Sibling Issues: Siblings of children with intellectual disabilities often experience mixed emotions. Many siblings become protective and supportive; however, they may also experience reduced parental attention, increased household responsibilities, emotional confusion, and concern regarding future caregiving responsibilities.

4.8 Employment and Career Disruptions: Parents frequently modify their employment to accommodate caregiving demands. Common consequences include reduced working hours, career interruptions, job resignation, limited opportunities for professional advancement and reduced retirement savings. These employment disruptions further contribute to long-term financial insecurity.

4.9 Future Concerns: Perhaps the greatest source of anxiety for parents concerns the future of their child. Parents worry about independent living, vocational opportunities, employment, financial security, marriage, social acceptance, long-term healthcare, legal guardianship and care after the parents become elderly or die. These lifelong concerns often persist even when children receive appropriate education and rehabilitation.

4.10 Quality of Life: The combined influence of psychological stress, financial burden, social isolation, educational barriers, and healthcare challenges significantly affects the overall quality of life of parents. However, research also demonstrates that quality of life improves when families receive:

- Early intervention services
- Family counselling
- Parent support groups
- Inclusive education
- Community acceptance
- Financial assistance
- Accessible rehabilitation services

A coordinated, family-centred approach involving healthcare professionals, educators, social workers, psychologists, policymakers, and community organizations is therefore essential for promoting resilience and improving long-term outcomes for both parents and children.

5. Government Policies and Support Systems

Over the past two decades, India has made significant progress in developing legislative and policy frameworks to safeguard the rights of persons with intellectual disabilities. The important initiatives include the Rights of Persons with Disabilities (RPwD) Act, 2016, the National Trust Act, 1999, the National Education Policy (NEP) 2020, Samagra Shiksha, the Unique Disability Identity (UDID) Project, disability pensions, health insurance schemes, vocational training programmes, and the contribution of non-governmental organizations.

However, it also emphasizes that awareness and implementation remain uneven across the country.

5.1 Rights of Persons with Disabilities (RPwD) Act, 2016

The RPwD Act, 2016 represents a major milestone in disability legislation in India. The Act recognizes multiple categories of disabilities, including intellectual disability, and adopts a rights-based approach rather than a welfare-based model.

The Act aims to ensure:

- Equality before the law
- Protection against discrimination
- Inclusive education
- Equal employment opportunities
- Accessible healthcare services
- Social security
- Barrier-free public infrastructure
- Participation in community life

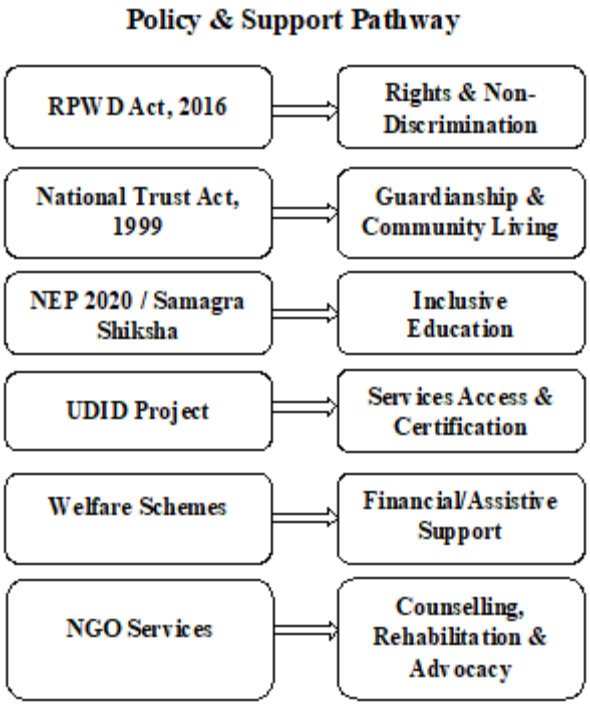


Figure 3. Policy and support pathway linking major Indian disability-policy mechanisms and service supports to family outcomes.

For parents, the Act provides legal assurance that children with intellectual disabilities have the right to education, rehabilitation, healthcare, and dignity. Nevertheless, implementation varies across states because of shortages of trained professionals, infrastructural limitations, and limited public awareness.

5.2 National Trust Act, 1999:

The National Trust Act provides legal protection and support for persons with intellectual disabilities, autism spectrum disorder, cerebral palsy, and multiple disabilities.

Its major objectives include:

- Legal guardianship
- Independent living support
- Community-based rehabilitation
- Parent empowerment
- Vocational rehabilitation

- Residential support services

Table 6. Government policies and support systems

Policy/support mechanism	Main support described	Implementation issue identified
RPwD Act, 2016	Rights, equality, non-discrimination, inclusive education, healthcare, social security and participation.	Implementation varies; shortages of professionals, infrastructure and awareness are barriers.
National Trust Act, 1999	Legal guardianship, independent living, community-based rehabilitation and parent empowerment.	Important for long-term security and future care planning.
NEP 2020 / Samagra Shiksha	Inclusive classrooms, teacher training, individualized support, assistive technology and early intervention.	Schools may still lack trained special educators, resource rooms and accessible infrastructure.
UDID Project	Standardized disability certification and easier access to welfare benefits.	Can reduce administrative burden when families can obtain and use certification.
Welfare schemes	Pensions, scholarships, education support, skill development, insurance, assistive devices and rehabilitation.	Awareness and procedural barriers can limit utilization.
NGOs	Counselling, parent training, rehabilitation, vocational support, community-based rehabilitation and advocacy.	Often bridge gaps between government services and families.

For many parents, guardianship provisions offer reassurance regarding future care arrangements, particularly when they become elderly or are no longer able to provide lifelong support.

5.3 Inclusive Education under NEP 2020 and Samagra Shiksha

Education is one of the most important determinants of future independence and social participation.
The National Education Policy (NEP) 2020 emphasizes:

- Inclusive classrooms
- Equitable educational opportunities
- Individualized learning support
- Teacher training
- Assistive technologies
- Early childhood intervention

Similarly, Samagra Shiksha seeks to strengthen inclusive education by providing educational support for children with disabilities within mainstream schools.

Despite these initiatives, many schools continue to experience shortages of:

- Special educators
- Resource rooms
- Assistive learning materials
- Accessible infrastructure
- Individualized Educational Plans (IEPs)

Consequently, parents often continue to struggle in securing quality education for their children.

5.4 UDID Project

The Unique Disability Identity (UDID) Project aims to establish a nationally standardized disability certification system.
The programme helps families by:

- Simplifying disability certification
- Facilitating access to welfare schemes
- Improving service delivery
- Creating a centralized disability database

For parents, the UDID card reduces administrative difficulties when accessing educational concessions, healthcare benefits, travel concessions, and financial assistance.

5.5 Disability Welfare Schemes

Various governmental programmes seek to reduce caregiver burden through:

- Disability pensions
- Scholarships
- Free education support
- Skill development programmes
- Vocational training
- Health insurance
- Assistive devices

- Rehabilitation services

Although these schemes provide valuable support, many families remain unaware of their eligibility or face procedural barriers during application.

Increasing awareness through community outreach and counselling services can significantly improve utilization.

5.6 Role of Non-Governmental Organizations (NGOs)

The paper emphasizes that NGOs play a crucial role in supporting families of children with intellectual disabilities through counselling, parent training, rehabilitation, and community awareness programmes.

Many NGOs complement government services by offering:

- Early intervention programmes
- Parent counselling
- Psychological assessment
- Special education
- Vocational training
- Speech and occupational therapy
- Community-based rehabilitation
- Family support groups
- Awareness campaigns
- Advocacy for disability rights

These organizations frequently serve as a bridge between government welfare programmes and families, particularly in underserved communities.

6. Discussion

The findings synthesized in this review indicate that the challenges experienced by parents are multidimensional and mutually reinforcing. The paper similarly concludes that social stigma, financial hardship, educational barriers, and inadequate healthcare collectively increase psychological stress and reduce family well-being.

Psychological distress among parents is not solely a consequence of the child's disability but also reflects inadequate social support, financial insecurity, limited rehabilitation services, and societal misconceptions. Caregiver stress tends to increase when parents encounter repeated discrimination, delayed diagnosis, inaccessible educational opportunities, or uncertainty regarding future care.

The review further suggests that the transition from a purely medical model of disability to a rights-based approach has substantially improved public policy. Nevertheless, legislative provisions alone are insufficient unless accompanied by effective implementation, adequate funding, trained professionals, and community acceptance.

Family-centred rehabilitation emerges as one of the most effective approaches for improving outcomes. Rather than focusing exclusively on the child, family-centred services recognize parents as active partners in intervention planning, educational decision-making, and rehabilitation.

The literature also demonstrates that resilience varies considerably across families. Strong family relationships, positive coping strategies, social support, and accessible community resources enable many parents to adapt successfully despite considerable caregiving demands.

7. Practical Implications

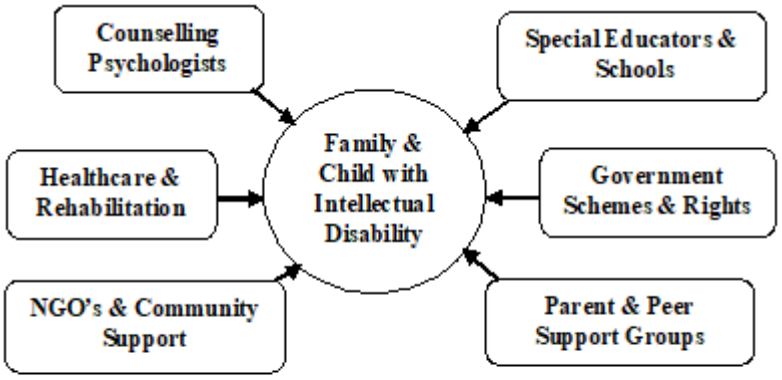
The findings of the present review have important implications for various stakeholders.

For Counselling Psychologists

- Provide individual and family counselling.
- Develop stress management programmes.
- Conduct caregiver support groups.
- Promote resilience and adaptive coping strategies.

For Special Educators

- Collaborate closely with parents.
- Develop individualized educational plans.
- Train parents in home-based educational strategies.
- Encourage inclusive classroom practices.



Coordinated Support can reduce burden, improve participation, and Strengthen resilience

Fig 4:Family-Centered Support Ecosystem

For Healthcare Professionals

- Promote early diagnosis.
- Provide multidisciplinary intervention.
- Educate parents regarding developmental expectations.
- Improve continuity of rehabilitation services.

For Policymakers

- Expand rehabilitation centres.
- Increase funding for inclusive education.
- Improve implementation of disability legislation.
- Simplify access to welfare schemes.

For Community Organizations

- Conduct awareness campaigns.
- Reduce disability-related stigma.
- Encourage inclusive community participation.
- Establish parent support networks.

8. Recommendations

Based on the review, the following recommendations are proposed.

1. Strengthen Public Awareness

Nationwide awareness campaigns should be conducted to reduce myths, misconceptions, stigma, and discrimination associated with intellectual disability.

2. Expand Early Intervention Services

Developmental screening and early intervention programmes should be made available at district and community levels to facilitate timely diagnosis and rehabilitation.

3. Improve Inclusive Education

Schools should appoint trained special educators, develop accessible infrastructure, implement Individualized Education Programmes (IEPs), and promote inclusive teaching practices.

4. Increase Financial Assistance

Governments should expand disability pensions, caregiver allowances, insurance coverage, and subsidies for therapy, assistive devices, and transportation.

5. Establish Parent Support Groups

Regular counselling sessions and peer-support groups should be organized in every district to reduce caregiver stress and promote mutual learning among families.

6. Improve Rural Service Delivery

Specialized healthcare, rehabilitation, and educational services should be expanded to rural and remote areas to reduce geographical disparities.

7. Strengthen Professional Training

Teachers, psychologists, healthcare providers, and social workers should receive continuous professional development on intellectual disability and family-centred care.

8. Promote Vocational Training

Vocational education, supported employment, and independent living programmes should be strengthened to improve long-term outcomes for individuals with intellectual disabilities.

9. Encourage Community Participation

Local self-government institutions, NGOs, educational institutions, and civil society organizations should collaborate to create inclusive and supportive communities.

10. Promote Future Research

Future studies should include longitudinal designs, rural–urban comparisons, evaluation of intervention programmes, and assessment of the effectiveness of disability policies from the perspective of parents.

9. Conclusion:

The present review demonstrates that parents of children with intellectual disabilities experience numerous challenges that extend far beyond the responsibility of caregiving. The social stigma, psychological stress, financial burden, limited healthcare services, educational barriers, and concerns regarding the child's future significantly affect the quality of life of both parents and children. It further emphasizes that stronger social support systems and effective implementation of disability-related policies are essential for promoting inclusion and improving family well-being.

The review confirms that caregiving for a child with intellectual disability is a lifelong commitment requiring continuous emotional, physical, financial, and social investment. Parents often experience chronic stress due to the demanding nature of caregiving, repeated medical consultations, educational planning, behavioural management, and concerns about long-term care. Mothers generally assume greater day-to-day caregiving responsibilities, whereas fathers frequently encounter financial pressures and concerns regarding future security. Consequently, the burden of caregiving affects the overall functioning of the family.

Social stigma continues to be a major obstacle despite increasing awareness regarding disability rights. Misconceptions, discrimination, and exclusion reduce opportunities for meaningful community participation and negatively influence parental mental health. The persistence of stigma indicates that legislative reforms alone cannot ensure inclusion unless accompanied by sustained public education and attitudinal change.

Expenditure on healthcare, therapy, special education, transportation, and rehabilitation often exceeds the financial capacity of many families. Employment disruptions, particularly among mothers, further reduce household income and increase economic vulnerability. Strengthening financial assistance programmes and simplifying access to government welfare schemes would substantially reduce caregiver burden.

Educational inclusion has improved through national policies such as the National Education Policy (NEP) 2020 and Samagra Shiksha. However, practical implementation continues to face challenges, including shortages of trained special educators, inadequate infrastructure, limited assistive technology, and insufficient individualized educational planning. Strengthening inclusive education requires coordinated efforts involving schools, families, teacher education institutions, and government agencies.

Healthcare and rehabilitation services also require considerable expansion. Early diagnosis and intervention significantly improve developmental outcomes, yet access remains unequal, particularly in rural and economically disadvantaged regions. Greater investment in multidisciplinary rehabilitation centres and community-based services is therefore essential.

The review also demonstrates that positive family adaptation is possible. Families receiving adequate counselling, social support, community acceptance, and professional guidance frequently develop resilience and effective coping strategies. Family-centred rehabilitation, parent empowerment programmes, peer support groups, and multidisciplinary collaboration significantly improve both caregiver well-being and child outcomes.

Table 7. Recommendations translated into implementation priorities.

Priority	Purpose	Suggested action
Public awareness	Reduce myths, misconceptions, stigma and discrimination.	Community awareness campaigns and rights-based communication.
Early intervention	Facilitate timely identification and rehabilitation.	District/community-level developmental screening and referral.
Inclusive education	Improve meaningful participation in schools.	Special educators, IEPs, accessibility and adapted teaching.
Financial support	Reduce recurring caregiver expenditure and income loss.	Pensions, allowances, insurance, subsidies and transport support.
Parent support	Reduce caregiver stress and promote mutual learning.	District-level counselling and peer-support groups.
Rural service delivery	Reduce geographical inequalities.	Expand specialist, rehabilitation and educational services.
Professional training	Strengthen family-centred practice.	Continuous training for teachers, psychologists, healthcare and social-work professionals.
Future research	Build stronger evidence.	Longitudinal, rural–urban, intervention and policy-effectiveness studies.

Overall, the evidence indicates that intellectual disability should not be viewed merely as an individual medical condition but as a social and developmental issue requiring comprehensive support systems. Governments, educational institutions, healthcare professionals, rehabilitation specialists, community organizations, and families must work collaboratively to create environments that promote inclusion, dignity, equal opportunity, and social justice.

10. Future Directions: The present review identifies several areas that warrant further investigation:

1. Longitudinal studies examining caregiver stress across different developmental stages of children with intellectual disabilities.
2. Comparative studies investigating differences between rural and urban caregivers regarding access to healthcare, education, rehabilitation, and welfare schemes.
3. Evaluation of counselling interventions designed to improve parental resilience, stress management, and family functioning.
4. Research examining fathers' caregiving experiences, which remain comparatively underrepresented.
5. Assessment of the effectiveness of inclusive education policies from the perspectives of parents, teachers, and school administrators.

6. Evaluation of community-based rehabilitation programmes and parent support groups in improving caregiver quality of life.
7. Cross-cultural comparisons exploring the influence of cultural beliefs and social attitudes toward disability.
8. Studies examining the long-term outcomes of vocational training, supported employment, and independent living programmes for individuals with intellectual disabilities.

Thus the future research integrating psychological, educational, sociological, and policy perspectives will contribute to the development of more effective interventions and evidence-based disability services.

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