CAREGIVER EXPERIENCES, REHABILITATION ACCESS, AND LEGAL PROVISIONS FOR CEREBRAL PALSY IN GUJARAT: A PRAGMATIC REVIEW FOR POLICY INSIGHTS

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ABSTRACT

Background: Families of children with cerebral palsy frequently encounter long-term physical, psychological, social, and financial challenges. In India, the Rights of Persons with Disabilities Act, 2016, provides a rights-based framework encompassing healthcare, rehabilitation, inclusive education, accessibility, and transportation. It is essential to examine the degree to which these provisions correspond with the experiences of caregivers in Gujarat.

Objective: To synthesise verified empirical evidence on caregiver burden and rehabilitation access in Gujarat and to interpret the findings against relevant disability-rights provisions.

Methods: A focused pragmatic review was conducted utilising Indian empirical studies and legal sources cited within the source manuscript. Bibliographic records and reported findings were meticulously cross-verified against original journal pages, indexed databases, official legislation, or court records. Evidence was systematically categorised into four domains: caregiver strain, social and economic consequences, access to rehabilitation, and rights implementation. Studies not specifically pertaining to cerebral palsy were employed solely for contextual interpretation, and incomplete or unverifiable citations were excluded.

Results: Studies conducted in Gujarat consistently demonstrate that the caregiving burden increases in correlation with the child's dependence and restricted self-mobility. Parents report disruptions in social relationships, health issues, financial difficulties, concerns about the child's future, inadequate support services, and limited access to trained professionals. Broader evidence from India highlights challenges such as inaccessible transportation, non-inclusive public spaces, stigma, and insufficient welfare support as interconnected sources of burden. These findings are pertinent to statutory responsibilities related to inclusive education, healthcare and rehabilitation, and transportation access. Additionally, a validated Gujarati caregiver burden instrument is available to facilitate the routine identification of families in need of additional assistance.

Conclusion: The evidence supports a family-centred interpretation of rehabilitation policy. Service models should combine child-focused therapy with caregiver screening, counselling pathways, decentralised rehabilitation, accessible transport coordination, and practical rights navigation. Current evidence is informative but limited by small, facility-based, and heterogeneous samples; stronger community-based implementation research is required.

Keywords: cerebral palsy; caregiver burden; rehabilitation access; disability rights; family-centred care; Gujarat.

INTRODUCTION

Cerebral palsy (CP) is a major cause of childhood motor disability and often entails continuing needs for therapy, assistance with daily activities, education support, mobility, and community participation. A systematic review estimated a pooled prevalence of 2.95 per 1,000 children surveyed in India and noted the limited quality and geographical coverage of available prevalence studies.[1] The clinical consequences of CP are experienced not only by the child but also by family members who coordinate appointments, provide physical assistance, make financial adjustments, and sustain care over many years.

Evidence from Gujarat indicates that parental concerns extend beyond impairment and motor function. In qualitative interviews, parents reported disturbed social relationships, health and financial difficulties, apprehension regarding the child's future, inadequate support services, and a paucity of suitably

trained physiotherapists.[2, 3] These findings suggest that the continuity and efficacy of rehabilitation are influenced by the family's health, resources, knowledge, and capacity to access services.

The Rights of Persons with Disabilities (RPwD) Act, 2016, redefines India's disability policy by emphasising principles such as equality, accessibility, reasonable accommodation, and enforceable public responsibilities. This legislation encompasses areas including inclusive education, healthcare, rehabilitation, grievance redressal mechanisms, and accessible transportation.[4] Nevertheless, the mere existence of legal entitlements does not inherently guarantee practical access. Families might face indirect costs, limited transportation options, frequent administrative procedures, or centralised services, even when statutory benefits are formally provided.

This review therefore examines caregiver burden and rehabilitation access as linked health-system and rights-implementation issues. Its objective is to synthesise verified empirical evidence relevant to Gujarat, distinguish local findings from broader Indian contextual evidence, and identify practical policy responses that remain proportionate to the strength of the available literature.

MATERIALS AND METHODS

Review design and evidence base

A pragmatic, focused review approach was chosen because the question involved synthesising diverse types of evidence, such as cross-sectional studies, qualitative research, psychometric validation, legislation, and judicial interpretations of reasonable accommodation. This review was not intended as a systematic review or meta-analysis, and no combined effect size was computed.

The initial evidence set included references from the source manuscript. Each citation was verified for complete bibliographic details and to ensure the population and claim matched. Verification sources included publisher pages, PubMed, PubMed Central, official India Code documents, and Supreme Court judgments. Studies were kept if their identity and key findings were clear and relevant to CP caregiving, rehabilitation, or disability rights. A study focusing on caregivers of children with different disabilities was not used to estimate depression among mothers of children with CP. Incomplete citations lacking recoverable year, volume, or pagination were excluded.

Synthesis and legal mapping

The retained evidence was organised into four domains: (i). caregiver strain in relation to the child's functional dependence; (ii). social, psychological, and financial consequences; (iii). measurement and identification of caregiver burden; and (iv). environmental and service-related barriers affecting access to rehabilitation. Gujarat-specific evidence formed the primary basis of interpretation. Evidence from another Indian state was used only to assess contextual consistency and was not presented as a Gujarat prevalence estimate.

Empirical findings were then mapped to selected provisions of the RPwD Act: section 16 on the duties of educational institutions; sections 25 and 27 on healthcare and rehabilitation; and section 41 on access to transport.[4] The Supreme Court's interpretation of reasonable accommodation clarified that equality may require positive, individualised steps rather than formal non-discrimination alone.[5, 6]

RESULTS

Caregiver strain and functional dependence

Functional dependence is the most consistently demonstrated determinant of caregiver strain in the evidence from Gujarat. In a cross-sectional study of 62 children and young adults with spastic CP and their mothers, those with limited self-mobility were associated with substantially higher caregiver strain than those who could walk. Mothers of children classified at the Gross Motor Function Classification System levels IV and V reported particularly high levels of strain.[3] This finding makes clinical sense because restricted self-mobility raises the need for more frequent and physically demanding help with transfers, positioning, toileting, feeding, and transport.

The severity of impairment does not solely determine family outcomes. Rather, dependence interacts with environmental variables, availability of assistive devices, familial support, and responsive services. For example, a child with significant motor impairments may have markedly different practical requirements in an accessible residence with dependable transportation than in a setting that requires manual carrying and frequent long-distance travel.

Social, psychological, and financial consequences

A study conducted in Gujarat involving 204 caregivers of children suffering from chronic illnesses demonstrated considerable psychological distress across various diagnostic groups. Notably, children with cerebral palsy (CP) encountered the most substantial financial burdens and experienced greater disruptions to their routines and social interactions in comparison to children with other chronic conditions.[7] Although

the overall sample was not exclusively comprised of CP cases, the subgroup analysis indicates that continuous rehabilitation and dependence may result in recurring direct and indirect costs.

The quality-of-life evidence from Anand highlights how important the environment is. Out of 116 caregivers of children with physical and mental disabilities, the environmental domain of the WHOQOL-BREF received the lowest score. Coping strategies tended to differ depending on the child's specific disability.[8] These findings aren't meant to be specific to CP prevalence, but they do emphasise that factors such as service availability, transportation, access to information, finances, and the physical environment play a vital role in caregiver well-being.

The Gujarat qualitative study provides context specific to caregivers of children with CP. Parents reported reduced social engagement, health concerns, financial hardships, apprehensions about future care, and unmet expectations concerning support services. These findings imply that adherence cannot be solely attributed to parental motivation. Missed or discontinued therapy may be influenced by other factors, including competing caregiving duties, prohibitive travel expenses, inaccessible infrastructure, or the inability to relinquish paid employment.[9]

Measurement of caregiver burden in Gujarati practice

Findings from various scientific studies suggest that conducting routine clinical evaluations of caregivers is both necessary and feasible. The Gujarati version of the Caregiver Burden Scale-Indian Population was evaluated in 144 caregivers of children with CP. The study reported satisfactory content and face validity, strong test-retest reliability across domains, and preliminary evidence supporting its construct validity.[10] The instrument encompasses various aspects of burden and facilitates rehabilitation teams in identifying families necessitating counselling, social-work intervention, equipment assessment, or adjustments to the home programme.

Here, we must clearly understand that these evaluations should be used to support care rather than label families. A high score is best interpreted as a trigger for conversation and referral. Reassessment may also indicate whether changes in equipment, treatment frequency, caregiver training, or service location reduce strain over time.

Environmental barriers and rights implementation

Broader qualitative evidence from India reinforces the relevance of environmental barriers. Mothers of children with CP in Tamil Nadu described inaccessible public transport, non-inclusive public spaces, inflexible work environments, stigma, social isolation, inadequate welfare support, and heavy travel-related expenditure.[11] Since this evidence was produced outside Gujarat, it does not confirm the extent of these barriers within the state. However, it shows that similar challenges faced by caregivers can result from structural factors common in low-resource Indian environments.

The RPwD Act provides a legal framework for addressing several of these conditions. Section 16 establishes duties related to inclusive education; sections 25 and 27 concern healthcare and rehabilitation; and section 41 concerns access to transport.[4] The practical significance of these provisions lies in whether families can access and use services without incurring disproportionate costs, physical risks, or administrative difficulties.

In Vikash Kumar v Union Public Service Commission, the Supreme Court explained reasonable accommodation as a positive obligation to remove barriers and facilitate effective participation.[6] Although the judgment arose in an examination context, its reasoning is relevant to rehabilitation systems: identical procedures do not necessarily produce equal access when families face materially different mobility, communication, financial, or support needs.

In Rajive Raturi vs. Union of India, the Supreme Court clarified that the RPwD Act mandates non-negotiable accessibility standards. The government cannot rely on optional policies, and new establishments will be denied building clearances. Existing structures must undergo mandatory retrofitting if non-compliant. This ruling makes accessibility a legally enforceable right, promoting inclusion of persons with disabilities across India.[5.] The following table 1 summarises the empirical evidence analysed for the study and constraints placed on their interpretation.

Table 1 Summary of the empirical evidence and the limits placed on its interpretation

Source and setting	Design/sample	Principal contribution	Interpretive limit
Ramanandi et al.,[9]; Gujarat	Qualitative interviews; 21 parents of children with CP	Identified social, health, financial, information, and service-support concerns	Small purposive sample; facility-linked experiences
Prakash et al.,[3]; Gujarat	Cross-sectional; 62 mother-child dyads	Higher strain among mothers of children with limited self-mobility	Single outpatient setting; cross-sectional design

Source and setting	Design/sample	Principal contribution	Interpretive limit
Khanna et al.,[7]; Gujarat	Cross-sectional; 204 caregivers across chronic illnesses	CP subgroup had marked financial and routine-life burden	Not restricted to CP; subgroup comparisons
Ganjiwale et al.,[8]; Gujarat	Cross-sectional; 116 caregivers of children with disabilities	Environmental quality-of-life limitations and varied coping	Mixed disability sample
Patel et al.,[10]; Gujarat	Psychometric study; 144 CP caregivers	Gujarati caregiver-burden measure showed preliminary validity and reliability	Validation study; not an estimate of burden prevalence
Vadivelan et al.,[11]; Tamil Nadu[7]	Qualitative interviews with mothers of children with CP	Transport, stigma, poverty, and non-inclusive policy as interacting stressors	Contextual evidence outside Gujarat

DISCUSSION

The evidence indicates a move from a child-only rehabilitation approach to a family-centred care model. This does not imply that caregivers automatically become patients or that parental burden should take precedence over child outcomes. Instead, rehabilitation plans should acknowledge the caregiver's role as a key factor in ensuring treatment continuity, safety, and ongoing participation. Achieving functional goals is less likely when the caregiver responsible for daily care is physically exhausted, facing financial difficulties, or unable to access services.

Routine caregiver screening and stepped support

A practical initial step is to include short caregiver screening during regular follow-ups for their child with CP. The Gujarati caregiver-burden measure provides a suitable local option. Screening results should trigger a stepped response: low scores might lead to preventive education; moderate scores could mean simplifying the home programme, reviewing equipment, or providing peer support; and high scores should prompt referrals to psychology, psychiatry, social work, or community services. The response should focus on the burden domain rather than relying solely on the total score.

Decentralised and flexible rehabilitation

The access issue cannot be resolved solely by advising families to attend more regularly. While districts and tertiary centres should uphold their specialist roles, follow-up can be effectively managed by trained primary-level staff through scheduled outreach clinics, tele-rehabilitation when appropriate, and structured caregiver coaching. Clustering appointments and providing flexible scheduling can minimise travel and work disruption. Home-based programmes should be prioritised, practical, and integrated with meaningful daily activities, rather than increasing feelings of guilt or imposing an additional burden.

Accessible transport and service navigation

Transport should be seen as part of the rehabilitation process, not an external inconvenience. Referral forms should specify mobility needs, preferred travel times, and coordination with local services. Facilities need accessible entrances, toilets, waiting areas, and transfer spaces. These measures turn the RPwD Act's accessibility and transportation responsibilities into service-level accountability.

Families need clear information on certification, accommodations, rehabilitation services, benefits, and grievances. A social worker or case coordinator can serve as a single point of contact. Legal information should be practical guidance, not an expectation to litigate. When entitlements are denied, it is important to have clear and accessible referral pathways to grievance officers and legal services.

Policy accountability and implementation indicators

Policy recommendations should be supplemented with quantifiable indicators. Examples encompass the percentage of CP services that evaluate caregiver burden, the waiting period for referred psychological or social-work consultations, the proportion of facilities satisfying accessibility standards, the travel distance and out-of-pocket expenses reported by rural families, treatment discontinuation attributable to transportation issues, and the percentage of families who receive documented information regarding disability rights. Such indicators enable evaluation of implementation effectiveness without asserting that legislation alone determines outcomes. Table 2 summarises the highlighted aspects of the proposed

framework that can be implemented to facilitate enhanced caregiver participation in caregiving without causing strain or burden.

Table 2 Proposed implementation framework derived from the synthesis

Observed problem	Relevant policy principle	Service response	Suggested indicator
High strain with greater physical dependence	Individualised support and reasonable accommodation	Caregiver screening, transfer training, equipment and home review	Caregiver score and referral completion
Travel cost and inaccessible transport	Access to healthcare, rehabilitation, and transport	Outreach, clustered appointments, accessible transport coordination	Travel distance/cost and missed visits
Financial and employment disruption	Substantive equality and continuity of care	Flexible scheduling, social-work referral, benefit navigation	Out-of-pocket cost and wage-loss reports
Limited information and support	Access to information and grievance redressal	Single-point navigation and written rights information	Proportion receiving documented guidance
Exclusion from education/community participation	Inclusive education and barrier removal	School liaison and accommodation planning	Accommodation plans implemented

LIMITATIONS

This review has a few limitations: it employed a purposive sampling approach rather than utilising a comprehensive evidence set, thereby restricting the scope of coverage. The majority of studies were cross-sectional, qualitative, or involved mixed disability groups, often with small sample sizes drawn from rehabilitation centres, which may underrepresent families who have dropped out or who have never accessed services. There was a notable absence of Gujarat-specific data to estimate the prevalence of depression, transport barriers, or rights violations among cerebral palsy (CP) caregivers. The legal mapping indicates either consistency or tension with statutory principles; however, it does not establish non-compliance. The service recommendations are policy suggestions that require further evaluation regarding feasibility, cost-effectiveness, equity, and potential side effects.

CONCLUSION

Caregiver burden in cerebral palsy (CP) is not merely an incidental family matter. It is closely connected to functional dependence, service organisation, affordability, accessibility, and social inclusion. Evidence from Gujarat indicates significant strain, financial disruption, social repercussions, unmet support needs, and the existence of a culturally appropriate burden-assessment instrument. The RPwD Act provides a rights-based framework, but implementation must be evident in how rehabilitation services are designed and monitored.

A defensible policy response integrates caregiver screening with tiered psychosocial support, adaptable rehabilitation, accessible transport, and pragmatic navigation of entitlements. These should be evaluated through community-based research rather than presumed to be effective. Enhancing caregiver capacity is essential for child rehabilitation, enabling sustained participation and long-term care.

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