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Problems Faced by Parents of Children with Neurological and Neurodevelopmental Disorders: A Narrative Review

Rohan Benoy, *Master of Social Work, Kristu Jayanti (Deemed to be University) Bengaluru, India*

rohanbenoy99@gmail.com

Abstract: Background: Epilepsy, cerebral palsy (CP) and autism spectrum disorder (ASD) are lifelong or long-term conditions in which parents become the child's primary carers, advocates and decisionmakers. The demands of this role reach well beyond the clinic and into the parents' own mental health, relationships, finances and access to services. ***Objective:*** To synthesise published evidence on the psychological, social, financial and healthcare-related problems faced by parents of children with neurological and neurodevelopmental disorders, with particular attention to the Indian context. ***Methods:*** A narrative review of 50 studies published between 2000 and 2026 (22 on ASD, 14 on CP, 12 on epilepsy and 2 on mixed neurological or neurodevelopmental conditions; 9 from India). Design, population, condition and outcomes were extracted for every study, and the findings were organised through thematic synthesis, guided by a framework that combines caregiver burden and parenting stress, the stress, appraisal and coping model, and the biopsychosocial ICF-CY perspective. ***Findings:*** Seven themes emerged: (1) unmet needs, information gaps and limited access to healthcare; (2) parenting stress, psychological distress and poor mental health; (3) caregiver burden and reduced quality of life; (4) coping and adaptation; (5) stigma, guilt and strained social relationships; (6) financial strain, employment loss, physical ill-health and gendered caregiving; and (7) social support, interventions and other protective resources. Parenting stress appeared as a shared outcome across all three conditions and was consistently higher where the child's symptoms or behaviours were more severe. Mothers

carried a disproportionate share of the burden. ***Conclusion:*** Parental problems in this field are multidimensional and interlinked rather than separate. Indian evidence remains thin, fathers are under-studied, and few studies follow families over time. Family-centred services, psychoeducation, counselling, peer support and financial linkage should be treated as part of routine care for these children, not as optional extras.

Keywords: *Parents; Caregivers; Caregiver Burden; Parenting Stress; Epilepsy; Cerebral Palsy; Autism Spectrum Disorder; Neurodevelopmental Disorders; Stigma; Social Support; India*

1. Introduction

1.1 *Neurological and neurodevelopmental disorders in childhood*

Neurological disorders affect the structure or functioning of the brain and nervous system, while neurodevelopmental disorders arise when development of the brain is altered early in life, shaping a child's communication, behaviour, learning or movement. The two groups overlap considerably in practice. Both are typically long-term, both usually require several professionals over many years, and neither can be treated in a single episode of care. For the family, a diagnosis is the start of a long-term caregiving arrangement rather than a short-lived crisis.

1.2 *Childhood epilepsy, cerebral palsy and autism spectrum disorder*

This review focuses on three conditions that dominate the family-impact literature. Epilepsy brings the unpredictability of seizures, daily medication schedules and constant concern about safety. CP is a disorder of movement and posture that often brings physical dependence, pain and, in some children, additional communication or cognitive needs. ASD involves differences in social communication and restricted or repetitive behaviour and is often accompanied by emotional and behavioural difficulties that parents must manage every day. The conditions differ in their demands, but the research on parents shows strikingly similar patterns of strain.

1.3 *From child diagnosis to family-level burden*

A child's condition does not stay inside the child. Reviews of the CP literature describe effects on parents' time, employment, social and family relationships, psychological well-being, physical health and finances (Guyard et al., 2011). Studies of ASD and epilepsy show the same spread of effects, and quality of life for the child and the parent often move together (Bompori et

al., 2014). Understanding the family as the unit of concern, and not only the child, is therefore central to both research and practice.

1.4 *Problems faced by parents: psychological, social, financial and healthcare*

Four broad groups of problems recur across the literature:

- **Psychological:** parenting stress, anxiety, depression, guilt, exhaustion and worry about the child's future.
- **Social:** stigma, isolation, strain in marital and family relationships, and the loss of social life.
- **Financial:** treatment and therapy costs, reduced or lost employment, and poverty compounding disability.
- **Healthcare-related:** inadequate information, difficulty finding available specialists, poor continuity of care and services that do not match what parents need.

1.5 *Rationale and research gap*

The international literature on this topic is large, but it has three limitations that matter for social work in India. First, only a small share of studies come from India, and they are mostly hospital-based and condition-specific. Second, the evidence is split by diagnosis, so reviews of ASD, CP and epilepsy seldom speak to one another even though parents report similar problems. Third, mothers dominate the samples, leaving the experience of fathers and the role of gender and culture inadequately examined. A review that places the three conditions side by side and reads them through a single framework can show what is shared, what is distinctive, and where Indian evidence is missing.

1.6 *Objectives and research questions*

The objectives of this review are to (a) describe the characteristics of the available literature, (b) identify and organise the problems faced by parents of children with epilepsy, CP and ASD, (c) examine the factors that increase or reduce these problems, and (d) draw out implications for practice, policy and research in India.

The review addresses the following questions:

i. What psychological, social, financial and healthcare problems do parents of children with neurological and neurodevelopmental disorders report?
ii. How do these problems vary by the child's condition, the child's characteristics and the parent's role or gender?

iii. Which coping strategies and sources of support are associated with better parental outcomes?

iv. What gaps remain, especially in the Indian context?

2. Conceptual Framework

2.1 *Caregiver burden and parenting stress*

Caregiver burden describes the objective demands of caring (time, tasks, costs) together with the subjective experience of strain. Parenting stress is the distress that arises when the demands of the parenting role exceed the resources available to meet them. Both concepts recur throughout the reviewed studies and are measured by a wide range of tools. The seven-dimension model proposed by Guyard et al. (2011), covering time, employment, social relationships, family relationships, psychological well-being, physical health and finances, offers a practical way of organising the specific problems parents describe and informs the structure of the findings below.

2.2 *Stress, appraisal and coping model*

The stress, appraisal and coping perspective holds that the effect of a stressor depends on how it is appraised and which coping resources are available. This view is supported by the reviewed evidence: parents who used positive reappraisal and problem-focused coping tended to fare better, while those relying on avoidance tended to fare worse (Ni'matuzahroh et al., 2022; Vernhet et al., 2019). In epilepsy, parenting stress was predicted jointly by child-related stressors, available resources and coping (Rodenburg et al., 2007). Social support operates along the same pathway, partly by lowering parenting stress and thereby improving quality of life (Wang et al., 2022).

2.3 *Biopsychosocial perspective (ICF-CY)*

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) treats outcomes as the product of body functions, activities, participation and environmental and personal factors. Applied to caregivers, it supports the idea that parental quality of life depends on child, caregiver and environmental factors acting together, and not on any single one (ICF-CY study, n.d.). This is the lens that allows psychological, social and financial problems to be read as parts of one picture.

2.4 *Integrated conceptual framework*

The three perspectives are combined into one framework. Child characteristics (condition, symptom severity, behavioural difficulty) and contextual factors (poverty, culture, gender roles, service availability) act as stressors. Parental appraisal, coping and available support mediate their effect. The outcomes are parenting stress, psychological distress, burden, physical health, financial strain and quality of life, which in turn influence the child's care and the family's functioning. The framework underpins the extraction of data and the grouping of themes in Sections 3 to 5.

3. Methodology

3.1 *Review design*

This is a narrative review with a structured, transparent approach to data extraction and thematic synthesis. A narrative design was chosen because the included studies vary widely in design, measures and conditions, which rules out statistical pooling and favours an interpretive synthesis across them.

3.2 *Search strategy*

The search combined terms for the population (parents, caregivers, mothers, fathers), the conditions (epilepsy, cerebral palsy, autism spectrum disorder, neurodevelopmental and neurological disorders) and the outcomes (stress, burden, quality of life, distress, coping, stigma, financial burden, social support, unmet needs).

3.3 *Databases and information sources*

The databases and sources searched, for example PubMed/MEDLINE, PsycINFO, Scopus, Google Scholar.

3.4 *Inclusion and exclusion criteria*

Studies were included if they (a) involved parents or primary family caregivers of children with epilepsy, CP, ASD or a mixed neurological or neurodevelopmental condition, (b) reported parental or family outcomes such as stress, distress, burden, quality of life, needs, coping, stigma, financial impact or social support, and (c) were published as peer-reviewed empirical studies or as systematic, integrative, narrative or meta-analytic reviews. Two studies concerning parents of adult children with ASD were retained because they illuminate long-term caregiving. Studies reporting only child outcomes, without any parental or family outcome, were excluded.

3.5 *Study selection*

PRISMA-style account: records identified, duplicates removed, records screened, full texts assessed, reasons for exclusion and the final number included. The final corpus is 50 studies.

3.6 *Data extraction*

For each study the following were recorded: authors and year, country or setting, child condition, caregiver population, design and sample size, instruments or methods, main findings and stated limitations. Each study was also mapped to the theme or themes it informed. A study could contribute to more than one theme.

3.7 *Thematic synthesis*

Extracted findings were read repeatedly, coded line by line for the problem or resource they described and grouped into descriptive categories. These were then compared across ASD, CP and epilepsy and refined into seven analytic themes, using the seven-dimension model of Guyard et al. (2011) and the integrated framework in Section 2 as sensitising structures. Convergent findings, divergent findings and gaps were noted within each theme.

4. Characteristics of the Reviewed Literature

4.1 *Publication characteristics*

The 50 studies span 2000 to 2026 (one undated). Interest has grown sharply: 26 studies were published from 2020 onwards, 15 between 2015 and 2019, 3 between 2010 and 2014, and 5 between 2000 and 2009. Seventeen of the 50 are reviews or syntheses (systematic, qualitative meta-synthesis, meta-analytic, integrative or narrative), and the rest are primary studies.

Period	Studies
2000–2009	5
2010–2014	3
2015–2019	15
2020–2026	26
Undated	1

4.2 *Geographic distribution*

Nine studies (18%) were conducted in India, spread across hospital settings in Hyderabad and South India and community or rural settings in Tamil Nadu. The remaining evidence includes

one study from Pakistan, two from China, one from the United Kingdom and a large body of work from other high-income settings and multi-country syntheses. The Indian studies are valuable for context, but they cannot yet support conclusions at the level the international literature allows.

4.3 *Caregiver populations and child conditions*

Child condition	Studies	Number
Autism spectrum disorder	3, 4, 21–40	22
Cerebral palsy	7–20	14
Epilepsy	5, 6, 41–50	12
Mixed neurological or neurodevelopmental	1, 2	2

Study numbers follow the order of the reference list. Mothers are the largest or only group in many primary studies (for example Gopichandran et al., 2020; Lee et al., 2020; Rezq et al., 2025). Fathers appear alongside mothers in a minority of studies (Davis et al., 2009; Batool & Khurshid, 2015; Li et al., 2022). One study includes grandmothers as caregivers (Wu et al., 2017), and two examine ageing parents of adults with ASD (Marsack & Samuel, 2017; Marsack-Topolewski & Church, 2019).

4.4 *Research designs*

Cross-sectional surveys using standardised scales dominate the primary research. Qualitative designs (in-depth interviews, grounded theory) account for a smaller group (Gopichandran et al., 2020; Davis et al., 2009), and one Indian study combined a survey with follow-up interviews (Chittem et al., 2022). Longitudinal evidence is rare, with only one study following families after diagnosis (Longitudinal study, 2023) and one examining stress before diagnosis (pre-diagnostic study, 2021). Several studies compared groups, such as epilepsy against asthma (Comparative asthma-epilepsy study, 2008) or children against parents' ratings (Comparative study, 2020). Because most designs are cross-sectional, the direction of many associations cannot be established.

4.5 *Major outcomes*

The outcomes studied can be grouped into seven families: needs and access to care; parenting stress and psychological distress; burden and quality of life; coping; stigma and relationships; financial, employment and physical-health effects; and social support and intervention effects. These families form the basis of the thematic findings in Section 5.

5. Thematic Findings

5.1 *Unmet needs, information gaps and access to healthcare services*

Parents repeatedly describe a gap between what they need and what services provide. In a Hyderabad children's hospital, a survey of 205 parents followed by interviews found widespread unmet needs around clear information about the diagnosis, arrangements for ongoing medical care and finding specialists when needed, as well as a need for someone to explain things and help with emotional coping (Chittem et al., 2022). An Indian needs-assessment found that most parents had clear unmet requirements spanning medical care, emotional reassurance, practical help and basic information (Indian caregiver-needs study, 2019).

The same pattern is seen internationally. A systematic review of 17 qualitative studies of CP identified unmet needs as one of four overarching areas of parental experience (Elangkovan & Shorey, 2020), and syntheses of ASD and epilepsy report difficulty accessing services and a shortage of information (Samsell et al., 2022; Breed et al., 2025). In epilepsy, caregivers carry the day-to-day work of medication schedules, seizure monitoring and appointments, and this management is itself emotionally and socially demanding (Tang et al., 2023). Parents' own knowledge and attitudes shape how epilepsy is handled at home and the family's well-being (Sadanandan et al., 2023), so gaps in understanding are themselves a source of difficulty. Parents' concerns reach beyond medical control: medication side effects, cognitive effects, safety, the child's future and independence, and fear of lasting brain damage (Concern-validation study, 2000).

Summary: Information, continuity of care and emotional guidance are the most consistently reported gaps, and they are as important to parents as treatment itself.

5.2 *Parenting stress, psychological distress and mental health*

Elevated stress and distress are the most consistent finding in the review. In ASD, parents of children with more severe symptoms were more stressed in an Indian sample (Ravichandran et al., 2026), and the pattern was echoed in Pakistan, where both impairment severity and parents' sense of capability as caregivers predicted stress (Batool & Khurshid, 2015). A study of 683 mother–father pairs found meaningful levels of stress, anxiety and depressive symptoms, higher among mothers and among parents of children with more severe symptoms (Li et al., 2022). A meta-analysis confirmed that children's emotional and behavioural problems are associated with greater parental psychological distress (Yorke et al., 2018), and a narrative review reached the

same conclusion about stress more broadly (Narrative review, 2016). Suthar and Sethi (2025) also reported significant psychological strain among mothers.

In CP, a large study of 194 caregivers found that greater psychological distress went with lower quality of life (Agni et al., 2025). Distress and maternal anxiety and depression were also linked with parents' poorer ratings of the child's quality of life (Davis et al., 2012; Maternal mental-health study, 2017). Higher parenting stress in mothers went with poorer health-promoting behaviours and health-related quality of life (Lee et al., 2020).

In epilepsy, stress was predicted by child-related stressors, parental resources and coping (Rodenburg et al., 2007), and was associated with depression, learning difficulties and seizure-related factors in children (Cushner-Weinstein et al., 2008). Parents of children with epilepsy reported notably higher parenting stress than parents of children with asthma, particularly around role restriction and emotional strain (Comparative asthma-epilepsy study, 2008). A recent UK study found common difficulties with sleep, stress, depression and anxiety (Coates et al., 2026), and an Indian study of epilepsy found stress and stigma side by side (South Indian study, 2019).

Summary: Distress is high in all three conditions, tied to the child's symptoms and behaviour, and especially heavy for mothers.

5.3 *Caregiver burden and quality of life*

Quality of life among parents is generally lower than in comparison groups, and the psychological domain is often the worst affected. In a study of 50 caregivers of children with CP using the WHOQOL-BREF, the psychological domain was most affected (Caretaker QoL study, 2024). Caregiver depression and the severity of the child's condition were consistently linked with higher burden in a systematic review of CP (Liu et al., 2023), and ICF-CY-based work shows that caregiver quality of life reflects child, caregiver and environmental factors together (ICF-CY study, n.d.). A study comparing mothers and grandmothers suggests that caregiver role can shape how caregiving is experienced (Wu et al., 2017), and parents' views of their own and their child's quality of life diverge as children reach adolescence (Comparative study, 2020).

In ASD, an integrative review of 15 studies and over 5,500 participants found lower physical, psychological and social quality of life, with symptom severity a consistent risk factor (Integrative review, 2022). Care burden is closely related to coping and well-being (Bozkurt et al., 2019), and, among parents of adults with ASD, burden predicted lower quality of life (Marsack & Samuel, 2017; Marsack-Topolewski & Church, 2019).

In epilepsy, a systematic review of 15 studies reported poorer quality of life than in the general population, with anxiety, depression and socioeconomic status contributing and mothers often faring worse than fathers (Puka et al., 2018). Loneliness was associated with poorer quality of life, and personal resources such as optimism acted as a buffer (Quality-of-life study, 2015). The child's health-related quality of life and the parents were closely connected (Bompori et al., 2014).

Summary: Burden and quality of life are multidimensional, linked to the child's condition and to the parent's mental health, and are best measured across several domains.

5.4 *Coping strategies and adaptation*

How parents cope matters as much as how stressed they are. A systematic review found that parents of children with ASD relied more on avoidance-based coping and sought social support less often than comparison groups, while problem-focused coping was linked to better adjustment (Vernhet et al., 2019). A further review found that positive reappraisal or finding a more constructive way of viewing the situation, was associated with better quality of life (Ni'matuzahroh et al., 2022). Suthar and Sethi (2025) reported that parents using more adaptive coping managed better, and Bozkurt et al. (2019) support examining burden and coping together.

Coping and adaptation also change over time. Stress can start before diagnosis, when weak social support, avoidance and general worry already predict higher parenting stress (pre-diagnostic study, 2021). In the year after an ASD diagnosis, family quality of life shifted, and parents' sense of capability and available support shaped the trajectory (Longitudinal study, 2023). In epilepsy, coping was one of three predictors of parenting stress (Rodenburg et al., 2007).

Summary: Adaptive coping, such as problem-solving and positive reappraisal, goes with better outcomes, and avoidance goes with worse ones. Coping is a process that begins before diagnosis and continues over time.

5.5 *Stigma, guilt and social relationships*

Stigma and guilt are prominent in the Indian evidence. Parents of children with epilepsy attending a South Indian tertiary centre experienced both stress and perceived stigma (South Indian study, 2019). Interviews with mothers in rural and peri-urban Tamil Nadu described physical pain, guilt, poverty-linked hardship, gendered expectations and social stigma together (Gopichandran et al., 2020). A systematic review of mothers' experiences of CP identified sacrifice and adaptation, guilt sometimes reinforced by cultural blame, stigma and marginalisation, practical and financial

strain, and difficult healthcare encounters (Smith & Blamires, 2022). Davis et al. (2009) found that caregiving affected parents' social well-being and personal freedom, and that parents often felt support was inadequate. A meta-synthesis of parents of children with ASD reported stigma from others as one of several features of lived experience, alongside emotional stress, family ripple effects and mixed hard and rewarding moments (Qualitative meta-synthesis, 2015).

Summary: Stigma and guilt sit alongside stress as real sources of suffering, and cultural blame and gender roles compound them.

5.6 *Financial strain, employment, physical health and gendered caregiving*

The seven-dimension review of CP identified time demands, employment restrictions, effects on social and family relationships, psychological and physical health consequences and financial burden (Guyard et al., 2011). Specific findings support each dimension. Financial hardship linked to poverty and gendered caregiving expectations were central in Tamil Nadu (Gopichandran et al., 2020). Caregiving affected parents' financial security and personal freedom (Davis et al., 2009), and financial strain was a significant predictor of lower quality of life among parents of adults with ASD (Marsack-Topolewski & Church, 2019). Mothers' physical health and self-care were affected, with higher stress going with poorer health-promoting behaviours (Lee et al., 2020), and poor sleep was common among caregivers of children with epilepsy (Coates et al., 2026). In epilepsy, socioeconomic status also contributed to parental quality of life (Puka et al., 2018).

Mothers appear across this literature as the main carers, and several studies report poorer outcomes for mothers than for fathers (Puka et al., 2018; Li et al., 2022). Because most studies sample mothers only, the specific experience of fathers is still poorly documented.

Summary: Money, work, physical health and gender are tightly linked, and caregiving costs fall most heavily on mothers and on poorer families.

5.7 *Social support, interventions and protective resources*

Social support is the best-documented protective resource. A meta-analytic structural model of 28 studies and more than 13,000 parents showed that support improves quality of life partly by lowering parenting stress (Wang et al., 2022). Mothers' perceived support is linked with better quality of life (Rezq et al., 2025), formal support services played a meaningful role among roughly 6,120 Chinese caregivers (Chinese formal-support survey, 2023/2024), and informal support from family and friends softened the link between burden and poorer quality of life in

ageing parents (Marsack & Samuel, 2017). Informational, emotional and instrumental support relate to different outcomes (Support study, 2025), and loneliness is a risk (Quality-of-life study, 2015).

Intervention evidence is encouraging. A synthesis of parent-focused mental-health interventions for ASD concluded that programmes can reduce stress, depression and anxiety and improve coping (Intervention synthesis, 2018). A network meta-analysis of 69 studies and 4,213 parents found measurable gains in stress, anxiety and depression from several psychological approaches (Network meta-analysis, 2024). All intervention evidence in the corpus concerns parents of autistic children; comparable evidence for CP and epilepsy is lacking.

Summary: Family, peer and professional support protect parents, and counselling and psychoeducation can reduce distress, but the evidence is concentrated in ASD.

6. Discussion

6.1 *Parenting stress as a shared outcome across conditions*

The clearest message of this review is that parenting stress and psychological distress are shared outcomes across epilepsy, CP and ASD. The reviewed studies used different instruments, countries and designs, yet they converge on the same conclusion: parents of children with these conditions are more stressed, more distressed and report poorer quality of life than comparison groups or general-population norms (Puka et al., 2018; Integrative review, 2022; Agni et al., 2025). That the pattern holds across three clinically different conditions suggests the strain comes less from any one diagnosis than from the common features of long-term, intensive caregiving in the face of uncertainty and limited support. The comparison of epilepsy with asthma points to an additional possibility, that neurological conditions may place distinctive burdens on parents beyond those of chronic childhood illness in general (Comparative asthma-epilepsy study, 2008).

6.2 *Child characteristics and parental distress*

The severity of the child's condition and the presence of behavioural and emotional difficulties are among the most consistent correlates of parental distress. This holds in ASD (Ravichandran et al., 2026; Yorke et al., 2018; Integrative review, 2022), in CP (Liu et al., 2023) and in epilepsy, where specific features such as depression, learning difficulties and seizure factors matter (Cushner-Weinstein et al., 2008). Two cautions apply. First, most designs are cross-sectional, so the direction of the relationship is unclear, and parental distress may also colour how

parents rate their child (Davis et al., 2012; Maternal mental-health study, 2017). Second, child characteristics explain only part of the picture: coping, support, self-efficacy and context also matter (Batool & Khurshid, 2015; Rodenburg et al., 2007). Child severity therefore sets the level of demand, but not the parent's response to it.

6.3 ***Stigma, gender and cultural context in India***

The Indian studies show how disability, poverty and gender interlock. Mothers in Tamil Nadu described stigma, guilt, physical pain and financial hardship as inseparable from expectations about who should provide care (Gopichandran et al., 2020). Cultural blame, which can reinforce maternal guilt, is a theme in the wider literature on CP (Smith & Blamires, 2022), and Indian families with epilepsy report stigma alongside stress (South Indian study, 2019). In a setting where informal family networks and caste, class and gender expectations shape caregiving, findings from high-income countries cannot be assumed to transfer. A needs-assessment of Indian parents shows that gaps in emotional reassurance and practical help are as important as gaps in medical care (Indian caregiver-needs study, 2019). A social-work perspective is therefore particularly well placed to address them, since it works with the family, community and service system together.

6.4 ***Interaction of psychological, social and financial problems***

The seven-dimension framework shows how problems cluster and feeds one another (Guyard et al., 2011). Financial strain and loss of employment increase stress. Stress and low mood reduce the capacity to seek help or look after one's own health (Lee et al., 2020). Stigma narrows social contact, and isolation in turn predicts poorer quality of life (Quality-of-life study, 2015). Poor information and limited access to services increase the daily load on parents and, with it, their distress (Chittem et al., 2022; Tang et al., 2023). This clustering is a practical argument for responses that address several problems at once and against treating each as a separate clinical question.

6.5 ***Social support, coping and parental resilience***

Support and coping appear to buffer the harm of stress, with several studies pointing to the same mechanism: support reduces stress, and reduced stress improves quality of life (Wang et al., 2022). Adaptive coping and personal resources such as optimism, flexibility, self-efficacy and resilience are associated with better outcomes (Ni'matuzahroh et al., 2022; Quality-of-life study, 2015; Coates et al., 2026). The finding that parents of autistic children use support less often than

comparison groups (Vernhet et al., 2019) suggests that barriers to seeking support, such as stigma and lack of accessible services, deserve attention in their own right. The encouraging intervention evidence (Intervention synthesis, 2018; Network meta-analysis, 2024) shows that these buffers can be strengthened.

7. Policy and Practice Implications

For practice, the review supports the following directions.

i. **Make family-centred care routine.** Assessing parental stress, mood and burden alongside the child's clinical review would identify distress early, since parental mental health and child outcomes move together (Bompori et al., 2014; Davis et al., 2012).
ii. **Strengthen information and navigation.** Clear explanations of the diagnosis, a named point of contact and help with arranging ongoing care respond directly to the most common unmet needs (Chittem et al., 2022; Indian caregiver-needs study, 2019).
iii. **Offer counselling and psychoeducation.** Parent-focused programmes can reduce stress, anxiety and depression (Intervention synthesis, 2018; Network meta-analysis, 2024), and are a natural fit for medical and psychiatric social work.
iv. **Build peer and community support.** Parent groups and formal support structures such as NGOs and government programmes address isolation and stigma, and support improves quality of life through lowered stress (Wang et al., 2022; Chinese formal-support survey, 2023/2024).
v. **Address stigma and gender.** Community awareness and engagement of fathers and extended family can ease the load carried by mothers (Gopichandran et al., 2020).
vi. **Link families to financial and employment support.** Disability entitlements, schemes and livelihood support target the financial strain consistently linked to lower quality of life (Marsack-Topolewski & Church, 2019).
vii. **Support from the time of suspicion.** Because stress begins before diagnosis (pre-diagnostic study, 2021), early developmental and screening services should include support for parents.
viii. **Plan for the long term.** Caregiving continues into adulthood (Marsack & Samuel, 2017), so services should plan for ageing parents and the transition to adult care.

8. Research Gaps and Future Research

The following gaps emerge from the evidence.

- **Indian evidence is limited.** Only 9 of the 50 studies are Indian, and they are mostly hospital-based, cross-sectional and condition-specific. Community-based and multi-site Indian studies, including rural and low-income families, are needed.
- **Fathers and other caregivers are under-studied.** Most primary studies sample mothers. Studies with fathers, grandparents and siblings, and on how caregiving is shared within the family, are needed.
- **Longitudinal research is scarce.** Only a few studies follow families over time or study the pre-diagnostic phase (Longitudinal study, 2023; Pre-diagnostic study, 2021). Trajectories of stress and adaptation through childhood, adolescence and adulthood are largely unmapped.
- **Intervention evidence is concentrated in ASD.** Trials and evaluations of counselling, psychoeducation and peer support for parents of children with CP and epilepsy, and in Indian settings, are needed.
- **Measurement is inconsistent.** The seven dimensions of impact are rarely measured together, and the lack of standardised tools makes comparison difficult (Guyard et al., 2011). Culturally validated instruments for Indian parents would help.
- **Cross-condition comparison is rare.** Few studies compare epilepsy, CP and ASD within the same population using the same measures.
- **Neglected topics.** Sleep, physical health and resilience (Coates et al., 2026), parenting style (Ravichandran et al., 2026) and the role of different kinds of support (Support study, 2025) merit further study.

9. Limitations

This review has several limitations. It is a narrative review, so the selection of studies is less exhaustive and less reproducible than in a formal systematic review, and a risk of selection bias remains. No formal quality appraisal was applied, so studies of very different rigour are synthesised side by side. The included studies are heterogeneous in design, instruments, conditions and settings, which prevents pooling and makes comparisons indicative rather than precise. Cross-sectional designs predominate, so causal claims are not warranted. Indian evidence is small in

volume, and many findings come from high-income settings that may not transfer. Samples are weighted towards mothers. Several included works are themselves reviews, so some primary studies may be counted indirectly more than once. Finally, the review is limited to published literature in English and may be affected by publication bias.

10. Conclusion

Parents of children with epilepsy, cerebral palsy and autism spectrum disorder face a connected set of psychological, social, financial and healthcare problems. Stress, distress and reduced quality of life are common to all three conditions, rise with the severity and behavioural demands of the child, and fall most heavily on mothers. In India, stigma, guilt, poverty and gender roles add to the load, and unmet needs for information and services remain widespread. Support, adaptive coping and parent-focused interventions offer real protection, yet the evidence for them is thin outside ASD and outside high-income settings. Future research should prioritise Indian community samples, fathers, longitudinal designs and intervention trials, and practice should treat the family, and not only the child, as the unit of care.

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