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Beyond Silence and Stigma: A Systematic Review of Parents' Lived Experiences, Community Knowledge, and Intellectual Disability

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Abstract

Stigma surrounding intellectual disability remains a persistent and multidimensional barrier shaping the lives of children with disabilities and their families. Parents frequently occupy a liminal position where personal caregiving experiences intersect with community attitudes, institutional practices, and structural inequalities. This systematic review synthesizes international literature examining parents' lived experiences of stigma, community knowledge, and misconceptions, and their implications for family well-being, social participation, and inclusive education. Drawing on peer-reviewed studies published between 2003 and 2025, the review integrates evidence from disability studies, mental health, sociology, and inclusive education. Findings indicate that stigma operates at interpersonal, institutional, and structural levels, often manifesting as courtesy stigma, surveillance of parental competence, and exclusion from educational and social systems. However, the review also identifies forms of parental resistance, advocacy, and meaning-making that challenge deficit-based narratives. By bringing together fragmented bodies of literature, this review advances an integrated conceptual understanding of stigma as a relational and socially produced phenomenon rather than an individual deficit. The paper concludes with implications for inclusive education policy, community-based stigma reduction, and future research, emphasizing the need to center parents' voices while addressing the broader socio-structural conditions that sustain stigma.

Keywords: *intellectual disability; stigma; parents' lived experiences; community knowledge; inclusive education*

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INTRODUCTION

Despite global commitments to inclusive education and disability rights, stigma surrounding intellectual disability continues to shape everyday experiences for children with disabilities and their families. Parents often become the primary interface between their child and wider social systems, including schools, healthcare, child protection services, and community networks. As a result, they experience stigma not only indirectly through their children but also directly through judgments of parental competence, morality, and legitimacy (Ali et al., 2012; Franklin et al., 2022).

Existing research demonstrates that stigma operates through multiple pathways, including public stigma, self-stigma, and courtesy stigma, each reinforcing exclusionary practices and internalized shame (Corrigan & Watson, 2002; Angermeyer et al., 2003). Within disability studies, scholars have argued that stigma is not merely an attitudinal problem but a social process embedded in power relations, institutional norms, and historical constructions of disability (Beart et al., 2005; Crabtree et al., 2016).

While there is a growing body of literature on stigma related to intellectual disability, research remains fragmented across disciplines. Studies focusing on parents' lived experiences often remain disconnected from broader analyses of community knowledge, cultural narratives, and structural conditions. Moreover, much of the stigma literature has been dominated by individual-level interventions, with limited attention to systemic and relational dimensions (Smythe et al., 2020).

There is a lack of integrative synthesis that brings together parents' lived experiences, community knowledge, and stigma within a single analytical framework. This fragmentation limits the development of inclusive policies and practices that address stigma beyond awareness-raising. The objective of this systematic review is therefore to synthesize existing literature to: (1) examine how parents experience and navigate stigma related to intellectual disability; (2) analyze how community knowledge and misconceptions shape these experiences; and (3) identify implications for inclusive education and social participation.

METHOD

2.1 Research Design

This study adopted a systematic literature review design to synthesize existing empirical and theoretical scholarship on parents' lived experiences of stigma related to intellectual disability and the role of community knowledge in shaping such experiences. A systematic approach was selected to ensure methodological rigor, transparency, and reproducibility, enabling the structured identification, appraisal, and synthesis of evidence across disciplinary boundaries. Systematic reviews are particularly suited to complex social phenomena such as stigma, where knowledge is dispersed across education, disability studies, sociology, and mental health research (Smythe et al., 2020).

Rather than aggregating findings to produce statistical generalisations, this review prioritised **conceptual integration**, allowing for the examination of how stigma operates relationally across interpersonal, institutional, and structural levels (Corrigan & Watson, 2002; Scavarda & Scambler, 2025). This approach aligns with interpretive traditions in disability research that view stigma as socially constructed rather than individually located (Beart et al., 2005; Crabtree et al., 2016).

2.2 Data Sources and Search Strategy

A comprehensive search of peer-reviewed literature was conducted across four major academic databases: Scopus, Web of Science, PubMed, and Google Scholar. These databases were selected to ensure broad disciplinary coverage, capturing research from health sciences, social sciences, and education. Searches were conducted using combinations of keywords and Boolean operators, including *intellectual disability*, *parents*, *family caregivers*, *stigma*, *courtesy stigma*, *community attitudes*, *social exclusion*, and *inclusive education*.

Reference lists of key articles were also manually screened to identify additional relevant studies not captured through database searches, a strategy commonly employed to enhance the completeness of systematic reviews (Ali et al., 2012; Reupert et al., 2021). The search strategy was designed to balance sensitivity and specificity, ensuring the inclusion of diverse methodological approaches while maintaining relevance to the review's core focus.

2.3 Study Selection Process

The study selection process was guided by principles adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework to ensure methodological transparency and rigor in the identification, screening, eligibility assessment, and inclusion of relevant studies. The review aimed to systematically synthesize literature examining parents' lived experiences of stigma associated with intellectual disability, community knowledge and misconceptions, and implications for inclusion and social participation.

A comprehensive search was conducted across four electronic databases: Scopus, Web of Science, PubMed, and Google Scholar. The initial database search yielded **428 records**, while an additional **17 studies** were identified through manual screening of reference lists and related literature. Following the removal of duplicate articles, **356 records** remained for title and abstract screening.

During the screening stage, studies were excluded if they did not focus on intellectual disability, parental or caregiver experiences, stigma-related constructs, or community perceptions. Articles that focused exclusively on clinical interventions without social or relational analysis were also excluded. After title and abstract screening, **94 full-text articles** were assessed for eligibility.

Full-text review was conducted using the predefined inclusion and exclusion criteria. Studies were excluded at this stage for several reasons, including insufficient relevance to stigma or parental experiences, lack of empirical or theoretical rigor, duplication of findings, or absence of a clear focus on intellectual disability. Following this process, **38 studies** were retained for the final synthesis.

The study selection process is summarized in Figure 1 using a PRISMA-informed flow diagram illustrating the stages of identification, screening, eligibility assessment, and inclusion.

2.4 Inclusion and Exclusion Criteria

Studies were included in the review if they met the following criteria: (a) focused on parents or family caregivers of individuals with intellectual disabilities or closely related conditions; (b) explicitly examined stigma, courtesy stigma, discrimination, or community perceptions associated with disability; and (c) were published in English between 2003 and 2025, reflecting both foundational and contemporary scholarship in the field.

Studies were excluded if they consisted solely of opinion pieces, commentaries, or descriptive accounts lacking empirical evidence or robust theoretical grounding. Studies were also excluded if they focused exclusively on medical or clinical outcomes without examining social, relational, or community dimensions of disability and stigma. This criterion was applied to ensure that the review synthesized analytically rigorous contributions capable of informing conceptual understanding and policy-relevant implications (Braun & Clarke, 2006; Smythe et al., 2020).

2.5 Data Analysis

Data analysis followed a thematic synthesis approach, informed by qualitative analytic traditions commonly used in systematic reviews addressing complex social phenomena (Braun & Clarke, 2006; Clarke & Braun, 2013). This approach enabled the integration of findings across diverse methodological designs, including qualitative studies, mixed-methods research, and theoretical analyses.

The analytical process involved three iterative stages. First, all included studies were read in full and subjected to initial familiarization, during which relevant data related to parental experiences of stigma, community knowledge, and institutional responses were extracted. Second, descriptive coding was conducted to identify recurring patterns, concepts, and explanatory frameworks across studies. Codes were not treated as fixed categories but were continuously refined through comparison across contexts and disciplines.

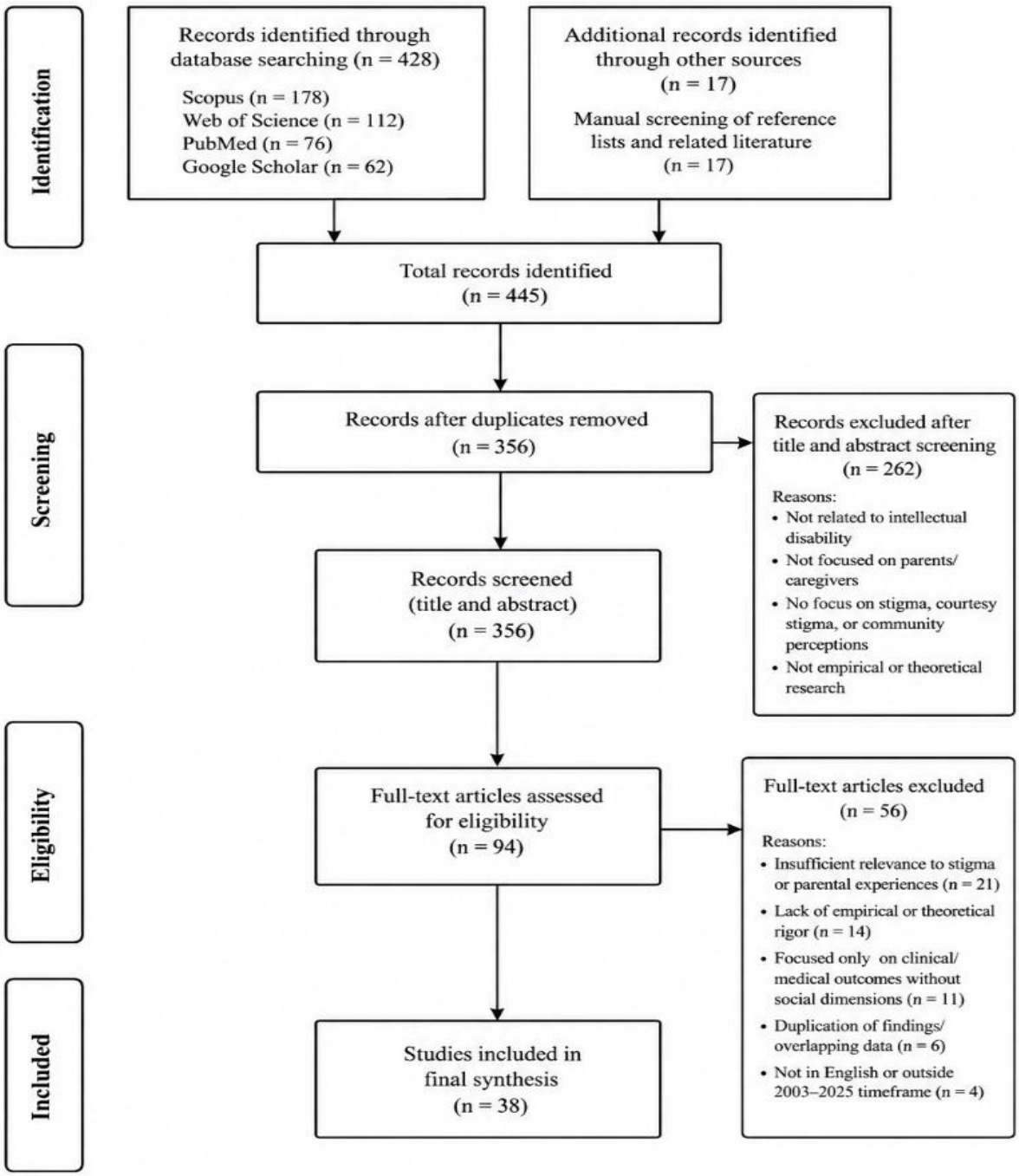
In the final stage, descriptive codes were synthesized into analytical themes that captured the relational and structural dimensions of stigma. These themes were interpreted through a critical disability lens, drawing on scholarship that conceptualizes stigma as socially produced and embedded

within power relations rather than as an individual or attitudinal deficit (Corrigan & Watson, 2002; Beart et al., 2005; Scavarda & Scambler, 2025). Particular attention was paid to how parents' narratives intersected with community knowledge, professional practices, and institutional structures, thereby shaping experiences of inclusion or exclusion.

Throughout the analysis, reflexive attention was given to the positionality of the researcher and the epistemic assumptions underlying the reviewed literature. This reflexive stance aligns with participatory and interpretive approaches in disability research, which emphasize the legitimacy of lived experience as a source of knowledge while critically interrogating dominant deficit-based discourses (Bergold & Thomas, 2012; Beail & Williams, 2014). The resulting synthesis sought not only to summarize existing evidence but also to generate conceptual insights capable of informing inclusive education policy and stigma-reduction strategies.

Figure 1

PRISMA Flow Diagram of Study Selection Process



RESULTS AND DISCUSSION

This section synthesizes findings across the reviewed literature to demonstrate how stigma surrounding intellectual disability is produced, sustained, and contested at the intersection of parental experience, community knowledge, and institutional practice. Rather than treating stigma as an individual attitude, the analysis conceptualizes it as a relational and structural process that regulates belonging, parental legitimacy, and access to social and educational resources.

3.1 Courtesy Stigma and the Moral Scrutiny of Parents

Across the reviewed studies, parents consistently experienced courtesy stigma, whereby negative social meanings attached to intellectual disability extend to family members, particularly primary caregivers (Angermeyer et al., 2003; Ali et al., 2012). This form of stigma was not limited to interpersonal interactions but was institutionalized through professional practices in education, healthcare, and child protection systems. Parents, most notably mothers, were frequently positioned as morally suspect, emotionally unstable, or inherently incapable, resulting in intensified scrutiny of parenting competence (Baum & Burns, 2007; Gould & Dodd, 2014).

These findings align with sociological interpretations of stigma as a mechanism of social regulation, reinforcing dominant norms of productivity, independence, and "ideal" parenthood (Scavarda & Scambler, 2025). Stigma functioned not merely to label difference but to justify surveillance, intervention, and, in extreme cases, family separation. Importantly, the literature challenges portrayals of parents as passive victims. Instead, parents actively interpreted, negotiated, and resisted stigmatizing encounters, although often at considerable emotional and psychological cost (Dickerson, 2003; Benders-Hadi et al., 2013).

This synthesis advances existing scholarship by illustrating how courtesy stigma operates simultaneously at interpersonal, professional, and policy levels, positioning parents as both caregivers and subjects of institutional control.

3.2 Community Knowledge, Misconceptions, and Social Distance

Limited, distorted, or deficit-oriented community knowledge emerged as a central driver of stigma across cultural and geographical contexts. Intellectual disability was frequently framed within narratives of tragedy, burden, or parental failure, contributing to social distancing and exclusion from community life (Booth & Booth, 2004; Franklin et al., 2022). Such representations not only shaped everyday interactions but also informed institutional decisions related to schooling, service eligibility, and parental credibility.

The review indicates that stigma is sustained not by ignorance alone but by socially sanctioned knowledge systems that privilege normative developmental trajectories while marginalizing difference (Beart et al., 2005; Crabtree et al., 2016). Smythe et al. (2020) demonstrated that stigma-reduction interventions, particularly in low- and middle-income contexts, often emphasized awareness-raising without addressing the structural and cultural conditions that reproduce stigma. As a result, improvements in knowledge did not consistently translate into reduced discrimination or increased inclusion.

These findings suggest that community knowledge operates as a form of power, shaping who is recognized as a legitimate parent and whose experiences are rendered invisible. Addressing stigma, therefore, requires interventions that move beyond information provision toward critical engagement with dominant social narratives and institutional practices.

3.3 Parental Resistance, Advocacy, and Identity Reconstruction

Despite pervasive stigmatization, parents were not merely recipients of social exclusion. Across studies, parents engaged in diverse forms of resistance and advocacy, including reframing disability narratives, challenging professional authority, and mobilizing collective support networks (Scavarda & Scambler, 2025). These practices enabled parents to reconstruct identities that contested deficit-based assumptions and asserted parental competence and moral worth.

The literature further highlights the relational nature of stigma resistance. Research on self-advocacy and identity formation among people with intellectual disabilities demonstrates how parental advocacy intersects with broader movements for recognition and rights (Anderson & Bigby, 2017). Resistance was therefore not solely an individual coping strategy but a collective and political **process**, shaped by access to resources, social capital, and institutional responsiveness.

This synthesis extends prior work by illustrating how parental resistance operates across psychosocial and structural domains, offering critical insights into pathways for stigma transformation rather than mere adaptation.

3.4 Implications for Inclusive Education

Stigma profoundly shaped educational trajectories by influencing school placement decisions, teacher expectations, and parental participation in educational processes. Inclusive education initiatives that failed to address stigma at the community and institutional levels risked reproducing exclusion under the language of inclusion (Slee & Tait, 2022; UNESCO, 2020). Parents frequently reported being positioned as obstacles to inclusion rather than partners in educational decision-making.

The findings underscore the need for systemic approaches to inclusive education that integrate stigma reduction, professional training, and community engagement. Such approaches must recognize parents as epistemic contributors whose lived experiences provide critical insights into inclusive practice. Without addressing the relational and structural dimensions of stigma, inclusive education reforms remain vulnerable to symbolic implementation rather than substantive change.

Table 1. Analytical Synthesis of Stigma Across Parental, Community, and Institutional Levels

Analytical Domain	Key Manifestations of Stigma	Theoretical Interpretation	Implications for Inclusive Practice
Courtesy stigma	Moral scrutiny of parents; surveillance of parenting competence	Stigma as social control (Corrigan & Watson, 2002; Scavarda & Scambler, 2025)	Reframe parental competence; reduce institutional bias
Community knowledge	Deficit narratives; social distancing	Knowledge as power; social construction of disability	Community-level critical engagement, not awareness alone
Institutional practices	Exclusionary schooling decisions; professional mistrust	Structural reproduction of stigma	Inclusive policy reform and accountability
Parental resistance	Advocacy, identity reconstruction, collective action	Relational resistance to stigma	Center parents as partners in inclusive education

CONCLUSION

This systematic review demonstrates that stigma surrounding intellectual disability is not an individual or attitudinal problem, but a relational and socially produced phenomenon embedded within community knowledge systems, institutional practices, and structural inequalities. Parents' lived experiences illuminate how stigma operates across interpersonal, professional, and policy

domains, while also revealing forms of resistance, advocacy, and identity reconstruction that challenge deficit-based narratives.

The findings underscore the limitations of individual-level stigma reduction efforts and highlight the need for integrated, systemic strategies that center parents as legitimate knowledge holders while addressing the broader social and institutional conditions that sustain exclusion. For inclusive education, this requires moving beyond symbolic commitments toward practices that actively confront stigma within schools, professional cultures, and community engagement processes.

Future research should prioritize participatory and context-sensitive methodologies, particularly in low- and middle-income settings, to ensure that interventions are grounded in lived realities and responsive to local sociocultural dynamics. Such approaches are essential for advancing inclusive education and social participation in ways that are both equitable and transformative.

AUTHOR CONTRIBUTIONS

Hussein Hussein: Conceptualization, Analysis, Writing Original Draft, Editing, Methodology, Validation, Review

DECLARATION OF COMPETING INTEREST

The authors declare no known financial conflicts of interest or personal relationships that could have influenced the work reported in this manuscript.

DECLARATION OF ETHICS

The authors declare that the research and writing of this manuscript adhere to ethical standards of research and publication, in accordance with scientific principles, and are free from plagiarism.

DECLARATION OF ASSISTIVE TECHNOLOGIES IN THE WRITING PROCCESS

The authors declare that Generative Artificial Intelligence and other assistive technologies were not excessively utilized in the research and writing processes of this manuscript.

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