

Raising Children with Developmental Disabilities or Delays in South Korea: Mothers' Experiences of Stress, Stigma, and Service Barriers

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Abstract

Mothers raising children with developmental disabilities or delays may encounter both demanding care arrangements and disability-related social judgement. This study explored how mothers in South Korea described these experiences in relation to stress and support. Seven mothers with prior experiences of stigma, blame, discrimination, or exclusion participated in in-depth interviews. Consensual qualitative research identified seven domains and 53 categories concerning daily care, emotional exhaustion, maternal self-evaluation, family relationships, public encounters, healthcare and welfare services, and educational settings. Mothers described treatment-centred routines, limited opportunities for recovery, recurring guilt, and concerns that their children's behaviour would be interpreted as evidence of inadequate parenting. They also reported difficult service navigation, inconsistent administrative guidance, and uneven accommodation of their children's needs. Respectful professional communication, practical assistance, and supportive teachers provided contrasting experiences of relief and recognition. The findings suggest that maternal stress was experienced at the intersection of care demands, social evaluation, and access to support. However, reported service barriers do not, by themselves, establish structural stigma, and the interviews do not demonstrate causal relationships among these experiences. The study offers a context-sensitive account of mothers' support needs and identifies priorities for evaluating coordinated, disability-informed, family-centred services.

Introduction

Raising a child with a developmental disability or delay can involve sustained coordination of health, educational, and community services alongside ordinary family responsibilities. The intensity and meaning of these demands vary across children, families, and service environments. Research comparing parents of autistic and non-autistic children has documented elevated parenting stress, while also showing that comparisons depend on the populations being studied (Hayes & Watson, 2013). These findings establish the importance of parental well-being, but they do not mean that disability necessarily produces distress or that children's characteristics adequately explain mothers' experiences. Understanding support needs also requires attention to how care is organised and how families are treated.

Stigma provides one perspective on these relational experiences. Goffman's (1963) concept of courtesy stigma concerns social discredit associated with a person's relationship to someone who is stigmatised. Affiliate stigma refers more specifically to the internalisation of stigma by associated individuals, including family caregivers (Mak & Cheung, 2008). These concepts should not be treated as interchangeable. A mother may experience demeaning treatment, anticipate criticism, or restrict an outing without necessarily endorsing the negative judgement herself. Similarly, guilt about limited time or frustration with caregiving does not automatically constitute affiliate stigma. Interpreting such experiences requires attention to whether the account connects self-evaluation to disability-related devaluation.

A further distinction concerns structural stigma. Link and Phelan (2001) locate stigma within relations of power, while Hatzenbuehler (2016) describes how societal conditions, norms, and institutional policies can restrict the opportunities and resources of stigmatised groups. This perspective makes service organisation relevant to the study of families' experiences. Nevertheless, long waiting lists, confusing forms, or inadequate communication cannot simply be classified as structural stigma without examining their relationship to disability-related disadvantage. General resource shortages, poor coordination, interpersonal disrespect, and exclusionary institutional practices may coexist but require different explanations. Mothers' accounts can reveal the consequences of these encounters without independently establishing the policies or mechanisms that produced them.

Existing qualitative research already documents stigma across several settings. Ng and Ng (2022) examined the accounts of 54 Chinese parents of autistic children and described experiences spanning schools, public encounters, and family or community relationships. Gilson et al. (2021) identified personal, professional, and service-level barriers to mental health support among mothers of children with a disability. Longitudinal research has also associated stigma-related experiences with later parental health, although such evidence does not establish the direction of relationships in a separate interview study (Song et al., 2018). The present study therefore does not begin from an absence of evidence that parents experience stigma or that support systems matter.

More recent work sharpens the question of how support is experienced in everyday life. Johnston and Burke (2026) examined family–professional partnerships among parents from low-resourced backgrounds, illustrating the importance of attending to parents' detailed accounts of those relationships. Zakirova-Engstrand and Wilder (2026) explored accommodations and the sustainability of daily routines in culturally diverse families of autistic children. Together, these studies direct attention beyond the presence of services to the practical and relational work required to use them. The remaining question is not simply whether mothers experience stress, but how treatment schedules, public judgement, family expectations, and professional encounters are connected within their accounts of particular lives.

South Korea provides a relevant context for examining these connections without treating national culture as a single explanatory variable. Grinker and Cho (2013) and Kang-Yi et al. (2013) describe how interpretations of autism, concerns about family standing, and expectations surrounding children's development can shape diagnosis and help-seeking. Yang et al. (2007) conceptualise stigma in relation to locally valued aspects of moral experience. These perspectives sensitise an analysis to maternal responsibility and social evaluation. They do not justify assuming that all Korean mothers are collectivist, that all families prioritise reputation in the same way, or that experiences observed in Korea are uniquely Korean. Such claims would require comparative evidence.

The present study focuses on mothers' accounts of stress, stigma, and support while raising children with autism spectrum disorder, intellectual disability, or developmental delay. The term 'developmental disabilities or delays' reflects the reported composition of the sample; it does not imply that these

conditions are diagnostically equivalent. Mothers were recruited because they had experienced stigma, discrimination, blame, or exclusion. Accordingly, the study seeks to understand the meanings and contexts of those experiences rather than estimate how common stigma is among Korean families.

The research question was: How do mothers in South Korea who report stigma or exclusion describe the connections among daily caregiving, social judgement, service encounters, and their own stress and support needs? Consensual qualitative research was used to examine shared experiences alongside differences across cases. The intended contribution is a bounded, context-sensitive account that can inform family support and service design, rather than a causal model of structural stigma or a general theory of Korean motherhood.

Method

Design and participants

Consensual qualitative research (CQR) was used to examine participants' accounts through within-case analysis, cross-case comparison, team consensus, and external auditing (Hill et al., 1997; Hill & Knox, 2021). This approach supported attention to common experiences while retaining differences in their contexts and meanings. Stigma concepts informed the research focus, but caregiving demands, social evaluation, and institutional barriers were not treated as equivalent phenomena. The distinction between a reported experience and its theoretical interpretation is maintained in the presentation below.

Participants were seven mothers raising a child with autism spectrum disorder, intellectual disability, or developmental delay. The children were reported to be 3–13 years old. Eligibility required at least one year since the child's diagnosis, at least six months of attendance at a child-development centre, residence at home rather than in long-term institutional or hospital care, and an experience of stigma, discrimination, blame, or exclusion. The reported exclusion criteria were institutional residence, a serious mental health or other condition that would make interviewing difficult or raise ethical concerns, and communication difficulties that prevented participation.

Purposive sampling sought mothers with experiences relevant to the research question and variation in child age, support needs, and residential context. Snowball sampling was also used. Recruitment in connection with child-development services and the requirement for prior stigma or exclusion produced a service-connected, experience-selected sample. These features supported exploration of the research question but limit conclusions about families who were not using services or did not interpret their experiences as stigmatising.

Accounts from seven mothers can provide detail about a focused experience, but sample adequacy depends on the specificity of the question and sample, the quality of dialogue, and the analytic demands, rather than on a universal numerical threshold (Malterud et al., 2016). Here, variation in diagnostic descriptions and children's ages restricts the depth of condition-specific comparisons. The analysis is

therefore presented as an account of these mothers' experiences, not as a comparison of diagnostic groups or an estimate of experiences across South Korea.

Research team and reflexivity

The research team comprised three judges and one external auditor. Two judges held doctorates in psychology and had previous CQR experience. The third was a master's student in psychology who undertook preparation in qualitative research and CQR before analysis. The auditor was a doctoral-level counselling psychologist with professional certification and substantial CQR experience.

The researchers' training in psychology and counselling could direct attention towards emotional distress and individual coping, while familiarity with Korean family expectations could make self-sacrifice appear unremarkable. Consensus discussions considered these assumptions and distinguished participants' meanings from theoretical interpretations. Multiple perspectives and auditing were used to challenge interpretations, not to eliminate researcher subjectivity or establish an objective account independent of the researchers' positions.

Interviews and ethics

In-depth interviews were conducted from February to March 2026. Participants received study information, consent forms, and a summary interview guide in advance and were told they could decline any question. Six interviews were conducted face to face and one online using Zoom, according to participants' circumstances and preferences. Interviews lasted approximately 80–150 minutes. Some were divided across sessions to accommodate participants and allow fuller discussion. Interviews were audio-recorded with consent, and the researcher prepared verbatim transcripts.

Open-ended questions covered daily caregiving stress, experiences of stigma and social judgement, emotional and behavioural responses, coping, and support. Further questions addressed encounters with healthcare, welfare, schools, and childcare institutions, including procedures, communication, disclosure, and service use. Because the interview guide explicitly addressed stigma and institutional experiences, the resulting accounts should not be presented as evidence that these concerns emerged without prompting.

The study received approval from the affiliated university's institutional review board, and participants provided written informed consent, including permission for audio-recording. Identifying details were removed during transcription and reporting, and participants are identified by numerical codes. The institution and approval details are withheld in this review copy to preserve author anonymity.

Analysis

The analysis proceeded through the main stages of CQR: preparation, within-case analysis, cross-analysis, and auditing. During the preparation stage, the research team reviewed the research questions and interview guide, completed the interviews and verbatim transcription, and familiarised themselves with the full data set. Identifying information, including personal names and specific locations, was removed during transcription.

For the within-case analysis, each judge independently reviewed the transcripts and organised the data into provisional domains. Core ideas were then developed to capture the essential meaning of each participant's account in concise language while remaining close to the original context and wording. The judges compared their independent analyses in consensus meetings, discussed differences in interpretation, and revised domains and core ideas through repeated reference to the transcripts rather than through majority voting (Hill et al., 1997; Hill & Knox, 2021).

During cross-analysis, the team compared core ideas across participants and developed categories representing shared and contextually distinct experiences. Categories were revised through comparison and return to the transcripts. The study used 'general' for categories identified in all seven cases, 'typical' for four to six cases, and 'variant' for two or three cases. Experiences identified in a single case were retained for within-case understanding but excluded from the cross-analysis table. These are the study's reported frequency conventions; the labels indicate distribution within this sample, not population prevalence, explanatory importance, or differences in institutional performance.

An external auditor reviewed the domains, core ideas, cross-case categories, and frequency classifications. The research team considered the auditor's comments, returned to the transcripts where necessary, and revised the analysis by consensus. An audit trail of coding decisions, category revisions, and consensus discussions was maintained throughout the analytic process.

The findings are presented under seven domains, with the complete category structure and reported frequency labels provided in Online Resource 1, Table S1. The narrative foregrounds illustrative connections and contrasting experiences rather than repeating a separate explanation for each category. Domain headings have been shortened or clarified for presentation; the category membership and frequency classifications have not been reanalysed. Interpretive connections across domains are developed in the Discussion and are not treated as an empirically tested sequence.

Results

The analysis yielded seven domains and 53 categories. Table 1 summarises the domains, while Online Resource 1 preserves the full category structure. Across the accounts, mothers described demanding daily routines, emotional strain, self-evaluation, and family tensions alongside public judgement and difficult or supportive institutional encounters. The following accounts include experiences reported across the sample as well as less widely shared experiences. The quotations illustrate participants' meanings rather than substantiate population-level claims.

Table 1
Overview of the seven domains

No.	Focus of the reported domain	Categories
1	Daily routines and the physical demands of care	7
2	Emotional exhaustion and efforts to manage uncertainty	8
3	Maternal self-evaluation, guilt, and role redefinition	9
4	Family responsibilities, financial pressure, and relationships	6
5	Public judgement, anticipated criticism, and social withdrawal	6
6	Healthcare and welfare encounters: barriers and support	8
7	Educational settings: uneven accommodation and sources of reassurance	9
Note. The 53 category labels and their reported frequency classifications are provided in Online Resource 1, Table S1. Domain headings clarify presentation; they do not represent a new analysis.		

1. Daily routines and the physical demands of care

Mothers described arranging paid work, travel, treatment attendance, and household routines around their children's schedules. Accompanying the child and waiting, reorganising routines, physical readiness, fatigue, recurring behavioural difficulties, and continuing care during illness were classified as typical. Constant vigilance during outings and travel was variant. These categories reflect different aspects of constrained time and physical availability rather than separate causal pathways.

"I originally had a job... but because I had to keep driving him to the centre, I ended up quitting... I just say my job is 'driver'. His personal driver... I fit everything around him and wait in the car." (Participant 5)

Participant 2 similarly described make-up treatment sessions extending into weekends, leaving little time outside the child's schedule. Mothers' accounts of fatigue included the practical work of transport and supervision as well as the difficulty of obtaining a break. Participant 1 described continuing to provide care despite a back injury:

"I hurt my back at work, and I still had to care for the child—it was truly desperate. My back wouldn't straighten but I still had to look after the child... The thought hit me at once: I really must not get ill." (Participant 1)

Participant 5 also reported postponing her own medical treatment because recovery would interrupt the child's care arrangements. These accounts indicate perceived difficulty making room for mothers' health needs. They do not establish that all mothers lacked alternative care or that their health conditions were caused by stigma. Immediate safety concerns, service schedules, available help, and maternal expectations were intertwined in the experiences described.

2. Emotional exhaustion and efforts to manage uncertainty

Mothers described frustration when difficulties recurred, fluctuating hope during treatment, and emotional exhaustion. These categories, together with feeling overwhelmed and recognising the limits of coping, were typical. Descriptions of depression and helplessness, mental health service or medication use, and accepting the possibility of long-term care were variant. Mental health terms in these accounts reflect participants' descriptions and reported service use, not diagnoses independently assessed in this study.

"Even in treatment, the child seems to get a little better... and that small progress gives you enormous hope, but a few days later, if a challenging behaviour appears, you fall back into despair... and because that keeps repeating, you become emotionally worn down." (Participant 1)

The emotional meaning of a difficult episode depended partly on what had preceded it. Participant 4 described the disappointment of seeing previously acquired routines become difficult again after a school break. Participant 6 described having little energy for household tasks when treatment extended into the weekend, while Participant 5 described periods of withdrawing to her room. Other accounts concerned finding brief relief through personal activities or support, but struggling to sustain that relief within the same daily demands.

Some mothers described accepting the longer-term nature of their child's needs. This was presented as an effort to make expectations more manageable, not a uniform endpoint reached by every mother. The coexistence of exhaustion, help-seeking, and acceptance complicates a simple account of either deterioration or successful adaptation.

3. Maternal self-evaluation, guilt, and role redefinition

Recurring self-blame and guilt were reported in all seven cases. Mothers questioned whether they had done enough, compared their children's progress with that of peers, and described tensions between being a devoted mother and recognising personal limits. High standards for an ideal parent and attributing developmental outcomes to oneself were variant categories; giving up personal needs, self-blame after anger or comparison, and recognising limits were typical.

"It was during COVID, so I didn't send him to daycare, and I did feel guilty—did I not play with him enough at the age when he should have been learning to talk, did I not talk to him enough?" (Participant 3)

Participant 1 described wishing to be a warm and entirely capable mother but feeling unable to meet that ideal physically and mentally. Such accounts expressed mothers' attempts to explain their circumstances. They are not evidence that pregnancy, employment, childcare decisions, or parenting caused their children's developmental difficulties. Nor was every expression of guilt explicitly linked to the internalisation of social stigma; some concerned competing responsibilities or regretted interactions.

Acceptance and redefining the parental role were typical, and acquiring expertise or taking a more active advocacy role was variant. Participant 7 described a less comparison-driven approach:

“I accept my child’s condition, I don’t compare him with peers, and I set a path the child and I can move along together and aim for that goal—I think that’s the way.” (Participant 7)

Participant 2 described learning more to support her child, and Participant 4 considered developing the expertise needed to provide services herself. These accounts suggest agency, but also the work mothers felt responsible for undertaking when available guidance did not seem sufficient. They should not be read as evidence that mothers had overcome stigma or no longer required support.

4. Family responsibilities, financial pressure, and relationships

Financial pressure, unequal caregiving roles, increased responsibility during a spouse’s absence, tensions with extended family, and guilt about attention to siblings were typical. Mediating sibling conflict was variant. Participants described the combination of treatment costs and reduced opportunities for paid work, as well as the effort of coordinating support for more than one child.

Participant 4 reported feeling that treatment decisions and planning fell primarily to her. However, practical imbalance did not always mean relational hostility. Participant 1 described additional stress during her spouse’s work-related absences while also describing him as apologetic and supportive. This contrast matters: mothers’ accounts did not justify treating all spouses or all family relationships as sources of blame.

“My sister-in-law said, ‘My child could talk fine by around this age; he’s a bit slow, isn’t he’—that hurt a little at the time.” (Participant 2)

Other mothers described criticism from extended family or comparisons that intensified their concern about being judged. Participants also worried that siblings received less attention or had to organise their activities around treatment. These are mothers’ perceptions of family relationships; children, siblings, spouses, and relatives were not interviewed. Consequently, the study cannot determine those family members’ own experiences or attribute their actions to a single cultural expectation.

5. Public judgement, anticipated criticism, and social withdrawal

Awareness of others’ gaze and social withdrawal were general categories. Avoiding outings, worrying about judgements of parenting, fearing a negative parental label, and criticising limited public understanding of disability were typical. Some accounts described overt criticism; others concerned the expectation that criticism might occur. The distinction between an experienced rebuke and an anticipated judgement was important to interpreting withdrawal.

“When the child let out a shriek on the bus, people would look over now and then, and it was embarrassing at times; so eating out is hard. I end up not going.” (Participant 7)

Participant 7 described worrying that people in a restaurant would interpret her child's behaviour as evidence that she was failing to feed him. Participant 1 described gradually reducing social outings as she became more self-conscious. Participant 6 described an attempt to prevent attention to the child in public:

"I deliberately stopped the child from talking outside. I told him not to talk when we go out, in case others heard. Just be quiet. Don't say anything." (Participant 6)

Such accounts show the perceived pressure to manage visibility as well as behaviour. They do not imply that suppressing a child's expression is appropriate, or that withdrawal reflects a fixed maternal trait. Mothers sometimes understood the problem as inadequate public knowledge rather than personal inadequacy. Their accounts therefore included both accommodation to anticipated judgement and criticism of the environments in which that judgement was expected.

6. Healthcare and welfare encounters: barriers and support

Waiting and access difficulties, non-empathic professional encounters, administrative difficulties, experiences of professional empathy, and requests for service improvement were all general categories. Difficulties finding a suitable centre, uncertainty during assessment and diagnosis, and mixed treatment experiences were typical. Negative and positive experiences therefore coexisted; the general frequency of one did not negate the other.

Mothers described long waits for assessment or consultation, uncertainty about which services were available, and reliance on other parents for information. Participant 1 reported waiting for both an appointment and a later assessment, while Participant 7 described a brief consultation after an extended wait. These are retrospective accounts of access, not independently verified waiting-time estimates. Difficult communication sometimes made an already demanding encounter feel blaming:

"Because the child kept crying and trying to leave, they said the assessment couldn't go ahead like this... 'What are you going to do, mother?'—they kept pressing me as if scolding..." (Participant 1)

Administrative work also involved repeated enquiries and uncertainty about eligibility. Participant 3 described receiving conflicting guidance even after presenting documentation. Participant 5 described having to persist before a workable form was identified:

"I kept phoning and coming in—this is the fourth or fifth time now, isn't it?... and they just said no, absolutely not... but in the end it turned out there was a form that did work." (Participant 5)

Participant 7 described paying directly for a service after being told that the timing of the child's attendance did not meet funding requirements. Across these accounts, mothers experienced finding information, clarifying rules, and coordinating arrangements as additional work. Whether particular barriers arose from discriminatory design, local interpretation of rules, resource scarcity, or other organisational problems cannot be determined from these interviews alone.

Supportive encounters were equally important. Participant 4 described staff helping with practical paperwork, Participant 6 valued a therapist's flexibility, and Participant 7 appreciated detailed observations and guidance that could be used at home. Participant 1 described the relief of being acknowledged:

"They often say things like, 'Mother, this must be so hard for you'... when they say 'that must have been the case', the hardship is greatly eased—there's that." (Participant 1)

Mothers valued more than a service's formal availability. Explanations, respectful treatment, responsiveness, and usable assistance affected how supported they felt. However, these accounts do not show that empathy by itself overcame access barriers or produced sustained changes in health. They identify features of encounters that mothers experienced as helpful.

7. Educational settings: uneven accommodation and sources of reassurance

Insufficient teacher understanding of disability was a general category. Mothers also described classroom environments that did not fit their children's needs, mixed experiences with school or childcare provision, requests for better support, difficulty with peer relationships, and supportive teachers; these were typical categories. Behaviour-focused control, overt school-related stigma, and anxiety about bullying were variant. Frequency labels do not establish whether healthcare or education was more stigmatising, particularly when children had different educational experiences.

Mothers described concerns that their children's behaviour was treated primarily as a disciplinary problem or that participation depended on the child adapting without adequate accommodation. Participant 5 also described the pain of public disclosure and labelling at a school event. By contrast, mothers' worries about possible bullying were anticipatory accounts and should not all be treated as confirmed incidents of victimisation.

"Because he can't defend himself... if the other kids pick on him he can't protect himself, so I'm anxious. I worry he'll be bullied." (Participant 5)

The need for concrete communication was recurrent. Participant 5 wanted information about classroom situations that could be discussed or practised with the child, rather than general instructions to behave differently. Participants sought clearer links among home, school, and treatment services, as well as safer and more predictable environments.

Positive examples showed that institutional contact was not uniformly experienced as exclusion. Participant 2 valued specific feedback about social interactions. Participant 7 described a teacher who helped classmates understand her child and avoided publicly humiliating him. Participant 5 recalled a teacher adapting sports-day participation to the child's sensitivity to sound. Mothers experienced such responses as reassurance and practical support, but the accounts do not establish how consistently these practices were implemented across schools.

Discussion

The study's contribution and its boundaries

This study offers an account of how seven service-connected mothers in South Korea understood stress alongside caregiving, social evaluation, and professional or institutional encounters. Its contribution is not the discovery that mothers of children with developmental disabilities experience distress, stigma, or service barriers. Those experiences are documented in earlier research (Gilson et al., 2021; Ng & Ng, 2022). Rather, the accounts illustrate how practical difficulties and judgements about maternal adequacy could become entangled within the same everyday situations, while supportive relationships created contrasting experiences.

For example, travelling between services was not only a time demand; it could restrict employment and opportunities for recovery. A child's behaviour in public could create an immediate support or safety need while also prompting concern about how the mother would be evaluated. An unclear administrative decision could require further coordination while leaving a mother feeling that obtaining support depended on her persistence. These connections are interpretive observations based on participants' accounts. They do not demonstrate a recursive causal process or show that one level of stigma generated another. We interpret this conjunction as a twofold demand: obtaining practical support while managing possible judgements of maternal adequacy. An appointment may be available while the encounter feels blaming; conversely, sympathetic communication may ease an encounter without removing an access obstacle. This distinction directs attention to both the usability of support and the experience of seeking it.

Care demands and the conditions for recovery

The accounts of treatment-centred schedules and continuing care during illness direct attention to the conditions under which mothers can rest, attend to their health, or maintain activities outside caregiving. Recent research on the sustainability of routines in families of autistic children similarly situates family adaptation within daily arrangements and available support (Zakirova-Engstrand & Wilder, 2026). The present accounts add examples of how mothers perceived the difficulty of pausing or rearranging those arrangements. They should not be generalised into an assertion that developmental disability necessarily entails unremitting crisis or that mothers' physical health problems result directly from stigma.

This distinction matters for practice. A recommendation to obtain counselling or medical care may be difficult to enact when transport, treatment appointments, and substitute care are unresolved. Psychological support remains potentially valuable; the study did not assess whether individual interventions were effective. The implication is to consider practical access to support alongside its content, rather than to dismiss coping-oriented help or assume that mothers simply need to make better

choices. Reported postponement of personal needs should invite questions about available alternatives, not a judgement that mothers are failing at self-care.

Separating stigma from other sources of strain

Mothers' descriptions of criticism, humiliating labels, or being treated as inadequate provide material for examining disability-related stigma. Concerns about future judgement are more accurately described as anticipated stigma, whereas internalised stigma requires evidence that negative social meanings have become part of self-evaluation (Goffman, 1963; Mak & Cheung, 2008). The presence of guilt across all seven cases therefore does not establish affiliate stigma in every case. Guilt may concern perceived causation, a regretted response to the child, limited time for siblings, or standards of maternal responsibility. These distinctions preserve the analytic value of stigma rather than making it a label for all distress.

The same caution applies to structural stigma. Mothers reported barriers across services, but institutional location alone does not make an encounter structural stigma. A disrespectful remark may reflect interpersonal devaluation, while a restrictive rule may reflect a wider exclusionary arrangement. Establishing the latter requires evidence of how rules, resource decisions, and implementation systematically disadvantage people on the basis of a stigmatised status (Hatzenbuehler, 2016; Link & Phelan, 2001). This study identifies experiences that warrant such investigation; it does not independently demonstrate discriminatory policy design or distinguish every instance of exclusion from under-resourcing.

A useful implication is to distinguish two questions: whether an encounter adds work or distress, and whether that disadvantage is specifically produced through stigma. Both questions matter, but they need not have the same answer. Future multi-perspective studies could examine eligibility documents, accommodation practices, referral processes, and professionals' accounts alongside mothers' experiences. That approach could clarify which problems call for anti-discrimination measures, which require service coordination or additional resources, and which involve both.

Maternal responsibility in a Korean context

Some mothers connected their children's development to their own adequacy and described criticism from people close to them. These accounts can be interpreted through the moral significance attached to being a capable mother, while recognising that the relevant expectations varied across families. Yang et al. (2007) draw attention to the locally valued relationships and identities threatened by stigma. Korean research on autism also highlights the relevance of developmental expectations and family concerns to diagnosis and support (Grinker & Cho, 2013; Kang-Yi et al., 2013). These sources provide context for interpretation, not a basis for treating national culture as a measured cause.

The findings should therefore not be read as a contrast between a uniformly collectivist Korea and an individualist West. The study includes no cross-national comparison, and similar concerns about

parental credibility and access to mental health support have been reported elsewhere (Gilson et al., 2021). Nor did the presence of extended family necessarily mean either support or stigma. The contrast between practical caregiving imbalance and a spouse perceived as caring demonstrates why concrete relationships are more informative than general assumptions about familism. Mothers also questioned public misunderstandings and redefined expectations, rather than merely reproducing a single cultural script.

Supportive encounters and priorities for services

The coexistence of difficult and helpful encounters is central to the findings. Mothers valued professionals and teachers who explained procedures, recognised their observations, assisted with practical obstacles, and adapted expectations to the child. This emphasis is consistent with research on family–professional partnerships and family-centred care (Dunst & Trivette, 2009; Johnston & Burke, 2026). In these accounts, support was not limited to reassurance: it included actions that made a situation more understandable or manageable.

Recognition is therefore a useful description of what mothers valued, but ‘protective mechanism’ would overstate what was demonstrated. The interviews did not establish whether supportive encounters preceded improvement, how long relief lasted, or which component produced change. Similarly, an account of a supportive teacher does not show that school-level inclusion was secure. These experiences instead identify potentially modifiable features of services whose implementation and effects should be evaluated.

Three linked priorities follow from the accounts. First, services can examine whether families receive consistent, understandable information about assessment, eligibility, and available help. Second, professionals can combine respectful communication with practical accommodation, while avoiding explanations that place all responsibility for a child’s participation on the mother. Third, coordination across health, welfare, and education can be evaluated in terms of the work it requires from families, including repeated enquiries, travel, and arranging care. These are priorities suggested by the accounts, not interventions whose effectiveness has been demonstrated by this study.

Mothers’ willingness to acquire expertise and advocate for children should not be taken to mean that adequate services can depend on persistent parental effort. Support should also remain accessible to families who have fewer resources, less time, or less capacity to navigate complex systems. At the same time, family-centred practice should not treat mothers’ perspectives as substitutes for children’s own preferences and experiences. Collaboration with children and disabled people is needed when designing accommodations and determining what participation and well-being mean in practice.

Limitations and future research

The study’s small, experience-selected sample and retrospective interviews delimit its conclusions. Participants were all mothers, had prior experiences of stigma or exclusion, and were connected to developmental services. The study cannot estimate prevalence, represent fathers or other caregivers, or

explain how experiences differ among families who are disconnected from services. Reports of experiences in all seven cases refer only to this sample; they do not establish a universal feature of Korean parenting or institutions.

Diagnostic and age variation broadens the range of accounts but reduces the depth of within-group interpretation. Autism spectrum disorder, intellectual disability, and developmental delay should not be conflated, and seven cases cannot support meaningful comparisons among these groups. Children's support needs and educational circumstances may also change across development. Information power is best considered in relation to this restricted analytic purpose, not invoked retrospectively to claim saturation or to remove the limitations of heterogeneous recruitment (Malterud et al., 2016). Future research could focus on a more closely defined transition or service context.

The interviews provide mothers' recollections and interpretations, not direct observations of professional practice, policy implementation, or children's experiences. Recall, current emotional circumstances, and stigma-focused prompts may have influenced which events were described. The study cannot determine temporal direction or establish that institutional barriers caused health changes, self-blame, or withdrawal. Accounts of symptoms and diagnoses were not independently assessed as outcomes. Longitudinal and multi-perspective research could examine how particular encounters, support arrangements, and interpretations change over time.

Finally, consensus and auditing do not remove the influence of the research team's disciplinary and cultural positions. The broad range of domains and categories risks dividing connected experiences into many descriptive units. The integrated narrative addresses presentation, but it does not substitute for further transcript-level analysis or greater sampling depth. Clear reporting of recruitment, interviewer relationships, analytic decisions, and the language and translation of interviews is necessary for readers to assess transferability and interpretive credibility.

Conclusion

For these seven mothers, caregiving stress was experienced alongside concerns about social judgement and the practical and relational conditions of obtaining support. Their accounts suggest that service navigation, maternal self-evaluation, and opportunities for recovery deserve attention together, without treating every difficulty as stigma or claiming a demonstrated causal cycle. Helpful encounters included respectful communication, usable guidance, and accommodation of children's needs. A bounded account of these experiences can inform the development and evaluation of support that reduces unnecessary work for families and respects both mothers' circumstances and children's dignity.

Declarations

Author Contribution

Seo Haeri contributed to the conceptualization of the study, data curation, formal analysis, investigation, and writing of the original draft. Minsun Kim contributed to the conceptualization and methodology, supervised the study, validated the results, and reviewed and edited the manuscript. All authors read and approved the final manuscript.

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