

ORIGINAL

Family Social Support for Children with Disabilities: A Case Study of Seven Families in Rappocini District, Makassar

Apoyo social familiar para niños con discapacidad: un estudio de caso de siete familias en el distrito de Rappocini, Makassar

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ABSTRACT

Introduction: the presence of a child with a disability in a family brings significant challenges that require emotional, social, and practical adjustments, so that the role of the family as the primary source of support becomes crucial in ensuring the growth and development, protection, and rights of children in their entirety amidst the social stigma and limitations they experience.

Method: this study employs a qualitative case study approach in Rappocini District, Makassar, to explore in-depth the forms of family social support for children with disabilities. Data were collected through interviews, observations, and documentation of seven families, and then analyzed using the Miles and Huberman model.

Results: this research shows that family social support, encompassing emotional, esteem, instrumental, informational, and social network aspects, is crucial in helping children with disabilities cope with social stigma and the challenges of daily life. However, psychological and economic barriers, access to services, and low disability literacy in the community reinforce social exclusion and weaken families' ability to provide optimal support.

Conclusions: this study highlights the importance of family support for children with disabilities. However, it shows that social stigma, psychosocial barriers, economics, and low access to services are key interrelated challenges, necessitating inclusive interventions and further research to strengthen the role of families and communities.

Keywords: Children with Disabilities; Family Social Support; Parent Community; Social Involvement; Family Acceptance.

RESUMEN

Introducción: la presencia de un niño con discapacidad en una familia conlleva desafíos significativos que requieren ajustes emocionales, sociales y prácticos. Por ello, el papel de la familia como principal fuente de apoyo se vuelve crucial para garantizar el crecimiento, el desarrollo, la protección y los derechos de los niños en su totalidad, en medio del estigma social y las limitaciones que experimentan.

Método: este estudio emplea un enfoque cualitativo de estudio de caso en el distrito de Rappocini, Makassar, para explorar en profundidad las formas de apoyo social familiar para niños con discapacidad. Los datos se recopilaron mediante entrevistas, observaciones y documentación de siete familias, y posteriormente se analizaron utilizando el modelo de Miles y Huberman.

Resultados: esta investigación muestra que el apoyo social familiar, que abarca aspectos emocionales, de autoestima, instrumentales, informativos y de redes sociales, es crucial para ayudar a los niños con discapacidad a afrontar el estigma social y los desafíos de la vida diaria. Sin embargo, las barreras psicológicas

y económicas, el acceso a los servicios y la baja alfabetización sobre discapacidad en la comunidad refuerzan la exclusión social y debilitan la capacidad de las familias para brindar un apoyo óptimo.

Conclusiones: este estudio destaca la importancia del apoyo familiar para los niños con discapacidad. Sin embargo, se demuestra que el estigma social, las barreras psicosociales, la situación económica y el escaso acceso a los servicios son desafíos claves interrelacionados que requieren intervenciones inclusivas y mayor investigación para fortalecer el papel de las familias y las comunidades.

Palabras clave: Niños con Discapacidad; Apoyo Social Familiar; Comunidad de Padres; Participación Social; Aceptación Familiar.

INTRODUCTION

Families play a crucial role in supporting the growth and development of children, including children with disabilities. Family support is a determining factor that helps children navigate physical, psychological, cognitive, and social limitations.⁽¹⁾ The presence of a child with a disability often requires families to make significant emotional and practical adjustments, especially when the child's condition does not align with parents' initial expectations.⁽²⁾ Children with disabilities are a vulnerable group who require special care, therapy, and supportive services. They also continue to face stigma, intimidation, and discrimination in various forms, including ridicule, insults, and social exclusion.⁽³⁾ Such stigma can have serious psychological impacts, leading to low self-esteem, lack of confidence, and the perception of being unable to achieve their future potential.⁽⁴⁾

National statistics indicate that the prevalence of disabilities among children aged 5-19 years in Indonesia is 3,3 %, equivalent to approximately 2 197 833 children (Coordinating Ministry for Human Development and Culture, June 2022). A 2022 survey by the Central Statistics Agency reported an increase in the number of persons with disabilities to around 22,5 million, up from 16,5 million in 2021. At the provincial level, data from the South Sulawesi Government's PPID recorded 3 634 persons with disabilities in Makassar City in 2022, with 171 of them residing in Rappocini District according to the Makassar City Social Service.

These figures highlight the essential role of families as the closest environment and primary source of protection and support for children with disabilities. Family social support is vital for enhancing children's sense of security, self-worth, and confidence.⁽⁵⁾ Previous research, including that by Fadlia Nur Fauzia Kumala et al. has shown that such support significantly influences children's confidence, openness, and courage. Children with disabilities also possess the same rights as their non-disabled peers—to live, grow, develop, participate, and be protected from all forms of violence and discrimination.⁽⁶⁾ However, children and adolescents with disabilities remain at risk of receiving inadequate emotional and social support due to negative attitudes, neglect, or misunderstandings regarding their needs.⁽⁷⁾

Family awareness of the needs of children with disabilities must be cultivated early. Acceptance of the child's condition, both physically and emotionally, enables families to provide compassion, care, and consistent support. Such support is rooted in the roles of parents and other family members as the first system of care surrounding the child.⁽⁸⁾ A supportive family environment creates conditions conducive to the development of adaptive skills for children with disabilities.⁽⁹⁾ From a systems theory perspective, family support functions as part of an interconnected structure influencing the child as a microsystem. When the family system does not function well, its subsystems—family members and the child—are likewise affected.⁽¹⁰⁾

Although prior studies have emphasized the importance of family support for children with disabilities, few qualitative studies have explored the specific forms of support and the multifaceted barriers faced by families in low-resource, urban Indonesian contexts such as Makassar, where community stigma and fragmented services remain significant challenges. Research examining how families navigate these barriers within dense, urban environments is still limited. Guided by social support theory and systems theory, this study seeks to address these gaps by examining how families provide support and what obstacles they face in doing so. The unique contribution of this article lies in offering an in-depth understanding of the forms of family social support and the multidimensional challenges encountered by families raising children with disabilities in an urban Indonesian setting, thereby enriching the literature on disability, stigma, and family support within Southeast Asian contexts.

METHOD

This study employed a qualitative approach using a case study design to gain an in-depth understanding of the forms of family social support provided to children with disabilities who experience stigma within their social environment. The case study design was chosen because it enables the exploration of complex social processes and subjective experiences that cannot be captured through quantitative measures. In this research,

the “case” refers to the collective experiences of seven families raising children with disabilities in Rappocini District, Makassar City, an urban area identified as having recurring incidents of stigma and bullying against children with disabilities. Rappocini District therefore serves as the contextual case setting, while the seven families function as embedded units of analysis within that case.

Population and Samples

Participants were selected using purposive sampling based on information provided by local disability advocates affiliated with the Ministry of Social Affairs. These advocates were contacted directly via telephone and community WhatsApp groups, where they identified families who had expressed challenges related to stigma. Advocates then facilitated the first introduction between the researcher and the families. The inclusion criteria were:

- children aged 7-18 years who have a documented history or lived experience of social discrimination or stigma;
- nuclear family members or close relatives who live in the same house as the child and are directly involved in daily caregiving.
- Families were excluded if they were unwilling to participate, unable to communicate experiences openly, or currently undergoing acute medical or psychological crises.

Participation was fully voluntary. The researcher provided written and verbal informed consent to all adult participants, and assent procedures were carried out with children when appropriate. Participants were informed about the study purpose, the types of questions asked, their right to withdraw at any time, the confidentiality procedures, and how their data would be used. To protect anonymity, all names, locations within the district, and identifiable details were replaced with pseudonyms, and data were stored in encrypted digital folders accessible only to the researcher. These ethical procedures ensured the protection of vulnerable participants and met qualitative research standards for studies involving minors and marginalized populations.

Data Collection

Data were collected through semi-structured interviews, direct observation, and document analysis. In-depth semi-structured interviews were conducted with seven families, usually involving mothers, fathers, or guardians who served as primary caregivers. Interviews lasted between 45-90 minutes on average and were conducted in participants’ homes to ensure comfort. The interview guide consisted of open-ended questions on forms of support, experiences with stigma, coping strategies, and barriers faced by families. All interviews were audio-recorded with permission and transcribed verbatim. The interview guide is available upon request. Direct observations were carried out during home visits. The researcher observed parent-child interactions, family routines, communication patterns, and the home environment, including the physical accessibility of the living space. Each observation session lasted approximately 30-60 minutes. Field notes captured both descriptive details and analytic reflections. Initial observations confirmed the presence of stigma, as several children were labeled “burdensome” or “abnormal,” which inhibited their engagement with peers. Document analysis involved reviewing relevant materials such as school reports, letters from disability advocacy groups, community meeting notes, and local government documents related to disability services. These documents provided contextual information about the social environment and service access in Rappocini District.

Data Analysis

Data were analyzed using the Miles and Huberman interactive model, which involves an iterative cycle of data reduction, data display, and conclusion drawing.

1. Data Reduction: Interview transcripts, observation notes, and documents were coded manually. The researcher sorted and condensed the data into thematic categories related to forms of family support (emotional, instrumental, informational, and appraisal support) and barriers (stigma, service limitations, financial constraints, and social exclusion).
2. Data Display: The coded data were organized into matrices and narrative charts that allowed patterns, variations, and relationships to be visualized. Narrative descriptions were constructed to capture the processes through which families provided social support and the challenges encountered.
3. Conclusion Drawing and Verification: Conclusions were developed gradually as patterns became clearer through repeated comparison of data sources. The validity of the findings was strengthened through triangulation, which included comparing interview data with observations and documentation, as well as conducting follow-up checks with several participants to verify interpretations.

This methodological approach ensured the credibility and trustworthiness of the findings while providing a comprehensive understanding of family social support for children with disabilities facing stigma in an urban

Indonesian context.

RESULTS

Table 1. Respondent Characteristics

No	Respondent's Initials	Parents & Work	Age & Type of Child Disability	Children's School
1	NZ	Mother S (37 years), father R (daily laborer)	NZ, 11 years old, physical disability since birth	-
2	AZ	Father S Saputra (construction worker), mother Y	AZ, hyperactive disability since the age of 5 years	5th grade elementary school, State Special School 1 Makassar
3	NR	Father SH, mother H	NR, 15 years old, physically disabled since childhood	Grade 2 of Junior High School, State Special School 1 Makassar
4	YN	Father JKW (fried rice seller), mother SY	YN, 13 years old, Down Syndrome since birth	Junior High School, State Special School 1 Makassar
5	IT	Father SP, mother NB	IT (Dg. G), 10 years old, physical disability since birth	State Special School 2 Takalar
6	MA	Father AN, mother DI	MA, visually impaired (totally blind) since birth	Grade 6 Elementary School, State Special School 1 Makassar
7	AF	Father JE, mother RY	AF, 13 years old, physical disability (imperfect legs)	Elementary School, State Special School 1 Makassar

Seven families participated in this study (table 1). The children were aged 10-15 years and experienced a range of disabilities, including physical impairments (four children), Down Syndrome (one child), hyperactivity (one child), and total visual impairment (one child).

Most parents worked in informal and low-income occupations (daily laborer, construction worker, fried-rice seller), which shaped many of the material and access constraints described later. Six of the seven children attended special schools (SLB), while one was not enrolled in formal education. These profiles set the context for understanding the types of support provided and the challenges encountered by families.

Forms of Family Social Support

Five overarching themes emerged regarding how families supported their children. Although all families provided several forms of support, emotional and instrumental support were the most consistently reported across participants.

Emotional Support

Six of the seven families relied heavily on emotional support to help children cope with teasing, exclusion, or emotional dysregulation. This support typically involved physical affection (hugging), verbal reassurance, and calming strategies. Parents often encouraged children to avoid confrontation. NZ's mother advised: *"If someone bothers you, come home quickly."* She also soothed her child during distress *"When he cries... I hug him and calm him down."* Parents of children with higher emotional sensitivity, such as those with Down Syndrome or hyperactivity, emphasized physical closeness *"When YN is angry... I just bring her close, hug her, stroke her."* These responses illustrate how families became the primary regulators of children's emotional well-being, compensating for the lack of access to formal psychological or behavioral services.

Building Daily-Life Competence through Informational Guidance

Five families provided regular informational support to strengthen children's functional independence. Parents guided children through daily routines such as hygiene, dressing, eating, and polite behavior. NZ's mother explained *"I teach him to bathe, brush his teeth... I show him how."* For the child with total visual impairment, informational support extended into environmental orientation. MA's mother taught spatial navigation *"Here is the cupboard, here is the door... so he knows the way in and out."* This form of support filled the gap left by the limited availability of occupational therapy or training programs, highlighting parents' role as informal rehabilitative agents in daily life.

Fulfilling Material and Assistive Needs under Financial Constraints

Instrumental support was the only support type provided by all seven families, though the extent varied due to economic hardship. Parents supplied food, diapers, vitamins, and occasionally assistive devices. However,

financial instability often limited consistency. NZ's mother reported *"I stopped [buying vitamins] because they cost 150 thousand a bottle."* Some parents invested in mobility aids or communication tools. AF's mother described *"He uses a wheelchair to go to Quranic study... sometimes I give him a phone for school groups."* This theme reflects an ongoing struggle to meet disability-related material needs in households with precarious incomes.

Reinforcing Confidence through Esteem-Based Support

Four families used praise, encouragement, symbolic rewards, or celebrations of small achievements to bolster children's confidence. In NZ's household, visible independence was recognized *"We are happy because he can do it himself."* IT's father provided motivational praise during fasting *"Dg. Gassing is the best at fasting... I always praise him so he becomes more enthusiastic."* Esteem support helped counterbalance stigma by reinforcing children's sense of capability and worth.

Uneven Participation in Social-Group Support

Participation in disability-related communities was mixed: three families actively participated, while four did not. Parents who joined groups found them valuable for sharing ideas and accessing activities *"We often share ideas... paper folding, coloring, baking."* (YN's mother). However, others avoided involvement due to anxiety or fear of their child being mocked *"I'm afraid my child will be laughed at."* (NZ's mother). This variation reflects how community stigma and parental confidence influence access to collective social support.

Barriers experienced by families in providing social support

Families encountered multiple intersecting barriers that shaped the quantity and quality of support they could provide.

Psychological and Emotional Adjustment Difficulties

Five families described early emotional struggles when accepting the child's condition or responding to their emotional behavior. YN's mother shared *"At first, it was hard to accept... he often cried loudly."* Some parents only achieved acceptance through exposure to other families *"After I joined other parents... I realized it wasn't just me."* These emotional barriers often delayed access to support systems or reduced consistency in caregiving.

Economic Hardship Affecting All Families

Economic constraints were reported by every family, shaping their ability to provide consistent material support, transportation, or therapy. NZ's mother noted *"Sometimes he suddenly wants something... but not having money is normal."* Transportation costs were a major barrier *"I want to give Grab... but sometimes I don't have money."* (MA's mother). Such limitations often led to inconsistent school attendance and unmet health needs.

Difficulties Accessing Health and Therapy Services

Four families struggled with navigating administrative processes and referral systems. IT's father explained *"We didn't know how to get from the health center to the hospital... then to the specialist."* Access improved only when families joined foundations *"Since joining Sipatokong... everything was taken care of."* (YN's mother). The finding highlights systemic fragmentation and a lack of informational support from institutions.

Challenges Accessing Education

Difficulties in transportation, school fees, and finding appropriate schools were common across five families. MA's mother described *"If I don't have a motorbike... sometimes I can afford Grab, sometimes not."* IT's father added *"The difficult part is taking him to school and picking him up."* These constraints limited routine participation in formal education.

Social Stigma and Limited Environmental Support

While all families experienced strong support from extended relatives, six families reported limited empathy or negative attitudes from neighbors. NZ's mother said *"Family supports me, but neighbors don't pay attention."* AF's mother echoed *"From the local environment, it's rare, if ever."* This persistent stigma in the immediate social environment shaped children's experiences of exclusion and parents' reluctance to join community groups.

Lack of Information and Disability Literacy

Several parents described limited knowledge about services, schools, or how to understand their child's

disability. AF's mother admitted "*I never looked for information... I just accepted it.*" MA's mother explained "*I didn't know where the special schools were... until a relative told us.*" This lack of information often delayed needed services or caused initial uncertainty in caregiving practices.

DISCUSSION

The central argument of this study is that families serve as the primary and most reliable source of social support for children with disabilities, yet their ability to provide this support is continuously shaped—and often constrained—by powerful forms of enacted, felt, and structural stigma within their social environment. This finding aligns with Sarafino's concept of social support as emotional, instrumental, informational, appraisal, and network-based assistance,^(11,12) but extends it by showing how the social context determines whether such support can be enacted consistently.

Family Support Within a Context of Stigma: A Goffmanian Interpretation

Goffman's theory of stigma provides a strong interpretive lens for understanding not only the experiences of children but also the behavior and coping strategies of their families.⁽¹³⁾ The findings reveal that parents navigate several interlocking dimensions of stigma that shape their support practices.⁽¹⁴⁾

Enacted Stigma: Bullying, Mocking, and Social Exclusion

The teasing, mocking, and discriminatory attitudes described by participants are examples of what Goffman terms "enacted stigma"—open expressions of rejection and discrimination. Children being called "*abnormal*" or "*burdensome*" demonstrate how stigma is reproduced in everyday interactions.⁽¹⁵⁾ This environment reinforces the family's role as an emotional buffer, explaining why emotional support emerged as the most common response. This finding mirrors earlier work,⁽¹⁶⁾ which shows that overt discrimination intensifies psychological distress in families and contributes to social withdrawal. What distinguishes the Makassar context, however, is that enacted stigma appears not only in peer interactions but also among adult neighbors, amplifying its impact.

Felt Stigma: Shame, Withdrawal, and Fear of Judgment

Several parents avoided community events or disability-related groups because they feared their child would be ridiculed. This aligns with Goffman's notion of "felt stigma," the internalized fear of being judged or devalued. For example, NZ's mother avoided community groups solely because of anticipated ridicule—an act of "managing a spoiled identity" on behalf of her child. This also reflects courtesy stigma, where stigma extends to anyone associated with the stigmatized individual. Parents' shame or reluctance to engage socially is thus not merely a personal emotion—it is a social product, shaped by how disability is perceived in their environment. This explains why only a minority of families accessed social-group support despite its potential value.

Structural Stigma: Limited Services, Complex Referrals, Economic Hardship

Economic barriers, inaccessible transportation, and complicated health-referral processes reflect Goffman's broader concept of stigma embedded in institutions. When public systems fail to accommodate disability needs, families encounter structural stigma.^(17,18) The difficulty IT's father experienced navigating referral pathways, or the reliance on foundations like Sipatokkong for therapy access, reflect systemic weaknesses that reproduce inequality. These findings are comparable to studies in other low-resource regions,⁽¹⁶⁾ where service fragmentation and financial hardship significantly hinder disability care. However, the Makassar context illustrates how structural stigma interacts with economic vulnerability, making support provision even more precarious.

Synthesis with Existing Literature

The five forms of family support identified in this study correspond with Sarafino's typology,^(11,12) confirming that families attempt to fulfill both emotional and practical needs. At the same time, this study adds depth by illustrating why these supports vary across families.

- The emotional distress and shame experienced by parents resonate with previous findings,⁽¹⁶⁾ but this study shows how such emotions translate into withdrawal from social-group support.
- Economic challenges align with other research highlighting the financial burden of disability care,⁽¹⁶⁾ yet here they are shown to directly shape educational access and therapy consistency.
- The difficulty accessing health services echoes,⁽¹⁹⁾ which notes the lack of disability-friendly service pathways.⁽²⁰⁾
- Limited understanding of disability by parents and communities reinforces findings in ⁽²¹⁾, which highlight low disability literacy as a root cause of stigma.

This study therefore both confirms and extends existing research by detailing how multiple layers of stigma intersect to shape family support practices in an urban Indonesian context.

Interpretation

The findings of this study demonstrate that families function as the primary system of care for children with disabilities, not only providing emotional and material support but also acting as buffers against the effects of stigma in their social environment. Using Goffman's theory, it becomes evident that family responses—such as withdrawing from social groups, maintaining emotional closeness, or carefully managing children's exposure to others—are strategies to navigate both enacted stigma (overt discrimination) and felt stigma (fear of judgment). This illustrates that family support is never exercised in isolation; it is shaped by how disability is understood, labeled, and socially constructed within the community.

Differential access to community networks further reveals how courtesy stigma influences parental behavior. Parents who feared ridicule or negative judgments avoided public interactions, reducing opportunities for their children to benefit from group-based support. Such avoidance strategies align with Goffman's concept of “managing a spoiled identity,” where families attempt to protect themselves and their children from anticipated stigma. This helps explain why only a minority of families in this study actively engaged with disability communities, despite acknowledging their benefits. Thus, variations in support are better understood as social consequences, not merely personal choices.

Structural stigma also plays a decisive role in shaping the support that families can provide. Limited access to health services, complex referral pathways, and economic barriers indicate that disability care remains heavily dependent on privately mobilized family resources. These constraints, consistent with prior studies ^(16,19), show how families are burdened by systemic gaps rather than individual shortcomings. The findings therefore highlight the intersection of social and structural forces that condition how families manage disability in everyday life.

Implications

The results underscore the need for multi-level interventions that address stigma at interpersonal, community, and institutional levels. At the interpersonal level, targeted parent-support programs could strengthen families' emotional resilience and reduce the burden of felt and courtesy stigma. This is crucial because parental withdrawal—often driven by anticipated ridicule—limits children's opportunities for social interaction and development. Programs led by disability professionals, peer mentors, or trained facilitators may help normalize disability and reduce parental isolation.

At the community level, public stigma-reduction campaigns are essential to transform negative attitudes that lead to enacted stigma such as bullying, stereotyping, and exclusion. Community education initiatives, including school-based anti-bullying programs, religious community engagement, and neighborhood awareness sessions, can foster environments where children with disabilities are treated with dignity. Improving disability literacy in the general population would reduce misperceptions and create more inclusive social spaces that encourage family participation in support networks.

At the structural level, the findings call for reforms in disability services, particularly in health and education sectors. Policymakers should simplify referral pathways, expand access to therapy and assistive devices, and subsidize transportation for families with limited financial resources. Strengthening inter-institutional coordination—between clinics, schools, and social services—would reduce the experience of structural stigma and support families who currently rely on fragmented systems. Ultimately, improving structural conditions is essential to ensuring that family support can function effectively rather than compensating for systemic failures.

Limitations

This study has several limitations that should be acknowledged:

- Small sample size (seven families) limits generalizability but remains acceptable for an in-depth qualitative case study.
- Single-district focus (Rappocini, Makassar) means findings may not represent experiences in other Indonesian settings.
- Potential social desirability bias, as parents may have presented their support in a more positive light.
- Lack of triangulation with service providers (teachers, health workers) which could have strengthened structural analysis.

Despite these limitations, the study provides valuable insights into the intersection of stigma and family support in an urban Indonesian context.

CONCLUSIONS

This study confirms that families play a key role in providing social support to children with disabilities. Based on Sarafino's theory, there are five forms of support: emotional, esteem, instrumental, informational, and social networks. This support is reflected in attention, motivation, fulfillment of needs, and guidance in daily activities. However, most families still experience limitations in accessing social networks, primarily due to social stigma and psychosocial barriers that cause them to withdraw from their environment. Furthermore, families also face various barriers to providing support, such as psychological distress, economic constraints, limited access to health and education services, and a lack of information about disabilities. These barriers are interconnected and demonstrate the strong construction of social stigma in family life. Therefore, the researchers recommend increased government support through integrated, inclusive services; active involvement of universities in research and advocacy; and empowerment of parents through community groups. Further research is also needed to assess the effectiveness of social interventions and compare conditions between families in urban and rural areas.

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