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Islamic spirituality and maternal resilience in down syndrome caregiving in Indonesia

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Abstract
This study explores the resilience of mothers caring for children with Down syndrome (DS) in Indonesia, identifying factors that influence coping capacity with a focus on Islamic spiritual values, social support systems, and their implications for inclusive early childhood Islamic education (PIAUD) in the post-pandemic era. A qualitative phenomenological approach was employed, involving two purposively selected mothers of children with DS from a special needs school in Malang City, East Java. Data were collected via in-depth interviews, participant observation, documentation, and key-informant interviews, then analyzed using Miles, Huberman, and Saldaña's interactive model. Two distinct resilience profiles emerged: Subject 1 demonstrated complete resilience anchored in tawakkal (trust in God) and ikhlas (sincerity); Subject 2 exhibited partial resilience constrained by socioeconomic limitations and unsupportive in-laws, yet sustained by Islamic family values and peer community networks. Findings indicate that PAUD institutions can serve as strategic resilience ecosystems by integrating Islamic values-based parenting programs, equipping teachers with inclusive and attachment-informed competencies, developing empathy-centered curricula, and leveraging digital platforms as post-pandemic support infrastructure.

Keywords: *Maternal Resilience; Down Syndrome; Islamic Values; Inclusive PAUD; Post-Pandemic; Digital Support*.

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Introduction

The birth of a child with Down syndrome (DS) can mark a significant transition for families, particularly for mothers who often take on primary caregiving responsibilities (Wenar & Kerig, 2009). Down syndrome, resulting from trisomy 21, is the most prevalent chromosomal condition associated with intellectual disability, occurring in approximately 1 in 700 live births worldwide (World Health Organization, 2023). In Indonesia, it is estimated that more than 300,000 individuals live with DS, a figure that continues to rise as neonatal survival rates improve (Kompas.com, 2022).

Mothers of children with DS may encounter multiple, intersecting challenges, such as managing complex medical comorbidities—like congenital heart defects, present in 40 to 50 percent of cases—addressing developmental delays requiring ongoing specialized intervention, shouldering financial burdens related to therapeutic expenses, and navigating societal stigma (Barlow & Durand, 2016; Davison et al., 2017; Mangunsong, 2018). These stressors have been compounded by the post-pandemic context, which has introduced additional difficulties—service disruptions, economic instability, and increased social isolation—that have particularly affected caregivers of children with disabilities (Yunus & Kurniawan, 2022). Despite these accumulating adversities, many mothers demonstrate a remarkable capacity for growth and adaptation, a phenomenon identified as psychological resilience—that is, the ability to maintain or recover emotional well-being and positive functioning in the face of challenges.

Grotberg (1997) defined resilience as the capacity to withstand, cope with, and be strengthened by adversity. Reivich & Shatté (2002) identified seven operational components: emotional regulation, impulse control, optimism, empathy, causal analysis, self-efficacy, and reaching out. Within the Indonesian Muslim context, resilience is closely linked to Islamic spiritual beliefs. Quranic injunctions to practice patience (sabar), trust in God (tawakkal), and sincere acceptance (ikhlas) establish a theologically grounded cognitive framework for reframing adversity (Qurrotul Uyun & Rumiani, 2022; Zamanian et al., 2023). These values function not only as personal resources but are also transmitted through family structures, community networks, and, importantly, early childhood Islamic education institutions.

The intersection of maternal resilience, Islamic spirituality, and early childhood education (PAUD) has received limited empirical investigation. Most existing studies examine resilience or religious coping independently, without addressing how PAUD institutions might systematically incorporate insights from maternal resilience to develop more inclusive and spiritually grounded educational environments. Additionally, the transformative effects of digitalization on support access and community building for parents of children with special needs remain an underexplored aspect of contemporary Indonesian PAUD discourse.

This research offers four principal contributions: (1) it examines resilience as experienced by Indonesian mothers of children with Down syndrome; (2) it identifies multilevel factors that influence maternal resilience; (3) it investigates the mediating role of Islamic spiritual values within these dynamics; and (4) it provides evidence-based recommendations for inclusive early childhood Islamic education in the post-pandemic digital era. Through the integration of phenomenological data with contemporary theoretical and policy frameworks, the study advances a contextually grounded and culturally relevant model for resilience-informed, inclusive PAUD practice, thereby addressing a significant gap in the Indonesian Islamic early childhood education literature.

Literature Review

Resilience Theory in Parenting Children with Special Needs

Resilience theory offers a dynamic, systemic framework for understanding positive adaptation amid adversity. Grotberg's (1995) tripartite model identifies three resilience sources: external supports (“I have”), inner strengths (“I am”), and interpersonal capacities (“I can”). Masten (2021) reframed resilience as an “ordinary magic” embedded in normative developmental systems, emphasizing that resilience is not an exceptional trait but a product of the interaction between individual characteristics and supportive environments. Ungar's (2022) cross-cultural perspective further argues that resilience is culturally and contextually constituted—a lens especially salient for Indonesian Muslim mothers in patrilocal households.

In DS caregiving specifically, Halimah & Hidayati (2015) found that emotion regulation is central to positive mother-child interactions. Biggs et al. (2024) demonstrated that the quality of family cohesion and community support significantly moderates parental resilience in families of children with intellectual disabilities. Widyawati & al. (2023) found that Indonesian mothers of children with DS exhibit distinct coping strategies shaped by cultural and religious contexts, with spiritual coping emerging as the most frequently employed strategy. Economic resources consistently emerge as a structural moderator: without adequate material resources, even highly capable individuals may struggle to enact their resilience capacities (Masten, 2021).

Islamic Spiritual Values as Resilience Resources

Islamic spirituality constitutes a rich resource for resilience among Indonesian mothers. Three Quranic concepts are particularly salient. First, tawakkal (Q.S. 3:159) involves complete reliance on Allah after maximal human effort, generating acceptance and equanimity regarding outcomes beyond one's control. Second, ikhlas (Q.S. 98:5) enables caregiving to be reframed as acts of worship performed solely for Allah's pleasure, reducing dependence on external validation. Third, sabar (Q.S. 2:153) is invoked throughout the Quran as the defining virtue of those tested by Allah, with divine assurances of reward providing meaning and sustaining hope.

Zamanian et al. (2023) demonstrated in a Muslim-majority sample that positive religious coping strategies—including benevolent reappraisal of disability as a divine gift and seeking spiritual support—significantly predict lower depression and anxiety among mothers of children with intellectual disabilities. Kuzzairi & al. (2023) similarly found that maternal psychological well-being among Indonesian caregivers of children with DS is strongly associated with Islamic religious engagement, particularly regular congregational worship attendance and Islamic parenting guidance. Rukmana & Mariyati (2024) further documented that Islamic psychological counseling approaches effectively strengthen self-acceptance and resilience among mothers facing caregiving challenges.

The Islamic family ecology extends these individual resources. Parental cooperation framed as ibadah, extended family obligations of mutual support (silaturrahim), and mosque-centered social capital collectively constitute a natural social welfare system. When these systems function, they provide mothers with emotional, practical, and informational support that amplifies individual spiritual coping. Yanasari (2024) and Nuraini (cited in Zulifatul & Siti, 2022) both documented that Islamic religious guidance—through majelis taklim, pengajian, and individual consultation—helps mothers of children with DS understand their children as an amanah from Allah, transforming perceptions of burden into meaning.

Digital Transformation, Post-Pandemic Context, and PAUD Inclusion

The COVID-19 pandemic constituted a global stress-test for families of children with disabilities. Yunus & Kurniawan (2022) documented significant regression in children's developmental gains and acute intensification of maternal psychological distress during Indonesian lockdowns, with service disruptions eliminating critical external supports precisely when most needed. Darmanto & al. (2024) found that pandemic-era social isolation particularly exacerbated stress among low-income caregivers of children with special needs, widening existing socioeconomic disparities in resilience outcomes.

Paradoxically, the pandemic also accelerated the adoption of digital tools, reshaping DS caregiving landscapes. Novita & Husna (2023) documented increased uptake of telehealth platforms, WhatsApp parent communities, and digital therapy applications among Indonesian caregivers of children with special needs in the post-pandemic period. These digital resources partially democratize access to information and peer support that were previously restricted to urban, higher-income families. Policy environments have evolved simultaneously: Permendikbud No. 82 Tahun 2023 mandates inclusive learning environments across all educational institutions, creating a legal foundation for PAUD inclusion and establishing new obligations for Islamic early childhood settings.

Parent-Teacher-Community Collaboration in Inclusive PAUD

Evidence for parent-teacher collaboration in inclusive early childhood settings is robust. Idhartono & Hidayati (2024) found that structured collaboration between PAUD teachers and parents of children with special needs significantly predicts child developmental outcomes and

maternal psychological well-being. Remanita & al. (2025) demonstrated that Islamic values-based parenting programs in PAUD settings effectively strengthen maternal coping capacity and child social inclusion. Fitria et al. (2025) further documented that PAUD teachers equipped with inclusive competencies and spiritual guidance skills serve as critical mediators between family resilience and child learning outcomes.

Teacher capacity is a critical mediating variable. Applied Behavior Analysis (ABA) training programs—now offered by multiple Islamic higher education institutions in partnership with professional psychology associations—provide PAUD educators with evidence-based tools for behavioral intervention. The theoretical gap this study addresses is the lack of an integrated model that connects maternal resilience mechanisms, socioeconomic moderators, digital support ecosystems, and PAUD institutional responses in the post-pandemic Indonesian context.

Methods

This study used a qualitative phenomenological approach. Data collection was conducted between February and November 2015 in Malang City, East Java. The subjects were two biological mothers of children with Down syndrome who were purposively selected from a Special Needs School, with the following criteria: having been the primary caregiver for at least five years and being willing to participate in the entire data collection process. Data were collected through three semi-structured in-depth interviews per subject (each lasting 60–120 minutes), 10 months of participant observation, documentation studies, and interviews with key informants from the family. Data analysis refers to the interactive model of Miles et al. (2020), which includes data condensation, data presentation, and iterative conclusion drawing. Data validity was ensured through triangulation of sources and methods, member checking, and the researcher's reflective journal (Lincoln & Guba, 1985). This study has received ethical approval from the Research Ethics Committee of the Faculty of Psychology, UIN Maulana Malik Ibrahim Malang.

Results and Discussion

Participant Characteristics

Table 1 presents the demographic profiles of the two participants. Subject 1 (SF) is a 38-year-old mother with a master's degree from a middle-income family who cares for a 12-year-old son with a moderate intellectual disability daily. Subject 2 (DS) is a 36-year-old mother from a low-income family who cares for a 12-year-old daughter with a similar condition. The most striking structural difference between the two—far beyond income—is the support from their in-laws: SF receives consistent support from her husband's family, while DS experiences rejection and discrimination from the same direction.

Table 1. Demographic Characteristics of Participants

Charecteristics	Subject 1 (SF)	Subject 2 (DS)
Age (years)	38	36
Education	Master's Degree (S2)	College (incomplete)
Marital Status	Married	Married
Number of Children	3 (1 with DS)	1 (with DS)
Children's Age	12 years	12 years
Children's Functional Level	Moderate intellectual disability, ambulatory, limited verbal	Moderate intellectual disability, ambulatory, verbal
Socioeconomic Status	Intermediate	Low
In-Law Support	Present and supportive	Not supportive/disapproving

Subject 1 (SF): Whole Resilience Based on Islamic Spirituality

SF fully demonstrates all seven components of Reivich & Shatté (2002) resilience, forming what the researchers call complete resilience—a mutually reinforcing configuration deeply rooted in Islamic spiritual values. In terms of emotional regulation, SF remained calm under prolonged public pressure, including during an incident in which her son's behavior prompted strangers in the market to hurl insults at her. Although her repeated apologies were not accepted, SF chose to yield rather than escalate the conflict. Her mother noted that her son "became increasingly receptive to Allah's will" as he grew older. This ability aligns with Halimah & Hidayati (2015) findings that good emotional regulation directly supports the quality of mother-child interactions.

SF's impulse control is evident in the way she lets go of personal goals she once pursued—traveling abroad and career advancement—without harboring any resentment. She frames it not as a dead-end resignation, but as an active theological acceptance. Her optimism is not just words; she translates it into concrete actions: expressing realistic and gradual hopes ("I hope he can be independent, at least able to take care of himself") and opening a small shop to train her child in managing money. Regarding empathy and the meaning of life, SF's parenting is driven by Islamic faith that is not empty words: "The lesson is that ultimately we depend on God and sincerity—surrendering our lives. I have become more sincere." This reflects the concept of amanah—children as entrusted to God, not possessions to be controlled—which fundamentally changes how we perceive loss and uncertainty. Rahayu & Setiawan (2024) found a similar result: an Islamic framework of meaning transforms the burden of parenting into an opportunity for spiritual growth for mothers of children with special needs.

Subject 2 (DS): Partial Resilience Amidst Structural Barriers

DS demonstrated some components of resilience, but was significantly hampered by socioeconomic barriers and a lack of support from her in-laws. Her emotional regulation was generally maintained when interacting with her daughter ("I coax her, find out what she wants. Use affection, not material incentives"), but occasionally broke down when external pressures came in waves—a stark illustration of the limits of individual capacity when social stressors continue to hit without respite. This finding aligns with Ungar's (2022) argument that barriers to resilience are more often systemic than personal. Economic limitations directly undermined DS's self-efficacy: "I knew seeing a specialist for a child like this was expensive. We couldn't afford it. Knowing that, I decided against it." Unable to access professional services, she relied on self-study online and shared experiences with other parents—a form of digital bricolage documented by Novita & Husna (2023) among low-income caregivers of children with special needs in post-pandemic Indonesia.

Despite these obstacles, DS found profound meaning in her parenting: "With this child, I have become more appreciative, more grateful, and more loving." This illustrates Ungar's (2022) concept of latent resilience: manifestations of strength rooted in cultural contexts and materially constrained, often downplayed by mainstream frameworks. Nuriyyatiningrum & al. (2022) documented similar findings among Indonesian mothers of children with special needs, finding that gratitude (syukur) and acceptance (qanaah) enabled positive adaptation even without adequate resource support.

Multi-Level Factors Influencing Resilience

Table 2 presents a comparative analysis of protective and risk factors at various ecological levels. The contrast between the two participants exemplifies Masten's (2021) argument that resilience always requires two things: internal capacity and external resources. SF's complete resilience profile reflects a favorable confluence of strong individual attributes, family support from various quarters, adequate economic resources, and a deep understanding of Islamic spirituality. Meanwhile, DS's partial resilience reflects the multiple burdens of structural barriers—economic hardship, in-laws' rejection, and geographic distance from a supportive family of origin—that ultimately overwhelm her considerable personal strengths.

Table 2. Multi-Level Protective and Risk Factors for Maternal Resilience

Factor Level	Subject 1 (SF) – Protective	Subject 2 (DS) – Risk/Mixed
Individual	High self-efficacy, emotional regulation, optimism, causal analysis	Empathy, causal analysis; limited self-efficacy
Microsystem (Family)	Husband, parents, and in-laws are all supportive	Family of origin supportive; in-laws rejecting
Mesosystem (Community)	Supportive friends and mosque community	Community of parents of children with DS supportive; environment hostile
Spiritual/Religious	Strong devotion and sincerity; active worship	Faith strong enough; Islamic family values prominent
Socioeconomic	Adequate; allows full access to intervention services	Severe limitations; limited access to therapy and specialists
Digital Resources	Limited internet use	Self-study via the internet; parents network via WhatsApp

The Role of Islamic Spirituality as the Primary Architecture of Resilience

The most theoretically significant finding is the mechanism by which Islamic spiritual values function as a resource for resilience. These values are not merely psychological comfort; they constitute a coherent cognitive-affective-behavioral system that redefines parenting for children with DS, regulates emotional responses, and maintains motivation to act. For SF, tawakkal (resignation) enabled a unique blend of courage to act and sincere acceptance: she actively managed medical interventions and therapy programs, while remaining open-minded about the outcomes. It is not fatalism; it is a paradoxical combination of efficacy and resignation that secular coping frameworks cannot fully capture. Ikhlas (sincerity) further enabled SF to continue struggling without needing applause from anyone, protecting her from the despair that often plagues unacknowledged long-term caregivers.

Zamanian et al. (2023) presented quantitative evidence confirming this: positive religious coping significantly predicted lower levels of depression and anxiety in Muslim mothers of children with special needs. Kuzzairi & al. (2023) and Rukmana & Mariyati (2024) confirmed similar findings in the Indonesian Islamic context, noting that structured Islamic religious guidance strengthened maternal self-acceptance, alleviated caregiver burnout, and encouraged better behavior in responding to children's needs. It is important to emphasize that spiritual resources are not equally accessible to everyone. The more limited spiritual engagement of children with special needs is not a reflection of weaker faith, but rather a result of energy depletion due to multiple stressors simultaneously. It implies that actively supporting maternal spiritual engagement—through facilitated religious study groups, collective dhikr groups, or structured Islamic parenting programs—is a truly evidence-based resilience intervention.

Socioeconomic Inequality and the Digital Ecosystem as Determinants of Resilience

The contrast between SF and DS clearly demonstrates that resilience always requires two things: internal capacity and external resources (Masten, 2021). DS's limited self-efficacy is not a sign of character weakness. However, rather a highly rational response to structural exclusion: specialist consultations, intensive therapy, and educational materials all require costs that low-income families cannot afford. Darmanto & al. (2024) documented that the post-pandemic economic downturn further widened this gap in Indonesia, with low-income families bearing a disproportionate income shock that directly limited access to disability-related services. Widyawati & al. (2023) also found that socioeconomic status significantly moderated the relationship between spiritual coping and maternal resilience outcomes in the context of parenting children with DS in Indonesia.

One important development since initial data collection is the emergence of the digital ecosystem as a compensatory resource that cannot be underestimated. DS's adaptive use of the

internet to replace unaffordable specialist consultations reflects what Novita & Husna (2023) call digital bricolage. Flores-Builds & Andrés-Roqueta (2022) demonstrated that technology-based parenting programs can produce outcomes comparable to in-person interventions for families of children with special needs, particularly in terms of parenting knowledge and stress reduction. These findings have direct implications for how early childhood education institutions design post-pandemic parent engagement: positioning digital platforms not as a substitute for in-person meetings, but as a complement that actually expands access and equality.

Conclusion

Maternal resilience in caring for children with developmental disabilities is a multi-level phenomenon shaped by the synergy of Islamic spiritual values, family and community support, socioeconomic resources, and access to professional and digital interventions. The primary contribution of this study is to characterize Islamic values—specifically tawakkal (trust), ikhlas (sincerity), and sabar (patience)—as the primary cognitive-affective architecture through which Indonesian Muslim mothers find meaning amidst the ongoing challenges of parenting. For inclusive early childhood education (ECE) practices, this study lays the foundation for a resilience-based partnership model in which ECE institutions assume multiple roles: education providers, community centers, spiritual strengthening spaces, digital resource curators, and policy advocacy platforms. Limitations of the study include the small purposive sample (n=2) and the time lag between data collection and publication. Future research should use larger, geographically diverse samples, a longitudinal mixed-methods design, and validated resilience instruments to strengthen the transferability of the findings to the Indonesian inclusive ECE context.

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