





The sacred trust: Spiritual meaning-making among Indonesian parents of firstborn children with autism



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Dates:

Received: 01 Nov. 2025
 Accepted: 27 Nov. 2025
 Published: 21 Jan. 2026

How to cite this article:

Widiastuti, A.A., Atmoko, A.,
 Eva, N. & Soares, D., 2026,
 'The sacred trust: Spiritual
 meaning-making among
 Indonesian parents of
 firstborn children with
 autism', *HTS Teologiese
 Studies/Theological Studies*
 82(1), a11132. [https://doi.
 org/10.4102/hts.v82i1.11132](https://doi.org/10.4102/hts.v82i1.11132)

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This qualitative phenomenological study explores how Indonesian parents theologically and spiritually interpret the experience of raising their firstborn child with autism spectrum disorder in a Javanese cultural context, drawing on in-depth interviews with eight parents – four Catholic and four Muslim – raising six sons and two daughters. The research reveals that spirituality functions not as a supplementary coping mechanism, but as the central axis of meaning-making, transformation and resilience. Findings show that parents consistently reframe their child not as a burden or divine punishment, but as a *sacred trust* [*amanah*], a *barakah* [blessing] or a divine 'message', deeply informed by Javanese values such as *sabar* [limitless patience], *legowo* [voluntary surrender] and *dilakoni dulu* [just live it first].

Contribution: This study introduces the 'Sacred Trust Framework', a culturally grounded model that integrates biblical and Islamic theology of firstbornness, Javanese-Kejawen cosmology and contemporary disability theology. The framework challenges Western, individualistic models of coping by centring relational spirituality, intergenerational care and embodied liturgies of daily life. By affirming that theology is lived not only in pulpits but in kitchens, therapy rooms, and the quiet perseverance of ordinary families, this research contributes to 'theology from below'. It offers a counter-narrative to deficit-based paradigms of disability.

Keywords: autism; spirituality; firstborn; Sacred Trust Framework; Javanese values.

Introduction

Parenting a child with autism spectrum disorder (ASD) is widely recognised as a profound existential and emotional journey – one that challenges assumptions about normality, success and divine providence. In the Global South, where access to formal support systems remains limited and stigma persists, families often turn to spirituality and cultural meaning-making as primary resources for resilience (Amadhila et al. 2024; Claassens, Shaikh & Swartz 2019; Irani et al. 2024; Widiastuti et al. 2025b). Nowhere is this more evident than in Indonesia, a pluralistic society where religious faith, local wisdom [*kearifan lokal*] and familial solidarity intertwine to shape responses to disability (Chaer 2015; Dhani 2023; Hanif 2016; Rahmawati 2015).

Despite growing interest in the spiritual dimensions of caregiving, a critical theoretical gap remains: most existing models – whether clinical, psychological or even theological – are rooted in Western, secular or individualistic frameworks that inadequately capture the relational, communal and culturally embedded spirituality of parents in non-Western contexts (Forrest, Du Preez & Brownlow 2021; Ng & Lu 2015). In particular, no existing theory adequately integrates: (1) the theological weight of firstborns across religious traditions; (2) the Javanese cultural-philosophical ethos of *sabar* [limitless patience], *legowo* [voluntary surrender], and *dilakoni dulu* [just live it first]; and (3) contemporary disability theology's call to reimagine human flourishing beyond cure or normalisation.

This study proposes the Sacred Trust Framework, a culturally and theologically grounded model of spiritual meaning-making in disability parenting, integrating Exodus 13:2 and Luke 2:23 on the consecration of the firstborn, Islamic notions of *barakah* [blessing] and *amanah* [sacred trust], Javanese Kejawen cosmology and contemporary disability theology (Volpe 2024). The framework demonstrates that when a firstborn child is born with autism, parents do more than cope – they theologically reinterpret the experience as a sacred trust that calls them into deeper patience, surrender and reimagined hope. Because the firstborn holds profound symbolic significance across Christian, Islamic and Javanese traditions, the child's atypical development generates not

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only medical concern but an ontological and relational rupture. Yet, as the findings show, this rupture becomes a generative threshold through which parents reconstruct identity, spirituality and caregiving purpose.

Drawing on in-depth interviews with eight Indonesian parents – four Catholic and four Muslim – raising their firstborn child with ASD, this qualitative study explores how the ‘Sacred Trust Framework’ operates in lived experience. We argue that for these parents, spiritual interpretation is not a secondary comfort but the primary hermeneutic through which they reframe suffering, reject deficit narratives and reclaim joy in small, relational victories. Their journey moves from initial shock and shame towards acceptance, gratitude and a vision of flourishing, deeply interwoven with Javanese values such as *sabar*, *legowo* and *dilakoni dulu*.

Furthermore, by centring the voices of mothers and father who navigate autism not as tragedy but as divine entrustment, this article makes three key contributions:

- **Theoretical:** It introduces the Sacred Trust Framework as a novel model of spiritual meaning-making that bridges theology, cultural anthropology and disability studies.
- **Contextual:** It offers one of the first empirically grounded accounts of lived theology in Southeast Asian disability parenting, filling a geographic and cultural void in global disability theology.
- **Pastoral:** It aligns to ‘theology from below’ by demonstrating how ordinary families – without formal theological training – become theological agents, crafting meaning not despite their child’s difference, but precisely through it.

Thus, in doing so, these parents offer a powerful counter-narrative to medicalised and medical or pathology-centred paradigms that overlook spiritual and relational dimensions of flourishing of autism – one that affirms the sacredness of vulnerable life and reimagines divine providence through the eyes of those who love a child deemed ‘imperfect’ by the world.

Research methods and design

Research design and philosophical orientation

This study used a qualitative phenomenological approach to explore how parents in Central Java, Indonesia, construct spiritual meaning while raising their firstborn child with ASD. Phenomenology was selected because it uncovers the essence of lived experience and is well-suited for examining how families interpret disability as a profound life event (Arabis-Quijote et al. 2023; Creswell & Creswell 2018; Hanurawan 2022; Pely 2025). Anchored in a constructivist–interpretivist paradigm, the study treats spirituality as a lived and relational phenomenon shaped by personal faith, Javanese cultural values and family–community dynamics rather than abstract doctrine. This orientation allowed us to examine how parents co-construct theological and cultural narratives that give meaning to disability within their everyday caregiving realities.

Participants

We conducted in-depth, semi-structured interviews with eight parents – seven mothers and one father – from Central Java, all of whom were raising their firstborn child diagnosed with ASD. The participants were recruited through purposive sampling and snowballing, facilitated by the local therapy centre, schools and parent support groups in Ambarawa and the surrounding areas. Inclusion criteria were: (1) biological parent of a firstborn child with ASD; (2) primary caregiver; and (3) willingness to share spiritual and emotional experiences. The participants included six parents of sons and two parents of daughters, ensuring gender diversity among the children. Reflecting Indonesia’s multireligious landscape, the participants comprised of four Catholics and four Muslims. At the time of the interviews, all children were between the age of 4 years and 12 years, and their diagnoses spanned a range of presentations, including ASD, with speech delay and global developmental delay. This composition allowed for a nuanced exploration of how faith, culture and the unique experience of parenting a firstborn child with neurodevelopmental differences intersect in shaping spiritual meaning, coping strategies and family resilience.

Data collection

Data were collected between December 2024 and June 2025 through face-to-face, in-depth interviews conducted in school, participants’ homes or quiet community spaces, with each session lasting approximately 60–90 min. All interviews were audio-recorded to ensure accuracy and were carried out in either Bahasa Indonesia or Javanese, depending on the participant’s linguistic preference and comfort. A semi-structured interview guide was used, organised around three core domains: (1) participants’ initial reactions and emotional journey following their child’s diagnosis; (2) their daily practices of care, coping strategies and family routines; and (3) their spiritual and cultural interpretations of their child’s condition – particularly how faith, local wisdom [*kearifan lokal*] and Javanese values shaped their understanding and response. Immediately after each interview, the researcher took detailed field notes to document nonverbal cues, emotional tone, environmental context and other observational insights that enriched the interpretive depth of the verbal data.

Data analysis

Data analysis followed a rigorous qualitative approach that integrated thematic analysis (Ahmed et al. 2025; Clarke & Braun 2017). The process began with familiarisation, during which all transcripts were read and re-read multiple times to achieve deep immersion in the participants’ narratives. This was followed by open coding, where initial codes were generated line-by-line directly from the verbatim data in their original languages (Bahasa Indonesia and Javanese), preserving cultural and linguistic authenticity. In the axial coding phase, these

initial codes were systematically grouped into meaningful subthemes and higher-order categories based on conceptual relationships. Then, in the selective coding, a core category emerged and was refined via constant comparison. All coding and analytical decisions were documented in an audit trail, and NVivo 12 (2018) software was used to manage, organise and retrieve codes efficiently while maintaining fidelity to the cultural and spiritual nuances embedded in the data.

Ethical considerations

Ethical approval was obtained from State University of Malang (reference: no. 01.10.30/UN32.14.2.8/ LT/2025), and written informed consent was secured from all participants. Ethically, we prioritised participant dignity and confidentiality. Pseudonyms were used, and all identifying details were removed. Participants were offered a summary of findings as a form of reciprocity and ensured the trustworthiness of the responses, considering them an authentic reflection of the participants' experiences. Data were stored on a password-protected computer and will be destroyed once results are published.

Results

This qualitative study reveals that spirituality functions as the central axis of meaning-making, coping and transformation for Indonesian parents raising their firstborn child with autism. Among the eight participants – six parents of sons (CI, AN, AR, HA, ER, and AD) and two parents of daughters (ALE and NA) – all described the diagnosis as their inaugural encounter with disability, marking a profound rupture in their expectations of parenthood. Across both Catholic (CI, ALE, ER, and AN) and Muslim (AR, NA, AD, and HA) families, spiritual narratives converged around a shared journey: from initial crisis and confusion towards acceptance, gratitude and redefined hope – deeply interwoven with Javanese cultural values such as *sabar*, *legowo*, and *dilakoni dulu*. For these parents, the fact that their first child was entrusted to them with autism became a pivotal spiritual event – interpreted not as misfortune, but as a sacred trust from God. Figure 1 illustrates the spiritual journey of Indonesian parents raising their firstborn child with autism as a process of meaning-making and faith transformation.

Initial crisis and existential disruption

Parents universally described a phase of shock, shame and existential questioning upon recognising their child's difference. This moment marked a rupture in their imagined future of parenthood, often accompanied by confusion, guilt and social discomfort. One participant recalled his bewilderment when first confronted with the reality of his son's condition:

'I was shocked – why was I invited to a national disability event?' (HA, 40 years old, male)

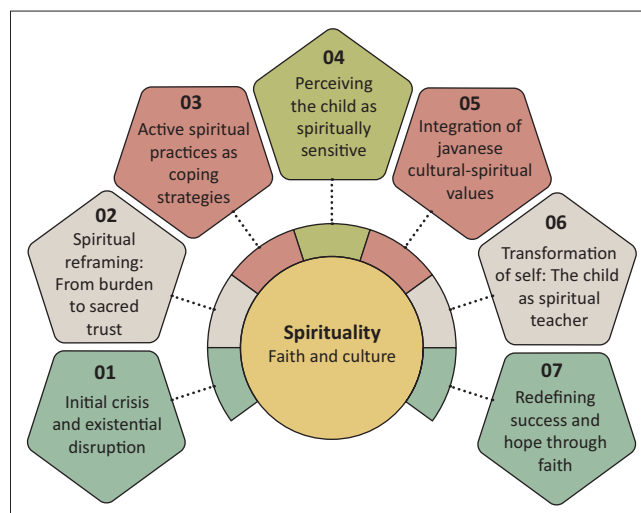


FIGURE 1: Spiritual transformation path of parents of firstborn children with autism.

Similarly, another participant expressed profound sorrow and empathy for her child's solitary struggle:

'Oh God, why does he have to struggle all alone like that?' (AR, 30 years old, female)

This initial crisis frequently triggered retrospective guilt. One participant shared a common sentiment of regret over early medical decisions:

'I regret rushing to leave the hospital back then.' (CI, 30 years old, female)

Social anxiety also emerged as a recurring theme, especially in interactions with other families. Two of the participants described the sting of public judgement:

'When playing with other kids, people often say, "Why can't he talk yet?"' (AD, 30 years old, female)

'Why can't he talk yet? Why is he still imitating?' (CI, 30 years old, female)

Parents' early emotional responses revealed a deep existential disruption that extended beyond the medical diagnosis, challenging their sense of identity, belonging and spiritual expectation – particularly because all children were firstborns who embodied their earliest hopes. Before spirituality became a meaningful framework, parents navigated confusion, shock, exhaustion, social anxiety and uncertainty about the future. Their movement towards acceptance was not linear but marked by ongoing oscillation between hope and discouragement, faith and frustration. Spirituality emerged slowly and often ambivalently, shaped by the broader psychological, social and economic pressures that structured their daily caregiving realities.

Spiritual reframing: From burden to sacred trust

A pivotal shift occurred when parents began to reinterpret their child's condition not as divine punishment or familial shame, but as a sacred trust [*amanah*] or a divine message – a reframing that functioned as both spiritual resistance and

emotional liberation. This transformation was especially profound given that all children were firstborns, embodying their parents' initial hopes and covenantal expectations of parenthood:

'God gave us this child so we could learn patience.' (CI, 30 years old, female)

'He is different, but still a gift to us.' (AD, 30 years old, female)

'Perhaps God entrusted us with something between a tiger and a cat.' (HA, 40 years old, male)

'They were born special, which means there's a message from God.' (ER, 46 years old, female)

'This is just my blessing ... a gift.' (AR, 30 years old, female)

'It's all God's path – we just walk it.' (AN, 49 years old, female)

Parents' spiritual reframing of autism was not passive resignation but an active attempt to reinterpret suffering through a sense of divine entrustment. Seeing their child as *titipan Tuhan* [God's gift] restored agency and purpose in caregiving, yet this sacred trust narrative never replaced practical concerns. Instead, spirituality coexisted with therapy efforts, financial pressures and hopes for long-term independence, revealing a layered coping process shaped by intertwined spiritual, biomedical, educational and psychosocial realities.

Active spiritual practices as coping strategies

Spirituality was not passive resignation but active engagement: prayer, ritual, pilgrimage and traditional healing were mobilised as tangible, embodied responses to uncertainty, exhaustion and medical limitations. These practices functioned not as magical solutions, but as liturgies of hope – ways of saying, '*We are still here; we still trust*':

'I pray constantly, left and right, with family in congregation ... My wife went to Umrah alone ... perhaps to pray for our children.' (HA, 40 years old, male)

'I took him to traditional healers and also to a *kyai* [Islamic spiritual teacher] ... After Grandpa massaged her twice ... she sat up right away.' (NA, 36 years old, female)

'If he stays away from modernity, eats cassava, he will surely heal.' (ER, 46 years old, female)

These acts – whether Islamic pilgrimage, Javanese massage, dietary ritual or communal prayer – reflect a pragmatic spirituality that integrates formal religion, ancestral wisdom [*Kejawen*] and embodied care. Rather than choosing between science and faith, these parents weave them together, creating a holistic framework for resilience that honours both medical effort and divine mystery.

Perceiving the child as spiritually sensitive

Several parents, particularly ER, described their child as possessing an extraordinary spiritual sensitivity – an intuitive capacity to discern the moral and emotional quality of those around them. This perception reframes atypical behaviours not as deficits, but as authentic responses to emotional dissonance or inauthenticity in social interactions:

'If someone's heart isn't good, he can sense it ... He can feel it when someone gives instructions while harbouring dislike ... If a person's heart is unkind, he can feel it.' (ER, 46 years old, female)

This belief reflects a spiritual epistemology in which the child's perception transcends conventional social cues and accesses a deeper, almost mystical awareness of human intention. For participant ER, this sensitivity validates her son's withdrawal, resistance, or meltdowns as morally coherent reactions – not behavioural problems. In this light, parenting becomes less about correction and more about cultivating emotional authenticity in the child's environment.

Integration of Javanese cultural–spiritual values

Spirituality among participants could not be separated from deeply rooted Javanese cultural frameworks. Core values such as *sabar*, *legowo* and the philosophy of *dilakoni dulu, nanti ketemu* [just live it first, understanding will come] provided a non-dualistic, process-oriented worldview that helped parents endure ambiguity without demanding immediate answers or cures:

'Patience has no limits ... You must be a little patient, patience has no limits ... Just live it first, you'll understand later ... We'd never experienced having a child like this before ... we just live it first.' (HA, 40 years old, male)

'It's *Kejawen* [Javanese spiritual tradition], like my grandmother used to be ... We just go through it first, over time, we learn.' (AN, 49 years old, female)

This cultural-spiritual synthesis functioned as a shared epistemology across religious boundaries – both Muslim and Catholic parents drew from the same Javanese well of wisdom. Rather than pathologising their child's difference, they honoured mystery, trusted process and embraced uncertainty as part of a larger, divinely ordered journey. In this worldview, understanding is not achieved through analysis alone, but through embodied perseverance – a way of being that is distinctly Javanese, deeply spiritual and profoundly resilient.

Transformation of the self: The child as spiritual teacher

Across religious and gender lines, parents described a profound shift in identity: from seeing themselves as 'fixers' or 'saviours' of their child to recognising themselves as students of life, with their child as the unexpected spiritual teacher. This transformation marked a journey from control to surrender, from shame to gratitude and from exhaustion to purposeful endurance:

'This child is teaching me patience ... At first we couldn't accept it; over time, we learned to embrace it.' (ER, 46 years old, female)

'When I think back, it felt so heavy then, but now I can smile.' (AN, 49 years old, female)

'Now he can say "mama," that alone makes me incredibly happy.' (CI, 30 years old, female)

'We'd never experienced having a child like this before ... we just live it first.' (HA, 40 years old, male)

This transformation need not be framed through Vanier's 'spirituality of weakness', a model now widely critiqued for romanticising vulnerability, instrumentalising disabled persons and being overshadowed by Vanier's ethical misconduct. Instead, the parents' experiences align more closely with contemporary disability theologians such as Nancy Eiesland (Wilder 2012), John Swinton (2011), and Laura MacGregor (2019), who prioritise dignity, agency, embodiment and relational belonging without idealising suffering. From this perspective, parents' growth arises not because disability is inherently ennobling but because they continually navigate a complex interplay of love, frustration, resilience and hope.

Redefining success and hope through faith

Parents consistently rejected medicalised or normative definitions of 'success' and instead redefined it through relational presence, incremental progress and faith-infused realism. For them, achievement was not measured by academic performance or speech fluency, but by moments of connection, responsiveness and dignity:

'Now he can say "mama," that alone makes me incredibly happy.' (CI, 30 years old, female)

'Just being able to answer a question, his grandparents are overjoyed.' (HA, 40 years old, male)

'Her gaze used to be empty; now she responds.' (NA, 36 years old, female)

'I want he to be able to write, interact, and be independent.' (ER, 46 years old, female)

'We're setting up a small farm so he can work independently someday.' (AN, 49 years old, female)

'I'm confident he'll be able to attend regular school – as long as we keep up with therapy.' (AD, 30 years old, female)

This redefinition enacts a counter-cultural ecclesiology of care: one that measures human worth not by productivity, conformity or 'recovery', but by presence, progress, and relational joy. Hope is not naive optimism, but a disciplined trust – rooted in daily effort [*usaha*] and divine grace [*doa*] – that the child, in all their uniqueness, will find their place in the world. In this vision, success is not about becoming 'normal', but about becoming fully themselves, embraced by family, community and God.

Discussion

The findings of this study illuminate a profound theological truth: the experience of parenting a child with autism – especially as a firstborn – functions as a sacred threshold, a liminal space where faith is not merely professed but forged in the crucible of daily care, uncertainty and love. Across religious boundaries – Catholic and Muslim alike – parents consistently interpreted the arrival of their autistic child not as divine punishment, but as a *sacred trust*, a *message from God*, or a test of *sabar* without limits. This reframing is not incidental; it is deeply shaped by the fact that this child was their first – the initial embodiment of their hopes, dreams and covenantal expectations of

parenthood (Cole & Molloy 2023; Lindroos et al. 2025; Redshaw 2022).

In many religious traditions, the firstborn holds symbolic and theological weight. In the Hebrew Bible, the firstborn belongs to God (Ex 13:2); in Christian spirituality, Christ is the 'firstborn among many brothers' (Rm 8:29); in Islamic tradition, the first child is often seen as a *barakah* that opens the door of divine mercy to the family (Jafari-Mianaei et al. 2017). When this 'first fruit' of marriage arrives with atypical development, the rupture is existential: the anticipated 'normal' child becomes a mirror of divine mystery rather than human design (Massmann 2022). Yet, rather than rejecting this dissonance, parents in this study transformed it into a site of spiritual formation. As one participant poignantly stated:

'Mereka dilahirkan spesial, berarti ada message dari Tuhan' ['They were born special, which means there's a message from God']. (ER, 46 years old, female)

Similarly, another participant offered a Javanese-Islamic metaphor:

'Mungkin Tuhan menitipkan antara harimau dan kucing' ['Perhaps God entrusted us with something between a tiger and a cat']. (HA, 40 years old, male)

These are not platitudes of resignation, but acts of theological imagination – attempts to narrate suffering within a cosmos still governed by grace.

This process aligns with the recent work of Buqa (2022) on meaning-making in suffering, that argues, 'meaning in suffering is not passively received but actively constructed through cultural and religious lenses' – a dynamic vividly demonstrated in our participants' narratives. Likewise, Manala (2018) emphasises that 'gratitude to God in the midst of hardship functions as a form of resistance against despair', with one participant declaring:

'Sekarang dia bisa bilang "mama," itu aja saya udah senang banget' ['Now he can say "mama," that alone makes me incredibly happy']. (CI, 30 years old, female)

Such gratitude is not a denial of pain, but a theological reorientation – a refusal to let suffering define the child's worth (Cohoe 2022; Deane-Drummond 2023; Horvat 2023).

This spiritual reframing is further enriched by Javanese cultural values that transcend formal religious doctrine. Concepts such as *sabar*, *legowo* and *dilakoni dulu, nanti ketemu* provide a non-dualistic framework for enduring ambiguity. Notably, these values appear equally among Catholic and Muslim participants – suggesting that in Java, spirituality is as much cultural as it is confessional. One participant's quiet affirmation:

'Kejawen ya, kayak mbahnya dulu' ['Kejawen, just like his grandfather used to be']. (AN, 49 years old, female)

And another participant's insistence that:

'*Sabar itu ndak ada batasnya*' ['Patience has no limits']. (HA, 40 years old, male)

This reveals a shared epistemology: truth is not grasped through dogma alone, but through embodied perseverance (Biro 2024; Kalmykova 2021; Lee 2025).

Crucially, this stands in contrast to dominant Western models of disability coping, which often emphasise individual resilience, cognitive reframing or acceptance through psychological insight (Brinkman et al. 2023; Venkatesan, Yashodhara-Kumar & Gopalkrishnan 2023). While these frameworks offer valuable tools for personal adaptation, they tend to decontextualise suffering from its communal, cultural and transcendent dimensions, treating meaning as a private, cognitive achievement rather than a shared, sacred process. In contrast, the Sacred Trust Framework emerging from our data presents a holistic, contextually rooted paradigm that integrates four interwoven dimensions: (1) the theological weight of firstbornness, drawing on biblical notions of consecration (Ex 13:2) and Islamic understandings of *barakah*; (2) Javanese-Kejawen cosmology, which centres values such as *sabar*, *legowo* and *dilakoni dulu* as pathways to wisdom through embodied experience; (3) relational spirituality, manifested in communal practices such as *doa berjamaah* [family prayer] and the intergenerational joy of grandparents [*mbahnya senengnya luar biasa*]; and (4) embodied liturgies of care, where every day acts – blending vegetables with eggs, undertaking pilgrimage to Mecca, or interpreting dreams as divine signs – become sacred rituals of love and trust. Together, these elements form a non-Western, spiritually saturated model of resilience that locates meaning not in the mind alone, but in the body, the family, the ancestors and the divine (Sattarzadeh 2022; eds. Thompson & Cox 2019; Widiastuti et al. 2025a).

This framework echoes Pohan et al.'s (2025) comparative work, which contrasts Western psychological models with Islamic-Javanese paradigms rooted in *tawakal* and communal harmony. Where McCullough sees meaning as cognitively reconstructed (Fosha, 2004), Fosha's AEDP emphasises that meaning arises from the visceral, relational processing of emotion within a secure therapeutic dyad. Our participants live meaning through ritual, relationship and daily acts of faith – a distinction that challenges the universality of secular coping theories. For them, meaning is not abstracted through introspection alone (Baggio 2020), but embodied in shared prayer, ancestral care practices and the quiet discipline of preparing a child's special meal. This lived spirituality resists individualistic frameworks by situating resilience within a web of familial, communal and divine interdependence (Prescott, Eppler & Rodriguez 2024).

Moreover, the fact that all children were firstborn intensifies the spiritual stakes. The first child is often the vessel of parental identity (Ackerman & Wiseman 2025; Prinds et al. 2018). When that vessel does not conform to societal or

developmental norms, the parents' sense of self – and their relationship with God – is destabilised. Yet, this destabilisation becomes generative. Parents described a journey from shame [*Dulu saya nangis terus ...*] to pride [*Sekarang dia bisa bilang "mama" ...*], from isolation to communal prayer [*Saya kanankiri saya doa wes berjamaah*], and from cure-oriented goals to relational flourishing. This mirrors what theologian Jean Vanier (1989) called 'the spirituality of weakness' – a recognition that true communion arises not in perfection, but in mutual vulnerability.

Jean Vanier's (1989) notion of a 'spirituality of weakness' has been widely critiqued for romanticising suffering and reducing disabled persons to instruments of others' moral growth (MacGregor 2019; Swinton 2011; Wilder 2012), concerns further amplified by his ethical misconduct. This study, therefore, avoids relying on Vanier and instead interprets parents' experiences through contemporary disability theology that emphasises agency, embodiment, mutuality and socio-material realities, presenting spirituality as one coping resource among many rather than a universally empowering force. These insights also align with Global South disability theologians (Amadhila et al. 2024; Buqa 2022; Claassens et al. 2019; Manala 2018), whose work underscores the interplay of spirituality, communal belonging, economic precarity and ancestral cosmology. Compared with Western theological frameworks, which often prioritise doctrinal or ecclesial categories, Global South perspectives illuminate a more integrated and embodied spirituality – an orientation reflected in the Indonesian parents' meaning-making and caregiving practices.

Finally, the redefinition of 'success' is perhaps the most radical theological insight. When a grandmother's face lights up because her grandson can now answer his name [*Dah bisa ditanya itu saja mbahnya senengnya luar biasa*], the family enacts a counter-cultural ecclesiology: one that measures worth not by productivity or conformity, but by presence, progress and relational joy. This aligns with disability theologians such as Eiesland (in Wilder 2012) and Swinton (2011), and finds resonance in pastoral care for the marginalised (Van der Merwe 2019). Yet, our participants go further: they do not wait for the church to include their child – they build a domestic church where the autistic child is already sacred.

In sum, parents in this study do not merely 'cope' with autism; they theologise through it, interpreting their firstborn child as a living parable of divine mystery that invites deeper patience, wider love and a more expansive vision of human worth before God. The Sacred Trust Framework thus provides a culturally grounded theological corrective to deficit-based clinical and ecclesial paradigms, affirming that the first child, in all their difference, is never a mistake but a message. Yet this study also recognises the limits and tensions of such spiritual interpretation: not all spiritual framings ease distress, and they often coexist with frustration, self-blame and social pressure to appear accepting. In some cases, spiritual narratives can obscure

structural challenges – including limited diagnostic access, therapy costs and enduring stigma. Acknowledging these realities prevents the over-romanticisation of spirituality and underscores that meaning-making is complex, uneven and inseparable from the psychological, social and economic conditions shaping parents' daily lives.

Conclusion

This study shows that Indonesian parents raising their firstborn child with autism draw deeply on interwoven Catholic, Muslim, and Javanese spiritual frameworks to transform disruption into meaning. Spirituality – expressed through concepts such as *amanah*, *barakah*, *sabar*, *legowo*, and *dilakoni dulu* – did not replace medical or psychosocial efforts, but operated alongside them as a relational and interpretive resource. The Sacred Trust Framework developed here highlights how parents theologise through their caregiving: reframing their child not as a deficit but as a bearer of divine mystery, cultivating hope through small developmental gains, and forming domestic practices of prayer, reciprocity and endurance. At the same time, the study acknowledges the limits of spiritual interpretation, noting that faith coexists with exhaustion, stigma, and economic strain. These findings invite pastoral leaders, theologians and policymakers to recognise the lived wisdom of caregiving families and to support forms of inclusion rooted in relational, culturally embedded spirituality.

Acknowledgements

The authors would like to thank their fellow researchers and institutions for their moral and intellectual support throughout the writing process. They are also grateful to the editors and reviewers who provided valuable input to improve the quality of the article.

Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

CRedit authorship contribution

Ajeng A. Widiastuti: Conceptualisation, Data curation, Methodology, Project administration, Resources, Writing – original draft, Writing – review & editing. Adi Atmoko: Data curation, Supervision. Nur Eva: Supervision, Writing – original draft. Domingos Soares: Supervision, Writing – review & editing. All authors reviewed the article, contributed to the discussion of results, approved the final version for submission and publication, and take responsibility for the integrity of its findings.

Funding information

This work was received funding from Satya Wacana Christian University, Salatiga, Indonesia.

Data availability

The data that support the findings of this study are not openly available because of reasons of sensitivity and are available from the corresponding author, Ajeng A. Widiastuti, upon reasonable request.

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