

TAKAFUL COVERAGE FOR CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD)

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Abstract: Autism Spectrum Disorder (ASD) creates substantial and continuing financial pressure for families, yet existing insurance and Takaful products rarely cover the therapies, long-term care needs, and guardianship planning that families require most. This paper proposes a Shariah-compliant Takaful product for children with ASD that combines medical and developmental therapy coverage, Hibah planning, parental death and disability protection, and a savings mechanism. It also integrates Badal Hajj and direct Waqf donation options to reflect Muslim families' religious and social welfare priorities. Using an exploratory qualitative design, semi-structured interviews were conducted with eight parents or guardians of ASD children in Malaysia and Indonesia. Thematic analysis identified five major themes: inadequate existing coverage, significant financial and emotional stress, strong demand for comprehensive long-term protection, concern about guardianship and estate planning, and perceived gaps in Takaful operator awareness. Participants indicated willingness to contribute approximately RM200-500 monthly, depending on coverage level and affordability. Grounded in Maqasid al-Shariah, the proposed product supports the protection of life, intellect, progeny, wealth, and faith while addressing an underserved market. The paper concludes with recommendations for Takaful operators, regulators, advocacy organizations, and researchers, and highlights the need for actuarial modelling, large-scale validation, pilot testing, and regulatory assessment before commercialization.

Keywords: Autism Spectrum Disorder, Takaful, Islamic insurance, Waqf, Hibah, Maqasid al-Shariah, financial inclusion, Malaysia, Indonesia

1. Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition associated with differences in social communication, restricted interests, repetitive behaviours, and varying support needs (American Psychiatric Association, 2013). Recent global estimates suggest that approximately one in 100 children are affected by ASD (World Health Organization, 2021). In Southeast Asia, rising diagnosis and awareness have increased the urgency for family-centred support systems. Malaysia has reported increasing ASD diagnoses among school-age children, while Indonesia faces similar pressure to strengthen services for childhood developmental disorders (Ministry of Health Malaysia, 2022; Wiguna et al., 2020).

The economic impact of ASD is significant because support needs often persist across childhood, adolescence, and adulthood. Families incur direct medical costs for diagnosis, psychiatric care, medication, and hospitalisation, as well as direct non-medical costs for speech therapy, occupational therapy, behavioural intervention, specialised education, transport, assistive devices, and respite care. Indirect costs arise when parents reduce working hours or leave employment to supervise therapy and caregiving (Buescher et al., 2014; Lavelle et al., 2014; Rogge & Janssen, 2019). Malaysian evidence estimates the average annual cost at RM35,365.62 per child with ASD, with developmental costs forming the largest component (Hamzah et al., 2020).

Despite this burden, many conventional insurance and Takaful products do not adequately cover developmental therapies or long-term care planning. This protection gap is especially important in Muslim-majority contexts where families may prefer Shariah-compliant instruments that avoid *riba*, *gharar*, and *maysir* and that express the Islamic principles of mutual help and social protection (Ayub, 2007; Billah, 2019). A product that combines Takaful coverage with Hibah, Waqf, and other Islamic social finance mechanisms can therefore respond to both practical and religious needs.

This paper proposes a comprehensive Takaful product for children with ASD and evaluates preliminary demand through qualitative interviews with ASD families in Malaysia and Indonesia. The paper contributes by linking special-needs financial planning, Takaful product innovation, and Maqasid al-Shariah. It addresses three objectives: to design a Shariah-compliant ASD-focused Takaful product, to assess preliminary demand and contribution preferences, and to identify implementation, regulatory, and policy considerations before commercialization.

2. Literature Review and Theoretical Foundations

2.1 Autism Spectrum Disorder Costs and Coverage Gaps

ASD-related financial strain has been widely documented. International studies show that the costs of raising and supporting a child with ASD are several times higher than for neurotypical children (Järbrink & Knapp, 2001; Cidav et al., 2012). Costs are not limited to clinical treatment. They include early intervention, therapy, specialised schooling, caregiver time, and long-term supervision. Parents, especially mothers, may reduce employment or exit the workforce, which produces income loss and long-term career effects (Montes & Halterman, 2008). Families may also deplete savings, delay other household investments, or incur debt (Sharpe & Baker, 2007).

Insurance coverage has not kept pace with these needs. Conventional health policies often focus on acute medical events, hospitalisation, and critical illness, whereas ASD families need regular developmental therapy and lifelong planning. Studies have identified unmet healthcare and service needs among children with ASD, including restricted provider networks, limited therapy coverage, and administrative barriers (Chiri & Warfield, 2012; Vohra et al., 2014). In countries where mandates exist, coverage can still be constrained by annual limits, eligibility rules, and provider availability (Shattuck et al., 2012).

In Malaysia and Indonesia, the issue is intensified by the high proportion of out-of-pocket expenses and by uneven access to specialised providers. Families in urban areas may be able to locate qualified speech therapists, occupational therapists, and behavioural practitioners, but those in rural or lower-income settings face scarcity and affordability barriers. These conditions

create a strong rationale for a risk-pooling mechanism that spreads cost, supports therapy access, and facilitates planning for the period when parents are no longer able to provide care.

2.2 Maqasid al-Shariah and Takaful Innovation

Maqasid al-Shariah refers to the higher objectives of Islamic law. Classical and contemporary scholars identify the protection of religion, life, intellect, progeny, and wealth as essential objectives (Al-Ghazali, 1937; Auda, 2008; Kamali, 2008). Contemporary Islamic finance scholarship argues that financial products should not only satisfy technical Shariah compliance but also advance welfare, justice, and inclusion (Dusuki & Bouheraoua, 2011). An ASD-focused product aligns strongly with this orientation because it protects children with disabilities, reduces family vulnerability, and channels collective resources toward social benefit.

Takaful is grounded in mutual assistance and shared responsibility. Participants contribute to a common pool through *tabarru'* and the Takaful operator manages the fund under structures such as *Wakalah*, *Mudarabah*, or hybrid models (Archer et al., 2010; Hussain & Pasha, 2011; Htay & Salman, 2013). Product innovation in Takaful has grown, yet many products still resemble conventional insurance structures with Shariah-compliant contracts. Scholars have called for more socially responsive models, including *Waqf-Takaful* integration for low-income participants and vulnerable communities (Mohd Ramli & Jalil, 2013; Ismail & Possumah, 2013).

Hibah also offers a relevant estate-planning mechanism. In Islamic financial planning, Hibah enables a living donor to transfer or designate assets in a flexible manner, subject to Shariah and legal requirements (Yaacob & Donglah, 2012). For families of children with ASD, Hibah can help parents specify how benefits and savings should be used for the child's future care and who should manage them. Combining Hibah with Takaful creates a more complete protection and planning solution.

3. Methodology

3.1 Sampling and Data Collection

This study used an exploratory qualitative design because the proposed product is novel and the purpose was to understand family experiences, perceived needs, and product preferences in depth. Semi-structured interviews were selected to allow participants to describe their current coverage, financial burden, long-term concerns, and reactions to the proposed product concept while still ensuring comparability across interviews (Lincoln & Guba, 1985).

Participants were recruited through autism advocacy organizations and social media groups in Malaysia and Indonesia. The inclusion criteria were: parent or guardian of a child formally diagnosed with ASD by a qualified professional; child currently receiving ASD-related therapy or services; Muslim family with preference for Shariah-compliant financial products; and willingness to participate in a 30-45 minute interview. Eight participants were recruited, comprising six from Malaysia and two from Indonesia. Although the sample is small, it is suitable for preliminary concept validation and for identifying themes that can inform larger quantitative studies.

3.2 Data Analysis and Ethics

Interviews were conducted via video conferencing between January and March 2024. The interview protocol covered seven areas: existing insurance or Takaful coverage, ASD-related expenses, importance of comprehensive coverage, long-term and guardianship planning, willingness to contribute, interest in Badal Hajj and Waqf features, and views on operator awareness and accessibility. Interviews were recorded with consent, transcribed, and anonymised.

Thematic analysis followed Braun and Clarke's (2006) six-phase approach: familiarisation, initial coding, searching for themes, reviewing themes, defining themes, and producing the report. Two researchers independently reviewed the transcripts and resolved coding differences through discussion. Ethical approval was obtained from Universiti Teknologi MARA's Research Ethics Committee. Participants provided informed consent and were informed that they could withdraw at any point without penalty.

4. Proposed Product Design

4.1 Core Coverage and Planning Components

The proposed product is designed as a family Takaful plan centred on the long-term needs of a child with ASD. It integrates immediate service coverage with longer-term protection and savings. The first component is medical and developmental coverage. Inpatient coverage would include hospitalisation, surgery, intensive care, psychiatric admission, and ASD-related co-occurring conditions. Outpatient coverage would include specialist consultation, diagnosis, medication, and routine monitoring. The distinguishing element is developmental therapy coverage for speech therapy, occupational therapy, physical therapy, behavioural intervention, sensory integration, assistive technology, and respite care.

The second component is Hibah planning. Parents may designate how benefits and accumulated savings should be used for the child and may identify guardians or trustees to manage the funds if both parents die or become incapacitated. This feature responds to the concern that children with higher support needs may remain financially dependent beyond childhood. The third component is death and disability protection for parents, including a lump-sum parental death benefit, total permanent disability benefit, and optional critical illness protection for the child. The fourth component is a Shariah-compliant savings and investment account invested in sukuk, Islamic equities, Islamic real estate investment trusts, or other approved assets. Maturity benefits may be paid when the child reaches a designated age, for example 25 or 30, to support adult care, training, or supported living.

Table 1. Proposed ASD Takaful Product Components

Component	Main Features	Purpose
Medical and therapy coverage	Inpatient and outpatient care; speech, occupational, physical, behavioural, and sensory therapies; assistive technology and respite care	Reduces the most frequent and costly ASD-related expenses
Hibah planning	Designation of guardians or trustees; allocation of Takaful benefits and savings for the child's care	Supports long-term protection after parental death or incapacity
Death and disability benefits	Parental death benefit, total	Provides capital and income

Component	Main Features	Purpose
	permanent disability benefit, and child critical illness option	support during major shocks
Savings and investment	Shariah-compliant investment account with maturity and partial-withdrawal options	Builds long-term resources for adulthood and continuing care
Badal Hajj and Waqf	Proxy Hajj allocation and optional Waqf donation to autism organizations	Adds spiritual value and community benefit

4.2 Innovative Islamic Features and Shariah Governance

Two Islamic features differentiate the product. The first is Badal Hajj. Upon parental death, a specified portion of the benefit may be allocated for proxy Hajj, subject to Shariah approval and operational arrangements with licensed agencies. This feature is meaningful for Muslim parents who may have deferred pilgrimage because of caregiving responsibilities. The second is direct Waqf donation to autism advocacy organizations. Participants may allocate a small proportion of contributions or benefits to a Waqf fund supporting therapy subsidies, caregiver training, advocacy, or research. This feature creates a continuous charity benefit while strengthening the autism support ecosystem.

Shariah governance must be embedded throughout the product. The Takaful structure should avoid riba through Shariah-compliant investment, reduce gharar through clear coverage terms and exclusions, and avoid maysir by operating as mutual assistance rather than speculative gain. An independent Shariah Advisory Board should approve the contract, investment policy, Hibah documentation, Waqf arrangements, and Badal Hajj procedures. Periodic Shariah audits and transparent reporting would be required to maintain participant trust.

4.3 Actuarial and Implementation Considerations

Commercial viability requires detailed actuarial modelling. Therapy utilisation is likely to be the largest claims driver, especially when coverage includes frequent speech, occupational, or behavioural sessions. Pricing must consider ASD severity distribution, age at entry, co-occurring conditions, provider charges, regional variation, lapse rates, investment returns, and regulatory capital requirements. Because the product targets a diagnosed population, adverse selection risk must be managed through waiting periods, annual limits, co-payments, tiered coverage, and careful underwriting. These measures should be balanced against the social objective of accessibility.

Operationally, the Takaful operator must build provider networks, verify therapist credentials, design claims rules, and offer digital channels for documentation and reimbursement. Therapy claims will be more frequent than typical hospitalisation claims, so efficient processing is essential. Market education is also critical because the interviews indicate that many families have not encountered agents who understand ASD or specialised coverage needs. Agent training should therefore include ASD awareness, sensitive communication, and the financial-planning role of Hibah, Waqf, and long-term benefits.

The plan should also specify transparent exclusions and evidence requirements. For example, therapy reimbursement may require diagnosis by a qualified professional, a written intervention plan, invoices from licensed providers, and periodic review of progress. Such rules protect the common risk pool while avoiding unnecessary barriers for parents. A practical

design would therefore combine pre-authorised therapy packages with a simple reimbursement route for services that are not yet available in the provider network. This dual pathway is important in Malaysia and Indonesia because service availability differs sharply by locality. It also allows the product to support early intervention, which may improve functional outcomes and reduce longer-term dependency. From a governance perspective, data collected through claims can be used to refine actuarial assumptions, identify underserved areas, and guide Waqf subsidies toward families with the highest need.

These design safeguards are intended to preserve fund sustainability without weakening the social purpose of the product. They also provide regulators and Shariah advisers with auditable evidence that benefits are paid for genuine ASD-related needs and managed equitably across participants.

5. Findings and Discussion

5.1 Main Themes

Thematic analysis produced five main themes. First, participants reported inadequate existing coverage and high out-of-pocket costs. Most had general health insurance or basic Takaful, yet the policies did not cover developmental therapies, which were the most regular and financially burdensome services. Monthly out-of-pocket expenses ranged from approximately RM1,500 to RM4,000, with therapy often accounting for 60-70% of the total.

Second, families experienced severe financial and emotional stress. Several participants described savings depletion, debt, reduced work hours, or a parent leaving employment to care for the child. Financial strain also created anxiety about continuity of therapy and the child's long-term wellbeing. Third, there was strong demand for comprehensive protection. All participants reacted positively to a plan combining therapy coverage, medical protection, death and disability benefits, savings, and long-term planning. Therapy coverage was consistently ranked as the most important feature, followed by long-term savings and guardianship planning.

Fourth, participants expressed strong concern about guardianship and estate planning. Many worried about who would care for the child and manage financial resources if parents died or became incapacitated, but few had formal arrangements. The Hibah component was valued because it offered a Shariah-compliant and flexible planning mechanism. Fifth, participants perceived gaps in Takaful operator awareness. They felt that agents and operators generally did not understand autism-related costs, therapy requirements, or the emotional realities of special-needs caregiving.

All participants indicated willingness to contribute within a broad range of RM200-500 per month, subject to household income and coverage level. Six participants considered RM300-400 reasonable for meaningful comprehensive protection. Badal Hajj was described by most participants as spiritually valuable, and the Waqf feature was viewed as a way to support other autism families while earning ongoing religious merit.

Table 2. Summary of Interview Themes

Theme	Evidence from Participants	Product Implication
Inadequate coverage	General plans did not cover regular developmental therapies	Prioritise therapy benefits and transparent limits
Financial and emotional stress	Families reported high monthly expenses, income loss, debt, and anxiety	Combine risk protection with savings and counselling-friendly distribution

Theme	Evidence from Participants	Product Implication
Demand for comprehensive protection	All participants valued a plan covering current and future needs	Offer integrated medical, therapy, death, disability, Hibah, and savings features
Guardianship concerns	Most families lacked formal long-term care arrangements	Embed Hibah and guardian designation support
Operator awareness gaps	Participants felt agents did not understand ASD	Require agent training and partnerships with advocacy organizations

5.2 Feasibility, Equity, and Commercialization Issues

The findings suggest that an ASD-focused Takaful product has potential market appeal among Muslim families who face high therapy costs and prefer Islamic financial solutions. The product also advances Maqasid al-Shariah by protecting life through healthcare access, intellect through developmental therapy, progeny through guardianship planning, wealth through risk pooling and savings, and faith through Badal Hajj and Waqf options. This alignment strengthens the product's social legitimacy and differentiates it from conventional insurance.

However, feasibility cannot be inferred from qualitative interest alone. Actuarial analysis may show that comprehensive therapy coverage requires higher contributions than some families can afford. Tiered plans may be necessary, such as a basic plan with lower annual therapy limits, a standard plan with broader outpatient and therapy benefits, and a premium plan with enhanced savings and long-term care benefits. Retakaful support may be required to manage large claims or catastrophic parental death and disability risks.

Equity must be considered. Families with the greatest needs may be least able to contribute. Waqf-subsidised contributions, employer group plans, government vouchers, and possible Zakat support for eligible families could improve accessibility, subject to Shariah and regulatory approval. Public-private partnerships may also reduce provider costs by expanding therapy networks and funding early intervention. Autism advocacy organizations can assist with outreach, product design, family education, and Waqf governance.

6. Conclusion and Policy Implications

6.1 Conclusion

This paper proposes a comprehensive Takaful product for children with ASD that addresses medical, therapy, financial-planning, and religious needs. The product combines developmental therapy coverage, inpatient and outpatient medical benefits, Hibah planning, parental death and disability protection, savings and investment, Badal Hajj, and Waqf donations. It responds to a clear protection gap faced by families whose greatest expenses are often excluded from standard insurance and Takaful plans.

Qualitative findings from eight participants in Malaysia and Indonesia indicate strong preliminary demand. Families described high out-of-pocket costs, financial and emotional stress, limited existing coverage, and deep concern about their child's future. They also expressed willingness to contribute to comprehensive coverage, especially when therapy benefits and long-term planning were included. The proposed product therefore represents both a commercial opportunity and a social finance innovation aligned with Islamic values.

6.2 Recommendations

Takaful operators should conduct actuarial modelling and large-scale market research before product launch. They should build qualified therapy provider networks, develop digital claims systems, train agents in ASD awareness, and design tiered contribution structures that reflect different affordability levels. Operators should also explore Waqf-Takaful integration to subsidise contributions for low-income families.

Regulators and policymakers should encourage socially responsive Takaful innovation through clear approval pathways, data support, consumer protection guidance, and public-private partnerships. Policy measures could include therapy subsidies, tax incentives, or group coverage arrangements for special-needs families. Autism advocacy organizations should collaborate with operators on product design, family education, Waqf governance, and policy advocacy. Researchers should develop actuarial models, compare cross-country support systems, and evaluate the long-term impact of financial protection on therapy access and family wellbeing.

6.3 Limitations and Future Research

This study is exploratory and has limitations. The sample was small, non-random, and recruited partly through advocacy networks, so it may represent families who are more informed or engaged than the broader population. Findings should be treated as indicative rather than definitive. The study validates the product concept but does not determine pricing, solvency, regulatory approval, or operational viability.

Future research should include representative quantitative surveys in Malaysia and Indonesia, detailed actuarial modelling using ASD-specific cost and utilisation data, pilot testing with real claims and provider networks, and regulatory feasibility assessments with Bank Negara Malaysia, Otoritas Jasa Keuangan, and Shariah Advisory Boards. Longitudinal evaluation after launch would also be necessary to assess whether the product improves therapy access, reduces financial stress, and strengthens long-term security for ASD families.

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Author Contributions

Zawawi Ahmad, Denna Haizar Fariz, and Mohammad Firdaus Mohammad Hatta contributed to conceptualization, writing, editing, and proofreading of the manuscript. Nur Darina Khalid contributed to technical support and manuscript preparation.

Conflict of Interest

The authors declare no conflict of interest.

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