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EXPLORING PARENTS' PERSPECTIVE ON TAKAFUL INCLUSION FOR CHILDREN WITH DISABILITIES IN MALAYSIA

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ABSTRACT

The Malaysian takaful industry continues to grow, yet children with disabilities remain inadequately protected due to limited access to inclusive takaful coverage. This study aims to analyse parents' perspectives on the availability, accessibility, and adequacy of takaful protection for children with disabilities in Malaysia. A qualitative research design employing thematic analysis was adopted. Semi-structured interviews were conducted with six parents of children with disabilities, and the data were analysed to identify recurring themes. The findings revealed three key themes: (1) takaful exclusion and accessibility issues, particularly for developmental disabilities such as autism; (2) parents' readiness and willingness to contribute financially towards appropriate protection; and (3) expectations for inclusive and holistic takaful solutions covering therapy, assistive devices, rehabilitation, and long-term care. These findings demonstrate a clear mismatch between existing takaful offerings and the protection needs of families with children with disabilities. The study highlights the importance of

developing more inclusive takaful policies that are aligned with the principles of social justice and financial inclusion. The findings provide practical insights for takaful operators and policymakers in designing sustainable protection models that better address the needs of persons with disabilities and their families.

Keywords: Takaful; Children with Disabilities; Financial Inclusion; Social Protection; Parents' Perspectives; Malaysia.

INTRODUCTION

The Takaful industry in Malaysia has shown encouraging growth in recent years. In 2023, participation increased by 7.55 percent, reflecting higher public awareness of Islamic financial protection (Malaysian Takaful Association, 2023). Despite this progress, many Malaysians remain under-protected. A Bank Negara Malaysia (2021) survey revealed that 47 percent of the population lack adequate coverage, while 35 percent expressed disinterest in Takaful products. These figures suggest a persistent gap between awareness and actual protection, particularly among vulnerable groups.

For families with children with disabilities, this gap carries significant consequences. Children with developmental conditions such as autism, Down syndrome, and cerebral palsy often require long-term medical care, therapy, and assistive devices, all of which impose substantial financial burdens on their families. In Malaysia, persons with disabilities (PWDs) are officially recognised across several categories, including physical, sensory, learning, and developmental disabilities (Suruhanjaya Perkhidmatan Awam, 2024).

The Malaysian government has introduced various policies to promote inclusivity for PWDs. The *Pelan Tindakan Orang Kurang Upaya 2016–2022* (Kementerian Pembangunan, Wanita dan Masyarakat [KPWKM], 2016) aimed to improve access to essential services, including healthcare and financial services. Similarly, the National Strategy for Financial Literacy 2019–2023 emphasised the inclusion of underserved groups through accessible financial and insurance products (Financial Education Network, 2019). At the international level, bodies such as the United Nations (2022) and the World Bank (2025) consistently recognise PWDs as vulnerable populations facing systemic barriers to financial and social protection.

Despite these policy commitments, the actual availability of Takaful coverage for PWDs remains limited. Most operators restrict coverage to physical disabilities, while children with developmental or cognitive conditions are frequently excluded. This disconnects between policy ideals and market reality

forms the foundation of this study. This qualitative inquiry seeks to understand these challenges from the perspective of parents, recognising that their experiences are deeply personal, contextual, and shaped by emotional, social, and financial realities that quantitative data alone cannot capture.

Problem Statement

Malaysia has introduced various policies to support persons with disabilities, including the Pelan Tindakan Orang Kurang Upaya 2016–2022 (KPWKM, 2016) and the Dasar Sosial Negara 2030 (KPWKM, 2023). These policies reflect the government's intention to build a more inclusive society. However, for families raising children with disabilities, the reality often feels different. Despite these policy commitments, many parents find that adequate Takaful protection for their children remains difficult to obtain.

While the Pelan Tindakan OKU explicitly identifies access to insurance and Takaful as a strategic objective under Teras Strategik 1 (KPWKM, 2016), this policy directive has yet to translate into meaningful change on the ground. Industry reports indicate that only a handful of Takaful operators offer coverage for persons with disabilities, and even this is mostly limited to physical impairments. Children with developmental conditions such as autism, Down syndrome, or cerebral palsy are frequently excluded (Wahab & Hassan, 2023). For parents, this exclusion is not merely an administrative inconvenience, it has real consequences for their children's well-being, their family's financial stability, and their peace of mind. Based on the issues described above, three interconnected problems can be identified:

1. Children with developmental disabilities are often left out of Takaful coverage

Although the Persons with Disabilities Act 2008 was introduced to protect the rights of PWDs, its implementation has been limited. The financial rights of PWDs are not clearly addressed in current insurance and Takaful regulations (Tahir et al., 2023; Hanafi et al., 2025). In practice, most Takaful operators still exclude children with developmental disabilities. When coverage is offered, it is usually only for physical injuries or disabilities caused by accidents (Wahab & Hassan, 2023). Many parents only discover these exclusions after their child is diagnosed, which can be a distressing and frustrating experience. Beyond the policies themselves, families also face practical barriers such as poor communication with service providers, a lack of disability-friendly facilities, inadequate healthcare infrastructure, and limited access to services in rural areas

(Clemente et al., 2022; Omar et al., 2023). These challenges suggest that there is still a considerable gap between policy intentions and the everyday experiences of families.

2. The absence of coverage places significant financial and emotional pressure on families

Without adequate Takaful protection, parents often have to bear the full cost of their children's healthcare needs. This includes expensive therapies, assistive devices, rehabilitation, and specialised medical care (Isamail & Said, 2025). For many low- and middle-income families, these costs can be overwhelming. Even families with some form of insurance often find that their coverage is insufficient to protect them from high out-of-pocket expenses (Validova et al., 2023; Isamail & Said, 2025). Beyond the financial strain, parents, particularly mothers, also experience significant emotional stress from coordinating care and navigating complex systems (Agarwal et al., 2025). Standard Takaful plans typically do not cover long-term care, assistive technology, or rehabilitation services. As a result, families must either find ways to pay for these services themselves or go without them. This can lead to ongoing debt, financial hardship, and emotional exhaustion (Knox-Vydmanov & Goursat, 2025; Azizatunnisa' et al., 2024). These difficulties highlight the need for financial protection that truly responds to the comprehensive needs of children with disabilities and their families.

3. Current practices may not fully align with Islamic values of justice and social responsibility

Islamic teachings place great importance on caring for vulnerable members of society, including persons with disabilities. Values such as justice (*al-'adl*) and mutual support (*ta'awun*) are central to Islamic finance and encourage the provision of financial protection that is accessible to all, regardless of physical or developmental condition (Alnaser, 2024; Binmahfooz, 2024). The Qur'an and Hadith offer clear guidance on accommodating individuals with disabilities, and historical institutions such as *waqf* and *bimaristans* reflected this commitment in practice. However, the current practice of excluding children with developmental disabilities from Takaful coverage raises questions about whether the industry is fully living up to these values. Such exclusion may contribute to financial hardship (*darar*) for Muslim families and may not fully support the broader objectives of Shariah (*Maqasid al-Shariah*), which include the protection of life (*hifz al-nafs*) and wealth (*hifz al-mal*) (Mahomed, 2021). Furthermore, this situation may also pose challenges to Malaysia's broader efforts to achieve inclusive social

protection, as outlined in the *Dasar Sosial Negara 2030* (KPWKM, 2023). When a significant segment of the Muslim community is left without adequate protection, it is worth reflecting on whether the Takaful industry is fully fulfilling its role as a provider of social justice and community solidarity.

These three problems; systemic exclusion, financial and emotional strain on families, and questions about alignment with Islamic values, are closely connected. Together, they point to a clear need for research that listens to the voices of those most affected. While existing studies have examined the technical and regulatory aspects of inclusive insurance, few have explored the lived experiences of parents and guardians. This study seeks to address that gap by exploring how parents of children with disabilities experience the current Takaful system, what barriers they face, and what they hope for in a more inclusive and supportive system. By centering the perspectives of families, this research aims to offer meaningful insights that can inform policy development, encourage product innovation, and contribute to a Takaful industry that truly embodies the Islamic values of compassion, fairness, and social responsibility.

Research Objectives

This qualitative study aims to explore and understand the lived experiences of parents and guardians of children with disabilities in navigating Takaful access and protection in Malaysia. Specifically, this research seeks to address the following objectives:

1. To explore and understand the exclusion and accessibility barriers encountered by parents in securing Takaful coverage for their children with developmental and cognitive disabilities, and to interpret the emotional and financial meanings they attach to these experiences.
2. To explore and interpret parents' readiness, willingness, and motivations to contribute financially towards inclusive Takaful schemes that cater to their children's unique needs.
3. To explore and interpret parents' aspirations and expectations for holistic and inclusive financial protection that encompasses therapy, assistive tools, rehabilitation, and long-term care provisions beyond basic critical illness coverage.

Literature Review

This section reviews existing literature related to Takaful protection, inclusivity challenges, and the experiences of families with children with disabilities. The review is organized into three main sub-sections: (1) challenges in Takaful

protection for persons with disabilities, (2) healthcare access and parental perceptions toward disability support services, and (3) policy frameworks and gaps in social equity. These sub-sections provide the contextual foundation for understanding the barriers and aspirations that parents face in securing inclusive financial protection for their children.

- **Challenges in Takaful Protection for Persons with Disabilities**

The Takaful industry in Malaysia has grown steadily over the past decade, yet persons with disabilities (PWDs) remain largely excluded from meaningful coverage. Studies have shown that most Takaful operators restrict their coverage to physical impairments or disabilities resulting from accidents, while children with developmental conditions such as autism, Down syndrome, and cerebral palsy are frequently excluded (Wahab & Hassan, 2023; Mukshar et al., 2023). This exclusion is not merely a technical underwriting issue but reflects deeper systemic barriers within the industry.

Several factors contribute to this persistent exclusion. First, underwriting practices in Takaful tend to view developmental disabilities as high-risk and uninsurable due to incomplete actuarial data and perceived uncertainties surrounding long-term care costs (Mahomed, 2021). Second, the lack of standardized definitions and assessment frameworks for developmental disabilities across the industry makes it difficult for operators to develop inclusive products (Hanafi et al., 2025). Third, there is limited regulatory pressure on Takaful operators to extend coverage to PWDs, as the Persons with Disabilities Act 2008 lacks explicit provisions for financial rights and enforcement mechanisms (Tahir et al., 2023).

The consequences of this exclusion are significant. Parents often only discover exclusion clauses after their child is diagnosed, leading to frustration, financial vulnerability, and a sense of marginalization (Omar et al., 2023). Families are forced to bear the full cost of essential services such as therapies, assistive devices, and specialized care, which can lead to debt and financial hardship (Isamail & Said, 2025; Validova et al., 2023). This situation is compounded by the fact that even when insurance is available, coverage is often insufficient to protect families from high out-of-pocket expenses, a phenomenon known as underinsurance (Zhang et al., 2025; Agarwal et al., 2025).

At a broader level, the exclusion of PWDs from Takaful protection raises important questions about the industry's alignment with Islamic values. Islamic teachings emphasize justice (*al-'adl*), mutual support (*ta'awun*), and the protection of vulnerable members of society (Alnaser, 2024; Binmahfooz, 2024).

The Qur'an and Hadith provide clear guidance on accommodating individuals with disabilities, and historical institutions such as *waqf* and *bimaristans* demonstrated this commitment in practice. Yet, contemporary Takaful practices appear inconsistent with these values, potentially undermining the industry's ethical credibility and its role as a vehicle for social justice (Mahomed, 2021; Ibrahim & Markom, 2024).

- **Healthcare Access and Parental Perceptions Toward Disability Support Services**

Beyond Takaful exclusion, families with children with disabilities face significant challenges in accessing healthcare and support services. Research conducted in Malaysia has identified several persistent barriers, including ineffective communication with healthcare providers, limited availability of disability-friendly facilities, inadequate healthcare infrastructure, and geographical inaccessibility, particularly in rural areas (Omar et al., 2023; Mohd et al., 2023; Said et al., 2024).

A study by Omar et al. (2023) found that parents and guardians of individuals with special needs in Selangor faced multiple challenges, including a lack of disability-friendly healthcare facilities, financial pressure, and limited support systems. Similarly, Mohd et al. (2023) reported that while healthcare staff generally showed positive attitudes, parents still encountered obstacles such as insufficient information, poor communication, and unresolved pathways to various services. These findings are consistent with broader international evidence. Clemente et al. (2022), in a scoping review, identified communication failure, financial limitations, attitudinal barriers, and organizational issues as major barriers to healthcare access for PWDs. Gréaux et al. (2023) further highlighted that healthcare costs, untrained workforce, and stigma remain significant challenges globally.

The financial burden is particularly severe for low- and middle-income families. Chow et al. (2024), in a systematic review of Malaysian families' experiences, found that limited public service capacity, high costs of private interventions, and geographic restrictions were major barriers to accessing interventions for children with neurodevelopmental disabilities. Validova et al. (2023) reported that underinsurance is highest among middle-income households, particularly for children with complex physical or behavioral needs. This financial strain is compounded by the emotional toll on parents. Agarwal et al. (2025) found that the demanding coordination of care and inadequate insurance coverage significantly impaired the mental health of parents,

particularly mothers, who bear the primary responsibility for navigating complex healthcare and insurance systems.

The challenges parents face extends beyond financial costs. Many families report difficulties in finding appropriate services, long waiting times, and a lack of continuity in care (Shafie et al., 2022; Chow et al., 2024). These barriers not only affect the well-being of children with disabilities but also place considerable strain on family relationships, employment, and overall quality of life. The cumulative effect of these challenges underscores the need for more responsive and inclusive support systems, including financial protection that genuinely addresses the comprehensive needs of disabled children and their families.

- **Towards Inclusive Protection: Policy Frameworks and Gaps in Social Equity**

Several policy frameworks have been introduced at both national and international levels to promote the inclusion of PWDs in social protection systems. Internationally, the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006) established legally binding obligations for states to ensure accessibility, non-discrimination, and social protection for PWDs. The 2030 Agenda for Sustainable Development (United Nations, 2015) further reinforced these commitments through Sustainable Development Goals (SDGs), particularly SDG 1 (poverty), SDG 3 (health), and SDG 10 (reduced inequalities), which explicitly call for the inclusion of vulnerable groups including PWDs.

In Malaysia, the Persons with Disabilities Act 2008 was enacted to promote the rights and well-being of PWDs. However, scholars have noted that the Act's implementation has been limited, with a welfare-based approach continuing to dominate rather than a fully rights-based one (Tahir et al., 2023). The Pelan Tindakan Orang Kurang Upaya 2016–2022 (PTOKU) explicitly identifies access to insurance and Takaful as a strategic objective under Teras Strategik 1, targeting all operators to offer at least one disability-friendly product (KPWKM, 2016). However, despite this policy directive, only a handful of Takaful operators have introduced such products, and coverage remains largely restricted to physical disabilities (Wahab & Hassan, 2023). This gap between policy intention and market reality underscores the need for continued monitoring and advocacy. The Dasar Sosial Negara 2030 (KPWKM, 2023) further reaffirmed Malaysia's commitment to inclusive and sustainable social development, while the Mid-Term Review of the Twelfth Malaysia Plan

(Government of Malaysia, 2023) emphasized the need to address vulnerabilities among B40 households and PWDs through strategies such as the integration of the PADU database for evidence-based targeting.

Despite these policy directions, significant implementation gaps remain. Kafaa and Nurhadi (2023), in a systematic review of social health insurance in three Southeast Asian countries, found that current programs lack specific mechanisms directly targeting PWDs and that benefit packages do not adequately address their specific health needs. Similarly, Knox-Vydmanov and Goursat (2025), in a study of social health protection in Cambodia, Lao PDR, and Viet Nam, found that while coverage among PWDs has improved, benefit packages continue to exclude essential services such as rehabilitation and assistive technology, leaving families with high out-of-pocket costs. Hanafi et al. (2025) identified that despite policy efforts in Malaysia, PWDs still face barriers such as infrastructure costs, digital inaccessibility, low financial literacy, communication gaps, and discrimination.

At the Islamic finance level, there is growing recognition of the need to align Takaful practices with broader social justice objectives. The Value-Based Intermediation for Takaful (VBIT) framework, introduced by the Malaysian Takaful Association (2021), seeks to promote sustainable and socially responsible Takaful practices. Mahomed (2021) argued that VBIT provides a robust framework for sustainable Takaful but requires clearer metrics and stronger integration with Maqasid al-Shariah objectives. Ibrahim and Markom (2024) demonstrated that there is strong alignment between Maqasid al-Shariah and the Sustainable Development Goals, suggesting that Takaful operators could play a more significant role in promoting social justice and sustainability.

However, the gap between policy aspiration and on-the-ground reality persists. Families with children with disabilities continue to face systematic exclusion from Takaful protection, financial strain from out-of-pocket healthcare costs, and emotional stress from navigating fragmented support systems. This disconnection between policy intentions and lived experiences highlights the need for research that centers the voices of families, exploring their actual challenges, coping strategies, and aspirations for a more inclusive and compassionate financial protection framework. By understanding these lived realities, policymakers and industry stakeholders can develop more responsive and equitable solutions that truly serve the needs of vulnerable communities in Malaysia and beyond.

RESEARCH METHODOLOGY

This section describes the research approach, participant selection, data collection methods, data analysis procedures, and ethical considerations adopted in this study. The methodology is designed to align with the qualitative nature of the research and the objectives of exploring parents' experiences with Takaful inclusion for children with disabilities in Malaysia.

Research Design

This study adopts a qualitative research design using Thematic Analysis as outlined by Braun and Clarke (2006, 2013). This approach is suitable for exploring complex and under-researched social issues where participants lived experiences provide valuable insights. By focusing on the perspectives of parents, this study seeks to identify recurring patterns and themes that reflect both challenges and aspirations in securing inclusive financial protection for their children.

Research Participants and Data Collection

A purposive sampling strategy was used to select participants who were parents of children with disabilities. Eligible participants were required to have at least one child with a recognised disability such as autism, Down syndrome, cerebral palsy, or learning difficulties, and must have had some experience dealing with Takaful matters, either directly or indirectly. This ensured that participants could offer rich, relevant, and varied information regarding the challenges and experiences in obtaining financial protection products on behalf of their children.

A total of six participants were interviewed. While modest in size, this sample is consistent with qualitative research where depth is prioritised over breadth, and where rich and detailed accounts are valued more than statistical generalisability (Creswell & Poth, 2018; Guest, Bunce, & Johnson, 2006). Data adequacy was reached when no substantially new insights emerged, indicating thematic saturation (Francis et al., 2010).

The participants represented diverse socio-economic backgrounds and different types of disabilities among their children, which enhanced the richness of the data. Recruitment was conducted through community networks, autism-support groups, referrals, and personal contacts to ensure information-rich cases (Patton, 2015).

As shown in Table 1, the participants varied in relationship to the child, type of disability, and age of the child, providing diverse perspectives that enriched the analysis.

Table 1: Participant Profile Summary

Participant	Relationship	Child's Diagnosis	Child's Age	Previous Takaful Experience
P1	Father	Moderate Autism (Daughter)	7 years	Yes
P2	Mother	Autism Spectrum Disorder (ASD) (Child)	7 years	Yes
P3	Father	Cerebral Palsy (Son)	5 years	Yes
P4	Mother	Moderate Autism, Non-verbal (Daughter)	7 years	Yes
P5	Father	Moderate Autism, Non-verbal (Daughter)	13 years	Yes
P6	Mother	Down Syndrome (Son)	9 years	Yes

Table 1 provides a summary of the parents who participated in this study. Some were fathers, others were mothers, and their children lived with different disabilities. This mix of backgrounds and experiences shaped the way the themes later emerged in the analysis.

Data Analysis

Data were analysed using Thematic Analysis as described by Braun and Clarke (2006). All interviews were conducted face-to-face (30–60 minutes each) in Bahasa Melayu, audio-recorded on mobile devices, and transcribed verbatim into

Microsoft Word. Transcripts were checked against audio recordings through repeated listening to ensure accuracy and to preserve contextual meaning.

The analysis proceeded through Braun and Clarke's six phases (2006, 2013):

1. Familiarisation with the data: Reading and listening to the transcripts repeatedly to gain an overall understanding.
2. Generating initial codes: Line-by-line coding of interesting features in the data, performed in Bahasa Melayu.
3. Searching for themes: Collating codes into potential themes.
4. Reviewing themes: Checking themes against the data and refining their boundaries.
5. Defining and naming themes: Articulating the essence of each theme.
6. Producing the report: Translating selected extracts into English for reporting, while retaining the original Malay phrasing where necessary.

Coding was performed manually by the primary researcher and reviewed periodically to ensure consistency. Thematic saturation was judged to have been reached when no substantially new themes emerged from additional transcripts (Guest, Bunce, & Johnson, 2006; Francis et al., 2010). The final analytic output comprised three main themes that reflect parents' experiences: (1) Takaful exclusion and accessibility issues; (2) Parental readiness and willingness to contribute; and (3) Hopes for inclusive and holistic financial protection.

Synthesis of Themes

Rather than claiming to develop a new theory, this study brings the themes together to show how they relate to one another. Parents' stories point to three connected patterns. First, many faced barriers in accessing protection, especially when exclusions applied to their children's conditions. Second, despite these challenges, parents showed a strong readiness to contribute financially, reflecting both responsibility and hope. Third, they often spoke about wider needs, such as therapy and long-term care, which are not usually part of existing products. When read together, these themes highlight the gap between what is currently offered and what families actually need. They also suggest directions for future policy and product improvements, while recognising that broader theory-building would require larger and more diverse studies.

Trustworthiness and Ethical Considerations

This study placed strong emphasis on ethical care and credibility. To ensure trustworthiness, the study drew upon the framework proposed by Lincoln and

Guba (1985), which establishes credibility, transferability, dependability, and confirmability as key criteria for qualitative research quality. Credibility was enhanced through prolonged engagement with participants, persistent observation, and member checking, where transcripts were returned to participants so they could check or add clarification.

Informed consent was obtained from all participants before interviews were conducted. Participants' names and any identifying details were removed in reporting. Because parents were sharing both financial struggles and their children's needs, interviews were approached with sensitivity. All coding and interpretation were done manually, which kept the researcher close to the data. Ethical approval was obtained in advance, and the process followed standard ethical principles in qualitative research (Creswell & Poth, 2018; Patton, 2015)

RESULTS AND DISCUSSION

This section presents the findings from the in-depth interviews conducted with six parents of children with disabilities. Using Braun and Clarke's (2006) thematic analysis, three primary themes were identified that reflect the participants' experiences, challenges, and expectations regarding Takaful access for their children. The findings are presented thematically, with each theme supported by relevant sub-themes and direct quotations (verbatim) from the participants to illustrate the underlying patterns and meanings that emerged from the data.

Overview of Findings

Through the thematic analysis of six semi-structured interviews, three primary themes were formulated, supported by corresponding sub-themes and direct quotations. These themes capture the major issues, lived realities, and aspirations of parents as they navigate the existing Takaful system for their children with special needs. The three themes are:

1. Takaful Exclusion and Accessibility Issues
2. Parental Readiness and Willingness to Contribute
3. Hopes for Inclusive and Holistic Financial Protection

Each theme is elaborated in the following sections with the help of verbatim quotes from the participants, which bring authenticity and depth to the findings.

Theme 1: Takaful Exclusion and Accessibility Issues

A prevailing theme throughout the interviews was the experience of marginalisation and restricted access to Takaful protection for children with disabilities. Most of the respondents expressed dissatisfaction that their children were either not covered at all or were excluded due to developmental conditions such as autism or cerebral palsy.

Parents consistently highlighted that Takaful plans are more receptive to physical disabilities compared to cognitive or developmental ones. This exclusion reflects a lack of inclusivity in the industry's policies and imposes significant emotional and financial burdens on families seeking protection for their children. Many parents only became aware of the exclusion clauses after their child was diagnosed, indicating a lack of early and clear information about product limitations. This late discovery, combined with the limited availability of suitable products, contributes to a general feeling of marginalisation within the financial protection system.

Supporting Verbatim (translated from Bahasa Malaysia):

- *"Do not sideline children with disabilities or those with special needs. That's all..."* (P1)
- *"I looked for specific takaful protection, but it was only available for those with physical disabilities."* (P3)
- *"I would say, allow autistic children to have takaful protection specifically for illnesses or issues not related to their autistic behaviour."* (P5)
- *"The most challenging part for me is to stop my child from hurting herself. This is one of the main reasons why children with autism are not allowed takaful protection."* (P5)

Sub-themes:

- Lack of inclusive Takaful policies
- Cognitive and developmental conditions are not covered
- Emotional impact of exclusion on parents and families
- Late awareness of exclusion clauses after diagnosis

These findings suggest that there is an urgent need for timely policy reform and product innovation within the Takaful industry to make coverage more inclusive and equitable towards the PWD community, particularly children with developmental needs.

Theme 2: Parental Readiness and Willingness to Contribute

The second notable theme that emerged from the data was the strong willingness and readiness among parents to contribute financially towards their children's protection. Despite the current exclusionary practices among various Takaful providers, most participants showed a significant willingness to pay higher premiums, provided the plan was relevant, inclusive, and designed to support their child's long-term development.

Some parents emphasised that their motivation was not driven by affordability concerns but rather by the desire to access more appropriate and higher-quality care, including moving to private healthcare centres or therapy facilities. A strong sense of responsibility and emotional investment was a major factor stimulating this willingness to contribute. Respondents also suggested that most parents would welcome collaborative efforts between healthcare professionals and Takaful companies if such partnerships promised better outcomes and prospects for their children.

Supporting Verbatim (translated from Bahasa Malaysia):

- *"There are parents or guardians who are capable of paying for Takaful to get treatment in a more comfortable place."* (P1)
- *"We want plans that cover developmental disabilities, not just physical ones. You could actually make money from that — it's profitable!"* (P1)
- *"Many of us are willing to contribute if the plan makes sense and helps our child's development."* (P6)
- *"At least offer a plan that covers basic therapy, assistive tools, or rehabilitation costs, not just critical illnesses."* (P6)

Sub-themes:

- Parents are willing to pay for inclusive coverage
- Demand for better-quality care (e.g., therapy, private treatment)
- Calls for collaboration between Takaful and healthcare providers
- Consideration of future planning and long-term care needs

This theme highlights that the core issue is not a lack of financial capability among parents but rather the absence of inclusive options. With supportive infrastructure and clear communication, many families are ready to

engage in Takaful participation for the betterment of their children's health and protection.

Theme 3: Hopes for Inclusive and Holistic Financial Protection

The third theme provides evidence of a strong hope among parents for a more comprehensive and compassionate Takaful system that takes into account the diverse and evolving needs of a child with a disability. Most respondents expressed a desire for protection strategies that go beyond simple critical illness coverage and instead focus on therapy, long-term care, assistive aids, and even post-parental provisions.

There was a clear call for the Takaful industry to adopt a more humane and inclusive perspective when designing policies, taking into consideration the everyday realities faced by parents. In their view, coverage should be based on actual developmental needs rather than being limited to physical or permanent disabilities caused solely by accidents. This hope was often accompanied by an appeal to Takaful providers to embrace moral and social responsibilities beyond profit margins in order to reach needy communities. Many respondents expressed a willingness to support or participate in such initiatives if they aligned with their long-term interests in their children's well-being.

Supporting Verbatim (translated from Bahasa Malaysia):

- *"Don't exclude children with disabilities. Some parents are willing to pay for better care options."* (P1)
- *"Takaful should not just focus on permanent disabilities from accidents. What about developmental disabilities?"* (P1)
- *"At least create a plan that covers therapy, assistive tools, or rehabilitation, not just critical illness."* (P6)
- *"We need policies that don't reject us just because our children are different."* (P3)

Sub-themes:

- Demand for specialised and inclusive Takaful plans
- Coverage for therapy, assistive tools, and long-term care
- Emphasis on social and moral obligations of the industry
- Need for acceptance and non-discriminatory policies

This theme reinforces the call for Takaful providers to view their role not just as financial institutions but as enablers of social justice. By developing

tailored plans that address the diverse realities of PWDs and their families, the industry has the potential to become a beacon of inclusive financial protection.

Synthesis of Themes

When viewed together, the three themes reveal a persistent disconnection between families' needs and the current structure of Takaful offerings. Parents are confronted with exclusions that leave major developmental conditions outside the scope of protection, yet they remain motivated and financially ready to participate if opportunities are made available. This combination of exclusion on the supply side and readiness on the demand side underscores a gap that is not simply technical but also social in nature.

The findings further suggest that the aspirations of parents extend beyond basic financial security. Their concern for coverage that includes therapy, assistive tools, and long-term care reflects a broader vision of inclusive financial protection that recognises disability as a lifelong journey. Rather than viewing disability as an uninsurable risk, families frame it as an area where sustainable financial solutions could strengthen both household resilience and social equity.

Taken together, these voices indicate that inclusive Takaful is not only a matter of product design but a test of the industry's ability to balance risk management with social responsibility. Closing the gap requires rethinking actuarial models, introducing regulatory incentives, and exploring entrepreneurial innovations that prioritise both profitability and fairness. In this way, the study contributes to ongoing debates on ethical finance, inclusive policy, and the evolving role of social impact in the financial services sector in Malaysia.

Summary

This study explored the lived experiences of parents and guardians of children with disabilities in navigating Takaful access and protection in Malaysia. Through thematic analysis, three major themes emerged from the data:

1. **Takaful Exclusion and Accessibility Issues:** Parents highlighted structural barriers, particularly the exclusion of children with developmental disabilities from Takaful coverage. Policies often only cater to physical impairments or accidental injuries, leaving out those with autism, Down syndrome, or cerebral palsy. Lack of transparency, rigid underwriting criteria, and limited inclusive product options were frequently mentioned challenges.
2. **Parental Readiness and Willingness to Contribute:** Contrary to perceptions that cost is the main barrier, participants demonstrated

strong financial willingness and emotional readiness to contribute to their children's protection. However, they found themselves restricted by the lack of suitable plans rather than affordability, suggesting a mismatch between demand and what the industry currently offers.

3. **Hopes for Inclusive and Holistic Financial Protection:** Parents expressed hope for a more compassionate and responsive Takaful system, one that provides long-term support, including therapy, assistive devices, and inclusive treatment options. There was also a shared call for the Takaful industry to align itself with social justice and moral obligations, especially in serving vulnerable populations such as children with disabilities.

Collectively, these findings underscore the need for policy innovation, industry empathy, and deeper collaboration between parents, medical professionals, and Takaful providers. The voices of parents highlight an urgent demand for inclusive financial protection that not only addresses risks but also supports the holistic development of children with disabilities.

CONCLUSION

This study explored the experiences of parents of children with disabilities in accessing Takaful protection in Malaysia. Three key findings emerged. First, children with developmental disabilities are systematically excluded from most Takaful plans, with coverage largely restricted to physical impairments. Second, parents showed strong willingness to contribute financially if inclusive plans were available. Third, parents aspired for holistic protection covering therapy, assistive tools, and long-term care.

These findings reveal a persistent gap between policy and practice. Although the *Pelan Tindakan Orang Kurang Upaya 2016–2022* (KPWKM, 2016) explicitly targeted insurance and Takaful access, most operators still exclude children with developmental disabilities. This calls for stronger enforcement of the Persons with Disabilities Act 2008 and product innovation that addresses therapy, assistive devices, and long-term care. For the Islamic finance community, this study reinforces the need to align Takaful with the values of justice (*al-'adl*) and mutual support (*ta'awun*).

Given the small sample size, future research should include larger, more diverse samples and the perspectives of Takaful operators. In closing, the voices of parents reveal an urgent need for change which is change that is both commercial and ethical. By responding with empathy and innovation, the

Takaful industry can fulfil its role as a provider of inclusive financial protection in Malaysia.

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