The High Cost of Autism Care in Malaysia: A Review of Financial Burdens and Policy Gaps

Mohd Hisham Mahamud[1], Nur Ezan Rahmat[2], Wan Ainul Asyiqin Wan Mohd Razali[3]

[1,2]Faculty of Accountancy, UiTM Shah Alam, Selangor, Malaysia

[3]Faculty of Business, Economics and Social Development, UMT, Terengganu, Malaysia

[*]Corresponding author

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ABSTRACT

Caring for children with autism spectrum disorder (ASD) imposes severe and ongoing financial strain on Malaysian families. This review synthesises domestic and international research, with a focus on direct costs—such as therapy, medical care, and education—and assesses the adequacy of government welfare, insurance, and institutional support. Findings reveal that families often face high out-of-pocket spending and fragmented support. The paper concludes with targeted policy recommendations to strengthen financial protection and institutional aid for affected households.

Keywords: Autism Spectrum Disorder; Direct cost; Policy gaps

INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition that disrupts social interaction, communication, and behavioural patterns. Worldwide, the incidence of ASD continues to rise, as highlighted by the World Health Organization's estimate that one out of every 100 children is affected (WHO, 2023). In Malaysia, ASD diagnoses have surged—growing more than twentyfold between 2006 and 2021 (Ministry of Health, 2022). This dramatic increase, fuelled by improved awareness and better diagnostics, has amplified both financial and social challenges for Malaysian households. Families navigating ASD face direct expenses for interventions such as speech and occupational therapy, special education, and other services. However, in low- and middle-income nations—including Malaysia—access to affordable support is frequently inadequate, and insurance coverage is minimal (Ismail & Jaafar, 2021). As a result, the economic strain on carers is substantial.

This paper reviews the literature on the economic impact of ASD in Malaysia, aiming to:

1. Identify and quantify direct costs borne by families;
2. Assess the role and effectiveness of governmental and institutional support in addressing these financial challenges; and
3. Provide a synthesised financial analysis based on current data.

By integrating empirical findings with policy analysis, the study aims to enrich discussions on improving support for Malaysian families with children on the autism spectrum.

LITERATURE REVIEW

Research over the past two decades has highlighted the substantial economic costs associated with ASD care, not just in high-income countries but also across developing nations. Initial studies, such as Ganz (2007), quantified the lifetime economic impact in the United States at over $3 million per individual, with non-medical needs—like special schooling and supported living—dominating total costs.

Later research broadened the focus, revealing that the indirect effects—such as parents, especially mothers, leaving the workforce or working fewer hours (Cidav et al., 2012)—compound direct financial outlays. In the UK and US, annual ASD-related costs are substantially higher than for other developmental disorders (Buescher et al., 2014), primarily due to more intensive care requirements and reduced family earnings.

Recent macroeconomic analyses have examined the interplay of direct, indirect, and societal costs (Horlin et al., 2014), showing that early intervention programs, though expensive upfront, may mitigate longer-term costs. Global comparisons (Chasson et al., 2018) consistently show that families in low- and middle-income settings, like Malaysia, endure a heavier burden because of limited state subsidies and insurance coverage.

Common direct expenses include therapy sessions, special education, medical consultations, and assistive devices. These costs are notably higher for children with severe ASD (Roddy & O'Neill, 2018; Zhao et al., 2023). Delays in diagnosis and intervention further inflate expenses, particularly in the initial post-diagnosis phase (Zhou et al., 2021). Insurance—where available—rarely covers the breadth of required services, often resulting in high out-of-pocket spending (Parish et al., 2015).

Overall, the literature underscores the evolving recognition of ASD's multidimensional economic toll, shifting from a narrow focus on direct expenditures to include broader indirect and opportunity costs faced by affected families.

METHODOLOGY

This study adopts a qualitative research design, primarily grounded in an extensive review of existing literature and policy documents related to ASD care costs in Malaysia and comparable international contexts. A systematic search was conducted using databases such as PubMed, Scopus, Web of Science, and Google Scholar between January 2007 and April 2024. Keywords included "autism spectrum disorder," "ASD," "cost of care," "financial burden," "economic impact," "Malaysia," and "policy gaps.". Accordingly, titles and abstracts were screened for relevance. Only peer-reviewed journal articles, official reports, and high-impact policy briefs in English were included. Studies focusing exclusively on indirect costs without clear financial data were excluded. A total of 35 sources were included in the final synthesis after full-text review and quality appraisal.

The identified sources were organised into two mains analytical categories: (i) direct financial costs (encompassing healthcare, therapies, and educational services), and (ii) governmental and institutional assistance (assessing availability, access, and adequacy of support schemas). Comparative thematic analysis was employed to extract, group, and interpret findings from both categories. This dual-focus approach enables an integrated assessment of the actual costs borne by families and the extent to which current public or private supports alleviate their financial challenges.

RESULTS

Direct Financial Outlays for ASD Care in Malaysia

Recent literature and community-based surveys consistently indicate that Malaysian families incur significant monthly expenses for ASD-related services. The most substantial outlay is often for specialised education, which can reach up to RM1,500 per month in private institutions. Regular speech and occupational therapy sessions add an additional RM800–RM1,000 monthly, with prices fluctuating based on session frequency and provider expertise. Private medical consultations may cost families another RM300–RM500 each month. Expenditure on assistive equipment (e.g., sensory tools, communication aids) further increases the overall monthly cost. Altogether, direct expenses commonly surpass RM4,000 in urban settings, where subsidised options are often unavailable or oversubscribed (Ismail & Jaafar, 2021; Abdul Wahid et al., 2020). Given that the national median monthly household income was RM5,209 in 2023, these costs represent a severe financial burden, especially for households below or near this threshold (IDEAS Malaysia, 2022).

Public and Institutional Assistance

The Malaysian government, through agencies like the Ministry of Women, Family and Community Development

(MWFCD) and PERKESO, provides some welfare and support schemes for families with children with ASD. These include:

Programme	Form of Support	Key Limitations
Children's Welfare Support	RM150–RM1,000/month	Restrictive eligibility, lengthy approval process
Persons With Disabilities Card (OKU)	Subsidies for health, schooling, parking	No guarantee of therapy funding, limited use
Early Intervention Programmes (EIP)	Access to educational/therapy services	Limited slots, urban-centric availability
Tax Relief (Disabled Child)	RM6,000 + RM2,000 (ASD specific) deduction	Only aids higher-income, tax-paying families
PERKESO Employment Incentives	Reskilling, employment matching for carers	Rarely accessible to full-time caregivers

Several NGOs also provide therapy and educational support (e.g., NASOM, IDEAS Autism Centre), yet these resources remain concentrated in major urban centres and often cannot meet rising demand.

DISCUSSION

Malaysian families raising children with ASD confront ongoing, multi-layered economic pressure—impairing not just household finances, but also parental employment and children's development prospects. Both direct out-of-pocket spending and broader opportunity costs (such as foregone wages or career advancement) are substantial.

Comparative Financial Impact by Income Level

By benchmarking ASD-related spending against national income data, the study highlights the acute affordability gap for both median- and low-income households. For a family earning the median RM5,209 monthly, direct ASD care expenditures averaging RM4,000 amount to roughly 77% of household income. After these expenses, little remains for basic living needs, pushing many families towards debt or asset liquidation.

For those at the poverty line (monthly income RM2,589), the situation is even more dire: direct ASD expenses may far exceed total earnings, leading to chronic deficits and reliance on extended family or external assistance.

When factoring in average government support (typically RM300–RM500 monthly), the overall burden is reduced only modestly. Median-income families still spend over two-thirds of their earnings on ASD care, and low-income households remain in deficit. These ratios significantly exceed international guidelines, which consider healthcare spending above 30% to 40% of income as catastrophic.

Geographic, Social, and Institutional Barriers

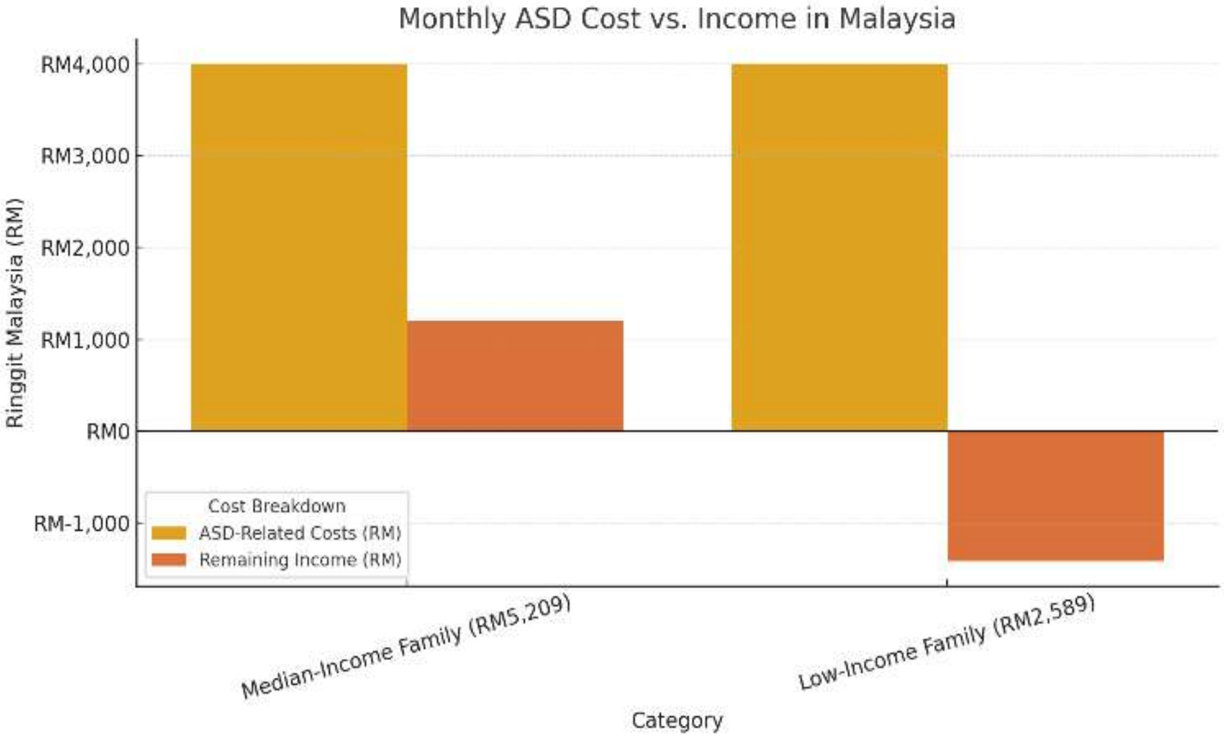
There are sharp disparities in access and affordability depending on a family's location. Urban families may have better access to services, but often face high costs and long waitlists. Rural households are especially disadvantaged, with scarce service providers and higher incidental costs (Yusof & Rahman, 2022). Furthermore, support programs are fragmented and inconsistently administered. Eligibility criteria exclude many who are most in need, and tax relief schemes tend to benefit only those in formal employment or higher tax brackets (IDEAS Malaysia, 2022). Meanwhile, insurance coverage for ASD-related care remains rare and inadequate.

Lasting Consequences and Coping Strategies

The economic toll of ASD care is not limited to immediate outlays. Families report enduring hardship, including chronic debt, reduced employment, and major lifestyle adjustments. Studies show that parents—often mothers—must scale back work or quit jobs to provide care, resulting in lasting loss of income and future earning potential (Ou et al., 2015; Ouyang et al., 2014). Lifetime ASD care costs have been estimated between $1.4 and $2.4 million per individual, underscoring the magnitude of the challenge (Rogge & Janssen, 2019; Buescher et al., 2014).

Families attempt to cope by cutting discretionary expenses, postponing investments, or leaning on informal social support, but these tactics rarely offset the overall financial strain (Bhuiyan & Islam, 2024).

The diagram below shows a visual cost comparison chart showing the monthly financial burden of ASD-related expenses on two household income groups in Malaysia.



For median-income families (RM5,209/month), about RM4,000 goes to ASD care, leaving only RM1,209. Meanwhile, for low-income families (RM2,589/month), ASD care exceeds their total income, resulting in a deficit. This stark contrast highlights the catastrophic financial impact of ASD care, especially on lower-income families.

POLICY RECOMMENDATIONS

To address these gaps, a multi-pronged and thematically organised policy response is recommended.

A. Financial Reform

Financial reforms are urgently needed to ease the immediate economic pressures on families. The government should establish a dedicated National Autism Support Fund to provide continuous financial relief tailored to therapy, transportation, and assistive equipment expenses. In addition, tax relief schemes should be expanded and restructured to include lower- and middle-income families who currently derive limited benefit from income-based deductions.

B. Geographic & Service Accessibility Reforms

Addressing geographic and service access disparities must become a core priority. This can be achieved by increasing the number of early intervention centres and therapy service providers in rural and underserved regions. The establishment of mobile diagnostic and intervention units would also help bridge the urban–rural service gap. A robust national data infrastructure is essential to identify service deserts, monitor resource distribution, and inform equitable policy planning.

C. Institutional and Legal Reforms

Institutional and legal reforms should focus on long-term structural support for families. Insurance providers should be mandated to include ASD-related services in their coverage portfolios. At the same time, caregiver protections in employment law must be strengthened—introducing flexible work arrangements, guaranteed leave policies, and job retention safeguards for parents who serve as primary caregivers. These reforms should be coordinated under a centralised inter-ministerial body to ensure harmonised implementation across the health, education, and social welfare sectors.

Collectively, these recommendations aim to build a more resilient and inclusive support system for children with ASD and their families in Malaysia.

CONCLUSION

This review highlights the profound and persistent financial challenges facing Malaysian families caring for children with ASD. The combination of high direct out-of-pocket expenditures for therapies, special education, and medical care, alongside indirect costs such as lost parental income, imposes a severe economic burden, particularly on families earning below the national median. Despite the existence of some government and welfare interventions, the Malaysian support system remains fragmented, selective, and insufficient to provide sustainable financial security or equitable service access. When compared with the United Kingdom, where universal healthcare and statutory educational support substantially reduce the direct financial burden for families, it becomes clear that the Malaysian approach is less comprehensive and fails to guarantee consistent assistance to all affected households, especially those in rural or low-income settings.

While this review draws from extensive secondary literature, future studies should incorporate primary data—including household-level surveys and caregiver interviews—to more accurately quantify the economic burden across income brackets, regions, and ASD severity levels. Longitudinal studies would also help track evolving costs and evaluate the impact of policy reforms over time.

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