

The Economic Burden of Families with Autism Spectrum Disorders (ASD) Children in Malaysia

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Abstract: The economic burden of families with Autism Spectrum Disorders (ASD) children that are far beyond the needs of typical children causes physical and mental stress for their parents. The study aims to examine the economic burden of parents with ASD children in Malaysia. Calculation is made using a cost-loss approach due to ASD that include direct, indirect and developmental costs. Using convenient sampling method, a total of 245 parents have filled out questionnaires through online or hard copies. Development costs represent the highest cost of RM20,989.33, followed by medical direct costs RM8,378.73, RM5,033.57 for non-medical direct costs and RM963.99 for indirect costs. The total cost of financing an ASD child is RM35,365.62 a year. This is a huge and burdensome amount for parents. The findings of this study may assist responsible parties in the planning of effective service provision to suit the need of parents with ASD children in Malaysia.

Keywords: economic burden, autism spectrum disorders, parents, children.

Autism, or Autism Spectrum Disorder (ASD), refers to a range of conditions characterized by challenges with social skills, repetitive behaviours, speech and nonverbal communication, as well as by unique strengths and differences. Now we know that there is not one ASD but many types, caused by different combinations of genetic and environmental influences (Autism Speaks, 2012). The term “spectrum” reflects the wide variation in challenges and strengths possessed by each person with ASD. Autism’s most-obvious signs tend to appear between 2 and 3 years of age. In some cases, it can be diagnosed as early as 18 months. Some developmental delays associated with ASD can be identified and addressed even earlier.

On March 27, 2014, the Centres for Disease Control and Prevention (CDC) released new data on the prevalence of autism in the United States. This surveillance study identified 1 in 68 children (1 in 42 boys and 1 in 189 girls) as having autism spectrum disorder (ASD). It is estimated that one out of every 600 children in Malaysia is born with autism. Recent statistics show that some 47,000 of the people in this country are autistic. Of the figure, it is estimated that four out of every 10,000 suffer from severe autism (Neik *et al.*, 2015).

Early intervention such using multidisciplinary educational and behavioural approaches (e.g., applied behaviour analysis, skill oriented training therapies for social and language development), prescribed medication for specific symptoms, such as anxiety, depression, attention deficit disorder, customized

sessions (physical and speech), and hyperactivity, obsessive compulsive behaviour (Mendoza, 2010). Unfortunately, caregivers of ASD children face numerous challenges and many studies reported increased psychological distress including depression (Sivberg, 2002; Weiss, 2002; Yirmiya, 2005).

Autism Speaks, the world’s leading autism science and advocacy organization, today announced preliminary results of new research that estimates autism costs society a staggering \$126 billion per year (U.S.) – a number that has more than tripled since 2006. (Autism Speaks, 2012). Based on the research by Drs. Knapp and Mandell funded by Autism Speaks (2012), a compiled information from recent studies of autism costs from multiple sources to calculate the current cost of autism associated with the current CDC-reported prevalence that 1:110 children are diagnosed with an autism spectrum disorder (ASD). The cost of autism continues to grow with the rise in prevalence.

The research also found that non-medical costs account for the greatest proportion of expenses. While direct medical costs, such as outpatient care, home care, and pharmacy, contribute significantly to overall expenses, non-medical costs, including intervention services and special education, child day care, and especially residential placements and care for adults who age out of school and can no longer live at home with parents account for the largest proportion of autism costs.

Autism Speaks President Mark Roithmayr stated

in his speech that, “The burden on families affected by autism is enormous”. He also mentioned that, “The extraordinary cost further exacerbates that burden. The time and effort involved in coordinating the care and treatment plan across a large number of providers has reduced the ability of many families to earn a living. Too many families are still denied insurance coverage for essential treatments and services, and the economics add to overall emotional burden on families” (Autism Speaks, 2012).

METHOD

This study is a cross-sectional quantitative study of observation type and convenient sampling techniques used in respondent selection based on inclusive and exclusive criteria. The inclusive criteria are; i) having a child diagnosed with ASD; ii) families originating or residing in Malaysia; iii) speak and write in Malay; and iv) able to use internet or postal service. Whereas the exclusive criteria are; i) family with more than one ASD child or disabled family member; and ii) families with more than one child or family members suffering from chronic illness and requires long-term care. However, these criteria are excluded as it will make the amount of expenditure earned larger, while the purpose of the study is to calculate the economic burden incurred by each family to raise a child who has ASD only.

Information regarding family expenditure is collected using Parents’ Financial Statements Form that had been adapted from Out-of-pocket Expenses. This form is divided into 5 parts which are; Part I Parents’ Demographic Information; Part II ASD Child Demographic Information; Part III and IV Expenditure List; and Part V Parents and ASD Child Productivity Loss.

Items in Part III and IV consist of expenditure list for direct cost and developmental cost. Direct cost consists of all expenditure related to medical treatment of illness (Mahadeva, 2012). There are two categories of direct costs which are medical direct cost and non-medical direct cost. Medical direct cost is expenditure for medical treatment sources that used to treat or overcome condition complication of an individual such as outpatient services, warded fees, diagnoses, medical treatment, surgery, medication and rehabilitation services. Whilst, non-medical direct cost includes transportation and accommodation cost related to the usage of medical services facilities (Rice, 1966).

Developmental cost is referred to expenditure for special needs education, special diet, supplementary diet and autism child care services (Wang, 2008). Meanwhile, item in Part IV is about indirect cost consisting of parents’ productivity loss cost and ASD child productivity loss cost (Sullivan *et al.*, 2008;

Chakravarti, 2008; Honeycutt *et al.*, 2004; Salmon & Reddihough, 2003). A pilot survey has been carried out to identify the compatibility of Parents Financial Statement Form and improvements have been done based on the pilot survey. Afterwards, the form is distributed online through email and private message on social media which is Facebook. Data obtained is analysed using average comparison and non-parametric Kruskal-Wallis and Mann Whitney U test.

FINDINGS AND DISCUSSION

A total of 365 parents with ASD children have completed the Parent Financial Statement Form online but only 245 respondents are considered based on the exclusive criteria. Based on the analysis carried out, the min of ASD child age in this study is 8.65 years old. For gender factor, 79.2% of research subject are male children and 20.8% are female children. Descriptive statistical analysis for racial factor shows that Malay is the majority with 57.1%, followed by Chinese 25.3%, others by 13.5% and Indian by 4.1%. Apart from that, 29.9% of ASD child with comorbid illness and 70.1% are without comorbid illness.

The average family household income of families with ASD children is RM6,141.00/month for year 2014. Comparison of ASD family household income with average state household income (Report on Household Income and Basic Household Malaysia 2016) shows that 69.8% of families with ASD child have household income exceeding average of state household income. Around 76.7% ASD child in this study received free treatment from government health clinics and hospitals. 36.7% of research participants receiving monetary assistance from Social Welfare Department (JKM), zakat or from Ministry of Education Malaysia (KPM) for ASD child schooling in the year 2014. Previous study showed that there was no relationship between household income and quality of life among disability teenagers (Shamsul *et al.*, 2013).

Average Family Economic Burden Category Cost

Based on Table 1, average cost incurred by families with ASD children in 2014 is RM36,728.43. Overall, developmental cost burden is the highest burden even though Malaysians receive medical services at government hospitals and health clinics. On average, families with ASD children spend RM21,928.58 for developmental costs, RM9,029.01 for medical direct costs and RM5,770.84 for non-medical direct cost. Comparison of components in the family economic burden shows the average cost of developmental needs is the highest despite the Government providing free education in schools and care in Community Rehabilitation Centre (PDK).

Table 1. Parents' economic burden

| | Minimum | Maximum | Min | Standard Deviation |
|-------------------------------------|--------------|-------------------|------------------|--------------------|
| Direct Medical Cost (RM) | | | | |
| Purchase of Medical Aid | 0.00* | 15,000.00 | 587.69 | 1,285.00 |
| Diagnostic Test | 0.00* | 6,000.00 | 317.47 | 693.09 |
| Surgery Ward | 0.00* | 30,000.00 | 1,021.25 | 3,129.45 |
| Entrance Fee | 0.00* | 48,000.00 | 695.75 | 3,473.67 |
| Alternative Treatment | 0.00* | 60,000.00 | 816.49 | 4,107.92 |
| Medicine Cost | 0.00* | 18,000.00 | 4,940.08 | 3,461.85 |
| Medical and Therapy Fee | 0.00* | 177,000.00 | 8,378.73 | 16,150.98 |
| Total | | | | |
| Direct Non-Medical Cost (RM) | | | | |
| Transportation Cost | - | 60,000.00 | 5,033.57 | 6,579.35 |
| Total | - | 60,000.00 | 5,033.57 | 6,579.35 |
| Developmental Cost (RM) | | | | |
| Domestic Helper | - | 60,000.00 | 3,212.57 | 7,340.95 |
| Nursery | - | 48,000.00 | 3,602.69 | 5,874.86 |
| Special Education | - | 38,400.00 | 4,427.26 | 6,496.89 |
| Special Dietary | - | 18,000.00 | 4,940.08 | 3,461.84 |
| Daily Necessities | - | 60,000.00 | 2,029.71 | 4,130.56 |
| Insurance | - | 25,000.00 | 1,262.08 | 2,237.18 |
| Others | - | 60,000.00 | 1,514.94 | 4,740.52 |
| Total | - | 309,400.00 | 20,989.33 | 34,282.80 |
| Indirect Cost (RM) | | | | |
| Parents Productivity Loss | - | 4,153.50 | 142.78 | 467.37 |
| Autism Child Productivity Loss | - | 9,695.10 | 821.21 | 2,853.10 |
| Total | - | 1,3848.60 | 963.99 | 3,320.47 |
| OVERALL TOTAL | | 560,248.60 | 35,365.62 | 60,333.52 |

Comparison of Economic Burden According to Age Group

Based on Table 2, the family economic burden of children with ASD in the age group 13-18 years was highest at RM11009.17, followed by age group 0-3 years old RM8,800.00, then age group 7-12 years old RM8,497.22 and age group 4-6 years RM7,845.25. Kruskal-Wallis test carried out found that there are no

significant differences between economic burdens with autism child age groups.

Developmental costs are highest for age group 0-3 years, followed by age group 4-6 years and age group 7-12 years. Studies have found that there are no alternative treatment expenses for the age group 19 years and above. This indicates that parents have stopped applying alternative treatment as they focus on transition process as their children grow up.

Table 2. Comparison of ASD economic burden according to age group

| Economic Burden Categories/ Age | 0-3 years old | 4-6 years old | 7-12 years old | 13-18 years old | 19 years and above | Kruskal-Wallis (p) Test |
|--|----------------------|----------------------|-----------------------|------------------------|---------------------------|--------------------------------|
| Direct Medical Cost(RM) | | | | | | |
| Services Rehabilitation | 5,750.00 | 4,867.27 | 5,109.90 | 4,175.00 | 4,892.031 | 0.849 |
| Alternative Treatment | 600.00 | 423.64 | 891.96 | 1450.00 | 0.00 | 0.361 |
| Medicine Cost | 1,150.00 | 471.52 | 1,183.92 | 930.00 | 184.62 | 0.781 |
| Purchase of Medical Aid | 204.17 | 616.67 | 509.02 | 1,181.25 | 212.31 | 0.168 |
| Diagnostic Test | 295.83 | 337.88 | 325.05 | 322.92 | 115.38 | 0.510 |
| Ward Entrance Fee Surgery | 800.00 | 1,128.28 | 477.37 | 2,950.00 | 907.69 | 0.024 |
| Total | 8,800.00 | 7,845.26 | 8,497.22 | 11,009.17 | 6,312.03 | 0.349 |
| Developmental Cost (RM) | | | | | | |
| Domestic Helper | 5,670.00 | 4,043.64 | 2,406.18 | 2,655.00 | 1,661.54 | 0.565 |
| Nursery | 6,730.00 | 4,730.30 | 2,568.25 | 2,615.00 | 1,670.77 | 0.070 |
| Special Education | 6,900.00 | 4,147.88 | 4,640.41 | 4,730.00 | 2,123.08 | 0.131 |
| Special Dietary | 5,750.00 | 4,867.27 | 5,109.90 | 4,175.00 | 4,892.31 | 0.849 |
| Daily Necessities | 2,700.00 | 1,820.00 | 2,180.92 | 1,873.00 | 2,169.23 | 0.655 |
| Insurance | 1,982.50 | 1,401.05 | 1,059.38 | 1,781.04 | 93.01 | 0.008 |
| Others | 1,360.00 | 956.36 | 1,995.46 | 2,525.00 | 461.54 | 0.014 |
| Total | 31,092.50 | 21,966.50 | 19,960.50 | 20,354.04 | 13,071.48 | 0.283 |
| OVERALL TOTAL | 39,982.50 | 29,811.76 | 28,457.72 | 31,363.21 | 19,383.51 | 0.406 |

* Survey participants received free medical services from Malaysia's hospital or health clinic or does not have the needs to receive certain medical services.

It was noted that youth and young adults with ASD receive little transitional support as they age towards adulthood. The transition from high school to postsecondary education or employment can be intensely challenging for both the individual with ASD and their family (Nicholas, 2016).

The difference in ward entrance fee surgery burden according to age group is also significant ($p = 0.024$). This expenditure is the highest for autism child in age group of 13- 18 years old, followed by 4-6 years old age group, age group 19 and above and 0-3 years old age group. Metabolism, gut, and immune function abnormalities have also been frequently described in ASD. Among children with ASD, gastrointestinal symptoms have also been associated with more frequent challenging behaviours (Chaidez, Hansen, & Hertz-Picciotto, 2013). Defects in mitochondrial function, redox sensitive metabolism, and carbon metabolism have also been reported in smaller subsets of ASD cases (Rossignol & Frye, 2012), though it remains to

be determined how these multisystem comorbidities may aid understanding of pathophysiology or potential etiologic subgroups.

Economic burden comparison for direct non-medical cost found out that age group of 0-3 years old record the highest amount, followed by age group 13 -18 years old, 19 years and above and 7-12 years. Indirect cost is the highest for age group 13-19 years old, followed by 7-12 years old and 4-6 years old.

Economic Comparison According to Household Income Group

Based on Table 3, it is found that below average household income bear higher expenditure compared to above average household income which is RM25,673.839. Below average household income group recorded the highest total average cost for services rehabilitation and medicine cost for direct medical cost category.

Table 3. Comparison family with ASD child economic burden according to household income group

| Economic Burden Category / Household Income | Above Average | Below Average | Mann-Whitney U (p) Test |
|---|------------------|------------------|-------------------------|
| Direct Medical Cost (RM) | | | |
| Services Rehabilitation | 5,678.11 | 4,620.70 | 0.005 |
| Alternative Treatment | 690.00 | 698.25 | 0.941 |
| Medicine Cost | 645.41 | 890.53 | 0.189 |
| Purchase of Medical Aid | 810.81 | 491.14 | 0.012 |
| Diagnostic Test | 404.05 | 280.00 | 0.117 |
| Ward Entrance Fee Surgery | 1,331.15 | 887.14 | 0.453 |
| Total | 9,559.53 | 7,867.76 | 0.317 |
| Developmental Cost (RM) | | | |
| Domestic Helper | 5,242.70 | 2,334.04 | 0.008 |
| Nursery | 4,821.08 | 3,075.44 | 0.289 |
| Special Education | 7,253.51 | 3,204.68 | 0.001 |
| Special Dietary | 5,678.11 | 4,620.70 | 0.005 |
| Daily Necessities | 1,835.68 | 2,113.68 | 0.393 |
| Insurance | 2,031.51 | 929.11 | 0.000 |
| Others | 1,483.78 | 1,528.42 | 0.562 |
| Total | 28,346.37 | 17,806.07 | 0.317 |
| OVERALL TOTAL (RM) | 37,905.90 | 25,673.83 | 0.317 |

Analysis carried out found that there is significant difference between household income groups with purchasing of medical aid ($p = 0.012$). Above average household income group bears higher purchasing of medical aid cost compared to lower household income group because they can afford medical aid. Despite having duty import exemption benefits for replacement aid and artificial/support aide given to OKU card holder, but family with ASD child still have to bear the cost of replacement aids and delivery cost of replacement aid from overseas (Department of Social Welfare, 2017).

Data also showed that there is significant difference between household income groups with services rehabilitation ($p = 0.005$). Above average household income groups again bears higher cost for services rehabilitation compared to lower household income group because they put in higher commitment for their child's therapy.

For developmental cost, results of the analysis found out that there is significant between household income group with maid component ($p = 0.008$), special education ($p = 0.001$), special diet ($p = 0.005$) and insurance coverage ($p = 0.000$). This finding showed that, the above average household income group chose to hire maid to take care of ASD child while they went out for work. This explanation is strengthened when there is no family of above average household income group spent on daily nursery. Apart from that, family from above average household income also able

financially to pay for a maid; two to three times more than a daily nursery fees.

Economic Burden Comparison Between Comorbid Group

Based on Table 4, group with comorbid illness bear total expenditure of RM9,158.58, whereby the amount is higher compared to group with no comorbid illness. Comparison between economic burden categories found that, there is no difference for the cost of purchasing medical aid between the group with comorbid and no comorbid illness ($p = 0.459$), diagnostic test ($p = 0.237$) and ward entrance fee surgery ($p = 0.066$), alternative treatment ($p = 0.401$) and services rehabilitation ($p = 0.154$). However, for medicine cost, group with comorbid illness bear higher cost compared to group without comorbid illness ($p = 0.004$).

Comparison between comorbid groups for developmental cost found group with comorbid illness allocated higher expenditure for daily necessities ($p = 0.001$). Based on the study, ASD child with comorbid illness required higher medical aid expenditure compared to ASD child without comorbid illness (Treating Autism Publications, 2014). This is because ASD children have different medical aid according to their level of development.

Table 4. Comparison of ASD economic burden according to comorbid group

| Economic Burden/ Comorbid Group | With Comorbid Illness | Without Comorbid Illness | Mann-Whitney U (p) Test |
|--|----------------------------------|-------------------------------------|------------------------------------|
| Direct Medical Cost (RM) | | | |
| Services Rehabilitation | 5,390.70 | 4,756.21 | 0.154 |
| Alternative Treatment | 865.35 | 626.55 | 0.401 |
| Medicine Cost | 978.59 | 750.34 | 0.004 |
| Purchase of Medical Aid | 553.38 | 601.70 | 0.459 |
| Diagnostic Test | 336.76 | 309.60 | 0.237 |
| Ward Entrance Fee Surgery | 1,033.80 | 1,016.12 | 0.066 |
| Total | 9,158.58 | 8,060.52 | 0.233 |
| Developmental Cost (RM) | | | |
| Domestic Helper | 4,438.31 | 2,712.41 | 0.250 |
| Nursery | 4,233.31 | 3,345.17 | 0.424 |
| Special Education | 4,097.75 | 4,561.72 | 0.974 |
| Special Dietary | 5,390.70 | 4,756.21 | 0.154 |
| Daily Necessities | 2,187.89 | 1,965.17 | 0.001 |
| Insurance | 1,476.07 | 1,174.76 | 0.808 |
| Others | 1,663.94 | 1,454.14 | 0.297 |
| Total | 23,487.97 | 19,969.58 | 0.624 |
| OVERALL TOTAL (RM) | 32,646.55 | 28,030.10 | 0.489 |

Lacks local medical aid and experienced technician in handling medical aid should be taken into consideration by the government to reduce the country economic burden and as well for family with ASD child.

Overall, the group without comorbid illness incurred higher expenditure cost compared to those with comorbid illness. This situation occurs as many parents of the group with comorbid illness choose to resign, have a lower average household income and receive financial aid from the government. Due to issue of forced resignation, most parents suggesting, that they are given the opportunity to work from home or given more flexible working hours. This suggests that the decision to resign and caring for the child can reduce the cost of a particular cost but the household income needs to be sacrificed.

CONCLUSION NAD SUGGESTION

Conclusion

The financial burden experienced by family with ASD children in Malaysia is still less comprehensible and are not addressed properly. Even though the Social Welfare Department had given subsidies to assist in buying support aid, there are still other aspects of needs yet to be handled. Information about ASD economic burden will be able to assist policy makers in policy planning based on solid evidence.

Suggestion

With the information about types of expenditure needed for ASD child care, the burden carried by ASD child parents is able to be explained and assistants can be given to them. Hence, this study can be made into an important reference to local policy makers, community welfare body as well as related non-governmental organisations to give assistance that are cost-effective for ASD group. To reduce the heavy loads the parents of students with disability, it is needed the real supports from the local policy makers, community welfare body, and non-governmental organization.

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