

Financial Burden of Living with **Autism**:

A **case study** of parents at **IDEAS Autism Centre**

By Shanuja Chandran



Executive Summary

Care, therapy and education for children with autism can be a financial drain on parents' incomes hence the IDEAS Autism Centre (IAC) was established to counteract this impact. This paper presents a case study of the Centre and if it has been able to provide parents with some financial relief besides giving them the opportunity to find employment if in the past they chose to remain unemployed to care for their child with autism.

The study finds that some parents were able to successfully find full employment after enrolling their children into IAC, whereas others were less successful – all parents nevertheless have benefitted from the low-cost high quality care that IAC has provided, as seen by improvements in their child's behaviour.

Introduction

IDEAS Autism Centre (IAC) was established to provide economic relief to parents of children with autism, both in terms of affordable care, education and therapy, thereby allowing them to continue employment or seek new employment. This study was conducted in order to gauge if the services provided by the Centre achieved these goals.

Author

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Special Needs Education in Malaysia

Malaysia has signed and ratified the Convention on the Rights of Persons with Disabilities in 2008 that calls for the development of quality of education and recognises that education is a right of persons with disabilities.¹ Based on the World Health Organization's (WHO) prevalence rate of learning disorders for children between ages 0 to 14 (6 to 10 percent), it was estimated that there were between 531,600 to 886,000 affected Malaysian children in 2007.

However, the Ministry of Education only recorded 15,195 students with learning disabilities. The ambiguity in these statistics reduces the efficacy of special needs education programmes, especially when resources are scarce.² Globally, UNICEF stated that a dominant problem in the disability field is the lack of access to education for both children and adults with disabilities.³

The Special Education Department of the MOE is responsible for coordinating and administering all special education programmes in mainstream schools. Children who have special needs and developmental delays are placed in self-contained classes known as the Special Education Integration Program (SEIP).⁴ There are 1,345 primary schools that have SEIP and 28 Special Education schools.⁵ Additionally, dedicated children with special education needs (SEN) can also be enrolled into the Inclusive Education Programme (IEP), which was offered in 2,798 schools in 2014.⁶ IEP allows up to five students with SEN to be integrated into mainstream classes if they are able to cope with the regular programme and curriculum. However, **none of these programmes specifically cater for children with autism.**

Autism in Malaysia

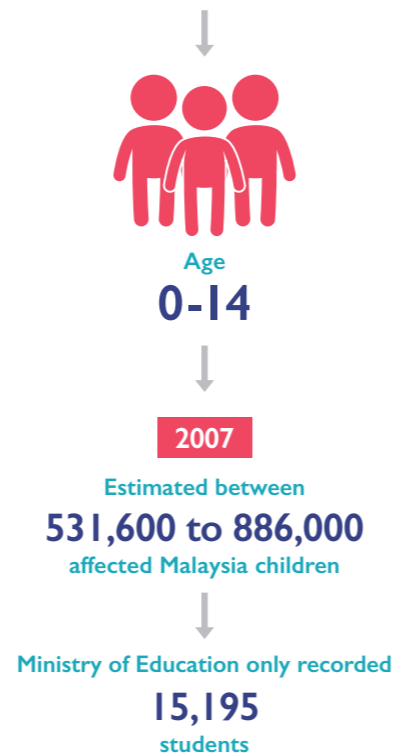
Autism knows no social and economic boundaries and can affect any family, and any child. It is a complex developmental disability that typically manifests in the first three years of life. The causes for the sudden surge in incidences of autism are debatable, but evidence suggests that behavioural and other therapeutic early interventions are crucial for a child with autism to improve their communication skills, develop independence and reduce maladaptive behaviour.⁷

A local survey reported that one in every 625 Malaysian children has autism.⁸ The Ministry of Health reported that autism cases are increasing, but many go undetected until the children are already in school.

It is reported that early intervention during the ages of 0 to 6 can reduce its impact and improve the child's development.⁹

In Malaysia, a significant number of children with autism are largely excluded from educational opportunities due to late detection of autism or a guardians' lack of awareness in identifying traits related to autism. Research shows finance and support for educational services for children with autism is a major concern for developing societies.¹⁰ Hence, we attempt to better understand resources available for parents from low-income households who have children with autism.

Prevalence rate of learning disorders for children



In Malaysia, a significant number of children with autism are largely excluded from educational opportunities due to late detection of autism or guardians' lack of awareness in identifying traits related to autism.

¹ United Nations, Convention on the Rights of Persons with Disabilities, 2006. Accessed from <https://treaties.un.org/doc/Publication/MTDSG/Volumepercent20I/Chapterpercent20IV/iv-15.en.pdf>
² Dr. Huberta Peters, Mental Health: Special Needs and Education, 2007. Accessed from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.385.2495&rep=rep1&type=pdf>
³ UNICEF, Children with Disabilities, 1999. Accessed from <http://www.unicef.org/education/files/vol2disabileng.pdf>
⁴ Jelas & Ali, Inclusive education in Malaysia: policy and practice, 2012. Accessed from <http://www.tandfonline.com/doi/pdf/10.1080/13603116.2012.693398>
⁵ Overview of Special Education in the Malaysian National Education System, PEMANDU, dated March 1 2015, presented at conference on Addressing Policies, Services & Support for Children With Special Needs.
⁶ Malaysian Education Blueprint Annual Report 2014, Chapter 3, Page 72.
⁷ Sharpe & Baker, Financial Issues Associated with Having a Child with Autism, 2007. Accessed from http://pfp.missouri.edu/documents/research/sharpe_financialissues.pdf
⁸ Hariati Azizan, The Burden of Autism, 2008. Accessed from <http://www.the-star.com.my/story/?file=percent2F2008percent2F4percent2F27percent2Ffocuspercent2F21080181>
⁹ Steve Nettleton, Pilot effort provides an early warning system for autistic children in Malaysia, 2008. Accessed from http://www.unicef.org/malaysia/health_education_8055.html
¹⁰ Peters, Inclusive Education: Achieving Education For All By Including Those With Disabilities And Special Education Needs, 2003. Accessed from <http://www.doc.mak.ac.uk/sites/default/files/InclusiveEduPeterspercent28Ipercent29.pdf>

The Financial Burden

Children with special needs require more health care than the general paediatric populace. According to the Autism Society of America (ASA), the average lifetime cost of caring for a child with autism in the United States is US\$2.4 million (approximately RM 9.6 million).¹¹ The figure includes medical treatments, special education, housing, and indirect costs like lost productivity.

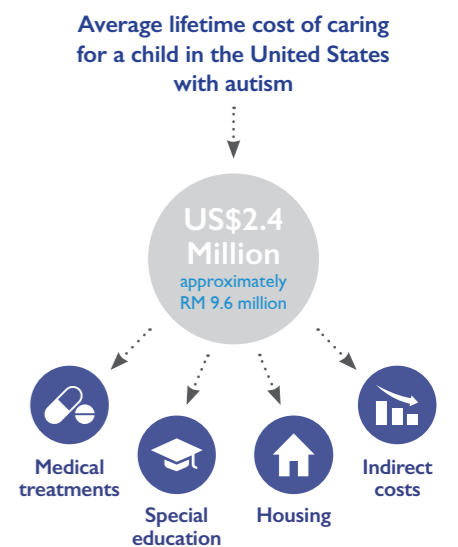
Bringing this back to Malaysia where the cost of living is significantly lower, the cost of raising a child with autism is still a major financial burden on low-income households. The Economic Planning Unit (EPU) reported that in 2014 the Monthly Gross Household Income in Wilayah Persekutuan Kuala Lumpur was RM10,629¹², while the Mean Monthly Gross Household Income of the bottom 40 percent in urban areas was RM2,928.¹³ This difference in household incomes becomes even more significant when considering the extra expenses for services required for a child with autism. For instance, speech or occupational therapy costs RM100¹⁴ per 45 minute session on average. A child with autism needs at least one session per week¹⁵, meaning at least 4 sessions of occupational therapy per month would take up **approximately 13 percent** of the **average household income** for a family in the bottom 40 percent.

In 2008, The Star newspaper reported that Malaysian guardians do not have the financial means to support their child with autism and many struggle to find the balance between employment and caring for their child.¹⁶ This dilemma is also influenced by

employers who may not provide flexible working hours besides problems with access to quality care such as a lack of health workers including speech physiotherapists. Besides that, support from the Government is crucial, but overwhelming bureaucracy problems hinder parents from seeking services needed for their children. A local study found that logistics and bureaucratic problems were the main issues when parents had to deal with a Government agency. For example, a parent stated that his disabled son does not go to school because in spite of government sponsorship for his child's special education, the school was too far from their home.¹⁷

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A study conducted on children with special healthcare needs defines family financial burden as the family's perception of financial stress caused by insufficient financial resources to meet the family's fiscal demands.¹⁸ However, costs associated with having a child with autism are not limited to the costs of intervention. The burden of these costs are magnified when care for the child implies a loss of income for a parent due to missed work, inability to work regular hours, or having to resign from their jobs. A study conducted in the United States showed that the extra expenses caused approximately 40 percent of families to experience financial-related burden when caring for a child with special needs.¹⁹

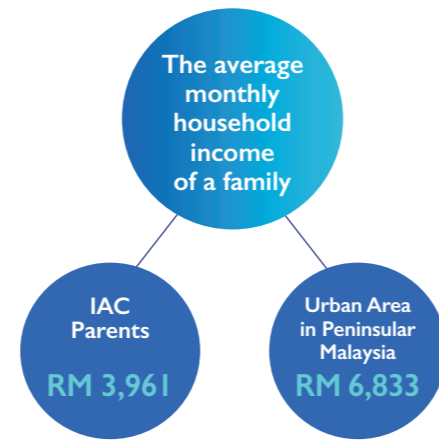


¹¹ Mandell, Estimating the Economic Costs of Autism, 2011. Access from <https://science.grantsautismspeaks.org/search/grants/estimating-economic-costs-autism-0>
¹² Economic Planning Unit, 2014. Accessed from <http://www.epu.gov.my/documents/10124f34c4fb1-cb4-4390-a497-9833f3e2225d>
¹³ Economic Planning Unit, 2014. Accessed from <http://www.epu.gov.my/en/household-income-poverty>
¹⁴ Hariati Azizan, The Burden of Autism, 2008. Accessed from <http://www.the-star.com.my/story/?file=percent2F2008percent2F4percent2F27percent2Ffocuspercent2F21080181>
¹⁵ Ibid, The Burden of Autism, 2008. Accessed from <http://www.the-star.com.my/story/?file=percent2F2008percent2F4percent2F27percent2Ffocuspercent2F21080181>
¹⁶ Hariati Azizan, The Burden of Autism, 2008. Accessed from <http://www.the-star.com.my/story/?file=percent2F2008percent2F4percent2F27percent2Ffocuspercent2F21080181>
¹⁷ Toran, Support for Parents of Children with Disabilities in Malaysia, 2013. Accessed from <http://docsdrive.com/pdfs/medwelljournals/sscience/2013/213-219.pdf>
¹⁸ Lindley & Mark, Children with special health care needs: Impact of health care expenditures on family financial burden, 2010. Accessed from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2872488/>
¹⁹ Kuhlthau, Hill, Yucel & Perrin, Financial Burden for Families of Children with Special Health Care Needs, 2005. Accessed from <http://link.springer.com/article/10.1007%2Fs10995-005-4870-x>

About The IDEAS Autism Centre (IAC)

IAC is an early intervention centre that provides care, education and therapy for children with autism from low-income households. It is one of the few centres in Malaysia that provides full-day care and therapy for children with autism and charges affordable fees. The IAC was established in November 2012 by individuals who were frustrated and unable to find affordable quality care, education and therapy for their children. IAC provides care for children up to 9

years of age, to enable them to enrol in a public school in either the SEIP or IEP.²⁰ IAC's duration of care is from 8.30am to 5.30pm, and the fee of RM300 per child per month is inclusive of occupational and speech therapy. The actual cost incurred per child is approximately RM 3,000, which means that each child receives the equivalent of a scholarship worth RM 2,700 per month (or the full RM 3,000 for those who are waived from paying fees) from IDEAS.



“
The IAC was established in November 2012 by individuals who were frustrated and unable to find affordable quality care, education and therapy for their children.
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The Study

The aim of the study is to assess the financial burden of autism for low income-households. Using the IDEAS Autism Centre as a case study, we analyse whether parents were able to find new employment or continue employment due to services rendered by the IAC.

Methodology

This study employed a quantitative research method. Questionnaires were given to parents of children enrolled in IAC. Questions were prepared to incorporate as many aspects as possible of raising a child with autism in a low-income household. These included property ownership, presence of siblings and the employment status of the parents. There were 30 questionnaires collected in total, all completed by the mother or father of the child. It is important to state that at the time the questionnaire was administered in 2015 April, one student at IAC was a part-time student and only attended the therapy sessions. The analysis was completed by averaging all responses. This paper does not take into account incomplete answers and acknowledges the void in the responses where relevant. It also does not look into the gender or ethnic background of its respondents.

Findings

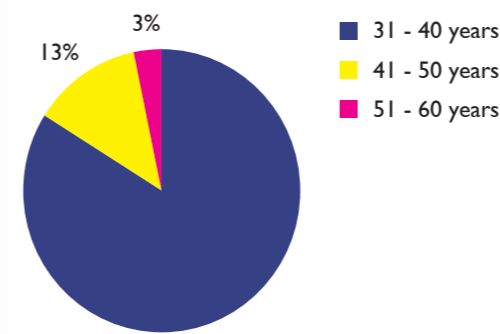
Our study showed a distinct financial burden faced by these families. Our respondents earn significantly less than the average household income and have extraordinary financial obligations as they have a child with autism. The average monthly household income of a family prior to enrolment in the IAC is RM3,961 in 2015, whereas the monthly household income in urban areas in Peninsular Malaysia is RM6,833, as reported by the EPU in 2014.²¹

²⁰ Ibid
²¹ Economic Planning Unit. Accessed from: <http://www.epu.gov.my/documents/10124/f34c4fb1-cb44-4390-a497-9833f3e2225d>

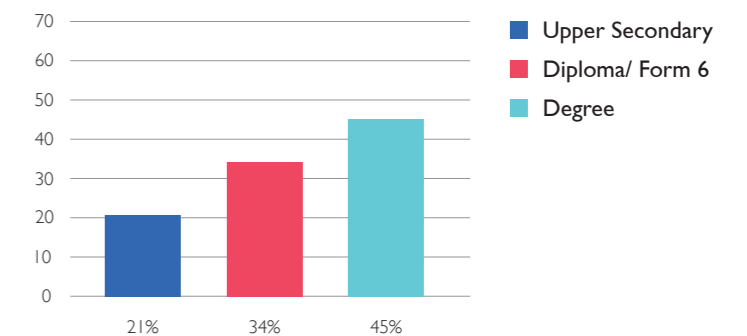
Description of average respondent and family

The majority of respondents were between 31 to 40 years of age (Graph 1) with an almost even split between degree holders and those with a secondary level education (Graph 2). Nearly half of the respondents or 47 percent were semi-skilled manual workers, followed by 23 percent who were unemployed, and 13 percent working as professionals (Graph 3).

Graph 1: Respondents' Age Group



Graph 2: Respondents' highest educational attainment



Graph 3: Respondents' type of occupation

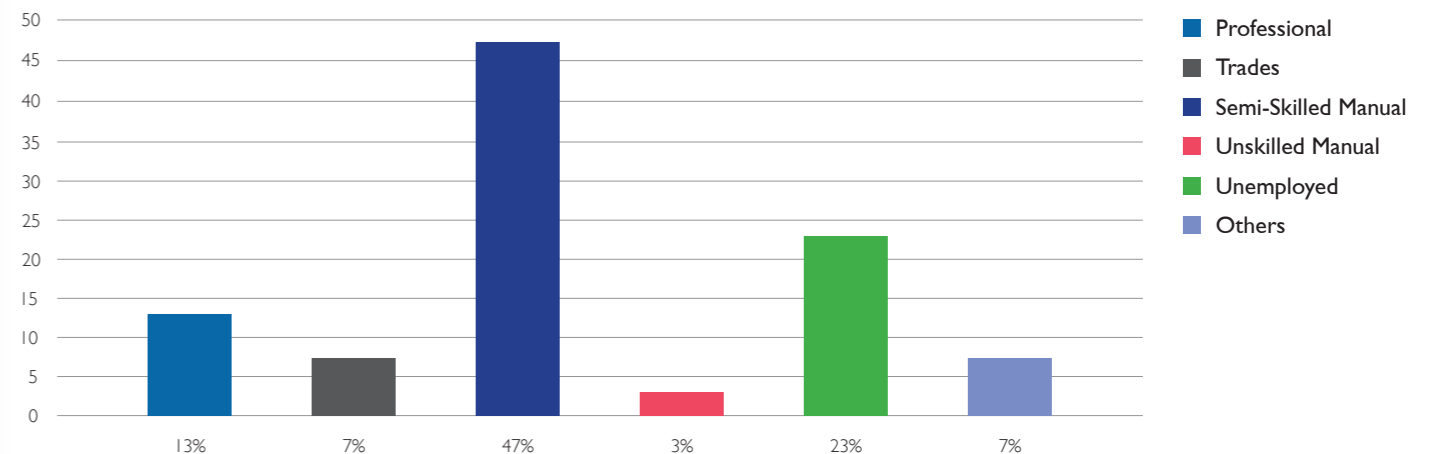


Table 1 reflects the state of IAC parents' financial obligations of the 30 households surveyed, 18 households had only one parent as the sole income earner, whereas in 11 households both parents were employed. 20 households owned a house, whereas 7 were either staying with their parents or renting a house.

Table 1: Respondents' financial obligations

Category	Total
Both parents employed	11
One parent employed	18
Property ownership – Own a house	20
Property ownership – Renting	5
Property ownership – Parents' home	2

The average family has three children with one enrolled in IAC and the rest either in government schools or they had children too young to be enrolled in school.

Graph 4: Education level of respondents' children not enrolled in IAC

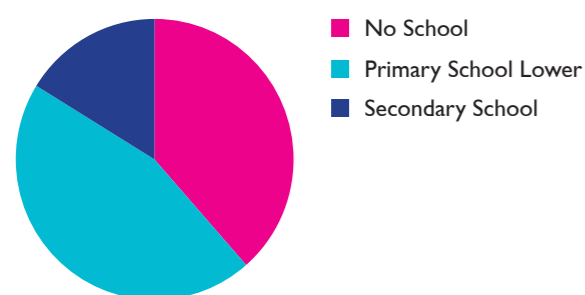


Table 2: Average working hours and income of respondents pre and post enrolment in IAC²²

Category	Pre-Enrolment	Post-Enrolment
Average working hours/per day	8.6 hours	8.7 hours
Average household income/per month	RM 3,962	RM 4,065
Average amount spent on child with autism	RM 453	RM 670
Changes in household income	No. of families	Percentage change in income
No change in household income	17	0
Increase in household income	6	20%
Decrease in household income	4	20%

Table 2 shows the changes in average household income per month for 27 respondents.²³ The slight increase in household income is justified by four respondents who stated that they had gained employment after enrolling their child in the centre.²⁴ However, one respondent stated that they had to leave their employment because they had to send their child for SEIP in government schools and classes at IAC.

²² Children were enrolled at various times during the 3 years since IAC has been in operation so the time when they were first enrolled to the time when the questionnaire was administered in April 2015 varies accordingly.

Table 3 depicts the percentage change in expenditure for respondents pre and post enrolment. Seven respondents reported not having any changes in their expenses upon enrolment at IAC, whereas 17 respondents experienced an increase in expenses for their child by an average of 84 percent.

Table 3: Percentage change in expenditure pre and post enrolment at IAC

	Number of families ²⁵	Percentage change in income levels and expenditures
No change in expenses on child with autism	7	0
Increase in expenses on child with autism	17	84%
Decrease in expenses on child with autism	6	52%

Many respondents cited IAC fees at RM300, approximately RM500 petrol and toll, and approximately RM300 for diapers and other necessities for their child as the reason for the increase in expenses. While the households experience an increase in expenditure, it should be noted that prior to enrolment at IAC their child only received occasional therapy sessions as more regular classes would have been unaffordable. One respondent said that prior to enrolment in IAC, she paid RM1,330 for therapy. However, at IAC, their child not only received regular therapy sessions (namely hypotherapy, hydrotherapy, pet therapy and other related activities such as gardening) but also benefited from preparatory classes for integration into mainstream schools and a variety of fieldtrips

to get them used to public interaction and full-day care. In addition to that, two of our respondents also cited the location of IAC as an issue as they would need to travel a significant distance twice a day to send their child to the centre.

Six respondents stated that they experienced a decrease in expenditure post enrolment. These respondents cited that prior to the IAC, the costs of caring for their child with autism were higher as the children were not enrolled in a consolidated daycare and therapy centre, unlike the IAC. These respondents paid additional fees for different services.

“*These respondents cited that prior to the IAC, the costs of caring for their child with autism were higher as the children were not enrolled in a consolidated service for day care and therapy, unlike the IAC.*”

²³ 27 responses were used for the financial analysis as 3 responses were considered void.

²⁴ Refer to footnote number 23.

²⁵ 30 respondents filled out their expenses pre and post enrolment at IAC.

Discussion of findings

This paper looked at the domestic income and expenditure of low-income households with a child enrolled in the IAC. To put things into perspective, the average household income of a respondent post-enrolment rose from RM3,962 to RM4,065. Although parents with children in IAC benefited from the care provided the financial strain faced parents still persists given that they have three or more children to care for. One respondent with two children enrolled in the centre reported that they only received financial aid from Jabatan Kebajikan Masyarakat (JKM) for one child [at a sum] of RM150, while this may help it is insufficient given the expenses incurred when caring for a child with autism.

Results related to the financial burden faced by these families can be generally grouped as follows:

- (1) Parent(s) have resigned from full-time employment or find it challenging to remain employed;
- (2) Families are burdened with financial responsibilities (rental, other children);
- (3) Financial assistance from the government is inadequate;
- (4) Affordability of IAC;
- (5) Some parents have gained employment and other benefits.

1. Parent(s) have resigned from full-time employment or find it challenging to remain employed -

Two respondents stated that they had to quit their job as IAC is far from their homes or workplaces. Many respondents have also cited long working hours in their line of work having pressured them into quitting their jobs. Additionally, some parents have opted to have one parent as the sole breadwinner to allow for the unemployed parent to care for the child with autism. Another respondent stated that both parents had to resign from their jobs as their carer fell ill and was no longer able to care for the child with autism. One respondent stated that both parents were employed full-time in the first year of their child's enrolment, but later one parent had to quit full-time and do independent work. The respondent said this was due to the child's uncle being unable to take the child to IAC anymore. One respondent said that if he were to work,

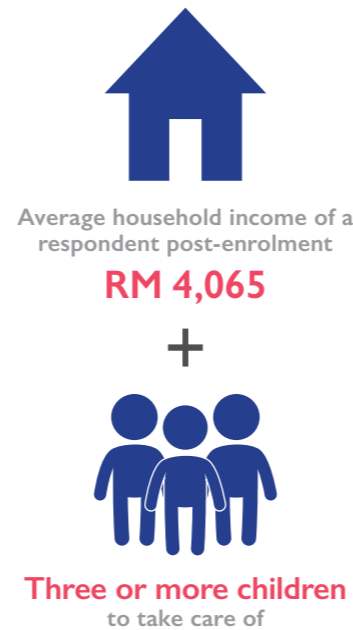
he would only be able to return home late and after Maghrib sunset prayers).

2. Families are burdened with other financial responsibilities (rental, other children) – Our respondents have other financial responsibilities which take up a significant portion of the household income and savings. Seventy percent of the respondents live in houses owned by them, whilst 17 percent live in rented properties, with two respondents stating that they live in their parents' house. In addition, 73 percent of our respondents have five or more individuals living in their households. The minority (37 percent) of our respondents have 5 people (children and adults) living in their homes.

3. Financial assistance from the government is inadequate – The Registration of Orang Kurang Upaya (OKU) by JKM is done voluntarily nationwide. In JKM, autism

is categorised as a learning problem and individuals with autism are eligible to apply for an OKU card. Seven of our respondents stated that they received financial assistance. Out of these, 5 respondents received a monthly aid of RM150 from JKM. Perhaps unsurprisingly, 23 of our respondents do not receive financial assistance from any other parties.

Many have reported that they were unaware of the financial assistance scheme for OKU. One respondent who has two children enrolled in IAC receives monthly allowance from the JKM for one child as he is an OKU cardholder, and stated that the amount of RM150 received is too little to meet the needs of the children. To further strengthen this point, our respondents have provided similar responses in saying that any form of financial assistance can be helpful in easing the burden of raising a child with autism for two reasons.



²⁴ Economic and Financial Developments in Malaysia in the Second Quarter of 2015, Bank Negara Malaysia 2015. Accessed from http://www.bnm.gov.my/files/publication/qb/2015/Q2/2Q2015_fullbook_en.pdf

First, the living cost in Malaysia is rising. Based on the Bank Negara Malaysia (2015) report, the inflation rate in Malaysia as measured by the Consumer Price Index peaked in the second quarter of 2015. The Q2 inflation rate increased to 2.2 percent from 0.7 percent in Q1 2015, reflecting the impact of the Goods and Services Tax (GST).²⁶

Second, the cost of learning aids (e.g. books, learning paraphernalia, workshops) for the children are high. With reference to the first point, our respondents stated that their incomes do not correspond to the living costs in Malaysia, in addition to having to raise a child with autism. They have said that financial assistance is able to ease the burden, albeit minimally. The second point is evident in the cost of therapies for children with autism. One respondent said that they were not able to afford third-party learning workshops for their child because of the cost.

4. Affordability of IAC – Firstly, many parents have expressed their concern in terms of affordability, in spite of it also being a full day care centre for the children. A respondent who receives RM150 per month from JKM stated that they would not be able to afford to send their child to IAC without the fee assistance from IDEAS. The fee assistance given by IDEAS is equivalent to a voucher system for parents to benefit from the services provided by IAC. Another respondent said that the RM150 from the government is inadequate²⁷ as compared to the expenses of raising a child with autism coupled with rising living costs.

Parents also felt that any form of financial assistance was helpful towards care for their child, with one parent stating that the help was particularly useful as he was unemployed. Many parents have also indicated extra expenses for petrol

and time as the IAC is located in Rawang. Parents have said that they spent an average of two hours per day on the road due to traffic whilst sending and picking up their children to and from IAC.

Our respondents have expressed that their children have had positive and significant changes upon enrolment in the IAC. Twenty-eight of our respondents stated that their child is more focused, is able to better communicate and has less tantrums. Many respondents also cited that their child is more disciplined and engaged. It is evident that having substantial support and care is crucial for the well-being of children with autism.²⁸

5. Some parents have gained employment and other benefits – Some parents have gained employment upon enrolment (for the full list of those who have been able to gain employment, and any other changes in activities once they enrolled their child into the IAC, refer to the Appendix). Four respondents claimed that they were able to gain employment post-enrolment, and

two more stated that they were able to volunteer and take up courses by employers or third-parties. An unemployed mother stated that she now volunteers at the Persatuan Autisme Muslim Malaysia. Parents who did not have a family member or an acquaintance to ferry their child stated that one parent had to quit their job to take responsibility of this task, while the other parent remained employed. Our respondents have also expressed financial difficulties as they come from low-income households and additional costs in caring for a child with a disability. However, they seem to have seen the benefits of sending their child to IAC. As noted in earlier sections, they have evaluated the trade-offs between being employed and being unemployed, in order to care for child. The latter being more important to them and hence their insistence, despite financial difficulties, on continuing to send their child to IAC. This is a reflection of the quality of care and therapy provided by IAC for the children, as respondents recognise the value in sending their child to the centre regardless of the sacrifices they may have to make in the process.

“A respondent who receives RM150 per month from JKM stated that they would not be able to afford to send their child to IAC without the fee assistance from IDEAS.”

²⁷ It should be noted that each student is sponsored between RM2,700 to RM3,000 per month equivalent to RM32,400 per child annually.

²⁸ IAC conducts a regular parental survey to gauge how parents perceive the services provided by IAC and where these services can be improved.

Conclusion

Overall the IAC has been moderately successful in mitigating the financial burden of parents. The full-day services have assisted some parents to seek full time employment, whereas others have opted to remain unemployed in order to better care for their child. Nevertheless, the IAC has only been able to relieve the economic burden of parents to a certain extent, as there are various external factors beyond the control of the IAC. Here, it is key to note that financial assistance to families with autistic children could contribute tremendously to in the well-being of these households.

Appendix

Table 4: Employment Status of Parents Who Reported Changes in their Employment Status and Any Other Changes in Activities Pre and Post Enrolment at IDEAS Autism Centre.

Parent No.	Employment Status	
	Prior to IAC enrolment	Post IAC enrolment
1.	Unemployed.	Working at Bank Negara Malaysia.
2.	Unemployed.	Working for RapidKL.
3.	Unemployed.	Working as a nurse.
4.	Unemployed.	Employed as a taxi driver.
5.	Unemployed.	Unemployed, but able to volunteer at the Muslim Autism Centre of Malaysia.
6.	Unemployed.	Unemployed, but has started sewing to generate additional income.

Notes

Notes

IDEAS is inspired by the vision of Tunku Abdul Rahman Putra al-Haj, the first Prime Minister of Malaysia. As a cross-partisan think tank, we work across the political spectrum to improve the level of understanding and acceptance of public policies based on the principles of rule of law, limited government, free markets and free individuals. On 17 January 2013, IDEAS was announced as the 5th best new think tank in the world (up from 13th in 2011) in a survey of 6,603 think tanks from 182 countries.

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