

Executive Summary

Financial Burden of Living with Autism

A case study of parents at IDEAS Autism Centre

Caring for a child with special needs results in increased spending for families. In addition to direct costs of intervention such as healthcare, education, and medical treatment, parents may also lose income due to missing work, lower productivity, and having to resign from their jobs in order to care for their child. In Malaysia, the cost of 4 sessions of occupational therapy per month takes up approximately 13% of the average household income for a family in the bottom 40%.

Author Shanuja assesses whether enrolling their children at IDEAS Autism Centre has helped parents find employment, and if it has helped ease their financial burden. The author conducted a survey with 30 parents of the children in IDEAS Autism Centre (IAC) and found that:

- a) **Mixed results on average household income following enrollment into IAC** - The average monthly household income for IAC parents was **RM 3,961**, compared to that of an urban household in Malaysia (**RM 6,833**). Following enrollment into IAC 60% of parents had zero increase in household income, 20% had an increase in household income and 20% had a decrease in household income. On average, the monthly household income for IAC families rose to RM 4,065 from RM 3,962.
- b) **Mixed results on expenses on children with autism** - Following the enrolment of their children into IDEAS Autism Centre, 7 families reported no change in their expenses on their child with autism, while 17 families reported an increase, and 6 reported a decrease. Families who reported an increase cited factors such as the IAC fees and transportation costs. However, prior to enrolment parents could not afford to regularly send their child for therapy classes. At IAC, their child not only received regular therapy sessions which includes 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.

Although parents with children in IAC benefited from the care provided by IAC, the financial strain faced by parents still persists:

- 1) **Parent(s) have resigned from full-time employment or find it difficult to remain employed:** Two respondents stated they had to quit their jobs due to the distance of IAC from their workplaces. Other respondents also chose to have one parent work full-time so the other could care for their children, whereas yet others added that they had to resign as their previous caretakers could not help care for their children anymore.
- 2) **Families are burdened with other financial responsibilities (rent, other children):** 17 respondents reported having to pay rent for their houses, with 2 stating they lived in their parents' homes, and 20 who owned their own houses. In addition, 73% of the respondents had 5 or more individuals living in their households.
- 3) **The financial assistance provided by the government is inadequate:** Only 7 respondents stated that they received financial assistance, with 5 of them receiving RM 150 monthly as aid from Jabatan Kebajikan Masyarakat (JKM). Many did not know of the financial assistance scheme for the differently-abled (OKU). In addition, the RM 150 received was noted as being inadequate due to the increasing cost of living in Malaysia, and the cost of learning aids and therapy being high.
- 4) **The affordability of the IAC:** Some respondents indicated they were concerned about the affordability of the IAC, with one respondent stating that without the fee assistance from IDEAS, they would be unable to send their child there. Others also mentioned the extra transportation costs.
- 5) **Some parents did gain employment and other benefits:** Four respondents were able to gain employment post-enrolment, with another volunteering and taking up courses by employers or third parties. One unemployed mother added she was currently volunteering at the Persatuan Autisme Muslim Malaysia. Some respondents added that they had to resign from their job to send their children to IAC.

Nevertheless, parents seem to have seen the benefits of sending their child to IAC, despite financial difficulties. Given the quality of care and therapy provided by IAC for the children, parents recognised the value in sending their child to the centre regardless of the sacrifices they may have to make in the process.

About the Author

Shanuja Chandran graduated with a Master of Health and Human Services Management from Deakin University, Melbourne. She is interested in the Social Determinants of Health. She believes that we should not isolate health and the healthcare system from other aspects of people's lives such as their productive capability and material wealth. Currently, she is an Analyst with a Digital Marketing firm.