

Early Intervention Program in Down Syndrome Children – Evaluating Parental Satisfaction at the Kiwanis Foundation, Kuala Lumpur, Malaysia

1. Abstract

Special needs education for children with developmental disorders requires adequate assessment and implementation of long-term management goals. Four percent of special needs children in Malaysia have been diagnosed with Down syndrome with services inaccessible to a majority of this population (Suhakam 2001). A qualitative study was carried out to evaluate parental satisfaction with the early intervention program at the Kiwanis Down Syndrome Foundation, Kuala Lumpur, Malaysia. It also explored experiences of parents and social implications of having a Down syndrome child. Parents expressed general satisfaction with the early intervention program although they communicated their concerns regarding issues pertaining to the diagnosis of a child and information provided subsequently after birth. They were also discontented with the current public education system for Down syndrome children and were frustrated with the level of stigma apparent in Malaysian society towards children with disabilities. A discussion centered on recommendations for a more holistic approach to providing services to families with Down syndrome children included: more empathetic doctors, improvements at the center, improvements of teachers' roles, advocating for better public special needs education, as well as public awareness to combat the problem of stigma. This study provided an insight into the functions of a support network for parents with Down syndrome children in a sub-optimal national special needs education system in Malaysia. It also aimed to create awareness among parents regarding their rights to proper services for their special needs child. This analysis will form a platform for further research on Down syndrome in the country and it hopes to promote the involvement of parents and educators to garner greater support from national policy makers in the field of special needs education.