

Parents Satisfaction with Early Intervention Programme in GENIUS Kurnia

Sazlina Kamaralzaman
Faculty of Health Science,
Universiti Kebangsaan Malaysia (UKM)
Kuala Lumpur, Malaysia
sazlina@ukm.edu.my

Nur Adia Syafika Mohd Noh, Suraya Shahuri, Hasnah
Toran, Nazmin Abdullah
GENIUS Kurnia,
GENIUS Division
Kuala Lumpur, Malaysia

Abstract—Parents involvement in autism early intervention program has been proven to improve children's communication as well as reducing the severity of symptoms. Parents involvement in early intervention programme is a common practice at GENIUS Kurnia in Malaysia. The objective of this study is to measure parents' satisfaction with the early intervention programme in this centre. Client Satisfaction Questionnaire (CSQ-8), an instrument to measure parents' satisfaction, was completed by 105 parents of children with autism were receiving early intervention services. This instrument was designed to assess clients' satisfaction with health services or programmes. Results revealed high scores in all domains, which indicates high parental satisfaction with the early intervention programme in GENIUS Kurnia.

Keywords—early intervention; children with autism; families

I. INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong complex developmental disorder, which affects social skills and autonomy. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the core features of ASD are: persisting deficits of social communication and interaction; restricted and repetitive behaviors, interests, activities. The effects of ASD and the severity of symptoms are different in each person [1].

Children and young people on the autism spectrum are reported to have difficulties with two main areas such as persistent difficulties with social interaction and communication. Moreover, they have limited and restricted interest, activities and repetitive pattern of behaviour. For example, they may develop an overwhelming interest in an object or activity, they may follow inflexible routines or rituals, they may make repetitive body movements, or they may be hypersensitive to certain sounds [2].

In the early 70s, the prevalence of autism was 3 or 4 in 10,000 children were identified with ASD. In 2014, about 1 in 59 children has been identified with ASD in the United States of America [3]. Besides that, the prevalence rate is 1 in every 38 children in South Korea [4]. However, the prevalence of autism in Malaysia is currently under-diagnosed and the last study conducted by the Ministry of Health (MOH) revealed a rate of 1 case in every 625 births [5]. With the increased number of children and individuals with autism, there has been an increased demand for early intervention programmes throughout the country and around the world. Early intervention should be provided as soon as a child was diagnosed with developmental

issue. Early intervention is a service, education and support given to help the development of children [6]. Early detection and intervention, offer better long term outcomes and improve family well being.

Early Intervention

According to Fantuzzo et al., early intervention can be defined as any early childhood programmes such as daycare programmes, pre-kindergarten, kindergarten, or specific preschool programme, aim to increase the social and behavioural development of young children [7]. Early intervention programmes were described as services and supports system for babies and young children with developmental delays and disabilities and their families. They may include speech therapy, physical therapy, occupational therapy and other types of services based on the needs of the child and family. Early intervention have a significant impact on a child's ability to learn new skills, overcoming challenges and increase the chance of success in school and life [3]. Early intervention programmes offer important support services for families of children with autism. Research shows that undergoing early diagnosis and providing interventions have major long-term positive effects on symptoms and later skills [8]. Fantuzzo et al. stated that parental satisfaction of early intervention programmes is important for child success and promotes resilience in parents and children [7]. According to Koegel, parental involvement and parental satisfaction of early intervention programmes is crucial to a child's social development [9].

Early Intervention Programme in Malaysia

The first Early Intervention Centre in Malaysia was initiated and established in 1987 by Malaysian care, a non-governmental organization (NGO), with the help of Robert Deller, a child psychologist from United Kingdom. The launch of the Ministry of Education into an early intervention service began in 2004 for children under the age of six who experienced visual, auditory and learning disorders. Lack of resources, trained staff and financial support are some of the issues faced by the Malaysian government to develop an early intervention centre. The NGOs rely largely on donations and volunteers to keep the centres running. Inevitably, long waiting list for enrolment developed as the number of special needs children continues to escalate.

In 2003, primary education was made compulsory for all children, but the services for students with learning difficulties remained limited and fragmented. Moreover, most services for children with autism are currently hospital based or only conducted by private centres. Children with disabilities are often managed by various departments with little integration. The chronic care for these children fatigues service providers and parents. There is a prevailing sense of hopelessness. Most services do not adequately address the emotional burden of the family. Hence there is a high "dropout" rate in the utilisation of rehabilitative services by parents [2].

The global rise of autism cases in Malaysia lead to an escalation of early intervention centres. Services are expensive and not many parents could afford the cost to send their children to privatise centres. Furthermore, most of these centers are located in the city which made it difficult for those living in rural areas to access the facility provided.

GENIUS Kurnia

GENIUS Kurnia, previously known as PERMATA Kurnia is an early intervention centre for children with autism and their families. It started its operation in December 2015 in Sentul, Kuala Lumpur. GENIUS Kurnia provides a high quality early intervention and special education to children with autism to prepare them for the mainstream schools. It is the first government-operated early intervention centre in the country. Three programmes are offered in GENIUS Kurnia such as Early Intervention & Family Support Programme, Pre School Programme and Community Education Programme.

The objectives of GENIUS Kurnia are:

1. To educate children with autism to become independent, contributing members of society.
2. To empower parents to enable them to provide appropriate care giving to nurture their children's development.
3. To provide training and consultation to teachers and therapists on evidence-based strategies in educating children with autism.
4. To heighten public awareness on autism and the challenges faced by individuals with autism and their families.
5. To become the model demonstration centre for future centres throughout the country.

GENIUS Kurnia applies the transdisciplinary approach, its team consists of various professionals such as occupational therapists, speech therapists, early childhood educators, special educators and social workers in order to give the best services for children with autism in Malaysia. Intervention strategies applied in GENIUS Kurnia incorporate evidence-based practice and naturalistic teaching with the transdisciplinary approach and active participation of parents.

A. Early Intervention Programme

The main objectives in early intervention programme are to enhance basic skills of children aged 6 and below and prepare them for the preschool programme. This programme operates once a week and two hours per session. During the

session, interventionists collaborate and encourage active participation of parents by training them to carry out the intervention on their children. Five goals are set up for the children to achieve in the early intervention programme such as early communication skills, toilet training, compliance to instruction, behaviour modification and pre academic skills.

B. Preschool Programme

The main objective in preschool programme is to prepare children with autism to enter mainstream classes in year 1. This programme operates from 8.30 a.m. to 4.00 p.m. on weekdays. The goals of preschool programme are to train social and adaptive skills, to prepare children for school readiness and train children in mastering the 3Rs (reading, writing and arithmetic).

C. Community Education

This programme includes training workshop for parents, medical and health professionals, teachers, university students and general publics. It includes weekend workshops, online education such as iKurnia including live streaming on weekend workshops and educational visits.

Parent involvement in autism early intervention has been proven to improve children's communication as well as reducing the severity of symptoms. According to Fantuzzo et al., parental involvement can be defined as parent interacting and communicating with the student, teachers, and/or any other administrators [7]. Georgiou stated that parental involvement includes learning at home, volunteering and decision making at school or the early intervention programme and four parenting tendencies i.e., emphasizing achievement, pressure, control, and personality development [10]. GENIUS Kurnia introduced a new strategy by encouraging parents' involvement from day one of enrolment. During sessions, parents are trained by interventionist to carry out the intervention on their children. This was a new paradigm shift from a child-centered to a family-centered approach. Family-centered practice encompasses a philosophy and a method of service delivery that underpins early intervention services and is considered best practise in fields concerned with optimal child development. Parents' knowledge, expertise and support were identified as valuable resources for the other parents, professional and the organization as a whole.

The objective of this study was to measure parents' satisfaction with the early intervention programme at GENIUS Kurnia.

II. METHODOLOGY

Parents of children with autism who were attending early intervention programmes in GENIUS Kurnia were invited to complete the Client Satisfaction Questionnaire (CSQ-8). The questionnaire were collected from 105 parents. Items in the questionnaire seek respondents' opinions and conclusions about the services they received. Response options differ from item to item, but all are based on a four-point scale. Examples include "How satisfied are you with the amount of help you have received?" (for which the response options are 1="Quite dissatisfied", 2="Indifferent or mildly dissatisfied", 3="Mostly satisfied", 4="Very satisfied", and "Have the services you received helped you to deal more effectively with your problems?" (Options for responses are 4="Yes, they helped a great deal", 3="Yes, they helped somewhat", 2="No, they didn't help", 1= "No, they seemed to make things worse". Data were analysed using SPSS version 20.

III. FINDINGS

As shown in Table 1, the results revealed high scores in all domains, which indicates high parental satisfaction with the early intervention programme in GENIUS Kurnia. The findings showed that parents were very satisfied and mostly satisfied with the early intervention services received. The highest percentage of parental satisfaction were reported by 81.0% of parents as they would recommend the early intervention service in GENIUS Kurnia to others. Apart from that, 75.2% and 74.3% of parents reported that they would come back to the services and found that the services received helped them to deal more effectively with their problems, respectively. None of the parents rated dissatisfied across all items.

The overall level of parental satisfaction with the early intervention programme in GENIUS Kurnia was shown in Table 2. The findings reported that most parents (97.3%) who received the early intervention service in GENIUS Kurnia were satisfied (very satisfied and mostly satisfied) with the services provided.

TABLE I. RESULTS OF PARENTS' SATISFACTION ON EACH ITEM IN CSQ-8

No.	Items	Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
1.	How would you rate the quality of service you received?	54.3%	40.0%	5.7%	0%
2.	Did you get the kind of service wanted?	46.7%	52.4%	0.9%	0%
3.	To what extent has our service met your needs?	38.1%	50.5%	11.4%	0%
4.	If a friend were in need of similar help, would you recommend our service to him or her?	81.0%	18.0%	1.0%	0%
5.	How satisfied are you with the amount of help you have received?	55.2%	42.9%	1.9%	0%
6.	Have the services you received helped you to deal more effectively with your problems?	74.3%	25.7%	0%	0%
7.	In an overall, general sense, how satisfied are you with the service you received?	55.3%	43.8%	0.9%	0%
8.	If you were to seek help again, would you come back to our service?	75.2%	24.8%	0%	0%

TABLE II. RESULTS OF PARENTS' SATISFACTION ON EARLY INTERVENTION PROGRAMME

Scale	Percentage (%)
Very satisfied	60.0
Mostly satisfied	37.3
Indifferent or mildly dissatisfied	2.7
Quite dissatisfied	0

IV. DISCUSSION

It is important to look into the quality amongst the quantity of treatment that the child is receiving [11]. Current literature suggests that early intervention is the most effective educational programme to increase behavioral outcomes and the overall development of the child [12,13,14,15]. McConachie and Diggle found some programmes have claimed 40 hours a week to be most effective [16]. In contrast, Roberts et al. recommended 15 to 25 hours a week as the amount needed for an effective early intervention programme [11]. Therefore, the involvement of parents in the early intervention were essential to increase the intensity of intervention received by the children with special needs and increase the practice at home by the parents.

The results of this study showed that majority parents who participated in early intervention programme in GENIUS Kurnia are satisfied with the services provided. The high degree of satisfaction demonstrates the importance and the necessity of the active parents' participation in early intervention programme in GENIUS Kurnia.

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