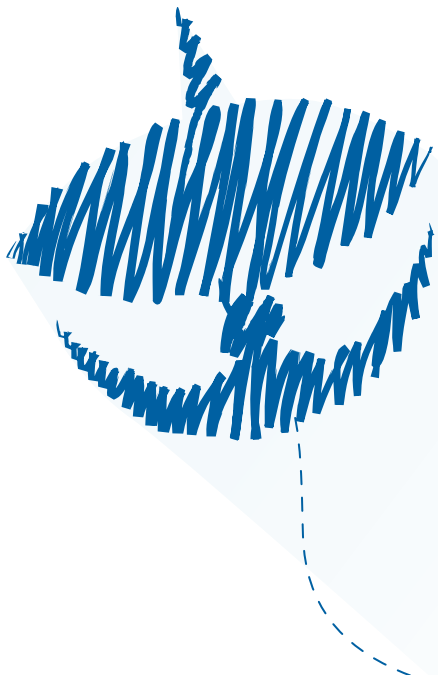
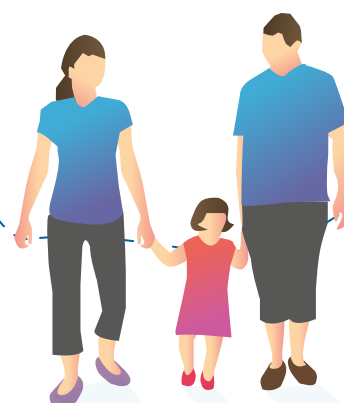


OCT 2015



Autism: Life After **Early Intervention**

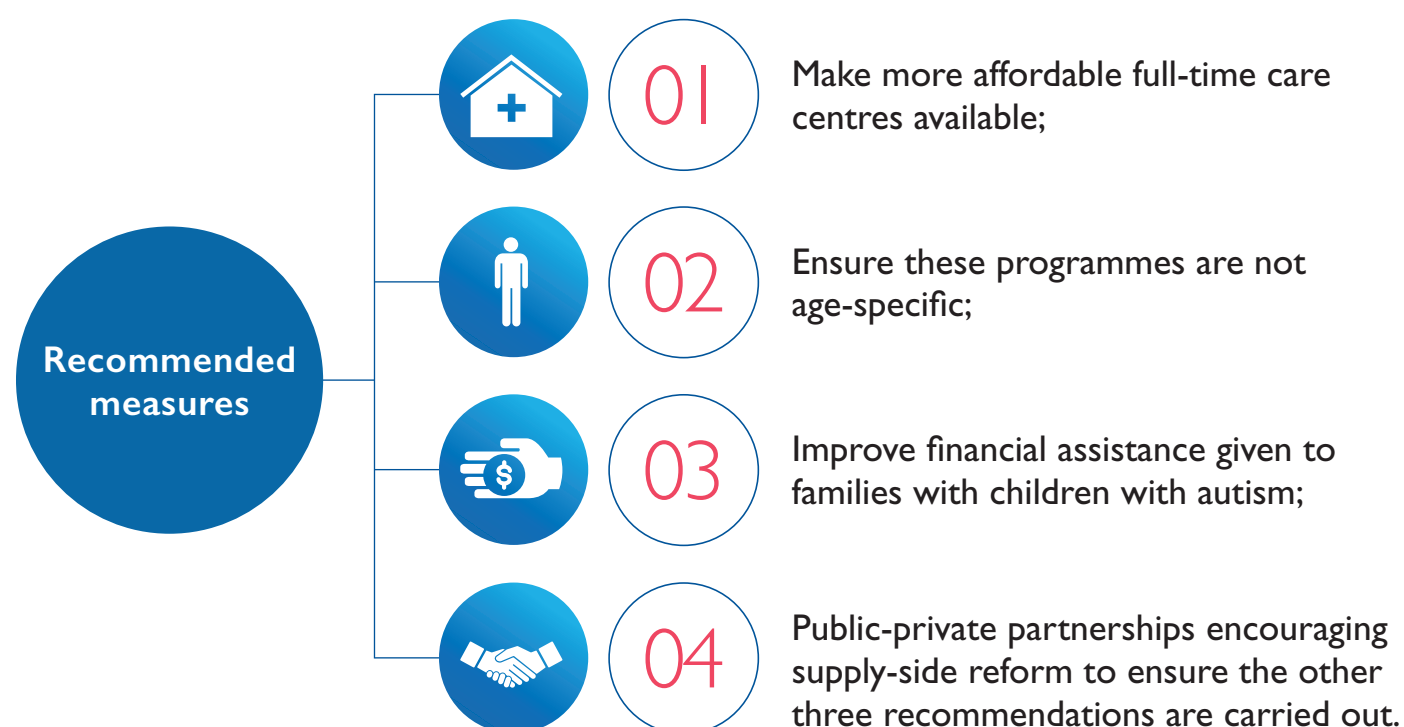
Carolyn Hong



Executive Summary

This paper looks at the educational, care and therapy options for children with autism who are between the ages of nine (upper-limit to when they are able to enter mainstream primary schools) and above.

Through interviews with parents, teachers and special needs education, care and therapy providers, and desk-based research the author documents the costs, curriculum, admissions policies and challenges of the main options available. The paper concludes that provision of educational, care and therapy options are lacking and too expensive for the average family in Malaysia. Hence, the paper recommends measures to be taken to improve this situation:



Author

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Introduction: Beyond early intervention programmes for children with autism

Autism is often a life-long condition although early intervention can assist a person with autism to attain some degree of independence and thrive.¹ While early intervention has proven to be beneficial for children with autism their needs do not end there.²

Children who do not continue to receive regular care, education and therapy after completing this first-stage of programmes may run the risk of losing the gains that they had made earlier. In Malaysia, the risk is particularly high for children who do not attend any care or learning centres, as there is a likelihood that they would be left at home without any further learning available.³

Ideas Autism Centre

The Ideas Autism Centre was set up in October 2012 with a mission to provide quality care, education and therapy for children with autism. It is designed to be affordable to low-income families based on a means test.

The main objective of the centre is to provide holistic early intervention, care, therapy and education to children with autism so that they will be able to attend mainstream government schools by ages seven to nine.⁴

Four children from the IAC's first intake will turn nine in 2016, and will join the special needs classes or Program Pendidikan Khas Integrasi (Special Education Integration Programme or SEIP) in government schools. Besides these four children, three of its seven-year-old children already attend mainstream school twice a week, and spend the rest of the week at IAC.

For more information on the centre, visit autism.ideas.org.my



¹ Autism: the Facts, NHS, <http://www.nhs.uk/Livewell/Autism/Pages/Autismoverview.aspx>, Accessed August 24th, 2015.

² Corsello, Christina. Early Intervention in Autism. (2005) *Infants & Young Children*, 18(2), pp. 74–85. https://depts.washington.edu/sei/iyf/corsello_18_2.pdf, Accessed August 24th, 2015.

³ Interview with Sharifah Salleh, the principal of the Ideas Autism Centre.

⁴ IDEAS Autism Centre, <http://autism.ideas.org.my/>, Accessed August 24th, 2015.

This paper looks at the options for care, education and therapy for older children with autism in Malaysia based on the need to continue seamlessly beyond early intervention programmes. It examines the needs, problems and issues facing children with autism from the ages of nine to 13, nine being the upper age limit for enrolment at the Ideas Autism Centre (IAC) and 13 being the upper age limit for primary school.

It discusses the support, teaching, care and therapy currently available in both the public and private sectors in Malaysia, and makes recommendations to plug some of the gaps, in particular the issue of affordability and continuity of progress that has been made for those who have benefited from early intervention programmes such as those offered at IAC.

To gain an understanding into these issues, interviews were conducted with a number of organisations which offer services for children with autism, as well as several parents in the low and middle-income groups. Additionally, an interview was also conducted with a retired special needs teacher who taught in government schools for 35 years of which 19 years were spent in special needs education.⁵ Interviews were conducted with at least one organisation from each of the following categories: private learning centres, non-governmental organisations or not-for-profit centres, and public services.



Autism is a complex brain developmental disorder which hampers a person's ability to communicate with other people, and to function effectively in society.⁶ It is a spectrum condition, hence often called Autism Spectrum Disorder; which means that people with autism share certain difficulties but this affects them in different ways. It can be termed as mild or high-functioning where the person can function almost normally, or severe where the person is unable to communicate at all.

Information on the prevalence of autism in Malaysia is scarce. However, guidelines published by the Ministry of Health (MOH) on detecting symptoms in children, indicates the prevalence to be around 1.6 in 1,000. This is low compared to the overall prevalence of autism of 14.7 per 1,000 (one in 68) children aged eight years in the United States, with the numbers growing over the years but it should be noted that the MOH guidelines noted that clinicians in Malaysia have been seeing an increasing number of children with speech delay and social communication difficulties who require further assessment.⁷

⁵ The retired teacher was willing to share her experiences under the conditions of anonymity.

⁶ What is Autism, NHS, <http://www.autism.org.uk/about-autism/autism-an-introduction/what-is-autism.aspx> Accessed August 24th, 2015.

⁷ Management of Autism Spectrum Disorder in Children and Adolescent, Ministry of Health Malaysia, <http://www.moh.gov.my/english.php/pages/view/217> Accessed August 24th, 2015.

2. Needs and abilities of children with autism, aged nine to 13

It must be noted at the outset that children with autism of the same age will have different abilities at any given point as autism is a spectrum disorder; hence needs will vary greatly. But in general, the needs and abilities of a child with autism at the ages of eight or nine can be expected to be significantly different from those of their earlier years, particularly if they have undergone early intervention programmes. For example, by the age of nine, some may have progressed far enough to join mainstream academic classes while others may only be ready to attend special needs classes. However, the most severe cases will not be able to do either.

2.1 Skills and abilities after early intervention programmes

At a younger age, many children with autism lack motor skills and have sensory problems, are often resistant to tactile sensations and may also be distressed by loud noise. With early intervention programmes once they reach seven to nine years old, many can be expected to overcome a number of these issues and are able to do more with their hands.⁸ They may also have overcome earlier behavioural problems and are able to follow some instructions and communicate.

According to Madam Nancy Boon, the head teacher at the Emmanuel Care Centre which provides supplementary therapy and education for special needs children, children of an older age are also often ready to be encouraged to expand their routine. She noted that children with autism, who are often fixated on rigid routine, can at this stage be encouraged to be more flexible and adjust to changes in their environment. At this point they are likely to be ready to move beyond early intervention programmes.

“At a younger age, many children with autism lack motor skills and have sensory problems, are often resistant to tactile sensations and may also be distressed by loud noise.”

2.2 Learning needs of children with autism after early intervention programmes

Given their expected new level of abilities and skills, the learning needs of children with autism at school-going age, thus, can also be expected to change. For those children who have made enough progress, academic education can be an option. They may be able to participate fully in the mainstream academic system, whether in a government or private institution.

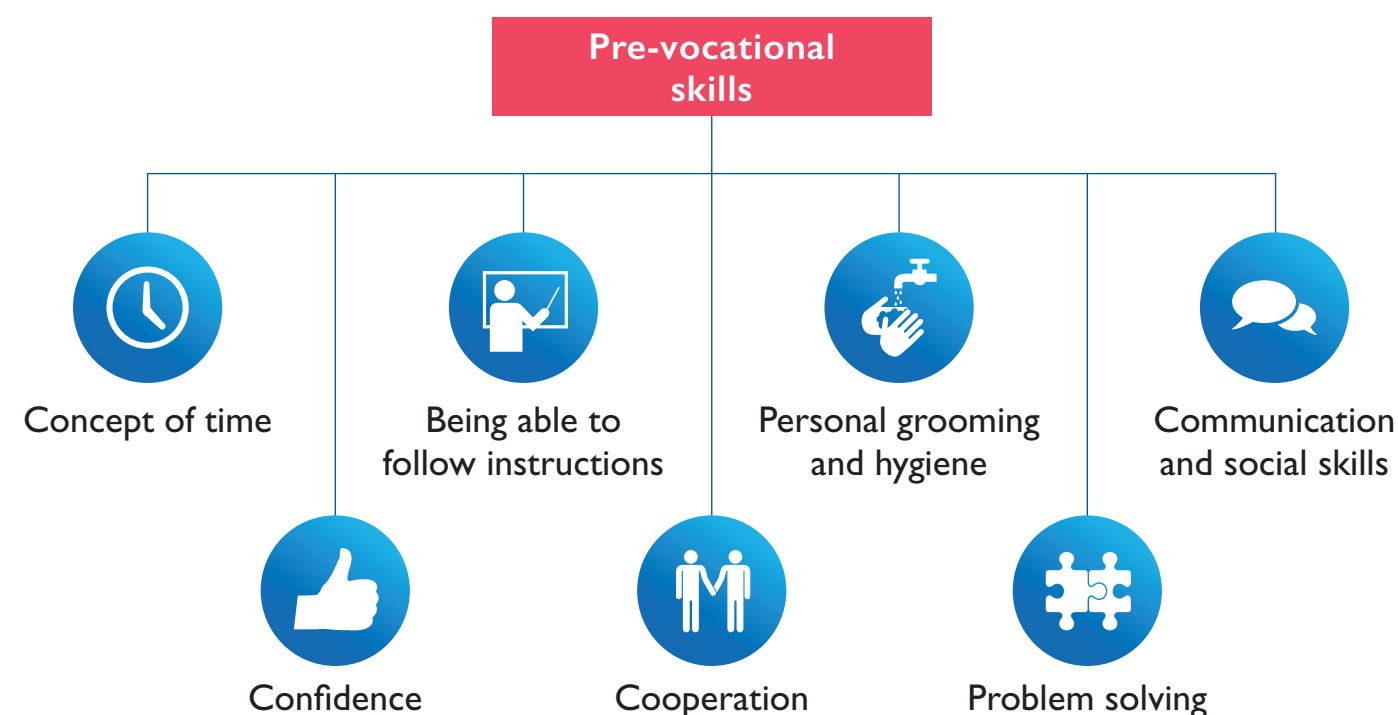
Those who are unable to join the academic system, their learning needs will be more basic. The focus is on living skills and social skills to allow them to be as independent as possible, and if possible, to join the workforce. As some may enter vocational courses later, those with adequate skills may also begin pre-vocational classes which begins between ages 11 to 14 and

onwards. Pre-vocational skills refer to skills which are prerequisite and generic to any employment situation.⁹ These include the concept of time, being able to follow instructions, personal grooming and hygiene, communication and social skills, confidence, cooperation, and problem solving.¹⁰

⁸ Interview with Madam Nancy Boon, head teacher of the church-based Emmanuel Care Centre which provides care for special needs children including children with autism. It is opened to all races and religions.

⁹ Pre-Vocational (11-14 years old), National Autism Society of Malaysia, <http://marcomnasom.weebly.com/pre-vocational-11-13-years-old.html> Accessed August 24th, 2015.

¹⁰ Ibid.



Case study: Single parent with a son with autism, now aged 21

She is a single mother with a son who was diagnosed with autism at a young age. He is now 21 with a disability severe enough to disqualify mainstream education or work as an option.

Her son was enrolled in early intervention programmes, and by the time he reached seven, he was deemed able to attend a special needs class in a mainstream school. However, that option did not work out well. A shortage of trained teachers and a big classroom size meant that he could not get the individual attention he needed. Furthermore, the mix of students with different disabilities in one class made learning even more difficult for him.

She took her son out of school at age eight. Then began her scramble to find a place for him.

“I’m all for early intervention, it does benefit the child. But what happens next? There is a lot of effort in early intervention programme but there’s a blind spot after they finish that,” she said.

She sent her son to a Kiwanis Centre for children with Down’s Syndrome. It wasn’t ideal but options were limited. After three years there, he reached the age limit for the programme. Then, she began her search again. Eventually, she sent him to NASOM’s pre-vocational and vocational programme where he remains until today. He’s in residential care, and goes home on the weekends.

She said there has to be a support system such as full-day centres that can help keep families intact by allowing parents to work to support the family and get respite.

3. Options after early intervention programmes

Both the public and private sectors offer learning programmes for children with autism at the school-going age. However, options are limited for children who are not able to attend mainstream school, and are from lower-income families. The cost of private education and treatment ranges from affordable at RM 3,600 a year to prohibitive at RM 33,000 a year.

3.1 Government / mainstream schools

3.1.1 Type of programmes available



The government has two main programmes to integrate students with disabilities into the mainstream education system. According to the Malaysian Education Blueprint 2013-2025, many high performing education systems have adopted such an inclusive approach, as a means to overcome discrimination against the disabled and to build an inclusive society.¹¹

In 2014, there were about 55,000 special needs students enrolled in Malaysian schools, with around 28,500 of them in primary school.¹² However, Special Education Schools, of which there are 33¹³, only cater for those with visual and hearing impairments. Those with other special needs can enrol into mainstream academic schools under two

programmes - ‘Inclusive Education Programme’ (IEP) and ‘Special Education Integration Programme’ (SEIP).

IEP was introduced to integrate up to five students with mild or moderate learning disabilities into the mainstream academic classes¹⁴ while students with more severe learning disabilities will join the SEIP which are separate special needs classes within mainstream schools. According to the Education Policy and Research Division in 2014, there were 320 special education needs classes in primary schools.¹⁵

Like other children with learning disabilities, children with autism may enter mainstream school starting from the age of seven. High

functioning children with autism, who can cope with regular academic system, can join mainstream classes under the IEP. An interview with a retired special needs teacher provided more insight into the processes required which include monitoring the children in the special needs class before selecting those with adequate language, communication and social skills to be enrolled in the regular class under the IEP. According to her, high-functioning students with autism can manage well in this programme if they have no behavioural problems.¹⁶

If the child manages well after the first exam, they will continue studying within the regular academic system. Some children

¹¹ Malaysian Education Blueprint 2013 – 2015, Chapter Four, PADU. http://www.padu.edu.my/files/meb_blueprint/Chapter%204.pdf Accessed August 24th, 2015.

¹² Quick Facts 2014, Ministry of Education, https://emisportal.moe.gov.my/emis/emis2/emisportal2/doc/fckeditor/File/Quickfacts_2014/Buku%20Quick%20Facts%202014.pdf Accessed August 24th, 2015.

¹³ Profil Sekolah Pendidikan Khas, MOE, http://www.moe.gov.my/cms/upload_files/BPKhas/PROFIL%20SEKOLAH3.pdf Accessed August 24th, 2015.

¹⁴ Malaysian Education Blueprint 2013 – 2015, Chapter Four, page 4-16, PADU. http://www.padu.edu.my/files/meb_blueprint/Chapter%204.pdf Accessed August 24th, 2015.

¹⁵ Ibid.

¹⁶ Interview with the retired special needs teacher who declines to be named.

are enrolled in the 'partially inclusive' programme, under which they join the regular classes for certain subjects like Art and spend the rest of the time in the special needs class. However, only a minority of students with special needs remain in IEP. In fact, in 2014 approximately six percent of students with special needs were in this programme.¹⁷

The majority, around 89 per cent, attend the SEIP¹⁸ and these classes are not just for children with autism but group together children with different special needs such as Down's syndrome, slow learners, dyslexia and attention deficit hyperactivity disorder.

3.1.2 Curriculum

As children in the IEP are considered part of the regular mainstream classes they are taught the standard curriculum suitable for their age group along with the other children.¹⁹ On the other hand, the focus for those in SEIP is on life skills. The first three years are focused on life skills such as hygiene and learning to dress themselves. The teacher then gradually introduces simple academic skills such as the alphabet and numbers. From year four onwards, the children also learn how to do simple cooking and preparation of food, folding clothes and laundry.²⁰

The classes follow regular school hours from 7.30am to 1pm. Primary school for special needs students end at age 14, after which they may enter secondary school for basic vocational training up to age 19.

3.1.3 Admission of Students

Parents will first be interviewed by the school to ensure that their children are ready for school. They need to show that the children are toilet-trained, independent, mobile and able to feed themselves. Once accepted, the school can nevertheless still ask the parents to remove their child after a three-month trial period if the child is deemed to be unfit for school. This can include disruptive behavioural issues.

3.1.4 Challenges

Although the intention of creating an inclusive education system is good, the quality of education provided has shortcomings, as acknowledged by the Blueprint²¹ and based on interviews with parents and teachers.

The retired special needs teacher noted that having a mixed class of children with different disabilities and levels of ability makes teaching a challenge. Children with autism, in particular, can be difficult to manage because of their inability to communicate. Each class has around eight students, with three teachers assigned to every two classes.

The Malaysian Education Blueprint noted a shortage of qualified teachers and professional support such as therapists, as well as inadequate curricular support for students with autism compared with those available for students who are visually and hearing impaired. The Blueprint also noted that the mainstream academic curriculum may not be suitable for students with autism

or other disabilities, and a more applied and vocational curriculum with life skills teaching would be better.

Hence, the Ministry of Education plans to modify the system to become one based on competency levels. High-functioning students with special needs will be encouraged to attend regular classes, and moderate functioning students will attend SEIP. Low-functioning students will be streamed to special education schools where a simplified curriculum focused on basic skills, life skills and social skills are taught.²²

A report, published in The Star, featured interviews with parents of special needs children²³ who have children attending government schools. The report noted that problems such as the shortage of qualified teachers and relevant professionals like therapists, limited support and funding for special needs education. The parents also said some teachers lacked proper training and compassion, and that the teaching was either weakly implemented or completely non-existent in some schools. Some parents with children in the IEP have found the curriculum to be too complicated, for instance the requirement to learn a second language.

This was also the finding of a policy paper published by IDEAS in August 2015. A mother from a middle-income family related how her daughter stopped progressing after entering Year One under the SEIP. She was later told that the teacher was overwhelmed, and could not cope with the individual needs of the children.²⁴

3.2

Private learning centres and related facilities

3.2.1 Type of programmes available

Private learning centres are essentially private schools for children with special learning needs, such as The Learning Connection (TLC) located in Solaris Mont Kiara.²⁵ TLC is an example of a higher-end private centre which offers comprehensive learning programmes in classrooms of up to seven children, led by one special needs teacher with an assistant. Individual learning programmes are created for each student. Hours at the centre are from 9am to 1pm for kindergarten, up to 2pm for primary level, and 3pm for vocational and home school centre, depending on level of the class. Fees are RM11,000 a term, with three terms in a year.²⁶

At TLC, children aged four to six can enter the kindergarten class and their progress to the successive levels will depend on the pace of their development rather than chronological age. This is because each student is given a set of individual goals to achieve from the start. There are no set age limits for any class except for kindergarten which is meant for those aged four to six.

"We only look at the students developmentally, where they are and will make the best fit," said Sara Brenneman, Director of The Learning Connection.²⁷

"We only look at the students developmentally, where they are and will make the best fit."

3.2.2 Curriculum

At TLC, the kindergarten level is focused on communication and language development, and pre-academic skills. Sessions are in group settings with students also having individual sessions with the speech-language therapist, and communication class with their classmates daily.

After kindergarten, students who are 'non-verbal' or have no communication ability, can move to the Level One class where they will continue with developing communication and language skills, as well as take part in group and outdoor activities to learn social rules. This includes walks around the neighbourhood, visits to parks and swimming.

For those with some communication skills, they will be placed in Level Two where communication skills are still taught but with a focus on making requests or verbal comments. They are also introduced to more academic skills.

Then, they can move onto Levels Three and Four to further develop their communication and language skills. Each level gets progressively more advanced with academic skills like reading and writing, and life skills like cooking being taught.

In the Transition Level, teenage and young adult students learn job, life and self-help skills such as reading and writing, and math in the context of purchasing goods. They also learn basic cooking and baking, and computer skills.

For students who are able to progress in the academic stream, TLC has a home schooling centre with classes that follow

a curriculum developed in the United States known as the Calvert Home School programme. The children will be taught this curriculum for their year, by specialised teachers and therapists. They work at a pace that suits them.²⁸

3.2.3 Admission of students

TLC admits students from the age of five, with no upper age limit set. At present, the oldest student is 22. It does not have any specific requirements for admission. Interested parents can send their child for a half-day visit to the most suitable class, during which time the class teacher will take note of the child's ability based on a checklist. If the child is found to be a good fit and if there is available capacity, the student can be admitted.

It is rare for students to be turned away. It only happens if the class is full, or if the students' needs cannot be met at the centre, and very occasionally, if the students are not English speakers.²⁹

3.2.4 Challenges

Affordability remains the main challenge in accessing such private learning centres. While they may offer some of the more comprehensive services for children with autism but the fees are beyond the reach of the average Malaysian family. Very few families can afford to pay over RM30,000 a year in fees alone with the median Malaysian household income at around RM4,500 a month.³⁰

¹⁷ Op Cit, *Malaysian Education Blueprint 2013 – 2015*, Chapter Four, PADU. http://www.padedu.my/files/meb_bleuprint/Chapter%204.pdf Accessed August 24th, 2015.

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ Op Cit, Interview with the retired special needs teacher who declines to be named.

²¹ Op Cit, *Malaysian Education Blueprint 2013 – 2015*, Chapter Four, PADU. http://www.padu.edu.my/files/meb_bleuprint/Chapter%204.pdf Accessed August 24th, 2015.

²² Ibid.

²³ Rajaendram, Rebecca, *Special Needs learners face obstacles*. The Star, August 24, 2014 <http://www.thestar.com.my/News/Education/2014/08/24/Special-needs-learners-face-obstacles/>

²⁴ Lim, Joanna, *Living with Autism in Malaysia*. Policy IDEAS no. 21. <http://ideas.org.my/wp-content/uploads/2015/07/Ideas-Policy-Living-with-Autism-Online-Version-FA-27-July.pdf> Accessed July 21st, 2015.

²⁵ The Learning Connection, <http://learningconnection.com.my/> Accessed August 24th, 2015.

²⁶ Interview with Sara Brenneman, Director of The Learning Connection.

²⁷ Ibid.

²⁸ The Learning Connection, <http://learningconnection.com.my/> Accessed August 24th, 2015.

²⁹ Ibid.

³⁰ *Report of Household Income and Basic Amenities Survey*, Department of Statistics Malaysia, https://www.statistics.gov.my/index.php?r=column&themeByCat&cat=120&bul_id=aHhTHVWVNVyZTFBua2dSUIBRL1Rjdz09&menu_id=amVoWU54UTl0a2lNWmdhMjFMMWcyZz09 Accessed August 24th, 2015.

3.2.5 Other centres

Other than full-scale learning centres like TLC, there are also private centres like Oasis Place which offers therapy as well as short learning sessions in hourly blocks. The intention is to supplement learning in mainstream school or private learning centres. Oasis Place's students range from as young as six months to young adults of 20 years old. Fees for therapy and short learning classes are RM180 an hour.³¹

Besides these centres, there is also the option of private tutors and therapists who hold one-on-one sessions at the client's home. The fee is typically RM150 an hour.³²

Other than full-scale learning centres like TLC, there are also private centres like Oasis Place which offers therapy as well as short learning sessions in hourly blocks.

3.3 Facilities set up by not-for-profit organisations

3.3.1 Type of programmes available

There are a wide range of not-for-profit organisations which offer support and services for children with autism, albeit with a major focus on early intervention. These are run by charitable foundations and religious organisations.

National Autism Society of Malaysia (NASOM)

The best-known one is the National Autism Society of Malaysia (NASOM) which was set up in 1986 by a group of parents and professionals to help deliver lifelong services to persons with autism.³³

It offers comprehensive and lifelong services for children and adults with autism, with the emphasis on the acquisition of skills.³⁴ The programmes include early intervention for children aged up to 13, transition programme for children ready to move to mainstream school, and after-school programmes to support children in school.

Specifically for children aged up to 10, services include intensive intervention programme where children can attend

one-to-one instruction at the centre in one-hour blocks. Parents are required to run the same programme at home for at least two hours a week.

Those aged up to 13 can also attend the transition programme to prepare them for mainstream school. And for those already in school, they can attend after-school support services to help them to adjust and continue to progress. These programmes are held for half a day, from 7.30am to noon, or 12.30pm to 5pm, five days a week. The fees are RM300 a month.³⁵

Those who aren't in school can attend pre-vocational programmes but only after the age of 14 where programmes are

7.30am to 3.30pm. The fees are RM440 a month.³⁶ Three of NASOM's centres also offer vocational programmes to teach skills in baking, cooking, laundry, housekeeping, sewing, handicraft and data entry services. It also has a sheltered workshop for those who have been attending NASOM's programmes, and aged 14 and above. NASOM also offers a residential service where persons with autism can live and work independently in a community setting for five days a week but places are limited to around 20 persons. Fees for this programme are RM1,040 a month.³⁷

Besides NASOM, several other non-profit or charitable organisations also run programmes or therapy for children with autism. Most of these are short sessions, ranging from one hour to half a day long.

For example, the Emmanuel Care Centre runs a support programme twice a week for both children who attend school and those who do not. About 80 percent of its children attend government school, with one or two in private schools, and the rest not in school. The programme runs for two-and-a-half hours in a classroom setting with four teachers to 10 students. It is a mixed group of children with different special needs with children of the same mental age placed together.

Another centre, Hwa Ming Autism Society, takes children up to 12 years old. Depending on their ability, the children may attend one-on-one sessions, or the group sessions held twice a week. The sessions are conducted in Mandarin. It also has a pre-vocational centre for children aged 12 to 20.³⁸

The Sau Sin Lum Centre takes children aged three to 12 or 13 years old in its two centres. They hold therapy sessions in one-hour blocks but do not have longer learning sessions.³⁹

Besides NASOM, several other non-profit or charitable organisations also run programmes or therapy for children with autism. Most of these are short sessions, ranging from one hour to half a day long.

3.3.2 Curriculum & Admission

The curriculum varies from centre to centre, and depending on the age group and capacity of the child. In general, the focus is on social and self-help living skills, physical exercise, arts and craft, and therapy like music. The students are also taught basic skills like folding clothes and managing the laundry.

Those focusing on vocational or pre-vocational programmes may offer training in specific skills set like baking and sewing but these are typically open to students of an older age, around 14 and above.

The age limit for admission varies among the centres. Some only take students at primary level up to age 14, while others have no age limit.

3.3.3 Challenges

The cost of attending these centres are lower than private learning centres but nevertheless, they may still be out of reach of low-income families. For hourly sessions, the cost ranges from RM40 to RM80 per hour; or for those in half-day programmes, the cost is RM300 to RM800 per month depending on the frequency of the sessions.

Other than NASOM's programmes, most are not full-day centres that take the children five days a week. Thus, although they may be more affordable, they do not provide the sort of comprehensive day-long services that many parents look for.

The age limit for admission varies among the centres. Some only take students at primary level up to age 14, while others have no age limit.

³¹ Interview with Maalathi Sockalingam, office manager of Oasis Place.

³² Op Cit. Interview with Sharifah Salleh, the principal of the Ideas Autism Centre.

³³ HATI, <http://www.hati.my/children/national-autism-society-of-malaysia-nasom/> Accessed August 24th, 2015.

³⁴ Information from brochures published by NASOM

³⁵ Information on fees obtained from NASOM Titivangsa branch

³⁶ Ibid

³⁷ Information provided by NASOM general office

³⁸ Interview with Ng Kui Ling, a teacher at the Hwa Ming Autism Society.

³⁹ Interview with Yee Chai Ching, rehabilitation staff nurse at Sau Sin Lum Centre.

Summary of options open to students with autism after age nine

Type of programme	Character	Challenges	Cost
Government schools	Two main options available: • Inclusive Education Programme (IEP) - children with learning disabilities may join the regular academic stream under the, if they are able to cope. • Special Education Integration Programme (SEIP) - They may also join which comprises separate classes for special needs students within the same school premises. The focus is on living skills.	There are a limited number of schools that provide these programmes. For example 1,345 primary schools which offer the SEIP programmes. Children of different levels of ability and types of disabilities are placed into one class, posing a challenge to effective teaching	Free
Private learning centres	The facilities offered depends on the centre. Some offer full-fledged learning facilities comparable to a school where students learn academic and living skills taught by specialised teachers and therapists. Other centres offer shorter classes and therapy sessions in one-hour blocks to supplement learning in schools or learning centres.	There are limited number of such centres, and the cost can be extremely high.	Around RM180 an hour for the short therapy programmes, or learning classes. For full-fledged schools, the fees can exceed RM33,000 a year per student.
Not-for-profit centres run by charitable foundations or religious groups	• NASOM offers a comprehensive range of services from early intervention to pre-vocational and vocational training. • There are also other centres that offer therapy and group programmes for children with learning disabilities, mostly short programmes of several hours duration for a few days in the week.	Places are limited in these programmes, and the majority only run a few hours a day.	Fees range from RM40 to RM80 per hour for short programmes. For longer half-day sessions, the fees are RM300 to RM800 per month depending on the frequency of the sessions.

Conclusion

From our study, it is clear that there is insufficient provision of services for children with autism. This is true for all age groups but is particularly pertinent for ages nine and above.

Existing services are mainly too expensive and well outside the reach of an average families. Additionally, many are not full time either. This means there is a significant risk that the children who need our help the most are not getting it.

Recommendations

As children with autism progress out of early intervention programmes, there is a need to develop more affordable options for their education especially for those who cannot join mainstream schools and the academic stream. Affordability, in particular, is a concern as autism is often a lifelong condition which requires continued care as those with autism have normal life expectancies.⁴⁰

“
There is a pressing need for affordable full-day learning centres specifically for older children with autism, which can meet their education needs.
”

5.1 Need for affordable full-day learning centres

There is a pressing need for affordable full-day learning centres specifically for older children with autism, which can meet their education needs. This is particularly so for children who have undergone early intervention programmes, and are ready for a more structured education programmes in a school environment but cannot enter government schools. They may be ready for pre-vocational training, or in the case of severe autism, a simple living skills programme.

Full-day centres are particularly important, especially for single parents or families where both parents work. A single mother whose son has autism, spoke of her experience

in trying to manage the care of her son while working. This would be a typical experience of many families, as she also recounted the experiences of other parents who had to rely on the extended family for support, and the tension and disruption that this often causes in family life.⁴¹

While government schools are an affordable option for children with disabilities, it is not open to children with severe disability and who are unable to cope with mainstream learning. Parents have also complained about the low quality of teaching.

Private learning centres may offer services that are tailored to the specific needs of

the individual child but they tend to be prohibitively expensive. The affordable centres run by not-for-profit centres or NGOs offer fewer services that are often limited to just once or twice a week.⁴²

Further, most programmes run for half a day. Full-day centres including residential ones are so limited. At present, NASOM's centres offer the most comprehensive affordable programmes but places are limited.

This leaves a vacuum for full-day affordable learning centres which can cater to the education needs of children with autism aged nine and above, especially those who are not able to attend government schools or other centres.

⁴⁰ Autism, Remedy's Health.Com Communities, <http://www.healthcommunities.com/autism/children/treatment-for-autism.shtml#sthash.8LkplsBc.dpuf> Accessed August 24th, 2015.

⁴¹ Interview with a single mother with a son with autism who is a middle-class.

⁴² See Section 3.1.4.

The Ideas Autism Centre, which is an affordable option for low-income families, may be a good model. It admits students based on a means test⁴³, and offers full-day care and comprehensive training for the child. At the moment, however, the upper limit on students' age is nine, and the centre is running at full capacity with 30 children.

5.2 Financial assistance

Care, education and therapy for children with autism, even at affordable centres, can be expensive for families on the lower end of the income scale. A significant segment of the Malaysian population will not be able to afford fees even in the low hundreds, let alone the thousands needed for private centres.

Some form of financial assistance is necessary to enable them to seek continued treatment for their children at private centres, especially those who cannot attend mainstream government school and do not qualify for special needs programmes.

“Many programmes are age-specific, with a cut-off age limit. This makes it difficult for parents who have to continually search for the next suitable programme for their child.”

5.3 Need for non-age specific programmes

Parents have voiced the need for continuing programmes which their child can follow as they progress in capability. Many programmes are age-specific, with a cut-off age limit. This makes it difficult for parents who have to continually search for the next suitable programme for their child.

Furthermore, there are very few programmes available for people with autism in their teens and adulthood, especially those who are not enrolled in education programmes whether academic or vocational. This becomes a serious problem for parents as their children grow up into adults with autism.

5.4 Public private partnership

Whilst both the public and private sectors offer services for children with autism, these programmes are often separate. Greater cooperation between both these sectors may help raise the quality and accessibility of these services.

For example, public education facilities for special needs students are currently mostly concentrated in the heavily-urbanised Klang Valley. The Ministry of Education's Special Education Department does have plans to expand beyond the Klang Valley but find that even the existing facilities are under-enrolled. This is likely due to a lack of awareness and diagnosis of children with learning disabilities, and the distance of these schools from homes.⁴⁴

The private and not-for-profit sector can help alleviate some of these issues, in partnership with the public sector. This could mean raising awareness among parents to help expand the reach of these schools, and providing transportation for students to the closest government schools.

The public and private sectors could also forge a closer partnership in sharing knowledge and expertise to help improve the quality of education and therapy in both sectors.

Another avenue that could be explored is for the government to commission private providers to run schools or learning centres for children with autism. The government could allocate an amount per child similar to the cost of educating a child with autism in a government school and pay the money directly to the provider based on the number of children that they have enrolled in their classes. This supply-side reform could change the way support is provided and could spur the growth of new providers catering for children with autism.

“Greater cooperation between both these sectors may help raise the quality and accessibility of these services.”

⁴³ Students pay only RM300 a month if their household per capita income is below RM1,500, and pay nothing if it's below RM500. (Per capita income is calculated by dividing the monthly household income with the total members. For example, a household income of RM6,000 for a family of six, works out to a per capita income of RM1,000.

⁴⁴ Phone response from personnel in PEMANDU's Education NKEA

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