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SETTING UP SPECIAL NEEDS CENTRES:

A focus on early intervention centres for the underprivileged

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The need for early intervention centres catering to parents from low-income households is not being adequately met by government or even private sector players.

Executive Summary

This paper looks at the gap in provision of early childhood care, education and therapy services for those with special needs with a specific focus on our experiences with the IDEAS Autism Centre (IAC), a full day child care centre for children with autism which includes education and therapy as well. The need for early intervention centres catering to parents from low-income households is not being adequately met by government or even private sector players.

Based on the experiences of the IAC we believe that there are two main challenges to providing affordable early intervention services for low-income households in Malaysia:

1) The financial sustainability – covering the high costs per student for early intervention programmes.

2) The registration process – with the Social Welfare Department or JKM.

The paper asserts that such centres need to operate as social enterprises to sustain the quality of service they provide while reaching children who most need these services. In light of this, this paper explores some potential avenues of sustainable funding that may create more a feasible model for early intervention care, education and therapy centres.

The registration process with the Social Welfare Department (JKM) can be cumbersome and confusing. In this paper we take a look at these requirements and if they are necessary to ensuring quality and affordable early intervention centres or not.

Sharing the experiences of IAC in addressing the two challenges above we hope will be valuable to others who are currently providing or looking to provide similar services. Additionally, we hope there will be a shift in policies to encourage more entrants to the market for provision of affordable early intervention care, education and therapy.

1. Special Needs Education

The premise of this paper is that all children with special needs deserve affordable care, education and therapy beginning with early intervention programmes. A look at the Ministry of Education's data on enrollment of children with special needs in government schools gives an idea of the minimum number of children in the country who have special needs. For example, in 2012, the total number of students enrolled in government preschools, primary schools and secondary schools was approximately 5.27 million students, while the enrollment in Special Education Programmes was approaching 51,000[1]. This means the number of students benefitting from special needs education in 2012 stood at approximately 1 percent of the total numbers of students enrolled in schools.[2]

On the other hand, a report on mental health and special needs by the World Health Organisation (WHO) estimates the rate of learning disorders globally vary between 6 to 10 percent of the child population. Applying this estimate to Malaysia, based on 2007 data, there are approximately 531,000 to 886,000 children who have learning disorders in the country.[3] Unfortunately, this estimate suggests that the challenge of early intervention for children with special needs is grossly underestimated in the country. On the other hand, the same figure gives a more realistic understanding of the magnitude of the challenge that faces the public and private sector with respect to early intervention programmes and provision of care, education and therapy for these children.

By underestimating the needs of the country's children, the government is, by admission, neither meeting demands nor the level of quality needed and expected. Our understanding remains that the Government cannot realistically nor effectively handle the estimated number of children with special needs thus requiring private sector providers to step in.

This paper explores the experiences of privately setting up early intervention centres within the context of rules and regulations as well as the current and future possibilities of funding these initiatives.

1 This includes children and adolescents up to the age of 17 years.

2 UNICEF, Children with Disabilities in Malaysia; Mapping the Policies, Programmes, Interventions and Stakeholder, May 2013.

3 Dr Huberta Peters, Mental Health: Special Needs and Education, ASEAN Journal of Psychiatry, 2007. Accessed from http://www.aseanjournalofpsychiatry.org/pdf/ASEAN_3_3_Huberta_Peters.pdf.

2. Delivery of Early Intervention Services

The delivery of early intervention services at affordable rates is key to improving access but also to improving the chances of all children with special needs to have a more productive future.

Governments in developed countries such as Australia, United States, Canada and Singapore provide comprehensive early intervention services for children with special needs. Hence there seems to be less of a need for the private sector to step in, especially to provide services for low-income households. However, the respective governments do not rule out the role of private sector in this area. For example, in Australia, the Department of Families, Housing, Community Services and Indigenous Affairs, gives out up to 12,000 Australian Dollars per child for early intervention services for a disabled child up to six years old.[4] Families can use these funds at any registered care and therapy provider in their respective states and territories.

In the United States, the Individuals with Disabilities Education (IDEA) Act 1986, looks at evaluation and assessment and early intervention service provision by States and grants for such services for the child.[5] While these countries do provide such services and funding, the services may not always comprehensively meet the needs of all children. The IDEA Act does not cover all children as it only covers children with a severe disability or a high special need. However, the private sector can fill in the gaps in these situations.

For example, in Singapore, the Centre for Cognitive Development was started exactly for this purpose. "Mr Chia Lee Hwe, founder of Cognitive Development Learning Centre, noticed that there was a group of "forgotten children" while he was part of the advisory committee for a primary school. They were children who did not have severe enough learning difficulties to be sent to special needs schools, but who could not cope well with mainstream academic work."[6] The centre was set up as the founders noticed that "existing mainstream ones had too few teachers trained in special needs."[7]

While governments can provide comprehensive care, education and therapy there will always be needs that may not be met. Hence this paper explores the experiences of setting-up early intervention centres, by specifically focusing on our experiences with IDEAS Autism Centre (IAC), within the context of Malaysia's rules and regulations as well as the current and future possibilities of funding these initiatives to keep them sustainable and delivering services where gaps exist in the system.

4 Better Start for Children with Disability. Accessed from http://www.betterstart.net.au/.

5 Wrightslaw, Early Intervention IDEA, 1986. Accessed from http://www.wrightslaw.com/info/ei.index.htm.

6 Learning Difficulties: More Help Now, http://www.healthxchange.com.sg/News/Pages/Learning-difficulties-More-help-now.aspx.

7 Ibid.

3. Autism

Autism Spectrum Disorder (ASD) covers a range of brain development disorders which can manifest themselves in children through difficulty in social interactions, communication and repetitive behaviours, which includes Asperger Syndrome as well. However, children with ASD are also inclined to be gifted in the areas of visual, arts, maths and music skills. Research on ASD has revealed that it is a result of a combination of gene mutations and environmental factors.[8] In Malaysia, it is estimated that one child in 600 has ASD.[9] Estimates of the number of children with special needs in Malaysia varies depending on the Ministry[10] that is gathering the data as they have different reasons to obtain the data. As they collect it in different formats, they rarely compare and collate the data in order to ascertain the bigger picture or the severity of the issue of special needs and disabilities in the country.[11]

8 Autism Speaks, What is Autism? Accessed from http://www.autismspeaks.org/what-autism.

9 Ministry of Health Malaysia Statistics, 2010.

10 The three main Ministries that gather data on special needs individuals (children and adults) are the Ministry of Health, Ministry of Education and Ministry of Women, Family and Community Development.

11 UNICEF, Children with Disabilities in Malaysia; Mapping the Policies, Programmes, Interventions and Stakeholder, May 2013.

4. The IDEAS Autism Centre Story

The IAC was established in November 2012 and the story behind the centre is a unique one to many who do not know a child with special needs.[12] For those who do know a family who has a child with special needs the events that led to the opening of the centre are all too familiar; a frustrated parent meets another parent who is equally frustrated and unable to find affordable quality care, education and therapy for their child. The parents decide that they are left with no choice but to set-up their own early intervention centres. These centres of course have many legal and financial requirements leading to parents as service providers' long journey to register and fund their ventures.

The IAC is an early intervention care, education and therapy centre caters to children with autism from low-income households. The centre aims to provide these intervention services for children until they are 9 years old[13] so that they can enrol in a mainstream public school in either the Special Education Integration Programme (SEIP) or Inclusive Education Programmes[14].

12 Special needs includes various physical and mental disabilities. These include hearing and visual impairment dsylexia, autism, cerebral palsy and down syndrome.

13 Children who have been diagnosed with special needs are able to enter standard one of school at 9 years old, two years later than those who do not have special needs.

14 SEIP (special classes for these students) or Inclusive Education Programmes (one to five students with disabilities integrated into mainstream classes) are for those with severe disability (down syndrome) or learning disabilities (e.g. autism and dyslexia). A third option is Special Education Schools but these are only for those with visual & hearing impairments.

It all started with a former employee of IDEAS, Mohd Fakhri Nor Affandi, who enrolled his son, Nouri, in a pre-school centre that was well aware of his child's condition. Both him and his wife had jobs hence they were grateful that their son, despite his autism, was well taken care of at this particular centre. However, after a while the centre declared that they were not equipped to handle Nouri's behavioural issues leading Fakhri to sue the company for false representation. He won the case but this left him with an autistic son who needed care that not many centres could provide. It also left him unemployed as he had to quit his job in order to take care of his son.

Fakhri knew he had to create a plan that included not only his son but other children, and the goal was to create a full-day care centre that provided early intervention services namely education and therapy. This way parents such as himself would be able to retain their jobs, and add value to the wider Malaysian economy while strengthening their personal finances.

As Fakhri began investigating the existing child care, education and therapy centres for children with special needs, he slowly realised that these services were not accessible to most middle-income families let alone low-income families. In fact, the centres that he visited charged fees ranging from RM 1,340 to 11,000 a month for full-day care and therapy services.[15] The more expensive example of RM 11,000

15 IDEAS Autism Centre (Taska) – An Appeal for Help (Concept Paper) by Wan Saiful Wan Jan, IDEAS, 2012. Please see Appendix 1 for a summary of the centres that were visited to better understand the extent and cost of early intervention services for special needs.

is of a higher-end private care and therapy centre while the more affordable example at RM 1,340 is one that received government grants to subsidise costs incurred by the centre. As the Tenth Malaysia Plan 2011 – 2015 states that approximately 40 percent of Malaysian households earn RM 2,300 and below, requiring them to pay even RM 1,340 per month per child with special needs remains unrealistic.

In short, Fakhri's experience was similar to many other parents who found themselves out of a job as they had to care for their special needs child full-time, drastically reducing the household income despite expenses rising with the child needing, among other basic amenities, care, education, therapy and regular medical check-ups. In fact, for many parents most of these are out of the question, which drastically reduces their child's chances of becoming an independent adult. Fakhri did not have to go far to verify his hunch that this was the case with hundreds of parents. In fact, this was verified by the doctors and psychiatrists at Hospital Selayang where he took Nouri for treatment. This was when he realised that there was a desperate need and demand for low-cost centres that provided early intervention services for children with autism which encompassed full-day care, education and therapy unburdening parents and enabling them to earn money. The idea of a low-cost early intervention centre was brought to IDEAS, who agreed to put in the first RM 400,000 of seed funding, and this was the beginning of a centre that now caters for 30 children on the ASD spectrum.

4.1 The Vision, Mission and Objectives of IAC

The overarching vision of the project is "Quality education for every child." This includes children with special needs, and specifically in IAC's case quality care, education and therapy for children with autism.

As IDEAS is a think tank, the mission for IAC, is "To research and develop a sustainable and replicable social enterprise model that can help disabled children from poor families, and subsequently promote the model to others."

The short term objectives of IAC in the first three years of its existence are shown in Chart 1 while the long term mission, vision and objective are shown in Chart 2.[16]

CHART 1: SHORT TERM OBJECTIVES OF IAC – THE FIRST THREE YEARS

High Quality Care & Comprehensive Professional Support	1. To provide high quality care and therapy for up to 30 autistic children in a caring environment, with a clear focus towards inclusion into mainstream education. 2. To support early stage autistic children under our care through: a. Sensory stimulation and training b. Speech & occupational therapy c. Training on social interaction skills d. Encouragement and support to be independent in self- management.
Financial	3. To create financial stability through charitable fundraising, both from corporate and individuals, as well as through the charging of fees. 4. To gradually take enterprising steps ways to generate revenue
Stakeholder education and engagement	5. To engage parents and stakeholders in the development of the centre. 6. To provide training to parents with autistic children 7. To provide training for those supporting autistic children

16 Ibid.

CHART 2: LONG TERM OBJECTIVES OF IAC – BEYOND THREE YEARS

Year 1 -3	+ To set up a sustainable pilot autism care and therapy centre that provides high quality care and therapy for up to 25 autistic children + To network with like-minded individuals and organisations who can support our current and future work, including researchers in social entrepreneurship and low-cost education + To explore and introduce enterprising methods to generate revenue
Year 3-4	All the above plus: + To produce publications documenting key lessons from our experience so that others can benefit from the knowledge that we have gathered
Year 4-5	All the above plus: + To look into replicating similar centre(s) that can contribute towards creating economies of scale + To make IAC Rawang a full-fledged and sustainable social enterprise

The long term and overarching objective for IAC is to grow into a social enterprise that develops a working and replicable model for delivery care, education and therapy for children with special needs or disabilities who are from poor families.

With the above in mind and as the idea for IAC began to take shape, the immediate challenges then became:

+ Finding funds;
+ Finding a location and premise;
+ Finding expert staff; and
+ Registering the centre with the appropriate authorities.

5. Funding IAC

Parents from low-income households require a care centre that consistently provides quality education and therapy for their children until they are old enough and prepared enough to enter mainstream schools.

The rules, regulations and guidelines listed in The Child Care Centre Act 1984 or Act 308, Section 8 are only the beginning of the quagmire of laws, many of which prove to be obstacles for those who come into the community armed with a mission of providing a valuable and affordable service to children with special needs.

Apart from various regulations proving to be unnecessary obstacles for a centre like the IAC, and potentially many others, funding and ways to create financial sustainability become the main challenges once a centre is set up. The other main obstacle to operating such centres is the high cost involved due to special equipment, learning materials and expert teachers and therapists involved. While the IAC provides a much needed service, it also tries to minimise its costs while providing quality services which are accessible to Malaysians who are middle-class and below.

Private individuals and organisations are making a push to provide these centres for those who need them the most, and should continue doing so because communities should continue to empower the wider society in which they live.

In the following sections, the paper recounts the IAC's experience of raising funds, what actions were taken when funds promised were not delivered, and future approaches that the centre will look to in order to ensure the sustainability of the centre.

Fortunately, the plan for the IAC was mooted at a time when enough funds were on hand to secure a premise, renovate it and hire some staff. The funds, approximately RM 400,000 (along with another RM 150,000 raised through private donations) were raised through a charity dinner for a cause and project that never took off, hence IAC become the beneficiary instead.

Regardless, the management team[17] was well aware that this was not sufficient for operations beyond the first year, even if the centre was to charge fees[18]. Hence, as noted in the objectives of the centre for the first three years of operations, financial stability was to be provided through donations and grants from corporations and individuals while the centre is working on generating revenue streams to ensure the sustainability of the services provided.

5.1 The difficulties of accessing Government grants

Along with funding from corporates and individuals, the IAC applied for a grant from the Government once the centre was up and running in 2012. The IAC submitted an application to the Ministry of Women, Family and Community Development (KPWKM), which was offering grants of approximately RM 500,000 for newly set-up special education centres at the time. IAC's application was initially fast-tracked through the Ministry, but there was no clear process on how to apply and eventually the IAC was told that it did not succeed in securing the grant.

While the failure to obtain a government grant was a setback for IAC, other avenues for funding were sought out and continue to be sought in order to ensure the future financial sustainability of the centre.

> However, the problem with being registered as a foundation, is that they are unable to apply for any grants from JKM.

CASE STUDY

KIWANIS DOWN SYNDROME FOUNDATION – NATIONAL CENTRE, SELANGOR

Laws that limit the ability of an organisation to seek government funding

KDSF is a foundation that provides early intervention programmes for children with Down Syndrome as well as support programmes for parents. They serve children up to six years old and have been around for 25 years. The foundation manages seven other centres that are located in Petaling Jaya, Johor Bahru, Klang, Seremban, Melaka, Kota Kinabalu and Kulai.

KSDF did not face issues registering but faced several obstacles when trying to secure funding from government. KSDF has chosen to be a foundation in order to keep their financials transparent so that all funds raised and disbursed were accounted for.[1] However, the problem with being registered as a foundation, is that they are unable to apply for any grants from JKM. For those at the foundation this situation is ironic as they believe they are providing a service that should essentially be the domain of the Government.

Fortunately, the Administrative Secretary of KDSF Angie Heng is glad that they have been able to continue raising funds and providing services for those who are in need. As the number of not-for-profit special education centres grows, the financial needs grow as well and this area is becoming highly competitive. Here, a strong fundraising team becomes necessary, as Angie Heng explained, to effectively advocate for and secure grants.[2]

1 Interview with Angie Heng, KIWANIS Down Syndrome Foundation, 8 October 2014.
2 Ibid.

17 IAC has a Board of Governors who meet every quarter and a management team who deal with finances and operational issues on a daily basis. The centre is run and the staff (therapists and facilitators/teachers) are managed by the principal.

18 Different amounts are charged based upon per capita household income. Currently parents either pay RM 300 per child if their per capita income is RM1,500 per month. Families who have a per capita income of RM 500 or less do not pay fees for their child to attend IAC.

5.2 Looking for donations from private individuals and corporations

Donations from individuals and corporations is the main avenue of funding that support the activities of the IAC. However, the complication with these types of donations is that it is limited as the IAC has not yet been given tax-exempt status. The IAC is placed under the parent company, IDEAS Berhad, as a special project. As the need to raise more funds from private individuals and institutional donors become increasingly evident, the management became acutely aware that the status of the centre under IDEAS Berhad meant that it was missing out on the opportunity to receive funding from organisations looking to donate to non-governmental organisations who were tax-exempt only. In other words, any donations and grants made to the centre were not tax-exempt and the organisation itself was taxed as a regular business under the parent company.

After further investigation into the matter, it became clear that the IAC would need to be moved to a separate entity which is likely to be a foundation. This foundation would then be the parent company of the IAC and would be able to receive funding in the form of tax-exempt donations which is beneficial to both the donor and receiver. However, this is subject to LHDN's approval of the IAC's application for tax-exempt status. While these processes are taking place IAC has been most fortunate in securing grants from Yayasan Sime Darby, Hong Leong Foundation, ECM Libra Foundation and the A&A Trust that will ensure the IAC is operational up to December 2015.

5.3 Creating Strong Private Sector Partnerships

In the meantime institutional funders continue to support the activities of the IAC. Creating strong buy-in from institutional funders who have been supporting the centre in its infancy is a particular strength of the IAC. For example, the centre has built a successful model of full-day care, education and therapy to an underserved population. It is dedicated to its previously stated mission and vision, including short and long term objectives, which have allowed it to bring on board several institutional funders as stated above.

However, the space for applying for grants and funds is becoming highly competitive. For the IAC, raising funds has not been without its challenges but the centre has been fortunate enough to secure operational funding for from 2013 through to the end of 2015. With this funding, the centre will now look to other means of funding future operations in order to create a sustainable social enterprise which caters to underprivileged children with autism.[19]

In the bigger landscape, what has also emerged in recent years is long-term partnerships between corporates and centres that provide education and training for children and adults with special needs. The premise being that these corporations will end up hiring graduates from these centres. For the example, SAP in the United States has been recruiting adults with ASD, specifically those with Asperger Syndrome, as they possess behaviours and skills that are valuable to the business such as attention to detail.[20] If, the IAC were to find a similar Malaysian company who is actively seeking to recruit adults with special needs, a long term business strategy would be to invest in quality early intervention programmes to ensure that these children eventually become employable adults.

5.4 Creating a sustainable social enterprise

Collecting funds via fees at cost or at a discounted rate is one approach that IAC is taking to create a revenue stream. Currently IAC charges either RM 300 per child per month or the fees are waived for households with a per capita income of below RM 500. The average cost per child is very high at approximately RM 2,900 per month.[21] This rate takes into consideration all costs such as management team, teachers, therapists and the principal at the centre, rent, learning materials, various fieldtrips, and meals for the children among others for a centre that caters for 30 children. As noted earlier, the centre is funded by various foundations[22], fees collected from parents, and occasional private donations. But as the centre grows and matures it continues to look at other means of funding its activities beyond the standard tried and trusted donation formula. Incidentally, as the centre grows the cost per child begins to drop slightly due to economies of scale.

19 IDEAS Autism Centre (Taska) – An Appeal for Help (Concept Paper) by Wan Saiful Wan Jan, IDEAS, 2012.

20 Autism Speaks, SAP Focus on Hiring Adults with Autism Featured on CBS News. Accessed from http://www.autismspeaks.org/news/news-section/sap-focus-hiring-adults-autism-featured-cbs-news.

21 IDEAS Autism Centre (Taska) – An Appeal for Help (Concept Paper) by Wan Saiful Wan Jan, IDEAS, 2012.

22 Yayasan Sime Darby, Hong Leong Foundation, Sapura Foundation, A&A Charitable Trust and ECM Libra Foundation.

There are a few other possibilities that the IAC can look to in order to bring in a steady stream of income to re-invest into the centre and expand the services it provides. For example, the IAC could partner with a for-profit company that operates in a related field, possibly a private hospital or education service provider. Assuming this for-profit company is prudently managed, a percentage of its profit can be allocated for the IAC operations on an annual basis. This would allow the company to not only enjoy tax deductions, given the IAC is granted tax-exempt status, but also support the operations of the IAC.

Another approach would be for the IAC to provide services using an internal quota where those who are able to afford the services at full-cost or more are able to subsidise or pay-it-forward to those who may be less fortunate so that they are able to benefit from the services provided as well. This may mean an expansion of the vision and mission of the centre to include "quality services for all who require it." Another approach would be to open an early full day care, education and therapy centre such as IAC (using similar modules, curriculums, and activities) which serves a different demographic in a different location, where fees charged are equivalent to or above cost. This could be a for-profit-educational service provider which then subsidises IAC.

Many have also gone on to develop franchise models to grow and upscale such centres allowing the services to reach a growing audience including the underprivileged. Globally, there are numerous examples of these models from the ubiquitous Kumon, which offers courses for children with various special needs[23], to more regional ones such as Bridge Learning, an early intervention centre based in Singapore. While these centres do not specifically cater to the underprivileged, if the model was tweaked using some of the aforementioned ideas, they could begin providing a valuable service for children from low-income households. However, in order for IAC to become a licensed franchiser, this requires the centre to have been in operation for at least three years[24] whereas currently it has only been in operation for two full years.

The IAC is also working on autism related research within the Malaysian context allowing the centre to develop and share the expertise it has accumulated potentially through a more scalable and replicable franchise model. This will fulfil the vision and mission of the centre to bring more affordable care, education and therapy for children with special needs to other potential centres. Developing such a repertoire of research and data will also help understand the problem of autism better within the country and enable the creation of modules that are more applicable to the Malaysian culture and context that can be used at future centres.

5.5 A different take on funding - vouchers

Lastly, a voucher system can be used to bring more quality service to more children who need early intervention services. Funders can provide scholarships to the children rather than for the entire centre, where the funding can either be provided by the private sector or government. This is one way to introduce market-based principles to welfare provision. It is different from the "fund the agency" approach that could lead to complacency because funding is secured regardless of what the students and parents say. Instead the approach would be "fund the students", so that the operator, or the IAC in this case does not become complacent and continues to strive to provide affordable quality special intervention. This way the choice is given to parents to assess the quality of care, education and therapy their child is receiving and if they are unsatisfied, they can move their children to another centre.[25]

The financial sustainability of IAC can be ensured using some of the many different approaches mentioned above and the goal is to make it a self-sustaining social enterprise that provides care, education and therapy for underprivileged children with autism in the country.

23 Kumon, Education for Children with Special Needs. Accessed from http://www.kumongroup.com/eng/enterprise/learners_w-special_needs/index.html.

24 Feedback from IDEAS Roundtable on Special Needs Centres on 11th November 2014, held at Shah's Village Hotel, Petaling Jaya.

25 IDEAS Autism Centre (Taska) – An Appeal for Help (Concept Paper) by Wan Saiful Wan Jan, IDEAS, 2012.

6. Registering an unconventional early intervention centre

In 2012, while the IAC had the required funding to begin its operations, there was one area yet to be addressed – registration with the Welfare Department or Jabatan Kebajikan Malaysia (JKM). The IAC faced some problems in registering with JKM, especially since the centre's plans were not conventional and did not always meet the requirements set by JKM for child care centres.

The Step by Step Process of Registering a Child Care Centre

1. Complete proposal, inclusive of vision and mission of the company and centre, and secure funding[26]. Ensure you have decided the category of care centre you will be providing from the list below.

THE CHILD CARE CENTRE 1984 [ACT 308]

The purpose of the formulation is to provide for the registration, inspection and enforcement of the childcare centre and for matters connected therewith for the health, safety and overall development of children first.

DEFINITION OF CHILD CARE CENTRE

In Section 2, Act 308 "child care centre" means any premises that receives four (4) or more children under the age of four (4) years from more than one household to be cared for by wages .

DEFINITION OF REGISTERED CHILD CARE CENTRE

"Registered child care centres" means a child care centre that is registered under section 7.

Under Section 6 (1) No person shall conduct or participate in the management of a child care centre that is not registered under the provisions of this Act.

Under Section 6 (2) of Act 308 provides that any person who contravenes subsection (1) commits an offense.

Source: http://www.jkm.simple.my/content.php?pagename=syarat-syarat_penubuhan_taska&lang=en)

TASKA CATEGORIES

Section 5 of Act 308 provides childcare centre into following 4 categories:

Home TASKA

- Received less than 10 children to the care of the home that was registered under Section 7.

Institutions TASKA

- Receiving 10 or more children in care

Workplace TASKA

- Receiving 10 or more children in care
- Established in the workplace or provided by the employer in an appropriate place for the convenience of staff.

Community TASKA

- Receiving 10 or more children in care.
- Established in a particular area and to receive assistance from the federal government or a state government.

Source: http://www.jkm.simple.my/content.php?pagename=syarat-syarat_penubuhan_taska&lang=en)

2. Begin the registration process of your business either under the Companies Commission of Malaysia (SSM) or Registrar of Societies (JPPM)
3. Find a premise that meets JKM[27] requirements under Child Care Centre Act 1984 and is approved by the Ministry of Health, Fire Department and Local Authorities. The inspection of the premises will occur at the same time that your application has been put in to JKM. Some of the processes may not have begun yet for example, records of children may not be available.

26 At this juncture it should be decided whether the centre is going to be providing services for children older than four years, if so, then special permission may be required from JKM and registration with the Private Education Department at the Ministry of Education may be required as it is also considered a pre-school.

27 Jabatan Kebajikan Masyarakat, The Conditions for Establishment of Child Care Centre (TASKA). Accessed from http://www.jkm.simple.my/content.php?pagename=syarat-syarat_penubuhan_taska&lang=en.

THE CONDITIONS FOR ESTABLISHMENT OF CHILD CARE CENTRES (TASKA)

The conditions for setting up TASKA are as follows:

i. Registered with the Companies Commission of Malaysia (SSM) or the Registrar of Societies (ROS). TASKA at home are excluded;

ii. Meet JKM minimum standards:

a) The ratio between caretaker and child are sufficient;

- under 3 years old = 1 : 5
- 3 to 4 years old = 1 : 10
- Handicapped Children (OKU) = 1 : 4

b) Caretaker is a Malaysian citizen aged 18 years and above;

c) Caretaker has attended and graduated Basic Child Care (KAAK);

d) Met children and floor space requirement ratio with a floor space of 2.5 square metres for a child at TASKA at Home and 3.5 metres for a child for other TASKA category.;

e) Prepare and display a balanced diet menu schedule and daily activities schedule according to children's age levels;

f) Care Centre (TASKA) have the necessary equipment and appropriate furniture, safe and sufficient for the needs of children;

g) Prepare and maintain records in child care centre (TASKA); and

h) Maintain cleanliness and safety on and off the TASKA premise

iii. Have the support or approval from technical agencies such as:

- Local Authorities (PBT);
- Fire and Rescue Department;
- Health Department; and
- Department of Lands and Survey (Sarawak only)

As a measure to simplify the TASKA registration process, Registration Certificate will be issued by the Social Welfare Department (JKM) to the operators who comply with the JKM minimum standards and conditions imposed under Act 308.

Source: http://www.jkm.simple.my/content.php?pagename=syarat-syarat_penubuhan_taska&lang=en)

4. Fill out the JKM form for registration for a child care centre.

TASKA REGISTRATION PROCEDURES ARE AS FOLLOWS:

i. Registration application can be made by the District Social Welfare Office (PKMD) nearby;

ii. TASKA establishment application guidelines can be purchased at any nearby PKMD for RM10.00;

iii. A complete registration application will be processed within 14 working days;

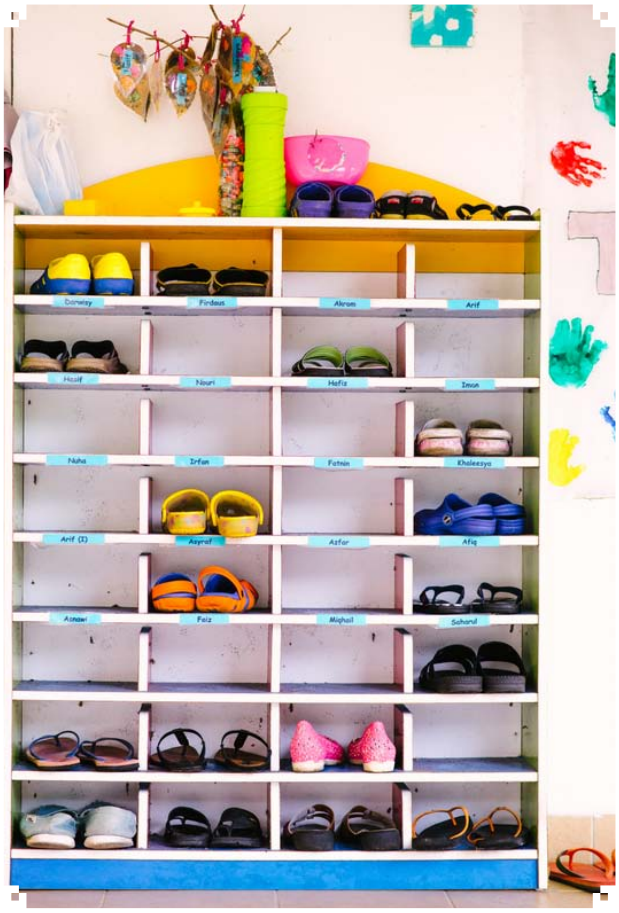
iv. Registration fee is RM50.00;

v. TASKA Registration Certificate issued by the Director of Social Welfare State; and

vi. List of registered childcare centre can be checked on the website JKM

Source: http://www.jkm.simple.my/content.php?pagename=syarat-syarat_penubuhan_taska&lang=en)

5. Once the centre has been approved by JKM, operations can begin.



6.1 Finding a location and premise

The IAC was registered as a taska under JKM and established as a special project under IDEAS Berhad. Registering a taska is no easy task, as the criteria for setting one up are numerous. However, many are necessary to ensure the safety of a child. The full list of conditions that a centre has to adhere to are listed in Act 308 under Part II section 8, stating that "Terms and conditions to be imposed".[28] The areas that this section looks at can be broadly categorised into three areas: the suitability of the premise, staffing requirements, and programme content and technicalities.

On the JKM website, it states that registration takes up to 14 days only. However this simply refers to the process of producing a certificate once the organisation has explicitly met the JKM requirements, passed inspections from other agencies as previously listed in the, 'The Step by Step Process of Registering Centre', and submitted the complete registration forms. In the opinion of those involved in setting up IAC of the registration process can take up to two to three years but, in many cases where the founding members know the "right people" many processes and permissions can be fast-tracked.[29] Luckily, this was the case for the IAC where the registration process was fast-tracked in order to get the centre operational within the shortest period.

Firstly, a premise[30] needed to be identified to house the IAC and to put in registration forms to JKM for approval. The capacity of a centre is based upon the area of the centre, where for example each child is required to be allocated a minimum space of 3.5 square meters.[31] The other premise requirements include getting the approvals from the following government agencies: Local Authorities, Fire and Rescue Department, Health Department and Department of Lands and Survey (Sarawak only).[32] Lastly, the act requires that the centre is "adequately and suitably equipped and maintained".

At the IAC, the premise has been approved by all the relevant authorities as listed in the Act 308 and the centre has acted with discretion in terms of capacity; even though JKM has granted the centre suitable for 52 children we have put a cap on enrolment at 30 in order to ensure a less crowded and more comfortable environment for the children. This is especially important for children with autism as they can be very energetic and require space to run about and give them an outlet for their energy.

As for the approvals from the relevant departments the IAC gained all the relevant permissions for JKM registration. What is important to note is that JKM fast-tracked the approval and registration of the IAC as a child care centre (taska) so that the centre would be eligible to receive the grants that were made available by the Ministry of Finance through the KPWKM. While this approval meant that the IAC was able to

28 Laws of Malaysia, Act 308, Child Care Centre, Act 1984, Section 8. Accessed from http://www.agc.gov.my/Akta/Vol.%207/Act%20308.pdf.

29 Interview with Fakhri one of the founders of IAC, 2 September 2014.

30 A premise is required to meet certain rules in order to pass Department of Social Welfare Services (Jabatan Kebajikan Masyarakat) inspection.

31 Jabatan Kebajikan Masyarakat, The Conditions for Establishment of Child Care Centre (TASKA). Accessed from http://www.jkm.simple.my/content.php?pagename=syarat-syarat_penubuhan_taska&lang=en.

32 Ibid.

begin operations sooner and provide a much needed service to the community, it brings into question the pace and process of registration and the arbitrary nature of some approvals.

6.2 Staffing

Skilled staff are the bedrock for centres such as the IAC. Special needs children require professional early intervention to create a foundation upon which they can succeed. In fact, the United Nations Convention to the Rights of the Child (UNCRC 1989) states that all children with disabilities have the right for their, "education (to) be directed to the development of… personality, talents, mental and physical abilities to her or his fullest potential."[33] At IAC there are seven fulltime staff who are directly involved with the children, with the appropriate qualifications and experience. This allows for teacher to student ratio of approximately 1:4, which is required for a taska for children with disabilities according to the JKM guidelines. However, centres that provide early intervention programmes such as the IAC, should be able to make decisions on such ratios in accordance to their expertise, based roughly on available guidelines and the need for the children at the centre.

The IAC not only offers care but also offers education and therapy for the children in order to prepare them for integration into mainstream schools. With this in mind, hiring individuals who are Malaysian (a requirement under JKM for taskas) becomes an issue especially with the lack of fully qualified speech therapists in the country. Each speech therapist that IAC has hired eventually leaves to join the Government services, mostly the Ministry of Health, to enjoy perks and pensions a small start-up centre such as IAC is unable to provide. However, retaining staff and trying to keep costs down to a minimum prove to be challenging. For example, hiring and retaining speech therapists, IAC has found it very difficult to hold down our speech therapists as they prefer to work for the government since there is a guaranteed lifetime income or they prefer to move to Singapore[34] for the higher salaries.

The guidelines that JKM have online, along with requirements under Act 308 with reference to the staffing of a child care centre limits the pool to which the IAC can look to when hiring experienced staff, especially speech therapists.

6.3 The thin line between child care centre (taska) and preschool (tadika)

Act 308 only covers child care centres meaning that it applies only to organisations that cater to children who are between the ages of zero to four hence by law these centres should be registered with the KPWKM under JKM. If children are above the age of four to five plus, the centre that they attend is defined as a preschool and should by law, be registered with the Ministry of Education (MOE), Private Education Division, under the Education Act 1961, as a preschool following the National Preschool Curriculum and national language of instruction.[35]

However, services that the IAC provides are unique - early intervention services for children with autism up to nine years old.[36] This means that the children at the centre will definitely exceed the age limit set by Act 308. This subtle difference in age groups and the definition of child care centre and taska make providing such services complicated. For example, the National Preschool Curriculum may not be relevant to a centre that caters to children with autism even if they are of preschool age. Additionally, being registered under KPWKM instead of MOE means that parents who send their children to the IAC are unable to access the fee assistance provided by the MOE for early child care and education. For example, if per capita income is below RM 500 then a family's monthly fee assistance for a disabled child is RM 300, which in the IAC's

33 Dato' Dr Amar Singh, Overview of initiatives & programmes, key challenges & obstacles to the full realisation of rights of children with disabilities in Malaysia, UNICEF, 2013.

34 Phone Interview with Dato' Dr Amar Singh, 28th August 2014.

35 Laws of Malaysia, Education Act 1961, Chapter 2 – Pre-school education and Chapter 8 – Special Education.

36 Children with special needs are given an extra two years before they are required by law to be registered and attending a mainstream school.

experience is significant for a family as it can be the difference between attending and not attending the IAC.[37]

IAC was able to overcome these complications as it is solely registered as a taska under Act 308 under JKM but not under the Private Education Department, Ministry of Education. It is unclear how operating such a centre with children aged two to nine which is not running the National Preschool Curriculum was registered under JKM within such a short period of time, whether it was due to the founders' "right connections" or to an exception written in the Act 308, or both. The Act 308, Part VI, section 26 notes that, "Provision to allow reception of children above the age of four years", and this may have been the case for the IAC. Thanks to its registration with JKM, the IAC can now provide 30 autistic children from low-income households with full day care, education and therapy, readying them for the challenges that face them in their future. However, not all centres who will apply for such exceptions will share the smooth and expedited experience as that of IAC. This needs to be re-looked at as the demand for special needs care and intervention become greater in Malaysia.

37 In IAC's experience some families are unable to afford the transportation costs required to come to IAC on a daily basis.

CASE STUDY

ASIA COMMUNITY SERVICE, PENANG

Rules which prevent centres that provide early intervention services from registering with JKM

ACS is a well-established non-profit organisation that aims to empower those with special needs, specifically children and adults with intellectual disabilities, to live more productive and fulfilling lives. Their services include respite care, early intervention therapy and care, and skills training for adults.

The centre, which has been around for 18 years, while providing early intervention services for those ages 0 to 6 years are not registered under JKM or the Act 308. Under the Act a child must be at the centre for at least three to four hours before the centre is considered a taska. Since ACS is caring for underprivileged children with special needs and providing therapy for them only two to three times a week for three hours each time they are not considered eligible to register under JKM. While not being officially registered with JKM may not be so much of an issue in itself, the organisation and those who seek its services are unable to apply for government funding or allowances. ACS has applied to be registered with JKM to avoid these restrictions in funding, but time and time again have been rejected by the department. This was described as "too by the book" behaviour by Ai-Na Khor, CEO of ACS.[1]

In this way many centres who are providing the care, education and therapy that special needs children deserve are arbitrarily not being recognised by the Government and the regulations are not serving to make these services more readily and widely available.

1 Interview with Aina Khor, Founder, Asia Community Service, 3 October, 2014.

7. Moving Forward

There seems to be a dire need for more early intervention centres in Malaysia based on estimated numbers of children with various special needs. However, the number of children with special needs from low-income households is unclear as no Ministry collects such data making it difficult for us to understand this problem better. What is apparent is that there are hundreds of low-income families out there who seek out services such as those IAC provides in order to ensure the best early intervention they can for their child. This also allows them to become better off economically as the stay-at-home parent becomes free to work.

The need exists, and as such the means to set-up early intervention centres and services should be encouraged, simplified and incentivised by the government. In fact, if they are really concerned legislation such as Act 308 should have a chapter on special needs and early intervention in order to provide a better context for those trying to provide such services.

While many rules and regulations are pertinent in order for government agencies, particularly JKM, to ensure the quality of the centres then this should be the focus of the legislation. However, the current Act 308 creates confusion as there are many requirements stated, for instance the ages of children who attend these centres, but then there is a Section that then allows any centre to circumvent this rule if they gain special permission from the relevant Ministry. Is there a point to legislation that is used at the discretion of the officers and ministers? A clearer approach would be to have general overarching regulations pertaining to the well-being of any child a centre serves and the quality of care, education and therapy the child receives. Currently, the regulations seem to be more focused on technicalities of the centre such as age range, number of hours the child is at the centre, the nationality of the teachers or therapists, rather than the quality of education the child is receiving.

The KPWKM needs to re-look into the processes that JKM has in place if they truly conducive to helping private players set up affordable high quality early intervention centres that serve underprivileged populations in Malaysia not on arbitrary technicalities.

As for funding, if government funding is made available for such initiatives, then the allocation processed must be transparent and consistent with minimal discretionary powers of ministry officials and ministers. It would be even better if the funding follows the child, similar to the concept of a "school voucher" system. This will encourage even more entrepreneurs to come into the picture thereby helping the government to provide the best quality support to every child in need.

The need exists, and as such the means to set-up early intervention centres and services should be encouraged and incentivised by the government.

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Appendix 1

PRICE COMPARISON OF CHILD CARE, EDUCATION AND THERAPY CENTRES IN KUALA LUMPUR AND SELANGOR IN 2012

Centre	Duration of care	Monthly fee of day care only	Fee for occupational therapy (per 45 minutes session)	Fee for speech therapy (per 45 minutes session)
A	8.00am – 12.30pm (4.5 hours) 8.00am – 5.00pm (9 hours)	RM 450 RM 660	RM 85	RM 85
B	8.00am – 2.00pm (6 hours)	RM 850	RM 80	RM 80
C	8.00am – 3.00pm (7 hours)	RM 850	RM 120	RM 120
D	8.00am – 12.30pm (4.5 hours) *Only for twice a week*	RM 7,200	inclusive	inclusive
E	8.00am – 2.00pm (6 hours)	RM 800	RM 80	RM 80
F	1 – 3 hours	not provided	RM 160	RM 160
G	32 hours divided into 16 sessions	RM 6,400	inclusive	inclusive
H	35 – 40 hours	RM 11,000	inclusive	inclusive
IDEAS Autism Centre	**8.30am – 5.30pm (9 hours)**	**RM 2,900**	**inclusive**	**inclusive**

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