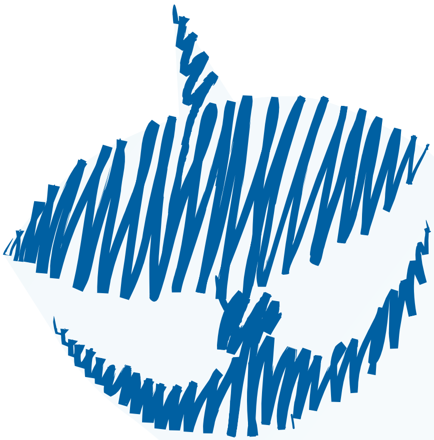
Policy
IDEAS
Nº. 21

JULY 2015



Living with Autism in Malaysia

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Abstract

Once regarded as a rare occurrence, the incidence of autism is now on the rise in Malaysia. This case study explores the level of support available to parents of children with autism through interviews with stakeholders in the field.

Four key areas were examined:

- Education and Care
- Healthcare
- Family and Society
- Long Term Planning

To understand the mechanisms through which income levels influence the parents' ability to obtain support, three in-depth interviews were conducted with families from low, middle and high income brackets.

Findings from the research indicate that while there are some services and supports available, large gaps remain in all four areas. The key findings indicate that there is a shortage of qualified care and education professionals. Furthermore, the cost for private healthcare care is still prohibitive, waitlists are long and there are an insufficient number of public spaces and businesses that take into account the needs of individuals with autism. Additionally, support services for long term planning such as employment and independent living are lacking for families from all income ranges. With this in mind the paper recommends the following:

Author

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Areas to look into

01 Training and awareness about autism for a wider audience;

02 Provision of more comprehensive forms of care;

03 Targeted and flexible financial assistance.

This needs to be done to ease the pressures faced by families who have individuals with autism as well as ensure that all individuals with autism are provided the opportunity to maximise their potential and contribute to our society.

> *But I ask you, those of you who are with us all day, not to stress yourselves out because of us. When you do this, it feels as if you're denying any value at all that our lives may have–and that saps the spirit we need to soldier on. The hardest ordeal for us is the idea that we are causing grief for other people. We can put up with our own hardships okay, but the thought that our lives are the source of other people's unhappiness, that's plain unbearable.*
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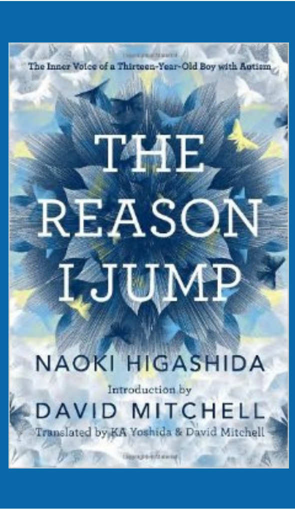
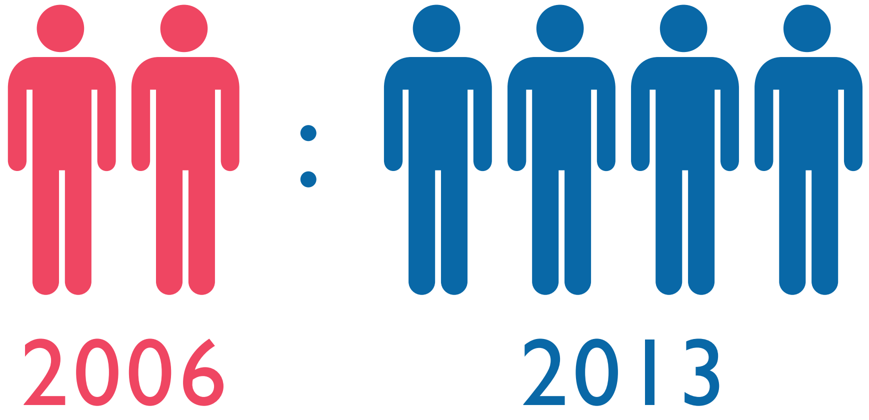
> *- Naoki Higashida, The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy with Autism*



Introduction

The significant number of children facing learning difficulties is now a well-documented phenomenon worldwide, with countries around the world giving more importance to addressing this issue[1]. Malaysia is no exception to this trend, where the number of children enrolled in special needs programs has more than doubled between 2006 and 2013[2]. Given the far reaching implications of this trend on the country's education system, health system, economy and society, a deeper understanding of these issues is vital.

> *The number of children enrolled in special needs programs has more than doubled between 2006 and 2013*



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[1] Unesco. The Salamanca Statement and Framework for action on special needs education: adopted by the World Conference on Special Needs Education; Access and Quality. Salamanca, Spain, 7-10 June 1994. Unesco, 1994.

[2] Data Pendidikan Khas 2013, Special Education Division, Ministry of Education. Cited in 'Overview of Special Education in the Malaysian National Education System'. PEMANDU. 2015.

Special Needs and Inclusive Education

The term "special needs" is increasingly used in the field of education, defined in the Salamanca Statement of 1994 as referring to "children or youth whose needs arise from disabilities or learning difficulties"[3]. It is important to note that this is an umbrella term that covers an extremely wide range of conditions, including medical, behavioural, developmental, social, learning and mental health issues. A person with special needs may face difficulty in one or more of these areas, and the complexity involved in an accurate diagnosis is a well acknowledged fact amongst professionals in the field[4]. Hence, while the term "special needs" is a useful indicator that a child may need additional services or supports, it does not provide any insight to the specific challenges they face as individuals.

In recent decades, there has been a shift away from the traditional model of excluding children with special needs from mainstream education, towards what is now commonly known as 'inclusive education'. This approach is guided by the belief that "all children should learn together, wherever possible, regardless of the differences or difficulties they may have"[5]. The Salamanca Statement argues that such education is important not only to provide all children with a quality education, but is essential in changing discriminatory attitudes and building a more inclusive society[6]. In Malaysia, the Ministry of Education aims to have 75 percent of children with special needs enrolled in inclusive programmes by 2025.[7]

> *All children should learn together, wherever possible, regardless of the differences or difficulties they may have.*

The Definition of ***Special needs:***

- Children or youth whose needs arise from disabilities or learning difficulties

Salamanca Statement of 1994

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[3] Unesco. The Salamanca Statement and Framework for action on special needs education: adopted by the World Conference on Special Needs Education; Access and Quality. Salamanca, Spain, 7-10 June 1994. Unesco, 1994.

[4] National Institute of Mental Health. http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml

[5] Unesco. The Salamanca Statement and Framework for action on special needs education: adopted by the World Conference on Special Needs Education; Access and Quality. Salamanca, Spain, 7-10 June 1994. Unesco, 1994.

[6] Ibid

[7] Ministry of Education. "Malaysia Education Blueprint 2013-2025." (2014).

Why Autism?

The Autism society of America describes an autism spectrum disorder as "a complex developmental disability (where) signs typically appear during early childhood and affect a person's ability to communicate, and interact with others. Autism spectrum disorders are defined by a certain set of behaviours and is a "spectrum condition" that affects individuals differently and to varying degrees[8]."

Autism spectrum disorders are becoming an increasingly common occurrence in our schools and society. The Centers for Disease Control and Prevention estimate that "the global prevalence of autism increased twentyfold to thirtyfold since the earliest epidemiologic studies were conducted in the late 1960s and early 1970s", citing an increase in prevalence rates of 1 in 2,500 to 1-2 in 100 children by the early 2000s[9]. An analysis of prevalence rates in countries with relatively long histories of autism screening provides a glimpse into what is now being called the 'autism epidemic'. In the United States, for example, 2010 data indicates that the prevalence of autism is as high as 1 in 68[10], and data from the United States and Canada point to an upwards trend in autism prevalence[11]. There is much discussion as to whether these trends are due to an actual increase in the incidence of autism, or simply improved detection and diagnosis; regardless, their implications remain significant.

At present, there is no epidemiological data available on the prevalence of autism in Malaysia. However, a smaller scale study by the Ministry of Health on children between the ages 18 to 26 months showed a rate of 1.6 in 1000 children, or approximately 1 in 625[12]. Given that many cases go undetected, and that additionally, practitioners in both the medical and education fields report an increase the amount of autism cases they are having to address[13,14], it is likely that the true prevalence rate of autism in Malaysia is higher. Given the increased prevalence of autism, this condition was chosen as the focus area of this research. The study is also intended to complement the work at the IDEAS Autism Centre, a not for profit organisation that currently serves 30 children diagnosed with autism spectrum disorders. Established in October 2012, the IAC provides early intervention care and education for children with autism below the age of 9, with the goal of eventually enabling them to attend mainstream primary schools. It is hoped that the findings highlighted in this case will further inform this work[15].

> *"IDEAS Autism Centre is a not for profit organisation that currently serves 30 children diagnosed with autism spectrum disorders."*

United States
2010
prevalence of autism

Children between
18 to 26 months
that have autism

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[8] Autism Society of America http://www.autism-society.org/what-is/

[9] Wingate, Martha, et al. "Prevalence of autism spectrum disorder among children aged 8 years-autism and developmental disabilities monitoring network, 11 sites, United States, 2010." MMWR Surveillance Summaries 63.2 (2014).

[10] Blumberg, Stephen J., et al. "Changes in prevalence of parent-reported autism spectrum disorder in school-aged US children: 2007 to 2011–2012." National health statistics reports 65.20 (2013): 1-12.

[11] Ibid

[12] Ministry of Health. Clinical Practice Guidelines: Management of Autism Spectrum Disorder in Children and Adolescents. 2014. <www.moh.gov.my>

[13] Ibid

[14] Stakeholder interviews conducted by author.

[15] IAC website http://autism.ideas.org.my/

Overview

Data on autism in Malaysia is still relatively scarce. Information on the quality of services available to children with autism and their families, as well as their long term well-being, is still largely anecdotal.

Guiding questions that shaped the research

- What is the nature of the challenges faced by parents of children with autism?
- To what extent do income levels mitigate these challenges?
- What are the most pressing problems faced?

This study provides a qualitative portrayal of the experiences of a small group of parents of children with autism from different socioeconomic backgrounds. The study did not formally evaluate any institutions or organisations - rather, the aim was to provide a clearer understanding of the scale and complexity of the issues as perceived by parents and other stakeholders. It is hoped that a deeper understanding of parents' perspectives will shed light on key issues that need to be explored further in order to effectively tackle the realities of autism in Malaysia.

Each issue discussed is followed by one or two excerpts drawn from interviews conducted throughout the study period. These vignettes have been left in the voice of the person interviewed, to retain and bring to life the complexity as well as the highly emotional nature of some of the issues at hand. They provide a direct lens not only into the suffering, but also the tremendous strength and courage that characterises the daily life of these families.

Methodology

To gain a broad understanding of the issues, a series of interviews were conducted with a variety of stakeholders, including special needs educators and medical professionals. These stakeholders were able to draw from their many interactions with parents, and as such, these interviews provided an overall picture, but also rich insight into the challenges faced.

Three parents were then selected for an in-depth interview[16]. All three families live in urban settings within the Klang Valley, and were recommended for the study on a referral basis. At least one child in the family had been diagnosed with an autism spectrum disorder that interfered with verbal communication and the ability to pursue a regular educational path. To investigate the effect of income levels, they were drawn from three categories: high income (monthly per capita income of >RM3,000[17]), middle income (monthly per capita income of RM501-RM2,999[18]) and low income (monthly per capita income of <RM500[19]). In order to explore the long-term impact of autism, all three families chosen had a child with autism that was over the age of 16. Face-to-face interviews were conducted with parents at a convenient location, either within or nearby their homes.

> *"These interviews provided an overall picture, but also rich insight into the challenges faced."*

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[16] For anonymous profiles of these parents, see Appendix A

[17] Average income for top 20 percent of households/ Average household size. 2012 Census data.

[18] Derived from the range between the high and low income brackets

[19] Data Pendidikan Khas 2013, Special Education Division, Ministry of Education. Cited in 'Overview of Special

Living with Autism: What are the challenges?

Raising a child with autism is a monumental task. The parents of these children need a high level of support from the education and healthcare systems, as well as the family and community at large. They also need to be able to plan for their children's long term well-being. The following section will address each of these needs in turn, exploring some of the salient problems identified by parents.

01

Education and Care

Broadly speaking, there are six main pathways available through either the public or private education systems for children with special needs in Malaysia, five of which are relevant to children with autism (see Table 1).

It is important to note that the following issues raised reflect the unique experiences of the parents interviewed, and are not a comprehensive review of the special needs education sector.

Specifically, parents interviewed were intensely focused on issues of access to education, rather than its quality. This corresponds to their experience – none of the parents interviewed had been able to successfully place their children in mainstream education beyond kindergarten. The mother from the high income bracket had eventually home-schooled her child, and the other two mothers had enrolled their children in Community-Based Rehabilitation programme, which do not lead to any formal education qualification.

> My two children go to a Pusat Pemulihan Dalam Komuniti these days. To be honest, it really isn't of any use, but JKM requires that I leave them there in order to qualify for the RM150 assistance per child. We need the money, and so we keep sending them. The teachers aren't trained and their pay is really very low – it's only RM800 per month, and so I really can't fault them. But sometimes, they can't even be bothered to make sure that my children are clean. My children are toilet trained, but they display repetitive behaviours and need to be prompted to move to the next step in their routine. That often doesn't happen at these centres.

-Middle income mother (low range)[22]

Table 1: Different Educational Pathways for Children with Special Needs in Malaysia[20,21]

Education Pathways	Administered by	Age range	Targeted towards special needs students?
National Curriculum	Public (MoE)	5 – 17 years	Children who are able to function in a mainstream classroom may attend, but limited resources do not allow for much individualised support.
Modified National Curriculum	Public (MoE)	5 – 17 years	The curriculum is modified mainly for visual and hearing impaired students. Not relevant to children with autism.
Special Education Integration Program (SEIP)	Public (MoE)	5 – 17 years	Special needs classes placed within mainstream school settings. Teachers have some form of special needs training. Children with different learning difficulties are typically grouped together.
Program Pemulihan Dalam Komuniti (PDK) or Community-Based Rehabilitation Programme	Public (JKM)	5 – 40 years	These centres provide day care, as well as some forms of therapy and/or life skills training.
International/ Private School	Private/ non-governmental management	Varies by school	Students attend regular classes with or without the help of a shadow aide, depending on their needs. Admission policies and degree of support provided vary from school to school.
Learning Centres/ Other Organisations	Private/ non-governmental management	Varies by organisation	Privately run centres or home-schooling centres that cater for children with special needs.

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[20] Stakeholder interviews conducted by author.

[21] Data Pendidikan Khas 2013, Special Education Division, Ministry of Education. Cited in 'Overview of Special Education in the Malaysian National Education System'. PEMANDU. 2015.

[22] Brief stakeholder interviews were conducted by the author with several families. However, in-depth interviews were only conducted with three selected families - one each from a high, middle and low income range.

Shortage of Qualified Teachers

From small private centres all the way to the largest international schools, the demand appears to be growing much faster than educational institutions' ability to handle and accept children with autism, resulting in a well-documented shortage of qualified special needs educators[23]. Across all types of educational settings, teachers and parents interviewed noted that many teachers they had encountered lacked sufficient training and support to cope with the rising demands of special needs education. As a result, in almost every setting, parents described long waiting lists and difficulty in securing a place for their child.

To cope with the lack of qualified educational support, all the mothers interviewed from different income backgrounds had made drastic changes in their careers, either by giving up their jobs to devote themselves to full time caregiving, or switching to careers in special needs education to be able to better provide for their child. Amongst more affluent parents, a surprisingly common response to the frustration of navigating the educational sphere was to establish privately owned special needs schools or centres that would cater to their child's needs.

Objections to Inclusion

Currently, only about 6 percent of students with special needs in Malaysia are enrolled in inclusive programs[24]. A common observation from parents and educators alike is that many parents of typically developing children react negatively to the idea of inclusive education. Perhaps due to the heavy emphasis placed on test scores that is deeply rooted in the Malaysian context, a frequent worry voiced by parents of typically developing children is that special needs children will "slow down" or "disrupt" their own children's learning.

These concerns go deeper than mere prejudice or lack of tolerance. There is some evidence that inclusive education, when implemented well, does not impact the learning outcomes of typically developing children, and can in fact lead to greater ability to engage in perspective taking and empathy[25]. However, inclusive education is difficult to put into practice, requiring a high level of skill from teachers, well trained classroom assistants where necessary, and a supportive school environment[26]. When poorly implemented, inclusive education can become extremely frustrating for all parties involved. As a result, principals and schools who offer such programs often face intense scrutiny and opposition, and inclusive education exists only for a small proportion of well-resourced schools in the public and private sectors. Until schools are much better equipped to implement inclusive education effectively, these objections are likely to persist.

> At first, for kindergarten, I placed my daughter in SEIP. The teacher that year seemed really dedicated. Then when she went to Std 1, I really felt the difference. She wasn't progressing any more. One day, when I went to visit her at school, I found her just sitting there, by herself, doing nothing. When I asked the teacher what was happening, she just told me she was overwhelmed with too many students and didn't have time to attend to everyone's individual needs. She'd been there all day and hadn't done anything else. I pulled her out that same day and never went back – I found it absolutely unacceptable that someone would treat my child in this manner.

-Middle income mother (high range)[28]

Shortage of Qualified Caregivers

Unanimously, all parents interviewed expressed feelings of being overwhelmed by the intensity of caring for their child. In all families interviewed, the burden of care fell largely to mothers. Fears of their children wandering off unattended, or inadvertently harming themselves or other people generally caused high levels of anxiety. On top of caring for their child, caregivers found that even daily routines and activities were very difficult to carry out, and struggled to find time for themselves and their other children.

None of the three parents interviewed employed a live-in helper, although this is a very common solution amongst middle to higher income families[27]. Even for those who do, this situation is not ideal for caregiving as there is a clear mismatch of skills – the hired help is a stopgap measure that allows parents to better manage day-to-day life, but does not meet the need for high quality care for children with autism. For the low and middle income parents, the main issue with hired help was cost. For the high income parent, there was a lack of trust that untrained live-in help would be able to provide the kind of quality she desired, as well as cost, given that she had many other expenses associated with caring for her child.

Again, the most common response to this gap in services resulted in mothers giving up their careers. Those who could, relied on family members who were able and willing to provide some form of care, but this relief varied from family to family. Formalised respite or replacement care, which would provide trained caregivers for short time periods and allow parents a window of time to do activities without their child, is rare.

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[23] Ministry of Education. "Malaysia Education Blueprint 2013-2025." (2014).

[24] Ministry of Education. "Malaysia Education Blueprint 2013-2025." (2014).

[25] Danish Clearinghouse for Educational Research. (2013). Evidence on inclusion.

[26] Ibid

[27] Stakeholder interviews conducted by author.

[28] Ibid.

02 Healthcare

The public health care system is also struggling to keep up with the growing demand for special needs services. At present, all children who are seen at government health clinics between the ages of 18-36 months are screened for autism, and referred to a specialist for further investigation if there are red flags that emerge in the assessment. Children may also be referred by parents, teachers or general practitioners in private practice.

Shortage of Specialist Care

While parents' perception of the quality of specialist care in the public health system was positive overall, access remains a problem at all levels of income. On one hand, it was encouraging to note that low and high income parents alike spoke positively about various doctors and paediatricians that had made a tremendous difference in their children's lives. However, waiting lists are typically long, going beyond a year for some highly sought after specialists. Parents spoke of a similar problem with hospital based therapy, with long waiting lists for services such as speech therapy, occupational therapy and physiotherapy that many children with autism require. Families typically had little control over the timing and frequency of such visits. Even with private health providers, parents reported similar difficulties in obtaining access.

Higher income parents had many strategies to gain access to the specialist care they require. Willing to pay for service, they opted for private therapy when necessary, and utilised their contacts within the medical profession to skip waiting lists. However, even parents in this income bracket spoke of the prohibitive costs involved in paying for private medical care at this level of specialisation.

Limited Awareness amongst Medical Practitioners

The symptoms of autism spectrum disorders show tremendous variability and are unique to each individual, and hence, require tremendous complexity and sophistication in diagnosis and treatment. The presence of many 'differential diagnoses'[29], that is, conditions distinct from autism that may nevertheless present symptoms that are similar to autism, means that diagnosis is often a complex and challenging task.

In both the public and private sectors, misdiagnosis by general practitioners is a common complaint, especially for less severe cases. Parents and educators interviewed felt that while family physicians generally seemed well equipped to identify and diagnose physical developmental issues, they were often unaware of early symptoms of autism, or dismissive of parents' concerns.

Some parents found even regular health visits unrelated to their children's autism to be challenging, due to the fact that there is little understanding or accommodation of their needs. For instance, children who are hyperactive or extremely sensitive to noise or crowds may find it extremely challenging to wait in a bright, noisy hospital waiting room. Children with autism may respond negatively to simple medical routines, such as having to change clothes, be alone without a parent or receive an injection, and yet parents felt that doctors and nurses across the board rarely took into account these considerations. While some hospital staff made allowance for these families, for instance, by giving them priority, this was not a uniform experience for all those interviewed.

> My son had to do a blood test the other day. The doctor told me to leave the room despite my explanation of his condition. He resisted fiercely, of course. The doctor got bitten eventually! I had warned him several times, but I guess he wasn't listening.

-High income mother

> I've given up on taking them for hospital visits. In the earlier years, I would make sure they made it to speech therapy, etc. My children can't handle crowds, and they can't handle waiting for a long period of time, so it is very difficult to keep the appointments. In the earlier years, I could still just pick them up and put them in the car. But now they are grown, they are stronger than me, so it's a little dangerous I feel. On top of that, I could only get appointments once in 6 months – what's the use of that? Sometimes I would come all the way only to be told that the therapist was on maternity leave or was ill. And so I've really given up on trying to bring them for therapy. Other mothers may have typically developing children that they can leave with friends or family. My family can't handle my children. Even during emergencies, or regular health check-ups, there is no special queue for us – my children have to wait in line with everyone else. When I try to explain to the nurses or even the doctors, they say, "This is standard procedure." I am sick and tired of hearing this phrase and trying to explain that in my case, regular procedures just should not and do not apply to us.

-Middle income mother (low range)[30]

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[29] MOH, American Autism Society http://www.autism-society.org/what-is/diagnosis/differential-diagnosis/

[30] Brief stakeholder interviews were conducted by the author with several families. However, in-depth interviews were only conducted with three selected families - one each from a high, middle and low income range.

03 Family and Community

With such heavy emphasis on the education and health care of children with autism, **fewer resources remain to be devoted to the families of children with autism.** However, such families are faced with tremendous pressures given the demands of raising and caring for an individual with autism, and do require support. Additionally, while there is tremendous potential for the community to play an active role in supporting individuals with autism, a lack of awareness amongst the general public has meant that this potential is largely unrealised. As a result, while parents interviewed were typically strong advocates for their children, they felt unanimously that **the process of bringing their children out was emotionally exhausting.**

Strain on Family

All kinds of pressures arise within a family with a child with autism, and the resulting strain that is often placed on marriages is well documented[31]. Parents of children with autism have to balance the needs of their child, busy therapy schedules, and perpetual financial worries. There may be serious disagreements between parents, and even the extended family, on best course of action. In the initial phases, parents may also go through a grieving process for the fact that their child will never be 'normal'.

In some families, parents without a typically developing child feel strongly compelled to try for another child that is 'normal'. This was an intriguing finding, given that studies show that the risk of autism recurring in siblings is estimated at around 2 to 18 percent[32,33]. In two of the three families interviewed, the desire for a typically developing child led parents to try a second and even a third time, leaving them with the responsibility of caring for three children with autism. Part of this seemingly irrational behaviour may be due to the lack of available child care and long term planning – parents may feel the need to have at least one typically developing child who will eventually shoulder some of the responsibility for the care of the sibling(s) with autism.

> "Parents of children with autism expressed a feeling of ultimately being alone in their journey."

In any event, families dealing with autism require many different kinds of support. At all levels, parents of children with autism expressed a feeling of ultimately being alone in their journey. While some parents were encouraged to seek counselling, child care or cost constraints often prevented them from pursuing this option.

> "Parents may also go through a grieving process for the fact that their child will never be 'normal'."

Cultural Issues

Cultural factors play a large role in parents' approach to their children. Considering the interviews were conducted exclusively with urban dwellers, there is a surprising prevalence of superstitious practices that are used in the hopes of 'curing' autism. Across all income groups, ethnicities, and education levels, there were numerous anecdotes of traditional treatments involving rituals ranging from exorcism to animal sacrifices. Often, the conflict between these beliefs and more modern, medically accepted therapies became the root cause of division between parents' preferred approaches. Across all income levels, there were also pervasive beliefs about the causes of autism. These beliefs have their roots in many cultures, and while there is greater awareness and understanding of autism today, ancient practices of exclusion and avoidance continue to influence the response of families and communities to autism. All parents interviewed described some form of social discrimination experienced towards them or their children, from subtle avoidance to more overtly insulting behaviour. Some parents experienced social isolation by other families who believe that the condition might be 'contagious', or bring bad luck. As a result of these cultural realities, even the most well-meaning parents were often intimidated by the stares, comments or even hostility frequently experienced in the larger community.

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[31] Naseef R, Freedman B (2012) A diagnosis of autism is not a prognosis of divorce. Autism Advocate. Fall: 9–12

[32] Ozonoff S, Young GS, Carter A, Messinger D, Yirmiya N, Zwaigenbaum L, Bryson S, Carver LJ, Constantino JN, Dobkins K, Hutman T, Iverson JM, Landa R, Rogers SJ, Sigman M, Stone WL. Recurrence risk for autism spectrum disorders: A Baby Siblings Research Consortium study. Pediatrics. 2011; 128: e488-e495.

[33] Sumi S, Taniai H, Miyachi T, Tanemura M. Sibling risk of pervasive developmental disorder estimated by means of an epidemiologic survey in Nagoya, Japan. J Hum Genet. 2006; 51: 518-522.

Lack of Autism Friendly Spaces

Although community involvement would be considered by most to be an essential part of a balanced life, integration into the community at large presents another major challenge for families with autism. Seemingly simple tasks can become extremely challenging with a child with autism. Waiting in line at the grocery store or the dentist, riding a bus or even going to a restaurant can be highly stressful events for the child with autism that often trigger behaviours seen as 'strange' by the general public.

Many simple changes would enable more families with autism to successfully navigate a space, but in the experience of parents interviewed, very few businesses or institutions currently put these measures into place.

Ironically, many of the changes that would make a business more autism friendly involve relatively low costs[34]. Some potential changes include an express queue for those with special needs, clear signposts and labelling, or the provision of accurate waiting times and flexibility to alter the lighting or music upon request in places such as restaurants or banks[35]. Other suggestions include making available gluten or casein free food for those on specific diets (frequently recommended for those diagnosed with autism spectrum disorders) on restaurant menus or at events.

> “Many of the changes that would make a business more autism friendly involve relatively low costs.”

Some people think it's bad luck to see a person with autism when you are pregnant. When my neighbour was pregnant, she mostly stayed inside. If she saw me approaching, she would go back in to her house. My sister came over and when I told her about it, she said "You're joking!" I said – "I'll show you again," and we went back outside. Sure enough, like clockwork, she went back into her house.

-High income mother

'After 6 years, the doctors told us we could try for another child. We tested both our blood samples to check for genetic defects – the blood was sent to Singapore. Then we had her, and she seemed normal for a while, but at 1.5 years, there were warning signs, and sure enough, our third child was diagnosed with autism. Some years later, I started a difficult conversation with my husband. You know men – they want normal kids at the end of the day, and it's difficult for them to accept having three children with autism. I suggested he re-marry, and so we started the divorce proceedings and I moved into low cost housing. We are still friends, and he still provides whatever financial support he can. His mother still takes care of the children on a daily basis, which is a tremendous help to me. But it's true – many parents of children with autism end up splitting up. The pressure is overwhelming, and for some families, it's just too much.'

-Low income mother

'My husband and I disagreed from the very beginning about the best way to approach helping our child. We lived with our in-laws at the time, who kept convincing him that I was wasting our money, that therapy was pointless. The little money we had for her treatment, they wanted to spend on paying a bomoh instead. I think he was in denial really – after all, to commit to therapy meant to acknowledge our child's condition, and he just couldn't do it. Our marriage only lasted two years after that. Our views were just irreconcilably different.'

-Middle income mother (high range)[36]

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[34] Job Accommodation network. (2014). Workplace Accommodations: Low cost, high impact. Retrieved from https://www.disability.gov/resource/workplace-accommodations-low-cost-high-impact-report/

[35] Dimensions. It's not all about wheelchairs and ramps: autism friendly environments. Retrieved http://www.dimensions-uk.org/support-services/autism-care/autism-friendly-environments/

[36] Brief stakeholder interviews were conducted by the author with several families. However, in-depth interviews were only conducted with three selected families - one each from a high, middle and low income range.

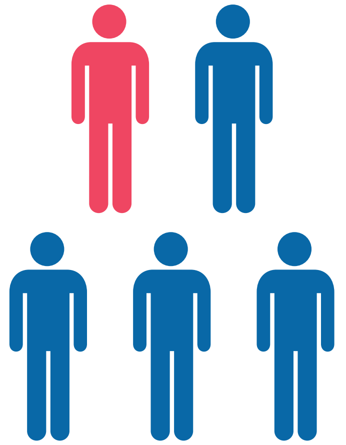
04 Long Term Planning

Most of the support available to individuals with special needs is focused on children, reducing dramatically as they transition into adulthood. This lack of long term support places an immense burden on parents, causing a large amount of anxiety. While the case of Malaysia mirrors a global pattern, there is a tremendous need for a shift towards longer term planning.

Living Independently

Data from the United States indicates that only one in five young adults with autism are able to live independently from their parents.[37] Given the lower levels of support available in Malaysia, it is likely that the national percentage is much lower. To successfully live on their own, individuals with autism often need to have access to some kind of 'supported living' arrangement. This would include options such as living with a group of people with special needs, where support staff also live on the same grounds, or living alone with support staff that regularly visit to provide assistance with living skills such as planning transportation, budgeting or a weekly menu. At present, these options are not available in Malaysia – and as a result, parents shoulder the burden of supporting individuals with autism far into adulthood.

This issue raises the question of how parents interviewed were planning for a time when their children would no longer have their support. Higher income parents were typically setting aside part of their income in anticipation of the time when they will no longer be able to care for their children. However, they were generally uncertain as to what the future held in store. Thus far, they had been unable to find homes that would, as one mother put it, "provide even basic dignity as a human being, let alone development and education." Lower income parents had no answers. Across the income spectrum, mothers interviewed expressed the hope that they would outlive their children.



In the United States only 1 in 5 young adults with autism is able to live independently from their parents.

> “To successfully live on their own, individuals with autism often need to have access to some kind of 'supported living' arrangement.”

I knew an adult who had moved back from the United Kingdom, who was on the autism spectrum. He had been able to live independently, in a kind of supported living arrangement. They had individual apartments, but they also had services such as a 24 hour nurse on staff and security. He was able to function there and even keep a job, but it really fell apart when the family moved back. He started a job at a bookstore, but soon after he started, was asked to leave. I guess the employer meant well, but didn't have the expertise to use his strengths. He would probably have done a really good job categorizing things, making sure things were in order, as many people on the autism spectrum tend to enjoy. For employers who are open to hiring staff with special needs, we need to support them with the right training too.

-Special needs educator, serving high income segment

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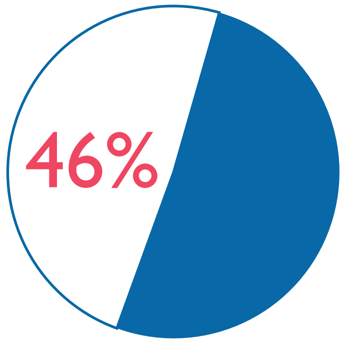
[37] Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

Employment

Currently, some organisations do attempt to provide training and employment opportunities that will allow individuals with autism to work.[38] The Special Education division of the Ministry of Education is beginning to pilot the Employment Transition Program, which will provide vocational training and internships for individuals in collaboration with educational institutions and corporations[39]. Many other centres and organisations have a generic approach to train special needs adolescents in some kinds of work, such as the production of handicraft or artwork. While these attempts provide initial steps in the right direction and should be commended, much improvement is required. A common misconception pertaining to this issue is the belief that all individuals with autism are merely suited towards low skilled, repetitive tasks. In stark contrast to this belief, studies show that approximately 46 percent of children with autism in the United States have average or above average intellectual ability. Additionally, there are numerous examples of individuals with autism who are extremely gifted in certain fields. In spite of this, studies indicate that most individuals with autism who are able to find work tend to find it in low skill, low paying jobs, that is, underemployment is common[40]. There is a need to recognise that autism affects individuals differently, and to varying degrees, and as such, this one-size-fits-all approach is insufficient. While a focus on training for low-skills employment is important for individuals with autism who demonstrate impaired intellectual ability, it ultimately excludes many capable individuals from finding meaningful employment.

While it is important to prepare individuals with autism to adapt to their work environment, it is equally important to prepare employers so that they are able to place individuals with autism in roles where they can experience success, and make the necessary adjustments to their work environments. Small changes, often cost less[41] - for instance, allowing trial work days instead of a conventional interview, or providing written or pictorial instructions - can go a long way in helping individuals with autism[42]. Without these adjustments, it is likely that many well-meaning employers would experience frustration in their attempts, and this would discourage them from hiring individuals with autism in future. At present, there is little training provided to employers, managers and co-workers to equip them for this challenge.

> *"Additionally, there are numerous examples of individuals with autism who are extremely gifted in certain fields."*



Children with autism in the United States have average or above average intellectual ability.

> What will happen when I'm gone? Wow, I don't know. My mind keeps going to a family I knew in Terengganu, where my husband is from. There were 16 children, 15 normal and 1 girl who was intellectually disabled. When the parents died, none of the other siblings wanted to take care of her, so she continued to live on her own in their house. She would go to the mosque and beg for food, and wander around the village. Eventually, she was raped, became pregnant and had a child, who was thankfully adopted. Nobody knows who raped her to this day. She died one day, hit by a car as she was roaming the streets. If this is what happened even with 15 normal siblings, I don't know what will happen to my family. I just thank God I had boys, and honestly, I can only hope that my children go before me.

-Middle income mother (low range)

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[38] iSayang website, http://pmspk.moe.gov.my/

[39] PEMANDU. 'Overview of Special Education in the Malaysian National Education System'. 2015.

[40] Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

[41] Job Accomodation Network. Low Cost, High Impact. 2014.

[42] Booth, Janine. TUC Disabled Workers Committee. 'Autism in the Workplace'.

Key Findings

Returning to the original questions that motivated this research, this section summarises the findings as they relate to the following:

What is the nature of the challenges faced by parents of children with autism?

To what extent do income levels mitigate these challenges?

What are the most pressing problems faced?

01

Parents of individuals with autism feel that they face severe challenges and receive inadequate support in key areas critical for their overall well-being. While many parents demonstrate tremendous strength and resourcefulness in navigating the landscape of autism, **they all expressed the need for greater support from government, businesses and the wider community.** Some of their needs are being met by different providers, both public and private, but there are many gaps in access and quality. In the community at large, there is low awareness of autism, and hence, a low level of support.

In terms of education and care, access to educational services is increasing, but there is still a **severe shortage of qualified professionals.** The absence of respite care places a huge burden on caregivers, particularly those who cannot rely on support from family or hired help. A negative perception of inclusive education by the general public can alsobe a challenge that hinders access to education. While specialised care is available in the healthcare system, **waitlists are long and the cost for private care is still prohibitive.** Additionally, while individuals with autism require specific accommodations, awareness amongst medical practitioners generally is low, causing difficulty in obtaining even routine medical services.

Caring for children with autism also places tremendous pressure on families, who struggle with strained relationships as well as pervasive cultural beliefs about autism. In society at large, there are an **insufficient number of public spaces and businesses that take into account the needs of individuals with autism.**

02

Higher **income mitigates only some of these challenges It is undeniable that income plays a strong role in enabling parents of children with autism to access support.** Wealthier parents could better afford to pay for private services, stop working, employ help and pay for support that reduced the burden of living with autism. They were also better able to use their connections to navigate the system, for instance, gaining quicker access to specialists in the public health system.

However, income could overcome the challenges faced only up to a certain point. For instance, some services, such as widespread gluten free options for food, or supported living arrangements, are not available even to those willing to pay. Additionally, **prevailing attitudes and community awareness are important aspects of support that cannot be purchased.**

03

The lack of services for adults with autism is a critical gap in the current provision of services. Long term planning and provision of services to individuals with autism is currently the most poorly served need of families with autism. Arrangements to support independent living of adults with autism is currently non-existent, and parents generally do not have options available to plan for a time when they can no longer care for their children. **Employment opportunities are often limited to menial, low skill tasks,** which may be suitable for some individuals but does not match the ability of many individuals with autism of above average intelligence. This gap is a source of major anxiety for families at all income levels.

Recommendations

While the following is not an exhaustive list, the recommendations below should take priority in the attempts to address the issues faced by families living with autism:

Recommendations to address the issues faced by families living with autism

- Training and awareness for a wider audience
- Provision of more comprehensive forms of care
- Targeted and flexible financial assistance

01 Training and awareness for a wider audience

> Shortage of well trained teachers and aides is the most pressing problem.

Across all segments of society, a key issue that requires significant attention is that of the need for increased awareness and skills to deal with the challenges of autism. In the education sphere, the shortage of well trained teachers and aides is the most pressing problem highlighted by parents, and while this remains a significant problem, has already received much attention. There is, however, a need to widen the pool of autism awareness. In the health sector, there appears to be a need for such initiatives to target all medical practitioners, rather than those specialising in autism. One example of this is the Center for Disease Control and Prevention in the United States, which offers extensive online training, downloadable curriculum, facilitator's guides and videos dedicated to educating medical practitioners about autism. Businesses should also be able to access training and guidance on how to become autism friendly employers. Such services are offered by numerous organisations abroad, such as the National Autistic Society in the United Kingdom, but are not widely available in Malaysia.

02 Provision of more comprehensive forms of care

> Respite care is a key element that is absent from the Malaysian autism landscape.

While a limited range of options are currently available to parents, there is a need for more comprehensive and longer term solutions. Respite care is a key element that is absent from the Malaysian autism landscape, but is a standard feature in the infrastructure of many other countries. For instance, under the benefits available through the United Kingdom's National Health Service, carers can request a trained caregiver to relieve them for a few hours at a time, and this service is often offered free of charge, or at a subsidised rate. Government incentives or corporate funding to establish such centres or extend the services of existing providers would provide a much needed catalyst for this particular demand. Such providers could specialise in autism or even serve individuals with different types of needs, hence catering to a wider market. Similarly, incentives to establish longer term care solutions for individuals whose parents who can no longer care for them is essential. Both public and private provision of these services would help to alleviate these problems.

03 Targeted and flexible financial assistance

Because the ability to mitigate the effects of autism and seek quality services differs so clearly across income groups, it would be beneficial to offer some kind of targeted assistance to families with autism. Rather than limit low income parents to public services, vouchers for private services could also be provided. This is particularly important in widening the available choices for such parents, given the wide range of services available. Flexible allowances, rather than those tied to specific services would be preferable, allowing families to prioritise the services most vital given their specific situation. Examples of this are the Carer's Allowance in the UK, which provides a means tested allowance to those engaged in full time caregiving. Another example is the Personal Independence Payment, which is a means tested allowance that takes into account an individual's daily living and mobility needs, but does not tie the allowance to the utilisation of related services, hence allowing for choice and autonomy in how this benefit is allocated.

> Rather than limit low income parents to public services, vouchers for private services could also be provided.

Conclusion

While autism may currently seem to affect only a small proportion of the population, it is important to acknowledge that it is likely to become an increasingly widespread concern in the near future.

It is imperative that businesses, government and individuals respond in a way that safeguards the dignity and well-being of this community, but also, creates an environment that empowers these valuable members of society to maximise their potential.

Acknowledgement

IDEAS would like to thank Dr. Fauzi Ismail, Consultant Child & Adolescent Psychiatrist for her feedback and comments at the drafting stages of this paper.

Appendix A

Income Bracket	Estimated Income Levels (per capita/ month)	Number of Children	Number of Children with Autism
High	RM4,000 - RM6,000[43]	2	1 (second child)
Middle	RM800[44]	3	3
High	RM200[45]	3	3

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[43] Author's estimate based on average salary for reported profession, property value and education levels.

[44] Disclosed by person interviewed.

[45] Disclosed by person interviewed.

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