

UNDERSTANDING MALAYSIAN PARENTS' EXPERIENCES IN
OBTAINING DIAGNOSIS, CAREGIVING AND EDUCATING
THEIR CHILDREN WITH AUTISM SPECTRUM
DISORDER (ASD) TOWARDS
INCLUSIVE EDUCATION

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INCLUSIVE EDUCATION**

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Doctor of Education

Cluster of Education and Social Sciences
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DECLARATION

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I hereby declare that this dissertation is the result of my own work, except for quotations and summaries which have been duly acknowledged.

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ABSTRACT

Inclusive education is the way forward for special education needs students in the 21st century and children with autism spectrum disorder are among the most difficult of special education students to handle. In order for inclusive education to be successful for this group of students, parent-teacher collaboration and cooperation is essential. It is therefore most important for teachers and parents to understand each other. The objective of this study is to explore parents' experiences in obtaining a diagnosis, caregiving and educating their ASD children as well as their future aspirations for them. This is to enhance mainstream as well as special needs educators' understanding of parents who often face a psychological loss termed ambiguous loss which can result in family crisis when their child is diagnosed with autism spectrum disorder (ASD). The intended study is a qualitative study and will be done through face to face interviews; asking parents caring for their ASD children open questions on the four areas in order to obtain rich and thick data. The data obtained will be transcribed and analysed via phenomenological analysis in order to provide the unique perspectives of Malaysian parents in these four areas.

Keywords: ambiguous loss, family crisis, inclusive education, parent-teacher collaboration and cooperation.

**MEMAHAMI PENGALAMAN IBUBAPA BAGI MENDAPATKAN
DIAGNOSIS, MENGASUH DAN MENDIDIK ANAK-ANAK
DENGAN AUTISME (ASD) UNTUK TUJUAN
PENDIDIKAN INKLUSIF**

ALLAN HON CHEN U

ABSTRAK

Pendidikan inklusif ialah cara terbaik untuk pelajar keperluan khas mara ke hadapan dalam abad ke21 dan kanak-kanak dengan autisme merupakan golongan pelajar khas yang paling sukar diajar. Untuk pelajar-pelajar ini berjaya di dalam pendidikan inklusif, kerjasama antara pihak ibubapa dan guru-guru sangat diperlukan. Oleh yang demikian, persefahaman antara golongan guru-guru dan ibubapa adalah sangat penting. Matlamat kajian ini ialah untuk meneliti pengalaman ibubapa dari segi mendapatkan diagnosa, mengasuh dan mendidik anak-anak mereka yang mengidap autisme dan juga aspirasi ibubapa untuk masa hadapan mereka. Kajian ini bertujuan untuk meningkatkan tahap pemahaman pendidik-pendidik arus perdana dan juga pendidik-pendidik keperluan khas mengenai tekanan psikologi kehilangan yang dinamakan ‘ambiguous loss’ yang sering dialami oleh ibubapa dan boleh menimbulkan krisis keluarga bila ibubapa menerima diagnose autisme. Kajian ini ialah satu kajian kualitatif untuk mendapat matlumat terperinci melalui temuduga bersemuka yang dipandu oleh 4 soalan terbuka untuk 4 bidang yang ditinjau. Maklumat yang diperolehi dalam bentuk audio dipinda ke dalam bentuk teks dan dianalisa melalui analisa fenomena untuk mendapat perspektif unik ibubapa Malaysia di dalam 4 bidang ini.

Kata Kunci: kehilangan yang samar-samar, krisis keluarga, pendidikan inklusif, kerjasama antara ibubapa dan guru

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LIST OF ABBREVIATIONS

| | | |
|---------|---|--|
| ABA | - | Applied behavioural analysis |
| ADHD | - | Attention-deficit Hyperactive Disorder |
| ASD | - | Autism Spectrum Disorder |
| BAP | - | Broader autism phenotype |
| CDC | - | Centres for Disease Control and Prevention |
| CRC | - | Convention on the Rights of the Child |
| CRPD | - | Convention on the Rights of Persons with Disabilities |
| DSM | - | Diagnostic and Statistical Manual of Mental Disorders |
| IDEA | - | The Individuals with Disabilities Education Act |
| MEB | - | Malaysian Education Blueprint |
| MOE | - | Ministry Of Education |
| MOH | - | Ministry Of Health |
| MOWFCD | - | Ministry Of Women, Family and Community Development |
| PECS | - | Picture Exchange Card System |
| PDD-NOS | - | Pervasive developmental disorder not otherwise specified |
| SEN | - | Special Education Needs |
| UNESCO | - | The United Nations Educational, Scientific and Cultural Organisation |
| UNICEF | - | The United Nations Children's Emergency Fund |
| USA | - | United States of America |

CHAPTER 1

INTRODUCTION

1.1 Background of the Study

Inclusive education is becoming a global trend now. Quoting Mitchell (2010), *“In almost every country, inclusive education has emerged as one of the most dominant issues in the education of students with special education needs. In the past 40 years, the field of special needs education has moved from a segregation paradigm through integration to a point where inclusion is central to the dominant discourse.”* Malaysia is of course, following suit. This is evidenced by the Malaysian National Education Blueprint 2013-2025, in which there are plans to have 75% of all special needs students in the inclusive education program by 2025 (Ministry of Education, 2013). The rise in inclusive education indicates that there is a near global agreement that it is an important cause to pursue although it needs to be implemented well in order to be effective.

Many countries have shown that they are receptive in principle to the concept of inclusive education through international conventions and agreements formulated by the United Nations namely the Convention on the Rights of the Child (CRC), the Convention on the Rights of Persons with Disabilities (CRPD) 2006 and the Salamanca Statement 1994 by its agency UNESCO. These initiatives promote the call for equal opportunities in education for all children as a basic human right and on the principles of equity. The governments of many countries following these agreements have formulated policies and legislations that promote inclusive schooling to ensure that all children are able to get an equitable education. For example, according to Whalon and Hanline (2013), more than

50% of all children with disabilities were excluded from the public education system in the United States of America (USA) prior to the enactment of the Education for All Handicapped Children Act 1975 and the Individuals with Disabilities Education Act (IDEA).

The main reason why inclusive education has become important is that the world has become very advanced technologically and these technology advancements has changed the way lives are lived. As the world becomes increasingly smaller due to connectivity, the acceptance of diversity and ensuring equal rights to all irrespective of differences has become very important as human rights issues to ensure fairness, kindness and peaceful living. The 21st century has brought different challenges and the acceptance of diversity is one important component of 21st century education. Academic learning in the 21st century is no longer about memorising facts and passing examinations as it encompasses and emphasizes collaboration, cooperation and communication. The attainment of soft skills is therefore very important to all students in the 21st century. To this end, education has become student-centred and individualized. Knowledge is constructed, differences in perceptions is acknowledged and appreciated and context is emphasized. All in all, inclusive education epitomizes the concept of 21st century needs and skills.

Inclusive education is therefore now a necessary component of 21st century education as it provides both able and disabled students opportunities to learn together and to interact closely, leading to better understanding and appreciation of human diversity. To educate the young to become more accepting of diversity, theory alone is not enough. Practice and real life experience is important and this can be achieved by the implementation of inclusive education. All students can therefore benefit from inclusive education. However, inclusive education is not easy to implement and it takes a lot of

effort to make it a success. Therefore, educators, parents and students must come together and work together so that inclusive education can be implemented successfully.

Another reason for the implementation of inclusive education is that the prevalence of learning disabilities, especially Autism Spectrum Disorder (ASD) is increasing every year. According to Boat and Wu (2015), autism prevalence studies conducted around the world has shown a dramatic increase. It is estimated that the prevalence of autism spectrum disorder (ASD) has increased by 30 fold in the United States of America (USA) from the time the first studies were conducted on autism in the 1960's and the 1970's until 2002. The current prevalence in the USA is estimated at 1:68 (CDC, 2015). There is no confirmed prevalence rate in Malaysia but the increasing trend is similar worldwide. Yeo and Teng (2015) mentioned that the Ministry of Health revealed that the prevalence of children with ASD in Malaysia is on the rise. Based on this trend, children with ASD will form the largest proportion of special education needs (SEN) children entering public schools all over the world. Many parents are not financially able to afford private intervention facilities, as they are very expensive. Private intervention facilities, even when available are also limited and concentrated in urban areas.

According to Lavelle, Weinstein, Newhouse, Munir, Kuhlthau, and Prosser (2014), educating an ASD child in the USA costs \$17,000 more per year than educating an average child. The economic burden associated with ASD is therefore substantial across multiple sectors of society especially in the education sector. Education is treatment for ASD children, as they need to be taught everything. Segregated learning has not been proven to be effective in the long term for these students, as they need communication skills and people skills the most in order to be functional and employable.

Inclusive education is therefore most important as it has been proven that it helps improve communication skills in ASD students and helps them fit better into society.

In Malaysia, there are laws that protect the rights of all children to obtain appropriate educational opportunities, e.g., the Education Act 1996. Based on the Ministry of Education's (MOE) lofty targets in the Malaysian Education Blueprint, the Malaysian government has not lost any time in showing that it is giving priority to the needs of the disabled. The latest Education (Special education) Regulation of 2013 revokes the earlier Special Education Regulation of 1997 which restricted entry to the National Special needs Education System to only children with special needs who were deemed 'educable' (UNICEF, 2014 June). However, in spite of policy shifts made to the Malaysian education system through the adaptation of international conventions and fine tuning local legislations towards inclusive schooling, the implementation and practice of inclusion has been rather slow in moving. This is because there is a lack of special education teachers, general curriculum teachers trained in including special needs especially ASD students (Mohamad Razali, Toran, Kamaralzaman, Mohamad Salleh and Mohd. Yasin, 2013; Gavalda and Tan, 2012; Saad, Ibrahim and Nayan, 2013), teacher aides and the usual inertia and uncertainty when people are faced with change.

Currently, students who are severely disabled and considered not able to benefit in a school-based system are educated in community-based rehabilitation centres under the Ministry of Women, Family and Community Development (UNICEF, 2014). Other children with disabilities in Malaysia are educated under the MOE through three options, which can be visualised on a continuum depending on the individual's abilities. These options are

1. Separate special education schools (which translates into total segregation)

2. Integrated programs in mainstream schools (which translates into sharing of infrastructure but otherwise segregated)
3. Inclusive programs ranging from partial to full inclusion (which translates into SEN students in some or all mainstream classes where appropriate)

Although there is an emphasis on inclusive education being the best option, Jelas and Mohd. Ali (2014) explained that the Malaysian Education System looks at placement of SEN students in inclusive education from the perspective of eligibility rather than individual's right and need. This easily gives teachers the right and the ease to avoid inclusion and push students into the older system of integration. In a study by Lee (2012), partial or full inclusion is not usually practised and the main method of delivery of special education services in Malaysia is still through integrated programs. Yap (2014) mentioned that in spite of 1742 schools offering inclusive programs and more than 58,000 SEN students needing inclusive education, the enrolment in inclusive programs in regular schools is still low. This can be evidenced by 2017 statistics in the Data Pendidikan Khas 2017 by the Ministry of Education Malaysia, which states that from the grand total of 79836 SEN students, only 15,480 (19.39%) are in inclusive programs in mainstream curriculum while 61,933 (77.58%) are in integrated programs.

From the aspect of academics, special needs schools and integrated programs are not lacking for the intellectual development of SEN students. However, there are two main weaknesses in these two options that can be remedied by inclusion. These two options are generally

1. Inadequate to get SEN students job-ready and society-ready.
2. Inadequate to get employers, peers and the rest of society mind-set ready.

In Malaysia, as in many other countries around the world, many people with disability are living below the poverty line as they are unemployed or are doing menial work. According to the United Nations (2007), globally, unemployment among the disabled of working age ranges from 80% to 90% in developing countries and 50% to 70% in industrialized countries. One of the reasons for this predicament could be because people with disabilities do not have enough skills to meet the requirements of the job market. The education system for SEN students therefore, needs to be improved to enhance job-readiness. Being educated separately isolates SEN students and makes them used to isolation and lower expectations. This does not augur well for SEN students who must be ready to function in the real world where they need to mix, interact and compete with the rest of the world. Many of the SEN students' disabilities can now be, to a certain extent ameliorated by technology and these students need to learn to use technological advances to the fullest extent i.e., in the context of the general environment and not in isolation in order to gain its full benefit. The higher expectations in inclusive programs and the abundance of role models will condition and motivate SEN students to learn more, perform better, get better qualifications, be more enterprising and fit better into social and work life.

Many people who have not had the experience of working with people with disability tend to doubt their capabilities even when they have the required qualifications. Segregation of SEN students do not protect them from biases of employers and peers when they reach employable age. Instead, it conditions society to think that they are incapable. Segregation promotes the medical model of disability, which posits that disability resides within the individual. The focus of this model is that the person is abnormal with limitation and weaknesses that needs to be fixed. Shifting towards the social model of disability enables society to realize that impairment is more of a social

construction where barriers imposed by society hinders full participation of people with different abilities (Bricout, Porterfield, Tracey and Howard, 2014).

Continuing different types of education for 'different' students perpetuates stratification of society and stigmatization of people with disability. This will ultimately cause discrimination towards people with disability. Many people with disability have the qualification and the capability but they are often discriminated against in terms of employment because of preconceived and out-dated thinking. In order to change the mind-sets of future employers and peers, typical students need to be exposed to working with SEN students through the use of inclusive education. With the growing numbers of students with ASD, inclusive schooling provides them and others with disabilities not only the appropriate academic credentials to get employed but also the appropriate experience of working with non-disabled peers in order to be able to fit into society, enjoy independent living and be contributors to the community (Khoo, Ta and Lee, 2012).

However, in order for inclusion programs to be successful in schools, students with special needs must be at a level that inclusion can be successful. This requires early diagnosis and intervention at an early age. In Malaysia however, there is an under-diagnosis of special needs. This is reflected in the data of the number of people with disabilities in Malaysia, which is very low compared to the estimates of people with disability in other developing countries in the world. According to the Malaysian Education Blueprint 2013-2025, The United Nations estimates that an average of 10% of a developing country's population lives with a disability. In Malaysia however, only about 1-2% of the population has been identified as having special needs and are enrolled in suitable special education programmes. The estimated total population of Malaysia in 2017 is 32.0 million (Department of Statistics Malaysia, July 31 2018) out of which

453,258 are people registered with disability (Department of Statistics Malaysia Official Portal, November 29, 2018). This accounts for only 1.42% of the population.

According to statistics, the proportion of students with special needs in the Malaysian education system as compared to people with disability is also dropping. From available data between years 2015-2017, although the number of people with disability and the number for SEN students have steadily increased, there has been a steady decrease in the proportion of SEN students to people with disability. The data is shown in Table 1.1

Table 1.1 Data on number of special needs students and number of registered people with disability in Malaysia from year 2015 to 2017

* Data Pendidikan Khas (2015, 2016, 2017) Kementerian Pendidikan Malaysia

** Laporan - Statistik Jabatan Kebajikan Masyarakat (2015, 2016, 2017)

| Year | Number of special needs students (SEN)* | Number of people with disability (PWD)** | Percentage of SEN to PWD |
|-------------|--|---|---------------------------------|
| 2015 | 72715 | 365677 | 19.89% |
| 2016 | 76166 | 409269 | 18.61% |
| 2017 | 79836 | 453258 | 17.61% |

This could be due to a few reasons. It could be an indication of under-diagnosis of SEN students. Parents may not know that their children have special needs (Teoh, Cheong and Woo, 2010) as a learning disability may be invisible. This possibility is likely because as noted by Chu, Mohd Normal, McConnell, Tan and Joginder Singh (2018), parents lack knowledge about ASD and as such, may not know that their children have it. There is also a possibility that young people with special needs are not being enrolled in the Malaysian education system for some other reason or that they have dropped out of school because the system could not fit their needs. This is supported by Koh's (2017) report which mentioned that of the 15,484 people with ASD registered with the social welfare

department (JKM), school-going age children between the ages of 7 to 12 years was the largest group. In addition, Koh also stated that this total number of persons with ASD is very low as many more are not registered with the JKM. Parents are usually the ones who enrol their children and they are also the ones who withdraw their children. As such, parents are the ones who can provide the information as to the reason why they are not enrolling their children or why they are taking out their children from schools. As ASD students are the hardest ones to educate inclusively (Mereoiu, Bland, Dobbins and Niemeyer, 2015) due to their difficulties and uniqueness (Delmolino and Harris, 2011; Morewood, Humphrey and Symes, 2011; Whalon and Hanline, 2013; Yeo, Chong, Neihart and Huan, 2014), they are usually the ones who are not enrolled or are the ones removed from schools by their parents. Parents are seen as experts on their own children and as such, good teacher-parent communication and collaboration together with adequate support and information on education program, enables them to provide appropriate early intervention; generalise teaching and learning out of school and emotional support for their children (Gravalda and Tan, 2012; Wong, Ng and Poon 2015).

Successful teams in implementing inclusive education in many countries have admitted that one of the key factors needed in implementing inclusive education is a close parent-teacher collaboration (Whitbread, 2004; Porter, 2015; Afolabi, Mukhopadhyay and Nenty, 2013; Hussin and Hamdan, 2016; Adams, Harris and Jones, 2016). Cooperation and co-teaching in schools among staff and teachers must be complemented by close school-home cooperation as well and this is something that is very difficult to achieve because parents do not understand educators and vice versa. Parents' involvement in their children's education is often limited because of perceptions of indifference and discrimination (Afolabi et al., 2013). Frustrations in getting a diagnosis and appropriate interventions often precede these perceptions (Okeke and Mazibuko,

2014) and conflict arise due to divergent perspectives about the child's needs (Elkins, Van Kraayenoord and Jobling, 2003).

Therefore, this study aims to look at parents' experiences in getting a diagnosis, caregiving, and educating their ASD children and their future hopes for them. It is by understanding parents that educators can get a clearer view of how to work with parents in order to improve the implementation of inclusive education.

1.2 Problem Statement

Inclusive education has been found to be beneficial for all students and has become a global trend in the 21st century. Studies conducted over the past 30 years have demonstrated that both SEN students and typical students when educated together in regular classrooms show improved academic performances (Teigland, 2009). Other than academics, typically developing students also get a better understanding of social justice and acceptance of diversity while students with disabilities such as ASD show more improvement in social behaviours because of the high expectations placed on them. As such, some countries like Finland and Ireland have fine-tuned their education system enabling them to move towards a nearly full inclusion ideal (Järvinen, 2007; Lombardi, 2005; Yeo et al, 2014). For other countries however, full inclusion has been elusive (Lee, 2010; Yeo et al, 2014, Afolabi et al, 2013; Lazarević and Kopas-Vukašinović; 2013) and the term inclusive schooling has been given a broader meaning due to the variation in practices in different countries (Sebba and Ainscow, 1996; Yeo et al, 2014). Many countries especially developing ones still use a dual education system to educate students with disabilities including ASD. Students with severe forms of ASD are educated in separate schools and those with milder disabilities in regular schools.

In Malaysia, inclusive education is still new and there are very few studies on it. Malaysia is however committed to the idea of inclusion as evidenced by the Malaysian Education Blueprint 2013-2025. From the aspect of infrastructure, Malaysia seems prepared for inclusive education. This is because government-supported schools and health centres are located even in remotest areas of the country and the Malaysian Government provides a lot of support in terms of financial budget to these two sectors. The number of students with disabilities especially those with learning disabilities, enrolled in the Malaysian education system is also increasing and it is assumed that the number of children with ASD within this group is on the rise following the global trend. However, the enrolment of students with special needs into inclusive education programs in Malaysian schools has not been encouraging. A UNICEF study authored by Moore and Bedford (2017) found that the structure of the Malaysian school system which emphasized the key performance indicator (KPI) evaluation system for schools discriminatory and puts children with disabilities at a disadvantage. Head teachers and teachers want the best results from their students in public exams and as such, do not want students with disabilities in their school. This is more so for students with behavioural and mental issues. The UNICEF study also noted that some special education teachers are of the opinion that inclusive education is not working and that many mainstream teachers lack self-efficacy when dealing with special needs students. Although there are no specific numbers, one can safely conclude that inclusive education is not working well in the Malaysian education system especially for the group that is most difficult to teach – the children with ASD. According to Lee (2018), although NASOM has estimated that the number of autistic individuals in Malaysia number about 300,000 with many more undiagnosed and unreported, there is less than 16,000 autistic individuals registered with the social welfare department indicating that many Malaysian

children with ASD are missing out in the inclusive education program. This is most perplexing because most parents of children with ASD realise that inclusive education is preferable for their children so that they can fit better into society (Elkins et al., 2003).

There are many challenges and issues faced by educators in running an inclusive program. As these students are included into mainstream classes, all teachers will need to be knowledgeable in how to manage them in the class and to get the best results possible from them. For secondary schooling, some parents although preferring inclusive education than segregation are worried that the special education teachers may not be able to support students well and may not communicate the child's needs to mainstream specialist teachers and families (Stokes and Macfarlane, 2011). Parents are largely dissatisfied with the ineffective communication system in secondary school and this concern is not without basis. Many teachers lack training in special needs and do not feel eager to take on special needs children especially those who are difficult to handle, i.e., those with ASD. Abdul Nasir and Erman Efendi (2016) found that special education teachers in Malaysia lack training and resources for teaching students with special needs. These two authors mentioned that 85% of special education teachers experienced moderate to high emotional distress due to the challenging behaviours of students with special needs, their own internal conflict and the perceptions from mainstream teachers and the administrative leadership. Many already feel pressured by the change to the constructivist student-centred teaching (from teacher-centred teaching) (Brooks and Brooks, 2001) and do not want to take on additional challenges. They feel that the old system of segregation is easier for them as it removes these students from their responsibilities. Studies have shown that teachers generally do not have enough confidence to take on the teaching of ASD children and parents are even less certain of the teachers' abilities to handle ASD children (Seggers, 2016). In a Malaysian study by

Low, Lee and Che Ahmad (2018), preservice teachers were reported to have minimal to moderate knowledge of ASD and lack knowledge about specific strategies to teach language and communication skills to students with ASD. However, many teachers who teach ASD children do not want to admit their difficulties especially to parents of the children they teach and prefer to ignore parental input. This denial is detrimental to inclusive programs. It should be noted that many parents have done their homework on educating their ASD child and may not only be more knowledgeable about the ASD child but also more knowledgeable in the methods to teach the child (Reupert, Deppeler and Sharma, 2014).

One however, does not need rocket science knowledge to teach ASD or other learning-disabled children for that matter and although there are many success stories in inclusive education programs, Hussin and Hamdan (2017) noted that implementation of inclusive education programs for Malaysian special needs children is hampered because the acceptance of teachers and students for inclusion into mainstream classes is slow in coming. The problem with ASD children is that their behaviour is varied, unstable and difficult to predict. Many have sensory issues that teachers do not have much knowledge about and do not have time to cater for. Solving or minimizing sensory problems will reduce problematic behaviour and make teaching and learning much more successful. Evidenced-based strategies that facilitate the presence, participation, acceptance and achievement of ASD students in mainstream education include challenging stereotypes, raising expectations, promoting peer understanding, developing social skills, adapting academic subjects and modifying conversational language (Humphrey, 2008). This requires a deeper understanding of the ASD child which can be acquired only through empathic and effective communication with the parents and the child. Ultimately, parents play a key role in ASD treatment as they are the ultimate experts on their children's needs

(Gavaldá and Tan, 2012). ASD students tend to compartmentalize their learning and are unable to generalize what they learn in school in other environments. Therefore, the hallmark of a successful inclusion program is one that transfers gains in school to the home and vice versa. As such, there is a necessity for reciprocal teacher-parent communication and cooperation.

Studies have shown that success in inclusive education have certain characteristics. The first is the early intervention program, which needs to start as early as possible so that communication and social issues in ASD children are tackled early. This intervention prepares students to become more able to communicate their needs and thus reduces social problems arising from the child's frustration due to the inability to convey his / her needs. The second is a holistic method where education encompasses all aspects of child development and not just the academics. This not only requires multidisciplinary approach but an entire school commitment to the child. The third is a close parent-teacher collaboration. Among these three characteristics, the close home-school relationship is seen as the most important because they pave the way for the other two characteristics (Schwartz, Billingsley and McBride, 1998).

However, in Malaysia, when parents and teachers meet, the child is already at school age and early intervention has been delayed. Parents have had a tough time getting professionals to meet their needs in diagnosing, coping and teaching their child for many reasons; one of them being the reluctance of doctors to expedite a diagnosis that may be wrong. Parents have usually been given the run around and by the time the child reaches school age, many parents are already at their wits' end. Many are worried and depressed about their children's future. These issues are hidden, complex and not seen by teachers who sometimes see parents as pushy, neurotic and not knowledgeable. Children with developmental delays and behavioural problems particularly those with ASD whose

parents are optimistic are found to fare better in the long term compared to similar children whose parents are pessimistic (Durand, 2001). This is because parents who are pessimistic about their child are afraid to actively intervene to educate or train their child for fear of aggravating behavioural problems. Parents who are optimistic challenge their child more and intervene more to push their child towards better communication skills. Therefore, parents' optimism may have served as a protective barrier against developing more severe behavioural problems and parents' pessimism as a risk factor for developing more challenging behavioural problems. As such, intervention for parents especially those who are pessimistic is needed to prevent the deterioration of behavioural problems in the child (Durand, Heinemann, Clarke and Zona, 2009) which will negatively affect educational programs. In order to work effectively with parents, teachers must first understand the parents' perspectives by understanding what they have gone through. Understanding the parents' perspectives is important so that teachers can communicate more effectively with parents to understand the child better and get the cooperation of parents to educate the ASD child successfully (Todd, Beamer and Goodreau, 2014)

The intention of this study is therefore to understand parents' state of mind through investigating their experiences in obtaining diagnosis, caregiving and educating their ASD children. The parent's aspiration for their ASD children is also investigated, as this will indicate their preparation for future challenges. It is hope that by knowing what the parents have faced, teachers will understand parental issues better and therefore better able to manage and educate the ASD child. Education is a social endeavour and the teacher's role is not complete by just pushing academic skills. The whole schooling process is important for the holistic development of the child. It is hoped that with better understanding into parents' perspective, teachers and school management with the full cooperation of and collaboration with parents will rise to the occasion to implement

evidence-based effective strategies and provide effective learning environments for the ASD children in their inclusive education program.

1.3 Objectives of the Study

Successful inclusive education requires close parent-teacher cooperation. The family and school community play significant roles in the lives of students with ASD as the home and school environment are the most important spheres of influence on them. Parents face many challenges bringing up their children with ASD. These issues, which may have both positive and negative impact on them and their families, are not usually experienced by others in their community. How parents negotiate these challenges and stresses associated with caregiving will have an impact on their involvement and support towards their children's education. Effective management of these issues will have a positive impact on parents' persevering involvement and support in their children's education. Therefore, the purpose of this study is to gather information on the experiences of some parents of children with ASD within the Malaysian context.

The information collected will give better understanding into several issues from the perspectives of Malaysian parents with ASD children so that educators and parents can cooperate and collaborate more effectively; thereby improving the implementation of inclusive education programs in mainstream classes. Specifically, the objectives of this study are namely to:-

1. Explore parents' experiences in seeking the diagnosis of ASD for their child.
2. Explore parents' experiences and strategies used in caregiving and its impact on their family for better management of their child with ASD.
3. Explore parents' experiences in dealing with the Malaysian education authorities for their children with ASD.

4. Explore parents' aspirations for their children with ASD in the present and future.

1.4 Research questions

To achieve these objectives, semi-structured face-to-face interviews were conducted between the researcher and participants, using an interview protocol with broad open questions relevant to the areas of enquiry namely, seeking diagnosis, care-giving, education and aspirations for their children with ASD. Within each broad open question, are a set of focusing questions to guide the interview process. This is because no one will have better knowledge than the participants themselves regarding their lived experiences and perceptions. The research questions answered by this study are:-

1. Seeking the diagnosis of ASD
 - a. What did the parents have to do to get a diagnosis?
 - b. What was the parent's understanding of ASD at that time?
 - c. How did the parents react to their child's diagnosis of ASD?
 - d. How did the parents cope with the diagnosis?
2. Caregiving
 - a. What did the parents do to get help for their child with ASD?
 - b. What type of treatment did the parents seek and why?
 - c. What methods worked? What methods did not work? Why was it so?
 - d. How does caring for their child with ASD affect others in the family?
3. Education
 - a. How did the parents go about educating their child with ASD?
 - b. What do the parents think they need from the education system?
 - c. What barriers do the parents and their child face?
4. Aspiration for the child with ASD

- a. How do the parents cope with new challenges as their child grow up to adulthood?
- b. How does educating their child now prepare him / her for the future?
- c. What future preparations are the parents making for their child especially for caregiving and education?

1.5 Significance of the study

The importance of this study is viewed from the contribution it will be making to research, practice and theory. The transformation in the way SEN students are educated in Malaysia is shifting towards inclusive schooling as emphasized in the Malaysian Education Blueprint 2013-2025. For individuals with ASD, inclusive education is not only the best way to educate them, education itself is the treatment for ASD. Although many mainstream teachers are experts in education, inclusive education is new in Malaysia and they are not familiar with having students with ASD in regular classrooms. An essential element for inclusive education to be successful is a close parent-teacher collaboration especially for students with ASD. This is where parental involvement comes in as each child with ASD has unique characteristics and their parents know them best.

The information collected in this study provides teachers, school administrators and other parents with some clarification and better understanding of the unique challenges and issues faced by parents of children with ASD. This works to improve openness and trust, facilitate easier communication and develop closer cooperation between teachers, school authorities and parents of students with ASD. The phenomenological approach used in this study gives participants the opportunity to voice out their experiences and be more visible with their story first hand. This in turn gives

policy-makers and school authorities knowledge on the required support, information and appropriate interventions for parents and students with ASD from their own perspectives.

Currently there is a lack of literature on the experiences of parents of children with ASD in Malaysia especially when it concerns planning and managing their education programs. This is supported by Ilias, Liaw, Cornish, Park and Golden (2017) and Neik, Lee, Lau, Chia and Chua (2014) who found that research on ASD was limited especially in Malaysia. Therefore this study serves to add on to existing research and provide views on educating individuals with ASD from their parents' perspectives as studies on the education of students with ASD is often from the viewpoint of the educators themselves. Hopefully this study can stimulate more interest for future research on the educational and psychosocial aspect of individuals with ASD and their caregivers within the Malaysian context; which in turn can provide the relevant authorities with more local information so that appropriate support and programs can be developed in tandem to their changing needs. It is also hoped that this study will promote better understanding of parental issues and concerns by educators so that the needs of ASD students in schools can be met. Effective and empathic communication between parents and teachers will foster close collaboration and cooperation between school and home; the most important pre-requisite for success in inclusion programs.

1.6 Limitations of the study

The limitations of this study is in three areas. This is in sampling, data collection and data analysis. In sampling, the participants consisted of a small group of Malaysian parents of children with ASD (mothers; as fathers did not show up) who were required to meet the selection criteria of having sought diagnosis for their child, were actively involved in caregiving and in educating them. This made the sample unique and specific

to the Malaysian context. As such, one aspect would be findings from this study cannot be transferred to other settings. Since this study was solely dependent on information provided by the participants, the accuracy and depth of the findings depended on the honesty and willingness of the participants to reveal the information requested during data collection. Similarly, during data analysis, the researcher needed to be and was aware of his own biases and prior knowledge on the topic that could influence the interpretation of the findings.

1.7 Operational Definitions

1. Autism spectrum disorder (ASD) or autism is used interchangeably. ASD is a general term that includes autism, Asperger's syndrome and pervasive developmental disorders not otherwise specified. This is based on the DSM-5 (2013) classification.
2. Medical model of disability: This model views disability as residing within an individual. It is defined as an abnormality or a deficit that needs to be cured or fixed.
3. Social model of disability: this model accepts that environmental barriers, negative attitudes and exclusionary practices of society intentionally or inadvertently contribute to the disability in people.
4. The term 'disabled' refers to difficulties encountered by individuals with ASD which are a result of them being 'damaged' or 'broken'.
5. Inclusive education implies that students with ASD and their typically developing peers are educated in age appropriate mainstream classrooms.
6. Special education needs refers specifically to children with ASD who are listed in the multiple disability and learning disability category in the Malaysian Education Blueprint 2013-2025.

7. Diagnosis implies that a child has been professionally certified as having ASD.
8. Intervention refers specifically to the management of education for children with ASD in an inclusive classroom environment.
9. Coping focuses on reactions and responses of parents to everyday challenges involving their children with ASD.

1.8 Summary of Chapter 1

There is nearly a worldwide agreement on the use of inclusive education for educating children with special education needs. This stand is also taken by the Malaysian government as evidenced by the Malaysian Education Blueprint 2013-2025 which aims to have 75% if not all SEN students in inclusive education by 2025. The rapid increase in children with ASD makes them the largest proportion of SEN who are also the most challenging group of SEN for educators. Although inclusive education is preferred for SEN (especially those with ASD) and typically developing students, implementation in Malaysia is slow. However, for children with ASD to succeed in inclusive schooling, early intervention, a holistic approach and a close parent-teacher relationship is required.

Parents of children with ASD are in a unique position as each child with ASD is different, making each parent an expert in their child. At the same time, parents of children with ASD face many challenges in bringing up their children with ASD. Understanding parents based on their own perspectives and experiences in seeking a diagnosis, caregiving, educating and planning ahead for their children with ASD will help educators work with them better to make implementation of inclusive schooling more successful. Currently there is a lack of literature on the experiences of parents of children with ASD in Malaysia especially when it concerns negotiating and managing their education. Therefore, the information gathered in this study will give school authorities

and policy-makers more knowledge on the required support, information and appropriate interventions for parents and students with ASD based on their own viewpoints.

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Informed Consent

Thank you for your participation in this research project. The purpose of this research is to provide future educators in inclusive education with parents' (of children with ASD) experiences in getting a diagnosis, coping with caregiving and educating their children so that educators can be more aware of what is needed to better implement inclusive education. The procedure of the research to gather information is through face to face interviews with parents of older children with ASD. The interview will be audio-recorded and transcribed without revealing the identity of the participant. The benefits of this research will be for future children with ASD in inclusive education and the risk to you as parents is that the interview may make you recall stressful episodes in your endeavours to bring up your child. Please note that participation is voluntary and you can stop at any time. All information collected will be only for academic use and your identity as well as your child's identity will not be revealed in any form.

Thank you.

Acknowledgement

Interview questions

Dear Parents,

The Malaysian Education Blueprint 2013-2025 stated that the Ministry of Education Malaysia aims to have 75% of all special needs students in inclusive education by 2025. Autism Spectrum Disorder students are one of the most difficult of SEN students to educate successfully in an inclusive setting. However, inclusive education is very important because it prepares the public to accept diversity and improves the opportunity for ASD students to be included into the future workforce. Teachers need to work closely with parents for inclusive education to be successful but are not able to do so because they not only do not understand what the ASD student needs and they also do not understand parents' perspectives, needs and experiences. Although teachers may know education best, it is parents who know their children best.

I am doing a study (in the field of education management and leadership) through interviews with parents to better understand parents' experiences with their children with Autism Spectrum disorder so that educators can work better with parents to increase the outcomes of inclusive education. Below is the list of interview questions this research will be based on.

- Can you tell me about your experiences in seeking a diagnosis for your child / children with ASD?
- Can you tell me about your experiences in coping with caregiving for your child / children with ASD?
- Can you tell me about your experiences in managing education for your child / children with ASD?
- Can you tell me about your aspirations for the future for your child / children with ASD?

