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Including Children with Autism Spectrum Disorder in Regular Schools: A Mother's Perspective

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Abstract: Since the implementation of 'Educational Blueprint 2013-2025' and 'Zero Reject Policy' in Malaysia, there are increasingly efforts from the Malaysian Ministry of Education to include students with Autism Spectrum Disorder (ASD) into regular mainstream education. A case study investigation was conducted with a mother with two children with different severity levels of ASD. In a semi-structured interview, the mother described her experiences and aspirations of education arrangements for both her children. Through the eyes of a mother, we find a strong belief that children with ASD could learn like others when given adequate opportunities and learning aids. This unique case study offers an archetypical representation of issues and challenges faced by parents of children with ASD in Malaysia, in advocating for inclusive education for their children.

Keywords: inclusive education, Autism Spectrum Disorder, attitude, parents

1. Introduction

1.1 Autism Spectrum Disorder

The increasing prevalence of young children diagnosed with Autism Spectrum Disorder (ASD) is becoming evident worldwide. World Health Organization reported that 1 in 160 children worldwide are affected by ASD^[1]. This marked a significant increase from the previously assumed prevalence of 4 per 10,000 in half a decade ago^[2]. Many factors are believed to have contributed to this increased prevalence, including changes in diagnostic criteria, development of the concept of a spectrum of disorders, increased public awareness, increased willingness and ability to diagnose ASD amongst health and educational professionals, availability of resource for children with ASD, as well as the possibility of a true increase in numbers^[3].

In Malaysia, the definition of autism in Diagnosis and Statistical Manual of Mental Disorders-fifth Edition, DSM-V^[4] has been generally referred to as the blueprint for diagnosis. According to DSM-IV, ASD is a developmental disability with qualitative impairments in three major aspects, namely deficits in reciprocal social interaction, deficits in communication and the use of idiosyncratic language and repetitive motor mannerism. Consequences of these deficits are seen in impairments of nonverbal behaviors, failure to develop age-appropriate peer relationships, lack of communicative interests and reciprocal interactions with others, delayed and disordered verbal language development, and atypical verbal and motor repetitions in individuals with ASD^[5]. At the moment, there is no channel to specifically identify students with ASD during school entrance in Malaysia. With the lack of this administrative prevalence figure, a substantial disparity between the availability of education arrangements for students with ASD and their specific educational needs remains.

1.2 Special education in Malaysia

Education for students with ASD in Malaysia is provided through mainstream education and special education programs by the Ministry of Education, community-based programs by the Department of Social Welfare and various individualized programs by non-government organizations. The special education programs by Ministry of Education are provided for under the Malaysian Education Act 1996, which include special education schools and integration programs in mainstream schools. Special education schools are mainly available to students with visual and hearing impairment. Students with ASD in Malaysia are generally grouped within the category of '*masalah pembelajaran*' (learning disabilities). This category includes all children with intellectual and other learning disabilities that are not grouped under visual and hearing impairment. Students with this category of disorders are arranged to special education classes in regular

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schools with integrated programs.

There are two forms of placement available through the integrated programs in Malaysia^[6], i.e., (1) special education class in regular schools and (2) inclusion in regular classes. The special class placement applies to those students who the teachers perceived as unable to attend to teachings in regular classes and hence these students receive their education exclusively in special education classes. In Malaysia, these special education classes are situated within the school buildings, together with the regular classes which are attended by other students in the school. Special education classes have a recommended ratio of one teacher to five students and the lessons are delivered by special education teachers. On the other hand, regular classes have a ratio of one teacher to over 30 students in most schools, and the lessons are delivered by regular teachers, who mostly do not have any prior training in special education. Therefore, in Malaysia, inclusion is usually only recommended to students who are perceived to be intellectually ready for academic learning in classroom and also behaviorally ready to follow the formal learning structure in regular classes^[7]. These students could be included in regular classes with students of the same chronological age or of different age. In regular classes, the teaching and learning are guided by the standard curriculum.

The implementation of inclusion for students with special needs in Malaysia ranges from integration during recess and sports to attending certain subjects together in regular classes, or to a full inclusion in regular classes. A thorough transition from a special education class to a regular class marks a full inclusion of a student with disabilities into mainstream education. The aim of inclusive education is to enable students with special needs to benefit from the upbringing and socialization processes in mainstream education. However, at this point in Malaysia, there is no legislation that focuses specifically on inclusive education for students with Autism Spectrum Disorder (ASD). Since the implementation of 'Educational Blueprint 2013-2025' and 'Zero Reject Policy' in Malaysia, there are increasingly more efforts from the Malaysian Ministry of Education to include students with ASD into regular mainstream education. One question to be addressed at the moment is what elements are needed for such an effort to be sustained and to be formally reinforced?

1.3 Inclusion for ASD students

Advocates of the full inclusion model believe that inclusive education should be implemented straight from the school entrance. Such an education model for students with ASD has now become the imperative move of educational reforms in many developed countries, including the United States and the United Kingdom^[8-9]. The main reason to promote inclusive education to students with ASD lies on their core deficits in social interaction and communication. Through placement in the regular classrooms, it is hoped that students with ASD have opportunities to learn social skills, from interacting with their typically developing peers with well-developed social skills^[10]. However, teaching students with ASD requires specific approaches and techniques that teachers in general classes might not be familiar with^[11]. Therefore, many inclusive frameworks require the presence of teaching assistants and parents who could provide additional promptings to address the specific learning need of these students. These practical issues, together with unnecessary stigmas associated with having students with ASD in regular classrooms; form the debate that whether the inclusion of students with ASD in regular classrooms will affect the provision of efficient education for other students^[12]. In many developed countries as previously mentioned, inclusive education is gradually chosen as the main policy imperative for students with ASD since it is championed as a means to remove barriers, improve outcomes and remove discrimination in education^[8].

As Professor Geoff Lindsay rightfully put it in the 2002 Gulliford Lecture, University of Birmingham,

"Inclusion is the policy framework. What is at issue is the interpretation and implementation of inclusion in practice. We need to ensure that there is a dual approach focusing on both the rights of children and the effectiveness of their education. There is a need to develop beyond concerns about input and settings to a focus on experiences and outcomes, and to attempt to identify causal relationships. We need research to inform policy and practice."^[8]

The trend towards inclusive education in many countries is partly contributed by parental advocacy movements. This is apparent in several case examples in United Kingdom and United States^[13]. In Malaysia, we begin to hear parents' voices in advocating for their rights to make choices of education placements for their children with ASD^[14]. These parental perspectives have the potentials to influence the shape of future education provision for children with ASD, including the extent towards a greater inclusion^[14]. However, parental perspectives in Malaysia have not yet been systematically examined to formally inform the establishment of a contextually suitable inclusion framework. In this paper, we aimed to fill this gap by examining parental perspectives on the needs of inclusive education for children with ASD in Malaysia from three aspects, from the lens of a mother with two children with ASD:

- (1) What is a parent's view of her children's current education system and what does she perceives as ideal for them?
- (2) What does a parent understand of inclusive education and its associated advantages and disadvantages?
- (3) What does a parent understand about the challenges in implementing inclusive education in Malaysia?

2. Methodology

We reported the qualitative findings of an exploratory study in this paper. The present study involved a single case study. We collected the data via an open interview with a mother, anonymously known as Mrs. M. She is a mother of two children with different severity levels of ASD. Her elder son, MB was observed to have mild ASD and her younger daughter, MG was diagnosed with moderately severe ASD. Mrs. M is a dedicated and informed parent who consistently attends early intervention services with her children. She also actively attends seminars and workshops on the topics of ASD. Mrs. M does not belong to any NGOs and parent advocacy groups, which makes her voice neutral and genuinely representing her personal insights. Mrs. M was invited to participate in this interview from the first author's social counterparts, considering the suitability of her background. Upon obtaining her consent, Mrs. M was asked to talk on her experiences and aspirations of education arrangements for both her children. We analyzed the interview data according to the three research questions we asked in this study and we reported the findings in turn below.

3. Results

3.1 M family

Mrs. M is in mid 30s and she has received education up to a diploma level. She is currently a homemaker. She resigned from her previous job as a finance clerk one year ago to better take care of her children. Mrs. M has two children, an elder son and a younger daughter. Her elder son, MB is now eight years old and her daughter, MG is four years younger. The boy, MB was first identified with language delay when he was two years old, and he was referred to a speech-language pathologist for this reason. MB was observed to have restricted communicative intents and to frequently exhibit temper tantrums. He responded rather well to an individualized speech and language intervention, which used Picture Exchange Communication System (PECS) as the primary remedial purpose. MB was discharged from the speech and language intervention after two years, with him gaining relatively adequate speech and language functions by then. MB had never obtained a medical diagnosis on his condition, but both his parents and the speech-language pathologists agreed that he showed signs of mild ASD.

The girl, MG was reported to have experienced relatively uneventful development in the first year after birth. She was found to be responsive to interactions and to start calling 'papa' and 'mama' at 13 months old. The mother noticed an abrupt change in MG when she reached 15 months old. MG was observed to show signs of regression in social interaction and atypical motoric actions, such as eyes blinking and hands flapping. MG was referred to a child psychiatrist to address her condition at age two. She was recommended for a series of early childhood intervention, including speech and language therapy and occupational therapy to address her delayed and atypical development in those areas. MG was officially diagnosed with severe ASD by the child psychiatrist at age three.

3.2 Mrs. M's view of her children's current education system and what she perceives as ideal for them

Mrs. M's son, MB attended kindergartens and then standard one in the primary school at age seven. He attended a Chinese primary school (*Sekolah Jenis Kebangsaan Cina*) in an urban area, in which there were as many as 40 students in his class. Towards the end of the first semester in the primary school, the class teacher requested to meet the mother, Mrs. M. The teacher expressed her concerns that MB was not doing well academically. MB was reported to be talkative and inattentive in the class. The teacher advised Mrs. M to look for a better education option for MB.

After the meeting, Mrs. M decided to transfer MB to another Chinese primary school. The school is a small-scale school, with only six students in a class. Mrs. M reported that MB was better attended by the teacher in the class and he was found to improve in both his attention span and academic performance since then. MB is now in primary three. He scored an average of 90 marks and above in his last examination for all the subjects. He also received numeral awards in drawing competitions throughout the years. MB appears to be a happy and confident boy when we met.

The girl, MG is currently attending early intervention centre and a playschool. She is minimally verbal and she requires repeated verbal and physical prompting in both language and motor activities. MG also has limited attention span. As a whole, she responds better to one-to-one teaching than in a group. Mrs. M has to register MG with a primary school next year and she is now considering the school choice for MG.

In the interview, Mrs. M was asked to comment on her educational choice for MG. She feels that she would prefer to send MG to a regular school with an inclusive option. According to her, “我是选择去普通学校 loh. 我 idea 是说 parents 一起合作, 一起, 能够的话, 我们一起学。” [I choose (to enroll MG in) a regular school, my idea is to have parents working together (with the teachers), together, if we could, together we learn.] Mrs. M also attributed teaching quality and

the use of vernacular language as reasons of her choice. She perceives the use of a vernacular language in regular classes, which is their home language, as an advantage to MG's being better integrated into the classroom activities. She expressed this view given her understanding that Malay is the only instructional language in special education classes.

Mrs. M also associated her choice to the preference of a small-scale school. She said, "MG 是去 normal 的, 可是要选小型的 loh." [(my hope is) MG is to go to a regular school, but (I) need to pick a small-scale school (for her).] Mrs. M related this choice with the previous experience she had with the elder son, MB. Mrs. M perceives that it is easier for a small-scale school to accept students with ASD in regular classes than for a larger school where the teaching and administrative demands on the teachers are higher.

3.3 What Mrs. M understands of inclusive education and its associated advantages and disadvantages?

Mrs. M was asked about her understandings of inclusive education, and she said, '应该是要有一个人, 或者是两个人专门 help. 至少两个人哦, 我看一个人也很难 handle, 两个人一起去 help, parent 啊, 自己要懂得去 centre 去学 loh, 去学, 学了 help 自己的小孩。' [It must have at least one, or two persons to specially help (the child in the classroom). I think two persons, I think one person is also hard to handle. Two persons go together to help, parents, they themselves have to go to centre (e.g., early intervention centre) to learn, to learn, then help their own children.].

Mrs. M commented on the advantage of inclusive education, '我相信可以, 如果是真的慢慢的教他, 教他, 他会一举两得, 其实一举两得 loh, 真的, 真的有 help 他。如果你只是送他去 normal 的, 走来走去, 走来走去, 真的也没有半样, 只是说在下课时大家一起吃东西, 我是觉得是说需要他一起。' [I believe inclusive education can (help her). If (we) slowly teach her, teach her, she will get 'two birds with one stone', it's really 'two birds with one stone', it's true, it's true that we can help her. If we just send her to the normal (school), she walks here and there, walks here and there, it doesn't make any difference. The only difference is she can eat with the others during recess. I feel that (I) need to be with her (to help her).]. Mrs. M did not comment on disadvantage of inclusive education.

3.4 What Mrs. M understands of the challenges in implementing inclusive education in Malaysia?

Mrs. M gave the insights that teachers and school principals are the main considerations in the implementation of inclusive education. Her major concern is the teachers. According to her, '去 normal 学校是, 老师是第一个 loh, 不会 handle.' [go to normal school, teacher is the first (factor), does not know (how) to handle (children with ASD)]. Mrs. M felt that the major decision on inclusion lies on the hand of the school principal. She said, '看校长 lah, 如果这个校长 OK, 觉得 OK, 我们就 OK loh.' [It depends on the principle. If the principle said ok, felt ok, we are ok.]

4. Discussion

Mrs. M's responses to the interview questions provided some pointers to the factors and issues associated with inclusive education in the context of Malaysia from the parent's perspective. We see that parents are not fully supported during the placement process. There are no explicit regulations outlined for the educational arrangements of students with ASD. Parents are not routinely provided with directions on how to make educational choices for their children with ASD during school entrance. Most parents of children with ASD would register their children either for a regular class or a special education class. For either choice, both parents and children are not given additional supports to address their specific conditions and needs. The findings pointed to aspects in the Malaysian education system which attempts of inclusion for children with ASD are not well-supported^[14]. In a study which involved 406 parents of children with special needs across Malaysia, 70% of the parents reportedly had attempted inclusion in the local regular schools, but only 40% of parents reported successful inclusion^[15].

For the case scenario of ASD as investigated in this study, Mrs. M's elder son, MB first attended a regular class with 40 students and it caused distress to all parties, including the child, the teachers and the parents when this attempt did not work as intended. On such occasions, parents are called to look for an alternative solution or 'to try their luck elsewhere', which causes further distress to them. The alternative solution would be to register MB in a special education class. This placement option was not available in that particular school and the onus fell on the parents to search for another alternative. Mrs. M's experience is not unique as parents who opted to have their child included in regular classes have often faced an uphill battle of finding the right school for their child. The transfer of MB to another Chinese primary school with only six students helped him to improve tremendously. Academically, he is able to follow the mainstream curriculum, hence in retrospect, special education classes is not be the best solution for him and full inclusion appear to be the best option.

Second, Mrs. M's understanding of inclusive education for students with ASD is to have a parent or a teacher assistant to provide additional helps to the students concerned in a regular class setting. Her view portrays an inclusive education model which is advocated by many parents and NGOs in Malaysia^[15]. Mrs. M provided her rationale to her preference of this model. She believes in the learning potentials of students with ASD; and that if more promptings were directly provided to these students, they will learn just like others in the class. In countries such as the United Kingdom and Australia, teacher assistants are formally trained by educational authorities and they are placed in preschools and primary schools to assist teachers in the classrooms^[11]. However, such system does not formally exist in Malaysia. In the attempts to include students with ASD in regular classes, one common trend in Malaysia now is to have either parents, instructors from NGOs, or even foreign maids to become the teacher assistants. These attempts are also limited to a handful of schools which are receptive towards the education needs of students with ASD. Overall, the lack of formality in this arrangement limits the growth of this system to cover more students and schools. It also has the risk of being short-life since it is pending on the school-level administrative decisions. The absence of explicit rules and regulations for such practices is also subjected to conflicts and misunderstandings between the parties involved. All these highlight the importance for inclusive education to be properly planned and then to be officially implemented for students with ASD. The planning of this move would need to consider the training of teacher assistants, outcome measures and information sessions for teachers and principals involved.

Third, Mrs. M expressed that her main concern of having her children in regular classes is the fear that the mainstream teachers do not understand the special learning needs of students with ASD, and the teachers also have limited trainings in handling the learning issues faced by these students. Mrs. M experienced it with the case of her elder son, MB where the teachers expressed their helplessness in addressing MB's special learning requirements, and hence recommended MB to be transferred to other educational settings. In fact, Mrs. M is not alone. Her concern is shared by the international community who promote inclusive education for students with ASD, including those in the United States, the United Kingdom, and many more^[16-17]. The lack of teacher knowledge about the nature of ASD and effective teaching techniques have been found to be the major contributor to the parents' dissatisfactions in education for ASD children^[17]. Many parents have related the lack of appropriate teaching and management strategies on the part of teachers as a result of the teachers failing to understand the nature of ASD^[17].

For a child with ASD to be successfully included in regular classes, certain supports must be made available. A potential support model is to have an itinerant specialist special education teacher to support both teachers and families in dealing with educational-related issues for students with ASD. This model is adopted by the Netherlands and the role of the itinerant specialist teacher as described by Lee^[7] showed that this model could be implemented in Malaysia with some changes in policy. The itinerant specialist's primary role is to support inclusive education for students with ASD. To achieve this goal, he or she will perform as an advisor, a trainer or a coordinator as the circumstances demanded. For example, in a school whereby inclusive education has been established, the specialist's role is to initiate a collaborative team meeting once a month with the parents, teachers, teaching assistant, the principal and even the students' private interventionists, such as speech-language pathologists. These meetings function to discuss issues and to seek solution collaboratively. Such attempts ensure that the students are receiving adequate and proper support from all people involved, and of equal importance, is to create a platform for school representatives and parents to communicate. Currently, special education teachers and teacher assistants for students with learning disabilities in Malaysia are mostly attached to special education classes. With some tweaking in policies, special education teachers can function as itinerant specialist teachers to bridge the gap for students with ASD in regular education schools.

Based on Mrs. M's feedback, another crucial step towards promoting inclusive education for students with ASD is to provide enough information resources to principals and teachers in regular schools. The general teachers need to have enough knowledge of ASD to identify at-risk students in their classroom. They also need to have specific trainings to address the students' specific learning needs. Most importantly, the teachers need to be able to provide professional consultations to the parents when necessary. Potentially, effective teacher trainings in these aspects will path way for a successful partnership between the schools and the parents in the implementation of a workable inclusive education framework for students with ASD in Malaysia. Mrs. M's observations on inadequate training of general education teachers to work with students with disabilities have often been found in research to be one of the major factors that hinder the success of inclusion^[18]. However, one limitation in this study is that the factor of peer interaction was not explored. Considering that peer interaction might contribute to both advantages and challenges of inclusive education, it is suggested that this factor can be explored in a future study.

5. Conclusion

The findings of this study illustrate the challenges and complexities in promoting inclusive education for students with ASD in Malaysia. However, through the eyes of a mother, we find strengths and a strong belief that children with ASD could learn like others when given adequate opportunities and learning aids. For such a belief to be realized, we need corporations from all the stakeholders involved. In our future research, we hope to further understand the elements that could contribute towards a workable inclusion framework in Malaysia by involving more informants, including parents, teachers and representatives from NGOs. In this study, we gathered a mother's voice and we identified from her interview that (1) a proper identification of students with ASD during school entrance, (2) the need of an itinerant specialist or coordinator for ASD case management in schools, (3) trainings for teacher assistants and (4) trainings for general teachers are amongst the key factors towards the implementation of inclusive education for students with ASD in Malaysia.

Conflict of interest

The authors declare no competing financial interest.

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