

## CHILDREN WITH AUTISM: THE EDUCATIONAL ASPECT

Dewi Amira Dania Binti Radin Ariff Taquiddin,  
Kulliyah of Medicine, International Islamic University Malaysia

Farah Nurena Binti Maidon,  
Kulliyah of Medicine, International Islamic University Malaysia

Nurul Anis Afiqah Binti Mohd Razapi,  
Kulliyah of Medicine, International Islamic University Malaysia

Nur Saidatul Nasuha Binti Rozaini  
Kulliyah of Medicine, International Islamic University Malaysia

Nur Afrina Farisah Binti Shafrul Afzam  
Kulliyah of Medicine, International Islamic University Malaysia

Aida Mokhtar  
AbdulHamid AbuSulayman Kulliyah of Islamic Revealed Knowledge and Human Sciences,  
International Islamic University Malaysia

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### ABSTRACT

*In Malaysia, there is a growing number of children with autism, according to the Ministry of Health. Children with autism and other disabilities are enrolled in special education provided by the country's government, the private sector, and non-governmental organisations (NGOs). An NGO that offers educational programmes to children with autism in Malaysia is the National Autism Society of Malaysia (NASOM). There are 15 NASOM centres in Malaysia and there has been a need for more studies on the NASOM branch in Kuantan hence, the study aimed to examine it mainly in terms of its educational programmes. The case study research design was adopted and qualitative research instruments were adopted such as the interview and observation of teachers and students in NASOM who are involved in the programmes. The findings generated three themes: NASOM services, Challenges in teaching children with autism, and Awareness of education for children with autism. The study used a grounded theoretical framework to generate a theory inductively from the data collected. The Theory of the Stakeholder Convergence of the Ideal Ambiance for Children with Autism was produced from the study upholding the importance of converging the stakeholders such as Parents, NASOM, and the public in providing an ideal ambiance for children with autism as they seek education. The paper provides recommendations to stakeholders regarding how to improve NASOM Kuantan's services for children with autism, overcome the challenges, and improve awareness so that children with autism can have a better quality of life in Malaysia. It is hoped that the study contributes to the field of education for children with autism through the theory.*

Key words: autism, NASOM, Kuantan, awareness, Persons with Disabilities Act 2008

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### INTRODUCTION

The Persons with Disabilities Act 2008 (PwD Act 2008) defines persons with disabilities (PwDs) as "...those who suffer from long-term physical, mental, intellectual, or sensory impairments, preventing their full and effective participation in society when faced with challenges" (Persons with Disabilities Act 2008, Malaysia, p. 9). The Malaysian government has created seven categories of PwDs under which they can be registered: Hearing Disability or Impairment, Visual Disability or Impairment, Speech Disability or Impairment, Physical Disability or Impairment, Learning Disability, Mental Disability or Impairment, and Multiple Disabilities or Impairments. Disabilities can affect a person at certain times in their life and their causes can be classified as congenital or acquired. Students with disabilities are encouraged to be diagnosed by a medical practitioner, an optician, an audiologist, or a psychologist as having a disability or multiple disabilities (Government of Malaysia, 2023). They are then encouraged to register with the Department of Social Welfare (JKM) to obtain a special card.

As of 31 May 2021, approximately 579,150 people were registered as PwDs with JKM in Malaysia, this accounts for approximately 1.8 percent of the Malaysian general population (Disability Data - Be Counted to Count, 2023). One type of disability is 'autism' which is usually categorized as a learning disability. "Autism is a disorder of neural development, characterized by impaired social interaction, communication, and by restricted repetitive behaviours" (Salleh et al. 2018, p. 65). The complexity of autism is also found in its spectrum feature as it encompasses various "manifestations of anxiety such as the severity of autistic conditions, developmental stages, and chronological age" (Bakar et al., 2020, p. 82). The complexity of autism is that it lies on a spectrum and hence, different persons with autism would have different capabilities, which is explained by the term 'autism spectrum disorder' or ASD.

The number of autism diagnoses is on the rise depicted through a study by the Ministry of Health that shows the latest figure in 2021 being 589 children aged 18 and below has autism which is an increase of five percent from 562 children in 2020 (Codeblue, 2022). Awareness of autism needs to be enhanced as people are still unfamiliar with it. Another study commissioned by the United Nations International Children's Emergency Fund (UNICEF) in 2016 revealed that roughly 60 percent of respondents were unaware of disabilities in general in Malaysia. The lack of awareness and understanding, as well as misconceptions of disability in Malaysia, appear to be key factors causing the restriction in opportunities available to children with disabilities in

comparison to their peers without disabilities. Hence, raising awareness of the existence of children and adults with disabilities is crucial because there is a general lack of understanding and acceptance of children with autism for them to have a good quality of life.

The PwD Act 2008 also mentions that students with disabilities in Malaysia shall not be excluded from receiving education. It defines 'Special Education' as a form of education for students who have special educational needs in schools that offer special education, or in mainstream schools that adopt the Integrated Special Education Programme or Inclusive Education Programme, at several levels such as preschool, primary, secondary, and tertiary education, or secondary education levels. As of June 30th, 2019, the Ministry of Education enrolled a total of 87,574 special needs students in public schools in Malaysia (Kannan, 2019).

Other than in public education, special needs education is also catered to students with disabilities in private educational institutions or learning centres managed by NGOs. The role of NGOs in the lives of PwDs is existent and this is mentioned in the PwD Act 2008, in Chapter 2 (p. 29):

**33.** (1) The Council, the private healthcare service provider, and non-governmental organization shall take effective and appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social, and vocational ability, and full inclusion and participation in all aspects of life.

An example of an NGO that provides educational programmes to PwDs is the National Autism Society of Malaysia (NASOM) which was established in 1986 by a group of parents for children with autism. There are 15 NASOM centres located all over Malaysia. In the East Coast region, there are two centres; NASOM Kuantan and NASOM Kerteh (Our Centres, 2022) of which the former is the focus of the study.

Islam is a way of life for Muslims, making the Islamic perspective important. Islam regards having a disability as having a challenge given by Allah. The Qur'an urges people to treat PwDs with kindness and protect them. Allah commands us not to look down on, label, or mock others, including PwDs (Surah Al Hujurat, 49: verse 11):

O you who have believed, let not a people ridicule [another] people; perhaps they may be better than them; nor let women ridicule [other] women; perhaps they may be better than them. And do not insult one another and do not call each other by [offensive] nicknames.

Children with autism and other disabilities should attend school as required by the PwD Act 2008 and United Nations Sustainable Development Goal No. 4. On the ground, many problems could hinder the access to education for children with autism. Unfortunately, the current special education system has several problems such as the lack of building access for children with physical disabilities, the lack of readiness in the form of barriers to positive perception amongst teachers and lecturers teaching children with disabilities, deficiency of resources in providing appropriate teaching materials, and the lack of early intervention programmes and equitable accredited examination for students with learning disabilities (Nasir & Efendi, 2016). Such problems within current educational facilities have made us intrigued to investigate educational institutions for children with autism in the case of NASOM Kuantan. Against this backdrop, the research study aimed to deepen our understanding of education for children with autism in terms of NASOM Kuantan's services, the challenges faced by teachers when carrying out their job, besides gauging the level of awareness with regards to education for children with autism to generate a theory in relation to the findings.

## **SIGNIFICANCE OF THE STUDY**

Education for children with autism is important to examine as the PwD Act 2008 has put forth the need for children with disabilities to be given access to education but whether this is working well on the ground is another area of concern. A study depicted that most teachers of children with disabilities in Malaysia felt they need more training, and they felt vulnerable and ill-equipped (United Nations Children's Fund (UNICEF), 2017). This study is significant as there has not been a comparable study in the past hence, recommendations are made to the current educational services offered by NASOM and a theory has been generated from the study using the grounded theory approach contributing a novel finding to the field.

## **RESEARCH QUESTIONS**

1. What types of services are available for children with autism in NASOM Kuantan?
2. What are the challenges faced by teachers of children with autism in NASOM Kuantan?
3. How could awareness of children with autism be enhanced?

## **LITERATURE REVIEW**

Previous research studies have focused on teaching facilities and assistive technologies, financing an autistic child, stress encountered by parents of children with autism, and the awareness of autism but there is a research gap of studies on NASOM Kuantan in terms of its services, challenges faced by its teachers and awareness of the importance of education and autism which this study attempted to fill.

### *Teaching facilities and assistive technologies*

Studies on teaching facilities and assistive technologies have been diverse in nature. There have been several studies on NASOM conducted in the past. One of the studies investigated how teachers in NASOM can enhance their teaching strategies in terms of knowledge, formation, and competencies which showed that the training given was effective but the strategies for teaching children with autism need to be improved (Bakar et al., 2022). A subsequent study also on NASOM found there needs to be improvements in the quality of teaching skills among its teachers because the research shows that they are moderate (Bakar et al., 2020). NASOM teachers were examined in a study on their perception of a mobile application integrating Augmented and Alternative Communication and video modelling approaches which they perceived as useful for children with autism to enhance their independence and to improve their character (Ahmad & Zulkharnain, 2020). Another study identified needs and problems in learning for children with autism from a technology perspective with three NASOM teachers interviewed (Ishak et al., 2023). The study found that it was challenging for the children to focus when learning as they had low cognitive ability and inadequate teaching methods hence, it was proposed that robots be used as an assistive tool to overcome the problem of teaching and learning for children with ASD. Surveys and interviews were conducted with experts, teachers, and parents through focus group discussions.

A subsequent study that sought many viewpoints from young people with ASD, their parents, schoolteachers, and NASOM teachers discovered that parents of ASD children must take greater responsibility for their children's education, life skills, and vocational preparation as several schools and disability services may not provide specialized services that cater to their children's needs (Tang, 2022). The study found several challenges in terms of vocational education such as "resourcing needs for vocational training and career transition programmes (including funding), provision for teachers' professional development, the need for skills training opportunities, language skills development, and social and behavioural development" (p. 226).

In another study, 63 parents of children receiving treatment at NASOM were provided with two surveys (Zulkifli & Rahman, 2021) the findings underscored the need for occupational therapists to include sensory components in feeding interventions as using these sensory integration or sensory-based approaches would enhance the processing of sensory information that will ensure that ASD children adapt well when having their meals.

Another study on NASOM students using a quasi-experimental method found that a culturally tailored social skills module that was irrespective of media (mobile application or paper) can effectively enhance social skills among students with ASD (Ibrahim, 2019). There was a study conducted on the potential use of a humanoid robot as an additional rehabilitation tool to aid children with autism (Shamsuddin, 2015). Other than the use of assistive technology, a few studies focused on the teaching and learning environment.

One such study developed a conceptual sensory design of the Autism Physical Learning Environment by identifying sensory issues for design consideration in a physical learning environment (Ghazali et al., 2018). A subsequent study's findings depicted that designing warm and friendly places for children with autism helps play a role in the children's development (Zulkanain & Mydin, 2019). We can see that a conducive environment would help in teaching children with autism.

A qualitative study found that students can be put together with other students who have mixed disabilities students in the Special Education Integrated Programme or formally known as Program Pendidikan Khas Integrasi (PPKI) school, but teachers should follow the ideal ratio when handling ASD students, there should be more occupational therapists attached to schools and more trainings, teaching and learning facilities found in PPKI schools (Mahat et al., 2018).

Another qualitative study examined three cases that are Calvary Victory Centre (Johor), Penawar Special Learning Centre (Johor), and NASOM One Stop Centre (Selangor) (Zulkanain & Mydin, 2019). The study determined that designing a space that provides a conducive environment for children with autism to be stimulated in would lead to effective learning.

The notion of customised pedagogies for children with autism was also emphasised in a final study that examined the effectiveness of an e-module known as 'The Story of Khamdy®'. The e-module was created to introduce 140 information and pedagogical strategies when teaching students with ASD in environments that are inclusive. Pre-service teachers found the module to be efficient and prepares them well to teach students with autism (Low, Lee, et al., 2021).

### *Financing a child with autism*

Financing a child with autism can be expensive. A study found the total cost of financing an ASD child is RM35,365.62 a year in Malaysia and that the financial assistance provided is not enough to cover the costs of catering to an child with autism (Kamaralzaman et al., 2018). Based on another study, it was found that most autism centres in Malaysia require children to undergo a diagnostic test, these schools offer a combination of classes and charge class fees in the range of RM356 to RM600 per month, thus catering towards middle to high-income families (Fikry & Hassan, 2016) putting the poor at risk of not sending their children to school.

A study revealed that despite the government having spent a lot, parents are reported to still be burdened by financial stress in raising children with ASD as there are different therapies, medication, education, and other treatments to seek (Jani et al., 2022). Moreover, about 93 percent of parents of children with ASD did not receive sufficient financial support for their child's therapy and felt that they should be offered alternative therapy sessions other than sending their children to a public hospital that offers monthly sessions, and to other private children development centres that are affordable and provide more therapy sessions. The study provides a better comprehension of *Waqf* as an option to assist the parents of children with ASD and a way to reduce government expenditure.

A study by Saunders et al (2015) that examined secondary data from the 2009-2010 National Survey of Children with Special Health Care Needs, found that of the children with ASD, 24 percent of them also had an intellectual disability (ID). More than half of the caregivers of children with ASD/ID reported financial difficulty (52 percent) and having to stop work to care for their child (51 percent) compared to those who had ASD alone. Caregivers of children with both ASD/ID were more likely to face financial difficulty, reduce work hours, and stop working altogether. However, there were no differences found between caregivers of children who only have ASD and only ID.

Some parents in Sarawak who were interviewed saw that the financial burden of ASD interventions was stated as a major issue by 97 percent of parents and 86 percent of educators (Teo & Lau, 2018). In addition, educators found that intervention at the basic level was often unaffordable for many parents who also established that finances would still be an issue, even for those deemed wealthy.

#### *Parents of children with autism and stress*

Another study indicates that parents of children with autism showed higher levels of stress compared to parents of typical children. This depicts the importance of paying attention to parents' mental state and wellbeing (Jx et al., 2017). Parents play a big role in the education of children with autism by encouraging them to attend school and raising them to be good human beings.

A study that was conducted on the caregivers of children with ASD who attended NASOM Kuantan, the psychiatry clinic and occupational therapy unit at Hospital Tengku Ampuan Afzan Kuantan, and caregivers who joined PIANIS (Persatuan Ibubapa Anak Istimewa Pahang) found that almost one-sixth of them were depressed, anxious and stressed encouraging doctors to do screening on them (Fatin et al., 2021). Another study found there were no significant differences between parental stress of those with different education levels, financial factors, and employment status (Helmi & Murad, 2022). Parents should go for stress management programmes especially for those who are older and those who are fathers, as they play a significant role in regulating the emotional well-being and improving parent adjustment capabilities, that enhance life satisfaction.

Using interpretative phenomenological analysis, semi-structured interviews were conducted with eight Malaysian mothers from different ethnic backgrounds (four Chinese, three Malays, and one Indian) (Ilias et al., 2017). The mothers perceived their child's ASD symptoms and behaviour problems (e.g., hyperactivity and sleep difficulties) as impacting their well-being. Coping strategies, such as acceptance, proactive mindset, character growth, spirituality, and parent support networks, and fostered wellbeing were recommended by the study.

Regarding parenting children with ASD, a study interviewed parents (n=21) of children with ASD (n=24) using a phenomenological framework to comprehend how parents perceived challenges (Yaacob et al., 2021). The findings generated four key aspects that were challenging to parents in terms of inadequate knowledge, psychological distress and stigma, lack of support, and barriers to services that needed addressing.

Basri and Hashim (2019) examined variations in parental stress between parents of children with ASD (n=21) and children who were Typically Developed (TD) (n=41) in Malaysia. Parents with ASD children were found to be significantly more stressed compared to parents of TD children.

Another survey study examined the relationships between Sense of Coherence (SoC), Coping Strategies, and Quality of Life (QoL) of parents of children with autism in Malaysia. The outcome of the study depicts that SoC and cognitive reframing are important factors associated with QoL and it is recommended that policy-makers and programmers at Autism Centres organise more training workshops for parents of ASD children so that their overall QoL can be better (Siah & Tan, 2016).

A qualitative study using interviews defines the conflict between work roles and family roles and provides recommendations to reduce the work-family conflict from the perspective of working parents of children with autism in Malaysia (Sitimin et al., 2017). Interview results specify that balancing work roles and family roles simultaneously is very challenging and that working parents require a nursery that accepts a child with autism, and they need support from their employer to reduce their work-family conflict.

In-depth interviews were conducted among 21 parents of children with ASD and the results depict three main themes. The first is 'Acceptance and Positive Outlook' which underlines the importance for parents to accept their child with autism as a form of coping strategy, the second theme 'Reaching for Helping Hands' reflects that the family is the most important form of support amongst the support systems identified such as social, emotional, government, and network support systems when faced with hardship and the third theme, 'Understanding Autism and Finding its Solutions' illustrates how parents manage their children with ASD using various methods using both professional and alternative approaches and the parents' goal was to enhance their children's capabilities and potential and prepare them for the future (Yaacob et al., 2022). It is apparent that parents of children with autism encounter a lot of challenges and play a big role in their children's life.

#### *Awareness of autism*

When it comes to awareness of autism amongst the public, a study shows that the public's awareness of autism is still low, and that social media platforms are not doing enough to distribute information on autism to the public (Low et al., 2021). The findings of a survey suggest that the Malaysian public has a moderate level of knowledge (72 percent) and a low level of positive attitude (57 percent) towards ASD with many Malaysians not understanding autism (Azmi et al., 2022). The deficiency of knowledge on autism can lead to negative attitudes to persons with autism and their families addressing the need for better awareness through social media and campaigns that can alleviate discrimination against ASD.

Another study that used a survey revealed that most respondents could recognise ASD as a type of learning disability, but they were less acquainted with the diagnostic features and remedial needs of ASD and had scarce knowledge about the social communication and language deficits of ASD (Low, Lay, et al., 2021). Respondents also reported different sources of attaining ASD knowledge according to their demographic profiles (namely age, gender, education, and occupation), which led to variations in the type of knowledge they obtained. There is a need to disseminate content-specific ASD awareness programmes through the right channels to make them more effective in creating awareness which would be an improvement to the present campaign.

When it came to the awareness of autism amongst medical and nursing students who would ultimately become frontliners, there were several studies that investigated this phenomenon. A study by Low & Zailan (2018) found that senior medical students had greater knowledge about autistic symptoms compared to their subordinates, but there was no clear indicator that they had attained knowledge through formal training henceforth there is evidence that there is the need for training on ASD in schools that offer medical programmes. A study on nursing students was conducted in Sabah that has seen an increasing prevalence of ASD children with 400 registered under the Sabah Autism Society (SAS); making the autism phenomenon a major concern. It

was found that nursing students in Sabah are aware, have a positive perception of autism, and agree that social media is important to enhance the awareness and perception of children with autism (Thomas et al., 2020).

When it came to students in general, another study found that although many polytechnic communities in Malaysia recognise the word autism, a great deal of them still do not know the general attributes of children with autism (Salleh et al., 2018). A study investigated the experiences of lecturers supporting students with ASD in a Malaysian tertiary education institute (Khairuddin et al., 2020). Knowledge and awareness emerged as a theme in which participants articulated concern about the absence of information as they had to support the ASD students they taught. Another study that compared between students in the University of Nottingham in the UK (N = 166) and the Malaysian branches (N = 195) found that Malaysian students were less willing to interact with people who had autism (de Vries et al., 2020). The findings suggest that knowledge, contact (willingness to interact), and acceptance were greater in the UK perhaps because of the lack of awareness of autism spectrum conditions (ASC) in Malaysia. It appears from the literature review that NASOM Kuantan that focused on examining NASOM services and challenges and awareness of the public of ASD using the interview and observation framed by grounded theory has not been conducted previously hence underlining the research gap that this study attempted to fill.

## **THEORETICAL FRAMEWORK**

Grounded theory was used to frame the research to generate a theory from data collected through interviews and observation. "Grounded theory sets out to discover or construct theory from data, systematically obtained and analysed using comparative analysis" (Chun Tie et al., 2019). Grounded theory is an important tool in qualitative research inquiry as it utilises an inquiry method that is 'systematic, inductive, and comparative' to produce a theory (Sharma et al., 2019). Comparative analysis according to the writers refers to the comparison of initial codes to other codes which are then condensed into categories.

## **METHOD**

A single case study was adopted as the research design as it focused on the single case of NASOM Kuantan. A case study is a research design that focuses on answering the 'how' and 'why' questions (Yin, 2018) giving the study depth and richness in data. The interview and observation qualitative instruments were used to collect data. Qualitative research instruments in the form of interviews and observation are usually adopted because they provide richer data compared to quantitative research that focuses on numbers (Bryman, 2018).

NASOM Kuantan has 30 students with autism and 10 teachers. The data on them was collected in 2023. Consent was obtained by the researcher from NASOM Kuantan for the data collection phase. The type of sampling adopted was purposive as the interviewee and subjects of observation were selected for the purpose of answering the research questions (Bryman, 2018). The Head teacher was selected because she was the main decision-maker in NASOM Kuantan and was able to provide first-hand information. The key criteria for selecting the interviewee were: he or she has to be a teacher working in NASOM Kuantan for over 10 years who is in a leadership role that can make decisions. The single interview is acceptable in qualitative research as "...the number of people required to make an adequate sample for a qualitative research project can vary from one to a hundred or more" (Baker & Edwards, 2017, p. 10). An interview guide was used that had seven questions corresponding to the research questions.

Observation was also carried out on 10 teachers and 30 students of NASOM who have autism while they were participating in activities at NASOM Kuantan. The students' ages ranged from six to 21 years of age and both genders were present. Most of the children with autism were Malay Muslim while a small number of them were Chinese. The data collection was also conducted with the consent of the parents of the children. The researchers took notes of what they observed, and photos of the children and teachers as they were doing their activities for research purposes. In order to ensure trustworthiness of the research and data collected, the research process was shown to another researcher who has vast research experience to get her validation on the research process:

...qualitative researchers must demonstrate that data analysis has been conducted in a precise, consistent, and exhaustive manner through recording, systematizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible (Nowell et al. 2017, p. 1)

The interview transcription and observations notes were uploaded to the qualitative software analysis programme known as NVIVO for the themes and codes to be generated as part of the thematic analysis. Thematic analysis is an approach that systematically identifies, organises, and interprets meaning patterns (themes) across a data set by using inductive-driven data coding and analysis (Braun & Clarke, 2012). There are six phases in the thematic analysis that were adopted by the researchers from generating initial codes and then placing them under themes (see Figure 1 below):

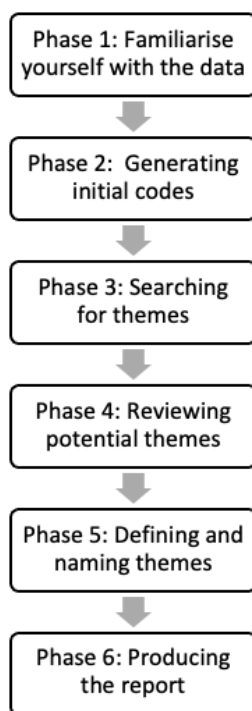


Figure 1: Phases of thematizing by Braun and Clarke (2012)

The comparative analysis method was also adopted in Braun and Clarke’s (2012) thematic analysis to ensure constant condensing of the themes. The codes placed under the themes provided more details about them that answered the research questions in more detail.

**RESULTS**

The data analysis generated three themes; ‘NASOM services’, ‘Challenges in teaching children with autism’, and ‘Awareness of autism’ (see Table 1).

Table 1: Research Questions, Themes, and Codes

Research Questions (RQ)	Themes	Codes
RQ1: What types of services are available in NASOM Kuantan?	NASOM services	Various teaching facilities available Teachers observant of their students
RQ2: What are the challenges in teaching children with autism in NASOM Kuantan?	Challenges in teaching children with autism	Different degrees of disability Students' behaviour challenging to manage. Lack of NASOM centres for children with autism in Pahang Parents in self-denial Financial assistance needed
RQ3: How could awareness of special needs education for children with autism be raised?	Awareness of autism	More awareness is needed. Visible Ronald McDonald sign on building wall

### **THEME 1: NASOM services**

There are several codes under the theme of NASOM services. The codes are: 'Various teaching facilities available', and 'Teachers observant of their students'.

For the first code 'Various teaching facilities', the interviewee mentioned that there are various services available for children with autism in NASOM Kuantan. There are early intervention programmes and vocational programmes offered by NASOM. The vocational programmes include activities such as batik painting and gardening. All the students with autism participate in the programmes, and it is routine for them to do so.

The second code 'Teachers are observant of their students', it was found from our observation that teachers were aware of their students' behaviour and could describe their students well, which was a good indication of their awareness of them and their good training in this aspect. A teacher described their students' behaviours well and made the researchers aware that the teachers were observant and tried to understand their students well.

### **THEME 2: Challenges in teaching children with autism**

Next, there are several codes under the theme 'Challenges in teaching children with autism'. The codes are 'Different degrees of disability', 'Students' behaviour is challenging to manage', 'Lack of NASOM centres for children with autism in Pahang', 'Parents in self-denial' and 'Financial assistance needed'. For the interviewee, the first challenge of teaching students with autism is the existent of different degrees of disability amongst children with autism. She mentioned that most practice nonverbal communication, so the teachers needed to be creative when teaching them. For instance, nonverbal children will not talk when they want to eat and go to the toilet. What makes it more complex is that each student is distinct and what works well when teaching one student may not work well with another leading to the need for customised teaching and evaluation. Learning about the student's disability and coming up with ways for that student to cope can help the student develop his or her communication and behaviour. The teachers also have problems managing the male students especially when they hit puberty because all the teachers are female.

The second challenge is in terms of managing the students' behaviours, as from our observation, the children in NASOM can be active and aggressive and difficult to manage. This is further proven when the interviewee scaled eight on the level of difficulty in managing the children with autism.

The third challenge is according to the Head teacher, the apparent lack of centres in Pahang for children with autism and the need for more centres that cater for them beyond 13 years old. This leaves a lot of children with autism with no place to receive education if they were not able to attend formal schooling.

The fourth challenge is that there are parents that are not accepting of their children with autism and hence are in self-denial. They do not send their children to NASOM or any other schools as a result of feeling this way. They need to accept the fact their children have autism and that they must be educated by the stakeholders concerned.

The fifth challenge is that some parents require financial assistance. They face problems sending their children to NASOM and paying their fees which need addressing by stakeholders including the government, the private sector, and NGOs.

### **THEME 3: Awareness of autism**

Furthermore, there are two codes under the theme 'Awareness of autism'. The first code is 'More awareness is needed amongst parents and the community' and the second code is 'The appearance of a Visible Ronald McDonald sign on the NASOM building wall' reflects the awareness felt by McDonald's as indicated by its contribution to and association with NASOM.

Based on the interview, there are many ways that are crucial to increase awareness regarding children with autism and their education in Malaysia. Firstly, the parents of children with autism need to accept the fact that their children were born with disabilities, and they should be aware of the importance of education for children with autism as they will be better informed about their child's physical and social development so that their children will improve. Moreover, the community also needs to take a role in increasing the awareness of the importance of education among children with autism by accepting persons with disabilities so that they can be assimilated within society. Plus, from our observation, there is a visible Ronald McDonald's sign on the NASOM building wall which shows that NASOM also gets sponsorship from Ronald McDonald House Charities which helps enhance awareness of autism by a big brand such as McDonald's in the private sector which is a significant development that needs to be emulated by other brands.

## **DISCUSSION**

It was found that the 30 students at NASOM were a perfect match for 10 teachers since each teacher oversaw three students making it manageable for special attention to be given.

### **NASOM Kuantan Services**

Various services for autistic children were offered by NASOM to keep them occupied. Children with autism behave differently than other children. They are likely to put objects in a line, play alone, and conduct repetitive actions from an early age (Rudy, 2 August 2023). They are also less likely to participate in games requiring make-believe, collaboration, or social communication. Many children without autism may behave in the same way as children with autism. However, children with autism are unaware of the activities and preferences of others as they find it difficult to read another person's nonverbal communication. Hence, in NASOM, they are actively participating in a scheduled routine for them to manage the difficulties of the unpredictability of everyday life easily. Activities like batik painting allow the children to express themselves visually through artistic means. It also

allows them to communicate their ideas which they might be unable to do verbally. Another activity in NASOM like gardening can also further encourage children with autism to build social relationships. They will be put into groups and will have a common goal for them to meet. This augments the bond between the children with autism at NASOM.

Secondly, the teacher mentioned that children with autism learn well through non-verbal communication because they are more visual learners. For example, they may excel at tasks requiring visual searching, such as locating a triangle within a complicated image. This may be because visual information is more concrete and easily processed than verbal and auditory information by children with autism. These strong visual abilities may be a result of the children's inclination to concentrate on details rather than the whole.

More assistive technologies other than traditional methods of support and activities ought to be embraced as NASOM teachers in a previous study perceive that Augmented and Alternative Communication and video modelling approaches are useful for children with autism to encourage their independence and to build their good character (Ahmad & Zulkharnain, 2020). Another study also recommends assistive technology be used in teaching and learning in the form of robots (Ishak et al., 2023). More state-of-the-art methods of teaching should be included like occupational therapists who include sensory components in feeding interventions (Zulkifli & Rahman, 2021) and innovative social skills modules (Ibrahim, 2019) or a humanoid robot as an additional rehabilitation tool to aid children with autism (Shamsuddin, 2015). A module that helps provide a variety of pedagogical approaches to pre-service teachers could be adopted so that customised teaching can be conducted effectively (Low, Lee, et al., 2021).

A few studies focused on the teaching and learning environment and its importance in making it stimulate children (Ghazali et al., 2018), by using warm and friendly places (Zulkanain & Mydin, 2019) for teaching and learning. A conducive environment would help in teaching children with autism effectively as found by these studies.

### **Challenges in Teaching Children with Autism**

A problem faced by the teachers of NASOM when handling the children is when they start to hit puberty. The reason for these difficulties is that puberty can be an especially difficult time for young people with autism. It can be challenging for them to cope due to sensory and emotional difficulties, repetitive behaviours, and a lack of social nuances, perhaps needing more training for teachers. The different degrees of autism that are on a spectrum require tailor-made forms of teaching. Previous studies have indicated that good teaching methods could be incorporated, and improvements could be made to NASOM services like better teaching strategies (Bakar et al., 2022) and better quality of teaching skills (Bakar et al., 2020).

In addition to the teachers' struggles, indeed, there are also the parents' difficulties as some face self-denial, when the parents deny the condition of autism in their children. The reason for this denial could be multiple reasons; it could be the lack of education, high expectations or simply fear. Expectations from parents could be destroyed upon hearing about the condition of their children with autism. This could lead to neglecting the child's condition hence having an inadequate amount of information to help them assist their children and thus not giving their children education. Parents are important people in ensuring their children with autism can progress. There needs to be empathy from stakeholders as it is clear from previous studies that parents of children with autism go through a lot of stress compared to parents of typical children (Jx et al., 2017). One-sixth of caregivers in Pahang were depressed, anxious, and stressed (Fatin et al., 2021). Parents were stressed regardless of their education level, financial factors, and employment status (Helmi & Murad, 2022). Mothers who were sampled regarded their child's ASD symptoms and behaviour problems (e.g., hyperactivity and sleep difficulties) as impacting their well-being (Ilias et al., 2017). There is also the financial situation that needs to be addressed like the introduction of *Waqf* by a study as a way of financing the education of children with autism (Jani et al., 2022). The lack of knowledge and the need to seek knowledge on autism by themselves was seen as a challenge for parents (Yaacob et al., 2021). Training for parents would be helpful and could be conducted by NASOM (Siah & Tan, 2016). Acceptance and a positive outlook are collectively one of some key elements for parents to adopt when caring for their children (Yaacob et al., 2022).

On the other hand, regardless of the parents' acceptance of their child's condition, if they are not financially stable, it would be difficult for children with autism to get the intervention and education needed.

### **Lack of Awareness**

Lastly, awareness of the community of children with autism, is currently insufficient and inadequate. The first prerequisite of awareness by parents is acceptance. Once acceptance is embraced, finding a medium for parents of children with autism and the public to express their views is important. Once a platform is established, spread it to everyone. For instance, if a parent was not accepting their child's condition, how would the child reach out for help? If children with autism are unable to express themselves, how would the community be aware of them? Parents are the only individuals heavily participating in the educational process and will continue to be profoundly included in the child's school experience for the rest of his or her life (Logsdon, 23 May 2022; Tang, 2022). If they were to not be involved, not only would society be unaware of the children's needs, but it would also hinder the children's cognitive development.

The low awareness found in this study is supported by previous studies that found awareness of autism by the public at an all time low (Low et al., 2021) as they had a moderate level of knowledge (72 percent) and a low level of positive attitude (57 percent) towards ASD with many Malaysians not understanding autism (Azmi et al., 2022). The lack of awareness is more apparent in Malaysia than in the UK (de Vries et al., 2020).

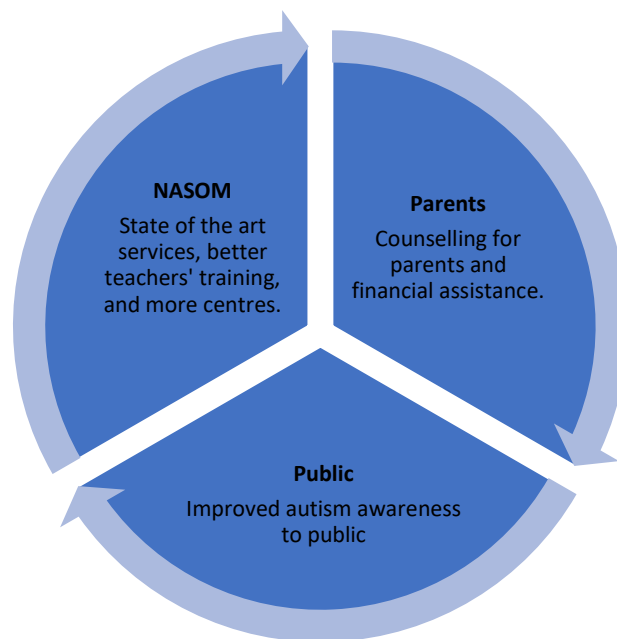


Figure 2: Theory of the Stakeholder Convergence of the Ideal Ambiance for Children with Autism

Figure 2 indicates the Theory of the Stakeholder Convergence of the Ideal Ambiance for Children with Autism. The ideal ambiance is made of three components comprising stakeholders that have to work together to build an ideal ambiance for bringing up a child with autism successfully. The stakeholders comprise NASOM, Parents, and the Public who need to come together in bringing up a child with autism.

## IMPLICATIONS/RECOMMENDATIONS

The following recommendations are made from the study:

### 1. NASOM Services

- a. More NASOM centres need to be built in Pahang to cater to more students with autism that are beyond 13 years of age.
- b. More training is needed for teachers at NASOM. They need to be sent for specialised training in dealing with children with autism using traditional and contemporary pedagogies with assistive technology as supported by previous studies (Bakar et al., 2022; Bakar et al., 2020). Schools for children with autism in Australia, the UK, and the US should be used as good examples and should be modelled after as seen in a previous study that found UK students were more accommodating of students with autism than Malaysian students (de Vries et al., 2020).
- c. More appropriate teaching facilities and programmes are needed to stimulate the children's cognitive ability. Batik painting and gardening alone are not enough to stimulate them and make them fit for integration into society. Assistive technological devices from robots to humanoids should be introduced to help students of all degrees of autism (Ahmad & Zulkharnain, 2020; Ishak et al., 2023; Shamsuddin, 2015).

### 2. Challenges

- a. Parents should be well-informed on their children's condition. A medical physician should advise parents early in the diagnosis of their children on appropriate centres and programmes to enroll their children in. Parents encounter a lot of stress (Fatin et al., 2021; Helmi & Murad, 2022; Jx et al., 2017) as they manage their children with autism and take a big role in ensuring they receive the education required (Tang, 2022). Parents could be offered free counselling by NGOs, and private and public institutions and be given training workshops so that their Quality of Life is enhanced (Siah & Tan, 2016).
- b. NASOM should garner more assistance from the government or private corporations for funding their centres and their students as parents feel burdened by the expenses of services needed for their children with autism in Malaysia and some researchers have proposed *Waqf* as a way of financing (Jani et al., 2022).
- c. The behaviours of students with autism should be managed better by teachers who could be better trained (Bakar et al., 2022). Students should not be allowed to act in inappropriate ways and should be taught right from wrong. There are several modules that could be created by academics in universities derived from research or sought by NASOM for its own use. For one, a multimedia interactive social skills module has been proven to be effective in improving the social skills of children with autism (Ibrahim, 2019).

### 3. Awareness

- a. More awareness is needed by the public on children with disabilities and more specifically children with autism. This can be done via the internet by including these children on posters and by showing their relevance in society.
- b. There was a visible Ronald McDonald sign on the wall of the building indicating that NASOM was being sponsored or had received sponsorship from the Ronald McDonald House of Charities. This shows the awareness of a private corporation and brand toward NASOM's existence. The government, the private sector, and the community need to do more in terms of creating awareness using the relevant media to target audiences. A lot of the previous literature has claimed that there is insufficient awareness of autism conveyed through social media (Low, Lay, et al., 2021; Thomas et al., 2020).

## CONCLUSION

Islam regards education highly and the Prophet Muhammad (peace be upon him) mentioned “*The seeking of knowledge is obligatory for every Muslim.*” Education is a fundamental human right for everyone according to the Universal Declaration of Human Rights, and this includes children with autism as supported by the United Nations Sustainable Development Goal No. 4: Lifelong quality education should be provided for all. The Malaysian government has also taken an initiative to protect children with disabilities' rights to education with the PwD Act 2008, that aims to protect disabled people and enhance their quality of life. There is an emphasis made on education in the Act, stating that children with disabilities shall not be prevented from obtaining education due to their disabilities. NASOM is one such initiative, as it provides education specifically for children with autism in Malaysia. Although there are many ways in which NASOM could be improved to keep up with the latest pedagogical methods and state-of-the-art teaching equipment, the centre itself is a good place by offering education to children with autism.

The case study used qualitative research methods providing the depth and richness of data. There were several limitations to the study. Qualitative studies cannot be used to generalise the findings to the population. This case study provides an in-depth examination of only one case in the form of NASOM Kuantan and this cannot be used to generalize to other NASOM centres in Malaysia. In the future, more interviews should be conducted in at least two NASOM centres to compare between them. In the future, quantitative research should also be done on parents and the community at large to gauge their attitudes, expectations, and perceptions of education for children with autism to provide more recommendations.

The study nevertheless was able to produce the Theory of the Stakeholder Convergence of the Ideal Ambiance for Children with Autism which puts forth the idea that for children with autism to be properly educated and having a good quality of life, there should be cooperation between three key stakeholders: NASOM, parents, and the public. There is room for improvement here as the roles of each stakeholder, assistance from the Government and the private sector provided to NASOM and the parents of children with autism need to be taking place for the ecosystem to work in facilitating children with autism in obtaining a better quality of life. Above all, awareness of children with autism so as to build empathy and assimilate the children in society needs to be augmented.

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