

Transitions of Young Adults with Autism Spectrum Disorder (ASD): Malaysian Parents' Perspectives

Nik Nadia Nik Nazri, Leela Koran

Faculty of Languages and Linguistics
University of Malaya

Kuala Lumpur, Malaysia

niknadia91@siswa.um.edu.my, leelako@um.edu.my

Abstract—Problem Statement: Research has shown limited opportunities for individuals with Autism Spectrum Disorder (ASD) once childcare services end. With a number of studies previously highlighting the prevalence of autism in children among the Asian population and the interventions undertaken that follow these results, it is imperative to now shift the focus to ASD among young adults and the issues that revolve around independent living. **Methods:** Structural observations and interviews were conducted with the parents of two sons identified to having varying degrees of ASD; a 21-year-old male with Asperger's syndrome, and his younger brother, a 19-year-old male with ASD at a more severe level. Semi structured questions were used to encourage respondents to express their views and elaborate on the various challenges faced during the period of transitioning for both children. The qualitative nature of this study gives us a valuable insight into dealing with the differences in ASD severity and revealed the trajectory of the progress from the point of diagnosis and other related matters that warrant attention. **Findings:** The parents report that they are left to deal with the challenges associated with transition as soon as the children with ASD reach a certain age. This is due to imminent withdrawal of the scaffolding provided via educational institutions and other establishments. It was also reiterated that while early interventions and special education are available in Malaysia for those diagnosed with ASD, an apparent limitation of the education system lies in the fact that these do not prepare the young adult with ASD for life beyond the system. The significance of these findings becomes evident in bringing into focus the challenges faced by parents of these children and their concerns about the future. This has implications for stakeholders, especially policy makers who need to invest in revisiting the targets and goals stipulated in Special Education Programmes. Parents' perspectives should be incorporated into both, the programmes for these children, as well as the training of special education teachers.

Keywords—Autism; transition; interview; observation

I. INTRODUCTION

Research into Autism Spectrum Disorder (ASD) is gaining attention in Malaysia with the increase in prevalence of reported cases of ASD [1,2, 3]. The National Autism Centre of Malaysia (NASOM) estimates a total of 9,000 children being born with ASD every year [4]. Recently conducted researches report on various issues concerning ASD such as awareness of characteristics of autism among parents and the general public [5] and medical students [6], communal support from social

media platforms for children with ASD [7] and school teachers' knowledge as well as perceptions [8], bearing evidence of research interest in this area. While most of these studies have addressed pressing concerns with a focus on the younger population with ASD in the country, information pertaining to those of the older age group is scarce.

The transitions of young adults with ASD in developing countries remain under-researched. Lifelong care and support are often mentioned as causes for concern in past studies even in developed regions [9], where researches revealed three frequently explored domains, namely social participation, school and work opportunities [10, 11, 12, 13], identified as challenges in transitions among young adults with ASD. Poor outcomes in these domains [14] consistently underpin worries among parents [15]. A focus on transition of youth and adults with ASD in setting the research agenda tends to be restricted to developed nations with more financial allocations for providing support for such individuals.

Little is known regarding the issues and challenges parents face in raising children with ASD in a developing country such as Malaysia and how these challenges affect their transitions. Thus, it is imperative to now shift our attention to the needs of the said individuals and investigate the commonly explored domains with a specific focus on Malaysian settings.

II. METHODOLOGY

A. Research Design

This study adopts a qualitative design using ethnographic observations and semi-structured interviews.

B. Setting & Participants

The setting for the initial observations was at a local support group and activity centre for parents with children on the autism spectrum in the outskirts of Kuala Lumpur, Malaysia. Parents of young adults with ASD were recruited for interviews. Data from only one set of parents of two individuals with ASD who are at the point of transitioning will be presented in this paper. Participants' identities were kept anonymous and will be referred to by the first letter of their initials, whereas the two individuals with ASD will be referred to as the initials, SY (21-year-old male with Asperger's Syndrome) and SJ (a 19-year-old male with severe autism).

The table below summarizes data pertinent to the participants that were interviewed.

TABLE 1: PARTICIPANT DATA

Participant	Gender	Age	Relationship with SY and SJ
Mr. L	Male	50+	Father, full time stay at home parent.
Mrs. L	Female	50+	Mother, full time working parent.

C. Data Collection Procedures

Structured observations of activities at the centre were carried out and field notes on these were recorded in two categories according to the context of observation and details of the interviews. Phillippi and Lauderdale’s (2018) [16] guideline provides the framework for this procedure. Both categories entailed information regarding the geographical setting, demographics, participants, interview responses, and critical reflections. This served as additional information that will complement the main interview data.

Interviews with the participants were conducted in two consecutive sessions; first with only the father and the second session with both the parents. The topics covered in the audio recorded interviews touched on domains included in research on transition of young adults and those with ASD [10, 17]. The participants’ responses were then transcribed and tagged to aid analysis. Interviews were conducted at the homes of the participants upon agreeing for appointment through prior meetings and text messages. Interviews lasted between 45 to 90 minutes.

D. Ethical Considerations

The participant information sheet detailing the data collection procedures were distributed to the potential participants. Their verbal consent was obtained prior to the interviews and written consent after the recorded data was reviewed with them. Interview questions were formed guided by the four major types of questions; hypothetical, devil’s advocate, ideal position and interpretive questions, used in research to elicit useful information in interviews [18].

III. FINDINGS

The parents’ responses during the interviews address their expectations about transition and their concerns about the future of the young adults with ASD. The data also include the narratives of their experiences in parenting the two children who had differing severity of ASD. The cause for their concerns can be traced back to diagnostic history and anecdotes about their children educational journey.

A. Parents’ Perspectives on Transition

The transition of the young adults with ASD into independent living was expected to occur at around the age when they complete their studies or when the educational support available to them was coming to an end. In the case of SY, as the 21-year-old was in his final year of a diploma course at the time of the interview, parental concerns about his potentials for moving on to live independently was evident. The following excerpt from the interview with Mrs L highlights both the parental concern related to transition and the challenges faced.

“For SY, I can say that he cannot be independent. Now he cannot be independent. Because from what I observe, he cannot lah. So, I need to guide him. Everything we also still need to guide him. But in terms of guiding him, we won’t obviously let him know that we guide lah. So just...give him more encouraging words, then he can go for, to step out for looking for his jobs lah.” (Mrs. L, Interview 2)

In contrast to SY, the parents recognised that for their younger son, SJ, although he had severe Autism, transition was expected to occur at an earlier age due to centres catering for children with autism halting services for individuals aged 18 and above. Since SJ was 19 years old at the time of the interview, his parent was concerned that “all these people (have) got nowhere to go” (Mr. L) when the scaffolding was withdrawn the year before. The following excerpt reveals the underlying belief that the parent held.

“At the end of the day, we will go away one day. We really need somebody to really take care (of them). And then these people who will take care of these people (adults with ASD) in a very caring...with a good loving heart. Taking care of these (type of) children” (Mr. L, Interview 3)

There is a notable difference in the two excerpts in terms of the expression of needs, i.e., for guidance and long-term care in the case of SY and SJ, respectively, that makes transition challenging. Mr. L asserted that there will not be a time when SJ can live by himself in the future even after attending simple life skills training or costly intervention programmes. Consequently, Mr. L looked for centres that provide full time care, as well as opportunities of guided work. His idea of guided work involves continuous close supervision during the working hours. Both parents agreed that SJ has a very short attention span. Observations of SJ in their home during the interview revealed that he was assigned tasks such as hanging clothes out to dry. While engaged in such tasks he was easily distracted leading him to abandon the task and wandering off. He was seen to be taking a long time to complete the task. Mrs. L reiterated Mr. L’s view that there must be constant supervision for SJ. Given this background, the parents are optimistic about the impending launch of a “shelter workshop” (Mr. L, Interview 2), a centre that offers monthly salary for guided work as detailed in the following excerpt.

“They will have the OT there. ...The workshop hour is from 10 to 4 o’clock lah, and this is for the daycare. Then the home, they need people to take care (of the workers). They need to employ all these people. (Mr. L, Interview 2)

At the time of the interview, the centre was still awaiting official procedures to be completed and to the best of his knowledge, it is the first of its kind to offer such services to persons with disabilities in Malaysia.

Although Mr. L foresees SJ spending his future at the shelter workshop, both parents remained uncertain about what lies ahead for SJ. Mrs. L considered options other than the shelter workshop such as arranging for SJ living with his brother, SY or extending his time at the “Life Chapel” (a church affiliated daycare centre for special individuals) (Mrs. L, Interview 2). Mr. and Mrs. L conclude that the future of independent living for SJ remains uncertain. Based on her observations of SY’s social interactions as well as the inconsistencies in his college and work performance, Mrs. L also formed the opinion that although he would be completing his studies soon, her eldest son is not ready for work or independent living, in general.

Factors Attributed to Challenges of Transition

Both the parents identify behavioral aspects of ASD and issues with the education system as the source of problems that arise during the transition stage.

Firstly, SY’s inability to form social relationships with the people around him and his underdeveloped sense of responsibility towards tasks assigned to him, be it in the form of college assignments or work-related tasks, were seen to be the root of the problem. Mr. L recalls that SY had friends during high school and even “now, but not so close.” (Mr. L, Interview 2). Nonetheless, SY was deemed competent in socializing at the workplace during his internship. According to Mrs. L as he often followed her to work and observed how she communicated with customers, she had the opportunity to focus on developing his social skills and participation in that context, constantly giving him advice on “how people treat you, how you go and build up relationship with people, how you handle the job...”.

SY’s early childhood and primary education experiences were marked with various incidents related to his behavioral difficulties. He was enrolled into three different kinds of schools during his primary school years; beginning with a Chinese vernacular school, an international school and finally settling into a government school. One interesting anecdote provided by Mrs. L illustrates SY’s inability to comprehend simple concepts in social situations which led him to being punished. The following excerpt shows SY’s lack of understanding about the concept of “stealing” and the related moral implications.

“That is the day that, when teacher come back and say he steal the book, I really punish him you know. He cry and cry and cry. To him, he... thought that he’s right, he didn’t do anything wrong. “I jaga (looked after) the book, the book (will) finish, of course I go take.” (Mrs L, Interview 2)

“During that time I didn’t know that type of children. So of, I would punish him lah.” (Mrs L, Interview 2)

The teacher’s negative reaction in this situation drove Mrs. L to also punish SY. The parent’s lack of awareness coupled with the teachers’ lack of knowledge about children with ASD in the end only further aggravated the problem. In particular, his

experiences with the teachers at the Chinese vernacular school saw SY repeatedly getting into trouble, while the experience at the international school brought them in contact with teachers who simply “don’t care” for students’ affairs (Mr. L, Interview 1) and academic performance.

Having had the experience of raising one child with ASD who was diagnosed at a very young age, made it possible for the parents to recognize early on the kind of assistance that SJ required. Consequently, he was enrolled into multiple intervention programmes (i.e. “NASOM”, “Life Chapel”, “Sensory Integration”, “speech therapy” and “music therapy”) where some of them had positive outcomes for SJ as attested in the following excerpt:

“In terms of work, I put him in ABA (Applied Behaviour Analysis) and ABA really worked on him. And he’s very good in copycat, imitation. That’s why, because he is good in imitation, that’s why now I can guide him to do job. What I do he just follow, follow.” (Mrs. L, Interview 2)

His enrollment into the ABA therapy improved SJ’s behavior and enabled Mrs. L to involve him in chores such as vacuuming and hanging clothes, albeit with full supervision. It appears that Mr. and Mrs. L had much fewer challenging parenting experiences with SJ than SY. However, Mr. L believed that these programs merely teach simple life skills and he emphasized SJ’s need for lifelong care makes the challenge of transition for SJ greater than that of SY.

B. Initiatives by Parents

The narratives exhibited sustained parental involvement from the diagnosis stage for the eldest son to exploring ways to improve the quality of life of both their sons. The excerpt below illustrates the interesting turn of events and the role they played that led to SY’s diagnosis of Asperger’s Syndrome at the age of 11.

“Then one day, I don’t know, Malay Mail or Star newspaper, somewhere come out. ...symptoms like my son. Really my son’s symptoms. Then from there only I go for the doctor. Dr. Suba and Professor Aimi. Have a write up about these types of children.” (Mrs. L, Interview 2)

It is evident that Mrs. L. was proactive in taking actions based on her newly gained knowledge and immediately brought SY for a second diagnosis (his first diagnosis at 4 years old of ADHD due to hyperactivity displayed during his preschool years). This was a major turning point for SY as what followed this diagnosis were significant in that it produced positive outcomes in terms of his behaviour and academic progress. His enrollment in the government school after the more definite diagnosis, Mrs. L recalls that she immediately saw “change” (Mrs. L, Interview 2). She was wholly convinced that this was due to the difference in the pedagogic style adopted by the teacher that suited children like SY as the following excerpts from both parents indicate:

“... (the teacher has) an objective for the children, and the children work for the objective and on top of

this one, they also got terms. ...you want them to study or do whatever work. So the children will follow and follow.” (Mrs. L, Interview 2)

“My son happy. (He) Go to school and said the teacher very good.” (Mr. L, Interview 2)

Following this, it appears that there were no major academic or behavioral issues during SY’s school years.

SJ’s early education was significantly less problematic. Nevertheless, the parents report to testing out a variety of interventions as mentioned in the following excerpt:

“During (SJ’s enrollment into) NASOM (National Autism Society of Malaysia) that time, everything try out. During that time, there is no info at all. Teacher also try out. Teacher will try everything and asked us to try essential oil. So, we just buy (essential oils) lah” (Mrs. L, Interview 2)

Mr. and Mrs. L persisted in their efforts to find the best intervention for SJ and tried “everything” and were fortunate that their attempts mostly produced positive results. They disclose that are still actively searching for the best intervention programme and centre for SJ. Faced with the lack of information and limited resources, these parents’ constant dedication to improving the quality of life for their sons saw them taking responsibility for dealing with the challenges of living with ASD as they feel both the SY and SJ are not ready for transition into independent living yet.

IV. DISCUSSION & ANALYSIS

A. Guidance & Scaffolding

A recurring theme in discussing transition for both the cases reported above was the inadequate support in early childhood that impinge on their readiness for independent living with ASD. Additionally, when most centres for autism and special education programmes in Malaysia cease to support them by the time the child reaches a certain age, parents are faced with the uncertainty of what the future holds for their children. As a result, parents such as Mr. and Mrs. L’s most likely continue providing guidance and scaffolding regardless of whether they are equipped financially or have the necessary resources [19]. These results are resonant with Mukaetova-Ladinska & Stuart-Hamilton’s [15] findings about the service users’ views on transition for adults with ASD. The strong need for more research on long term management of individuals on the autism spectrum encompassing their social and personal needs, regardless of the severity is reiterated.

B. Special Education Agenda for Teacher Training

Following the chance occurrence of finding a trained special education teacher in the government school for SY, challenges involving academic performance and school life became significantly reduced and this possibly enabled him to progress to college education. Such occurrences may be a rarity in Malaysia as a recent survey revealed that current special education teacher preparation programmes in Malaysia may still be inadequate for handling students diagnosed with ASD [20, 21]. Additionally, there exists neutral to negative perceptions in some areas of the country towards accepting children with ASD in mainstream schools in Malaysia, mostly due to the lack of awareness on ASD and limited knowledge on the appropriate teaching techniques [22]. Similarly, non-governmental organisations or special education centres should equip themselves better, as SJ’s successful experiences during his childhood with dedicated teachers and therapists have been beneficial to the child and his parents. As this finding exhibits the positive impact an understanding teacher or caregiver can have on a child with a developmental disability, it is imperative that necessary resources, support and professional training are provided in special education to ensure that effective teaching takes place for children with ASD [23,24,20] .

C. Parental Involvement

Although the findings of this study attest to the role that parents play in dealing with the continued need for scaffolding once the education programmes withdraw such support, heightened maternal involvement documented here is in line with how mothers have often been given the role of the primary caregiver for children with ASD [25] and their proactive steps in finding the best way to improve their children’s lives. Mothers of children with ASD have also been known to mention similar challenges such as frequent behaviour problems, toileting issues, and hyperactivity [26], all of which Mrs. L mentioned.

It is apparent that the young adults with ASD in this study have greatly benefitted from their parents’ initiatives, despite the subject of disability being fraught with misinformation and stereotypical views among the South East Asian society [27]. Furthermore, due to late diagnosis, there were more challenges for the parents. The present study underlines the importance of participation of parents in the diagnosis and interventions for individuals with ASD which is expected to lead them to eventual transition into independent living.

V. CONCLUSION

The findings from the interviews and observations in this research confirm the common concerns documented from families facing similar predicaments in developed countries. Although there are limitations in terms of the number of participants involved in the present study, the conclusion arrived at endorses the need for more researches to be done on young adults with ASD involving a larger sample size and even extend the possibility of exploring the perspectives from the young adults with ASD themselves to confirm or refute the evidence provided by their parents. Future researches should also consider factors such as geographical location to explore the issue of transition for those with ASD. Do the challenges faced differ in urban and rural areas? Does the socioeconomic status of parents affect their access to information regarding ASD and interventions? Are the challenges faced by parents of such young adults similar to those facing the present generation of parents? How will this affect the transition opportunities of the next generation of those with ASD?

The implications of the findings serve as a call for action from stakeholders and policy makers in Malaysia to review the goals of the current special education and the intervention programmes for children with ASD. Collaborations between parents and educators are also highly recommended. These steps are expected to ensure a smoother transition process for young adults with ASD and minimize the challenges faced by their parents.

ACKNOWLEDGMENT

The authors would like to thank the participants of this study for their valuable contribution.

REFERENCES

- [1] Ilias K, Cornish K, Kummar AS, Park MS, Golden KJ. Parenting stress and resilience in parents of children with Autism Spectrum Disorder (ASD) in Southeast Asia: A systematic review. *Frontiers in psychology*. 2018 Apr 9;9:280.
- [2] Draft Management of Autism Spectrum Disorder in Children and Adolescents. Malaysia:MaHTAS, Ministry of Development Division, Ministry of Health Malaysia, 2014.
- [3] Neik TT, Lee LW, Low HM, Chia NK, Chua AC. Prevalence, Diagnosis, Treatment and Research on Autism Spectrum Disorders (ASD) in Singapore and Malaysia. *International Journal of Special Education*. 2014;29(3):82-92.
- [4] The National Autism Society of Malaysia (NASOM), [Internet]. Available from www.nasom.org.my
- [5] Dolah J, Yahaya WA, Chong TS. Potential of interactive multimedia learning awareness (IMLA) in enhancing awareness of autistic characteristics among parents and society in Malaysia. *Electronic Journal of Computer Science and Information Technology (eJCSIT)*. 2011;3(1):19-25.
- [6] Low HM, Zailan F. Medical students' perceptions, awareness, societal attitudes and knowledge of autism spectrum disorder: an exploratory study in Malaysia. *International Journal of Developmental Disabilities*. 2018 Mar 15;64(2):86-95.
- [7] Roffeei SH, Abdullah N, Basar SK. Seeking social support on Facebook for children with Autism Spectrum Disorders (ASDs). *International journal of medical informatics*. 2015 May 1;84(5):375-85.
- [8] Majin M, Hashmi SI, Sombuling A. Teachers' knowledge and perception towards children with autism spectrum disorder (ASD): a preliminary study, 2017.
- [9] Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical psychology review*. 2014 Feb 1;34(1):73-86.
- [10] Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of autism and developmental disorders*. 2011 May 1;41(5):566-74.
- [11] Friedman ND, Warfield ME, Parish SL. Transition to adulthood for individuals with autism spectrum disorder: current issues and future perspectives. *Neuropsychiatry*. 2013 Apr 1;3(2):181.
- [12] Wehman P, Schall C, Carr S, Targett P, West M, Cifu G. Transition from school to adulthood for youth with autism spectrum disorder: What we know and what we need to know. *Journal of Disability Policy Studies*. 2014 Jun;25(1):30-40.
- [13] Baker-Ericzén MJ, Brookman-Fraze L, Brodtkin ES. Accelerating research on treatment and services for transition age youth and adults on the autism spectrum. *National Autistic Society*, 22 (1), 2018.
- [14] Hendricks DR, Wehman P. Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on autism and other developmental disabilities*. 2009 Jun;24(2):77-88.
- [15] Mukaetova-Ladinska EB, Stuart-Hamilton I. Adults with Autism Spectrum Disorder (ASD): service user perspective on ageing transition (s). *Journal of Autism*2016. 2015;2(1):1-1.
- [16] Phillippi J, Lauderdale J. A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research*. 2018 Feb;28(3):381-8.
- [17] Biggs EE, Carter EW. Quality of life for transition-age youth with autism or intellectual disability. *Journal of autism and developmental disorders*. 2016 Jan 1;46(1):190-204.
- [18] Strauss AL, Schatzman L, Bucher R, Ehrlich D, Sabshin M. *Psychiatric ideologies and institutions*. New Brunswick, NJ: Transaction, 1981.
- [19] Milen MT, Nicholas DB. Examining transitions from youth to adult services for young persons with autism. *Social Work in Health Care*. 2017 Aug 9;56(7):636-48.
- [20] Toran H, Westover JM, Sazlina K, Suziyani M, Mohd Hanafi MY. The preparation, knowledge and self reported competency of special education teachers regarding students with autism. *Pertanika Journal of Social Science and Humanities*. 2016 Mar 1;24(1):185-96.
- [21] Low HM, Lee LW, Che Ahmad A. Pre-service teachers' attitude towards inclusive education for students with Autism Spectrum Disorder in Malaysia. *International Journal of Inclusive Education*. 2018 Mar 4;22(3):235-51.
- [22] Razali NM, Toran H, Kamaralzaman S, Salleh NM, Yasin MH. Teachers' perceptions of including children with autism in a preschool. *Asian Social Science*. 2013 Sep 1;9(12):261.
- [23] Simpson RL. Evidence-based practices and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*. 2005 Aug;20(3):140-9.
- [24] Yeo KJ, Teng KY. Social Skills Deficits in Autism: A Study among Students with Autism Spectrum Disorder in Inclusive Classrooms. *Universal Journal of Educational Research*. 2015;3(12):1001-7.
- [25] Braunstein VL, Peniston N, Perelman A, Cassano MC. The inclusion of fathers in investigations of autistic spectrum disorders. *Research in Autism Spectrum Disorders*. 2013 Jul 1;7(7):858-65.
- [26] Ilias K, Liaw JH, Cornish K, Park MS, Golden KJ. Wellbeing of mothers of children with "AUTISM" in Malaysia: An interpretative phenomenological analysis study. *Journal of Intellectual & Developmental Disability*. 2017 Jan 2;42(1):74-89.
- [27] Wong ME, Poon KK, Kaur S, Ng ZJ. Parental perspectives and challenges in inclusive education in Singapore. *Asia Pacific journal of education*. 2015 Jan 2;35(1):85-97.