PARENTS' PERSPECTIVES OF THE TRANSITION TO INDEPENDENT LIVING FOR YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER

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2022

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DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS (LINGUISTICS)

FACULTY OF LANGUAGES AND LINGUISTICS
UNIVERSITI MALAYA
KUALA LUMPUR

2022

UNIVERSITY OF MALAYA
ORIGINAL LITERARY WORK DECLARATION

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Matric No: TOA160014

Name of Degree: Master of Arts (Linguistics)

Title of Project Paper/Research Report/Dissertation/Thesis ("this Work"): Parents' Perspectives of the Transition to Independent Living for Young Adults with Autism Spectrum Disorder

Field of Study: Human Communication Disorders

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PARENTS’ PERSPECTIVES OF THE TRANSITION TO INDEPENDENT LIVING FOR YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER

ABSTRACT

Aim: This present study aims to explore parents’ perspectives on the transition to independent living of young adults with ASD in Malaysia, particularly in the domains that define transitioning, namely; social participation, school and work opportunities. **Methodology:** Semi-structured interviews were conducted with 4 parents of young adults with ASD where they expressed their views and elaborate on the various challenges faced during the period of transitioning for their children related to these domains. **Findings:** All the parents held the view that the young adults with ASD were not ready for transition to independent living despite being of the age expected to. This is attributed to various factors including lack of public awareness, teachers’ limited knowledge of strategies for dealing with children with ASD, financial limitations to consider other alternatives and the limited number of centres that provide long term support were the issues raised by parents of young adults diagnosed with autism. As for parents of the young adult diagnosed with Asperger’s Syndrome, difficulty in social communication was consistently highlighted. However, they are hopeful for the future if there is an improvement in the awareness among society, schoolteachers and professionals, as well as increased efforts to create a more conducive and supportive school and working environment for your adults with ASD. **Limitations:** Repeating this study in rural areas and with more participants may increase generalizability of study.

PERSPEKTIF IBUBAPA MENGENAI PERALIHAN KE KEHIDUPAN BERDIKARI BAGI BELIA YANG MENGALAMI KECELARUAN SPEKTRUM AUTISME

ABSTRAK

Tujuan: Kajian ini bertujuan untuk meneroka perspektif ibu bapa mengenai peralihan kepada kehidupan secara berdikari bagi golongan belia yang mengalami ASD di Malaysia, terutamanya dalam domain yang mentakrifkan peralihan, iaitu; penyertaan sosial, sekolah dan peluang pekerjaan. **Metodologi:** Temu ramah separa berstruktur telah dijalankan bersama 4 ibu bapa kepada belia dengan ASD yang menyatakan pandangan mereka dan mengulas tentang pelbagai cabaran yang dihadapi sepanjang tempoh peralihan untuk anak-anak mereka yang berkaitan dengan domain-domain ini. **Dapatan Kajian:** Kesemua ibu bapa berpandangan bahawa belia dengan ASD tidak bersedia untuk beralih ke kehidupan secara berdikari walaupun telah sampai usia yang diharapkan untuk berbuat demikian. Ini adalah disebabkan oleh pelbagai factor seperti kurangnya kesedaran masyarakat umum, pengetahuan terhad guru-guru berkaitan strategi menangani kanak-kanak penghidap ASD, kekangan kewangan untuk mempertimbangkan alternatif lain dan terhadnya bilangan pusat yang menyediakan sokongan jangka panjang merupakan isu-isu yang dibangkitkan oleh ibu bapa kepada belia yang didiagnosis dengan autisme. Bagi ibu bapa kepada belia yang didiagnosis mengalami Sindrom Asperger, kesukaran dalam komunikasi sosial sering diketengahkan. Namun, mereka berharap untuk masa hadapan jika ada peningkatan kesadaran di kalangan masyarakat, guru sekolah dan golongan profesional, serta peningkatan usaha untuk mewujudkan sekolah dan persekitaran kerja yang lebih kondusif dan yang mampu memberi sokongan kepada belia dengan ASD. **Batasan Kajian:** Dengan cara mengulangi kajian ini di kawasan luar bandar dan dengan penglibatan lebih banyak peserta dapat meningkatkan generalisasi kajian.

ACKNOWLEDGEMENTS

First and foremost, I would like to thank my esteemed supervisor Dr. Leela Koran for her tutelage, invaluable advice, meticulous scrutiny, and patience during the making of this research study. She has guided me through every stage of this dissertation and this work would not have been possible without her. I would also like to thank the lecturers and fellow researchers for providing me with their insightful comments and suggestions to help improve my dissertation. My deepest gratitude also goes to the respondents who were so willing to agree to, as well as volunteer to be a part of this study. Their contribution to this study was highly appreciated and I hope results of this study would be of some help to them in the future.

My appreciation also goes to my family, friends and work colleagues who have given me their emotional support during my postgraduate journey, with special thanks to my close friends Yap Sook Yee, Chen Tien Mie and Rabiatul Adawiyah Rafihi for their continuous encouragement.

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CHAPTER 1: INTRODUCTION

1.0 Background of Study

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disability which varies in terms of severity and type of symptoms observed in different individuals (DSM-5: American Psychiatric Association, 2013). With increasing ASD prevalence rate among children reported in various developed and developing countries (Lim, 2015; Kim, Leventhal, Koh, et al., 2011; Friedman, Warfield & Parish, 2013), service provision planning and social policies for long-term support for such individuals become important. In their review of research on services for adults with ASD, Shattuck, Roux, Hudson, Taylor, Maenner and Trani (2012) list education, employment and social participation among the key areas that determine successful outcomes for these individuals as they transition to independent living. In a related paper, Sosnowy, Silverman and Shattuck (2018) conclude that development of services aligned with the needs of individuals with ASD should begin with the perspectives of affected individuals themselves and collaboration of their family members and the society, as well as policy makers. Success in transitioning to independent living for young adults with ASD impacts the quality of life (QOL) of the individual and his or her family. These findings have strong implications for the individuals with ASD and their families in developing countries where the condition and needs of the individuals have only recently received research attention.

1.1 Statement of Problem

A majority of the recent studies that have been conducted on ASD have been primarily on children with ASD research and less research have focused on those who have transitioned to adulthood or are during the transition age (Taylor & Seltzer, 2011). To date, there has been few reviews that have investigated ASD in transition age youth and adulthood where much of the past research that has been conducted was in the west within the context of varying government policies and societal views (Wehman et. Al., 2014; Baker-Ericzén, Brookman-Frazee, & Brodkin, 2018; Tobin, Drager & Richardson, 2014). Baker-Ericzén, Brookman-Frazee & Brodkin (2018) have also noted that this area of research is still in its infancy and suggests for more research on treatment and services for transition age youth and adults on the autism spectrum.

With limited documentation on ASD research in developing nations (Daley, Weisner & Singhal, 2014) such as Malaysia, studies on young adults with ASD who have reached the age at which scaffolding provided through educational institutions are no longer available are even more scarce. Studies related to ASD in Asia in general are lacking, with even the prevalence of ASD in Malaysia to this date remains unknown with no updated official statistics (Eow, Gan, Lim, Awang & Shariff, 2020). Furthermore, ASD is widely considered a topic that is often faced with stigma and discrimination among Asian communities (Ilias et al., 2018) which may have contributed to its lack of qualitative studies where interviews and field notes are often involved. It is however worth noting that research area in ASD have only recently been gaining traction in Malaysia; one study by Kamaralzaman, Toran, Mohamed and Abdullah (2018) explored the economic burden of families with children with ASD, whereas other local studies (Ilias, Liaw, Cornish, Park & Golden, 2017; Teo & Lau, 2018; and Chu et al., 2020) used interview data of parents of children with ASD. However, these researchers have also stressed on the need for more studies of the same vein.

1.2 Rationale of Study

As the present researcher is from an education background, by looking into the obstacles faced by parents related to schooling, employment and socializing, this will give a more thorough understanding on how to accommodate to the needs of a student with ASD during their childhood and adolescent years. This information will be of great use in thinking of ways to prepare students with such disabilities or learning difficulties for transition to independent living and will be useful information for other parents, teachers, and policy makers. With matters such as inclusive education in the country being a concern and teachers having limited knowledge of handling children with disabilities (Min & Wah, 2020), it is vital to identify what is lacking and what can be maintained in the country's education systems. This will aid in the planning of special education arrangements that best cater to those with ASD with the hope of giving these individuals better preparation for facing adulthood, which in turn will improve their quality of life.

Personal experience of the present researcher having a family member with ASD (Asperger's Syndrome) is one of the reasons why this study is being conducted. Although communication has always been a challenge among family members, it became increasingly more difficult after he has completed secondary school studies and is now continuing his studies in college far from home. Conducting this study would hopefully shed some light on how other parents of young adults with ASD cope with such challenges and share their own experiences of raising a young adult with ASD in the country, especially with the consideration of the available governmental policies and services. By getting different perspectives from people who have family members with ASD (not limited to Asperger's Syndrome but all spectrums of ASD), this would not only help the present researcher's family members, but also provide useful information for other families facing similar predicaments.

1.3 Significance of Study

With ASD studies in Asia focusing mainly on its prevalence among society and its interventions among children, (Hossain et al., 2017), there is a great need to now proceed in improving the quality of life of these individuals who have become adults or are in the transitioning period into independent living. With that, research that is qualitative in nature should be increased to complement data from the quantitative studies.

The present study which uses semi structured interviews, would help gain deeper insight of the challenges faced by families living with a family member with ASD who is transitioning into independent living in a country with differing social structures and mentality to the west. There may exist different approaches taken by parents, teachers and the society in general which may help in a better understanding of those with ASD in Asia. Parents and teachers may also take into consideration results of this study to develop more ways of improving the developmental process for those with ASD. More programmes and services on creating awareness can be developed by policy makers of the country if more evidence from a variety of ASD research are provided.

1.4 Research Questions

The following research questions will guide this study;

1. How do parents express their perspectives on the young adults' readiness for transition into independent living?

2. What do the linguistic expressions/ resources used by the parents reveal about the challenges faced raising their children with autism and Asperger's Syndrome?

3. What are the salient linguistic features in the parents' discussions of their plans and hopes for the future support of young adults with ASD in transitioning into independent living?

1.5 Definition of Terms

The three terms, ASD, transition age and independent living will be frequently used throughout this study. The three terms are explained in more detail to delve deeper into their definitions from various literature.

1.5.1 Autism Spectrum Disorder (ASD)

The American Psychiatric Association (2013) defined autism spectrum disorder (ASD) as individuals who possess persistent deficiencies in social participation, with behaviours, interests and activities that are repetitive and often stereotyped. In reference to a draft by The Ministry of Health, Malaysian Psychiatry Association and Academy of Medicine Malaysia in their Draft Management of Autism Spectrum Disorder in Children and Adolescents (2014), a similar definition was given where ASD is described as "a neurodevelopmental disorder characterized by impairments in communication, behaviour and social functioning beginning in childhood." The draft further lists the common co-morbidities frequently associated with ASD such as intellectual disability, attention deficit hyperactivity disorder (ADHD), sleeping issues, epilepsy, gastrointestinal problems, motor coordination as well as other psychiatric disorders (e.g. Tourette syndrome, chronic tics, anxiety/phobic disorder, depressive disorder and oppositional/conduct disorder).

As stated in the definitions given, impairments in social participation and ASD related behaviours are more apparent and present during the early stages of childhood, though these symptoms may return during adolescence and adulthood (Mason et. al, 2019). Despite previous studies suggesting ASD may be hereditary, there is currently still no concrete evidence that proves this (Shailesh, Gupta, & Ouhtit, 2016). ASD have also statistically been proven to be more prevalent among males than females at a ratio of 4:1

(Yeargin-Allsopp et al., 2003), supported by most of the literature that featured a prominent number of males than female, including this present study.

ASD, an umbrella term for individuals with autism ranging from all spectrums, will be used throughout this present study, with the participants of this research diagnosed with Asperger's Syndrome (mild form of ASD) and autism (severe form of ASD). Wiggins et al. (2019) stated that, "a diagnosis of autistic disorder requires the presence of at least six of 12 total symptoms from three domains (two social, at least one communication, and at least one behavioral), and onset before 36 months of age. A diagnosis of Asperger disorder specified qualitative impairments in social interaction and presence of restricted interests and repetitive behaviors, but no cognitive, language, or non-social adaptive delays noted in early development."

In their study on symptoms of Autistic Disorder (autism) among adults and adolescents, Seltzer et al. (2003) recognized "behavioral concerns (obsessions, aggression, tantrums), social and communicative concerns (inappropriate or inadequate social skills) to be among the frequent tell-tale signs of one who is diagnosed with ASD and autism. This study focused on three domains that are frequently associated with those that have autism; communication (e.g. spoke in phrases of at least three words daily, nonverbal communication such as pointing to express interest, conventional gestures, nodding and shaking to indicate yes or no, stereotyped utterances, idiosyncratic language, echolalia), reciprocal social interaction (e.g. nonverbal behaviours that regulate social interaction, social relationships, shared enjoyment, socioemotional reciprocity) and restricted, repetitive behaviours and interests (unusual preoccupations, repetitive behaviour and mental acts, hand and finger mannerisms, complex body movements, repetitive use of objects, unusual sensory interests, circumscribed interests). The study discovered that in all three domains, symptoms in adults are less severe than adolescents.

Though Asperger's Syndrome is often defined as having similar symptoms with those with high functioning autism, some studies have attempted to differentiate between the two (Koyama, Tachimori, Osada, & Takeda, 2007; Noterdaeme, Wriedt, & Hohne, 2010). The major diagnostic difference between the two ASD subtypes, Asperger's Syndrome and autism, is that language acquisition occurs at the expected age for individuals with Asperger's Syndrome. However, those with Asperger's Syndrome struggle with grasping social situations and the pragmatic aspects of verbal communication when communicating with those who are typically developed (Koyama, Tachimori, Osada, & Takeda, 2007). After exploring the various definitions of both subtypes, to understand the participants recruited in this study better, the present researcher uses the definition of Asperger's Syndrome over the definition of High Functioning Autism as the participant involved in this study was officially diagnosed with the former, and the other children, autism (also referred to as Autistic Disorder in some studies).

1.5.2 Transition Age

Transition age may be termed as "transitional age youth" (Chan, 2017; Martel & Fuchs, 2017) or "age of transition" (Harris, Freeman, & Duke, 2011) in literature. The term "transition age" that will be frequently used in this present study generally shares the same meaning as the other alternative terms mentioned, a phase where independence is imminent and one must face various demands of adult life such as educational planning, ways to seek for employment as well as time and money management (Mmusi & Van Breda, 2017).

There have been various definitions of the term within medical and social sciences literature and it was found that the age group for the transition age vary among countries and researchers. By observing recent literature that involve participants or subjects in their transition ages, among the defined ages ranged from 18 to 25 years old (Cargnelutti et al., 2021) and 16 to 24 years old (Lund & Cmar, 2020). In the ASD Draft by the Malaysian Ministry of Health, it was highlighted that the transition age is classified as those who have exited the school system, indicating the age range to be approximately 18 years old to 22 years old. As this study is using the Malaysian context, the present researcher will use the definition of transition age given by the Malaysian Ministry of Health as this will aid in a better understanding of the responses given by the parents.

1.5.3 Independent Living

"Independent living" can also be referred to as "autonomy" in literature related to other types of disabilities (Stefánsdóttir, Björnsdóttir, & Stefánsdóttir, 2018; Frielink, Schuengel, & Embregts, 2018; Oguntayo, 2021). Inguglia, Ingoglia, Liga, Coco, and Cricchio (2015), in their study on autonomy and its relation to adolescence and emerging adulthood, defined autonomy as changes in one's physical and cognitive abilities as well as one receiving more responsibilities and rights as an individual. Their study also discusses its relation to parents, as with other studies involving independent living or autonomy (Daddis & Smetana, 2005; Burke, Arnold, & Owen, 2018; Miller, Schleien, White, & Harrington, 2018), indicating parents as an important factor in one's transition to independent living. Although making decisions and having one's own preferences are the basic rights to all individuals, Clark, Olympia, Jensen, Heathfield, & Jenson (2004) opined that those with disabilities may be faced with certain limitations to these rights.

Hence, by relating back to the earlier definition of ASD and its subtypes, autism and Asperger's Syndrome, parents may have differing ideas as to what 'independent living' means and what it encompasses. Their definitions will be coloured by their children's competence and abilities in which will determine their thoughts on their children's readiness for transition into independent living, an insight where the present study may be able to provide.

1.6 Limitations of Study

There are a few limitations to this study that should be addressed. As the results of this study focuses exclusively on respondents from Malaysia, these perspectives may only be applicable to the Malaysian context or among similar countries. Therefore, generalizability of this study may be lesser for researchers from non – Asian countries. Furthermore, with the setting of the present study being in the urban settlements, results may differ from those who are from the rural parts of the country and may not be applicable where less services are accessible.

Readers may also consider the sample size used in the study to be too small for the purpose of generalizability. As with all research that are qualitative in nature, it is common to have few participants. In the case of this present study, data from three families were used, and as the goal of this study is to gain insight, detailed responses of the participants' experiences, it is fitting that the data is taken from these three families where extensive data collection and analyzation can be made. Stake (1978) supports this and believes that case studies (often using individual cases) may be epistemologically similar with readers' experiences, "thus to that person, a natural basis for generalization".

Lastly is the limitation where only parental accounts were used and not the young adults themselves. As this condition involves a spectrum of disorder, the range of severity would vary. Some of them remain non-verbal throughout their lives while others may continue to have difficulties with social communication. This being the case, it is the norm in our society for parents to continue to play the role of decision-makers for young adults with ASD. This thus becomes a barrier for direct participation of individuals with ASD in studies on issues that impact them. When accessing the perspectives of the individuals with ASD is not feasible, the input from their family members can give us equally valuable insights.

1.7 Conclusion

This chapter addresses the background and the problem statement in the context surrounding this study as well as the reasons behind conducting this study. The background, statement of problem, rationale and significance of study have been forwarded, along with the primary research questions that will be guiding this study, definition of a selection of terms that will be used frequently in the following chapters, as well as the limitations of the study. Chapter Two will be discussing the various past studies revolving around the research topic in more detail.

CHAPTER 2: LITERATURE REVIEW

2.0 Introduction

This study sought to explore parents' perspectives on the transition of young adults with autism spectrum disorder (ASD) to independent living in Malaysia. The following literature review will synthesize and evaluate the related literature surrounding this research area.

One research paper that has driven this present study forward is the paper titled 'Services for Adults with an Autism Spectrum' Disorder (Shattuck, Roux, Hudson, Taylor Maenner, & Trani, 2012). As the main purpose of the study is to investigate parental experiences of children with ASD during their transition stage, one must first identify the most frequently researched domains that determine a successful transition into independent living, and this study provided a review of literature on services that support the success of transition for young adults with ASD and listed the domains of social participation, education, and work opportunities for adults with ASD. Success in these three domains have been shown to determine the improvement in quality of life for individuals with ASD. The study highlighted the lack of findings on areas such as socioeconomic positions, issues of service cost/efficiency, studies on adults aged 29 years and younger, where most of the studies that were found focused more on employment. This review concluded these areas to be investigated further to move this research forward.

This literature review is divided into five sections. The first section reviews the discourse analyses variations such as critical discourse analysis and systematic functional linguistics that can aid in the analysis of the responses. The second section delves deeper into discourse studies but with a focus specifically on the area of disabilities. Next, the review is further narrowed down to disability discourse studies that primarily focus on ASD. To provide some background information on ASD, the second last section informs on the latest research in ASD such as the advancements that have been made, along with the current state of awareness on ASD among the public and stakeholders. With much of the ASD research revealing issues focused on individuals with ASD during childhood, the last section addresses the few recent studies that reveal the issues relating to individuals with ASD who are in the middle of transitioning or have already transitioned into adulthood. The latest research associated with these groups of individuals' issues and challenges that were commonly highlighted were found to be in the domains of social participation, work and school opportunities, which will be highlighted in the section.

2.1 Discourse Variations

In this section, we first look at the types of discourse that have been used in studies of disabilities through the analysis of narratives as the present study is in the qualitative nature. Jørgensen and Phillips (2002) in their book, Discourse Analysis as Theory and Method, defined the meaning of 'discourse' as *"the general idea that language is structured according to different patterns that people's utterances follow when they take part in different domains of social life, familiar examples being 'medical discourse' and 'political discourse'. Discourse analysis is an analysis of these patterns."* (p.1). Qualitative studies on disabilities have used a variety of discourse analyses to gain a deeper understanding of how disability is constructed by the individuals with disabilities and their families. (Avdi, Griffinm, & Brough, 2000; Broberg, 2010; Lavlani, 2015; O'Byrne, & Muldoon, 2018). Before we proceed to review findings from these studies, it is crucial that we look at the types of discourse analyses that can potentially be used for analyses.

Bucholtz and Hall (2005) proposed a framework to analyse identity through linguistic interaction. Five principles were proposed with the first being the emergence principle where the authors suggest that identity emerges from the specific conditions of linguistic interaction, something constituted through social action and language. Recognizing that identity is emergent can be seen in cases where the speaker's language does not follow the social category in which they are normatively assigned to, in other words, speakers using linguistic forms (e.g. idiomatic phrases and lexical items) that are generally understood as not 'belonging" to the speaker. The second principle is the positionality principle suggesting a correlation between the social behaviour with age, social class and gender (macro identity categories). These can be seen through how the speaker position themselves in society using language that imply these macro identity categories such as the speaker's age or social class. While the first two principles related to the nature of being of the speaker, the third principle, the indexicality principle, concerns the mechanism in which the identity is constituted where linguistic forms are used to construct identity positions. This may be through overt mention of the identity categories or labels, implicatures and presuppositions of the speaker's or other's identity positions, evaluative and epistemic orientations to ongoing talk, interactional footings and participant roles, and lastly through the use of linguistic structures and systems conforming to specific personas and social groups. Hence, the processes of labelling, implicature, stance taking, and code choice contribute to constructing identities, both in the micro and macro sense. The fourth principle is the relationality principle that emphasizes identity as a relational phenomenon, highlighting the sameness/differences, genuineness/artifice and authority/delegitimacy. Lastly, the fifth principle, the partialness principle attempts to capture the dynamic of how partiality is construed by one kind of identity relation and how it is produced through contextually situated and ideologically informed configurations of self and other. These five principles represent the various ways in which researchers approach the subject of identity.

Additionally, Stamou, Alevriadou, and Soufla (2016) gives an example of the use of Critical Discourse Analysis (CDA) to analyse the representations of three disability groups (blind, deaf and those with physical disability) on a social media platform from the perspectives of individuals with disability and their families. Categorized according to the three conceptual models of disability, namely the individual/medical, minority/social and affirmative, Fairclough's (1992, 2003) sociocultural strand as a framework was also used to guide the analysis. The study attempted to link the micro-level of text and talk to the macro-level of underlying power relations in society through the discursive practices upon which language use is drawn. One of the major analytical resources frequently used to analyse text is Hallidayan linguistics (Halliday, 1994). Discourse first focuses on the text, focusing on what the speaker says or do not and how they say it, contributing to the meaning conveyed. When we use language, we produce three types of functions, ideational (producing a particular version of the world), interpersonal (expressing attitudes and the building of social relationships with others) and textual (organizing both the ideational and interpersonal information of the text in a coherent whole). Second, discourse is also viewed as a discursive practice involving the processes of text production and consumption, taking into consideration the norms and conventions in producing or interpreting a particular text. Third, discourse is also considered a social practice which refers to the broader social context that influences the text and discursive practice, which includes the ideological effects and power relations with which these texts imply. Therefore, the study focuses the ideational and interpersonal meanings of Facebook posts, where the ideational aspects were considered tools of lexicalization (lack or abundance of words talking about a specific subject may mark the speaker's indifference or preoccupation with it) and transitivity (interpreting experience through processes in the speaker’s use of grammatical category of verbs and nouns). As for the interpersonal analysis of the posts, the ‘personal deixis’ (references made about the speaker and/or reader/hearer and the social relationship established between them through selection of the person in personal or possessive pronouns), ‘speech acts’ (assertive, expressive, directive act, commissive and declarative acts) and ‘evaluation’ (construction of the speaker’s role through the expression of their feelings and subjective judgements in the text such as the use of the evaluative adjectives/adverbs) were considered. Outcome of this CDA study revealed that people with disabilities and their families showed the different representations of disability varied in their use of the social media platform as well as possessing diverse views and ideological standpoints on how they identify disability and their attempts to overcome their challenges.

Extending the use of Hallidyan linguistics, Systemic Functional Linguistics (SFL) is another qualitative tool to analyse interviews in discourse (Fernandez, 2018) where semantic meanings can be revealed through the grammatical and lexical choices of the respondent. To show an example of the use of SFL systems of analysis on an interview text, the researcher analysed one excerpt on how an interviewee construed her experience as a foreign language learner using thematic analysis, mood system and appraisal analysis, as well as the ergative analysis. Procedure of analysis began with dividing the text into clauses, then the text was analysed in terms of the SFL systems, identifying the patterns and choices connected with contextual aspects, then lastly interpreting the significance of the text’s organizational choices written to highlight meaning of the text. Similar to the previous study’s use of CDA, this study defined the three sets of systems of lexicogrammatical choices by Halliday and Matthiessen (2013) and Thompson (2014), analysing the textual (text flow), interpersonal (interactional meaning) and ideational (representational meaning) metafunctions. The data of the study were presented according to systems, namely the thematic, mood and transitivity systems. Through the metafunctional analysis of the interviewee's linguistic choices, it can be seen how the interviewee had viewed herself at the centre of her learning process, how she experienced this process in a positive way that is different from her experience, as well as assess how SCOBA (Schema for the Complete Orienting Bases of Action) is an important educational tool, giving the researcher a deeper understanding the student's awareness of her own learning process. Through the various SFL systems previously mentioned, at the textual level, the interviewee suggested many themes to express how importance learning Italian was for her. On an interpersonal level, the interviewee reacted positively towards the use of SCOBA. Finally, at the ideational level, the interviewee detailed how learning Italian with SCOBA was important for her. SFL facilitates qualitative research where social meanings mediated through the linguistic choices are highlighted.

2.2 Disability Discourse

With the subject of the present study on ASD, it is important for us to look now into discourse variations within the area of disabilities. This will be vital in helping us comprehend how society generally perceives disability in their thinking and speech and how this too directly influences the interactions and expectations of individuals with disabilities (Haegele & Hodge, 2016). Stakeholders such as parents, teachers and the government play important roles in help shape the conceptualization of disability as their mindsets will also affect how these individuals see themselves in relation to their disabilities and their competence (Haegele & Hodge, 2016). Hence, review of the disability discourses will aid researchers in how to improve on the available findings on how we as a society define and discuss the topic of disability in favour of a more inclusive society for the disabled community.

As of today, there exists two theoretical models of disability that have been widely used in past studies, namely the social model and the medical model (Haegele & Hodge, 2016). The medical model of disability views disability as an impairment in an individual, something that must be “fixed”, drawing a distinctive line between an individual who is typically developed, and an individual who is atypically developed. This view may be an influence from how the medical syllabus are taught in some medical schools where students progress from learning about the “normal” human body (normal structure function and behaviour) then later study about the “abnormal” human body (abnormal structure function and behaviour) before they enter the clinical stages of their medical course (Brauer & Ferguson, 2015). Therefore, medical doctors are supposedly the “cognitive authority” when it comes to the conceptualization of disabilities as their views will be wholly supported by scientific facts where such impairments must be cured with the aim of normalizing the human body as they have been taught (Humpage, 2007). The social model on the other hand views disability as “unique” to an individual (instead of “fixing”, society must adjust oneself to suit the social environment that an individual with disability is living in), where the subject of “social inclusion” and “participation” have been frequently advocated for by scholars and disability activists (Humpage, 2007). The social model of disability promotes the increase of empathy and awareness people with disability while simultaneously decreasing the environmental barriers that exist in the society (Haegele & Hodge, 2016). Instead of catering to the society, the society is required to be more understanding and cater to these individuals.

Haegele and Hodge (2016) and Grue (2017) published critiques of both models where they highlighted its strengths and weaknesses. One of Grue’s (2017) notable insights is that while the classification of disability using the medical model may lead to multiple government incentives and benefits, this may also limit one’s opportunities for education and employment at places with non-disability friendly environments (e.g. infrastructure, awareness). As for his critique of the social model, eliminating the biophysical causation from the individual in discourse also does not represent one’s full disability experience.

Haegele and Hodge (2016) agrees and concludes in their findings where they offered a third perspective besides the two models, an "embodiment" (of the social and medical models). This embodiment, as opposed to referring to the existent models, encourages society to have individuals with disabilities be included in the planning and implementation of the accommodations and modifications made that will suit their needs best.

Nonetheless, these models can also serve as useful tools for discourse analysis of how society views and reacts to disability through parents' and caregivers' responses. Manago, Davis and Goar (2017) applied the use of social and medical models into examples of stigmatization from parents of children with disabilities. The study examines the use of four combinations of stigma resistance techniques, namely, medical challenging (invoke medical labels to educate about disability/use as reasons for child's behaviour during tense encounters or strangers' negative evaluations), medical deflection (behavioural and medical adjustment to tone down disability to have children "fit in"), social challenging (request for society to make amendments and modifications to infrastructure and communication to accommodate to individuals with disabilities) and social deflection (apologize, hide impairments and avoid encounters with society to protect child from stigmatization). Findings showed that parents applied the use of the social and medical models to varying situations and whenever they feel the need for either model (e.g. invokes the medical model with use of medical labels when faced with moments of stigmatization, invokes the social model when attempting to challenge inconvenient infrastructure for the disabled).

Elsewhere, discourses that correlates disability with other marginalizing factors such as gender and settlements have also been brought to light. Don, Salami and Gajarieh (2015) applied disability discourse in the context of girls with disabilities in rural Iran where the researchers investigated the interaction between gender, disability and rurality (Bryant & Pini, 2010) also with the use of narratives. The study aimed to give voice to the three commonly disadvantaged groups, namely girls, people from rural areas and people with disabilities. As this study emphasizes on the gender, instead of using the medical and social models, a gendered discourse framework was used to conduct the linguistic analysis (Sunderland, 2004) where relevant linguistic features (e.g. ideas, opinions, behaviour) that were involved in helped to shape these discourses were scrutinized within a particular context, whereby in the case of this study, girls with disabilities in a rural area of Iran. Their findings highlighted numerous challenges faced by the girls such as discrimination among society, transportation and mobility issues within the school compounds, as well as discrimination from the teachers, classmates and school staff.

However, Manago, Davis and Goar (2017) concluded that neither of the two models have managed to capture the whole experience of one possessing a disability. Therefore, regardless of which frameworks are used in discourse, there is a need to have more studies that use lived experiences of these individuals to understand the viewpoints from those with the disability themselves. It is hoped that such future narrative studies are able to produce a new model of disability which can either merge or be independent of the medical and social models for discourse as this new model may be a more accurate representation of individuals with disability as it takes into account entirely from the ones who are experiencing the disability themselves or those who have experienced raising the individuals with disability themselves and not through the lens of doctors, scientists, advocates and scholars. With that, it is hoped that the present study can fill in this research gap by including responses of the parents of persons with disabilities where we may be able to deduce the ideal theoretical model of disability from their lived experiences.

2.3 Discourse on ASD

While disability discourse research often discusses all types of disabilities, few have been focused solely on ASD. This section aims to review the limited studies on discourse of ASD and by the end of the review, to know what more that needs to be explored within this area. This section will be divided into two groups of research: (a) the perspectives of the individuals with ASD themselves and their parents, and (b) the effects of ASD on the parents and caregivers of individuals with ASD.

2.3.1 Perspectives of Individuals with ASD and their Parents/Caregivers

Among the methods commonly used by researchers to gain a more in depth understanding of those affected by ASD are the use of narratives (McAdams, 2008) and thematic analysis (Braun & Clarke, 2006) in their discourses, as there are some information that cannot be obtained by merely using quantitative methods. However, the lived experiences of those directly affected by the challenges young adults with ASD commonly face on the areas of social participation, post-secondary education and employment are limited. It is also important to note that narratives from the individuals themselves only consist of those who are high functioning, which is understandable considering the limited speech individuals with autism possess. The following qualitative studies provided various valuable insights into the lives of individuals with ASD as well as their parents' experiences.

In one qualitative study, Hurlbutt and Chalmers (2004) investigated the experiences of three adults with high functioning ASD using multiple interviews, reflective essays, phone calls and emails over a period of 9 months. Their findings revealed a wide range of obstacles such as difficulty in obtaining and securing employment, lack of awareness among the general society and issues relating to their lack of acceptable social skills. The respondents also gave their own views on other issues such as the need for providing more support for adults with ASD to live in a community setting would be more appreciated and preferred than group living arrangements that are normally offered to individuals with ASD. In relation to unemployment and underemployment challenges, they advocated job mentors for individuals with ASD for guidance. They believe that the negative work experiences were not caused by their work quality and discipline but their inability to deal with people in social situations, hence the need for mentors to guide them in these areas. Not limited to guidance in social communication in workplace settings, even for general communications such as developing meaningful relationships with others is something that they wish for. Besides the need for more properly and thoroughly trained parents and administrative staff on how to deal individuals with ASD, the authors further suggested that the staff at these training sessions and conferences on autism should be well paid to prevent a high turnover, as change in staff can be a disappointing and upsetting experience for individuals with ASD.

Portway and Johnson (2005) conducted unstructured interviews, also with individuals with high functioning ASD, but in contrast to the Hurlbutt and Chalmers study (2004), they added in the perspective of parents. This study highlighted the challenges of individuals with ASD facing short term and long-term considering their "non-obvious disability". Challenges everyday included constant misunderstandings, bullying, isolation and loneliness, while long term risks included poor performance in academics and employment. The study reported that the young adults cannot seem to "stand on their own feet" and had high dependency on their parents, with most of the young adults still living with their parents or living elsewhere with some form of support (only one lived alone without any support). They further noted that besides the general care being provided daily such as food and shelter, a much deeper level of "care" was also provided such as constant monitoring, companionship and seeking opportunities in areas of daily activities, socializing, education and employment. The researchers concluded that effects on mental health such as anxiety and depression that were reported by the young adults of the study may have stemmed from late diagnosis as the results of the study indicated that there are many benefits in early detection of ASD as compared to those who were diagnosed much later. The study also discussed the need for ASD research to look into the possibility of negative effects and their perspectives on labelling themselves following diagnosis. The authors believe that not all individuals with Asperger's Syndrome will accept the diagnosis or need the official label.

For the study conducted by Sosnowy, Silverman and Shattuck (2018), the authors interviewed young adults with ASD as well as their parents, similar to the study by Portway and Johnson (2005). However, the topics were more focused. The young adults with ASD and their parents were queried and had their answers compared, with the most commonly associated areas of transition and findings revealing their views on the following topics; (a) the balance of security and autonomy, (b) post-secondary education and holistic support needs, and (c) work as a source of engagement and empowerment. A majority of the findings of this study revealed similar issues to the Hurlbutt and Chalmers (2004) and Portway and Johnson (2005) studies such as employment difficulties, the young adults' inability to live without their parents' constant care and support, and their communication skills deficits contributing to negative effects on their mental health and social lives. It was found that the parents and young adults shared similar ideals and values relating to the outcomes of young adulthood; "security and continuity through transitions, education and employment as means of broadening opportunities, and environments where young adults with autism were valued and supported." Among the main concerns that were raised was the need for extra assistance once the young adults with ASD are enrolled to college where support and services must be individualized and aligned to the needs of each the students with ASD. On the subject of employment, the authors mentioned that employment was not merely a means for financial independence but social benefits and giving their children a sense of self-worth. Similarly, this study also requested a more supportive setting and more service provision centres to aid young adults with ASD in job seeking.

While there have been studies that have provided narratives on the individuals with ASD and their families' experiences on transition in developing nations, the majority of the literature is from the developed nations. With differing cultures, mental psyche and available services in the developing countries, there may be a difference in the challenges faced by young adults with ASD and their families, and it is through these qualitative, in-depth studies, these challenges were able to be identified and improve their quality of lives. Hence, this present qualitative study aims to explore further these issues and challenges, but in the Malaysian context.

2.3.2 Effects of ASD on Parents & Family

With the reviewed qualitative studies on ASD frequently mentioning the lack of awareness and support from the society, schoolteachers, and medical professionals, this in turn prompts researchers to explore how ASD directly affects the family members and caregivers of individuals with ASD.

Two studies explored experiences of raising children with ASD in Malaysia from the parents' perspectives with the first study focused on the wellbeing of mothers of children of different ages with ASD (ranged from 5 to 23 years old) (Ilias, Liaw, Cornish, Park, & Golden, 2017), and in Ilias' follow up study two years later considered the perspectives of both parents (Ilias, Cornish, Kummar, Park, & Golden 2018) with this time highlighting the risk and resilience among both parents, the mothers and fathers of children with ASD. Similar themes were uncovered such as identifying ASD symptoms and seeking diagnosis, effect of challenges faced raising a child with ASD on family life, the lack of awareness of ASD in Malaysia and coping strategies. It should also be noted that both studies had an emphasis on the effects of having a child with ASD on their wellbeing. While their experiences provided various challenges which impacted them negatively, the parents in the two studies expressed the positive outcomes where the mothers that were actively engaged in their children's treatments also helped foster their own wellbeing. The mothers also expressed the feeling of contentment and discovering a sense of purpose through their respective roles of motherhood raising a child with autism. Talks of adaptation and acceptance of their children's condition were also highlighted in the latter study where parents perceived an improvement in their relationship with their spouses or family members.

One significant study mentioned of the financial burden of families with ASD in Malaysia by Kamaralzaman, Toran, Mohamed and Abdullah (2018). Parents were asked to complete a Parent Financial Statement Form online where they were required to provide an estimation of their expenditures such as direct medical costs (e.g., medical aid, diagnostic tests, treatment, therapy) and developmental costs (e.g. domestic helper, nursery, special education, daily necessities) for raising children with ASD. Overall, it was found that the development cost is the biggest financial burden for most of the respondents, despite free education provided by the government. A comparison between households with high and low income was also conducted; the below average household income group recorded the highest total average cost for rehabilitation services and cost of medicine, while the higher household income group spent significantly higher for medical cost and rehabilitation services compared to the below average income household as they placed a high importance on therapy for their children and due to their ability to afford them. It should also be noted that being an OKU (Person with Disabilities) card holder entitles the family and individual with ASD of various exemption benefits, though the authors reported that the family would still have to bear the cost of replacement aids. This study also noted parents in the study cease applying alternative treatment for their children who are over 19 years old, indicating little transitional services and aids for those in the transition age or who are already in adulthood.

Hence, the present study hopes to corroborate these findings on how ASD has affected parents and caregivers of individuals with ASD and how this too specifically affects the individuals with ASD in their transition into independent living, which very few studies have so far addressed.

2.4 Current Development of Research in ASD and Current State of Awareness

To gain a better understanding on the issues and challenges faced by families with individuals with ASD and how this has indirectly or directly affected the transition into independent living, it is also important to see the current advancements of ASD research to complement the findings of these narrative studies.

ASD research began with primarily focusing on the deficits associated with the condition such as socializing, communication and imaginative play, as well as conducting profiling based on these deficits among young children (Levin, Fox, Zeanah, & Nelson, 2015). Following this are studies that focused on the diagnosis and intervention programmes for dealing with these deficits where later, researchers began focusing on studies that test the efficacy of these interventions. Prevalence studies (Crane, Chester, Goddard, Henry & Hill, 2016; Hossain et al., 2017, Qiu et al., 2020) then help to gauge the size of the problem in specific populations in various countries around the world.

Despite these efforts, recent studies still reveal a low level of awareness about ASD among the stakeholders. The subject of awareness among the community and public in general have been highlighted in past research (Alsehemi, Abousaadah, & Sairafi, 2017) and recently in Malaysia in one recent study by Low (2021). Factual aspects of ASD such as its prevalence more apparent among male than female, ASD persisting until the child reaches adulthood and ASD being incurable were unbeknownst by a majority of the respondents. It is also interesting to note that this study consisted of respondents possessing high levels of educational qualifications, which suggests a lower level of knowledge regarding ASD general public. Among the notable highlights of the findings showed a high percentage of respondents citing TV as one of their main sources of information on ASD. Mass media have been known to give distorted information regarding disabilities and one example of this instance came from one research conducted by Wendorf Muhamad and Yang (2017) on the portrayal of autism in American newspapers. The more pressing concerns affecting individuals with ASD and their families such as research funding and the limited resources and services available failed to be highlighted, with the newspapers instead choosing to focus on the emotional aspect and sensationalized stories of the families dealing with the disorder to attract the public audience. With mass media being a powerful tool in the spreading of information in this current day and age, Low's (2021) suggestions for a more focused dissemination of information on ASD to the public is agreeable to prevent further public misconceptions about the disorder.

By taking into account the low level of awareness among even the educated individuals, it is then to no surprise that schoolteachers in governmental schools are no different. Latest studies conducted on the knowledge of ASD among preschool teachers in China (Liu et al., 2016), knowledge and perception of ASD among general schoolteachers in Turkey (Rakap, Balikci, & Kalkan, 2018) and a study on raising the awareness of ASD among Greek nursery and primary school teachers Giannopoulou, Pasalari, Korkoliakou and Douzenis (2019) all showed schoolteachers lacking the knowledge and management of the disorder. Liu et al. (2016) offered an interesting take on the awareness level among the preschool teachers in China by correlating their knowledge with the types of schools in China and the regions in which the teachers are from. The questions involved in the study included topics on their knowledge of typical and atypical child development, their perspectives on the needs of children with ASD, their interest and advocacy for children with ASD, and lastly their knowledge of local institutions and organizations available that are dedicated to individuals with ASD. Among the highlights of the findings is the popular belief of the respondents' beliefs in the use of traditional Chinese medicine and its correlation to ASD, citing that ASD may be the cause of a yin/yang imbalance, an idea that heavily suggests its relations to mental illness (Xu & Yang, 2009). This traditional belief of ASD was coupled with their inaccurate knowledge of the disorder which according to the authors may have stemmed from the Chinese terms of the word autism, its literal translations equating to "isolation disease" or "loneliness disease". Hence, this may have further promoted their ideas that ASD is curable and can be "outgrown". Interestingly, the study from Greece (Giannopoulou, Pasalari, Korkoliakou & Douzenis, 2019) showed the nursery and primary school teachers held a similar view that autism is similar to psychosis. Besides that, teachers in China who showed a significantly more accurate knowledge of the disorder were found to have had previous experience dealing with children with disabilities. What makes this finding interesting here is that the authors related the reason for the teachers' lack of interactions with children with special needs to the types of schools and regions in which they are from. Teachers who taught at schools with less demanding quotas such as the district schools (the more prestigious and student selection driven schools such as Province level schools allow enrollment of a smaller number of children with special needs) and teachers who were from larger cities were better positioned to learn and receive training on special needs education. While the teachers in China showed interest in improving their knowledge of ASD to help provide better education to children with ASD, the teachers in the Greek study implied a somewhat negative attitude towards the presence of a child with ASD in their classrooms and believe such children should be taught in separate educational settings entirely. These results show that not all teachers are comfortable with the concept of integration and inclusion in the classroom for children with ASD, which authors viewed may be due to their lack of confidence in handling such children. Elsewhere, while Rakap, Balikci and Kalkan (2018) investigated the knowledge and perceptions about ASD on Turkish general education teachers encompassing similar topics (i.e. ASD traits, causes, diagnosis, efficacy about ASD, evidence based practices in ASD and training related to ASD), in contrast to the two studies from China and Greece, the majority of the preschool and primary school teachers correctly endorsed at least 5 of 7 of the diagnostic traits of ASD. Although these are promising findings, the respondents also displayed inaccuracies in their understanding of the causes of ASD such as its relation to mental illness, malnutrition and vaccinations, in line with the two studies from China and Greece. These three studies show that lack of knowledge and awareness about ASD among general schoolteachers is still low even in the more developed nations.

More worryingly, medical professionals have also been found to lack the knowledge to treat ASD or other developmental disabilities in general. One significant study by Moyle, Iacono and Lidell (2010) explored the knowledge and perceptions of newly graduated medical officers on the topic of developmental disabilities (DD) in public hospitals around Malaysia. The research aimed to discover the medical lecture content and clinical practice experiences during undergraduate medical training among the house officers, which then proceeded to question their roles in the identification and management of DD. It was discovered that the medical content and clinical examination training of DD was inconsistent and lacking across the medical training offered in various countries, with greater deficits in East and Middle Eastern nations compared to those who received medical training in Malaysia and other western nations. As a result, this contributed to the respondents' uncertainty and lack of confidence in diagnosing patients with DDs as well as its management. Other concerns included inability to have access information relating to DD, lacking the knowledge to know when to intervene as well as the failure to be informed of the importance of early intervention. With their lack of confidence in identifying DD within the primary practice setting, most medical practitioners tend to refer the patients to specialists instead of diagnosing and managing themselves. The subject of inconsistent medical training across nations were brought up once again in the emphasis on the study of some DD more than others in some countries, and which area of medical specialization DD is most likely be identified by (e.g. in Australia, DD are more commonly treated by paediatricians whereby Malaysia, by psychiatrists, reported in a study by Lennox and Diggens, 1999). Such issues will further delay the accurate diagnosis where this will adversely affect health outcomes of children with developmental delay leading children and parents to suffer further and face distress respectively. Low and Zailan (2016) in another study exploring similar aims to Moyle, Iacono and Lidell six years later among Malaysian medical students showed that final year students possessed more increased knowledge on the symptoms of ASD as opposed to the first-year students. However, in line with Moyle, Iacono and Lidell's study, it is unclear whether this was due to the medical training. Similarity of symptoms between ADHD and ASD (Miller, Iosif, Young, Hill, & Ozonoff, 2018; Adamo, Hodsoll, Asherson, Buitelaar, & Kuntsi, 2019) have also contributed to cases of inaccurate diagnosis among medical professionals which once again will delay accurate diagnosis and pose a risk to the ongoing developmental of the child.

2.5 Issues in Transition for Young Adults with ASD

Evidently from the previous section, much of the recent research on ASD still revolve around individuals with ASD during childhood, be it international or local studies. Despite this, research on transitions have been seen to progress over the years where the findings have continued to associate independent living with opportunities in domains such as social participation, education and work (Shattuck, Roux, Hudson, Taylor Maenner, & Trani, 2012). This section explores some of these studies.

As individuals with ASD are known to have social deficits (DSM -5: American Psychiatric Association, 2013), challenges in creating deeper and meaningful relationships are expected, as reported by one study on adult women with ASD. Kanfiszer, Davies and Collins (2017) aimed to look into the social experiences of these women correlating living with ASD in relation to gender identity and social relationships. All respondents in the study agreed of having experienced maltreatment from people and noted on the difficulty of forming social relationships. The correlation between ASD and other mental health disorders such as anxiety have also been identified (White, Oswald, Ollendick, & Scahill, 2009; Bejerot, Eriksson, & Mortberg, 2014). Mental health disorders may further affect performance and experience of important milestones such as entering university. High school counsellors have been reported to brainstorm various strategies in fostering college readiness among young adults (Dipeolu, 2014).

However, the numbers still suggest a low rate of university enrolment among individuals with ASD (Wehman et al., 2014), even with those completing their tertiary studies having additional difficulty in securing and maintaining employment (Shattuck, Roux, Hudson, Taylor Maenner, & Trani, 2012.). In one of the more recent studies on transition planning, implementation and outcomes for students with ASD (Snell-Rood et al., 2020), the findings revealed that the services available for them after completing school were still inadequate due to issues such as the lack of planning, and services that were overburdened. Further, the said services also failed to include the development of the necessary skills for obtaining and maintaining employment. The authors proposed implementation of high-quality transition planning by providers, organizations, parents, schools and employers. Zainal and Hashim (2019) conducted a case study for its implementation of a transition programme for students with learning disabilities in Malaysia, one of the few limited studies on transition in the country. Although it does not focus on ASD specifically, the study reported a few positive outcomes such as the involvement of employers in the programme in matching each individual with a learning disability to a job that is based on their abilities.

Despite developments as above in helping to identify the elements that may lead to successful employment, this area of research can still be developed further. However, there have been recent research attempting to recognize factors that can facilitate employment for the long term for individuals with ASD. Hedley et al. (2018) studied a focus group with adults with ASD in a 3-year employment and training programme. Themes that emerged from this study included aspects of what facilitates success in employment, the obstacles and the outcomes of the training programme. What the authors tagged as “enablers” are the modified work environment, allowance, supportive leaders and coworkers and presence of a trained facilitator or consultant, whereas the “challengers” encompassed difficulties in conducting tasks, individual factors, distraction and socializing problems which are among the common issues relating to work opportunities for adults with ASD (Shattuck, Roux, Hudson, Taylor Maenner, & Trani, 2011; Wehman et al., 2014). Westbrook et al. (2012) and Hendricks and Wehman (2009) expressed that there is still a need for additional research in this area, reiterating the need for more studies on the issue and challenges related to transition into adulthood for individuals with ASD.

2.6 Conclusion

This chapter has highlighted the methodology used in and findings of previous research and identified the gap in literature which essentially concerns the paucity of studies focusing on populations in developing countries. As the objective of the present study is to look at the perspectives of parents on the transition to independent living for young adults with ASD, it is imperative that we take the suggestions for future research mentioned in the past studies such as the need for more qualitative studies, more focus on young adults and in regions where this area has not been studied yet (i.e. developing nations) to address the knowledge gap of this research area. With the literature in these areas reviewed, the next chapter will discuss the methodology adopted and adapted from these past studies in this qualitative study in an attempt to answer the research questions posed.

CHAPTER 3: METHODOLOGY

3.0 Introduction

The Methodology chapter will address the method and methodology used in this study. This chapter encompasses four aspects of the methodology, namely the setting, participants, data collection procedures and approach to analysis.

The present study employed the qualitative methodology to explore the parental perspectives on the transition of young adults with ASD during the transition stage into independent living. As the research questions for this study aimed at exploring the lived experiences as well as the concerns of the respondents in the areas or social participation, education and work opportunities, naturally, the use of interviews would aid considerably in obtaining such data. With the aims of the study in mind, the method of telling the stories of individual experiences while also exploring the life of the individuals is in line with what the study wishes to explore. Although narrative analysis has often been regarded as an approach that explores lived experiences, "the social, cultural, familial, linguistic, and institutional narratives within which individuals experiences were, and are, constituted, shaped, expressed and enacted" as well (Clandinin, 2013).

3.1 Setting & Participants

An intervention and support group for parents of children with ASD called 'Parents' Resource for Autism Malaysia' (PR4AM), was selected for this purpose. The researcher discovered the centre whilst searching for parent support groups on social media platforms such as Facebook and blog sites. An appointment was made with the owner of the centre, Mr. Y (one of the participants of the present research), through a phone call and it was agreed a meeting will be conducted at the centre. PR4M is situated in a suburban area of Kuala Lumpur, Malaysia.

Before the commencement of the first meeting, the researcher requested permission from Mr. Y to conduct field notes/observations during all visits to the centre in which he allowed as the preliminary step to the present study.

Participants for this study include four parents of young adults with autism. The table below includes information about the participants that were recruited. Participants' identities were referred to by the first letter of their names. The individuals with ASD are referred to as the two initials of their first names. The table below summarizes information regarding the participants involved in this study.

Table 3.1: Information on Participants

PARTICIPANT	GENDER	AGE	RELATIONSHIP WITH YOUNG ADULT WITH ASD
Mr. Y	Male	50+	Father, full time stay at home parent of two sons with autism, one nonverbal and verbal (WJ & WX)
Ms. N	Female	50+	Working parent of a son with autism, verbal (BW)
Mr. L & Mrs. L	Male & Female	50+	Working parents to two sons; one nonverbal sutism (SJ) and one with Asperger's Syndrome (SY)
Mr. Y	Male	50+	Father, full time stay at home

			parent of two sons with autism, one nonverbal and verbal (WJ & WX)

It should also be noted that all the adolescents with ASD involved in the present study are male. This is in line with research that suggests ASD affects boys more frequently than girls at a 4:1 ration (Yeargin-Allsopp et al., 2003).

3.2 Data Collection Procedures

Semi structured interviews were conducted in this study.

3.2.1 Interviews

Each participant was interviewed for a total of two times (except for one participant Ms. N) where each interview lasted approximately 60 to 120 minutes. Verbal consent from the interviewees were taken prior to conducting the interview. The interview was recorded using a phone recorder and put onto a table near to both, the participant and researcher. Places that were chosen to conduct the interview were quiet spaces with minimal external sounds to capture participants' answers clearly. The written consent was taken after member checking has been conducted. A donation was given to the centre as a token of appreciation for their participation in this study. The Participant Information Sheet and Consent Form are in Appendix A.

A set of questions were prepared based on the four major types of questions taken from Strauss, Schatzman, Bucher and Sabshin, (1981), as cited in Merriam and Tisdell, (2015); "hypothetical, devil's advocate, ideal positions and interpretive". As these questions have been proven to elicit useful information in interviews, they served as a guide to formulating the relevant questions. Hypothetical questions are questions that ask the respondents what they might do in a particular situation. Hypothetical questions normally begin with “What if…” or “Suppose…" (e.g. Suppose it would be my first day at the ABA centre. What activities would I be doing?). Devil’s Advocate questions challenges the respondent to give their opinion on an opposing view (e.g. Some parents say it is unnecessary to diagnose their children and they are better off without a label to prevent any stigma from society. Do you agree with this?). Ideal Position questions ask respondents to describe in detail an ideal situation (e.g. Describe an ideal job for your son.) Interpretive questions advance tentative explanations or interpretations of what the respondent has been saying to obtain a reaction (e.g. Did you find the teachers at the international school different from what you expected after you enrolled SY there?). although there were guided questions for the study (Appendix B), probing questions were formed on the spot during the interview in response to the answers given by the respondents. As the research questions for the present study aim to look at parents’ perspectives of the transition to independent living for young adults with ASD, the guided questions were constructed using the three domains that have been commonly associated with success in transitioning to independent living, namely social participation, school, and work opportunities. Hence, the answers to these questions will inevitably relate to parents’ thoughts on transition to independent living which are mainly focused on these three areas, be it in terms of their children’s readiness, the challenges they have faced and currently facing in areas of transition to independent living, as well as their plans for the future.

Transcription of the audio recording were carried out after the completion of each of the eight interviews. Transcripts are stored in a password protected storage and can be made available if the need arises. These interview questions have been reviewed by an academician in the specialization of clinical linguistics to review for its feasibility and suitability to the respondents and research context. Minor changes to the interview questions were recommended by the expert, hence these changes were applied. The interview questions that guided this study are listed in Appendix B.

The present researcher first addressed the parents' thoughts on their sons' readiness for transition in the areas of the three domains (social participation, school and work opportunities) related to independent living. Next, the participants recalled the diagnosis history and the events that led to the formal diagnosis. Then lastly, prominent childhood experiences that exhibited growth, improvements, challenges that may have been factors in influencing their current views on their sons' readiness were revealed. Although the questions were asked in a chronological order, the participants would switch back and forth from anecdotes of the present time and the past, especially if the past events were of great importance and impactful for the family.

English was the main mode of communication between the present researcher and participants, with Malay also being used at times during the interview. Translations are included in the excerpts.

3.3 Approach to Analysis

This present study adopted the six-step thematic analysis approach (Braun & Clarke, 2006) for analyzation of data. Firstly, all transcriptions were read repeatedly to familiarize with the data. Although questions were asked to respondents according to the order of the guided questions (Appendix B) (i.e. codes were questions regarding readiness, then questions regarding challenges within the three domains, initiatives by parents), the answers were found to be scattered in various parts of the transcription data. This was due to parents' responses that were in a non-linear manner where some answers were situated in other parts of the data (e.g. answers to question 10 on hopes for the future may also be within the answers for question 6 on the child' working experiences, revealing parents' suggestions on the ideal working environment for their child in the future). Hence, by familiarizing with the data, this also gave the researcher more guidance on where to locate the answers as well as how to arrange the data for the coding process later. Secondly, generation of the initial codes in a systematic manner was conducted, collating the relevant data to each code. The codes are (a) readiness for transition, (b) challenges factors attributed to challenges in transition and lastly (c) initiatives by parents. As the research questions guided the forming of the interview questions, the codes were generated accordingly. Initially, the code "initiatives by parents' was one of the codes and the third theme. This code was also used during the coding process using the Nvivo qualitative data analysis computer software package. However, after further analysis and discussion on the findings, the final theme during the write up of the dissertation was changed to "Parents' Plans for the Future of Young Adults with ASD" as this was a more suitable theme and is in line with answering the final research question on parents' future plans for their children with ASD. Thirdly, themes were then identified from the codes where excerpts were collected for each of the formed themes. As mentioned previously, the NVivo coding aided the researcher in locating all the related excerpts for each research question. After all excerpts are collected through the NVivo coding process, the possible themes were discussed. The researcher believes that the themes should be presented in such a way where they are aligned with the research questions. Hence, the potential themes would include the keywords from the research questions such as "readiness", "challenges" and "future". Fourth, is the review of the potential themes and the coded excerpts to verify its relationship with the entire data set and the study's research questions. Once confirmed, the fifth step was conducted which was defining and the naming of the themes with further analysis of the data to refine each theme and its related excerpts for more clarity one final time. The three themes that were finalized are as follow; (a) Parent's Perspectives of the Readiness of the Young Adults with ASD for Transition into Independent Living, (b) Challenges Parents Have Faced and that have

Persisted in Their Experiences of raising Their Children with Autism and Asperger's Syndrome and (c) Parents' Plans for the Future Potentials of the Young Adults with ASD. The last step is the production of the findings data where the final analysis of the selected excerpts was conducted while relating the data analysis to the proposed research questions and literature. Appendix C shows a sample of the NVivo coding process that was downloaded from the software, showing all the references (excerpts) for one of the codes, "Readiness for Transition". Below is a summary of the steps for conducting the thematic analysis.

1. Transcription reading and familiarization
2. Generate initial codes in a systematic manner
3. Identify themes from the codes
4. Review themes
5. Define and name themes
6. Finalize themes

Identification of the semantic meanings through grammatical and lexical choices of the respondents were conducted as a supplement to the thematic analysis. The linguistic analysis for this present study borrowed certain elements from the Systemic Functional Linguistics approach (Halliday & Matthiessen, 2013; Thompson, 2014). Young (2009) opined that instead of looking at the text as formal and syntactic objects, SFL looks at text in a functional and systematic way where text is understood through which a culture unravels in its social context. Hence, the use of the three sets of systems of lexicogrammatical choices by Halliday and Matthiessen (2014) and Thompson (2014) on the parents' responses, namely the thematic structure, mood and transitivity systems, can reveal the different levels of meaning of a particular text. With each of the three analysis systems aiming to reveal different levels of meaning such as the text flow, interactional and representational meaning from the responses, this can provide the researcher more information with regards to the manner in which the participants narrate their experiences in terms of revealing how certain events made the participants feel and the extent of the significance of these events in their lives (McAdams, 2008), thus emphasizing the importance of addressing areas of transitioning with ASD in need of attention from the policy makers and the public. Each research question used the appropriate system of analysis to reveal its functionality in their respective contexts. The first part of the analysis is using the thematic analysis from the coding that is in line with the research questions of the study as follow: (Theme A) parents mention their perspectives on their children's readiness for independent living (their perspectives), (Theme B) parents mention the challenges faced in raising their children with Autism and Asperger's Syndrome (their challenges), and (Theme C) parents talk about their hopes and plans for their children's future support of the young adults with ASD in their transition into independent living (their hopes and plans). To study the thematic structure of the text (Thompson, 2014), the analysis will focus on the way the answers flow and its overall cohesiveness and coherency exploring how the parents organize their answers to the questions by switching from one theme to another to make more sense of their answers (e.g. when asked about the challenges of raising their child, Theme B, the parent answers the question and gave additional information to support their answers by suggesting ways to overcome these challenges in the future, Theme C) (Rubin & Rubin, 2012). Next, the mood and appraisal system helps the researcher analyze interaction between the speakers in the interview such as detecting the polarity (use of positive or negative words) of their answers (the parents' differing views on their children's readiness for transitioning into independent living: "will never be ready for independent living", "not ready for independent living, but maybe in the future") and detecting modality in probability or usuality where the researcher identifies or construe the region of uncertainty that is situated between a *"yes"* or a *"no"* to a question (e.g. parents using the term *"always" in "always sitting in the naughty chair"* when giving an account of their child's hyperactivity, and *"I don't know"* in *"I don't know what is going to happen when I (am) gone*" when asked what the parent's thoughts were on her thoughts of her child transitioning into independent living). Lastly, the transivity & ergative analysis helps the researcher to examine the clause in its entirety (Halliday and Matthiessen categorizes this analysis as "clause as representation"). This includes deciphering the agent of the text (e.g. did the speaker use "I" frequently as the medium to represent themselves as showing agency?) and analyzing the manifestation of the speaker's or writer's grammatical and semantic choices to represent the process types; material (doing), behavioural (behaving/seeing), mental (feeling, thinking), verbal (saying), relational (having identity) and existential (existing). In the context of the present study, parents were frequently asked their perspectives on the subject matter, hence their answers often used the mental and relational processes, then elaborating using material and relational processes "*Like those that are Asperger's are high functioning, I believe they can live by themselves (live = material process). No matter how I train (him), I don't think so (he) can live by himself (I don't think = mental process)."* The three systems of analysis as explained above will be used to identify the salient linguistic features and expressions from the parents' responses to the three themes:

Theme A: their perspectives on their children's readiness for independent living (their perspectives analyzed by using the mood and appraisal analysis)

Theme B: the challenges faced in raising their children with Autism and Asperger's Syndrome (their challenges analyzed by the transitivity and ergative analysis)

Theme C: parents talk about their hopes and plans for their children's future support of the young adults with ASD in their transition into independent living (their hopes and plans analyzed by the thematic structure).

The full data analysis is featured in Chapter 4, Findings and Discussion.

3.4 Ethics Clearance

Research ethics was obtained by the University of Malaya Research Ethics Committee (reference number: UM.TNC2/UMREC – 695).

CHAPTER 4: FINDINGS & DISCUSSION

4.0 Introduction

The main purpose of this present study is to be informed of the perspectives of parents of young adults with autism on their children's readiness for transition into independent living. This chapter of the dissertation will report the findings from the responses of four parents who participated in the study, Mr. Y (parent to WJ and WX), Mr. and Mrs. L (parents to SY and SJ) and Ms. N (parent to BW). Excerpts of the interview data will be presented to support the findings from the four parents.

Explained in the Chapters 2.1 (Discourse Variations) and Chapter 3.3 (Approach to Analysis), this study will be adopting elements from Systemic Functional Linguistics (Halliday & Matthiessen, 2013; Thompson, 2014) to supplement the thematic analysis conducted in this study, namely the three analysis systems (mood and appraisal, transitivity and thematic structure) to aid the identification and explanation of the semantic meanings through the grammatical and lexical choices of the respondents. Research Question 1 (Section 4.1) uses the mood and appraisal analysis, Research Question 2 (Section 4.2) uses the transitivity and ergative analysis and lastly, Research Question 3 (Section 4.3) uses the thematic structure analysis.

4.1 Parents' Perspectives on the Readiness on the Readiness of the Young Adults with ASD for Transition into Independent Living

The interview data of the four parents, i.e. Mr. and Mrs. L, Ms. N and Mr. Y indicates that they held the view that the young adults with ASD i.e., SJ, SY, BW, WX and WJ were not ready for transition at the time of this research. Each parent spoke at length about the abilities of the young adult with ASD and their performance in terms of activities of daily living, to explain why they felt the adult was not ready for living independently. Interestingly, two clear patterns emerged from the parents' explanations. Firstly, there were the ones who felt the individual with ASD will never be ready, and secondly those who saw potentials for transitioning in the near future though the child was not ready at present. Evidence from the data that demonstrate these two patterns will be discussed in the following subsections. Their answers were seen to be influenced by their children's ability and the living skills they are able to do within their capacity.

4.1.1 Will Never Be Ready for Independent Living

All the parents have differing views on their child's current readiness for transition to independent living. For three of the parents, Ms. N and Mr. and Mrs. L, as both children are from the severe end of the autism spectrum, both parents collectively agreed that their children at the present moment are not ready for transition and will never be ready. They held the view that their sons SJ and BW who were both at the time the study was conducted, 19 and 17 years old respectively, will never be ready for transition to independent living.

"…we will go away one day. We really need somebody to really take care (of him)." (Mr. L, Excerpt #1)

Mr. L expresses the *"need"* for his youngest son SJ to be taken care of by someone *("really need somebody to really take").* The use of the intensifying adverb *"really"* twice in the sentence underlines the necessity for someone to take good care of him after they have passed or unable to take care of him anymore, where the latter use of the word *"really"* in the same sentence was for the need for him to be *"really looked after"* suggesting care and guidance in all aspects of his life. Borrowing elements from the Halliday and Matthiessen (2013) framework on SFL, the mood and appraisal system appears to support the use of the adverb *"really",* that falls under the adverbs that serve as mood adjuncts of modality under the counterexpectancy (exceeding) category (pp. 188 189,), which when used, means “nothing else than”. Hence, in the context of this clause, Mr. L appears to be definite in his answer where he expresses that he wants his son to be taken care of, and he will settle for no other alternative, further indicating that independent living for SJ is impossible and he will never be ready for this transition into independent living.

Ms. N, on the other hand, justifies her stance by comparing her son with those who have Asperger’s syndrome.

> “No...he’s not like those Asperger’s, high functioning. Like those that are Asperger’s are high functioning, I believe they can live by themselves. No matter how I train (him), I don’t think so (he) can live by himself.” (Ms. N, Excerpt #2)

She expressed that those who are high functioning can make the transition to independent living, whereas for her own child, she does not think this transition is possible. She explains that *“no matter how I train…”,* indicating that regardless of the quality or frequency of the training she provides for BW, it will not be sufficient to prepare BW for independent living. Her use of indirect negation (Halliday & Matthiessen, 2013, pp. 188 -189) in (*“I don’t think so…)”* in the above excerpt for her concluding statement to the question on whether BW can live independently appears to show her negative point of view on the matter where she does not think BW can live by himself. I can also be noted that she may have shown some elements of modality in her view (her degree of possibility), her uncertainty (“I don’t think…”), as opposed to giving a definite answer (a “yes” or “no”), thus, not completely ruling out the possibility of BW being able to make the transition into independent living.

Mr. L also draws on the distinction between the high and low functioning persons with disability within employment opportunities, one of the determinants of successful transition to independent living. He raises concerns about the lack of employment opportunities for young adults with ASD that becomes a hindrance for transition to independent living.

> "…after school, all these people (young adults with ASD) got nowhere to go. No place for them. Where do they want to go? Normally, the government (that hires) those who are OKU (disabled persons), they (will) always want the high function one" (Mr. L, Excerpt #3)

Similar to Ms. N, the mood and appraisal system analysis reveal Mr. L's own negative point of view as a response to the question on his child's readiness where he reveals a dead-end situation with the use of negative words *("nowhere", "no place)* as there is *"nowhere to go"* and *"no place for them"* available for those in a similar predicament to SJ, a valid reason as to why he would like a place with full time care. Mr. L elaborates that when education provision (school) comes to an end, the young adults with ASD appear to reach a dead-end as they have *"nowhere to go".* He reinforces this idea stating that there is *"no place for them".* He implies that while employment opportunities are available in government organizations for "OKU" (Malay term for persons with Disability, PWD), the high functioning PWDs are preferred by the employers. His suggestions to overcome such employability issues for young adults with ASD who low functioning like his son SJ includes setting up shelter workshops. In the excerpt below, Mr. L's explanation for the concept of sheltered workplace reveals how being gainfully employed is seen as a facet of living independently.

> "You send your son there and they will work there. And they (shelter workshop) will pay...They can earn about RM400 a month, three to four hundred. At least (they are) occupied. And then they go there and train and got people take care of them so that they can be independent. They will provide food, lunch and teatime for them." (Mr. L Excerpt #4)

From the excerpt, he relates being "independent" in a setting where there are *"people (that) take care of them".* In this attempt at elaborating on the concept of the shelter workshop Mr. L links to the question of independence for the young adult with ASD with the different aspects of being "employed". Firstly, he mentions *"send"* there and *"will work".* This can be interpreted as looking at "independent living" as spending time away from the family and "working" or being employed. He goes into details about the amount they will be paid and the training they will be provided. He justifies the apparent low payment of RM400 per month with *"At least (they are) occupied".* Mr. L also mentions *"people take care of them"* and that their basic needs such as meals will be provided for. To him, this entails independence for the young adult with ASD. It is interesting to note that Mr. L does not overtly refer to his son SJ in discussing this option. However, in his earlier description of SJ, Mr. L does mention that *"if you don't supervise, he won't finish the job. He will just do one, then leave there and go run around throwing some water, lie on the bed."* This explains why he sees training and being taken care of at the Shelter Workshop to be essential in his son's transition to some degree of independent living.

Mrs. L also provided her views on enrolling SJ into the Shelter Workshop in the excerpt below;

> "Because we thought like putting him into (the shelter workshop) but (the shelter workshop) only start next year (in) April, or maybe May. So these few months I will put him to this centre first. If this centre can help, I will delay (enrolment) for (the shelter workshop). At least I want to see some behaviour, or something change. Because he still got a few things that he need to change." (Mrs. L, Excerpt #5)

Mrs. L clearly states that she would "delay" placement in the shelter workshop if she finds that the centre he is at can help improve her son's behaviour as she feels there are still problems that needs to be addressed before he can be enrolled in any workshops.

Additionally, the commencement date of the shelter programmes seems to favour her decision.

Ms. N, another mother of a young adult with ASD shares here views on uncertainties that lie ahead when asked about her son BW's readiness for transition into independent living. The following excerpt showcases her *"not knowing"*.

> "I don't know what is going to happen when I (am) gone. Something I cannot predict. The only thing I can do is I am going to keep some money for him. So, some people might say, "if you don't have a plan, you sound like (an) irresponsible mum." (Ms. N, Excerpt #6)
>
> "Should I let go? I mean, many people of people say I should let go and put him in a home. I said I will let go. But not now. Maybe in 10 years. Because he is only 17." (Ms. N, Excerpt #7)

Having implied that her son BW was not ready for independent living at the time of the interview, Ms. N shares her concerns about when she is *"gone"*. Although this appears to be similar to Mr. L's comments about future possibilities, Ms. N has a plan for dealing future outcomes that she is unable to predict where she sees providing financial security as a solution. Ms. N once again appears to be using another instance of indirect negations (Halliday & Matthiessen, 2013, pp. 188 -189) in *"I don't know"* in *"I don't know what is going to happen ..."* indicating her negative tone towards the matter as well as her uncertainty (polarity and modality) for what lies ahead for her son in the future. Her answer also shows evidence that she is not being irresponsible, which is how she thinks she may be perceived by others. Elements of self judgement, or evaluation with regards to ethics (Fernandez, 2018) appears to be evident here, as well as in *"I should let go"*, signifying that although she feels that letting go of her son is the "right" thing to do, she would like for BW to stay with her until the time comes when she will eventually have to *"let go"*. Her emphatic *"not now."* captures the sentiments of the three parents, Mr. L and Mrs. L and Ms. N; herself, about their stand on the issue of transition to independent living for the 18 to 20-year-olds with ASD.

4.1.2 Not Ready for Independent Living, but May Be in the Future

Three of the parents, Mr. and Mrs. L and Mr. Y believe that their children are currently not ready for independent living, however they may be ready in the future. Here, they explain the reason why they believe so.

In commenting about readiness for their eldest son SY who has Asperger's syndrome, Mr. and Mrs. L revealed that the young adult is not ready for transition at that time but may be in the near future. Mr. Y also holds the same perspective about the prospect of his sons WX and WJ to transition to independent living.

In the following excerpt, he expressed his thoughts on whether his two sons are ready for independent living after they finish their formal schooling;

"...if they can be totally independent, thanks God. That's the best. If not, it will be in the group home." (Mr. Y, Excerpt #8)

For Mr. Y, he expressed in the above excerpt that WX and WJ may be able to make the transition to independent living in the future. Mr. Y responds with a hypothetical *"if they can be totally independent ..."*. The intensifying adverb *"totally"* highlights the ultimate in terms of what he sees as *"the best"* scenario for both his sons i.e. one that he would be grateful to God for. As opposed to Ms. N and Mr. L, it can be seen here that by looking at the polarity (Halliday & Matthiessen, 2013, p. 145) of Mr. Y's answers, he seems to have begun his response to the question on his sons' readiness with optimism in terms of polarity (use of positive polarity words under the modal operators category such as *"can"* in "*if they can*"). This is a possible indication that he is optimistic in his point of view regarding the state of readiness of his children to transition into independent living. However, he concluded his answer with an "*If not*" (use of negative polarity words such as *"not"*), when addressing an alternative option for his children if they are not able to live in the future independently, elaborating that the less ideal outcome would be to place them "*in the group home".*

His positive point of view is shown in his efforts at preparing them for the potential transition, which includes training to carry out everyday tasks that he elaborates about in the following excerpt.

> "Of course now we are training (them) – even now, on real life, we go out and training them to use money and (going to the) shopping mall...I ask them to choose what you want to buy, (let them) make decisions, choose the chicken, give to the people to weigh...I teach him how to use the credit card." (Mr. Y, Excerpt #9)

He revealed that he trains them doing everyday tasks such as *"how to use money",* grocery shopping and decision making for everyday situations. As he mentioned in Excerpt #8, if after his efforts to train them with the independent living skills mentioned in excerpt #9 independent living is still not possible when he is no longer able to care for them or is not around, their transition would be to live 'independently' in a group home.

Mr. Y revealed he has difficulty *"depend(ing)"* on others to care for his sons but hopes to be more trusting and learn "to let go".

> "I think I am not as good to let him go. It's not good. I have to let go. Even school trips sometimes I will tag along. So some of the parents think 'are you crazy?". I follow them behind. But now I am getting better. But I still don't let them go to have certain outings by themselves. Unless they are trained teachers, trained therapists." (Mr. Y, Excerpt #10)

Mr. Y, in a similar predicament to Ms. N earlier, though he admits he is not comfortable in letting his sons be independent, also understands that he needs to *"let go"* (self judgement appraisal in *"I have to let go"*) eventually (Fernandez, 2018). This is a possible indication that his use of self judgement here may suggest the possibility of letting his sons live independently in the future. Interestingly, his idea of "living independently" and "letting go" it is not to let go of the reigns completely *("outings by themselves"),* but merely to pass the responsibility on to teachers and therapists. Therefore, he sees the training of these professionals to be essential in making transition a possibility. Mr. Y's frequent use of the word *"trained"* suggests that it is imperative that whoever he transfers the care to is well versed and equipped with the knowledge of handling individuals with autism, a recurring concern for all the parents with children with disabilities in general.

With the subject of work being one of the domains that are determiners of successful transition to independent living, the parents also gave their views on their children's job prospects. Though apprehensive about the idea of his sons working under any kind of environment as both are prone to having meltdowns, Mr. Y is willing to cast aside his worries. Mr. Y discussed the shelter workshop project mentioned by Mr. L previously, with various ideas for the kinds of services the shelter workshop can provide to match the capabilities of adults with ASD. He suggests "*cleaning, F&B (food and beverage)"* as *"all the autistic group, they are good at cleaning because they are meticulous."* He strongly believes in the shelter workshop project and will be content if his sons are sent there after they end their education provision, especially with the supervision, guidance and full-time care offered at the shelter workshop.

For their eldest son with Asperger's Syndrome, SY, Mr. L and Mrs. L both did not agree on his current readiness to transition into independent living. However, both parents remain optimistic where they mention that with correct guidance now, he may be able to make the full transition to independent living in the future.

Mrs. L explains that he still requires support, and at the time of the interview, *"cannot be independent."*

> "For SY,...now, he cannot be independent. Because from what I observe, he cannot (be independent). 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 (him). So just…give him more encouraging words, then he can...step out...looking for his jobs." (Mrs. L, Excerpt #11)

Both parents commented on deficits associated with ASD observed in SY which involve his mental (cognitive) skills and basic (psychomotor) skills. Following the same pattern of the use of modal operators *(*negative polarity in *"he cannot be independent"* for the word *"cannot"* from Halliday & Matthiessen, 2013, pp. 145), Mrs. L stated that SY is currently not ready for independent living because he *"cannot be independent"*. Mrs. L reiterates again this fact after providing her reason as to why she does not think he can be independent *("Because from what I observe, he cannot")* where she shared that it is due to the need to guide him in *"everything",* suggesting that SY is unreliable in making any kind of decision by himself in all aspects of his life. Therefore, to prepare SY for the working world and independent living, Mrs. L gives him life advice which she calls "*encouraging words"* to prepare him for working life in the future.

She provides instances of SY's irresponsible behaviour which has her question SY's level of self-awareness and responsibility in *"everything he do".*

> "When he was young, (when) he step(s) into the house, (his) shoes, sock, back, coat, you look back, everything (he) throw. SY is like that. Now(adays) also the same thing. When he comes back, he won't close the (house's main) gate. Sometimes forget outside gate. When I come back, every day (the gate) open." (Mrs. L, Excerpt #12)

> "I always ask him whenever he do things, (He is) Very careless. He never think twice. (In) Everything he do(es)." (Mrs. L, Excerpt #13)

Once again, she highlights his behavioural deficits which can be interpreted as a lack of responsibility. Her repeated use of the word *"everything"* emphasizes that this behaviour is observed in "all" kinds of situations (everything he do, everything he throw (things around the room) etc.). She further adds that SY *"never thinks twice"* underlining his lack of awareness and inability to reflect and think about the consequences.

Mrs. L further comments on how SY's difficulties in socialization is related to difficulties in transitioning to in independent living, with communication being another aspect that determines a successful transition to living independently. She comments on SY's inability to form meaningful connections with people, despite doing well in work related conversations that involve technical jargons and structured talk.

> "Go to the customers. Purchase. And then communicate with the customer. (He) can handle all this…for work, okay. But if it comes to communicate relationship like that type, worse. (Mrs. L, Excerpt #14)"

From the excerpt above it can be ascertained that Mrs. L recognizes SY's skills at dealing with customers when he follows her to work. However, she stresses that this is merely applicable *"for work"* and adds that for relationships involving a higher level of emotional connection, SY is unable to do so.

She revisits these behavioural aspects later in the interview while discussing SY's abilities in looking after his younger brother, SJ, as well as her worries on his preparedness to enter working life if he does not improve his current behaviour;

> "...encouraging words is very important. So nowadays when I send him to school in the car, I will give him a lot of outside experience, how people treat you, how you go and build up relationship with people, how you handle the job, what you need to pay attention. (He is) Autistic (but we) can still give him a lot of input. Let him have the preparation (for him) before he go out to work. So when he go out to work, I cannot control already. (He needs to) Solve his problems by himself already. Because now, I still can guide you,...what I tell you now is let me take care of him." (Mrs. L, Excerpt #15)

She explains she will still *"let him go out to work"* in the future, and once again reiterates the importance of providing SY with *"encouraging words"* for preparation before he goes. As she has mentioned previously, life advice such as *"how people treat you, how you go and build up relationship with people, how you handle the job, what you need to pay attention (to)"* are vital *"inputs"* for preparation of transition into independent living. Again, she attempts to shield her son from his disability related issues surfacing during his interactions outside the home by making behavioural changes, by teaching him how to communicate with other people. However, for now, she would like to *"take care of him"*, indicating that she prefers for SY to be under her care where she can guide him on everything, minimizing potential issues he may face alone due to his lack of social communication skills.

Mr. L however seemed to have a more positive outlook on his son's prospects for independent living, merely choosing to comment on SY's more positive behavioural traits. For example, he talks about how SY is able to travel and cook by himself. The following excerpts are examples of these positive traits provided by Mr. L.

> "He can drive. And then, it's like, today I need the car. (So) then he (has) to take a, LRT station there, take a bus…." (Mr. L, Excerpt #16)
>
> "He is independent. He can cook. He can do everything himself. Very simple cook(ing). He takes some vege (vegetables) from the fridge, and then he just do (cook) it altogether, some meat, and then fry together, then eat with the rice. He can cook rice. Sometimes we ask him to cook the rice. He can do all this." (Mr..L, Excerpt #17)

Mr. L spells out that SY is able to drive and cook *(*positive polarity in *"he can drive", "he can cook","he can do all this"* with the use of the word *"can",* Halliday & Matthiessen, 2013, p. 145*),* followed by a concluding statement saying that SY *"can do everything himself".* Positive polarity can also be seen present through the repetition of the word *"can"* in the mentioned clauses with regards to SY's competency and ability to conduct everyday living tasks, thus suggesting SY can live life on his own in the future.

Despite these mentions of positive traits, when the subject of interpersonal skills is brought up, Mr. L agrees with his wife on SY's inability to maintain meaningful relationships with his friends *("He has friends…But not so close lah. Not the buddy, buddy one…")* This exhibits their shared thought of SY's lack of interpersonal skills.

4.1.3 Conclusion

While Mr. L chose to highlight SY's positive behavioural traits and the basic skills one needs to live independently such as cooking and driving, Mrs. L commented on SY's deficits associated with ASD such as difficulties in socialization and lack of responsibility instead. Both however have hinted that he has the potential to transition successfully if equipped with sufficient advice and guidance prior to the transition, as well as supervision from close family members after transition has taken place.

Overall, Mr. and Mrs. L and Mr. Y have expressed that their children, SY, WJ and WX respectively, are currently not ready for the transition to independent living, however with the current ongoing preparations mentioned such as advice and training for conducting everyday tasks, they may be in the future.

4.2 Challenges Parents Have Faced and That Have Persisted in Their Experiences of Raising Their Children with Autism and Asperger's Syndrome

All the parents have reported various perspectives and challenges on the transition of their children with autism and Asperger's Syndrome to independent living. Hence, before addressing the challenges, this section intends to (a) trace back to their developmental history, then proceed to exploring (b) the issues they encountered during intervention prior to and following the diagnosis, which may have been factors as to why the young adults with ASD have not reached the state of readiness for independent living.

4.2.1 Early Stages: From Noticing Symptoms to Getting a Diagnosis (Challenges in Noticing Symptoms and Obtaining Accurate Diagnosis)

All the parents reported noticing signs that led them to seek medical attention. While Mr. and Mrs. L appeared to have had no issues with getting their son, SJ diagnosed, Mr. Y shared about the problems they faced in finding medical practitioners who could give an accurate diagnosis to his children. On the other hand, Ms. N and Mr. and Mrs. L were required to seek for diagnosis twice as the first diagnosis was inaccurate for BW and SY respectively.

Mrs. L explains how she managed to get both of her sons, SY (first diagnosed with ADHD) and SJ to be diagnosed.

> "...and this one (points to SJ) (diagnosed) when he was two years old, (because) he (had) no speech. During that time I bring both of them (SY and SJ) to UH (University Hospital) to do all the tests. and this one (SJ), 2 years old." (Mrs. L, Excerpt #18)

In analyzing the linguistic expressions and resources used by Mrs. L, the transitivity and ergative analysis was used (Halliday & Matthiessen, 2013, pp. 211 - 310). Mrs. L appears to have used material processes (physical actions = *"I bring both of them to UH to do all the tests"*) (Halliday & Matthiessen, 2013, pp. 245 - 259) to explain her actions when being asked about the diagnosis of her children. The use of the material processes seems to have put Mrs. L at the center of her experience in seeking diagnosis for her children. How she shared she had physically brought her sons herself to the hospital indicates her proactiveness. Since SJ *"had no speech"* by the time he was two years old, and the parents had access to a medical professional who could carry out the relevant tests, they were able to get him diagnosed at a public university affiliated hospital. At this point of time, while SY was diagnosed for ADHD due to his hyperactive behaviour, SJ was diagnosed for autism for still not developing speech at the age of two years old.

Mr. Y on the other hand faced somewhat delayed diagnosis for both, WJ and WX, due to inaccurate diagnosis for WJ and delayed identification of symptoms for WX. Mr. Y recalls that he recognized his first son's (WJ) limited speech and unusual mannerisms early on *("no speech, rocking, no eye contact, pacing around")* and sought diagnosis from his paediatrician at a local hospital. However, his paediatrician informed Mr. Y that because WJ is "a boy", it is normal for him to behave like that, assuring Mr. Y that WJ will eventually grow out of his behaviour.

Unconvinced with the doctors' explanation, Mr. Y searched these symptoms on the internet using the Yahoo search engine where he discovered the word "autism". He searched for a doctor in the country who could provide a proper diagnosis and discovered a local psychologist from another private hospital that was able to give a diagnosis for autism. This then led to WJ getting the formal diagnosis of autism at the age of two years old, the same age as SJ, only for Mr. Y, it took him more effort than Mr. and Mrs. L.

Conversely, the developmental history for his second son WX differed from his elder brother WJ, as identification of WX's symptoms were late. Mr. Y admitted that his symptoms were overlooked as he showed normal speech development, unlike his older brother. After Mr. Y was later involved in an Early Intervention Programme (EIP) organized by a local autism parent support group whereby therapists and trainers from Australia aided with the intervention programmes and carry out diagnostic procedures, WX was accurately diagnosed with autism by one of the Australian doctors at the age of three years old.

> "...we hire, we bring in some...therapists. ABA trainers, therapists. From Australia. Autism Resources in Australia. They came in and actually train, and go to visit the parents, and then look at the kids, and then come up (with a) programme. Then we follow their programme and then videotape it, and then send to them. Then they suggest what to do next, and then they come back here every 6 months. And then do...interview with the parents. And then propose many things how to do. Mostly ABA (Applied Behaviour Analysis)." (Mr. Y, Excerpt #19)

In contrast to Mrs. L, Mr. Y provided a more extensive use of material processes (*we bring in some…, we follow their programme, and then videotape it and then send to them”*) when being asked about the diagnosis, implying heavy initiatives after learning of the diagnosis of his children. Given that these visits were only available after a lapse of six months, the parents resorted to video recording the intervention that the parents carried out following the instructions given and sending it to the experts to be reviewed. The parents were then given information about the subsequent steps.

Mr. Y’s experience of difficulties in finding a doctor who could correctly diagnose his children seems to have differed from Mrs. L’s case as she successfully sought diagnosis from a government hospital. This may be due to the government hospital being affiliated with a research university where doctors are most likely to be up to date with the latest advancements in medicine. Interestingly, Mr. Y summed up his experience with the fact that 15 years ago, even his “*my paediatrician doesn’t know anything about autism”* indicating little knowledge among even the medical professionals at the time on ASD.

As for Ms. N’s son, BW, he underwent two formal diagnoses around the age of three. The following excerpt illustrates the reason for the repeated consultation with the psychologist.

> “He was diagnosed two times. ...when he was three. She (the doctor) is a psychologist. Second time was when he (was) applying for the OKU card. Letter from the clinic. I cannot remember what the doctor diagnosed. Put the label like as ASD or what. Because at that time it is not important for me, whatever it is. We just wanted to get an OKU card.” (Ms. N, Excerpt #20)

For Ms. N, she used fewer material process clauses (Halliday & Matthiessen, 2013, pp. 224 - 245) in her answer to the question on diagnosis, instead using mental process clauses (her feelings) to describe her experience *(“…at that time it is not important for me, whatever it is”*). She spoke passively of her child’s diagnosis account, in contrast to

Mr. Y and Mrs. L who spoke in a more active voice. Her main objective at the time was merely to obtain documentation to support her application for an OKU (Persons with Disabilities) card. Her inability to recall the diagnosis suggests that the diagnosis was unimportant to her *("I cannot remember what the doctor diagnosed. Put the label like as ASD or what.")* From the excerpt she elaborates that she could not recall the diagnostic label given as it was unimportant to her (at that point in time). In fact, she goes on to comment that his disability was obvious based on the symptoms he displayed and from her perspective, getting the OKU card was more important and it did not matter to her if the label ADHD or ASD was used. Mr. N's stance on her son's disability in Excerpt #20 seems to show her avoiding the use of the medical label given to her son completely as perhaps a way of avoiding circumstances where her child's disability is highlighted, especially as ASD shows no visible impairments.

Similarly, for SY, delayed diagnosis was the main challenge faced by Mr. and Mrs. L as his initial diagnosis was for attention deficit hyperactivity disorder (ADHD) at a local hospital with his brother SJ being diagnosed with autism at four years old. It was only later during the later stages of SY's primary school years that he was accurately diagnosed with Asperger's Syndrome.

Mr. and Mrs. L first identified signs that were unusual in his behaviour (hyperactivity), coupled with his speech and writing (jumbled word order) during his preschool. With regards to the transitivity and ergative analysis, Mr. L provided examples of SY's difficulty in forming correct sentence structures by using verbal process clauses (indicating use of language = "*The way he talked, he speak,... "House my", "mother my".*) (Halliday & Matthiessen, 2013, pp. 300 - 310):

> "From (when he was) young we know already. The way he talked, he speak,..."House my", "mother my". Then, from there we sent him to see the doctor. Psychiatric (doctor)." (Mr. L, Excerpt #21)

Hence, based on his hyperactivity, speech and writing issues, Mr. and Mrs. L obtained a formal diagnosis for ADHD during his preschool years. However, Mrs. L then discovered a news article on Asperger's Syndrome in the local newspaper (her "*first time"* hearing of such term);

> "Then one day, I don't know...somewhere come out. ...symptoms like my son. Really my son's symptoms. Then from there only I go for the doctor. (These doctors) have a write up about these types of children (those with Asperger's Syndrome)" (Mrs. L, Excerpt #22)

Mrs. L stated that the symptoms featured in this newspaper article matched her own son's symptoms and prompted her to bring SY for a second formal diagnosis at 11 years old, where he was eventually diagnosed with Asperger's Syndrome. She refers to children with Asperger's Syndrome as *"these types of children",* signifying her lack of knowledge on the subject at the time, as well as revealing what society frequently refers to children such as SY. From this excerpt it appears that Mrs. L used the relational process clause (Halliday & Matthiessen, 2013, pp. 259 - 300) to note on the attributes and identification of the children she is referring to *"(these types of children").*

All the parents interviewed have successfully obtained the formal diagnosis for their children, despite going through different experiences. They also reported to have difficulties progressing to early intervention after the diagnosis, although their individual challenges somewhat differed.

4.2.2 Challenges Faced Prior to and After Diagnosis

While the process of obtaining a diagnosis for SJ was without complications, Mr. and Mrs. L faced other hurdles afterwards, as did Mr. Y. However, Ms. N, who also faced difficulties with diagnosis, reported less challenges in following up with intervention where this was most likely due to her financial status. For SY who is the only child diagnosed with Asperger’s Syndrome, the majority of the challenges faced by Mr. and Mrs. L was due to his limited social communication skills.

All the parents state the general lack of awareness to be a major challenge in the intervention steps they took following the diagnosis, where Mr. Y had previously noted how this also posed a problem during his process in getting a formal diagnosis for WJ and WX. He and Mr. and Mrs. L further encountered issues with lack of trained teachers as well as the high costs of service provision centres for children with autism. SY who attended school along with other typically developed children faced complications mainly related to his social communication deficits, where these issues were prominent during his primary school years.

4.2.2.1 Problems Faced During Primary School Years

As SY’s symptoms are less apparent than the parents’ children from this study, it is evident from the parents’ tone and accounts that more is expected of him than from his younger brother SJ. As SY was merely lacking in social skills, he was enrolled into schools like a typically developed child. However, as SY only received his delayed diagnosis at 11 years old, many challenges were related to his primary school experience.

It was found that the majority of the stories regarding SY from the interview were the subject of teachers with limited knowledge of children with disabilities during SY’s early childhood and school years. Mrs. L first discusses his hyperactive behaviour during his kindergarten days in his extracurricular art lessons after he was diagnosed with ADHD. She mentioned in the excerpts below SY frequently getting into trouble with the teachers;

> “(He) cannot stay still in the class...And then he went into the kindergarten,...he play with water, hitting people in the classroom, he will be outside running the whole field. In the end I bring him back and take him to (another kindergarten) also same thing. He will be sitting on the naughty chair until (he) left the school. I don’t know how many years. 3 or 4 years. Everyday also naughty, naughty. They made him to sit in the corner on one of the chairs for don’t know how long.” (Mrs. L, Excerpt #23)

> "He's very naughty. The first lesson, the teacher kicked him out. I beg the teacher to give him three lessons. I said "I don't care what you do, just keep him in." Then the teacher (was) very strict (with) him. Punish him. At last, he still he can stay with the teacher." (Mrs. L, Excerpt #24)

As the teachers have limited knowledge on ways to handle his hyperactivity, he was constantly treated as a badly behaved child. Her repeated use of the word "*naughty*" in both excerpts above showed how these "*naughty"* episodes *("…he play with water, hitting people in the classroom, he will be outside running the whole field")* were daily occurrences *("everyday")* at that point of time. There seems to be a sense of desperation in her narrative when she recalled herself begging the teacher to give him lessons *("I beg the teacher to give him three lessons. I said "I don't care what you do, just keep him in.").* This account evidently showed how she was left with no other options and highlighted her challenges in finding a learning centre that accepts SY. From the excerpts above, the repeated use of the same, negative adjectives used by Mrs. L in this account shows an emphasis on SY's attributes (relational process clause = *"everyday also naughty, naughty, naughty"*) (Halliday & Matthiessen, 2013, pp. 259 - 300), thus, underlining the seriousness of his behavioural issues during his childhood.

This behavioural pattern extended to his primary school years. Mr. L and Mrs. L recalled many instances in one of SY's earliest schools, a Chinese vernacular primary school, where in all events they recalled, SY failed to comprehend simple concepts and social situations, in which this behaviour was misunderstood by his teachers. In the following excerpts, Mr. and Mrs. L gave anecdotes on how SY failed to understand the concept of stealing where this eventually escalated into more behavioural problems;

> "...he go and take...from an ice cream stall and he didn't pay the money and teacher said he is stealing. Actually, it's not stealing. He don't know, he go and take. If you want to eat, you go and take. That time he was still in primary one or two. Then the teacher come and call one of us and see (us). And then they said he is stealing and all that. And my wife said he won't steal. He don't know. He doesn't know that is wrong. The teacher

has to correct him. “How can you say he is stealing? This is not stealing. He is special.” And then they (teachers) all cannot accept (his behaviour).” (Mr. L, Excerpt #25)

“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, Excerpt #26)

“During that time I didn’t know that type of children (Asperger’s Syndrome). So of course, I would punish him.” (Mrs. L, Excerpt #27)

In all accounts of the incidents mentioned above, Mr. L and Mrs. L agreed with each other that SY’s behaviour was misunderstood by the teachers as he had difficulty in comprehending what stealing is and thought *“he didn’t do anything wrong.”* Mr. L gave his own thoughts about the incident, *“How can you say he is stealing? This is not stealing….And then they (teachers) all cannot accept (his behaviour).”* He further explains son’s behaviour by calling out the teachers for their failure to recognize children with SY’s condition and labels him as *“special”* (further use of relational process clause to note on his attributes or/and identification which appears to sound like he is defending his son’s actions in this account) (Halliday & Matthiessen, 2013, pp. 259 – 300). Furthermore, Mrs. L expressed her own lack of knowledge on the situation and gave a similar reaction to the teachers in which she puts the blame on herself for not being informed of *“that type of children”* (referring to children with Asperger’s Syndrome, another use of relational process) (Halliday & Matthiessen, 2013, pp. 259 – 300).

Mrs. L further revealed that SY was struggling academically and had problems with learning and showed some disinterest in learning (a common trait of those with Asperger’s Syndrome), where this was also misunderstood by teachers who again, viewed this as problematic behaviour;

“I go find out everything for him you know. He finish all the homework, he won’t pass up. Not even one he pass, I don’t know why. He don’t like the teacher. The whole homework he won’t pass up. The whole time I work until 11, 12 also he won’t pass up. So I know that he cannot stay in the school.” (Mrs. L, Excerpt #28)

> “The last time that he cried...because the teacher really, really talk bad about him. Saying that “You better go home. You don’t study well. These type of children, worse. Useless.” He come back and sit beside me and he cry and cry and cry.” (Mrs. L, Excerpt #29)

SY’s learning difficulties/disabilities led to his teacher to label him as *“useless”* as he did not *“study well”* according to Mrs. L, suggesting limited potential if his poor academic performance continues (use of verbal process clauses seems to be used her to show a vivid account of what the teachers have been saying about SY = *“You better go home. You don’t study well. These type of children, worse. Useless.”*) (Halliday & Matthiessen, 2013, pp. 300 – 310). Mrs. L says the negative comments from the teachers had made SY very upset which eventually prompted her to move him out of the Chinese vernacular school and enrol him into a private international school.

Despite SY requesting to be placed in a government school, Mr. and Mrs. L assumed private schooling would be a better option for someone with learning issues such as SY and hoped the teachers at the school are better trained to handle such children. However, there was no improvement after SY moved to a private international school, a shift that was initially thought to improve his educational experience compared to his previous school. Mr. and Mrs. L reflected on SY’s experiences during this period and its effects on his academic performance;

> “They don’t really, teach. My son is not really that good (academically). So you know the teacher also don’t bother much. During the assessment month, (the teacher said) “your son still cannot catch up with a lot of things” All these types of things (comments). They’re supposed to teach... (Mr. L, Excerpt #30)

> “As long as you pay them, they will treat your son normal.. It’s just like that. They don’t care. If you are good, you are good. If you are no good also they don’t care.” (Mr. L, Excerpt #31)

> "I get one to one (private) tuition to him. I let him go for a lot of tuition. No focusing. …report come back it's all gagal (failure)." (Mrs. L, Excerpt #32)

Mr. L commented on how the teachers at the international school *"don't care"* for the students and did not seem to be better equipped to deal with the children with learning difficulties than the teachers from the Chinese vernacular school. Feedback on his academic performance from the teachers were also unhelpful as SY still failed many subjects despite private tuition.

Even with the expensive cost of private international schooling and personal one on one tuition, SY's academics failed to yield better academic performance in both of his previous schools. The combination of teachers' lack of knowledge and support in the Chinese vernacular and private schools are highlighted in Mr. and Mrs. L's accounts of SY's early academic challenges.

It was at this point of time he received his diagnosis of Asperger's Syndrome during his private international school years*, "...standard 5, 10, 11 years (old)",* where the doctor advised her to transfer SY to a government Malay medium primary school.

> "I was asking the doctor, "What should I do? Everything you let me know I just follow. What (do) I need to do help my son?" So first week come out, I pull him out from the school. Pull him out from the private school. Then I said where should I go? Kebangsaan (National). Ask me to put him into the normal (Malay medium) school." (Mrs. L, Excerpt #33)

Mrs. L's narrative *("Everything you let me know I just follow. What (do) I need to do help my son?")* showed how she was prepared to do *"everything"* and is willing to follow anything suggested by the doctor, showing her proactiveness and desperation in finding ways to help her son. She can also be seen to accept his medical condition and is willing to conform to the doctor's suggestions and ways to *"cure"* SY. It is therefore understandable that Mrs. L used many material processes *("I was asking the doctor, What (do) I need to do help my son. I pull him out from the school. Then I said where should I go?")* (Halliday & Matthiessen, 2013, pp. 224 – 245) in the excerpt above as this depicts her actions and shows her agency towards finding a better educational environment for SY.

There were no more mentions of SY's struggles in secondary school which was revealed to be a more positive experience by Mrs. L as she said he was guided by a teacher trained in special education where the school also practices an integration programme. Evidently from the parents' accounts of SY' primary school experiences, teachers with the knowledge and training to handle and teach children with disabilities was shown to be the main reason for SY's eventual improved academic and behavioural outcomes where only his social communication deficit with his peers remains.

4.2.2.2 Problems that Persisted During Adolescence: Social Communication Deficits

For SY, issues in social communication continued as he progressed to secondary school, where Mr. and Mrs. L mentioned of no more significant problems in his academics as he completed secondary school and enrolled into college. When asked on whether SY is currently undergoing any interventions for Asperger's Syndrome, Mr. L says the doctor thinks now *"he should be okay already"* as the only deficit holding him back is his social skills;

> "He can handle himself. Just, we call him normal lah. The only thing, social skill not so good. Communication not so good" (Mr. L, Excerpt #34)

From the excerpt above, Mr. L is of the opinion that SY is able to *"handle himself"* implying his ability to function like his typically developed peers *("we call him normal")* and the *"only thing"* that is holding him back in making the successful transition to independent living is his lack of *"social skill(s)"* and *"communication"*. It can be assumed that compared to SJ, SY's younger brother who is on the more severe end of the autism spectrum, and with SY showing abilities to function as a normal adult, Mr. L therefore views SY as "normal", even with SY's apparent social communication deficits. This is an interesting example of how parents classify their children according to their abilities, and not their official diagnosis as autism or Asperger's Syndrome, especially in cases where both children are easily compared as they live in the same household such as Mr. L's family.

Examples of his lack of social skills can be seen in anecdotes involving SY's difficulty in comprehending social situations where he struggles to respond appropriately to verbal and nonverbal cues. Mr. and Mrs. L shares one story of SY, who at the time of the study was studying fashion design, volunteered to make a dress for his aunt as a birthday present;

> "…he('s) very funny one. He do (make a dress) for (his) auntie as a birthday present. When you give people present, normally, you give (the present). But after (he) do already for (the) auntie, he said "I charge you the material cost." (Mr. L, Excerpt #35)
>
> "The labour cost got charge. Mother pay one. …he charged (his) auntie the material cost, Rm150. Auntie said "your son give me present, charge me money. He (SY) said, "…(but) I don't charge her labour cost". ... (if) you go and buy (the dress) outside, (it would be) four, five hundred dollars. I only charge the rm150 only. The material cost only. I don't charge you labour cost. That is my present to you. The labour cost. My hard day's work. Take me more than a month to finish." (Mrs L, Excerpt #36)

The story in the excerpts above began with a relational process clause given by Mr. L, indicating beforehand his son is "*funny*" (or in the context of this story, "unusual" attribute), also suggesting that the anecdote that will be told will highlight this attribute of SY. This story also confirms that similar to SY's previous school experiences where he could not make sense of what *"stealing"* is, here, he was not able to make sense of what "gifting" is. For SY, he could not understand what he did wrong in asking for material cost from his aunt even though he made her the dress as a gift. Mrs. L labels began the anecdote by saying that SY is *"funny",* a word that may be used to express her son's misunderstanding of the situation being humorous for being the main cause of the story being funny or it can also be used to describe SY's odd (/funny) behaviour. In her explanation of the misunderstanding, she uses the word "normally" to describe what a typically developed person would do in the situation and then proceeded to explain what SY did instead, highlighting SY's misunderstanding and his failure to grasp such concepts. This type of narrative is one would expect in an explanation of odd situations, in which considering SY's condition, this situation proved to be odd which in turn makes the story humorous or "funny".

SY also appears to have trouble in forming long lasting friendships according to his parents. Mr. L says that *"he has friends",* in which Mrs. L added *"but no so close. Not the buddy one",* implying these friendships may not extend to meaningful, lasting relationships that one would expect to have. When asked about his college life, even though Mr. L commented his life is *"okay",* Mrs. L further commented that he still has *"no friends".* She also added her thoughts on SY's relationship with other people;

> "No friends also (in college). But now he got one Indian friend. The teacher there, lecturer there. I think one year, this year only join. He really can click with this teacher. This one is very famous in the Tamil market. I know his name is Bara, Cikgu (teacher) Bara. He always come back and say Cikgu (teacher) Bara. And he learn a lot from this cikgu (teacher). Last time that teacher, Teacher Kenneth. That one, cannot click with him. When (the) teacher cannot click with him, he refuse to study one you know. He got no mood to go to school one. Always make excuse, excuse don't want to go (to college). And the (lecturer's) work also cannot finish. That's why he retain another year in college" (Mrs L, Excerpt #37)

This excerpt shows SY's difference in response towards people that he gets along and do not get along with. Mrs. L complains that due to his behaviour in refusing to attend and do the lecturer's tasks simply because he did not like the lecturer was the reason why SY was required to extend his year at the college. His behaviour is shown here to not only affect his relationships with people, but also affect his academic performance.

Interestingly, on the subject of language acquisition, SY is able to acquire multiple languages like a typically developed child, namely, Mandarin, English and Malay. However, for Mandarin, a language he was exposed to from his household, as well as his short stint at the Chinese vernacular primary school, he has become less proficient in the language, as explained in the next excerpt by his father;

> "Mandarin is because in primary one he was in Chinese school. But he cannot write. Now he cannot read already. (Laughs) That's why he cannot read and cannot understand the Chinese words. But he can understand, he can converse. He can speak Mandarin, he can understand mandarin. But he cannot write. That day he tried to write his name. Almost forgotten how to write his name in Chinese already. But still can manage to write it. But we ask him to write some more he cannot" (Mr. L. Excerpt #38)

Mr. L says that although SY can speak Mandarin, after leaving the Chinese vernacular school and enrolling into government Malay mediums school for the majority of his primary school years, this seemed to be a major factor that contributed to his deteriorated proficiency in Mandarin. As a result, although he is able to speak Mandarin, he has now forgotten how to write in the language. Hence, at the time of this interview Mr. L confirmed that he has better language skills in both, Malay and English, *"he can speak English, Bahasa and Mandarin His first language normally English lah".*

He continues to reveal SY's proficiency of the Cantonese, Hakka and Hokkien Chinese dialects in the two excerpts below;

> "…he can speak mandarin. Cantonese also is not very good. Dialect lah. Our dialect is Hokkien. He totally cannot. I'm Hokkien. My wife is Hakka. These two he cannot. But Cantonese got (he has a) friend who he speaks Cantonese with) so sometimes he understands. But you ask him to talk, opposite, (he cannot)." (Mr. L, Excerpt #39)

> "…Hakka I don't think he understands. Mother tongue he never learned from the mother. Mother and father never talk (in the Hakka dialect). Mother only speaks Mandarin to him. He can understand Mandarin, (but) he cannot write, he cannot read" (Mr. L, Excerpt #40)

Mr. L explains that infrequent use of the dialects among Mr. L, Mrs. L and SY ultimately contributed to SY's low proficiency in the three dialects. Only in the presence of peers who speaks the dialect, he will practice using the language. His language ability may also have influenced his choice of friends where SY was said to have only Malay friends even after he has progressed to secondary school and college;

> "Yes. He has friends. In the secondary here, after Form 3, in the Kelana Jaya here. SMK Kelana Jaya here, he got friends. But not many Chinese friends or Indians. Only Malay. Even after school, they go to the KLCC there, got cosplay there. Even when they left school already after form 5, they still call him and they go to cosplay together. There KLCC there, they have cosplay. He like it. When once he goes to one, he likes it. The Malay school kids altogether." (Mrs L, Excerpt #41)
>
> "All his friends are Malay. Last time in school also he can get along with Malay, but cannot get along with Chinese." (Mrs L, Excerpt #42)

As Mr. and Mrs. L have mentioned previously of his preference in using English as his main language of communication, as well as his ability to write and read in both English and Malay but not in Mandarin, these factors may have contributed to him corresponding better with the Malays than the Chinese.

Mr. and Mrs. L have exhibited SY's ability to acquire multiple languages (in line with the multilingual society that he lives in) similar to that of a typically developed child. However, his lack of social skills has affected his use of the said languages as a social tool to communicate with others.

As for the children with autism, their ability to communicate is more limited compared to SY with a few of the children discussed in this present study being non-verbal. Mr. Y shares how he attempts to overcome these communication issues by using electronic devices, PEC (Picture Exchange Communication) and the WEC (Word Exchange Communication) to converse with his sons when he needs to;

> “This is another form of communication... Even WJ, he can actually use PEC, Picture Exchange Communication (computer aided pictures for communication). *shows how to use* When he doesn’t know what he wants, I show him this, he will choose one.” (Mr. Y, Excerpt #43)

Mr. Y here shows the use of electronic devices as among his initiatives in improving social communication between each other.

Ms. N on the other hand says that BW would only converse with her if he *“wants”* something;

> “He only talk to me if there is something that he really, really wants. Especially food.” (Ms. N, Excerpt #44)
>
> “Like sometimes he feels like he is too boring, he want to go out, he will say “Mummy, shopping mall… So I will... ask “Okay which shopping mall you would like to go? And he says “Sunway (shopping mall).” “Sunway is so boring. We just been there last week. Can we go to 1U (shopping mall)?” “Okay.” He will always say okay.” (Ms. N, Excerpt #45)

From the excerpts, BW only communicates when he feels the need for it (Ms. N responded using verbal processes for the entirety of excerpt #45 to show an example of the kind of communication that occurs between her and BW). Ms. N does not mention any further type of communication with him outside of this which suggests that BW is most likely to only converse with his mother and not anyone else.

4.2.2.3 External Factors: Societal Awareness and Acceptance

One of the main challenges mentioned by all the parents was the general lack of awareness among all stakeholders. This can be traced in all parental experiences during childhood following the diagnosis.

Ms. N reflects on how she faced many rejections from extracurricular classes due to the teachers' inability to handle BW as he was too *"hyper".*

> "...when he was young, I was looking for a lot of classes for him. Gym class, art class, piano class, whatever class, all rejected him. Because he is very hyper. No teacher and no centre want to teach (him). Even though kindergarten. Kindergarten also don't want (him). I bring him for trial, they say 3 hours. I leave him for 3 hours. Just an hour (later) the teacher called me "Can you please come and pick him up? We cannot take him, he is too hyper." So, no centre want to accept him. So why I teach piano? Because the parents come and look for me and say "Please teach him because I cannot find a teacher or a centre for my daughter or for my son", I said "okay." (Ms. N, Excerpt #46)

She comments that the experiences of often facing rejections made it difficult for her to enrol him anywhere as the centres and kindergartens *"all rejected him"* and *"no centre want to accept him",* highlighting her desperate situation *("all rejected....", "no centre...")* similar to Mrs. L's situation earlier. This narrative tone has been a recurring theme throughout this present study and underlines the challenges that are commonly faced by parents raising children with ASD. Ms. N however noted that these experiences eventually influenced her to be more lenient in accepting requests to teach music to children with disabilities as she herself understands the plight of parents with similar predicaments as hers.

Mrs. L adds another dimension in discussing the problem of awareness at the societal level. She explains that the people around her simply *"don't understand"* her situation:

> "Why I say that awareness is important it's because…when I bring my children out, people don't understand. My parents also don't understand. My mum also don't

understand. My family members all don't understand. They always say that "your parents never taught you correctly" (Mrs. L, Excerpt #46)

She singles out the society, her family members and her own parents in failing to *"understand"* her son's condition and mentions the *"people"," parents", "mother", "family members",* implying that everyone around her does not "understand" her situation and BW's condition. Mrs. L further comments on how the society often places the blame on the parents for the children's odd and difficult behaviour, implying bad parenting instead. She mentions of the need for more awareness on ASD to educate the public, an instance where she invokes autism to challenge the public's negative evaluations towards her parenting skills and towards her son.

Mr. Y agrees with this view and shares his own thoughts on the matter and similar experiences he faced to Mrs. L;

"They will (normally) tell their kid, "See? This is a spoiled brat just like you. Papa don't buy you this, don't be like this boy here." (Mr. Y, Excerpt #47)

Mr. Y expressed that he would like parents to educate their children on ASD and not quickly jump to conclusions when they see odd behaviours in public and thinking this is due to the child being *"a spoiled brat"* (Mr. Y uses verbal processes to give an example of this anecdote = "*See? This is a spoiled brat just like you. Papa don't buy you this, don't be like this boy here"*) (Halliday & Matthiessen, 2013, pp. 213 – 217, 300 - 310). Hence, Mr. Y and Mrs. L shares the same sentiment regarding more awareness among family members and society in general on the medical condition to help erase such negative views towards their incompetence in parenting.

With the lack of centres in the country, Ms. N and Mrs. L also made efforts in sending their children to other centres that cater to typically developed children. As a result, they found that the teachers and the public have difficulties in accepting children with ASD, which poses more obstacles for the parents in bringing up a child with autism. As the lack of general awareness already seen as a major issue for all the parents, this also foreshadows lack of awareness among the teachers and facilitators at the available centres in the country.

4.2.2.4 Lack of Teacher Knowledge on Strategies for Dealing with Children with ASD

Teachers were reported to have little knowledge of ASD and understanding on the suitable teaching strategies for handling children with ASD. Mrs. L and Mr. Y shared their experiences with one of the main centres for ASD in the country, NASOM (National Autism Society of Malaysia);

> "During (SJ's enrolment into) NASOM (National Autism Society of Malaysia) that time, everything (we) 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, Excerpt #48)
>
> "I think because NASOM initially, their people have no training. Severe one. They have no choice. Sometimes they have to restrain them." (Mr. Y, Excerpt #49)

From both parents' accounts, it can be seen that the teachers at the NASOM centre evidently do not have access to knowledge of strategies in dealing with children with autism, with Mrs. L trying *"everything"* with regards to intervention (Mrs. L uses material processes to describe her efforts and initiatives = "*everything (we) try out"*) (Halliday & Matthiessen, 2013, pp. 224 - 245), and with Mr. Y revealing the centre's use of restraints on the children at the centre when things get out of hand. As the parents themselves were ill equipped with the correct knowledge as according to Mrs. L, *"no info at all"* was available to refer to at the time, she and the teachers *"tried out...everything"*. When asked to buy essential oils, no further questions were asked and she *"just buy"*.

Even with the government integrated schools (PPKI), Mrs. L and Mr. Y shared similar experiences where both gave accounts of parents being told to *"standby"* in the canteen in case they are unable to control their children during the school's daily classes;

> "Even I send them to (one of the integrated national schools, PPKI) ...they have a board for the special needs children. But the teacher go there and just sit. Even if the children there have anything happen, they cannot handle, call the parents, all parents standby in the canteen. They just call every parent and they come. They don't do anything for the children. Anything they want the facilities, all they got. But the teacher don't know. So I don't know whether the teacher is not well trained or the teacher is lazy, we don't know." (Mrs. L, Excerpt #50)
>
> "I went to school all the time. I stayed at the canteen. So, whenever they having some issues, they will call me. Since 2007." (Mr. Y, Excerpt #51)
>
> "Teacher just want us to be there. Because they cannot handle it. They cannot handle any case for autism case. They actually want me to be there. "You just stay at the canteen please." (Mr. Y, Excerpt #52)

The parents explain that keeping the parents close by during the classes is a normal precautionary measure as the teachers' strategies of handling children with ASD were inadequate. These accounts of the teachers' actions at the PPKI are somewhat comparable to the teachers at NASOM as both centre and school are unable to provide proper interventions and handling of children with autism as well as other disabilities. Mr. Y believes that the reason the teachers at NASOM have poor handling of the children may be due to them having *"no training"* in special education. Frequent mentions from both, Mrs. L and Mr. Y on the teachers who *"cannot handle"* the children and how they often *"don't know"* what to do highlights the issue of the lack of special education training teachers and trainers at schools as well as the centres in the country. As the excerpts above mentioned many attributes of the teachers at the centres, it is to no surprise that there are many verbal processes used by the parents to describe the attributes of the teachers that lack the training for dealing with children with ASD *("But the teacher go there and just sit. Even if the children there have anything happen, they cannot handle, call the parents,* *all parents standby in the canteen. They just call every parent and they come. They don't do anything for the children..)* (Halliday & Matthiessen, 2013, pp. 259 - 300).

It was found that both sets of parents reported similar issues where teachers have limited knowledge in their strategies of handling children with autism, be it at government schools and centres or NGOs. The repeated mentions of the lack of teachers who are trained throughout the interview has indicated that this is among one of the significant challenges parents have faced repeatedly during the early childhood stages following formal diagnosis. Other programmes do not appear to be alternatives that were available for these parents, hence the parents resorted to register their children at easily accessible, government/NGO run schools and centres.

4.2.2.5 Financial Constraints: Affordability of Intervention Programmes

With the enrolment of their children into schools and centres handled by the government and NGOs, the parents reported similar issues in lack of trained professionals, and this led some of them to seek alternatives such as those from the private sectors.

Nevertheless, Mr. Y voiced his issue with affordability of the quality enrichment programmes and private schools he enrolled WJ and WX to;

> "We used to run, provide enrichment program whereby we hire therapist to come. But not now. We cancelled that because of the financial limitations. Because therapist is not cheap." (Mr. Y, Excerpt #53)
>
> "Private school...whereby they have integration and allow them to go to normal school, but they are sitting behind (the class)....I left earlier. Because financially, I cannot afford it. It is too expensive. They left at Primary 2, 2009. Getting too expensive for me. I had to fork out like 8000 a month." (Mr. Y, Excerpt #54)

Both, the enrichment programme and private school were *"too expensive"* for Mr. Y, despite them being mentioned to practice integration and possessing *"well trained"* teachers. This shows that although private run centres and schools may have solved the previously mentioned issues such as lack of trained teachers in special education, they also come at a cost and may not be affordable for all families.

Ms. N who has been enrolling BW to private centres and programmes from the beginning, has made no mentions of lack of trained teachers in her experiences, but acknowledges that she is also aware of private run centres' high prices. She mentions that the current centre BW is enrolled to, where at that point of time, the centre has informed her that they will soon be providing a new curriculum for teenagers. She expressed her worry over the newly structured fees that comes with the new syllabus;

> "...the price (for the new curriculum) is also new, (so) I have to consider (laughs). (So) I try my best now to teach him independence (independent living), doing everything." (Ms. N, Excerpt #55)

Ms. N. says that the new curriculum will provide small group teaching with a syllabus that focuses on the necessary skills needed for independent living (e.g. use of public transportation, grocery shopping) but due to its high fees, she will try her best to "teach him independence (independent living)" instead, implying that she may not enrol him into the new programme as it is too expensive for her and instead teach BW herself.

She mentions her parents commenting on how she has been constantly *"wasting money"* on expensive therapies and programmes for BW;

> "My parents even told (me) I went to go and waste all my money. "Boys is like that. Always delay. You just wait." (Laughs) I said "No ma." I say "He's a bit different than other kids." You give him the toys and he just throw it during tantrums. He mess up everything. Bring him to the therapy he is not cooperate. Below 45 minutes, he charge me about RM170 years ago. He throw tantrum for 30 minutes, then just learn for 15 minutes and I still had to pay 400 dollars. My mother said "You are wasting money." (Ms. N, Excerpt #56)

While Ms. N argues that her son BW is *"different",* her mother suggested that BW displayed behaviour commonly associated with boys and insisted he will eventually grow up normally (a similar comment made by Mr. Y's private hospital paediatrician when he first sought diagnosis for WJ). Even with BW being uncooperative or the lessons unfruitful, Ms. N was still required to pay the full amount of each expensive private therapy session, hence her mother's disagreement. Her experience also shows that not all private therapists can provide positive results with the high cost.

4.2.3 Conclusion

For SY, his challenges from his first diagnosis of ADHD, and his second diagnosis of Asperger's Syndrome have mostly revolved around his social communication deficits, where until today, can be seen to have a significant effect on his school and work opportunities. This effect will in due course affect his future and quality of life, and with Asperger's Syndrome being a lifelong disorder, SY's transition into adulthood may still feature persistent obstacles if without the correct guidance, support and environment.

For BW, SJ, WX and WJ, although the alternative services for early intervention seem to solve the previously mentioned issue of lack of trained teachers and awareness among the general public and teachers, parents have reported its high cost as the main reason they did not enrol or discontinue their children from them. With the issue of lack of quality services available in the country for children, this foreshadows the parents facing similar challenges for when their children transition into adulthood.

4.3 Parents' Plans for the Future Potentials of the Young Adults with ASD

All parents give their own views on their plans for their children's future in relation to living and working arrangements and public awareness.

4.3.1 Living and Working Arrangements

As autism is a lifelong condition, all the parents interviewed expressed that they would like their children to be placed at centres that provide long term support. They collectively agreed on the lack of service provision centres, homes and centres available in the country for adults with ASD. Ms. N believes more autism centres need to be set up by the government, *"especially for the teenage group."* Mrs. L extends her concern from Mr. L previously on having no options on where to send SJ after he becomes an adult;

> "...For the teenage. Now they (the centres) are only up to 12 years old only. Even school can only bring them up to 19." (Mrs. L, Excerpt #57)

By analyzing the thematic structure, we can see the way the respondents' answers flow throughout the interview, their organization of answers, and the introduction of new elements (Thomspson, 2014). From excerpt #57, it appears that Mrs. L first answers the question by stating that she hopes there will be more homes and service provision centres *"for the teenage"* (Theme C = hopes and plans for the future support of young adults with ASD in transitioning to independent living), introducing a new theme (living and working arrangements), allowing an exploration of themes proposed by the respondent. To strengthen her reason, she recalls back the previous challenges mentioned in the first theme (Theme A = their perspectives on the young adults readiness for transitioning into independent living) by mentioning that young adults with ASD have *"nowhere to go"* as the available service provision centres, homes and schools in the country only provide services until the end of their adolescence and does not extend until adulthood.

She further comments on the need to improve the quality of the service provision centres, homes and schools, as well as calling for more teachers with accreditation specializing in special education training which the government should consider, relating to her and Mr. L's previous accounts of teachers lacking in training from the previous theme of the challenges they faced. This may have been used to strengthen this suggestion (Theme B = challenges faced raising their children with autism and Asperger's Syndrome) in the context of the thematic structure analysis (Thompson, 2014);

> "...we need to build up more centres and more accreditation for the special need people…So hope that the government can do something about this." (Mrs. L, Excerpt #58)

Mr. Y however believes the reason the government is not taking the necessary action to improve the situation for families with members with ASD is due to their problem not appearing to be significant is great *"(the government) only want the numbers").* Mr. Y believes this to be the reason for the small funding given by the government to fund autism centres in the country.

With that, Mr. Y suggests more Malaysian parents to seek diagnosis for their children so that the increase in numbers will contribute to the number of registered children with autism in the country, hoping the government will view the issues faced by parents as worth looking into.

> "What we need from the government actually is to accept that there is a lot of number of autistic kids. But you cannot blame the government over that. The reason is that a lot of parents are not registering their kids. If you don't register, then there are no numbers. There is only about 35 thousand autistic registered. There should be about half a million (of registered children with autism in the country)." (Mr. Y, Excerpt #59)

With these low numbers, Mr. Y believes that it is not enough for the government to invest monetary support to the autism community. He pinpoints this as the main issue which by the end of it all, leads to the lack of services that the government can provide in the country for children with ASD, forewarning more concerning results for life-long support services for adults with ASD.

Mr. Y reveals his ideal situation where he would like to rely on the Jabatan Kebajikan Masyarakat (Social Welfare Department) to take care of WX and WJ in the future;

> "By the time, if I'm dead, and they're not independent, I want them to be able to stay in a home whereby there will be people can take care of them. We can depend on their nephews or whatever, but I don't think you can really depend on them. Because from what we have seen, they probably might not be able to take care of them. I would like to trust, have faith in my heart that somebody is taking care of them. But I am also the kind of person who don't believe in totally entrusting to other people. Unless it's a formal procedure whereby social service that will take care of everything. I need to have some kind of (concept whereby) JKM, Jabatan Kebajikan Malaysia play an important role and make sure that the OKU are taken care of." (Mr. Y, Excerpt #60)

Here, Mr. Y shares his ideas of an ideal arrangement for WX and WJ where the Social Welfare department takes the correct steps in ensuring that the persons with disabilities who are placed in the group homes are well *"taken care of"*. His narrative in the excerpt above sees him mentioning multiple times how his ideal arrangement of a group home would be somewhere where there are people "to take care of them" *("...people can take care of them", "... they probably might not be able to take care of them", "...somebody is taking care of them, ...make sure that the OKU are taken care of",* underlining the importance of social support towards those with ASD and people taking good care of them in all aspects of their daily lives.

Ms. N revealed her preference for working conditions while keeping in mind BW's limited social abilities where she also emphasizes more on the importance of supportive and understanding staff as opposed to merely keeping them occupied on a daily basis.

> "I am looking for somewhere, I don't know where. I don't know there is a centre or a group for the teenagers,...(where) they have a coach, they have the support. They send the kids to a certain place for work. They still provide support to make sure they are okay in the working environment. I am looking for that kind of setting." (Ms. N, Excerpt #61)
>
> "...have the coach to make sure they are safe and the environment is okay. It's not just throw them there at work. Needs someone to monitor." (Ms. N, Excerpt #62)

Ms. N echoes Mr. Y's concerns with regards to the social environment of the workplace where she mentions in both excerpts that she wishes for the staff at BW's future workplaces to *"provide support", "make sure they are okay and make sure they are safe"* and the *"environment is okay."*. She places more importance on these factors and prefers for BW to be comfortable emotionally and not simply *"throw them there to work"*. Here, frequent use of the word *"support"* implies that social support is imperative and the main factor she pays attention to when considering her BW's working/living environment in the future. It can be seen that her son's safety and comfort are important to her, considering BW's condition. By turning to the analyzation of the thematic structure, suggests Ms. N reminding her answers to Theme A on her child's readiness where she expressed that she should place BW in a home. Hence, in the above excerpt she explains her ideal living and working arrangement for her son.

Concerns on the amount of care and support are once again examples of parents of children with disabilities frequently highlighted in disability discourse. Providing sufficient support, socially as well as physically is imperative to improve their children's quality of life.

4.3.2 Public Awareness

Mrs. L concluded that raising public awareness is the first step in helping address all the challenges that have been mentioned;

> "So instead of educat(ing) our children, we need to educate outside people also. To accept this type of people. If they can accept these types of children, and get respect from the society, at least they will give a helping hand. So awareness to the public is very important." (Mrs. L, Excerpt #63)

Mrs. L expressed that she would like society to *"accept these types of children"* and *"get respect from society",* implying the lack of respect and acceptance among the general society in the country towards those with ASD and their families. She emphasized on more awareness to the public with the aim to educate on ASD with the hopes of the society giving a helping hand. The introduction of a new subtheme (public awareness) seems to be in line within the analysis of the thematic structure (Thompson, 2014) where the new subtheme may have been developed from the answers to the previous theme (challenges they had faced with society's perceptions and responses), and this may have indirectly have the respondents recall these challenges in emphasizing on educating the public.

Similarly, Mr. Y he wishes for more empathy from the public in understanding the difficulty of raising a child with ASD *("Society needs to know that there is a lot of big challenges bringing up an autistic kid.")* and inclusion for those with ASD in the future to *"make them feel welcome".*

> "....sometimes you see things in public which is odd. There must be some reason behind their oddness. So don't jump into conclusions…Try to contact them. Let's say I saw someone who is autistic. In the public, I just go up and say "hi". Just do contact with them. They don't bite. Just say hi. Or maybe try to explain to your kids…You need to tell your kids (and educate their children on disabilities)" (Mr. Y, Excerpt #64)

He wishes for more understanding and empathy from the society towards those with ASD and wishes for parents to educate their own children on the subject. The public should not be so quick to *"jump into conclusions"* and he suggests them to *"do contact with them"* instead of singling the families out. Mr. Y challenges the society to accept his sons as they are and accommodate to their behaviour by attempting communication with them. His suggestions hopes will translate to lessen the stigmatization towards parents with children with ASD. Similar to Mr. and Mrs. L's hopes for more awareness on ASD after negative schooling experiences involving SY, Mr. Y reiterates this need based on his own negative experiences with the public in Theme B (account of a passer by telling his own child that Mr. Y's odd behaviour stemmed from them being a *"spoiled brat"*).

Mr. Y further stresses the need for widespread awareness for government services and the importance of producing Standard Operating Procedures (SOP) for any scenarios that involve persons with disabilities.

> "You point a gun to autism kid, "put your hands up!" They will just walk straight up to you. Probably won't even put your hand up. Probably will shoot him. Thought they would endanger yourself. But where do you shoot him? You shoot him in the leg or you shoot him in the head? So sometimes there are some things, the SOP has to be there. But thing is, how do you know? That is the difficulty, how do you know? Moreover, autism face doesn't have the look (of someone who is disabled)." (Mr. Y, Excerpt #65)

He highlights how lack of understanding of autism causes the society to be more prone to jumping to conclusions regarding children with autism as they *"don't have the look"* of someone disabled. As the image of having a disability would immediately lead to one imagining a deformed individual, for Mr. He explains that government services such as the police force will be faced with complications and difficulty in deciding their actions when they are tasked with handling adults with autism as their *"face doesn't have the look"*. With no ways to identify those with autism, future situations can prove to be difficult for all parties involved, hence Mr. Y's suggestion for protocols that must be planned and implemented by the higher authorities to avoid undesirable scenarios. Hence, Mr. Y here actively rejects that this issue stems from the individual with disability but with the society's lack of awareness and no disability indicators available for society to identify them with. The lack of awareness and disability indicators must be arranged by the higher authority and not the responsibility of the child or family.

All the parents share the same hopes and suggestions, signifying common challenges faced by parents during their children's transition to independent living. Addressing the parents' hopes and suggestions mentioned in this section for the future of young adults with ASD and their families may ease the transition to independent living for future parents.

4.4 Discussion

The present research aimed to explore parents' perspectives of the transition to independent living for young adults with ASD. Findings demonstrate that the parents of young adults with ASD have differing views on their children's current readiness for transition to independent living. The most prominent finding from this research is that all the parents possessed differing expectations and ideas on what defines independent living, and results suggest they correlate this to the severity of their children's condition. It is fortunate that one family from the study's respondents has two children of different ASD severity levels as there exists clear differences that can be seen from the responses of the parents towards both children. It is from here we can see that the parents viewed being "independent' for their child with autism (work in a sheltered workshop with the presence of trained teachers to overlook and care for the individuals with ASD) and their other child with Asperger's Syndrome (expected to secure employment and live independently similar to that of a typically developed adult) tailored to what is expected of the two children and their respective abilities. For the child with Asperger's Syndrome, his parents expect more from him as his only deficit is social communication but is able to live independently and conduct daily living tasks. As the child with autism has limited abilities compared to his older brother with Asperger's Syndrome, much less is expected from him, and the child being "independent" for the parents simply means being independent 'of' the parents which would be followed by the transfer of care to others. Another parent in the present study confirms this shared view of a different definition of what independent living is for a child with autism who possess limited abilities compared to other higher functioning individuals. Differences in views from parents of the same family is also another significant finding as the mother viewed being independent for the child with Asperger's Syndrome through the lens of cognitive ability (social competency, awareness of responsibility), while his father instead commented on his motor skills and his ability to carry out daily living skills such as driving and cooking. To the best of the researcher's knowledge, there are limited studies where two children with ASD on different spectrums are from the same family. In the study by Sosnowy, Silverman and Shattuck (2018), parents also held the same views as one of the parents in the present study where they shared that employment for their children with ASD was not for gaining financial independence but for other reasons such as its social benefits, providing their children with a sense of self-worth and simply giving them *"something to do"* after they have ceased ASD services and enter adulthood. One parent mentioned how she felt pressured to plan for her child's future extensively and thought people think of her as a "bad parent" or "irresponsible", a common perception by the public and the parents themselves reported in studies by Ilias et al. (2017) and Ilias et al. (2019). However, the parent's view in wanting to have her child live with her for as long as she can is in fact agreeable to ASD literature which showed that most children with ASD live with their parents until they reach adulthood (Portway & Johnson, 2005; Sosnowy, Silverman, & Shattuck, 2018). The parents in this study all mentioned their difficulty in "letting go", even if it is the transfer of care to family members as they question if others are able to provide the care and support the parents themselves given in the future. This of course can also be due to the effects of all past challenges they have faced during the raising of their children which have influenced them to give such views on transition to independent living for their children with ASD. Hence, on the interpersonal level of linguistic analysis using the mood and appraisal system (Halliday & Matthiessen, 2013), the interview text seem to support parents' generally negative responses where they expressed that their children are currently not ready for the transition into independent living, thus stating that they would like their children to be under their care for as long as possible, in line with the research findings of the mentioned studies under this theme. Moreover, parents who are uncertain in their answers and what lies ahead for their child (their degrees of probability leaned more to negative outcomes) was also mentioned to be a common perception among parents of children with ASD in previous studies (Ilias et al., 2017; Ilias et al., 2019).

All the parents revealed various factors that have attributed to the challenges they are currently facing during the transition of their children to independent living where they mentioned similar challenges to many past studies; parents' admission of their own lack of awareness on ASD, challenging experiences with family members, frequent behaviour issues with their child such as hyperactivity (Ilias et al., 2017; Ilias et al., 2019). Similar symptoms to ADHD (Miller, Iosif, Young, Hill, & Ozonoff, 2018; Adamo, Hodsoll, Asherson, Buitelaar, & Kuntsi, 2019) have also been the cause of inaccurate or delayed diagnosis by medical professionals where this was experienced by one of the parents in this study. One of the parents mentioned his paediatrician's inability to identify ASD after seeing his son had no speech, and this may be due to ASD being more commonly treated by psychiatrists instead of paediatricians compared to other countries (Lennox & Diggens, 1999; Moyle, Iacono & Lidell, 2010). However, it should also be noted that this parent consulted a paediatrician at a private hospital, whereas another set of parents in this study consulted a paediatrician from a research univeristy affiliated government hospital and received accurate diagnosis. This occurrence may be due to the latter hospital being more up to date with the latest advancements in medicine, being a research univeristy affiliated hospital. This information also proves that although medical students study human abnormalities in their medical education curriculum (Humpage, 2007; Brauer & Ferguson, 2015), recent studies on medical students and house officers still revealed a low level of awareness and knowledge on the identification of ASD symptoms and its treatments (Moyle, Iacono & Lidell, 2010; Low & Zailan, 2016). As the results from this present study was retrospective and explored experiences of the parents from approximately 15 years ago, findings from recent literature have shown that there has not been sufficient progress in increasing the level of awareness of ASD in Malaysia among medical professionals, despite the latest studies showing the increasing prevalence of ASD (Crane et al., 2016; Hossain et al., 2017, Qiu et al., 2020). All the parents also mentioned the lack of awareness and access to knowledge on ASD that is present among many of the schoolteachers and centres in the country, in line with reports by recent studies on awareness among schoolteachers in western and eastern regions (Liu et al, 2016; Rakap, Balikci, & Kalkan, 2018; Giannopoulou, Pasalari, Korkoliakou, & Douzenis, 2019). This is especially detrimental for individuals who do not show obvious signs of disability such as those with Asperger's Syndrome as the parents of the young adult with Asperger's Syndrome in the present study faced numerous occasions where he was punished for his social oddity. Moreover, reports by the parents of persisting social communication deficits that continue through adulthood for high functioning individuals with ASD is confirmed by Kanfiszer, Davies and Collins (2017) where the concept of constant 'misunderstanding' and 'being misunderstood' were present in both, the present study as well as previous studies (Portway & Johnson, 2005; Kanfiszer, Davies & Collins, 2017). However, the parents of the young adult with Asperger's Syndrome did not mention mental health issues, thus negating literature (White et al., 2009; Bejerot, Eriksson, & Mortberg, 2014). Interestingly, the young adult with Asperger's Syndrome at the time of the study was in his final year of college, showing that a small minority of high functioning individuals with ASD do indeed have the ability to continue education to the tertiary level, in spite of Wehman et al. (2014) reporting a low rate of university enrolment among individuals with ASD. Another interesting finding from this study is the ability for high function individuals with ASD to acquire multiple languages similar to that of his typically developed peers. This was possible due to the young adult with Asperger's Syndrome in this study who grew up in a household which practiced multiple dialects and the converse of multiple languages (a normal occurrence considering Malaysia consists of a multiracial society where the majority uses at least two different languages). Despite this, his lack of social communication skills has hindered his ability to practice these acquired languages. All the parents however did not make any mentions of cultural or religious beliefs relating to their children's condition, as opposed to previous studies that were conducted in eastern nations (Portway & Johnson, 2005; Xu & Yang, 2009; Ilias et al., 2017; Ilias et al. 2019). This may be partly due to the question on culture and religion not being asked explicitly by the researcher or the parents simply did not identify with any cultural or religious beliefs relating to ASD. At the ideational level of linguistic analysis using the transitivity and ergative analysis (Halliday & Matthiessen, 2013), the types of processes used by the parents were analyzed to understand the linguistic expressions and resources used in revealing the challenges they faced raising their children with autism and Asperger's Syndrome. With the parents' responses addressing obstacles they had faced, the use of material, mental, relational and verbal processes seem to be prominent in the data as these processes aided the readers to understand the situation and empathize with the parents. The material process where respondents talk about their physical actions and frequently use the "I" medium demonstrate that the parents are the ones who had brought the processes into existence, putting themselves in the center of experiencing these experiences they shared. They presented themselves with agency while mentioning all the initiatives that they had taken with regards to the topics within the theme such as identifying symptoms, taking their children for a diagnosis and changing schools to improve their children's educational environment. Another possible frequently used process by the parents under this theme was the verbal process where respondents indicate the use of language by recalling, recreating, reporting, sharing or narrating past conversations/talk with their children's teachers, doctors or family members to give a vivid account of the anecdote to the interviewee. This in turn helps the interviewee to heighten their understanding of the anecdote and the message the parents want to convey. In the case of the challenges that are being addressed in raising their children with ASD, these anecdotes with verbal processes may also evoke feelings of empathy and sympathy. Besides that, with the focus of the interview being on the parents' children, there is also a significant amount of relational process use in their responses. As they are required to describe attributes and provide identifications of their children that will reveal the difference between their children with ASD and typically developed children, it is typical for parents to excessively use this process in their anecdotes. Lastly, it can also be noticed that there were fewer uses of the mental process in revealing their feelings and what they are thinking when sharing their challenges. However, this may be due to the interview questions being structured in such a way that the parents' feelings were not addressed.

It was generally agreed by all the parents that raising awareness is vital and one of the very first steps that will prevent the common challenges faced by parents and young adults with ASD. However, with the social stigma surrounding disabilities more apparent in the eastern regions, it is perhaps recommended that future researchers and stakeholders look to perspectives of parents and individuals with ASD (Braun & Clarke, 2006; McAdams, 2008), as well as exploring disability discourse to make more sense of how society perceives disability in their thinking and speech as this directly affects their behaviour, interactions and expectations towards these individuals with ASD (Sunderland, 2004; Bryant & Pini, 2010; Don, Salami, & Gajarieh, 2015; Haegele & Hodge, 2016; Grue, 2017; Manago & Davis, 2017). More affordable services and full-time centres for adults with ASD by the government were also proposed to ease the financial burdens of the families of children with ASD (Kamaralzaman, Toran, Mohamed, & Abdullah, 2018).

One parent also mentioned the need for employers of individuals with ASD to provide a comfortable working environment and support staff which has also been mentioned in past studies (Hurlbutt & Chalmers, 2004; Hedley et al., 2018). However, recent studies have revealed efforts in implementing transition programmes for high school students to teach them the necessary skills for transition to independent living or preparation for employment (Dipeolu, 2014; Zainal & Hashim, 2019, Snell-Rood et al., 2020), a positive sign for the future of young adults with ASD. Nevertheless, Westbrook, et al. (2012) and Wehman et al., 2014 agreed that there is still a great need for additional research in this area as issues with maintaining employment is still occurring even for those who have completed tertiary studies (Shattuck et al., 2012). Besides that, with latest studies showing low levels of awareness among the general society (Alsehemi, Abousaadah, & Sairafi, 2017; Wendorf, Muhamad, & Yang, 2017; Low et al. (2021), parents have expressed they wish for more acceptance of individuals with ASD in the future to ease the stress and worries of the parents at public places, as well as for promoting inclusion for their children. At the textual level of linguistic analysis using the thematic structure (Thompson, 2014), the flow of the text and the coherency of the parents' answers according to the themes were examined. The interview text seems to have showed many recollections of their perspectives of their children's readiness for transitioning to independent living, as well as their own challenges of raising their children with ASD to reinforce their hopes and plans for the future support of their children with ASD. Therefore, coherency was present in their answers as their answers were logical and rational. The parents' answers also introduced new subthemes under this theme (introduction of new subthemes were also present under the two other main themes) namely the (a) living and working arrangements, and (b) public awareness, allowing the exploration of new themes for the study that were introduced by the interviewee instead of the interviewer. This shows that the thematic investigation also shows the possibility of new insight from someone other than the researcher, providing more holistic findings.

In conclusion, this study represents the perspectives of parents on the transition to independent living for young adults with ASD. Analysis of the interview responses through the three sets of systems of lexicogrammatical choices that look at different levels of meaning to facilitate the qualitative findings revealed the following. At the interpersonal level, the interview text revealed that the parents seemed to possess a negative outlook on their perspectives of their children's readiness to transition into independent living. At the ideational level, frequent use of material, mental, relational and verbal processes revealed that the parents' recollections were detailed in describing the challenges they faced while raising their children with ASD. Lastly. At the textual level, the parents' responses to their plans and hopes for the future support of their children with ASD in transitioning into independent living suggest that all their answers were influenced by their previous answers to the questions on their children's readiness to transitioning to independent living and the challenges they had faced during the raising of their children with ASD. Besides the linguistic analysis findings, one highlight from the present research is the parents' differing ideas of what independent living encompasses that is directly related to each child's ability and severity of condition. While a minority of the findings from this study opposed findings such as the absence of issues related to mental health among individuals with ASD, as well as cultural and religious ideas that may have affected their views on ASD, the majority of the findings were aligned with literature, such as the challenges faced by parents, and their hopes and recommendations for the future.

CHAPTER 5: CONCLUSION, IMPLICATIONS AND FUTURE RESEARCH

5.0 Introduction

The present research aims to be informed of parents' perspectives on the transition of young adults with ASD in Malaysia. Research questions are as follow;

1. How do parents express their perspectives on the young adults' readiness for transition into independent living?

2. What do the linguistic expressions/ resources used by the parents reveal about the challenges faced raising their children with autism and Asperger's Syndrome?

3. What are the salient linguistic features in the parents' discussions of their plans and hopes for the future support of young adults with ASD in transitioning into independent living?

To answer the research questions, a qualitative approach was adopted by conducting semi structured interviews with the parents where analyzation of the linguistic features of their answers borrowing elements from SFL was also conducted. A total of three families (four parents) were interviewed where all subjects of the study were male, and at the time of the study, during their transition age. Severity of ASD ranged from mild (Asperger's Syndrome) to severe (autism).

Parents have reported that the young adults with ASD are currently not ready but have the potential to be ready in the future, while there are others who say that the young adults with ASD will never be ready and will require long term support. This divided opinion is not based solely on the severity of the deficits associated with ASD, but on the parents' differing notions of what independent living means. The difference in their definition of independent living seems to have been coloured by their children's abilities.

Results showed the need for a review of the special education syllabus in schools, more autism centres that cater for young adults/adults and the necessity for more awareness within the society. These factors have been mentioned by all the parents where these have influenced their views on their sons' current readiness for transition with regards to the three domains; social participation, school and work opportunities. The notion of "independence" may also require redefinition as parents' views on the requirements for independence were found to be highly dependent on the degree of autism. Expectations of the ability to transition to independent living for individuals with Asperger's Syndrome revolve more around cognitive abilities, whereas for individuals with autism revolved more around their physical abilities.

For the young adults diagnosed with autism, the parents' views stemmed from the challenges faced in their experiences of raising their children where these challenges have been attributed to the lack of public awareness, teachers' limited knowledge of strategies for dealing with children with ASD, financial limitations to consider other alternatives and the limited number of centres that provide long term support. As for the young adult with Asperger's Syndrome, although he has successfully progressed to college, the parents are of the opinion that his lack of social communication skills is the main hindrance for his transition to independent living, a challenge that has been persistent throughout his childhood until the present day.

5.1 Implications for Practice

Results of the study discovered several areas that warrant attention from the government and public.

Among them is the need for revision of the special education syllabus in government schools, taking into consideration students' various disabilities and their capabilities, be it ASD as well as other disabilities. Teacher training such as identification of developmental/learning disabilities and the correct management of students with such disabilities should be taught to all teachers in the country. This has been proven to better the understanding of the child's competency level and lessen misunderstandings between students, teachers, and parents.

Increased general awareness among the society will also lead to better acceptance of children and adults with ASD. This includes better treatment and services where the public accommodates to the needs of those with disabilities in place of individuals with disabilities accommodating to the public. Increased public awareness is the first step in lessening the stigma surrounding those with ASD in which according to the present research will lead to more families formally diagnosing their children for disabilities.

These findings have implications for the various stakeholders involved in service provision and policy decisions where the three stakeholders that warrant attention are from the government (revision of the special education syllabus and training of teachers), the society (increase public awareness) and the other parents of children with ASD (identification of symptoms of ASD and seek diagnosis).

Future research should consider inclusion of participants from the rural areas to determine whether the challenges faced differ from those living in the urban settlements. A larger sample size that also include older adults with ASD is crucial to improve our understanding about issues that persist in adulthood as well as to improve the generalizability of findings.

5.2 Future Research

Evidently, from the review of literature there is a lack of studies using qualitative methods in autism research. There is still a considerable amount of research concerning the prevalence and awareness among society and determining the effectiveness of intervention programmes in other countries. Studies that are qualitative in nature are few, especially in the Asian region. As the present research was conducted in an urban area where access to centres and intervention programmes and awareness are assumed to be better than those who are living in the more rural areas, inclusion of participants from the latter will be useful to determine whether the challenges faced by parents and adults with ASD differ in comparison to families living in the urban settlements.

More studies in the English language are also needed as one of the challenges while conducting the literature review was the language barrier. Several papers which had the potential to be useful for the present research from the English abstract were found to be of different languages with no translation. Difference in cultural and mental psyche between nations will also be reflected in the types of challenges faced by families.

More studies concerning young adults during the transition period and adults with autism should also be encouraged to further understand the needs of parents and adults with autism to improve their quality of life once intervention programmes have ended. Without such information, less is known regarding the challenges that adults with autism face every day and how stakeholders can help. Even with the few qualitative studies available on young adults/adults with ASD, participants were mostly from parental perspectives. Interviews from the perspectives of the young adults/adults with ASD themselves should also be considered for future research to help fully understand their needs. A larger sample size will further help improve the generalizability of the research and aid in being informed of the common challenges faced by most parents in raising young adults with ASD during the transition phase.

5.3 Conclusion

This study has shown that parents’ perspectives can inform improvement of service provision that have the potential for supporting transition to independent living for young adults with ASD. The various challenges highlighted in this present study exhibited similar challenges faced among the three families, indicating various areas for improvement in the areas of social participation, school and work opportunities for young adults with ASD. Collaboration between stakeholders involved such as the parents, special education teachers, government agencies, non-governmental organizations and the society is vital for improving the quality of life for individuals with ASD and their families that the policy makers need to adopt a multiperspectival approach for further development in this area.

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