

SOCIETAL VIEWS TOWARDS ASD INDIVIDUALS AND ITS IMPACT



EXPLORING THE SOCIETAL VIEWS TOWARDS ASD AND ITS IMPACT ON THE  
QUALITY OF LIFE OF ASD INDIVIDUALS IN MALAYSIA

BELLE KOR MING HUI

CHUA HUI QIN

IMRAN BIN MOHAMMAD AZLAN

A RESEARCH PROJECT

SUBMITTED IN

PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR  
THE BACHELOR OF SOCIAL SCIENCE (HONS) PSYCHOLOGY

FACULTY OF ARTS AND SOCIAL SCIENCE

UNIVERSITI TUNKU ABDUL RAHMAN

APRIL 2022

Exploring the Societal Views towards ASD and its Impact on the Quality of life of ASD  
Individuals in Malaysia

Belle Kor Ming Hui, Chua Hui Qin, Imran bin Mohammad Azlan

Universiti Tunku Abdul Rahman

This research project is submitted in partial fulfillment of the requirements for the Bachelor of Social Science (Hons) Psychology, Faculty of Arts and Social Science, Universiti Tunku Abdul Rahman. Submitted on April 2022.

# SOCIETAL VIEWS TOWARDS ASD INDIVIDUALS AND ITS IMPACT

## ACKNOWLEDGEMENTS

Without a doubt, this thesis would not be possible without the support and collaboration of several individuals and organizations. A core part of our study would not have been fulfilled nor would it come to fruition in terms of participation and understanding of ASD as a whole if not for such individuals and organizations that has given us their cooperation. For that reason, we are grateful to Ms. Rusmawati Binti Abdullah, the vice principal at the National Autism Society of Malaysia and Ms. Delima Ambar Shah, the representative at the Malaysia High Functioning Association.

We are thankful to our lecturer and supervisor in Universiti Tunku Abdul Rahman for guiding us, aiding, and providing ample knowledge in this thesis. Without them, the progress of our thesis would be slowed or even lost, moreover we would not know what to do in some circumstances and who to refer to for advice. Thus, we are appreciative to Ms. Lee Wan Ying and Mr. Tay Kok Wai.

To every single person that had a hand in helping our research, we would like to express our deepest gratitude. The work that has been put into this would not look the same and not worth the effort, without the countless support and aid that is provided. This thesis would not have been possible and finished without everyone's involvement and support.

BELLE KOR MING HUI

CHUA HUI QIN

IMRAN BIN MOHAMMAD AZLAN

# SOCIETAL VIEWS TOWARDS ASD INDIVIDUALS AND ITS IMPACT

## APPROVAL FORM

This research paper attached hereto, entitled “Exploring the Societal Views Towards Asd and Its Impact on the Quality of Life of Asd Individuals in Malaysia” prepared and submitted by Belle Kor Ming Hui, Chua Hui Qin and Imran bin Mohammad Azlan in partial fulfillment of the requirements for the Bachelor of Social Science (Hons) Psychology is hereby accepted.

---

Supervisor

(Ms. Lee Wan Ying)

Date: \_\_\_\_\_

# SOCIETAL VIEWS TOWARDS ASD INDIVIDUALS AND ITS IMPACT

## Table of Content

	Page
Abstract	i
Declaration	ii
List of Tables	iii
List of Graphs	iv
List of Abbreviations	v
Chapters	
I Introduction	1
Background of Study	1
Problem Statement	5
Research Objectives	7
Research Questions	8
Significance of Study	8
II Literature Review	12
Quality of Life and ASD	12

# SOCIETAL VIEWS TOWARDS ASD INDIVIDUALS AND ITS IMPACT

Societal View towards ASD	13
Impact of Societal View on Those with ASD	17
Coping with ASD	20
Theoretical Framework	22
Conceptual Framework	23
III Methodology	25
Research Design	25
Sampling	26
Data Collection	28
Data Collection Procedures	30
Validity and Reliability	32
Reflexivity	34
IV Results	38
Data Analysis	38
Demographic Information of Participants	40
Qualitative Analysis	41

# SOCIETAL VIEWS TOWARDS ASD INDIVIDUALS AND ITS IMPACT

V	Discussion	78
	Isolated	78
	Poor Quality of Life	80
	Healthy and Positive Coping Mechanisms	82
	Implications of the Current Research	83
	Limitations and Recommendations	86
	Conclusion	89
	References	91
	Appendices	
Appendix A	Informed Consent Form Sample	110
Appendix B	Demographic Form Sample	114

### **Abstract**

Problems such as isolation, stigmatization and unemployment have troubled the quality of life (QoL) of those with Autism Spectrum Disorder (ASD), these problems are connected with the society's perception of ASD individuals. This research explores the societal views towards those living with ASD and the impact of it on their QoL. Semi structured one-on-one interviews with 5 ASD individuals are used to focus on the individual impact from ASD individuals, while purposive sampling method was used. What was founded was the isolation and the poor QoL from ASD individuals because of societal views, aligning with previous research, however participants also exhibit healthy and positive coping mechanisms, not aligning with previous research. The findings verify how societal views affect those with ASD negatively but also how those with ASD do not cope as dependently as assumed. The research implication can expand the knowledge of ASD and gives material to spread accurate information of ASD. It can also be used as a basis for future research and filling in research gaps by providing a more in depth look of the Malaysian context. However, caution is needed as the narrow demographic of sample population, homogeneousness of ASD functional level and single source perspective limits the research. To conclude, there is an impact of societal views of ASD towards the treatment of ASD such as isolation and poor QoL, however coping wise was positive, with this it provides implications to help spread knowledge of ASD and fill in research gaps.

**Keywords:** Societal views, Autism Spectrum Disorder, qualitative research



DECLARATION

We declare that the material contained in this paper is the end result of our own work and that due acknowledgement has been given in the bibliography and references to ALL sources be they printed, electronic or personal.

Name: BELLE KOR MING HUI

Student ID: 1903380



Signed:

Date: 4th April 2022

Name: Chua Hui Qin

Student ID: 1802927



Signed:

Date: 4th April 2022

Name: Imran bin Mohammad Azlan

Student ID: 1804381

Signed:  \_\_\_\_\_

Date: 4th April 2022

List of Tables

Tables	Page
1 Demographic Information of Interviewees of the Current Study	41

## List of Figures

Figures		Page
1	Conceptual Framework Model of the Current Study	23
4.1	Essence of the Analysis and the Five Main Themes	43
4.2	Theme 1: Isolated by Society and Sub themes	45
4.3	Theme 2: Difficulties Adapting to Society and Sub theme	51
4.4	Theme 3: Focusing on Self and Sub themes	61
4.5	Theme 4: Support in Life and Sub themes	67
4.6	Theme 5: Spreading Awareness to Others and Sub themes	71

## List of Abbreviations

No.	Abbreviation	Full Name	Page
1	ASD	Autism Spectrum Disorder	1
2	QoL	Quality of Life	1
3	RQ	Research Question	8
4	SDGs	Sustainable Development Goals	10
5	WHOQOL	World Health Organization Quality of Life	12
6	SRS	Social Responsiveness Scale	12
7	SMOD	Social Model of Disability	22
8	MAHFAA	Malaysian High Functioning Autism Association	27
9	SERC	Scientific and Ethical Review Committee	28
10	UTAR	Universiti Tunku Abdul Rahman	28
11	ADHD	Attention-deficit/hyperactivity disorder	37
12	GDD	Global Developmental Delay	37

## **Chapter I**

### **Introduction**

#### **Background of Study**

There is an expression, ‘If you have met one Autistic person, you’ve met one Autistic person’. This expression reflects the unique and varied nature of autism because no two Autistic people are the same. Autism Spectrum Disorder (ASD) by definition is a neurodevelopmental disorder that is defined by certain traits that include deficiency in social communication and signs of limited interests and repetitive behaviors (Hodges et al, 2020).

#### ***Social Treatment towards ASD individuals***

The life of those with ASD are obviously dissimilar than those of a neurotypical person, but there has been evidence that suggest that the social treatment of those with ASD are poorer in comparison to others that do not identify with ASD. The poor social treatment can be seen with a controversial incident involving an 11-year-old non-verbal ASD boy by his special education teacher. Particularly, in this incident the boy is given the “Most Annoying Male” award much to his dismay (O’Kane, 2019). This situation is not a surprise when looking at research that shows that children with ASD experience a lower level of acceptance and a high level of rejection compared to other groups that do not identify with ASD (Symes & Humphrey, 2010) and in a study that those with ASD typically have narrow and unfavorable judgment made against them (Sasson et al., 2017). This overall shows that there is a disparity between the treatment of ASD and non-ASD groups, with those with ASD receiving the shorter end of the stick.

With the treatment above, one has to wonder about the wellbeing of those with ASD and according to research, there is a worrying trend on the quality of life (QoL) and suicide rate of those with ASD. When looking at the QoL, which is connected to QoL of those with ASD, it is reported that statistically those with ASD have less QoL compared to their

nonclinical peers with the factor of participating in society seems to be the sole factor in one research (Schmidt et al., 2015). Furthermore, when looking at the suicidal rates, there is a study in Denmark who found that those with ASD are 3 times more likely to commit suicide than those without ASD (Kölves et al., 2021). With this, there is a need to address these issues of low QoL and high suicidal rates amongst individuals with ASD for their well being.

### ***Social Treatment towards ASD individuals in Malaysia***

In another study held in America, they stated that it is important for others to be more aware and accepting of social presentation differences that puts those with ASD apart from the rest which in the end can help with the perception and judgment of those with ASD to be more positive (Sasson et al., 2017). When looking in the context of Malaysia, a point is to be made about the low awareness of ASD in Malaysia can in turn provide an unsuitable environment for those with ASD. One can make a point that low awareness may affect the lack of knowledge or ignorance on the topic of ASD as well contributing negative perception towards the disorder. As with a study in Karachi, Pakistan (Anwar et al, 2018) stating low awareness and lack of knowledge are connected to one another, with a suggestion to implement more awareness programs to encourage further knowledge of ASD among parents.

**Bad Perception.** Bad perception can be viewed in a study made in the Malaysian context of a community in Selangor. This community has a bad perception towards ASD. To clarify, 22% of participants see those with ASD as a threat to their community while 61% of participants use slanderous words such as being mad or a lunatic, in contrast with 29% of respondents who are more compassionate in their comments, using words such as sad or sorrowful. In contrast, the community has a good attitude towards those with ASD (Mohamed et al, 2017), clarifying that they have the capacity to treat those with ASD fairly. Because of their lack of awareness, they have a bad perception of ASD.

**Lack of Knowledge.** Lack of knowledge or ignorance on the other hand can be seen in another study, it is reported that the majority of parents in Malaysia are ignorant about ASD when they first receive a diagnosis that their child falls under ASD and that the parents themselves reported to have faced social stigma by their own community because of their child's behavior (Ilias, K. et al, 2019), showing that the average Malaysian parents are lacking in awareness in the topic of ASD.

***Factors that Influence the Lack of Awareness of ASD in Malaysia***

But there is a question of why Malaysia is susceptible to a lack of awareness in ASD. The root of this lack of awareness may be due to the cultural environment, a lack of education on ASD and media coverage.

**Collectivistic Culture.** Different from the individualistic culture of the western environment, Malaysians are mainly seen as having a collectivist culture environment which impair their awareness of ASD. In collectivist culture those who are different from the majority and do not adhere to the societal norms will be frowned upon; and this applies to the ASD minority group as well (Papadopoulos et al., 2012). This in the end may make those with ASD be ostracized and be distant from the rest of their community, coupled with those with ASD and around them to try to hide and follow along the group rather than acknowledging the condition in order to fit in more within the collectivist culture. This overall has a negative impact on ASD and overall hinder the awareness of ASD in Malaysian society.

**Education on ASD.** As mentioned before between Malaysia and Singapore, it is clear that Malaysia has a lack of knowledge when it comes to ASD, which directly affects the education of Malaysia that centers around ASD and in turn affects the general awareness of ASD (Neik et al, 2014) . In the education sector, the qualifications and merits of these teachers in Malaysia to even teach those with ASD or even educate those on the topic of ASD

is put into question when one looks at their competency and knowledge around ASD. Even though there are teachers in Malaysia that have awareness of ASD, it has been proven that these teachers are still lacking in knowledge and have difficulties in teaching students with ASD as they are unaware of their various cognitive, social and emotional differences (Majin et al., 2017; Toran et al., 2010; Wei & Yasin, 2017). With this one can see, even in the educational sector of Malaysia that the awareness of ASD might be skewed due to lack of knowledge of those who are expected to be competent and knowledgeable on ASD.

**Media Coverage.** Media coverage plays an important role in circulating knowledge of ASD to the average person, however the accuracy and the portrayal of ASD might hinder the awareness of the condition no matter the intention. The media portrayal of ASD in Malaysia is proven to not be accurate enough to educate the public on ASD. As seen in a study that states the leading media in Malaysia are not circulating enough accurate information of ASD which may be connected to the low public awareness of ASD, and there needs to be a continual effort to circulate more information to the public by leading media (Hui et al, 2021). However, there has been improvement and more portrayal of ASD, evident in two Malaysian films that relies heavily on ASD as the main theme which are titled “Redha” and “Guang”, with the former released in 2016 referred to as an authentic and realistic portrayal of ASD and the latter released in 2018 being critical acclaimed as well as being based off of the director’s brother ASD condition. These two films may pave the way for better awareness, but there still needs to be more work in circulating information of ASD by the media to further promote the acceptance of ASD in Malaysia.

### ***Progress on the Awareness of ASD***

This lack of awareness overall goes in line with the research conducted by Neik et al (2014) to highlight the current prevalence, diagnosis, treatment and research on ASD in Malaysia and Singapore, which found that the awareness of ASD still falls short for Malaysia



when compared to Singapore. However, there has been improvement as seen by Chu et al., (2021) to raise awareness of ASD in Malaysia. The researchers found that increasing knowledge and awareness of ASD leads to better attitude towards ASD but should focus more on spreading more information on ASD to increase acceptance. But overall, this is one step and there needs to have a more push for awareness for ASD in Malaysia.

### ***Conclusion***

In essence, this research aims to put into perspective and explore the social view that is present in the lives of those living with ASD in Malaysia.

### **Problem Statement**

First of all, a lowered awareness of ASD will indirectly hinder ASD individuals in acquiring their necessary life assets, leading to low QoL among the group. Autistic adolescents have lesser or insufficient life assets as compared with typically developing peers (Franke et al., 2019). These life assets refer to positive social interaction and close relationships; such as social support, parent-child relationship and teacher-student bond. Studies investigating this issue indicate that the ability to acquire and the amount of life assets they have at hand is a significant influence towards their QoL (Franke et al., 2018; Furlong et al., 2013). Past research indicates that Malaysians have a relatively low awareness level on Autism (Clark et al., 2012; Neik et al., 2014). And as they are receiving less social support from people and environment around them due to stigmatization and negative labeling caused by low awareness on ASD from the public (Botha & Frost, 2020), it will be even more difficult for them to successfully build social relationships that are essential for a better QoL.

As ASD groups are having lower QoL, they will inevitably have poor mental health issues, as one's QoL and mental health are found to be closely interrelated (Lombardo et al., 2018). A lowered awareness among the public regarding ASD will lead to a higher social

demand on ASD individuals, as there are many misconceptions surrounding the disorder. This higher social demand will cause ASD individuals to be more aware of their limitations, lowering their QoL and putting them at a higher prevalence of having mental health issues (Moss et al., 2015); as they are constantly reminded of their shortcomings. Lowered QoL might indirectly lead them to be exposed to other comorbid conditions such as social phobia, separation anxiety disorder and obsessive-compulsive disorders; which worsens their mental health condition (Zaboski & Storch, 2018).

Consequently, substance abuse risk, as well as suicide and crime rates was also found to be increased when facing long term mental health issues (Sæther et al., 2019; Shukor et al., 2021). With lower QoL, people are more likely to have more depressive symptoms and hence, facilitate more suicidal ideation in one self (Morales-Vives & Dueñas, 2018). Lower QoL is also believed to affect higher crime rate due to the sense of lack of security in themselves (Chenevier et al., 2021). The Ministry of Health Malaysia (MOH) has also mentioned that suicide rate is positively related to some other mental factors such as depression, anxiety disorders.

Additionally, low awareness on ASD groups indicates more social stigmatization on them (Yu et al., 2020). Due to the social stigmatization and negative view surrounding them, employers are unwilling to promote inclusiveness in the workplace even if they are competent in their job, making it difficult for them to fit in. This impacts their employability skills, which is a crucial aspect in achieving independence among those with ASD (Adnan et al., 2012). Underemployment or unemployment is commonly seen among working adults who are diagnosed with ASD (Ohl et al., 2017). Bullying in the workplace is also reported due to their executive functioning and social communication deficits, leaving their employment experience poor or unemployed (Ibrahim et al., 2021). Surprisingly, based on Shattuck et al. (2012), the employment rate of ASD groups is even lower than those who are

having speech disabilities or other related mental impairments and are highly related to people's concerns on their comorbidity diseases. In consequence, unemployment rate is highly believed to affect higher crime rates such as theft and robbery (Bennett et al., 2020; Ramli et al., 2018), as these individuals have no steady income and have trouble supporting themselves, even if they have the ability to perform so. It will also impact the country's image as it brings more national burden by impacting the security of Malaysia.

Furthermore, the increased stigmatization of ASD among society will contribute towards social isolation among ASD individuals (Orsmond et al., 2013), as the majority will see them as different and would not associate themselves with ASD individuals. This social isolation stems from the negative stigma and perception regarding ASD, not only increasing their suicidal thoughts (South et al., 2021) but also increasing their risk in developing other mental health conditions or comorbidities. Moreover, it may lead to higher mortality rate as per reported by, declining in one's QoL is highly correlated with increasing mortality risks (Kowalewska et al., 2020; Hülür et al., 2017).

In a nutshell, we strive to increase awareness regarding ASD in the Malaysian population regarding the influence of our societal view on ASD individuals through the lens of ASD individuals themselves. This increased awareness will hopefully lead to a better QoL among the ASD population in Malaysia, where they can live without the heavy pressure of stigmatization.

### **Research Objectives**

The core objective of the present study is to explore the ASD individual's perspective of society's view on them, as well as the impacts of it towards their QoL. The influence of societal view and coping mechanisms implemented by ASD individuals will also be explored throughout the research. The research objectives are as below:

1. To explore the social experience and challenges of ASD individuals from the perspective of those living with autism in Malaysia.
2. To explore how societal views affect the QoL of ASD individuals in Malaysia.
3. To explore how ASD individuals cope with the negative societal views in Malaysia.

### **Research Questions (RQ)**

The research questions are as below:

1. What are the social experiences and challenges of ASD individuals in Malaysia?
2. What is the impact of local societal views on the QoL of ASD individuals in Malaysia?
3. How do ASD individuals in Malaysia cope with negative societal views?

### **Significance of Study**

The results of the current study will be able to bring light on the impact of our societal views on ASD individuals, which will encourage others in holding future educational campaigns regarding ASD knowledge. These campaigns would be able to spread awareness among the public, warming Malaysians up to the idea of ASD and normalizing it. As mentioned previously, the collectivistic culture in Malaysia will ostracize those that do not adhere to the social norm. Hence, by normalizing autism among the Malaysian public, it is expected that the negative social stigma and social isolation will be reduced. Consequently, the QoL of ASD individuals will be heightened, as society will be more accepting of them, reducing negative issues caused by alienation, such as poor mental health and increased risk of substance abuse.

Other than that, these campaigns would be able to increase the Malaysian public knowledge on ASD and debunk common misconceptions, such as relating ASD to spiritual origins, savant beings or intellectually disabled. Past research found that having accurate information and knowledge on ASD acts as the main component when forming views

towards others (Chambres et al., 2008; Samsudin et al., 2018). For example, if notified that someone is autistic before they have contact with that individual, they will be more inclined towards feelings of empathy and compassion, rather than annoyance and ostracization.

Hence, this would further contribute in alleviating social isolation caused by negative societal views.

Additionally, we would be able to provide a more accurate media portrayal of ASD individuals, which shapes our view on the ASD group significantly (Low et al., 2021).

Portraying the reality of ASD individuals will be crucial in stimulating public empathy and kindness towards the group, reducing the negative stigma surrounding them. Studies in the Asian region show that media portrayals of ASD are often misleading as they include only selective information about the disorder (Garner et al., 2015; Tang & Bie, 2015), used to appeal towards the preferred direction of the creator. Through exploring the social experience and challenges of ASD individuals through interviews, we would be able to get a raw, unfiltered first person perspective which includes the hardships and realities of living with ASD, not through the coloured lens of a witness or a producer.

All of the above flows down to the same cause, that we will be able to reduce the negative discrimination and isolation surrounding ASD individuals. A positive view towards ASD will contribute towards many aspects; increased employment rate and social opportunities, better mental and physical health as well as lowered suicide rates, which are all related to a heightened QoL.

Other than ASD symptoms, another factor of unemployment amongst ASD individuals is that employers hold a negative stigma towards them (Rosa, 2018), resulting in either unemployment or underemployment. By reducing the social stigma on ASD, employers should be able to hold a more accepting and empathetic view towards the ASD population, as not employing someone purely due to them being autistic would be frowned

upon then. This would provide ASD individuals with more employment opportunities, which will contribute towards Reduced Inequalities, one of the 17 Sustainable Development goals (SDGs) set by the United Nations for a better future. Consequently, the national burden would also be alleviated, allowing the government to better utilize our resources in other needed areas.

In addition, increased awareness and reduced social stigmatization would also improve the mental and physical health of ASD individuals. This is because QoL is positively linked with our health, and as one goes up, so does the other (Grant et al., 2009). It is predicted that comorbidities originating from negative social views such as depression should be reduced, along with the rates of suicide and substance abuse. Crime rate as a result of substance abuse would also be reduced in turn. Thus, we would also be able to move a step closer towards Good health and Well being, another one of the SDGs, under the goal 3.4 and 3.5, targeted towards promoted mental health, reduced suicide rates and reduced rates of substance abuse (*Goal 3 | Ensure Healthy Lives and Promote Well-Being for All at All Ages*, n.d.).

Lastly, the study will be able to fill in the existing research gap regarding ASD in Malaysia. The majority of research done on the influence of societal views on ASD has been conducted outside of Malaysia, particularly in America (Blaxill et al., 2021; Ganz, 2007; Maich & Belcher, 2014). Research in America has noted on the societal attitudes of the public on those with ASD (Flood et al., 2012); yet this research is still limited in Malaysia, with only two cross-sectional studies done (Chu et al., 2021; Low & Zailan, 2016). Additionally, local past studies have been mostly regarding the perception of people towards ASD, not based on the experience of those with ASD themselves, especially among the perception of others on autistic children (Low et al., 2019; Low et al., 2021; Sitimin et al., 2017). In a more narrow view, research done in Malaysia regarding ASD usually favor small

targeted groups as their target population, focusing on teachers (Majin et al., 2017; Omar et al., 2013; Toran et al., 2010; Wei & Yasin, 2017), parents (Ibrahim et al., 2021; Ting & Chuah, 2010) and mothers (Ilias et al., 2016; Yeo & Lu, 2012). These targeted populations give us detailed understanding of ASD on their selected areas, however research on the overall Malaysian population is still brief and unexplored. Hence, the present study will be able to contribute to ASD research in Malaysia, particularly on the experience of ASD individuals from the perspective of ASD individuals .

## Chapter II

### Literature Review

#### Quality of Life and ASD

By Jenkinson's (2020) definition, Quality of life (QoL) is the level in which a person is comfortable, healthy, and capable of participating in or enjoying life events. QoL is inherently vague and is commonly connected with happiness, because of this it is known that QoL is a key part in subjective well being (Diener, 2000). Because of the relation, QoL is also connected with other subjective well being components such as affective balance and life satisfaction.

In a study by Mason et al., (2018) that specifically views the QoL of ASD adults stated that the QoL of ASD adults is lower in comparison to the general populace. Mason et al., (2018) uses the World Health Organization Quality of Life (WHOQOL) assessment tool for 4 domains: physical health, psychological health, social relationships and environmental health. When studied it is found that ASD adults scored lower in all four domains. Interestingly it is also found that younger participants scored a higher QoL in psychological and environmental domains than their older peers. In terms of gender, men have a higher rate in the physical domain while women are rated higher in the social domain. To look at the factors that positively impact QoL, being employed, receiving support and being in a relationship have been seen as positive factors for QoL but each affect different domains. However it is seen that two factors negatively impact QoL across domains which is having a mental condition and having a higher rate in Social Responsiveness Scale (SRS).



## **Societal view towards ASD**

### ***Cultural and Religious views towards ASD***

Culture has been found to be a strong influence in shaping our perception towards ASD, and past cross cultural studies have examined the significant link between the culture and ASD perception (Brugge et al., 2005; Welterlin & LaRue, 2007). Most of the religious views surrounding ASD can be boiled down to either positive or negative, with mainly Asian countries holding more negative perceptions (Daley, 2004; Riany et al., 2017), relating them to karmic sins from their previous life or their parents (Gabel, 2004; Park et al., 2010; Riany et al., 2016). Countries outside of Asia, such as the US and UK have significantly more positive views and relate ASD as a medical disorder that can be cured (Bagatell, 2010), and with other cultures such as religious cultures believed by Latinos and African-Americans perceive giving birth to a child with a mental disorder considered lucky and a blessing from the gods (Skinner et al., 1999).

The negative view from the Asian culture can be traced back to their collectivistic culture, which emphasizes on group harmony (Keshavarz & Baharudin, 2009); whereas the individualistic culture from the US advocates more on individual diversity (Hwang & Charnley, 2010). In Malaysia; a nation with a collectivistic culture, those who are different from the majority and do not adhere to the societal norms will be frowned upon; and this applies to the ASD minority group as well (Low & Zailan, 2016; Papadopoulos et al., 2012). Consequently, the community under the collectivistic culture will distance themselves from individuals who do not adhere to societal norms, even families of those with ASD hiding their situation from others, fearing discrimination and isolation from their community. Hence, in a cultural view; the negative stigma in Malaysia regarding ASD originates from the inability to 'fit in' the group social norms, and not based on ASD symptoms (Stewart et al., 2010).

### ***Perspective of ASD from different social groups***

The societal view and experience here will be segregated into two categories; the primary group, where the ASD individual will have frequent contact and relationships with, such as family and teachers, and the secondary group, where the group size is bigger in size and more formal, such as media portrayal and employers.

**Family and parental views towards ASD.** The family view towards ASD has been found to be strongly linked with the cultural background of the parents themselves (Samadi, 2020). Specifically, they are found to be significantly impactful towards ASD individuals, as they are linked with the parenting style and treatment received (Ravindran & Myers, 2012; Stahmer et al., 2011). Families from highly religious backgrounds may be more prone towards spiritual treatments to ‘cure’ their child (Jegatheesan et al., 2010). A qualitative study done among the collectivistic culture of Somali found that most parents and elders believe that autism is a phase that will go away on its own and that there is nothing wrong with their children (Fox et al., 2016). This belief may seriously delay proper diagnosis and treatment in the early developmental stages (Cohen & Miguel, 2018; Daley, 2004), which is crucial timing in promoting the development of their life skills.

The studies that have been conducted regarding the sibling perception towards ASD show mixed results, showing both positive responses and negative views. In the negative aspect, siblings reportedly had troubles with their ASD sibling’s aggressive outbursts (Mascha & Boucher, 2006), and felt embarrassed of their sibling’s condition (Petalas et al., 2012). In a positive light, siblings reported having fun with their ASD sibling’s behaviour (Rivers & Stoneman, 2003) and were proud of them (Moss et al., 2019). Additionally, a study by Sage and Jegatheesan (2010) links back these perceptions towards their siblings to their cultural background. The American family that was individualistic fostered positive sibling

relationships, whereas the Vietnamese family that was collectivistic fostered negative sibling feelings towards ASD.

In the parental sense, guilt is reported to be a main component in parental views towards their child with ASD (Sage & Jegatheesan, 2010). Parents might feel this way due to multiple factors, including feeling that it is due to maternal factors, genetic inheritance and an overall sense of responsibility (Elder, 1994; Gray, 1994; Mercer et al., 2006). Unsurprisingly, the more aware and knowledgeable parents were about ASD, the less sense of guilt they felt about their child's condition (Dardennes et al., 2011; Mak & Kwok, 2010). Some parents even relate their guilt towards their choice to vaccinate their child, believing in the common myth that their child's autistic symptoms originate from vaccination (Mercer et al., 2006).

Several reports have also mentioned that parents are most likely to internalize negative stigma from the public (Gray, 2002; Mak & Kwok, 2010) and in consequence, view their child as incompetent and dependent and unconsciously treat them like so. This might be due to the sense of responsibility perceived by the parent on their child's condition, that others will blame them for their 'failed' upbringing (Penn et al., 2000). Embarrassment felt from the stigma of 'failing to properly take care' of their autistic child might influence them to perceive that they are actually doing something wrong (Gray, 1993), and that the proper behaviour of their child will predict the performance of them as parents too. This behaviour in the long term will then be internalized by the child too, believing that they are inept and unable to fulfill their social responsibilities, when they might actually have the capability to do so. All of the above suggests that the parental knowledge and view regarding ASD plays a significant impact towards the lives of their children, further validating the need to increase awareness about ASD.

**Teachers' views towards ASD.** Teachers' views towards ASD individuals are mostly based on the knowledge they have regarding it. Several quantitative studies across the world have shown deficiencies in the knowledge of ASD among teachers (Jehan et al., 2017; Rodríguez et al., 2012; Syriopoulou-Delli et al., 2011), with those working in government schools having better understanding than those in private schools (Arif et al., 2013). Although the majority are aware of ASD, most of them are unclear on the symptoms and support services available. Common misconceptions regarding ASD were also observed, with some teachers mentioning that ASD originates from childhood trauma or that ASD individuals had fixed symptoms (Barned et al., 2011). Most of the teachers reported learning about ASD through the media as well, which might be a predictor towards the misconceptions of ASD among them. A large part of teachers are also hesitant in teaching ASD students, suggesting that only special education teachers teach them due to their knowledge and experience advantage (Alghazo et al., 2003; Barned et al., 2011).

**Media portrayal towards ASD.** The media portrayal of ASD typically shows ASD individuals as patients or high functioning savants. The patient portrayal shows ASD individuals as people who are dependent on others and child-like, framing them as a burden to both society and their families (Tang & Bie, 2015). Victimization is also a common theme, by presenting that they are not cared for by society, and are mistreated (Jones & Harwood, 2009). This leads viewers to be imprinted with the concept that ASD individuals are incapable and need help from others, whereas they might be perfectly capable themselves. On the other hand, ASD individuals were reportedly characterized as dangerous and aggressive (Ray & Hinnant, 2009), with high IQ and genius-like skills (Draaisma, 2009). This is impactful towards ASD individuals, as viewers will have higher expectations for them due to the perception of them being savant like in common media (Huws & Jones, 2011).

**Employers view towards ASD.** The majority of employers are reluctant in hiring ASD individuals, mostly because they perceive that the cost of hiring them outweighs the benefits (Hernandez et al., 2000). It is reported that they hold stigmatized attitudes and think that ASD individuals are incapable of following through with work and that they have low productivity as compared to your average employee (Graffam et al., 2002). Additionally, employers from bigger companies were less apprehensive in hiring ASD individuals, as they cared less about the cost to value ratio, due to the abundance of resources that the organization is able to provide (Scott et al., 2017). This negative attitude towards hiring ASD individuals may be rooted from the misconceptions surrounding ASD, as well as the lack of knowledge they have on ASD (Ju et al., 2013; Scott et al., 2017). Hence, further implying the importance of spreading awareness on ASD among the public.

### **Impact of Societal View on those with ASD**

How society views ASD may have an impact on their QoL. When it is viewed in a negative light, those with ASD might develop problems in their life or to themselves. These problems can manifest themselves such as concealing their ASD condition, having low self esteem, not participating in society, social rejection and unemployment.

#### ***Concealing ASD***

One of the biggest impacts of society's view on ASD is how those with ASD are open with their condition. Having ASD is seen as a negative trait to have, which ends with those with ASD struggling to disclose and discuss their condition willingly. As proven in a research by Botha et al., (2020) clarifying that participants in the study, the ASD individuals are trying to cope with the society's autism stigma and the negative implications that come with it, versus how they view themselves.

***Low self esteem***

How those with ASD perceive their own condition may affect their self esteem. Those with ASD according to a study by Nguyen et al, (2020) that those with ASD have a significantly lower global self esteem than the usual developing individuals. Alternatively, in the same study it is also found that there is a high global self esteem among those with ASD when ASD is more positively associated with giftedness, emotional resilience and power.

***Low social participation***

How deeply those ASD engage themselves in their community or society is important as it impacts their QoL and functioning according to Orsmond, et al (2013). The researchers also found that in their study that young adults with ASD have a higher rate of not seeing their friends, not getting calls from their friends, not being invited to activities as well as being socially isolated when compared to other disability groups such as those with intellectual, behavioural and learning disabilities. In the factors that contribute to low social participation, researchers found that low conversation and functional skills as well the factor of living with parents have been shown to impact negatively on low social participation. This point is further supported by Schmidt et al., (2015) that highlight in his study that those with ASD have comparatively low QoL than non-ASD, with social participation being the sole factor contributing to the low QoL. With society's view, one can see that with a negative view can further worsen the social participation of ASD

***Social Rejection***

ASD and social rejection have been connected through multiple research. A research by Symes & Humphrey, (2010) found that those with ASD have a low level of acceptance and a high level of rejection compared to those that do not identify with ASD. As stated in the previous paragraph, those with ASD are more likely to face social isolation than their peers (Orsmond et al., 2013). A study by Kwan, et al (2020) brought up that social isolation of

children with neurodevelopmental disorder is a worldwide issue. It is found that based on real-world social behavior, a typically developing person has a negative first impression of those with ASD and leads to a less intention to further pursue social interaction.

### ***Unemployment***

Those with ASD face social challenges in their lives due to a problem in adapting to the social environment, this has made it difficult for them to get or maintain a job. Chen et al. (2014) found that those with ASD in the workplace have external problems that make it difficult for them to succeed in their employment. One of the problems is the employer's attitude. How the employers perceive and worry in hiring those with ASD impacts the employment of ASD themselves. A majority of employers of those who reject hiring people with ASD have common factors such as concern on employee's ability to work in the company's set ways, focus on the adaptability of employees, a worry for the possibility of negative effects and are less open to new information. This is concerning as that means some people with ASD may hide their condition in order to get hired. Employer's perception of people with ASD highly impacts on how likely they are to hire them.

### ***Quality of life***

The results of the societal view on ASD have influenced how those with ASD lived their life, affecting their QoL. When looking at QoL of ASD individuals, results showed that they score low in physical health, psychological health, social relationships and environmental health domains (Mason et al., 2018). One can see that as a result of how societal views of ASD affect them and makes it hard for them to thrive better for themselves. Concealing one's own condition such as ASD which is common in the community has done more harm than good in the psychological health of ASD individuals (Botha et al., 2020). ASD individuals have reported less global self-esteem than typically developing individuals, as the findings suggest that individuals with ASD have lower global perceptions of their own

self worth, this is worrying as this may lead to ASD individuals not being confident in leading their lives and achieving a greater QoL (Nguyen et al., 2020). One can also see that a lower self worth may influence the factor of social rejection and low social participation, both are intertwined with each other.

Social rejection is a worldwide issue particularly as it affects children with ASD, as they will be driven further to not participate in society (Kwan et al., 2020). Participation in society is an important contributor to a low QoL as a study by Schmidt et al., (2015) found that social participation is the sole factor to a low QoL. Lastly, the low employment of ASD is an important factor that influences an ASD individual's QoL. Some companies have a negative perception of ASD, which makes it hard for ASD individuals to have a job, even so these negative perceptions may pressure ASD individuals in the workplace (Chen et al., 2014). Overall, one can imagine that it is very difficult for ASD individuals to maintain and take care of their lives, let alone their QoL with the impacts of societal view affecting their every life aspect.

### **Coping with ASD**

ASD groups are said and defined by society as having some kind of impairments in themselves in which they will perform less social interaction and tend to behave in a distinct way (Botha et al., 2020). People are born with basic needs to be accepted within the society so that they're viewed as majorities in society. People with Autism will practice their daily lives in terms of physical, social and emotional in a societal acceptable way.

To physically cope well with societal expectation on ASD physically, they need to seek professional help and work closely with educational and legal professionals (Kahana et al., 2015). There is an option available to practice proactive management of ASD. It can help to develop the abilities of children with ASD at the maximum and hence, reduce stress or burden in their families at the minimum (Myers & Johnson, 2007). For proactive



management, they will have customized strategies and plans throughout the process under supervision of their parents and healthcare professionals via education regarding life knowledge and academic knowledge (Davis, 2002; Margetts et al, 2006).

### ***Adaptive Morphing***

In order for ASD groups to cope well within society, one of the social coping styles they will often practice is adaptive morphing, commonly known as masking. Also called as autistic morphing which will help in adapting themselves into the society based on the social situations and expectations (Lawson, 2020). They are hiding and camouflaging their real emotions and behavior as long as the stigma on Autistic groups is ongoing. According to Shattuck et al. (2012), people in ASD groups will tend to hide their real emotions so that they can perceive more socially desirable responses from the public (Tierney et al., 2016) and they even camouflaged themselves at working environments and their daily life so that they will be having better social relationships with others (Hull et al., 2017). However, camouflaging brings many negative consequences such as exhaustion, stress, improper or no treatment provided as the symptoms are not found (Hull et al., 2017).

As mentioned previously, social coping with ASD in society may somehow cause stress in themselves. Emotion dysregulation has always been a serious and common problem among ASD groups and it even affects their daily life in terms of physical and mental health conditions (Cai et al., 2018). Adaptive and maladaptive strategies are both utilized in coping with societal views on ASD including distraction and avoidant strategies and it is shown to have greater effect in lower depression and stress level among ASD groups (Pouw et al., 2013). It is one of the useful strategies to cope with societal perception on ASD which is to convince themselves that the issue of societal perception is not serious to look into. It is a kind of strategy that rephrases one's own words and persuades one's own self in viewing the world (Joormann & Stanton, 2016).

### **Theoretical Framework**

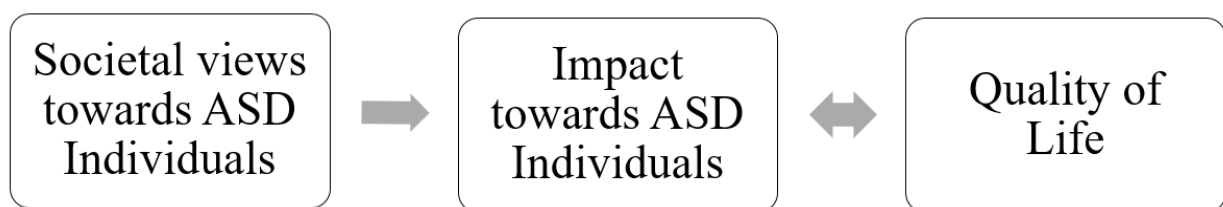
The social model of disability (SMOD) puts value on the fact that what society's defined as disability is socially constructed (Oliver et al., 2012). The SMOD defines impairment and disability as two different concepts. Impairment is any medical condition that leads to disability. Disability on the hand, is the connection between those with impairments and the environment that they are put under, be it in a physical, communicative or social way. To put as an example, person A has the impairment of having the inability to walk, as such he is forced to use a wheelchair. Person A wants to go to a building but could not as the building only has stairs to go inside of it. In this situation, what keeps person A from going inside the building is not his inability to walk but that the stairs are making it inaccessible for people like person A from entering the building freely like others. The connection between person A's impairment and the physical environment of which are not friendly towards his impairment has made his impairment a disability. As such in the SMOD, the building can accommodate those like person A by building a ramp for ease of use of wheelchairs. SMOD opposes the medical model of disability, vying to make those with disability to be corrected. For example, in the previous situation the medical model of disability seeks to have person A physically able to use the stairs instead of accommodating to person A's impairment. The point of the SMOD is to not view those with disability with pity and need to be cured, but as equals deserving the rights as others.

SMOD has shown to have the possibility of being implemented in the ASD context (Woods, 2017). Woods (2017) argued that those with ASD face demands from society to adapt to become more neurotypical, of which those with ASD experience a less control of their lives and thus experience harm to their mental health. As such SMOD can be used by helping those with ASD to be accommodated in the social environment. By tackling the

negative discourse of autism and the categorisation of the autism label, Woods (2017) can reach ASD emancipation.

As such SMOD is appropriate to be used in the study, as it tackles the social environment and expectation of ASD individuals' effects on their QoL, be it negative or positive. The model can be used as a basis to develop on how society can further accommodate ASD individuals and how those with ASD can cope with the expectation present.

### Conceptual Framework



*Figure 1.* Conceptual Framework Model of the Current Study

Figure 1 proposes the conceptual framework used for this study, depicting the relationship between the three variables. Societal views towards ASD individuals act as the independent variable, with impact towards ASD individuals as the dependent variable. QoL here is interrelated with impact towards ASD individuals, with QoL influencing the Impact towards ASD Individuals and vice versa.

As mentioned above, the SMOD theorizes that disabilities are social constructs, and that someone who is impaired becomes disabled because society does not accommodate them. When putting it in the ASD perspective, the societal view towards ASD acts as the social barrier in disabling ASD individuals. It is our negative societal views that influence negative outcomes and challenges towards ASD individuals, such as unemployment. Consequently, it leaves them disabled and dependent on others. Past studies even mention that the labeling of ASD as disabled, having a deficit or a disorder further reinforces negative

societal views towards them (Woods, 2017). This indicates that our neurotypical society is not accommodating towards ASD individuals, causing their impairments to become disabilities.

In addition, past studies mention that societal views towards ASD influences ASD individuals significantly, such as social isolation. This situation will then decrease the QoL among them, causing negative outcomes such as poor mental health and a higher risk of suicidality. Hence, it is observed that the impact towards ASD individuals are interrelated with their QoL, with one affecting the other and vice versa. The current model will aim to explore the societal views towards ASD individuals and the impact of societal views towards them. Additionally, we will also examine the relationship between QoL and the impact towards ASD individuals.

### **Chapter III**

#### **Methodology**

##### **Research Design**

###### ***Qualitative Research***

The current study adopted a qualitative research design. Qualitative studies allow the researcher to explore and ask questions starting with why, after mass data from quantitative data acquired. Although quantitative data is useful in making claims backed with lengthy evidence, qualitative research allows us to delve deeper into the reasons why these claims were made. In the case of the current study, it is observed from previous research that ASD individuals face various difficulties when fitting into society. Hence, the researchers aim to explore the reasons for this through the eyes of the sample themselves, as well as their feelings towards this issue.

By opting for qualitative research, the researchers are also able to explore broader and wider into the subject on hand. The information collected may be out of the initial hypothesis and guesses, providing the researchers with a wide range of data, which may not be acquired with quantitative research.

###### ***Phenomenological Study***

The current study also utilized the format of a phenomenological study, in which we explore everything surrounding the phenomena at hand. It aims to explore the lived experiences of the target population, and derive data from the descriptions that they provide. Since the current area of research is limited within Malaysia, it is appropriate to utilize this method to gather more information about it via the participants themselves (Donalek, 2004). Additionally, reflexivity is also practiced throughout the write-up, as to ensure that the data derived and described are authentically from the sample's viewpoint, and involving little to no perspective from the researcher. By adhering to this practice, we will be able to obtain data

that is truly from the vantage point of the participants, and fulfill the aim of phenomenological research.

## **Sampling**

### ***Sampling Method***

Purposive sampling was mainly used to gather participants, in which participants will be hand picked by the researchers so that their background information fits the inclusion criteria and research requirements. Not only was it used because the research focused on a specific population, but also considering the limited number of ASD individuals that can be reached out to contribute to the study, purposive sampling was chosen.

However, due to the limited accessibility to these individuals, snowball sampling was also incorporated to obtain more participants. With snowball sampling, it allows researchers to obtain respondents from difficult to reach populations compared to other methods. This particular sampling method is a simple, cheap and efficient way of gathering participants, citing that little workforce or plan are needed.

### ***Sampling Size***

Five ASD individuals in total were recruited for the study as interviewees. Aligning with the above justification regarding the sampling methods, only a small group of participants were recruited for the study due to the time restrictions of a student paper, as well as due to the limited target group and its availability. Despite the small number, five is just enough for us to attain data saturation. As referred by Fusch and Ness (2015) that suggests that when it comes to qualitative research, it is recommended to have a group of at least 5 participants in order to reach data saturation.

Data saturation is a point whereby no new data is brought to light in the research, this in turn tells the researchers that collecting data may stop (Faulkner & Trotter, 2017). Fusch and Ness (2015) discusses that for some researchers, data saturation may be reached at a

number as small as six interviews depending, but it depends on the population's sample size. This notion is supported by a research done by Guest et al, (2020) where they found that the first five to six qualitative research interviews gave a large part of new information in the data, the researchers suggest that data saturation should be assessed initially after five interviews.

### ***Recruitment of Participants***

Four of our participants were recruited through an ASD facilitating organization, Malaysian High Functioning Autism Association (MAHFAA). Our researchers got in touch with the members of the management, who recruited participants within their organization by the name of the current study. The other one of our participants was recommended to our researchers through personal connections, and we reached out and recruited them via their social media account.

### ***Inclusion and Exclusion Criteria***

The inclusion criteria of the study is as followed:

1. The participant must be diagnosed as a high-functioning ASD individual.
2. The participant must be literate enough to understand the interview questions and the nature of our study and its objectives.
3. The participants must have no hearing impairment or speech problems.
4. The participant must be of age and not a minor, between the ages of 18 and above.
5. The participant must be a Malaysian citizen, born and raised.

In this sense, participants that fulfill the above criteria will be able to participate in the current study.

### ***Ethical clearance and approval***

Prior to the data collection process, possible ethical issues were reviewed and approved with relevant committees, such as the supervisor of the current study, Universiti Tunku Abdul Rahman (UTAR) Scientific and Ethical Review Committee (SERC). The study was approved for ethical clearance under expedited review, under the terms that:

1. The participants' informed consent be obtained prior to the commencement of the research;
2. Confidentiality of participants' personal data must be maintained; and
3. Compliance with procedures set out in related policies of UTAR such as the UTAR Research Ethics and Code of Conduct, Code of Practice for Research Involving Humans and other related policies/guidelines.
4. Written consent be obtained from the institution(s)/company(ies) in which the physical or/and online survey will be carried out, prior to the commencement of the research.

### **Data Collection**

#### ***Demographic Information***

Demographic data of the participants are required to ensure that they fit within our target population, for the purposes of providing data context from our information gathered from them. Participants were required to fill in their demographic details that the researchers were interested with in a demographic form provided, including their age, ethnicity, religion, religion, state of birth, state of residence, highest level of education, duration since diagnosis, ASD severity and living situation.

#### ***Semi Structured One-to-one Interview***

The lived experiences of ASD individuals in Malaysia was explored through the perspective of our participants themselves, through one-on-one interviews. One-to-one



interviews were considered because the study would like to collect data that is rich in information and is focused more on the individual impact that the interviewee perceived to have had from societal perception, which is important in exploring the possibilities of how those ASD view the impact of societal perception have on their lives. It is also to avoid group dynamics such as group thinking that may influence the data, which goes against the importance of individual experiences of each interviewee.

Another point to consider is the social difficulties that those with ASD encounter because of their disorder, such as slight cognitive deficits and potential temper issues, coupled with the nature of exploring how societal perception impacts their lives. Hence it would be more ideal to conduct interviews where the interviewer would be only handling one interviewee at a time. Additionally, sensitive personal experiences might be brought up through the interview process, which in turn might be potentially discouraged if in a group setting, due to privacy concerns. The confidentiality of each interviewee would also be kept safe as they are interviewed individually with only the researchers in the call. Additionally, open-ended questions were used throughout the interview, to facilitate the collection of diversified data, as the participants were free to answer in any direction. This allowed the researchers to obtain rich heterogeneous information from each interview.

### ***Interview Questions***

Below encompasses the interview questions used in each interview session:

RQ1: What are the social experiences and challenges of ASD individuals in Malaysia?

1. What is your social experience like in Malaysia?
2. Do you think society has a certain expectation or perceptions towards ASD individuals like you? If so, could you describe it?

3. How do your ASD symptoms affect your daily life and do you think that it affects how others perceive ASD individuals? How so?

RQ2: What is the impact of local societal views on the quality of life of ASD individuals in Malaysia?

1. Do you think that the expectations and perceptions of the public have an effect on you? If so, could you explain how? And if not, why?
2. What were your feelings and emotions when you first realized society's views on you? How do you feel now about those views?
3. Will you take any initiative in order to meet the societal expectations of you?

RQ3: How do ASD individuals in Malaysia cope with negative societal views?

1. How do you socialize with someone once you know they have negative views on ASD?
2. Do you form a coping mechanism as a result of negative societal views? If so, can you explain how?
3. How do you react when someone confronts you with their negative views of ASD?

## **Data Collection Procedures**

### ***Obtaining Consent***

**Consent Form.** Before the interview sessions, consent forms were prepared prior for participants to fill in. In the consent form, participants acknowledged that the entire interview session will be voice recorded and they'll have their right to accept or refuse if they're uncomfortable. Information of every group member such as full name and contact number were provided in the consent form so that participants can contact any of the researchers if they had any concerns and issues so as to provide a sense of security to them. Participants will also be acknowledged through the consent form that all data and information gathered

after the interview session will be used for academic purposes only and not for third parties' use.

**Informed Consent.** During the interview session, participants were asked once again to consent to the audio recording of the entire interview session, and their rights as an interviewee were restated by the interviewer to ensure that they are clear and acknowledge the interview process. Recording only started after verbal consent was provided.

### ***Procedures of Data Collection***

**Demographic Form.** A demographic form was provided to the participants together with the consent form before the interview session began. Participants were required to fill in their demographic details that the researchers were interested with. The form was sent as a PDF to their contact number via Whatsapp along with the consent form for them to complete before attending the interview sessions. They then signed and filled in both forms and sent them back to the researchers.

**Interview Process.** All interviews were conducted using Microsoft Teams, considering the safety of both researchers and participants during the pandemic. Additionally, Microsoft teams were also utilized due to its usability, including live transcripts, unlimited recording hours, etc. Prior to the interview, researchers confirmed once again on the completion of consent and demographic form for each interviewee. The interview link was sent to each participant on the morning of their interview session, and a text reminder 5 minutes before the session. All researchers attended each interview, exchanging roles as interviewer and observer across each interview. The interview sessions ranged from 15 minutes to 2 hours, depending on the content shared by individual participants.

After verbal consent was given, researchers proceeded to start the recording of the sessions and introduced themselves, whilst starting with the interview questions. The interviewer also asked additional questions depending on the flow of the conversation. At the

same time, the researchers also noted down their personal observations throughout and after the interview, for the use of future reference during data analysis.

The interview session ended after the interviewer expressed their gratitude towards their contribution to the current study, and the participant was informed that they could ask or share additional questions after the session via Whatsapp if they wished to do so. A transcription of the interview was done manually after the interview, with reference to the recording and the live transcription data.

## **Validity and Reliability**

### ***Validity***

Validity in qualitative research is vastly different when compared with quantitative research (Winter, 2000). Researchers argue that validity is inapplicable in qualitative research, but it is mutually agreed that a form of quality check is necessary (Golafshani, 2015). Hence, multiple past studies have attempted to come up with a replacement for the form of validity in terms of qualitative studies, such as trustworthiness; proposed by Lincoln and Guba (1985). They mentioned that to ensure that the results of a research is considered valid, it is important to develop the reader's trust in our interpretation of our findings. Criteria mentioned in the study regarding how researchers can establish trustworthiness in their data include establishing credibility, dependability, confirmability and transferability. In this sense, the current study applied this four dimensional standard to demonstrate validity in our data.

**Credibility.** Credibility refers to the accuracy of the researcher's interpretation of the interviewee's answers and point of view (Tobin & Begley, 2004). The current study exhibited this criteria by utilizing data triangulation, in which we collect and compare data from different sources, including the interview transcript, the second coder and past literature.

**Dependability.** This involves ensuring that the findings of the current study is replicable, if conducted with the same population sample and context (Tobin & Begley, 2004). We achieved dependability through thorough explanation on our methodology and reflexivity within the researchers. The incorporation of reflexivity in the writing will be gone into detail in later sections.

**Transferability.** As its name suggests, transferability refers to the generalizability of the findings of the study in future research (Forero et al., 2018). Since the results of the current study is subjective to the participants personal background, experiences and demographic variables, it would be difficult to transfer the current content into other similar studies due to its qualitative nature. In order to establish the current criterion on our study, we provided thick descriptions of our findings, elaborating on how and why the situation and other variables interplay with the current phenomena.

**Confirmability.** Confirmability can only be achieved through the prior achievement of the above criteria (Lincoln & Guba, 1985). It is defined as the level of agreement that other researchers would have on our findings and analyses. Therefore, the current study demonstrated confirmability through the achievement of the above mentioned criteria, utilizing data triangulation, thick description of method and analysis and so on.

### ***Reliability***

Reliability in qualitative research often refers to the consistency of data and the ability to replicate the same study which result in similar findings. Lincoln and Guba (1985) mention that reliability cannot be achieved without demonstrating validity first, hence the current researchers are able to establish reliability throughout the study by achieving both dependability and confirmability, in which detailed accounts for methodological and analytical process are provided, along with the concept of reflexivity throughout the analysis.

**Inter-coder reliability (ICR).** In addition, inter-coder reliability was practiced in the current study. Inter-coder reliability defines the consistency and agreement between multiple coders on how they code the same data. Specifically, the current research calculated the percent (times) of agreement among coders on our coding judgements, such as the choice to categorize data in one theme and not another. There are two coders assigned for each interview and coders will expose themselves and code the same interview transcript individually, then the amount of times coders agree on the same coding will be summed up, resulting in our ICR.

Past researchers have pointed out that the concept of ICR in qualitative research may be futile, as the disagreements between coders might be different but valid, with their own individualized perspectives towards the data (Lombard et al., 2002). However, ICR was decided to be implemented in the current study due to the transparency it provides on the researchers judgements, which facilitate reflexivity and trustworthiness. As mentioned previously, dependability is the ability for other researchers to be able to replicate the same study, with yield of similar results. Hence, the methodological process in which researchers code and categorize their themes should be described in detail to provide a thick description so that other researchers and readers will be able to understand the thought processes behind our decisions. Additionally, ICR helps to keep up the consistency of data, and shares the workload of interpreting large masses of data among researchers without losing data cohesion (O'Connor & Joffe, 2020), as it facilitates internal communication and constant self reflection on our personal biases within the research team.

### **Reflexivity**

This implies actively examining our thought process and the decisions we make throughout the data collection process. In this sense, the researchers of this study acknowledged our personal biases and backgrounds and its implications on how we analyze

and see our data during the write up. These internal and external thought processes were recorded to keep a clear account of our judgements and why we made them. It will be effective in minimizing the researcher bias during analysis. Additionally, the perceptions of the researchers and their possible personal biases are also accounted for in the section below.

**The Perspectives of the Researchers: Researcher 1.** Personally, I do not have any relations with Autism throughout my life. I was only exposed to it through university courses and mainstream media, who often depict ASD individuals as dependent and miserable. With the increase of ASD related content exposed to me throughout my university life, I became more interested in ASD individuals and how they experience life. I began to wonder if they actually saw their lives as miserable as others thought, or if they saw it with a positive attitude or a neutral view. Because of this, I will be more inclined to understand their perspectives and how they see others and themselves, which might reflect in my analysis and writing.

Plus, due to my exposure towards miserable depictions of ASD individuals through the media, I might also have an unconscious pity towards them, thinking that it is a default that they need to be saved and helped. Hence, this might affect my writing and how I portray them and their experiences in the results and discussion. Since my initial perception was of pity, I kept in mind to not overly victimize them and interpreted data with data triangulation in mind. This was done by cross checking their non verbal expressions and tone of voice when interpreting their statements and any underlying information. Additionally, I also managed by bias by setting myself in a third person's perspective when interviewing participants, and asked additional neutral questions only when it went with the flow and were relevant to the research questions. I did not push the participant to agree on my personal biases and did not reveal them to the interviewee, so that their claims were made entirely on their opinion and not influenced by mine.

**The Perspectives of the Researchers: Researcher 2.** Before really getting into this project, I have only surface understanding on ASD individuals. Due to limited exposure and opportunities in exposing to the ASD community, I have only academic knowledge on ASD. Previously I have met with someone living with ASD which was my neighbor years ago. She often possesses more extreme thinking and behaviors which match with society's view that I have perceived previously. Although no one around me is clear about ASD, it is said to be one of the common mental disorders in Malaysia. In my initial opinion as received from society, ASD individuals are said to have more personality traits which are not preferred by others.

Therefore, due to some perception from me generated from the public, I often view ASD individuals as helpless and clueless. Honestly, I will tend to view ASD individuals in an empathetic manner. It will affect my perception of what they are saying which leads me to affect my writing. After I have aware on my biases, I always remind myself to view at the central point, neutrally. Basically to view the participants' feelings and their perception as an outsider without siding with any of them.

**The Perspectives of the Researchers: Researcher 3.** As a person who has a younger brother living with ASD, this puts me into a test of what I truly know about ASD. There is no denying that with my background and knowledge that there will be a semblance of bias in my writing. From my experience and knowledge of my brother, there is a possibility that I may have projected a specific idea of what an ASD individual is. Such ideas may take the form of how they socialize, communicate, act, live and cope. Thus, when I was exposed to more individuals with ASD, I was intrigued and slightly surprised by the range of how ASD manifests itself and affects different people in its own way. Truly defined by its own definition, ASD is a spectrum that cannot just be generalized easily. However, I truly believe in wanting to understand and help those living with ASD such that those like my brother can



live a fairly comfortable life. My bias and my experience towards my brother may reflect on my analysis and writing in a way that I would be more inclined to take the side of those with ASD and may relate back to the participant's experience to my brother's. As such I took into consideration of this when writing and analyzing the data to make it fair and not skewed the data, I will reflect back and analyze if my thoughts are based fairly or due to my experience with my brother.

Additionally, I have interned before at a psychology center where my task may involve taking care and teaching children with developmental disabilities such as Attention-deficit/hyperactivity disorder (ADHD) and/or Global Developmental Delay (GDD). Thus I may have an ingrained idea of how an individual with developmental disability may act and behave. Though, I do realize that the interview will be conducted with adults rather than children, which may look different based on age. Nonetheless, my experience working with kids living with developmental disabilities may also reflect on my discussion and results. As such, I take into consideration the participant's own experiences and view, as well act accordingly and appropriately to my writing so that I do not generalize their symptoms and experiences.

## **Chapter IV**

### **Results**

#### **Data Analysis**

##### ***Thematic analysis***

The study used a thematic analysis method to examine the data collected. One of the widely used analytical methods in the qualitative research field (Braun & Clarke, 2006) It identifies, analyses and reports themes in a large group of data. Thematic analysis relies on themes, as Braun & Clarke (2006) says that what is considered a theme is something that shows significant importance between the data and the research question, that also depicts a patterned response or meaning in the data. Thematic analysis aims to describe the patterns in qualitative data, finding out what is common and interpreting to seek if it answers the research question.

The advantage of this method is its flexibility, it does not require as it does not rely on complex theoretical knowledge as other methods while also being accessible to researchers that are early in their career (Braun & Clarke, 2006). Another advantage is its usefulness in analyzing a population's experience or view, as King (2004) points out that thematic analysis is a method that can be useful in studying the views of research participants which is useful in our research as it wants to identify the different experiences of ASD individuals under societal view.

##### ***Procedures of Thematic Analysis***

There are processes in conducting thematic analysis as seen in the original guideline by Braun & Clarke, (2006) however they point out that it is not a fixed process, as such it is encouraged to apply flexibility, such as adding relevant steps (peer debriefings, data triangulation, etc) depending on the data and the research question. The procedures of

thematic analysis for the current study include six steps in total, data familiarization, coding, theme formation, theme review, theme naming and description and report write-up.

**Data Familiarization.** In the first phase of conducting thematic analysis, the researchers familiarize themselves with the data by transcribing, reading and re-reading the transcripts to have some sort of idea on each interviewee's perspective, as well as taking down notes when relevant. This allowed them to reflect on the data after the initial observation during the interview, and may help the interviewer in gaining a new perspective from the data. All researchers went through the 5 transcripts at least once, to gain a better understanding of them.

**Coding.** In this second phase, the researchers will generate initial codes identified from the mass data. The mass content of the transcripts are slowly sifted through and labeled, which allows the researchers to be able to glance through and get a general grasp of the main ideas presented in the content better. Two coders were assigned to each transcript, and did their coding individually without referencing the codes of others. This facilitates the emergence of different codes on the same content, allowing the researchers to gain a broader and different aspect of the data.

**Theme Formation.** After coding each transcript twice, an excel sheet was made to compare and contrast the codes made for the same data, and to enable the researchers to zoom out and try to identify groups and patterns in the data. The coders first went through each other's codes and either agreed or disagreed with the code, in which a peer discussion was made to compromise and agree on something better. In this process, codes that were irrelevant to the research questions and codes that appeared too little were removed. The leftover codes that were agreed on were used for the researchers to identify and group codes based on any overarching themes.

**Theme Review.** After grouping codes together, the researchers went through each theme to analyze the suitability of them in answering each research question. In this process, themes that were similar or overlapping were grouped together, either forming a theme or a sub theme. The themes were also reviewed and refined to be more comprehensive and coherent in the report. Subsequently, the final sub themes were then grouped under an overarching theme that ties everything together.

**Theme Naming and Description.** After a thorough review of the theme, Braun and Clarke (2006) emphasize to capture the essence of the themes, which is what the theme represents. In this step, labels of the theme were formed and refined, to ensure that the name of each theme accurately encompasses and explained the codes and content of it.

**Report Write-up.** Lastly, after all previous steps, the full write up was done with the full set of themes regarding it. Tables and diagrams were made for easy reference, and are included below and in the appendix. Introductions regarding the description of the themes were included as well.

### **Demographic Information of Participants**

Table 1 indicates the demographic information collected from all five ASD interview participants. Their age ranges from as young as 20 to 36 years old, with a mean of 28.6 years. Only one of our respondents is female, with the other 4 all male. All of them are of Malay ethnicity and Islamic. The mean duration since diagnosis is 42.2 months, ranging from 150 months to 1 month only. Additionally, 4 of them are living with their family, with one other participant living alone.

**Table 1***Demographic Information of Interviewees of the Current Study*

Interviewee	Age	Gender	Ethnicity	Religion	State of Birth	Duration Since Diagnosis (months)	ASD Severity	Living Situation
P1	32	Male	Malay	Islam	Kedah	6	Mild	Living with family
P2	27	Male	Malay	Islam	Johor	150	Mild	Living with family
P3	28	Male	Malay	Islam	Kedah	24	Mild	Living alone
P4	20	Male	Malay	Islam	Cyberjaya	20	Mild	Living with family
P5	36	Female	Malay	Islam	Kuala Lumpur	1	Mild	Living with family

### Qualitative Analysis

This section explains the five themes that have emerged from the raw data, with 17 sub themes under them, as well as the essence encompassing the five main themes. The five main themes are as follows: isolation by society, difficulties adapting to society, focusing on self, support in life and spreading awareness to others. Each theme will be discussed in detail in the later section, and individual figures regarding each main theme and its sub theme will be included below as well. Explanations regarding how the researchers concluded with the below themes will be given, with appropriate evidence quotes from the interview transcripts to support them.

Additionally, the research questions of the current study have been answered by the emerged themes. In specific, the research questions are answered by the following themes in order:

RQ1: What are the social experiences and challenges of ASD individuals in Malaysia? This is answered by theme 1, isolated by others; in which their social experience in Malaysia is found to be sidelined and isolated by others.

RQ2: What is the impact of local societal views on the QoL of ASD individuals in Malaysia? This is answered by theme 2, difficulties adapting to society; in which due to the societal views put on them, the participants find it hard to adapt in society, in areas such as work and education. The specific areas of difficulties will be gone into detail later.

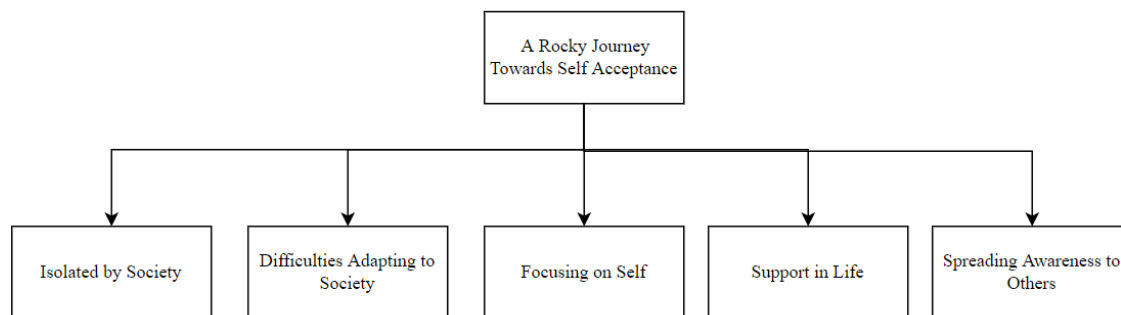
RQ3: How do ASD individuals in Malaysia cope with negative societal views? This is answered by the last three themes, theme 3, focusing on self; theme 4, support in life; and theme 5, spreading awareness to others. Through their negative experiences in life, the participants mostly take on a positive attitude and focus on themselves with supportive figures and pillars in their life, all while putting an emphasis on the importance of spreading awareness to others.

### ***The Essence: A Rocky Journey Towards Self-Acceptance***

In this section, we will discuss the essence emerged from the data, which encompasses the five main themes derived. Through the data analysis process, a main essence of the whole of data emerged, as the overarching theme of “A rocky journey towards self acceptance”. Under this essence are the five main themes, as depicted in figure 4.1. These themes represent the stages or parts of the social experience of an ASD individual in Malaysia, and how they dealt with it.

The essence is named as a rocky road towards self acceptance, as our participants share about their experiences as a story, from how they were treated in the past and how they

have come to accept it as a part of life and improve themselves instead. Throughout this journey, they share about the hardships they went through, such as not being understood and being bullied by others while facing difficulties in life, which is reflected in the wording of ‘rocky journey’ in the essence.



*Figure 4.1.* Essence of the Analysis and the Five Main Themes

Theme 1, which represents the first part of our participants’s rocky journey, revolves around being isolated by society. Although as higher functioning ASD individuals, they reported feeling isolated and ignored by society, as they were discriminated against throughout their life. Their feelings tend to concentrate on not being understood and loneliness, as well as their helplessness and frustration towards their social experience. Whether during school or work, they mentioned that people tend to leave them out of things and see them as different.

As represented in theme 2, difficulties adapting to society; this perspective of others seeing them as different influenced their life significantly, in areas such as employment and education. This in turn evolved into many mood issues, including being so depressed to the point where they dropped out of school one week before finals; feelings of frustration towards self and self blaming for the negativity surrounding them, etc.

However, in all of our participants, this did not seem to break them down, and rather developed into a motivator towards their now positive outlook on themselves and their ASD. Themes of working and loving themselves emerged as a major connection between all

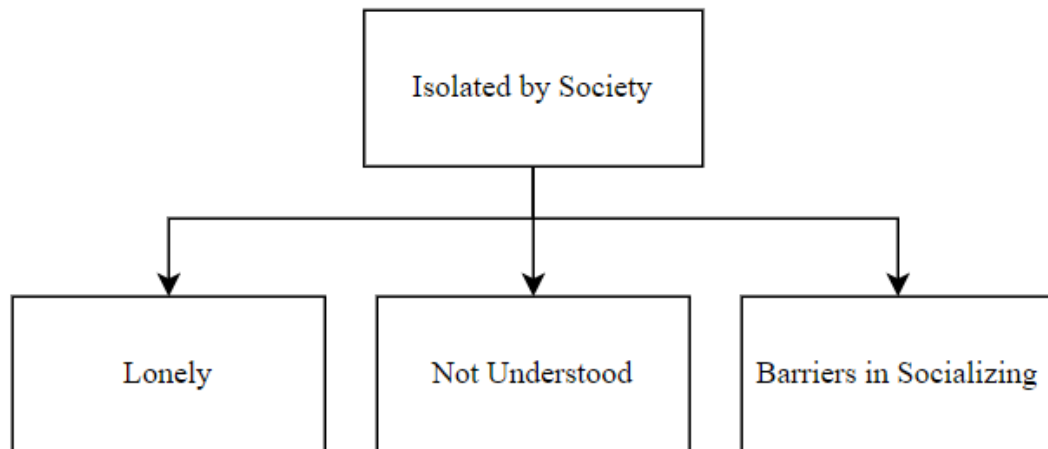
participants, as they all claimed that the most important thing towards themselves now is focusing on themselves and ignoring negativity, which is depicted in theme 3, focusing on self.

In accordance with theme 4, support in life; they also speak strongly about the importance of their mothers and family members in introducing and reinforcing their positive mentality within their core, even after their mom passed on. Other sources of support also come from teachers and religion, and vary from their personal upbringings and experiences.

Furthermore, as illustrated in our final theme, theme 5, spreading awareness to others; claimants on the urgency and significance of spreading awareness among the Malaysia public also rose up as a highly discussed topic amongst their statements, and most claimed that problems should be easily solved with the increase of knowledge and awareness amongst society. They also agreed that in comparison to the 90's, the acknowledgement and mentality regarding mental disorders such as ASD have improved substantially, in which they spoke about their belief in the positivity it will bring as it continues on.

In the next section, we will be discussing in further detail regarding each theme from one to five and their exact description and content, through the comments made by participants throughout the interviews.



***Theme 1: Isolated by Society***

*Figure 4.2.* Theme 1: Isolated by Society and Sub themes

The following theme expresses the identified reasons our participants feel left out from society, as well as their feelings regarding this situation. Sub Themes within this theme include loneliness, not being understood and barriers in socializing. As mentioned previously, most participants claim to feel lonely and not understood throughout their experiences with society, and felt that they were sidelined through these experiences. Feelings of isolation were also increased through their issues faced during socializing with others, as they claimed that due to others differentiating themselves with them, it is hard to get close and form relationships, even though they yearn for it. Participants describe not being understood by others, whilst not understanding others at the same time.

This theme reflects towards RQ1 in our research. Participants explained their experience as lonely due to a certain extent of rejection and avoidance by members in society. As they are not understood by the public, people tend to stay away from them which increases their sense of loneliness and socializing barriers especially when it comes to friendship, even intimate relationships with others resulting in their emotional burden. People

will also possess lesser understanding of them as minorities and this became part of their difficulties in interacting with society.

**Lonely.** This sub theme represents the feelings of loneliness and reasons for it among our participants. The reasons for it tend to originate from difficulties in forming friendships, their longing for companionship and close relationships, and their lack of ability to fit in with others.

The claims from Participant 3 below are based on their experience at school, and their troubles in seeking out new friends. A lack and difficulty in finding friends served as a major influence towards their feelings of loneliness. Their words also hint on their yearn for close relationships, whether friendships or romantic relationships, despite their insistence on not being bothered by it.

*“Sometimes I’m thinking why I am not having a lot of friends, I wished that I have a person to talk and accompany...” (Participant 3)*

*“Actually, if you’re asking if I am lonely, I am lonely all the time. Since childhood I don’t have many friends, but I have used to it. But if I am seeing couple or family in public, I will feel envy somehow.” (Participant 3)*

Not only do they feel alone due to a lack and yearning for close relationships, another reason also stems from not being accepted and being able to collaborate with others.

*“During the Covid-19 pandemic, everything changed, for example how to create what you call the assignment, how to get the classmate for the assignment. For example, because some of them have already group members but for me, it is very hard...” (Participant 1)*

The feelings of loneliness also caused them to look inward and identify problems within themselves, resulting in self-blame, despite the fact that it is not their fault.

*“...did I made mistake but nowadays I feel paranoid delusional, and I will think back is that person mocking me? I will think back is the person telling me the right things, is it I am acting just like what he says.” (Participant 3)*

Another claim by Participant 5 tapped on her frustration towards herself, as her inability to do certain things made her feel alone. This statement aligns with Participant 2’s words, both blaming themselves for being unable to ‘fit in’ and their isolation from others.

*“But like for me, I just fell through the cracks and my parents did not realize that I was having issues, so for me I had to learn all these skills by myself, and just, you know, keep on thinking why? Why do I feel different from other people? Why do these people just sail through life easily?” (Participant 5)*

**Not being understood.** This sub theme depicts our participants' experiences of not being understood by others and their justifications for it. Their justifications include not being accommodated by others, being misunderstood regarding their ASD symptoms and being misunderstood during their social interactions with others. All five of our participants reported having experiences of not being understood by others, and sometimes not understanding why others feel a certain way.

Participants 1 and 3 comment on their experiences of not being accommodated by others, specifically their teachers. Despite being clear and reasonable on their needs and

requests, they were brushed off but then blamed afterwards on their inability to perform like the average. This clear depiction of the accommodating acts from Malaysian educators contributed significantly towards their feelings of isolation.

*“I already mentioned to that lecturer that “I am a learning disability OKU, I have the rights to have additional time”. but somehow some other lecturer neglected to give extra time, so when I, when the, when I was supposed to get the extra time...when the management unit called me, “Why you get an F”. So, I said, “This is the lecturer that maybe they do not know it is me, but myself”.” (Participant 1)*

*“Back then I had this emotional breakdown and couldn't study in class, I like to self-study. I requested to go back home and study for a few weeks because I found that I can't really study at school, but they didn't let me to. It is the typical Malaysian's response especially in a boarding school. They think that everyone can do it then why you can't do this.” (Participant 4)*

Another comment made by Participant 2 describes their frustration of being misunderstood of their ASD symptoms and being viewed as rude despite them not being so. They imply that others view them as different from others, as the way they speak is different and assumed as being crude.

*“People expect me to talk in a certain way, they think I'm less polite or something. It's tiring.” (Participant 2)*

A claim by Participant 5 mention her annoyance on being misunderstood during her social interactions with others.

*“...and talking to people...it’s hard to relate to them. So when I try to relate, either people don’t understand me or I misunderstood them.” (Participant 5)*

In addition to their experiences, our participants also acknowledge that people do not understand them, and accept that people are probably never going to understand them. The self acceptance depicted throughout the words of Participant 3 will be discussed further in theme 3, focusing on self.

*“I don’t really focus on them as I need to learn to accept. Not everyone can accept the way you are, and I cannot expect people to be disciplined like me...” (Participant 3)*

*“ I need to accept it, not everyone will accept who you are but everyone is different.” (Participant 3)*

**Barriers in Socializing.** This sub theme encapsulates how social barriers cause them to feel isolated by society. The barriers in specific are due to their individual ASD symptoms of social limitations, anger management issues and cognitive limitations. This leads to them having trouble with relationships and interactions with other people. Consequently, this adds on to others isolating themselves with them, as they do not portray the social norm during interactions.

Additionally, this comes across as a significant issue for those who yearn for close relationships, as it directly affects their ability to maintain one. Hence, it further impacts their

feelings of isolation, as their attempts at reaching out seem to work out badly or come across a lot of obstacles.

Participant 2 mentions having difficulty adhering and understanding the point of being polite during social interactions, leaving him with mostly negative social experiences.

*“... I feel like being polite never really helps...I mean, they talk like they just expect this of people.” (Participant 2)*

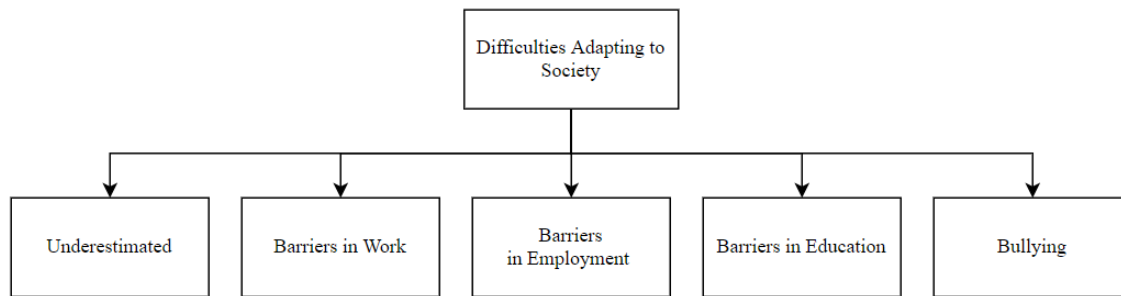
Participant 3's anger issues lead to him being bullied and distanced from others, despite him meaning well and wanting to develop friendships with others.

*“Even when I'm in university they will say they don't know me and called me as “si gamuk” which is mean as a person who always getting frustrated easily...but I will still wish that I can meet a person to chat well.” (Participant 3)*

Participant 5 claims that due to her cognitive limitations, she has a hard time understanding others during social interactions, which makes her feel like an outlier.

*“I feel like I'm outside of a bubble, kinda like I'm in a house looking out of a window and talking to people, you know what I mean? (Participant 5)*

She adds that it is mentally exhausting for her to interact normally with others, as she has to think a lot and observe before socializing. Although this does not disrupt her relationships with others significantly, it impacts her day to day life and further reinforces her perception of an invisible barrier between her and others.

***Theme 2: Difficulties adapting to society***

*Figure 4.3.* Theme 2: Difficulties Adapting to Society and Sub themes

Theme 2 is well explaining RQ2. It explains how participants' negative social experience and limitations in themselves developed into adapting difficulties with the public in society. Due to the public's lack of understanding of ASD, their capabilities are underestimated and are vulnerable to bullying. They are also facing barriers in themselves of not being able to cope with their daily functioning by others and are not given a proper chance to prove themselves.

Because of the symptoms and the negative perceptions of ASD, it influences and creates obstacles on how those living with ASD adapt to society. Being underestimated and bullied has made it difficult for those with ASD to be seen as equal and capable by society, while barriers such as work, employment and education has made it difficult for those with ASD to properly integrate into society. Each and everyone of the participants have experienced some form of difficulties when adapting to society hindering them from living a comfortable life.

**Underestimated.** Refers to the general low expectation and misjudgement from society onto those with ASD, either from ignorance or a general lack of knowledge that affects them from a social, academical and workplace perspective. The expectations experienced by the participants are low to the point that some would describe it as not having any expectation at all.

It can be seen because of the expectation and how those living with ASD operate differently from those who do not live with ASD, it is hard to convince and prove to people on the efficiency and effectiveness of their skill. Because of being underestimated, it prevents them from advancing and conforming to society.

Participants have shown their experience with being underestimated and how it affects them even if for some it came out of pity. As participant 1 pointed out that, while there are good intentions to cater to those with ASD such as giving easy parts in assignment, they did not properly consider the ramifications and consequences of such treatment on those with ASD.

*“...they deliberately give the introduction and conclusion, why? Because they do not want to give to certain groups to “break their heads” and to have a hard time to think... It is honestly dangerous...” (Participant 1)*

*“... Yes, I met these people a lot. They will say feel sorry for me as nobody wants to be as autism, but I always tell myself that I just leave them....” (Participant 3)*

*“...people do not understand autism and when they know I am autistic they will start to think that I can't do my job well...” (Participant 4)*



*“...Because in a way autistic people have to prove to others that they can do things. Because people don't trust in their abilities and what they can do....” (Participant 5)*

Educators showed up in a few of the participants' sentences on being underestimated. Exemplifying that even the people who are responsible for the education of those living with ASD can further hinder their progress in life and not understand their issues.

*“...teachers do not encourage me to take UPSR because she claims that I cannot answer...” (Participant 1)*

*“...Teachers don't understand as well... my son has autism and the headmistress was like why didn't you send him to sekolah khas?...The school didn't understand that although he can cope academically, he still has a lot of issues socially” (Participant 5)*

One can also see that social expectations such as trends and norms can be seen as difficult for those with ASD to conform to that some may find unnecessary, but they may be judged for not following it, and deemed as incapable or not normal for not doing so.

*“...people expect me to talk in a certain way, they think I'm less polite or something. It's tiring. I don't find it useful...” (Participant 2)*

*“...There's some trends or social norms that they think Autistic children are not capable in certain aspects, but everyone is the creation of beauty...” (Participant 3)*

*“...There are many more societal expectations like how these kids fit in the trends or needing a lot of friends, for me those unnecessary. It depends on what societal expectation is...” (Participant 4)*

Some participants gave insights on why some people and society have a lowered expectation on them which can be described as being seen as a lack of awareness of what ASD actually is, ranging from being seen as cognitively underdeveloped or a general confusion on how ASD works,

*“... When I was young, people are expecting autistic children are lacking some biological development and they can't do anything. So, they will have kind of perceptions on me that I can't do anything and easily getting frustrated...”*  
*(Participant 3)*

*“... society's view is that they expect people with ASD is very destructive, very active. Some people expect them to be very smart, but some people expect them to not be able to go to school. So yeah, that's what I have realized...” (Participant 5)*

**Barriers in working.** This theme refers to the difficulties that those with ASD find with working or executing their task, while also looking at how this difficulty affects how they effectively execute their task. Many of those with ASD who are working may find it hard to fulfill certain jobs. This can range from a lack of accommodation for employees with ASD to certain jobs being unsuited for those living with ASD. Leading to a difficulty in adapting to their work environment.

*“...it was just for a restaurant job... I think I just decided not to further pursue since they asked if I can be there for like really long in the day, like morning until close to night time...” (Participant 2)*

*“...Because I am the type of person who can do one thing at a time. Hence, certain jobs might not be suitable for me...” (Participant 4)*

*“... I’m already working. I struggle with executive functioning... Trying to start my project and things like that is what I think is really affecting me right now...” (Participant 5)*

Because of their condition, it affects how they want to do their work and prove to others that they have the capabilities to do something if given the chance. This difficulty affects how well they adapt to their work environment. As participant 4 addresses that because they could not adhere to Malaysian culture and society, it is hard to prove to others of his capabilities because of his unorthodox way of working.

*“... all I ask is to be given a chance to show your results but most of the times, with Malaysian’s rigid mentality we have in our culture and society, the chance isn’t given...” (Participant 4)*

Participant 5 have a similar view as in because of the condition affecting those with ASD and how they work, oftentimes those with ASD have to work twice as hard to prove their capability.

*“...So if they do something, they have to work twice as much as other people to just to prove that they can do it...” (Participant 5)*

**Barriers in employment.** This theme refers to the hardship that those with ASD face when finding employment. All 5 of the participants agreed that it is hard for those living with ASD to find employment either from personal experiences or from exposure to others with ASD. The difficulties can stem from competing with others, employers being unaccommodating or discriminatory, which lead to a low employment rate of those living with ASD and may cause those living with ASD to be too dependent on others.

One of the participants explained that no matter the form where the recruitment stems from, it is difficult for those with ASD to seek employment and it takes effort to get an opportunity to find work. Participant 1 shared his experience:

*“... we want to get completely secure the workplace is very hard because we in Malaysia millions of citizens that wants to apply as well...It does not matter if it is from the SBA, SPP and also from e-recruitment” (Participant 1)*

In a similar sense, they also tapped on their helplessness with the employment system for OKU adults in Malaysia, and how it adds an extra barrier for them in gaining employment.

*“Sometimes these things takes years to get an opportunity to work, however currently for the OKU group (including the ASD group), they are expected to take an exam for the public. Because before this, most of them, they are unlikely to maybe because of the system where they cannot use a screen reader and such. They must go through*

*PSEE, an exam to enter the public service. So when this are required, the group will be excluded.” (Participant 1)*

A participant provide their perspective that some employers may act discriminatory and may turn away from hiring someone if the employer knows that they have ASD leading to some to keep quiet that they have ASD. Participant 5 stated that:

*“...If we revealed that we have autism and then people don't want to hire us, it shows more about the employer than about me, really because their employer is being discriminative and things like that...” (Participant 5)*

Participants also provide a deeper insight as to why it is hard for them or others to be hired or stay in a job, ranging from personal boundaries to their own limitations. They explained their situation:

*“...I am very sensitive with others' sexual jokes or any other jokes that is beyond my boundaries, they start to discriminate, and I will leave them...” (Participant 3)*

*“... It is depending on the job scope. It will be depending on how they found their strengths and weaknesses, and to find a job in that area. But maybe on the lower end, like communication skills may be hard for them...” (Participant 4)*

Participant 5 points out that there is little government initiative to help those with ASD to acquire jobs, which as the participant claims is maybe the reason there is low

awareness and why employers are hesitant to hire those with ASD. He further explains how the difficulty of securing a job left individuals with ASD no choice but to depend on others.

*“...there’s little support from the government in encouraging employers to hire these people...” (Participant 5)*

**Barriers in education.** Refers to the difficulties those with ASD face when learning either in school or in universities. Many of the problems stem from the fact that the educators do not understand how to accommodate students with ASD leading to their grades being dropped due to ignorance. This can cause a problem of the difficulty of those with ASD pursuing their education.

Participant 1 clarifies that because of the possibility of ignorance and lack of awareness of his lecturer which led to the participant not being accommodated, their grade fell as a result.

*“...they may be like lack of advocacy or lack of empathy or lack of understanding some of the lecturer, so I got maybe an ‘F’...” (Participant 1)*

*“... I requested to go back home and study for a few weeks because I found that I can’t really study at school, but they didn’t let me to...” (Participant 4)*

The participants also observe that there is a lack of understanding from peers without ASD towards those with ASD. This problem is claimed to stem from schools not being inclusive and lack of awareness of what ASD is.

*“... Because during that group assignment or whatsoever sometimes I have face discrimination... Because they will do the exact part because they don't want to get my headache, do not want me to get tired, do not want to give me a chance...”*

*(Participant 1)*

A participant also said that online classes are challenging for those with ASD.

*“...Especially when it uses online learning, is really challenging because from what I understand in my opinion because some of those with autism, they prefer to have class physically when compared to online class...” (Participant 1)*

Furthermore, Participant 5 also mention on the school's lack of understanding on the multifaceted characteristics of ASD symptoms, and how they have to pay more attention towards their children's learning as a result.

*“The school didn't understand that although he can cope academically, he still has a lot of issues socially, so that's why we want to keep an extra eye on him...”*

They carry on with their frustration with the school system and policies in how they treat ASD students. This segregation of neurodivergent and neurotypical is created by the systematical barriers that hinder the interactions and familiarization with people who are different from them.

*“ So, when they don't learn together, they are being isolated from the moment that they enter school. How can we expect them to be accepted when they are older?”*

*(Participant 5)*

**Bullying.** Refers to the common experience of those with ASD faced against people who either try to seek harm or intimidate them. There is a concerning level of bullying that goes far as threatening them physically as well as affecting their mental health. While bullying such as insults are common, there are cases indicating that the bully act maliciously to the point of trying to ostracize them from their friends. There is a frequency in participants' experience of being bullied by their peers.

*“I am very careful with someone because of my experience which is very common with history of being bullied” (Participant 3)*

*“When I was back in school before, I was already being bullied by people even before primary school” (Participant 4)*

The extent of the bullying goes as far as physical threat and affecting their mental health, as participant 3 pointed out regarding his experience.

*“I used to be good with someone, but it turns into bullying. He confronts me by warning if I do anything with them and he is showing me a knife” (Participant 3)*

As well as participant 4 experience back in school where the bullying progress to the point where they went on a downward spiral of depression.



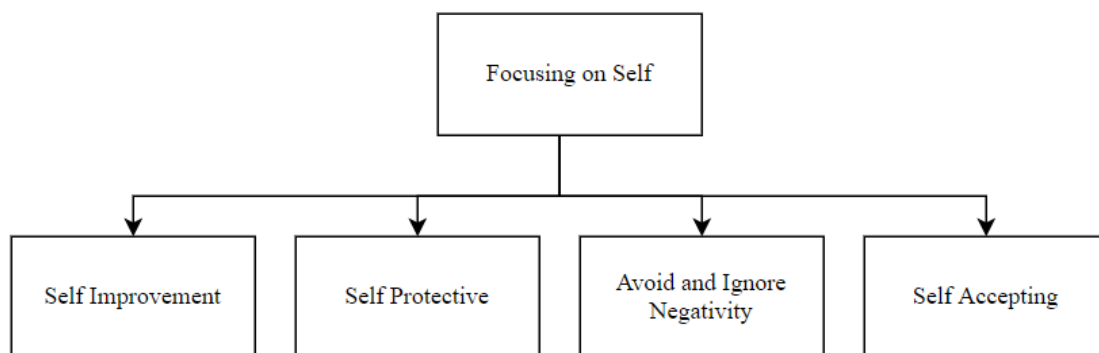
*“This went up to a point where I stopped studying and not wanting to be there. This developed into depression” (Participant 4)*

The experience that those with ASD encounters with the method of bullying ranges from insults to ostracizing them severely.

*“There are some autism kids if they get insulted then they will be quiet, so it’s like provoking to put it simply. It’s like bullying” (Participant 1)*

*“bullying got worse on a certain point where these people were controlling my friends by asking them to stay away from me and so, it started to affect my social life in that way” (Participant 4)*

### **Theme 3: Focusing on Self**



*Figure 4.4.* Theme 3: Focusing on Self and Sub themes

Theme 3 is addressed to RQ3. Some of the ASD individuals work on themselves as the most effective way in proving themselves to the public. They emphasize self-enhancement on their barriers while accepting symptoms or insufficiencies among

themselves. To cope with societal views that are unacceptable and affect them emotionally, ASD individuals use methods of avoidance and self-protection against negative perceptions and comments on them.

There is a pattern amongst the participants as they mature into adulthood then they start to focus on themselves more. From having problems within their lives, many of the participants try to cope by improving on themselves more, protect themselves from being discriminated against, avoid negativity and/or by accepting who they are. These methods lend themselves to how they deal with those who are discriminatory against them or by societal's perception.

**Self improvement.** Refers to how those with ASD strive and eventually finding themselves wanting to improve themselves more. There is an effort even through the difficulties they face that they focus on improving themselves more. Some of the participants have difficulties managing their symptoms but they keep pushing themselves to improve as they try to move forward.

*“...Sometimes it can be controlled, but in other times it cannot be controlled. But for myself, I have no problem because possibly these things ends quickly, so I understand. So as the saying goes, ‘Do not give up, we have to try to do new things’...”*

*(Participant 1)*

*“...I used to blame when I was young back then, but slowly I learn as much as I can to develop and improve myself...” (Participant 3)*

For some other of the participants, they would try to move on from societal pressure and focus on improving themselves as a functional human being.

*“...We cannot control how others are going to view on you but the thing that we can focus is how to focus on developing the self...” (Participant 3)*

*“...I don't need many friends, so it really depends on what the societal expectation is. If it's like getting a job or doing some volunteer work or being a functional human being, then yes of course I will...” (Participant 4)*

**Self Protective.** Refers to how those with ASD try to protect themselves and their rights. Some participants want to stand their ground when being threaten or confronted with discrimination. It is worth noting that for participants, they would normally avoid confrontations but they can stand up for themselves when their rights or boundaries are threatened.

*“...So I spoke with them, they actually have the right to do whatever they want either academically or curriculum...” (Participant 1)*

*“... He confronts me by warning if I do anything with them and he is showing me a knife. So that I mentioned, you know I am not doing anything wrong and if you do this, are you willing to take the risk...” (Participant 3)*

*“...Unless it's worth fighting, like for my rights and things like that. Then I will confront them...” (Participant 5)*

Participants also show that to protect themselves, they must set boundaries as one participant pointed.

*“...if I’m doing something to offend you, you will also get angry am I right? So, why are you crossing my line?...” (Participant 3)*

**Avoid and Ignore Negativity.** Refer to how those with ASD strive to avoid negativity to affect their life. This method is common in all of five of the participants in the study especially when confronted with discrimination and if the participants see that there is no way to change their mind.

*“...for me even when people insult me, I do not feel anything. I just act normally. I just simply ignore it...” (Participant 1)*

*“...just avoid them...” (Participant 2)*

*“...If they are willing to communicate and listen to you then it’s fine but if they’re not going to listen to you then just leave them...” (Participant 3)*

*“...I will just stay quiet or just go away because there’s no point. I guess that’s how I cope, I just don’t go with these people...” (Participant 4)*

*“...I don’t like confrontation. So during confrontation I was like, okay, okay, okay, bye. Just like that, I cannot do confrontations...” (Participant 5)*

For a few of the participants, they would dive deeper into the specific people and things that they would like to avoid.

*“...please avoid the negative side, like gossips, know-it-all, close minded, this person cannot this, negative thinker...” (Participant 1)*

*“...Those are the people then I tend to avoid because in the end even if I’m trying to explain to these people, it doesn’t work as they’re not there to understand you. They are just to judge you...” (Participant 4)*

**Self Accepting.** Refer to how those with ASD, even with their past and the troubles with their peers, try to accept themselves for what they can do and who they are despite what they have experienced during their life.

*“...eventhough I enter university late, but age is not a problem, these quotes I kept to my heart...” (Participant 1)*

*“...I need to accept it, not everyone will accept who you are but everyone is different...” (Participant 3)*

*“...I mean, no one is perceived when it comes to effects to my life. It just become part of my life now ... “ (Participant 4)*

*“And biggest one is don’t be in denial, because I realized some parents are in denial about their kid’s conditions.” (Participant 5)*

Some of the participants initially do not understand some of the difficulties and differences that they face are symptoms of ASD, but they eventually come to accept it.

*“...This is due to some misunderstanding because if I had understood that I am Autistic, I would have said and been given another way to do things...” (Participant 4)*

*“...for me, I just fell through the cracks and my parents did not realize that I was having issues, so for me I had to learn all these skills by myself...” (Participant 5)*

For participant 4, even with his frustration in his past, he comes to accept that it is a part of his life and try to work things out.

*“...It just become part of my life now. Everyone has a different character but we’re just trying to do it right. So, for me it’s just how I work things out...” (Participant 4)*

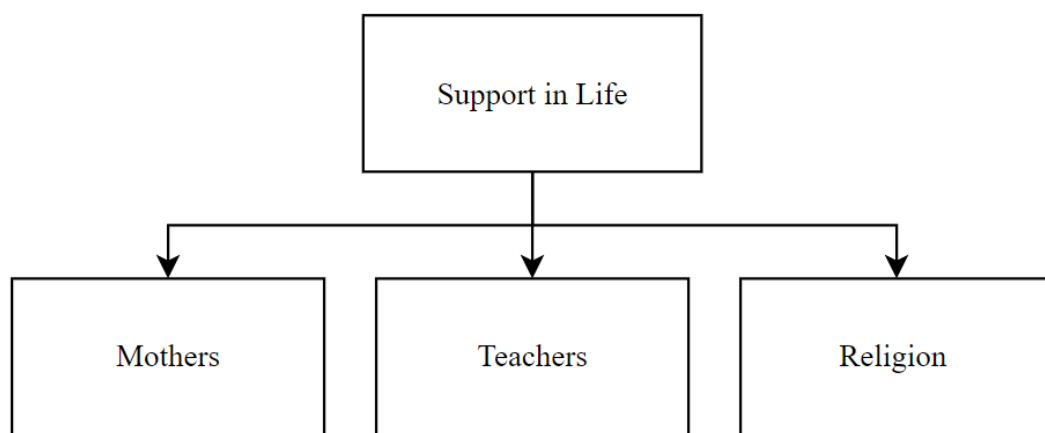
One of the participants would see criticism directed to them personally or related to their symptoms, but they would like to accept criticism as a way to improve themselves and to move forward.

*“...I made mistakes before by expressing aggressiveness to others. But then I realized I cannot be selfish, and people deserve to be safe as well, it’s not that easy but I have to keep going...” (Participant 3)*

One of the participants emphasized on being open and accepting publicly, in turn creating a positive environment for her and her children with ASD.

*“...I'm open about my children, so people around me are accepting of my children and other ASD children as well. And adults as well...” (Participant 5)*

#### ***Theme 4: Support in life***



*Figure 4.5.* Theme 4: Support in Life and Sub themes

Theme 4 is answering RQ3 as well. It indicates how and which aspect of social support impacts ASD individuals the most. In the view of ASD individuals, mothers and teachers are impacting them largely by providing necessary physical and social support throughout their time dealing and coping with their ASD symptoms. Religion is considered as an external support which creates motivation and encouragement throughout their life.

Throughout the journey experienced by participants living with ASD, despite the difficulties faced all along the time, support and assistance that they receive from community and people around were said to be effective for them to cope with difficulties and barriers met in daily life. Their emotional well-being is well increased with social support during or even before their diagnosis of ASD including mothers, teachers and religion.

**Mothers.** As per the participants, mothers had been reported as the most supportive one throughout their span with ASD. The ASD individuals mentioned that their mother's presence has been helpful and hopeful for them especially before and during their early diagnosis.

The below statements of our participants mention that their mother acts as an important role in providing physical care, emotional accompaniment, and psychological support throughout their lives.

*"... my mother motivates me when I was in school and in university, from a supportive, motivational, and compelling aspect." (Participant 1)*

*". She said that I am a gift to her when she passed away..." (Participant 3)*

*"... she's the one back then when I wanted to quit school and everyone was surprised. But my mother has been supportive from that." (Participant 4)*

*"Since then, until now, she's been supporting me and motivating me all the time. I wouldn't be here right now without her." (Participant 4)*

Their mom is acknowledged as a person who stays by the side of ASD individuals. Participant 3 mentioned that even before their formal diagnosis of ASD, their mother has been playing a role of dealing and coping with their symptoms such as aggressive action, frustrations, repeating behaviors, and others. Through their words, it is clear that they respect



and see their mother as a significant figure in their life, in which they are always there to help and talk to them.

*“She is a strong woman. Every time when I am frustrated or if I am going to do something which might hurts her, I am much impressed on how she deals with me. I am impressed with her patients of being a woman.” (Participant 3)*

*“...even if I called her early in the morning when I want to be frustrated and aggressive in my dorm in university. She is very patient and answer my call back then.” (Participant 3)*

*“... how my mom manages my temper and aggressiveness. I used to run around but my mom is so clever that she knows I like to draw and often bring paper and pen with her wherever she goes.” (Participant 3)*

*“My mom just used repetitive behavior with me on how to socialize...How to manage bad temper? How to manage bullies?” (Participant 3)*

**Teachers.** Teachers tend to bring a large impact to ASD individuals on their personality and behaviors, even persistent until their late life. Teachers also act as the first people who they interact with in society. Academic institutions are viewed as an important agent among society for ASD individuals especially when they're still adolescents during

school days. School is the place where they will be most of the time other than their home. Most of our participants agree that teachers act as a significant impact towards ASD lives.

As per Participant 5, she emphasizes on the importance of understanding teachers who know how to handle neurodivergent and neurotypical students simultaneously.

*“That’s really important because the kids will go to school and then the teachers will have to deal with the kids and educate other children, neurotypical children, those with no issues to accept the children.” (Participant 5)*

Participant 1 also agrees that lecturers have helped him significantly throughout his university life.

*“Because only these lecturers can be requested if they have free time. So, there are a lot of lecturers that helped me.” (Participant 1)*

One of the participants did mention that other than traditional school or special school for ASD children, KinderKaizen, where they can play and explore their skills throughout the process can be better and more comfortable for them. They can develop their skills well there and eventually affect their emotions and feelings, bring more self-confidence instead of sending them to traditional school to teachers, where they are forced to follow the rules and learn.

*“We send him to KinderKaizen, if you know, Kiderkaizen is a pure play center. So what he does everyday is he plays from morning to the afternoon, from 9am to 5pm,*

*he plays. After sending him there, within a few weeks from not talking at all, he started talking. You know, he is more responsive. He has more skills than just sitting at home.” (Participant 5)*

**Religion.** One of the participants has emphasized on the importance of religion to him. It plays as a sense of belief and faith to them, something that is always there for him other than any members in the society. It is virtually present but to the participant, it is physically present by his side whenever needed. It is said to be an important part of his life where it will not disappear and leave him alone. Other than a sense of belief, it eventually provides a sense of relief when he is dealing with society toughly. It has boosted their self-confidence, as they know their efforts are all well worth it and they deserve the equal rights as any others.

*“In the al-Quran it says that we are all good human beings, the best creation and human are beyond all limits and boundaries. All of us are the best creation of God and how should we lower down ourselves? If nobody is looking at you, remember the God is looking at you, your struggle and your patience. There will be those good times coming.” (Participant 3)*

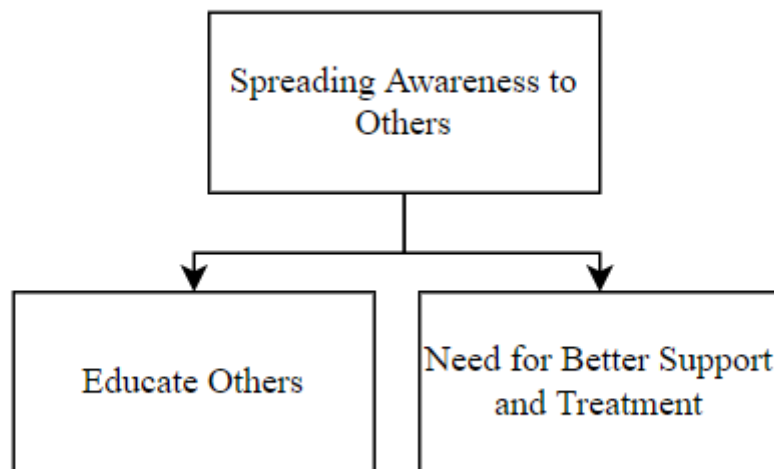
*Theme 5: Spreading awareness to others*

Figure 4.6. Theme 5: Spreading Awareness to Others and Sub themes

The last theme is well addressed to answer RQ3 on ways to cope with ASD by explaining how ASD individuals use their own effort to influence society's view on them while demanding for more support from the public towards the ASD community. Other than being willing to share their knowledge and experiences with the public who lack awareness of ASD, proper support and treatments are demanded by the ASD community for others who are in the same situation as them. These are to ensure that they will have sufficient resources in coping with ASD physically, psychologically and emotionally.

Even if ASD individuals face some perceptions and opinions by society, they are willing to contribute more to their community to benefit others who're in the same situation with them. They are hoping to be heard, listened to, and cared for by others in the society. It includes educating others and emphasizing on the need for better support and treatment.

**Educate others.** This sub theme explains how most participants stated that whenever they faced some discrimination, bias, or negative perception by others in the society, they are willing to share more knowledge and information of ASD with them. In a way it helps in

solving the public's doubt and misunderstanding on ASD and the community. They are providing proof, facts, or real-life experience so that the public can acknowledge accurate information on ASD.

As per Participant 5's words, they agree that it is important for others to be educated on this issue so that it is able to travel through word of mouth.

*"I think it's really important for the parents or, you know, people with ASD to talk about it and to educate people about ASD and so that the awareness keeps on increasing." (Participant 5)*

Other than that, Participant 1 mentioned that they will provide factual information in combating negative views towards ASD.

*"If they say negative things for example like things towards ASD or some other slangs, I will give them facts. Sometimes I will call these facts for example, does coke and vaccine cause autism? The answer is no. It does not cause autism, and with the problem of vaccination, these things do not cause autism." (Participant 1)*

They also mention their proactivity in holding talks in the goal of getting more people involved and educated on this issue.

*"I too have conducted a series of motivational talks at schools, IPT and programs that is established by ISEE, International Special Education Exhibition that is held*

*yearly. Where this platform is established to bring awareness or understanding to the groups involved, such as Autism whether in IPT, in schools and so on.” (Participant 1)*

Also, they mentioned when there's someone who is having lesser understanding of ASD groups, they might not understand what are their real needs and approach that best fit them. They play the role of helping others by spreading more information about ASD through his real life experience and insight.

*“Other than that, I also gave them insight on how to help these group of people when they board an airplane. In that I will give my briefing to the staff of AirAsia on how we need to handle these group of people, so that there will be a rise of problems during when they ride aboard a flight. ” (Participant 1)*

However, as most of the participants seem to avoid others who are having negative perceptions on them, they will normally share the information about ASD voluntarily when they feel the person's honesty and genuinity.

*“I would normally read this situation and if this person is being honest or he just really doesn't know. Even if he's being rude but he didn't understand it and he didn't mean it. I will then try to explain.” (Participant 4)*

*“For example, if they have a negative view, but they’re coming to us, they want to know something and to learn something new, that’s fine because they didn’t know about it.” (Participant 4)*

Participant 3 adds on that although they are willing to educate others, they do not tolerate and ignore people who are ignorant and not willing to learn.

*“If they are willing to communicate and listen to you then it’s fine but if they’re not going to listen to you then just leave them.” (Participant 3)*

**Need for better support and treatment.** This sub theme describes how ASD individuals claim that other than single-way effort from ASD individuals, the public, especially the government and health sector are urged to provide more and proper health support and treatments towards the ASD community.

Some physical and policy-related support by the public and government are to be established for the ASD community so that their welfare can be prioritized. It could help in reducing their stress and lower possibilities of having emotional burden due to some external and internal limitations. Additionally, it also provides the chance for ASD individuals for prove themselves to others, and overthrow the underestimation of ASD groups.

Participant 1 mentions that better support is needed from the media, and suggestions on how they should do so.

*“That is from the perspective of society, other than maybe the media need to focus on or gain more knowledge in order distribute more information, details or awareness for the group. Either from printed newspaper, electronic media or in official media such as BERNAMA, Jabatan Penerangan and so on. Maybe they can make a video in a way to help the group on how to correctly help them from a traditional means and through radio.” (Participant 1)*

They also add on regarding the relevant training that can be provided towards ASD groups, not only to spread awareness but also equip ASD individuals with the needed skills in life. This is supported by other participants as well, agreeing that ASD individuals will flourish with sufficient training.

*“... maybe the officials at the universities need to have DET (Disability Equality Training) periodically, not just for scholarship week but also maybe in any program, like once a month or once every semester in order to bring forth awareness.”*  
*(Participant 1)*

*“It just autistic individuals are different in some form but if they’re trained well, they can also manage to develop their skills as same as or even beyond normal people.”*  
*(Participant 3)*



*“If we can treat them well and provide treatments, we can do a lot of things that we can... To help in enabling them so that they can be functional people in society.”*

*(Participant 4)*

Participant 5 also mentions how schools can better support ASD students, by developing and upholding an inclusive school environment with no rejection towards special kids.

*“The biggest, biggest thing that I think really needs to happen is a no reject policy in schools. Because right now if you have ASD or you know hyperactive kids or whatever, it’s hard to get into schools.” (Participant 5)*

Participant 4 adds on how providing a better place for ASD groups are the responsibility of everyone, and not just the responsibility of ASD groups themselves.

*“I think it’s a job of us in society to be able to facilitate them and give them a place where they can maximize their strengths. That’s why we have MAHFAA for example and we have kids with us.” (Participant 4)*

## **Chapter V**

### **Discussion**

The current study aimed to understand the societal experiences of ASD individuals and its impact towards their quality of life, and how they cope with them. The information yielded from interviews are similar to those of past literature, with slight differences in between. Aligning with past research, ASD individuals face many challenges in their life, in aspects such as education, relationships and employment; as they have been isolated and misunderstood by others. Although these obstacles do impact their lives, they do not give up and submit themselves as weak and dependent. They emphasize focusing on the self and also have a positive attitude towards their lives, with the support of significant others, such as their parents and religion. In accordance with the significance of study, stress is put on spreading awareness regarding ASD, and how it would be beneficial towards ASD groups.

In addition, the findings presented in the current study are supported by our conceptual framework, that societal views do impact ASD individuals, which then in turn influences their quality of life. However, it is to note that societal views are not the only factor that impacts the quality of life of ASD individuals, but other factors such as their individual symptoms also come into play.

Three main groups of findings have been summarized to reflect each research question, including their social experiences mainly characterized as isolated; a poor quality of life due to local societal views; and a healthy and positive coping mechanism as their solution to the situation. Implications of the findings and limitations and recommendations will be discussed further in later sections of this chapter.

#### **Isolated**

In the experiences of ASD individuals, they characterize themselves as an outlier and different from others. This is in accordance with past findings, claiming that ASD individuals

tend to be lonely due to unsuccessful attempts at socializing and the various barriers in socializing as an ASD individual (Ee et al., 2019). Findings from the current study show that ASD individuals have a hard time socializing with others, mainly misunderstandings regarding their ASD symptoms, such as anger rumination and cognitive limitations. These ASD symptoms make it easy for others to misunderstand them during social interactions, and failed attempts at socializing may cause others to stray away from them, as they do not fit in the norm. This applies to our theoretical framework, the social model of disability; in which their limitations in socializing with others are influenced by the societal views of their symptoms, adding another barrier to their already difficult social experience. Additionally, the mental exhaustion originating from cognitive limitations may possibly lead to a decreased motivation in socializing with others, despite feelings of loneliness.

These findings link past studies with ASD individuals feeling stereotyped due to their ASD symptoms (Mazumder & Thompson-Hodgetts, 2019). However, in other studies, ASD individuals although score higher on the loneliness scale, show lesser social motivation in socializing. Their sources of loneliness seemed to originate from a lacking sense of belonging in society, a feeling that they are not welcome (Deckers et al., 2017). Although this low social motivation is correlated with living with family members as mentioned in the literature review, this situation is not apparent within the findings of the current study.

In another view, past studies suggest that individuals who are lower on the spectrum tend to characterize loneliness by describing they are isolated from society as a matter-of-fact, without the negative implication of them feeling lonely. However, in individuals who are high functioning, loneliness was described accurately, and that they felt sad and miserable when they were isolated by others (Merkler, 2007). The results of the current study align with this statement, as only high functioning ASD individuals participated and appeared sad and helpless when talking about the fact that they are lonely. It is also

observed that their affliction towards their loneliness is further increased when in actuality, they crave social relationships, but have given up on laying hope on others.

In addition, their isolation from others does not only originate from societal perceptions and misunderstandings regarding their ASD symptom, but also from the systematic barriers revolving around their life, in areas such as employment and education. These systematic barriers are characterized by policies and rules within society that make it harder for them to perform as well as others. Further details on the barriers will be discussed later, but it is brought up here due to the isolation they feel when they are systematically barricaded away from others, and how these systems actually unconsciously shape others in staying away from them.

### **Poor Quality of Life**

Our findings suggest that ASD individuals face poor quality of life, with multiple barriers throughout aspects of their life, including employment and work, education and being underestimated. This situation is similar with past findings in the literature review, that ASD individuals show a lower level of quality of life as compared to neurotypical people. It also answers the second research question, about the impact of societal views on ASD individuals.

Our findings also indicate that it is indeed hard for high functioning ASD individuals to seek and be employed, and that barriers in employment source from the discriminative perspective of employers towards ASD and the competition they face. This aligns with past literature on the employment rate for those with ASD, low and being overqualified for the position they are at (Chen et al., 2014).

Being overqualified for the position also aligns with our findings, in which the demographic information shows that most of our participants are actually highly educated with degrees and even doctorate certificates. However, three out of five of them are not

employed. Our findings also show that the replies that they get from companies are scarce and oftentimes not in line with their educational background. In a similar sense, this situation is also seen in schools, where high functioning ASD individuals are jumbled up together with all the other special kids in one class, where the learning speed and content is far below their optimal level of learning for their age.

Employers are one of the major reasons towards securing employment for ASD individuals. And findings that support this statement in the study aligns with previous surveys, that employers are hesitant to hire them. The specific reasons for their hesitancy is unclear within this study, but past literature suggests that it may be linked to the employer's concern on performance and their assumption on the performance of ASD employees (Nesbitt, 2000).

Other than that, another barrier faced during working is in regards to workplaces and employers who are not accommodating towards them, hindering their ability to perform to their full ability. This seems to stem from the employer's limited knowledge regarding ASD characteristics, leading to misunderstandings regarding how ASD individuals do tasks. This is shown in the school settings as well, where teachers are not educated on ASD and neglects the needs of ASD students as a result, based on the rationale that everyone should be able to perform the same.

Systematic barriers towards securing employment for ASD individuals have also been a frustration of ASD individuals, in a sense that they would have to take additional exams and tests to be qualified to seek employment in Malaysia. Similarly, the same situation is seen in school systems as well, who endorses inclusivity but actually unintentionally promotes segregation among ASD individuals and neurotypical people. This aligns with our theoretical framework, which is the social model of disability; in how ASD individuals are not

dependent solely due to their limitations, but also due to the systematic barriers unintentionally set up by society.

Findings also indicate that apart from barriers faced in life, ASD individuals also have a poor quality of life as they are often underestimated and bullied by others. As mentioned by past findings, bullying of others towards ASD individuals are positively correlated with dropping out of school and surrounding school life with refusal and negativity (Ochi et al., 2020). This compromises their education and mental well being, leading to a poorer quality of life. Additionally, this links back to their social experience of being isolated and bullied.

As opposed to past studies in the literature review, our results show that ASD individuals are not shameful and closeted about their ASD, potentially due to the fact that our data collected are from higher functioning ASD individuals. Findings show that their opinion towards this is that open discussions should be held to heighten awareness on ASD, and that they themselves should not be ashamed of their ASD to facilitate these discussions.

### **Healthy and Positive Coping Mechanisms**

The coping mechanisms identified throughout our data are as shown in theme three, four and five. Our findings present that they mainly cope through focusing on themselves and having a supportive figure in their life, whilst emphasizing on the need for better awareness on ASD among the public. Due to the higher functioning nature of our participants, they do not demonstrate any deficits in nonverbal communicative behaviors and repetitions in motor functions, hence the coping mechanisms discussed will be more on how they cope with negative societal views instead.

Although our participants have faced a period of poor quality of life, findings suggest that they are positive and optimistic towards life in general. Self accepting and protective attributes seem cultivated from the supportiveness of supporting figures in their life, such as parents and religion. Advice, acceptance and care from their mothers seem to grow and

reinforce their self worth and understand that it is nothing to be shameful of, whilst taking on the initiative to work on themselves. This leads to them viewing the same world in a different light, and talk about their past negative experiences as small issues. This strategy is in line with past findings regarding the management strategies used by ASD individuals to cope with stigma, mentioning that they will directly debunk negative comments made towards them and act as an advocate for the ASD group (Han et al., 2021).

It is to note that their coping mechanisms are learnt after experiencing negative social experiences, and it took a long journey for them to gain self acceptance. This situation may be avoided if professional help was provided early, which would have taught and reinforced their self acceptance, minimizing the doubts and blame that they put towards themselves. However, most of our participants were diagnosed at a later age, in their early or late twenties, which left their teenage years full of confusion and difficulties. It is important for parents to be more aware and attentive to the development and livelihood of their children and watch out for any signs of autism, so that these ASD individuals are able to receive the support they need as soon as possible.

### **Implications of the Current Research**

The research shed a light on how the societal views affect those with ASD in Malaysia such as our participants, findings such as isolation and a poor quality of life has been seen in the research as well as supported by past studies, however concerning participant's coping mechanism does not align with what was found in past studies. These contrasts and similarities in studies may give a unique perspective towards those with ASD. With the information given this will provide material that further the understanding of those with ASD. In turn, potentially helping in spreading awareness and empathy to the public as well as acknowledging the quality of lives of the ASD individuals, may improve and develop a better way to treat the quality of life of ASD individuals. Practical use of the research can

be used in campaigns and media that will invertedly shape our view of ASD, thus it may alleviate problems among the ASD communities such as unemployment and their health, be it mentally or physically.

Holding educational campaigns centered around knowledge of ASD to the masses will help in spreading awareness and normalizing by forming an accurate view of ASD to the public (Chambres et al., 2008; Samsudin et al., 2018). As this research has found, there are still many that isolate those with ASD and there is a poor quality of life among those with ASD as well. Acknowledging this will give a better understanding and empathy to the public. There is also a point to be made on those with ASD coping mechanisms. With this study, the perception that those with ASD are to be pitied and looked down on may be averted in favor of a more realistic portrayal of it. By correcting misconception and acknowledging the social ramifications towards ASD individuals in the campaign, it would reduce negative social stigma and isolation. Normalizing ASD in Malaysian can also help the problem of the collectivist culture in the country that has hampered ASD individuals in terms, such as alleviating the problem of isolation and stigmatization.

With the findings of the coping mechanism of ASD individuals, there is an argument to be made that society should push for more educational campaigns designed and held by those with ASD for ASD individuals. By this way, support may be found and those with ASD who found it hard to cope may find solace in others like them in similar situations on how to cope healthily and effectively. Many of the participants faced difficulty adapting in their childhood, by this initiative, they may find those similar to them that they can look up to or take as a role model, thus individuals may share their experience or coping abilities that may help other individuals living with ASD. Research indicates that those with ASD are effective in sharing information with one another, in contrast to when those with ASD and those without ASD share information (Crompton et al., 2020).



This research can also be used as a reference to provide accurate media portrayal of ASD. By accurately portraying how society influences ASD and how they cope, will give a more understanding towards those with ASD. It will raise the empathy of the public while also not pitying those with ASD as mentioned previously, thus not misleading or generalizing the life of those with ASD. With this, it will help shape how society views ASD (Low et al., 2021), thus normalizing and ridding it of stigma.

With this information as well as the possible implementation of the campaigns and portrayal, this can help in the employment of ASD. Accepting rather than isolating those purely based on their condition may reduce stigmatization, which in a research indicates that an inclusive culture in a company reflects a more positive experience (Griffiths et al., 2020). Thus, those with ASD may be more easily hired based on their merit rather than on their condition. On the bigger scale, mass acceptance of employment for ASD can help the country by all in large, by increasing the work force and diminishing the national burden. With this, it can give way for ASD to prove themselves and their potential.

By increasing and acknowledging the poor quality of life of those with ASD, there will be more discussion on the mental and physical health of these groups. Negative social views will be more acknowledged by the public and it's affected on ASD individuals that has given way to their depression and substance abuse rates. As research indicated, there is a positive relationship between quality of life and one's health (Grant et al., 2009). Thus, the deadly consequences of those factor that may contribute to suicide or crime may be also acknowledged and reduced.

The research holds an importance in knowledge and filling in the research gaps of ASD in Malaysia. This will help in increasing the research on the influence of societal views of ASD in the context of Malaysia, rather than what is more commonly conducted in America (Blaxill et al., 2021; Ganz, 2007; Maich & Belcher, 2014). This can give an opportunity to

explore the perspective of those with ASD in Malaysia and give those with ASD in Malaysia a voice to be heard. The research may also give a starting point for future research to be held in the Malaysian context in order to investigate the perspective of those with ASD or the societal views towards ASD.

In the end, the research would fulfill the sustainable development goals (SDG), namely the goal of reduced inequalities as well as the goal of good health and wellbeing. This research has the capability of doing its part in advancing the goals. Providing a way for those living with ASD to reduce the discrimination and inequality that society has put onto them as well uplifting their health and encourage their wellbeing. By reducing income growth inequality, equal participation and reducing discriminatory practices to those who are living with ASD by acknowledging and spreading awareness of ASD, it is possible to reach the SDG goal of reducing inequalities. Moreover, the suicidal rate of those living with ASD and the health effect of substance use due to negative social views may reach the SDG goal of good health and wellbeing. For that the future of those living with ASD may look more positive and with that, a finer and a more sustainable future for everyone.

### **Limitations and Recommendations**

The results found throughout the study brought us a rare glimpse into the social experiences of ASD individuals in its raw form, and brought into light the importance of spreading awareness and increasing knowledge regarding autism. Nonetheless, the results must be interpreted with caution and there are some limitations that should be borne in mind. The limitations include the narrow demographics of the sample population, homogeneousness of ASD functional levels and a single source of perspective.

#### ***Narrow Demographics of Sample Population***

First of all, the narrow characteristics of the sample results in difficulties of generalizing to all populations. All the samples are from the same race and state of residence,

which is from the prime invested state in Malaysia, Selangor. Participants are mostly males and are high functioning. Due to COVID-19 restrictions, samples can only be recruited via online which resulted in limited resource of sample. Other than that, all participants are from higher education and have experience of participating in society. Since participants are from urban areas which are exposed to higher job opportunities, education and medical healthcare systems, they might have a higher life satisfaction and better perception of societal views. As a result, the findings may be hard and improper to be generalized to all ASD individuals, as the result may vary due to many demographic variables, such as ethnicity, autism severity, age when they were diagnosed, the culture in their current state/town, etc.

Future research is suggested to obtain data and information from multiple states where different states in Malaysia possess different culture, lifestyle and resources availability, not to exclude different age range, gender, religion, and other characteristics. A wider scope of information will be acquired and would be better applicable towards the general Malaysia population. This wider set of data would be helpful in developing ASD awareness campaigns that would better apply to the people of all areas in Malaysia. On the other hand, they could also narrow their sample and go deeper in exploring the experiences of a certain niche population, for example recruiting ASD individuals with Level 2 or 3 of severity from a rural town in Penang.

### ***Homogeneousness of ASD Functional Levels***

As our participants are high-functioning ASD individuals with mild symptoms of ASD, they might possess better self-adaptation and coping skills than other ASD individuals. They might be better in masking themselves in adapting to the society and coping with different perceptions by accepting their real self, predicting higher life satisfaction and

quality of life as compared with others. In this case, the perception and views of our participants might not be suitable to represent everyone in the ASD community. Hence, the results might be difficult to generalize to other ASD individuals of different functional levels.

Therefore, future research is suggested to include ASD individuals from different functional levels, from level 1 to 3, to obtain a more comprehensive understanding of their experiences and to be better generalized to the overall population. Similar to the previous recommendation, researchers of future studies can also opt to narrow down their sample to only focus on one functional level, which would provide the public with a better understanding of how ASD individuals of different functional levels vary in their social experiences.

### ***Single Source of Perspective***

Although the research is focused on the societal view on ASD individuals, it only focuses on how ASD individuals perceive these societal views. Hence, it is said to be lacking perception from multidimensional agents in society. Throughout the research, only stands of ASD individuals can be obtained, to an extent where participants might prevent or avoid revealing truth or statement as an action of self-protection. When only one-sided perceptions are obtained, it might not be suitable to generalize their views into every individual in society. When it comes to employment issues which have been discussed in the research, employers might possess different attitudes and perspectives. The same goes to other individuals with normal functioning but not solely bias on ASD individuals.

Researchers are suggested to expand their data collection to be from people close to ASD individuals, such as family members, employers, etc. This would allow them to obtain diversified data, which would compare and contrast the different perspectives of the same

issue. Future studies can also opt for a convergent parallel approach, in which both qualitative and quantitative data are collected to provide multiple dimensions of information. By opting for a convergent research design, researchers would be able to achieve the best of both worlds, and be able to compare and contrast data within the same research.

### **Conclusion**

As in current society where people are living with low awareness of ASD which has been an important determinant in the quality of life of ASD individuals, it is important to understand how societal views impact an ASD individual in their daily life, while learning to cope with societal views in Malaysia. Results of the research shows that ASD individuals in Malaysia are having social barriers most of the time which results in their difficulties in adapting to the society due to different perceptions perceived by every ASD individual.

The social barriers mentioned have impacted ASD individuals as they claimed to have a significant decrease in quality of life where it mainly roots from difficulties in their education until career life, symptoms that cause them to be isolated from others in the society. In order to cope well with their barriers throughout their life, they have been working on themselves while spreading more awareness, mostly effort by themselves. It is surprisingly opposing previous studies that had emphasized on professional support and treatment towards ASD individuals.

The result of this study has shown that ASD individuals in Malaysia experience mostly negative experiences which impacts their quality of life. This has contributed to the Malaysian context by providing new findings that mostly focus on the self of ASD individuals, with proper and sufficient social support for further exploration in future studies. With better understanding on the demand of ASD individuals, more interventions and efforts

can be proposed and implemented to provide better and proper support for ASD communities.

### References

- Adnan, M. Y., Daud, M. N., Alias, A., & Razali, M. N. (2012). Importance of soft skills for graduates in the real estate programmes in Malaysia. *Journal of Surveying, Construction & Property*, 3(2), 1–13. <https://doi.org/10.22452/jscp.vol3no2.4>
- Alghazo, E. M., Dodeen, H., & Algaryouti, I. A. (2003). Attitudes of pre-service teachers towards persons with disabilities. *College Student Journal*, 37(4), 515–522.
- Anwar, M. S., Tahir, M., Nusrat, K., & Khan, M. R. (2018). Knowledge, awareness, and perceptions regarding autism among parents in Karachi, Pakistan. *Cureus*, 10(9), e3299. <https://doi.org/10.7759/cureus.3299>
- Arif, M. M., Niazy, A., Hassan, B., & Ahmed, F. (2013). Awareness of autism in primary school teachers. *Autism Research and Treatment*, 2013, 1–5. <https://doi.org/10.1155/2013/961595>
- Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos*, 38(1), 33–55. <https://doi.org/10.1111/j.1548-1352.2009.01080.x>
- Barned, N. E., Knapp, N. F., & Neuharth-Pritchett, S. (2011). Knowledge and attitudes of early childhood preservice teachers regarding the inclusion of children with autism spectrum disorder. *Journal of Early Childhood Teacher Education*, 32(4), 302–321. <https://doi.org/10.1080/10901027.2011.622235>
- Bennett, P., & Ouazad, A. (2020). Job displacement, unemployment, and crime: Evidence from danish microdata and reforms. *Journal of the European Economic Association*, 18(5), 2182–2220. <https://doi.org/10.1093/jeea/jvz054>
- Blaxill, M., Rogers, T., & Nevison, C. (2021). Autism tsunami: The impact of rising prevalence on the societal cost of autism in the United states. *Journal of Autism and Developmental Disorders*. Published. <https://doi.org/10.1007/s10803-021-05120-7>

- Botha, M., & Frost, D. M. (2020). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and mental health, 10*(1), 20-34. <https://doi.org/10.1177/2156869318804297>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brugge, D., Kole, A., Lu, W., & Must, A. (2005). Susceptibility of elderly Asian immigrants to persuasion with respect to participation in research. *Journal of Immigrant Health, 7*(2), 93–101. <https://doi.org/10.1007/s10903-005-2642-8>
- Cai, R. Y., Richdale, A. L., Uljarević, M., Dissanayake, C., & Samson, A. C. (2018). Emotion regulation in autism spectrum disorder: Where we are and where we need to go. *Autism Research, 11*(7), 962-978. <https://doi.org/10.1002/aur.1968>
- Chambres, P., Auxiette, C., Vansingle, C., & Gil, S. (2008). Adult attitudes toward behaviors of a six-year-old boy with autism. *Journal of Autism and Developmental Disorders, 38*(7), 1320–1327. <https://doi.org/10.1007/s10803-007-0519-5>
- Chen, J. L., Leader, G., Sung, C., & Leahy, M. (2014). Trends in employment for individuals with autism spectrum disorder: A review of the research literature. *Review Journal of Autism and Developmental Disorders, 2*(2), 115–127. <https://doi.org/10.1007/s40489-014-0041-6>
- Chenevier, R., Piper, A. T., & Willis, C. (2021). Migration, crime and life satisfaction in Chile: Pre and post-migration evidence.
- Chu, S. Y., Lee, J., Wong, Y. Y., Gan, C. H., Fierro, V., & Hersh, D. (2021). Knowledge mediates attitude in autism spectrum disorders? Data from Malaysia. *International Journal of Developmental Disabilities, 1–10*. <https://doi.org/10.1080/20473869.2021.1975254>



- Clark, M., Brown, R., & Karrapaya, R. (2012). An initial look at the quality of life of Malaysian families that include children with disabilities. *Journal of Intellectual Disability Research*, 56, 45–60. <https://doi.org/10.1111/j.1365-2788.2011.01408.x>
- Cohen, S. R., & Miguel, J. (2018). Amor and social stigma: ASD beliefs among immigrant Mexican parents. *Journal of Autism and Developmental Disorders*, 48(6), 1995–2009. <https://doi.org/10.1007/s10803-017-3457-x>
- Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. *Autism*, 24(7), 1704–1712. <https://doi.org/10.1177/1362361320919286>
- Daley, T. C. (2004). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science & Medicine*, 58(7), 1323–1335. [https://doi.org/10.1016/s0277-9536\(03\)00330-7](https://doi.org/10.1016/s0277-9536(03)00330-7)
- Dardennes, R. M., al Anbar, N. N., Prado-Netto, A., Kaye, K., Contejean, Y., & al Anbar, N. N. (2011). Treating the cause of illness rather than the symptoms: Parental causal beliefs and treatment choices in autism spectrum disorder. *Research in Developmental Disabilities*, 32(3), 1137–1146. <https://doi.org/10.1016/j.ridd.2011.01.010>
- Davis, J. J. (2002). Disenfranchising the disabled: The inaccessibility of Internet-based health information. *Journal of Health Communication*, 7(4), 355–367. <https://doi.org/10.1080/10810730290001701>
- Deckers, A., Muris, P., & Roelofs, J. (2017). Being on your own or feeling lonely? Loneliness and other social variables in youths with autism spectrum disorders. *Child Psychiatry & Human Development*, 48(5), 828–839. <https://doi.org/10.1007/s10578-016-0707-7>
- Diener E. (2000). Subjective well-being. The science of happiness and a proposal for a national index. *The American psychologist*, 55(1), 34–43. <https://doi.org/10.1037/0003-066X.55.1.34>

- Donalek, J. G. (2004). Demystifying nursing research: Phenomenology as a qualitative research method. *Urologic Nursing*, *24*(6), 515–517.  
<https://europepmc.org/article/med/15658739>
- Draaisma, D. (2009). Stereotypes of autism. *Philosophical Transactions of the Royal Society B: Biological Sciences*, *364*(1522), 1475–1480.  
<https://doi.org/10.1098/rstb.2008.0324>
- Ee, D., Hwang, Y. I., Reppermund, S., Srasuebkul, P., Trollor, J. N., Foley, K. R., & Arnold, S. R. (2019). Loneliness in adults on the autism spectrum. *Autism in Adulthood*, *1*(3), 182–193. <https://doi.org/10.1089/aut.2018.0038>
- Elder, J. H. (1994). Beliefs held by parents of autistic children. *Journal of Child and Adolescent Psychiatric Nursing*, *7*(1), 9–16.  
<https://doi.org/10.1111/j.1744-6171.1994.tb00184.x>
- Faulkner, S. L., & Trotter, S. P. (2017). Data saturation. *The International Encyclopedia of Communication Research Methods*, 1–2.  
<https://doi.org/10.1002/9781118901731.iecrm0060>
- Flood, L. N., Bulgrin, A., & Morgan, B. L. (2012). Piecing together the puzzle: Development of the societal attitudes towards autism (SATA) scale. *Journal of Research in Special Educational Needs*, *13*(2), 121–128.  
<https://doi.org/10.1111/j.1471-3802.2011.01224.x>
- Forero, R., Nahidi, S., de Costa, J., Mohsin, M., Fitzgerald, G., Gibson, N., McCarthy, S., & Aboagye-Sarfo, P. (2018). Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. *BMC Health Services Research*, *18*(1).  
<https://doi.org/10.1186/s12913-018-2915-2>
- Fox, F., Aabe, N., Turner, K., Redwood, S., & Rai, D. (2016). “It was like walking without knowing where I was going”: A qualitative study of autism in a UK Somali migrant

- community. *Journal of Autism and Developmental Disorders*, 47(2), 305–315.  
<https://doi.org/10.1007/s10803-016-2952-9>
- Franke, K. B., Hills, K., Huebner, E. S., & Flory, K. (2019). Life satisfaction in adolescents with autism spectrum disorder. *Journal of autism and developmental disorders*, 49(3), 1205-1218. <https://doi.org/10.1007/s10803-018-3822-4>
- Furlong, M. J., You, S., Renshaw, T. L., Smith, D. C., & O'Malley, M. D. (2013). Preliminary development and validation of the social and emotional health survey for secondary school students. *Social Indicators Research*, 117(3), 1011–1032.  
<https://doi.org/10.1007/s11205-013-0373-0>
- Fusch, P., & Ness, L. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20, 1408–1416. <https://doi.org/10.46743/2160-3715/2015.2281>
- Gabel, S. (2004). South asian Indian cultural orientations toward mental retardation. *Mental Retardation*, 42(1), 12–25. [https://doi.org/10.1352/0047-6765\(2004\)42](https://doi.org/10.1352/0047-6765(2004)42)
- Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics & Adolescent Medicine*, 161(4), 343–349.  
<https://doi.org/10.1001/archpedi.161.4.343>
- Garner, A., Jones, S., & Harwood, V. (2015). Authentic representations or stereotyped ‘Outliers’: Using the CARS2 to assess film portrayals of autism spectrum disorders. *International Journal of Culture and Mental Health*, 8(4), 414–425.  
<https://doi.org/10.1080/17542863.2015.1041993>
- Goal 3 | *ensure healthy lives and promote well-being for all at all ages*. (n.d.). United Nations. <https://sdgs.un.org/goals/goal3>
- Golafshani, N. (2015). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8(4), 597–607. <https://doi.org/10.46743/2160-3715/2003.1870>

- Graffam, J., Smith, K., Shinkfield, A., & Polzin, U. (2002). Employer benefits and costs of employing a person with a disability. *Journal of Vocational Rehabilitation, 17*(4), 251–263.
- Grant, N., Wardle, J., & Steptoe, A. (2009). The relationship between life satisfaction and health behavior: A cross-cultural analysis of young adults. *International Journal of Behavioral Medicine, 16*(3), 259–268. <https://doi.org/10.1007/s12529-009-9032-x>
- Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness, 15*(1), 102–120. <https://doi.org/10.1111/1467-9566.ep11343802>
- Gray, D. E. (1994). Lay conceptions of autism: Parents' explanatory models. *Medical Anthropology, 16*(1–4), 99–118. <https://doi.org/10.1080/01459740.1994.9966111>
- Gray, D. E. (2002). “Everybody just freezes. Everybody is just embarrassed”: Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness, 24*(6), 734–749. <https://doi.org/10.1111/1467-9566.00316>
- Griffiths, A. J., Hanson, A. H., Giannantonio, C. M., Mathur, S. K., Hyde, K., & Linstead, E. (2020). Developing Employment Environments Where Individuals with ASD Thrive: Using Machine Learning to Explore Employer Policies and Practices. *Brain sciences, 10*(9), 632. <https://doi.org/10.3390/brainsci10090632>
- Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLOS ONE, 15*(5). <https://doi.org/10.1371/journal.pone.0232076>
- Han, E., Scior, K., Avramides, K., & Crane, L. (2021). A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Research, 15*(1), 12–26. <https://doi.org/10.1002/aur.2652>

- Hernandez, B., Keys, C., & Balcazar, F. (2000). Employer attitudes toward workers with disabilities and their ADA employment rights: A literature review. *Journal of Rehabilitation, 66*(4), 4–16.
- Hodges, H., Fealko, C., & Soares, N. (2020). Autism spectrum disorder: Definition, epidemiology, causes, and clinical evaluation. *Translational pediatrics, 9*(Suppl 1), S55–S65. <https://doi.org/10.21037/tp.2019.09.09>
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). “Putting on my best normal”: Social camouflaging in adults with autism spectrum conditions. *Journal of autism and developmental disorders, 47*(8), 2519-2534. <https://doi.org/10.1007/s10803-017-3166-5>
- Hülür, G., Heckhausen, J., Hoppmann, C. A., Infurna, F. J., Wagner, G. G., Ram, N., & Gerstorf, D. (2017). Levels of and changes in life satisfaction predict mortality hazards: Disentangling the role of physical health, perceived control, and social orientation. *Psychology and aging, 32*(6), 507. <https://doi.org/10.1037/pag0000187>
- Huws, J. C., & Jones, R. S. P. (2011). Missing voices: Representations of autism in British newspapers, 1999–2008. *British Journal of Learning Disabilities, 39*(2), 98–104. <https://doi.org/10.1111/j.1468-3156.2010.00624.x>
- Hwang, S. K., & Charnley, H. (2010). Making the familiar strange and making the strange familiar: Understanding Korean children’s experiences of living with an autistic sibling. *Disability & Society, 25*(5), 579–592. <https://doi.org/10.1080/09687599.2010.489305>
- Ibrahim, N. H. M., Rahman, P., & Dahlan, A. (2021). Parent’s experience on employment issues faced by young adult with autism spectrum disorder (ASD). *Malaysian Journal of Medicine and Health Sciences, 17*(SUPP 3), 75–83.

- Ilias, K., Cornish, K., Park, M. S. A., Toran, H., & Golden, K. J. (2019). Risk and resilience among mothers and fathers of primary school age children with ASD in Malaysia: A qualitative constructive grounded theory approach. *Frontiers in Psychology, 9*(2275), 1–20. <https://doi.org/10.3389/fpsyg.2018.02275>
- Ilias, K., Liaw, J. H. J., Cornish, K., Park, M. S. A., & Golden, K. J. (2016). Well Being of mothers of children with “A-U-T-I-S-M” in Malaysia: An interpretative phenomenological analysis study. *Journal of Intellectual & Developmental Disability, 42*(1), 74–89. <https://doi.org/10.3109/13668250.2016.1196657>
- Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on Autism and Other Developmental Disabilities, 25*(2), 98–109. <https://doi.org/10.1177/1088357610361344>
- Jehan, I., Ayub, A., Naeem, B., Ahmed, W., Srichand, S., Aziz, K., Abro, B., Najam, S., Murtaza, D., Janjua, A., & Ali, S. (2017). Knowledge and perception regarding autism among primary school teachers: A cross-sectional survey from Pakistan, South Asia. *Indian Journal of Community Medicine, 42*(3), 177. [https://doi.org/10.4103/ijcm.ijcm\\_121\\_16](https://doi.org/10.4103/ijcm.ijcm_121_16)
- Jenkinson, C. (2020). Quality of life. *Encyclopedia Britannica*. <https://www.britannica.com/topic/quality-of-life>
- Jones, S. C., & Harwood, V. (2009). Representations of autism in Australian print media. *Disability & Society, 24*(1), 5–18. <https://doi.org/10.1080/09687590802535345>
- Joormann, J., & Stanton, C. H. (2016). Examining emotion regulation in depression: A review and future directions. *Behaviour research and therapy, 86*, 35-49. <https://doi.org/10.1016/j.brat.2016.07.007>

- Ju, S., Roberts, E., & Zhang, D. (2013). Employer attitudes toward workers with disabilities: A review of research in the past decade. *Journal of Vocational Rehabilitation, 38*(2), 113–123. <https://doi.org/10.3233/jvr-130625>
- Kahana, E., Lee, J. E., Kahana, J., Goler, T., Kahana, B., Shick, S., ... & Barnes, K. (2015). Childhood autism and proactive family coping: Intergenerational perspectives. *Journal of Intergenerational Relationships, 13*(2), 150-166. <https://doi.org/10.1080/15350770.2015.1026759>
- Keshavarz, S., & Baharudin, R. (2009). Parenting style in a collectivist cultures of Malaysia. *European Journal of Social Sciences, 10*(1), 66–73.
- King, N. (2004). Using templates in the thematic analysis of text. *Essential Guide to Qualitative Methods in Organizational Research, 256–270*. <https://doi.org/10.4135/9781446280119.n21>
- Kølves, K., Fitzgerald, C., Nordentoft, M., Wood, S. J., & Erlangsen, A. (2021). Assessment of suicidal behaviors among individuals with autism spectrum disorder in denmark. *JAMA Network Open, 4*(1), e2033565. <https://doi.org/10.1001/jamanetworkopen.2020.33565>
- Kowalewska, B., Cybulski, M., Jankowiak, B., & Krajewska-Kułak, E. (2020). Acceptance of illness, satisfaction with life, sense of stigmatization, and quality of life among people with psoriasis: a cross-sectional study. *Dermatology and therapy, 10*(3), 413. <https://doi.org/10.1007/s13555-020-00368-w>
- Kwan, C., Gitimoghaddam, M., & Collet, J. P. (2020). Effects of social isolation and loneliness in children with neurodevelopmental disabilities: A scoping review. *Brain sciences, 10*(11), 786. <https://doi.org/10.3390/brainsci10110786>

- Lawson, W. B. (2020). Adaptive morphing and coping with social threat in autism: An autistic perspective. *Journal of Intellectual Disability-Diagnosis and Treatment*, 8(3), 519-526. <https://doi.org/10.6000/2292-2598.2020.08.03.29>
- Lincoln, Y. S., & Guba, E. (1985). *Naturalistic inquiry* (1st ed.). SAGE Publications.
- Lombard, M., Snyder-Duch, J., & Bracken, C. C. (2002). Content analysis in mass communication: Assessment and reporting of intercoder reliability. *Human Communication Research*, 28(4), 587–604. <https://doi.org/10.1111/j.1468-2958.2002.tb00826.x>
- Lombardo, P., Jones, W., Wang, L., Shen, X., & Goldner, E. M. (2018). The fundamental association between mental health and life satisfaction: results from successive waves of a Canadian national survey. *BMC Public Health*, 18(1), 1-9. <https://doi.org/10.1186/s12889-018-5235-x>
- Low, M. H., Lay, W. L., Che Ahmad, A., Ghazali, E. E., Phaik, K. T., & Sien, A. S. L. (2021). A survey of lay knowledge of autism spectrum disorder in Malaysia. *Jurnal Sains Kesihatan Malaysia*, 19(01), 49–57. <https://doi.org/10.17576/jskm-2021-1901-06>
- Low, H. M., Lee, L. W., & Che Ahmad, A. (2019). Knowledge and attitudes of special education teachers towards the inclusion of students with autism spectrum disorder. *International Journal of Disability, Development and Education*, 67(5), 497–514. <https://doi.org/10.1080/1034912x.2019.1626005>
- Low, H. M., & Zailan, F. (2016). Medical students' perceptions, awareness, societal attitudes and knowledge of autism spectrum disorder: An exploratory study in Malaysia. *International Journal of Developmental Disabilities*, 64(2), 86–95. <https://doi.org/10.1080/20473869.2016.1264663>



- Maich, K., & Belcher, C. (2014). Autism spectrum disorders in popular media: Storied reflections of societal views. *Brock Education Journal*, *23*(2), 97–115.  
<https://doi.org/10.26522/brocked.v23i2.311>
- Majin, M., Hashmi, S. I., & Sombuling, A. (2017). Teachers' knowledge and perception towards children with autism spectrum disorder (asd): A preliminary study. *Prosiding Simposium Psikologi Dan Kesehatan Sosial-I*. Published.  
<https://conferences.cseap.edu.my/spksi2017/>
- Mak, W. W., & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine*, *70*(12), 2045–2051. <https://doi.org/10.1016/j.socscimed.2010.02.023>
- Margetts, J. K., Le Couteur, A., & Croom, S. (2006). Families in a state of flux: The experience of grandparents in autism spectrum disorder. *Child: Care, Health and Development*, *32*(5), 565–574. <https://doi.org/10.1111/j.1365-2214.2006.00671.x>
- Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *The British Journal of Development Disabilities*, *52*(102), 19–28.  
<https://doi.org/10.1179/096979506799103659>
- Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism research: Official journal of the International Society for Autism Research*, *11*(8), 1138–1147.  
<https://doi.org/10.1002/aur.1965>
- Mazumder, R., & Thompson-Hodgetts, S. (2019). Stigmatization of children and adolescents with autism spectrum disorders and their families: A scoping study. *Review Journal of Autism and Developmental Disorders*, *6*(1), 96–107.  
<https://doi.org/10.1007/s40489-018-00156-5>

- Mercer, L., Creighton, S., Holden, J. J. A., & Lewis, M. E. S. (2006). Parental perspectives on the causes of an autism spectrum disorder in their children. *Journal of Genetic Counseling, 15*(1), 41–50. <https://doi.org/10.1007/s10897-005-9002-7>
- Merkler, E. E. (2007). *The experience of isolation and loneliness in young adults with high-functioning autism* (Phd Dissertation). Carolina Digital Repository. <https://doi.org/10.17615/a0qj-dx59>
- Mohamed Nur Adli, K., Thurgaa, R., Beulah Devakirubai, G., Fatimah Zahidah, F., Luqmanul Hakim, Z., Muhammad Ikram, H., Geetha, S., Siti Amira, J., & Sabariah, A. H. (2017). The knowledge and attitude of autism among community in mukim Dengkil, Sepang, Selangor. *International Journal of Scientific and Research Publications, 7*(2), 220–225. <http://ijsrp.org/>
- Morales-Vives, F., & Dueñas, J. M. (2018). Predicting suicidal ideation in adolescent boys and girls: the role of psychological maturity, personality traits, depression and life satisfaction. *The Spanish journal of psychology, 21*. <https://doi.org/10.1017/sjp.2018.12>
- Moss, P., Eirinaki, V., Savage, S., & Howlin, P. (2019). Growing older with autism – the experiences of adult siblings of individuals with autism. *Research in Autism Spectrum Disorders, 63*, 42–51. <https://doi.org/10.1016/j.rasd.2018.10.005>
- Moss, P., Howlin, P., Savage, S., Bolton, P., & Rutter, M. (2015). Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study. *Autism, 19*(7), 832–841. <https://doi.org/10.1177/1362361315585916>
- Myers, S. M., & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics, 120*(5), 1162-1182. <https://doi.org/10.1542/peds.2007-2362>
- National autism society in Malaysia (NASOM). (2014). NASOM. <https://www.nasom.org.my/>

- Neik, T., Lee, L.W., Low, H.M., Chia, N.K., & Chua, A.C. (2014). Prevalence, diagnosis, treatment and research on autism spectrum disorders (ASD) in Singapore and Malaysia. *International journal of special education*, 29, 82-92.
- Nesbitt, S. (2000). Why and why not? Factors influencing employment for individuals with asperger syndrome. *Autism*, 4(4), 357–369.  
<https://doi.org/10.1177/1362361300004004002>
- Nguyen, W., Ownsworth, T., Nicol, C., & Zimmerman, D. (2020). How I see and feel about myself: Domain-specific self-concept and self-esteem in autistic adults. *Frontiers in Psychology*, 11. <https://doi.org/10.3389/fpsyg.2020.00913>
- Ochi, M., Kawabe, K., Ochi, S., Miyama, T., Horiuchi, F., & Ueno, S. I. (2020). School refusal and bullying in children with autism spectrum disorder. *Child and Adolescent Psychiatry and Mental Health*, 14(1). <https://doi.org/10.1186/s13034-020-00325-7>
- O'Connor, C., & Joffe, H. (2020). Intercoder reliability in qualitative research: Debates and practical guidelines. *International Journal of Qualitative Methods*, 19, 160940691989922. <https://doi.org/10.1177/1609406919899220>
- O'Kane, Caitlin (2019, June 4) Family outraged after boy with autism receives "Most Annoying" student award from school. *CBS News*.  
<https://www.cbsnews.com/news/indiana-boy-with-autism-receives-most-annoying-student-award-from-school>
- Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with Autism Spectrum Disorder. *Work*, 56(2), 345-355. <https://doi.org/10.3233/WOR-172492>
- Oliver, M., & Barnes, C. (2012). *The new politics of disablement* (Second Edition, Revised ed.). Palgrave Macmillan.

- Omar, H., Hussin, Z., & Siraj, S. (2013). Teaching approach for autism students: A case in Malaysia. *Procedia - Social and Behavioral Sciences*, *106*, 2552–2561.  
<https://doi.org/10.1016/j.sbspro.2013.12.293>
- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*(11), 2710–2719.  
<https://doi.org/10.1007/s10803-013-1833-8>
- Papadopoulos, C., Foster, J., & Caldwell, K. (2012). ‘Individualism-Collectivism’ as an explanatory device for mental illness stigma. *Community Mental Health Journal*, *49*(3), 270–280. <https://doi.org/10.1007/s10597-012-9534-x>
- Park, S. Y., Glidden, L. M., & Shin, J. Y. (2010). Structural and functional aspects of social support for mothers of children with and without cognitive delays in Vietnam. *Journal of Applied Research in Intellectual Disabilities*, *23*(1), 38–51.  
<https://doi.org/10.1111/j.1468-3148.2009.00550.x>
- Penn, D. L., Kohlmaier, J. R., & Corrigan, P. W. (2000). Interpersonal factors contributing to the stigma of schizophrenia: social skills, perceived attractiveness, and symptoms. *Schizophrenia Research*, *45*(1–2), 37–45.  
[https://doi.org/10.1016/s0920-9964\(99\)00213-3](https://doi.org/10.1016/s0920-9964(99)00213-3)
- Petalas, M. A., Hastings, R. P., Nash, S., Reilly, D., & Dowey, A. (2012). The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, *37*(4), 303–314.  
<https://doi.org/10.3109/13668250.2012.734603>
- Pouw, L. B., Rieffe, C., Stockmann, L., & Gadov, K. D. (2013). The link between emotion regulation, social functioning, and depression in boys with ASD. *Research in Autism Spectrum Disorders*, *7*(4), 549–556. <https://doi.org/10.1016/j.rasd.2013.01.002>

- Ramli, S. F., Firdaus, M., Uzair, H., Khairi, M., & Zharif, A. (2018). Prediction of the unemployment rate in Malaysia. *International Journal of Modern Trends in Social Sciences*, *1*(4), 38-44.
- Ravindran, N., & Myers, B. J. (2012). Beliefs and practices regarding autism in Indian families now settled abroad. *Focus on Autism and Other Developmental Disabilities*, *28*(1), 44–53. <https://doi.org/10.1177/1088357612458970>
- Ray, L., & Hinnant, A. (2009). Media representation of mental disorders: A study of ADD and ADHD coverage in magazines from 1985 to 2008. *Journal of Magazine Media*, *11*(1). <https://doi.org/10.1353/jmm.2009.0004>
- Riany, Y. E., Cuskelly, M., & Meredith, P. (2016). Cultural beliefs about autism in Indonesia. *International Journal of Disability, Development and Education*, *63*(6), 623–640. <https://doi.org/10.1080/1034912x.2016.1142069>
- Riany, Y. E., Cuskelly, M., & Meredith, P. (2017). Parenting style and Parent–Child relationship: A comparative study of Indonesian parents of children with and without autism spectrum disorder (ASD). *Journal of Child and Family Studies*, *26*(12), 3559–3571. <https://doi.org/10.1007/s10826-017-0840-3>
- Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, *33*(4), 383–394. <https://doi.org/10.1023/a:1025006727395>
- Rodríguez, I. R., Saldaña, D., & Moreno, F. J. (2012). Support, inclusion, and special education teachers' attitudes toward the education of students with autism spectrum disorders. *Autism Research and Treatment*, *2012*, 1–8. <https://doi.org/10.1155/2012/259468>
- Rosa, S. D. R. (2018, February 26). *Why is the autistic unemployment rate so high? Thinking person's guide to autism.*

<http://www.thinkingautismguide.com/2018/02/why-is-autistic-unemployment-rate-so.html>

- Sæther, S. M. M., Knapstad, M., Askeland, K. G., & Skogen, J. C. (2019). Alcohol consumption, life satisfaction and mental health among Norwegian college and university students. *Addictive behaviors reports, 10*, 100216.  
<https://doi.org/10.1016/j.abrep.2019.100216>
- Sage, K. D., & Jegatheesan, B. (2010). Perceptions of siblings with autism and relationships with them: European American and Asian American siblings draw and tell. *Journal of Intellectual & Developmental Disability, 35*(2), 92–103.  
<https://doi.org/10.3109/13668251003712788>
- Samadi, S. A. (2020). Parental beliefs and feelings about autism spectrum disorder in Iran. *International Journal of Environmental Research and Public Health, 17*(3), 828.  
<https://doi.org/10.3390/ijerph17030828>
- Samsudin, J. B., Noor, N. B. M., & Salleh, N. B. M. (2018). Attitudes towards autism spectrum disorder in urban area in Malaysia. *International Journal for Studies on Children, Women, Elderly And Disabled, 5*, 216–220.
- Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on Thin Slice Judgments. *Scientific Reports, 7*(1). <https://doi.org/10.1038/srep40700>
- Schmidt, L., Kirchner, J., Strunz, S., Brożus, J., Ritter, K., Roepke, S., & Dziobek, I. (2015). Psychosocial functioning and life satisfaction in adults with autism spectrum disorder without intellectual impairment. *Journal of Clinical Psychology, 71*(12), 1259–1268.  
<https://doi.org/10.1002/jclp.22225>
- Scott, M., Jacob, A., Hendrie, D., Parsons, R., Girdler, S., Falkmer, T., & Falkmer, M. (2017). Employers' perception of the costs and the benefits of hiring individuals with autism

spectrum disorder in open employment in Australia. *PLOS ONE*, 12(5), e0177607.

<https://doi.org/10.1371/journal.pone.0177607>

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L.

(2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129(6), 1042-1049.

<https://doi.org/10.1542/peds.2011-2864>

Shukor, S. A., Tajudin, A. A., & Baharuddin, A. S. (2021, April). *Legal perspectives of mental illness among children in Malaysia: A critical review*. International Conference On Syariah & Law 2021 (ICONSYAL 2021).

Sitimim, S. A., Fikry, A., Ismail, Z., & Hussein, N. (2017). Work-family conflict among working parents of children with autism in Malaysia. *Procedia Computer Science*, 105, 345–352. <https://doi.org/10.1016/j.procs.2017.01.232>

Skinner, D., Bailey, D. B., Correa, V., & Rodriguez, P. (1999). Narrating self and disability: Latino mothers' construction of identities vis-à-vis their child with special needs. *Exceptional Children*, 65(4), 481–495. <https://doi.org/10.1177/001440299906500404>

South, M., Costa, A. P., & McMorris, C. (2021). Death by suicide among people with autism: Beyond zebrafish. *JAMA Network Open*, 4(1), e2034018. <https://doi.org/10.1001/jamanetworkopen.2020.34018>

Stahmer, A. C., Brookman-Frazee, L., Lee, E., Searcy, K., & Reed, S. (2011). Parent and multidisciplinary provider perspectives on earliest intervention for children at risk for autism spectrum disorders. *Infants & Young Children*, 24(4), 344–363. <https://doi.org/10.1097/iyc.0b013e31822cf700>

Stewart, S. M., Lee, P. W. H., & Tao, R. (2010). Psychiatric disorders in the Chinese. *Oxford Handbooks Online*. Published. <https://doi.org/10.1093/oxfordhb/9780199541850.013.0023>

- Symes, W., & Humphrey, N. (2010). Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (ASD) in mainstream secondary schools: A comparative study. *School Psychology International, 31*(5), 478–494.  
<https://doi.org/10.1177/0143034310382496>
- Syriopoulou-Delli, C. K., Cassimos, D. C., Tripsianis, G. I., & Polychronopoulou, S. A. (2011). Teachers' perceptions regarding the management of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(5), 755–768.  
<https://doi.org/10.1007/s10803-011-1309-7>
- Tang, L., & Bie, B. (2015). The stigma of autism in china: An analysis of newspaper portrayals of autism between 2003 and 2012. *Health Communication, 31*(4), 445–452.  
<https://doi.org/10.1080/10410236.2014.965381>
- Tierney, S., Burns, J., & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the autistic spectrum. *Research in Autism Spectrum Disorders, 23*, 73–83.  
<https://doi.org/10.1016/j.rasd.2015.11.013>
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing, 48*(4), 388–396.  
<https://doi.org/10.1111/j.1365-2648.2004.03207.x>
- Toran, H., Hanafi, M., Yasin, M., Tahar, M., & Salleh, N. (2010). Special educators' level of training, knowledge and confidence of autism. *Jurnal Pendidikan Malaysia, 35*(1), 19–26. <http://pkukmweb.ukm.my/~jurfpnd>
- Wei, L. S., & Yasin, M. H. M. (2017). Teacher training to increase teacher's competency in teaching autism child. *Journal of ICSAR, 1*(1), 1–5.  
<https://doi.org/10.17977/um005v1i12017p001>



Welterlin, A., & LaRue, R. H. (2007). Serving the needs of immigrant families of children with autism. *Disability & Society*, 22(7), 747–760.

<https://doi.org/10.1080/09687590701659600>

Winter, G. (2000). A comparative discussion of the notion of “validity” in qualitative and quantitative research. *The Qualitative Report*. Published.

<https://doi.org/10.46743/2160-3715/2000.2078>

Woods, R. (2017). Exploring how the social model of disability can be re-invigorated for autism: In response to jonathan levitt. *Disability & Society*, 32(7), 1090–1095.

<https://doi.org/10.1080/09687599.2017.1328157>

Yeo, Y. K., & Lu, X. (2012). Parenting stress and psychological distress among mothers of children with autism in Johor Bahru and Hangzhou. *Journal of Educational Psychology & Counseling*, 6, 129–153.

Yu, L., Stronach, S., & Harrison, A. J. (2020). Public knowledge and stigma of autism spectrum disorder: Comparing China with the United states. *Autism*, 24(6),

1531–1545. <https://doi.org/10.1177/1362361319900839>

Zaboski, B. A., & Storch, E. A. (2018). Comorbid autism spectrum disorder and anxiety disorders: a brief review. *Future neurology*, 13(1), 31-37.

<https://doi.org/10.2217/fnl-2017-0030>

## Appendix A

### Informed Consent Form Sample



Greetings. We are students from Bachelor of Social Science (HONS) Psychology, Faculty of Arts and Social Science, Universiti Tunku Abdul Rahman. We are currently conducting our Final Year Project titled "Exploring the Societal views towards ASD and its Impact on the Quality of life of ASD individuals in Malaysia" as part of our coursework.

Presented below are some information about the project.

#### Purpose of the Project

The purpose of this assignment is to fulfil our learning objectives to discover the societal perspectives on ASD groups who are aged above 18; and to spread awareness towards the impact of societal views towards them to contribute more for them in coping with it.

#### What Would This Involve?

It involves the participation in audio/video recorded interviews by the interviewee who are from ASD groups with average to high intellectual functioning and no/little speech issues, aged 18 and above for responses on some questions. The interview process will take approximately 30 minutes to an hour. Besides, some demographic data will be collected.

#### The Risk

In general, there should be no risk involved in this process. Nevertheless, some might report minor discomfort since personal concerns are discussed. It is important to acknowledge that you have the right to withdraw from the study at any time without prejudice.

#### Confidentiality

The recorded interview will be handled in a private and confidential manner; and only our project group and our supervisor will have access to it. The content of the interview will be reported in an augmented manner and the identity of the participant will remain anonymous. Hence, the confidentiality of the participant is ensured.

#### Voluntary Basis

The participation is voluntary in nature. As mentioned above, if you do not wish to participate or would like to withdraw from the study at any time, you have the right to do so. There is no obligation to provide a reason and there is no penalty.

#### Payment and Compensation

No payment is required to participate in this interview. Similarly, there will be no compensation for the participation.

#### If I have any question / complaint, whom can I contact?

Ms. Belle Kor Ming Hui  
Final Year Student  
Faculty of Arts and Social  
Science  
Universiti Tunku Abdul Rahman  
E-mail: [bellekor@lutar.my](mailto:bellekor@lutar.my)  
Contact number: 016-2032237

Ms. Chua Hui Qin  
Final Year Student  
Faculty of Arts and Social  
Science  
Universiti Tunku Abdul Rahman  
E-mail: [huiqinc@lutar.my](mailto:huiqinc@lutar.my)  
Contact number: 018-9191390

Mr. Imran bin Mohammed Azlan  
Final Year Student  
Faculty of Arts and Social  
Science  
Universiti Tunku Abdul Rahman  
E-mail: [imrant@lutar.my](mailto:imrant@lutar.my)  
Contact number: 016-3111264



**Written Consent Form  
Agreement to Join the Interview**

**Exploring the Societal views towards ASD  
and its Impact on the Quality of life of ASD individuals in Malaysia**

Hereby, I \_\_\_\_\_ (I/C No.) agree to join the interview mentioned above voluntarily. The project is conducted by undergraduate students of Bachelor of Social Science (HONS) Psychology from Universiti Tunku Abdul Rahman. We have been informed and understand the purpose and the procedure of the interview. We understand that the interview will be recorded, all information collected in the interview will be kept confidential and private, and the data will only be presented in an augmented manner. Our signatures below signify that we have read, understood, and agreed with all the information given. If we agreed to participate in the interview, we understand our right to withdraw from the interview at any point of it without penalty of any form.

Name of Participant: )

Signature of Participant:

Date:

## Appendix B

### Demographic Form Sample

#### Demographic Form for Interviewees

Q1. Age (in years old)

---

Q2. Gender

Male

Female

Q3. Ethnicity

Malay

Chinese

Indian

Others (Specify): \_\_\_\_\_

Q4. Religion

Islam

Buddha

Hindu

Christian

Others (Specify): \_\_\_\_\_

Q5. What is your highest education? (e.g. SPM, Diploma, Degree, Master)

---

Q6. State of Birth (e.g. Kuala Lumpur, Penang, Malacca)

---

Q7. State of Residence (e.g. Kuala Lumpur, Penang, Malacca)

**Demographic Form for Interviewees**

---

Q8. Condition level of ASD (e.g. quarterly checkup and mild medication, only checkup with no medication needed, mild ASD, etc)

---

Q9. Duration since Diagnosis (in months)

---

Q10. What is our current living situation? (Select all that apply)

- I live on my own
- I live with family
- I live with friends
- I live in a Supported Living Situation
- Others (specify): \_\_\_\_\_