



**A NARRATIVE INQUIRY ON MALAYSIAN PARENTS'
AND CAREGIVERS' EXPERIENCES IN DETECTING
AUTISM, SEEKING INTERVENTIONS, CHALLENGES
AND ADAPTATIONS**

BY

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the degree of Doctor of Philosophy**

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ABSTRACT

There is a lack of knowledge among Malaysian parents in detecting signs of autism in their children. This situation could lead to late detection and intervention. Children's condition would be harder to improve and this would affect the parents' and caregivers' well-being. Thus, parental awareness and knowledge is important for early diagnosis of autism. This study explored parents and caregivers' experiences in recognising signs of autism, providing intervention for their autistic children at home, coping with their challenges and making adaptations. The study used a qualitative research approach with a narrative inquiry method. A total of eleven respondents were interviewed. In-depth interviews and four non-participant observations were carried out. The study found ten signs of autism that parents and caregivers had noticed in their children's behaviour. Children's delay in speaking was common and the most noticeable sign for all eleven respondents. Respondents admitted having no knowledge and awareness about autism or signs of autism at the beginning. The periods before and after the detection of autism, were difficult periods and many respondents had expressed feelings of sadness, worried as well as frustration. The severity of autism played an important role in alerting parents or caregivers to speed up the process of investigation. Respondents had used many types of interventions for their children and these included behavioural, developmental, family based, therapy based, alternative interventions and medications. Islamic practices were also used by Muslim respondents. Coping strategies used by respondents were problem and emotion focused strategies as well as adaptive and maladaptive strategies. The role of religion as an emotion-focused coping strategy is an important one as it enabled respondents to use a more flexible practice intervention which helped improve their children's development and also overcome their challenges and cope with their lives. Findings from this study gave added knowledge and information on Malaysian parental concerns about the signs of autism, provide suggested interventions for parents, and effective adaptive strategies to face their challenges in caring for the autistic child. The findings are not only beneficial to parents and caregivers but also to teachers, school authorities, practitioners and curriculum developers.

خلاصة البحث

هناك قصور في المعرفة بين الآباء المализيين في الكشف عن علامات التوحد لدى الأطفال، ويمكن أن يؤدي هذا إلى التأخر في الاكتشاف والتدخل في العلاج، وبالتالي تكون حالة الطفل أكثر صعوبة في التحسن، وهذا يؤثر على الوالدين وعلى مقدمي الرعاية، لذلك فإن اكتشاف الوالدين المبكر لمرض التوحد مهم جداً. هذه الدراسة تستكشف تجارب الآباء ومقدمي الرعاية في معرفة علامات التوحد لدى الأطفال الذين يعانون من التوحد في البيت، والتحديات التي يواجهونها والتكيف معها. واستخدمت الدراسة المنهج النوعي مع أسلوب سرد القصة. وتم إجراء مقابلات متعمقة مع أحد عشر شخصاً مع الملاحظة غير المباشرة للمستجوبين. وقد وجدت الدراسة أن الوالدين ومقدمي الرعاية قد لاحظوا عشر علامات للتوحد في سلوك أبنائهم. ومن أبرز علامات التوحد التي لاحظها كل المستجوبين هي عدم الكلام أو التأخر فيه. وأقر جميع المستجوبين بعدم وجود معرفة ولا وعي بالتوحد أو علاماته في البداية، وأن فترة ما قبل اكتشاف التوحد وفترة ما بعده فترات صعبة، وأعرب كثير منهم عن مشاعر الحزن والقلق والإحباط. وقد لعبت خطورة مرض التوحد دوراً هاماً في تنبيه الآباء ومقدمي الرعاية في تسريع عملية التحقيق. وقد استخدم المستجوبون أنواعاً متنوعة لعلاج أطفالهم شملت التدخلات السلوكية والإنمائية والأسرية، والعلاج الطبيعي، والأدوية البديلة، كما استخدم الآباء المسلمون الممارسات الإسلامية. ومن الاستراتيجيات التي استخدمها المستجوبون، استراتيجيات التأقلم، والتركيز على المشكلة، والتركيز على العاطفة، فضلاً عن استراتيجيات التكيف والتهيئة. وقد أدت استراتيجيات التركيز على العاطفة إلى استخدام استراتيجيات أخرى أكثر مرونة مما ساعد في التغلب على التحديات وتحسين وضع أبنائهم. وأوضحت نتائج الدراسة مزيداً من المعرفة والمعلومات عن اهتمامات الوالدين المализيين بعلامات التوحد، والتدخلات المقترحة للآباء والأمهات، واستراتيجيات فعالة للتكيف. هذه النتائج ليست مفيدة للآباء ومقدمي الرعاية فقط، ولكن أيضاً للمدرسين ومسؤولي المدارس، والممارسين، ومطوري المناهج الدراسية.

APPROVAL PAGE

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DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any degrees at IIUM or other institutions.

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Signature.....

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TABLE OF CONTENTS

Abstract	ii
Abstract in Arabic	iii
Approval Page	iv
Declaration	v
Copyright	vi
Acknowledgements	vii
List of Tables	xii
List of Figures	xiii
CHAPTER ONE: INTRODUCTION.....	1
1.0 Introduction	1
1.1 Background of Study	2
1.2 Statement of the Problem	8
1.3 Purpose of the Study	11
1.4 Objectives of Study	12
1.5 Research Questions	13
1.6 Significance of Study	13
1.7 Definition of Terms	15
1.7.1 Autism Spectrum Disorder.....	15
1.7.2 Asperger Syndrome.....	16
1.7.3 Interventions.....	16
1.7.4 Parents’ or Caregivers’.....	17
1.7.5 Narrative Inquiry.....	17
1.7.6 Family Adaptation.....	17
1.8 Limitations and Delimitations.....	18
1.9 Summary of Chapter	19
CHAPTER TWO: LITERATURE REVIEW.....	20
2.0 Introduction.....	20
2.1 What is Autism?	20
2.2 Causes of Autism Spectrum Disorders (ASD).....	21
2.3 Comorbidity in Autism	24
2.4 Theoretical Framework.....	28
2.5 Conceptual Framework	31
2.6 Detection of Autism.....	37
2.6.1 Parental Concern in Detecting Signs of Autism.....	37
2.6.2 Signs of Autism.....	43
2.6.3 Age of Autism Symptom Onset.....	46
2.6.4 Autism Screening Tools: Methods Used to Screen Autism.....	47
2.7 Studies On Parents’ and Caregivers’ Interventions for Children with Autism	48
2.7.1 Early Intensive Behavioural Intervention.....	49
2.7.2 Interventions to Obtain Eye Contact	49

2.7.3 New Social Communication Intervention for Children with Autism.....	52
2.7.4 Dietary Supplements Intervention.....	52
2.7.5 Parent-focused Intervention.....	56
2.7.5.1 Parent-Child Interaction Therapy.....	56
2.7.5.2 Triple-P.....	59
2.7.5.3 Incredible Years.....	62
2.8 Challenges Faced by Parents and Caregivers of Children with Autism	63
2.8.1 Parental or Family Stress	64
2.9 Parents' and Caregivers' Adaptation.....	68
2.9.1 Coping Strategies Employed by Parents of Autistic Children....	69
2.10 Researches on Autism In Malaysia.....	76
2.11 Summary of Chapter.....	81
CHAPTER THREE: METHODOLOGY.....	82
3.0 Introduction	82
3.1 Rationale for Qualitative Research Design.....	82
3.1.1 Narrative Inquiry	82
3.2 Role of the Researcher	84
3.3 Sampling	85
3.4 Data Collection Techniques.....	87
3.5 Data Collection Procedure	90
3.6 Data Analysis	91
3.7 Issues of Trustworthiness	93
3.7.1 Credibility of Research.....	93
3.7.2 Transferability of Research.....	96
3.7.3 Dependability of Research.....	97
3.7.4 Confirmability of Research	97
3.8 Ethical Procedures.....	98
3.9 Summary of Chapter.....	99
CHAPTER FOUR: STORIES FROM PARENTS AND CAREGIVERS.....	100
4.0 Introduction	100
4.1 Story 1	100
4.2 Story 2	109
4.3 Story 3	118
4.4 Story 4	128
4.5 Story 5	137
4.6 Story 6	143
4.7 Story 7	153
4.8 Story 8	163
4.9 Story 9	172
4.10 Story 10	180
CHAPTER FIVE: FINDINGS FROM INTERVIEWS AND OBSERVATION.....	185
5.0 Introduction	185
5.1 Detection of Autism: Signs from the Child.....	185

5.1.1	Speech Delay, Communication and Socialisation Problem.....	185
5.1.2	Tantrums, Aggressive Behaviour and Self-Injury.....	196
5.1.3	No Eye Contact.....	199
5.1.4	Autism Regression.....	201
5.1.5	Late Physical Development; Child's not Meeting the Developmental Milestones.....	202
5.1.6	Living in Their Own World and Peculiar or Strange Behaviours.....	202
5.1.7	Different and Peculiar Way of Playing.....	203
5.1.8	Problems with Loud Noises.....	204
5.1.9	Childlike Behaviours.....	205
5.1.10	Repetitive Behaviours.....	207
5.2	Responding to the Child: Parents' and Caregivers' Experiences in Providing Interventions for their Children with Autism.....	208
5.2.1	Experiences in Toilet Training.....	208
5.2.2	Experiences in Enhancing Self-help Skills.....	210
5.2.3	Experiences in Enhancing Eye Contact and Socialisation Skills.....	211 212
5.2.4	Dietary Intervention.....	212
5.2.4.1	Back to Nature Food.....	216
5.2.4.2	Change Menu.....	217
5.2.4.3	Diet Elimination.....	218
5.2.4.4	Medication.....	219
5.2.5	Suitable Indoor and Outdoor Activities.....	227
5.2.6	Approaches to Reduce Children's Tantrums.....	230
5.2.7	Islamic Practice.....	233
5.2.8	Parents or Caregivers' Teaching Approaches and Behaviour Modification Issues.....	239
5.3	Challenges Parents and Caregivers Faced in Taking Care of Children with Autism.....	239
5.3.1	Dealing with Child Temperament and Self-Injury.....	242
5.3.2	Child's Aggressive or Anti-social Behaviours.....	247
5.3.3	Child's Hyperactivity.....	248
5.3.4	Problems when Child is Stressed or Having Sickness.....	249
5.3.5	Dealing with Child Sexual Urges.....	249
5.3.6	Lack of Social Skills.....	250
5.3.7	Slow in Learning New Skills.....	251
5.3.8	Stress and Well-being of Parents and Siblings.....	253
5.3.9	Community Awareness and Family Support.....	256
5.3.10	Other Related Issues.....	256
5.3.10.1	Difficulty to Enrol in Special Education School.....	257
5.3.10.2	Untrained Teachers in Special Education School and Home schooling.....	261
5.3.10.3	Lack of Facilities in Hospitals.....	262
5.3.10.4	Financial Constraints Faced by Parents and Caregivers.....	263
5.3.10.5	Distant and Time Constraint.....	263
5.3.10.6	Limited Time Spend with Children because of Work.....	265

5.3.10.7 Unpredictable Future.....	265
5.4 Parents' and Caregivers' Experiences of Coping with Children with Autism.....	265
5.4.1 Accepting Responsibility and be Positive.....	268
5.4.2 Social Support from Family and Community.....	270
5.4.4 Social Isolation.....	275
5.5 Summary of Chapter.....	275
CHAPTER SIX: DISCUSSION AND CONCLUSION.....	276
6.0 Introduction	276
6.1 Parents' and Caregivers' Experiences in Detecting Signs of Autism.....	276
6.2 Parents' and Caregivers' Interventions.....	286
6.3 Challenges Faced by Parents and Caregivers	293
6.4 Coping Strategies Used by Parents and Caregivers.....	300
6.5 Recommendation for Future Research.....	308
6.6 Limitation of Study.....	308
6.7 Conclusion.....	309
6.8 Implications of the Study.....	310
REFERENCES.....	312
APPENDIX A : DAYS, TIME, AND PLACES INTERVIEWS WERE CARRIED OUT.....	330
APPENDIX B : DAYS, TIME AND PLACE OBSERVATIONS WERE CARRIED OUT.....	331

LIST OF TABLES

<u>Table No.</u>		<u>Page No.</u>
6.1	Parents and Caregivers Noticing Signs in Their Children's Behaviours	281
6.2	Children's Age When Autism was detected and Types of Autism and Comorbidity in Children	283
6.3	Time Gap between Parents' and Caregivers' Concern to Diagnosis of Autism	286
6.4	Types of Interventions used by Parents and Caregivers	287
6.5	Summary of Parents' and Caregivers' Experience in Providing Interventions and the Types of Interventions Used	292
6.6	Challenges faced by Parents and Caregivers of Children with Autism	298
6.7	Parents' and Caregivers' Coping Strategies	303

LIST OF FIGURES

<u>Figure No.</u>		<u>Page No.</u>
2.1	Bronfenbrenner's Ecological Systems Theory	29
2.2	A Conceptual Framework of Factors Influencing Parents' and Caregivers' Experiences in Detection of Autism, Intervention, their Challenges and Adaptations	36
6.3	Challenges Faced by Parents and Caregivers	300
6.4	The Parents' and Caregivers' Teaching Approach	304
6.5	The Religion and Emotion-Focused Triangle for Children with Autism	307

CHAPTER ONE

INTRODUCTION

1.0 INTRODUCTION

Autism is a brain disorder that affects an individual's ability to learn, communicate, socialise and develop normally and results in having repetitive behaviours and narrow interests (Jasni et al., 2011). According to UNICEF (2014), children with autism have learning difficulties and their developments are not the same as normal children. Howlin (1999) described children with autism as more physically dependent on their parents and people looking at the children's behaviours would think that they were misbehaving or had poor discipline as opposed to understanding that the child is mentally disabled. From the many definitions of autism, we learn the signs of autism in children. To date, majority of Malaysian parents and caregivers lacked awareness and handling skills related to autism (Jasni et al., 2011; Amar (2008)). Amar (2008) noted that parents would not bring their children to be checked by health professionals to determine the children's condition.

Having a child with autism would mean parents and caregivers as well as the family members have to manage their lives and care for their children with autism. Amar (2008) mentioned that children with autism, especially those with severe autism, have difficult behaviours that can be puzzling and confusing to their parents and family members. Parents or caregivers need to accommodate the needs of children with autism and care for them. Many of these parents and caregivers in Malaysia have high prevalence rate of stress and experience psychological disturbances (Nikmat et al, 2008). Similarly, Paynter et al. (2013) who conducted a study on Australian

families with autistic children found that many of the parents and caregivers of children with autism experience high level of stress. They experience increased psychological distress in caring for a child who has autism compared to other families with normal children. Due to this, parents and caregivers need to make adjustments to fit the needs of their children with autism as well as to accommodate the needs of other members of the family. Thus, family adaptation is crucial for family well-being because they have to be able to understand and adapt themselves or make changes to their lives to suit the needs of the child with autism in the family. Therefore, there is a need to learn about Malaysian parents' and caregivers' coping strategies for children with autism and the sort of support they need to understand their children's challenging behaviours so as to cope with life.

1.1 BACKGROUND OF STUDY

Researches concerning autism in Malaysia are relatively new if we were to compare Malaysia with the Western countries (See, 2012). Before 2003, most of the autistic children were classified under mental retardation and hearing disability category and it was only after 2008, children with autism were placed under the learning disability category (See, 2012). Jasni et al. (2011) in their article mentioned that autism in Malaysia was misconstrued as a mental illness and these children were mostly kept at home and not given any opportunities to improve their conditions.

See (2005) noted that there were different ministries in Malaysia which provide services for children with autism at this time. These include Ministry of Education, Ministry of Health, and Ministry of Women, Family and Community Development which the Social Welfare Development placed an important role. Along the same line, there were also Non-Governmental Organisations which also provide

services for children with autism. She mentioned that the Ministry of Health was responsible to identify and screen disabilities in special children while the Ministry of Education was in charge of providing Early Intervention Programmes and educational services for children as well as individuals with autism. The Ministry of Education also catered for children with other disabilities such as children with hearing and visual impairment and learning difficulties such as Down syndrome, mild autism or Asperger Syndrome, Attention Deficit Hyperactive Disorder (ADHD), mild mental disabilities and also specific learning difficulties such as Dyslexia. The Ministry of Health and the Ministry of Education recognised the importance of early detection and intervention for children with autism and they provided services and facilities for parents and caregivers for early detection and intervention for these children. However, these were still not enough to face the fast growing number of disability cases.

In 2005, the Malaysian Health Ministry had stated that the number of autistic children was only one in every 10,000 children diagnosed with autism. However, statistics taken in 2013 Health Ministry's record, showed an increased number of 117 cases of autism and 87 cases of ADHD in 2011 and the following year, the number had increased to 170 cases of autism and 96 cases of ADHD. In addition, the figures quoted by The Malaysian Times dated on the 28 March 2014, had given the estimated number to be one in every six hundred children while the statistics shown recently stated that there were about 47,000 individuals who are autistic in Malaysia and from this figure, four out of every 10,000 children and adults have severe autism. It also mentioned that from every 5 children with autism, 4 of the children are male.

Though there is no statistical data documented in Malaysia in relation to the number of children and adult with autism, data from Western countries have shown the current ratio of children with autism is 1: 150. However, Ong et al. (2013) noted that the number of children with autism has gradually increased from 1: 5,000 in 2001 to 1:100 in 2010. Due to the growing number of children with autism, the Malaysian Ministry of Health had to provide more services for parents and caregivers as well as making the services easily accessible to all parents and caregivers who wish to obtain them (Amar, 2008).

Detection of autism as well as other disabilities in Malaysia was mainly left to the Ministry of Health and the Ministry of Education. Parents' and caregivers' who were concerned about their children's behaviours had consulted health professionals which led them to the screening process. Amar (2008) noted that from 2005 to 2006, the Ministry of Health through its Health Development Division had conducted a pilot programme to screen disabilities among young children at the early age of 5 months, 12 months, 18 months and 4 years. In 2011, the Ministry of Health had started the Health Record for Baby and Child from infant to 6 years and in 2012, the health monitoring programme had extended to the national level whereby this programme had begun screening children at the prenatal stage to 6 years old. Early detection efforts for autism and ADHD as well as other learning disorders among children had utilised the Modified Checklist for Autism or the M-CHAT to screen young children. Earlier, Amar (2008) noted that two other screening tools, which include the Denver-II Developmental Screening Test and the Schedule of Growing Scale II (SGS) were also used to detect developmental problems in children. However, he mentioned that these tools lack sensitivity and specificity because instead of screening children's disability, health professionals used it to monitor the children's progress.

In addition, the National Early Childhood Intervention Council (NECIC) (2013) mentioned that there were several shortcomings of the health monitoring programme. Firstly, it was not accessible to the urban poor as well as parents and caregivers living in rural areas. Next, since the programme was not compulsory, its effectiveness depended mostly on the parents' and caregivers' perseverance to follow up with private medical institutions, state health departments and health centres.

Detection of children with disabilities was also done in schools. The National Early Childhood Intervention Council (NECIC) (2013) noted that children attending mainstream schools, were asked to take the Literacy and Numeracy Screening (LINUS) Programme, where tests were conducted over a period of three years of the child's primary 1 through primary 3 and all of the children in the mainstream schools have to pass. Should a child fail the LINUS screening tests repeatedly over the three year period, his or her parents were asked to refer the child to the Ministry of Health for further medical assessment and screening. Similarly, the LINUS screening tests were not able to detect all forms of learning disabilities. The threshold of the screening tests was low, so it made some children with learning disabilities able to pass the tests. Special Education Division, Ministry of Education (2013) mentioned that although the tests identify a child with a learning disability, it was up to the parents of the child to carry on with the process of assessment at the Ministry of Health. Hence, parents and caregivers play major roles in not only detecting a child's disability but also providing interventions for their children.

Autism intervention programmes were first run by Non-Government Organizations (NGOs) such as National Autism Society of Malaysia or NASOM and they played an important role in providing interventions especially the Early Intervention Programmes (EIP) for young children with autism. From the NASOM

handout (2008), it indicated that NASOM was formed in 1987 by a group of parents and professionals who later provided a range of support services to assist parents and caregivers to improve their children's autistic behaviour. Their approach was basically using behavioural techniques.

Next, Amar (2008) mentioned that the EIP programme was highly structured, specialised and designed to fit individual children's needs. He added that the programme includes communication therapy, physical therapy, social skill development as well as behaviour modification therapy. The EIP programmes were run and delivered by trained professionals in a consistent and coordinated manner. Their therapies are usually carried out in one to one ratio with one therapist to one autistic child or in a small group environment. However, Amar (2008) also mentioned that these services were inadequate as they were fragmented, hospital based and they did not address the emotional burden of the caregivers and the rest of the family. In addition, medication and diet intervention were not emphasized and most of the service providers for children with autism had adopted approaches and techniques from industrialised countries which were not really suitable for Malaysian parents and caregivers.

There were numerous researches done on challenges faced by parents and caregivers of children with autism in Malaysia. The two earliest researches were done by Zasmani in 1993 and two years later, Kasmini and Zasmani in 1995. Zasmani's (1993) findings showed that parents and caregivers with autistic children were significantly stressed and they underwent intense crisis after the child's diagnosis was done. There were many negative feelings experienced by parents and caregivers and these include the feelings of grief, hopelessness, anger, rejections as well as depression.

Besides the negative feelings, Zasmani (1993) mentioned that the severity of the child's autistic condition is also a predictor of parental stress. Parents and caregivers were embarrassed and disappointed to take their child out in public places. This is because society did not understand the child's conditions. So, parents and caregivers tend to isolate their child at home. In another research done by Kasmini and Zasmani (1994) on children with Asperger Syndrome noted that parents and caregivers of children with Asperger Syndrome needed support to cope with their unique problems and teachers in Special Education schools were asked to be trained so that they were more aware of their children's conditions. Later, Liaw (2008) found five negative feelings and behaviours which included continuous stress, anger-love paradox, self-blaming, fear and phobia. Thus, the literature shows that parents and caregivers having children with autism in Malaysia experienced very stressful lives.

There were not many researches done on parents' and caregivers' coping strategies in Malaysia and there was one research done by Ting and Chuah in 2010 on Malaysian parents' and caregivers' coping strategies. Their findings showed that parents and caregivers with autistic children had coped with their lives because of their religious beliefs and they had family support. Thus, using religious means were considered as a positive coping strategy and this strategy helped parents and caregivers with autistic children to cope with their lives. However, Hastings et al. (2005) viewed parents and caregivers who used religious means to cope with their challenges were using a denial strategy instead of a positive coping strategy.

Therefore, Malaysian parents and caregivers with autistic children needed to make life adjustments to meet the needs of the child with autism and at the same time they need to accommodate the needs of other members of the family. Thus, failure to do so would affect the well-being of the whole family. Parents and caregivers of

children with autism have to understand and make changes to their lives to suit to the needs of the autistic child in the family.

1.2 STATEMENT OF THE PROBLEM

There are many problems faced by parents and caregivers of children with autism in Malaysia. Sufean et al. (2008) commented on the challenges faced by parents and caregivers of autistic children, which included lack of financial support, insufficient teaching resources and staff, and difficulties to integrate and implement intervention programmes. Similarly, Natasya (2010) in her article in the New Straits Times entitled “Money and distance are letting down children with autism” mentioned that Dr. Hasnah Toran from Universiti Kebangsaan Malaysia stated that most of the Special Education schools in Malaysia do not have enough teachers to cater for every child who is autistic and that many parents are finding it hard to send their autistic children to the centres due to the distance between the centres and their homes.

In the article, another important issue raised was the high cost of intervention programmes that made many parents with autistic children could not afford to pay for the programmes. In addition, the next problem faced by parents with autistic children was their children have to be educable before they could be accepted into Special Education schools (Pang, 2009). She added that these children with autism were only taken in if they could manage themselves and were ready to learn while those children who did not meet these conditions were expected to find other places for help. Thus, all these problems gave parents and caregivers of children with autism no choice but to look after their children at home. This would mean parents and caregivers would have no specific guidance or advice from health professionals on how to conduct interventions for their children at home. Thus, parents and caregivers had to manage

their children all by themselves without the support and guidance from health professionals. This task would be a difficult one for them to handle.

Matters got more serious when Pang (2009), after conducting a survey, found that there was lacked of knowledge and awareness among parents and caregivers about signs of autism. She indicated that even after diagnosis of autism, parents and caregivers failed to act quickly to start intervention for their children who were diagnosed with Autism Spectrum Disorders (ASD). She said that some parents were reluctant to admit that their children needed professional help and often delayed in giving treatment to their children and this resulted in late intervention and therefore, making it difficult for these children to function as normal children. Similarly, Jasni et al. (2011) conducted a preliminary investigation on the Malaysian society's awareness of autism and found there was a lack of awareness among parents of autistic children and parents with normal children, caregivers and unmarried women on the signs of autism. Moreover, the lack of knowledge and skills is not only for parents and caregivers but also the Malaysian public. In a research done by Jin and Chin (2012) on public awareness and discrimination for parents with children with autism, they found there was a lack of awareness and understanding about children with ASD among the general public in Malaysia. Therefore, these studies showed that there is a gap among Malaysian parents, caregivers and the public on the signs of autism. This study would fill in the gap by exploring parents' as well as caregivers' experiences in detecting signs of autism.

It is important for parents and caregivers to know the autism signs early so that early intervention could be given. However, do parents and caregivers know how to provide interventions for their children as well as manage their lives with the children with autism at home? In the article written by Amar (2008), he commented that many

studies have concentrated mainly on autism centres and hospital interventions, which use expensive tools and interventions. However, these methods or interventions were not suitable or appropriate for Malaysian parents and caregivers to conduct intervention in their own home simply because they cannot afford to buy all the expensive tools or instrument. Amar further mentioned that most of the autism centres and services provided in Malaysia have adopted models from industrialised countries and this may not be suitable or applicable to meet the vast needs of autistic children in Malaysia.

Amar (2008) also commented that most of the service providers for autism are currently fragmented, hospital based, inadequate and it is not a priority in the medical development and many parents have opted out from using these services. He added that the lack of parental experiences in recognising signs of autism could lead to late detection and intervention. He also stressed that parental concerns are important data and health professionals must see to their concerns and assist them by providing enough information for parents and caregivers to cater for their children. He added that it would be harder to improve their children's condition unless early intervention is given. Similarly, Hasnah in Natasya (2010) had emphasised that there is a need to find the best practices to manage children with autism within a local context and not merely adopting practices from established nations. Thus, with the problems faced by parents and caregivers, there is a need to have practical interventions to fit the needs of children with autism in Malaysia. Hence, there is a gap in parents' and caregivers' experiences in recognising signs of autism and what interventions were suitable and effective for them to use at home for their children with autism.

Recognising signs of autisms and providing effective interventions are crucial for parents' and caregivers' well-being. Jasni et al. (2011) mentioned that Malaysian

parents with autistic children are stressed due to the lack of knowledge on how to cope with this unique problem. In an early study, Zasmani (1993) noted that parents of autistic children were embarrassed and disappointed with their children's behaviours in public places. Kasmini and Zasmani (1995) added that a family having a child with Asperger's Syndrome needed support to cope with their life. Thus, parents and caregivers do not have any guidance on how to recognise autism signs as well as to take care and manage their autistic children at home. Without proper guidance given to parents and caregivers of children with autism, they will not be able to detect autism and provide needed interventions for their children and also to assist them to face challenges and cope with these challenges. Therefore, it is clear that there is a need to fill the gap to study parents' and caregivers' experiences in detecting signs of autism and providing intervention so that parental and caregiver stress can be reduced.

1.3 PURPOSE OF THE STUDY

The main purpose of the study is to identify and describe the experiences of parents' and caregivers' in detecting signs of autism in their children. The study is interested to learn when parents and caregivers first noticed any developmental delays in their children's development and the signs of autism that made parents suspect that their children had some abnormalities.

Secondly, the study intends to describe parents' as well as caregivers' experiences of their past, current and future practices in providing intervention as well as managing their children at home. From the data collected, the researcher intends to develop some practical and useful suggestions for other parents and caregivers on how to care and educate their children with autism. These suggestions would be more suitable and appropriate for Malaysian parents and caregivers who have children with