

**SERVICES AVAILABLE TO AUTISTIC CHILDREN AND  
THEIR FAMILIES IN MALE', MALDIVES**

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MALE', MALDIVES

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A Project submitted in partial fulfillment of the requirements for the degree  
of Bachelors in Primary Health Care

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## **DECLARATION**

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I hereby declare that this Project is the result of my own work,  
except for quotations and summaries which have been duly  
acknowledged.

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Date: 5<sup>th</sup> June 2014

# SERVICES AVAILABLE TO AUTISTIC CHILDREN AND THEIR FAMILIES IN MALE', MALDIVES

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## ABSTRACT

**Background:** Children with autism spectrum disorder (ASD) require early intervention programs following diagnosis. They need specialized treatment and services throughout their life. The aim of this study was to identify the services available to autistic children and their families from the institutions in Male'.

**Methods:** In this descriptive cross-sectional study, data about accessible services were collected through a self-administered questionnaire and via interviews with service providers. The participants included 30 parents of children with ASD studying at special education need (SEN) class at Imaaduddin School, Male'. Additionally 3 teachers from SEN class and 2 specialists from the service providers participated in this study.

**Results:** Children with ASD in Male' find it difficult to access to specialized services though the diagnostic testing is good at institutions. Nearly 86% of the participants agreed that the specialized services are available at institutions treating ASD children in Male'. As an initial treatment, speech and behavioural therapies were given to the children and it counts 21 respondents among 30. As well, the services provided from the caregivers are paid and it concerns the families. However, the government pays MVR 2,000 as an allowance and they get financial support from other organizations and individuals. 84% of the parents are satisfied with the education program at SEN class. Overall, the parents questioned about the effectiveness and quality of services.

**Conclusion:** The children with ASD and their families receive diagnostic and specialized care from the service providers though the effectiveness and quality is lower.

**Keywords:** autism spectrum disorder, services, service providers, institutions.

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## LIST OF ABBREVIATIONS

**ASD:** Autism Spectrum Disorder

**MIPSTAR:** Maldives Institute for Psychological Services, Training and Research

**MAA:** Maldives Autism Association

**CSM:** Care Society of Maldives

**SEN:** Special Education Needs

## **CHAPTER 1**

### **INTRODUCTION**

#### **1.1 Introduction to Chapter 1**

This chapter attempts to present the research context, provide an explanation of the background information on autism and the need for the study, and outlines the research questions, aim, objectives, research purpose and delimitation of the study.

#### **1.2 Background information on autism**

Autism is considered as a complicated disorder in brain which involves difficulties with socializing and communication as well as lack of interest in their surroundings and repetitive behaviour. (Release, 2008) Usually autism is grouped with related disorders and communally it is referred as autism spectrum disorder (ASD). The principal causes of ASD are uncertain. Presently, there is no cure for the disorders as well as treatments are partial or limited. (Release, 2008) However, with proper treatment or medications can assist the autistic children to function healthier or better. (Autism Spectrum Disorder (ASD), 2014)

The treatment given to children with ASD might not affect all children in a similar manner. Nonetheless, it is very important to seek the help of the professionals who has experience in treating ASD. (Autism Spectrum Disorder (ASD), 2014) The early intervention services and other therapies can improve the child's development. These services include therapies given to aid the autistic children to interact with people, to

communicate and with motor skills (Release, 2008). Hence, it is essential to seek medical advice if a parent thinks his or her child has ASD. This would help the parents to seek accessible and adequate services for their children from the service providers of ASD.

### **1.3 Need for the study**

In Maldives, the increasing prevalence of ASD has become a national concern, though the services are lacking. As well, the parents try to interact with the service providers to find the best treatment for their children. To my knowledge, the special services required to children with ASD are provided by a few institutions and namely Care Society of Maldives, Autism Association of Maldives, Special Education Needs (SEN) class at Imaaduddin School as well as recently established Maldives Institute for Psychological Services, Training and Research. Additionally, the services they provide are limited. On the other hand, these special services are easily accessible to the children with ASD living in the capital city of Maldives, Male'. The children with the disorder living in other parts of the country are in need of these. It is necessary for those children to visit Male' whenever they require a special treatment regarding their ill-health. The institutions should provide appropriate treatment and support to the parents since the benefits are high for the children.

In Maldives, limited research has been carried out in the field of autism. According to a lecturer at SEN class, Imaaduddin, the prevalence rate of ASD and the population living with the disorder is unknown in Maldives. According to her, recently they initiated a survey to identify the number of people living with ASD in Male'. However, it they were unable to complete the survey due to ineffective cooperation and assistance from the relevant authorities and other institutions. This is the main reason why the treatments and other therapies have not improved in the country

according to the said teacher. She mentioned that the services provided from the institutions are poor and the support from the governmental body is insufficient. As I have got the full cooperation from the SEN class, Imaaduddin School, I intended to select the sample from there and to give an overall idea of the study subject which could be applied to whole population living with ASD in Male’.

#### **1.4 Research Questions**

The main issues I am addressing in this research are services available to autistic children and their families. I am interested in the dimensions of accessible services in the institutions located at Male’ from the parents’ perspectives through assessing their expectations and perceptions of services available. I therefore will like to answer the following questions in my study;

- Do the children with autism and their parents receive adequate services at institutions established in Male’?
- What are the available services to the children with autism and their parents?
- Are the parents satisfied with the services their children receive at institutions focused on treating autistic children in Male’?

#### **1.5 Aim**

The aim of this study is to identify the services available to the autistic children and their families from the institutions established in Male’, Maldives.

#### **1.6 Research Objectives**

The goal of this study or this research project seeks to explore the services available to autistic children and their families in Male’. There are three objectives of this research study: (1) exploring the services available to the autistic children at institutions established in Male’, (2) understanding the social support and other

treatments (including counseling) available to the parents and other family members of children with ASD in Male', and (3) ensuring that the autistic children and their families receive adequate and essential services from the institutions established in Male'.

### **1.7 Research Purpose**

Since research done involving children with this condition and their families, I hope my study would contribute to the body of knowledge in the field of autism in the country. In addition, this research hopes to aware the service providers and other relevant institutions regarding needed services and steps to improve the already existing services. Similarly, this would help the institutions to introduce and design new programs which incorporate modern treatment options at affordable rates. Moreover, this research enables to identify the types of services available to the children with ASD in Maldives. Additionally, this would help to open interest among researchers in health and social sector to pursue further research related to ASD.

### **1.8 Delimitation of study**

I have to define my scope of research in order to make things apparent. I am focusing my study on the service providers who treat autistic children in Male'. This includes all the service providers or institutions of all sizes, be it small or big, without considering the capacity of them. I am interested in how parents perceive the services they receive in these institutions. Even though the capacity of the institutions matter, I assume that the services they provide are almost similar. This study is limited to the services available at institutions in Male' because my sample is drawn from the autistic children in SEN class, Imaaduddin School, Male'. In addition, the parents who participated in this study have had experiences with the autistic services available

from other institutions in Male'. In this study, the word service will refer to any treatment, therapy or program intended for autistic children and their families.

## **1.9 Dissertation Outline**

### **1.9.1 Chapter 1 Introduction**

This chapter introduces the study or dissertation subject in general with background information on autism, need for the study, the questions that the study attempts to address, aim of the research, objective, research purpose, research delimitation and lastly the dissertation outline is briefed.

### **1.9.2 Chapter 2 Literature Review**

This chapter reveals the extent of understanding of the author on the linked subjects of the study. Various discussions and arguments studied in the current literature have been simplified in this chapter to illustrate the degree of knowledge collected from significant publications.

### **1.9.3 Chapter 3 Methodology**

This chapter describes the methodology used for the research study. It discusses the research design being used and provides reasoning for the choice. In addition, it defines the study population and sample, and instrumentation that have been used. Also, it defines the framework of data analysis that has been used for the research and the ethical considerations.

### **1.9.4 Chapter 4 Data Analysis and Results**

This chapter is exclusively dedicated to present the data collected from the survey. This analyses the background of the participants at the beginning and proceed to present summaries and analysis of them. The analysis is projected to provide an

interesting understanding on the research outcomes to enable the discussion on the following chapter.

### **1.9.5 Chapter 5 Discussion**

This chapter is the most significant which facilitate a discussion on the results available from the survey in chapter 4. This discussion is designed with reference to the results published in the obtainable literature in Chapter 2 (Literature Review).

### **1.9.6 Chapter 6 Conclusion**

The conclusions based on the results and related discussions are drawn in this chapter. Additionally, defined aim and objectives of the study is reconsidered to verify if the study meets the set aims and objectives. Lastly, limitations encountered during the study are discussed and suggestions for further researches are provided in this chapter.

### **1.9.7 Reference and Appendices**

In this chapter, the list of references and other related information which have not been integrated into the central body of text are provided.

### **1.9.8 Conclusion**

In conclusion, autism has become a national concern with the increasing incidence. It is a condition which affects the way children communicate, interact with others and their motor skills. However, early intervention programs and other therapies could enable the children to develop healthier. In this basis of conditions I have proposed the study to focus on services available to autistic children and their families in the second half of the chapter. In the final part of the chapter, I have also justified my choice of subject and context and provided background information. Eventually I

have set the study questions, aim, objectives, research purpose and delimitation of study as well.

### **1.9.9 Definition of terms**

**Services:** refers to any program or service focused on autistic children

**Institutions:** refer to institutes providing services to autistic children

**Interventions:** refer to treatments and services of autism



## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 Introduction to Chapter 2**

This chapter brings up various references to the obtainable literature on the concepts of services available to autistic children and their families. This part provides a platform to implement the study. I will discuss issues about the services available to the children with ASD and state appropriate literature in order to enrich my understanding of the subject and deliver answers to my research questions. The existing research results discussed in this chapter are also meant to provide the needed background and guidance for the research defined.

My topic is generally focused on services available to autistic children and their families and the literatures are based on explanations perceived through a person's thoughts. My research questions are about the different services they receive and if they are satisfied or dissatisfied with the services and the service providers. In addition, to gain a better understanding of accessible services, I will acknowledge past studies conducted on this area.

## **2.2 Autism Spectrum Disorder**

Autism Spectrum Disorder (ASD) is a developmental disability that occurs in the development of children that can cause significant social, communication, and behavioral challenges (National Center for Autism, n.d.). According to the professionals working at institutions to treat people with ASD, autism is not a disease. It is a lifelong multiple disorder of brain development and is characterized by difficulties in verbal and nonverbal communication as well as social interaction and repetitive behaviours or actions (What is Autism, n.d.). However, the hallmark characteristic of ASD is the lessened or absence of social interaction. Even as an infant, babies with ASD may be unresponsive to the people around. Additionally, a child may develop normally for a period of time and then withdraw and turn out to be uninterested to social engagement ("Autism Fact Sheet: National Institute of Neurological Disorders and Stroke (NINDS)", 2014). As well, the people with ASD may have infrequent sensory comforts like watching constantly at moving objects. (What is Autism, n.d.) Likewise, some people with ASD find loud noises unpleasant and as a result they try to avoid such instances. The same thing happens when there is an immediate change in light intensity or temperature and when there is a smell. In general, a child with ASD finds it difficult to cope with changes. Nonetheless, if the child is aware of a change, he or she can cope with it better. Similarly, some of them do not like being touched or cuddled, but there are a number of children with ASD who like to hug their family members and relatives (What is Autism, n.d.). As well, they do not understand and are not aware of the feelings of others. Additionally, the children with ASD are having problems with communication skills. They find it difficult to interact with people and often repeat words or phrases they know. The level of difficulty in speaking depends on the severity of the disorder (Nordqvist,

2013). On the other hand, they are fond of repeating a same action again and again. Besides their learning may be unpredictable as it changes for individual child with ASD. Their social and learning skills do not develop at the same speed as normal children (Nordqvist, 2013).

The symptoms of ASD appear early in the childhood. The severity of ASD depends on the way that children's brains process the information, and due to this people with ASD have a different ways of understanding and reacting to people and events (National Center for Autism, n.d.). Of course the biggest challenge facing ASD patients will be, getting an effective treatment and live as a normal human. To get an effective treatment, these patients should be provided with various services that fulfill most of their needs. To achieve fairness those with ASD also should have the opportunity to access various services. It is a duty of the government of each country, to provide these services. In different countries of the world, various types of services are available for ASD patients.

The cause of ASD is uncertain. However, a recent research has identified a relationship to genetic links (Australia, n.d.). The diagnosis for ASD is made by an examination or assessment including observations and meeting the children, their parents and caregivers or service providers (Australia, n.d.). The experts gain information in regard to their strengths and weakness or difficulties. In particular, their communication, social interactions and restricted and repetitive behaviours and actions are considered when diagnosing a child for ASD. Also, there are no laboratory investigations including blood tests to detect ASD (Australia, n.d.).

### **2.3 Worldwide prevalence rate of ASD**

According to Autism Spectrum Australia research shows that 1 in every 100 children is predicted to have ASD and there are about 230,000 Australians living with the disorder (Australia, n.d.). The Centers for Disease Control and Prevention, USA estimates that the prevalence rate of ASD is about 1 in 68 children (Autism Spectrum Disorder (ASD), 2014). In China, the first cases of autism were identified in 1982 in Nanjing. After that the interest towards autism increased in the country. As a result, with the increased incidence rate, people who seek medical services have increased significantly. However, a nationwide epidemiological data on ASD has not been carried out in the country. In 2007, a regional study conducted at Beijing presented that the incidence rate in the region was 1.34 per 1000 children. In Harbin city, the prevalence rate was 2.27 per 1000 children in 2010. In general, it has been estimated that approximately 7.8 million people including children and adults live in China.

### **2.4 Special Interventions**

For children with ASD, effective early intervention programs are the initial step in the treatment. These intervention programs after diagnosis can help at best to achieve the full potential in them. For the families with ASD children, the period after diagnosis is a challenging time. The parents not only experience various emotions, they are confronted with decisions in regard to the intervention programs for their children. They find themselves faced with waiting lists, a variety of different services combined with a desire to assist their children at the earliest.

As stated by law, everyone has equal rights whether the person is with a disability or not. Also, it should be maintained from an early age to visit institutions where they provide knowledge, experiences and skills to enhance the lives of the individuals and to reach a high level of freedom. As a result of their particular development, going to

any institute would mean services and treatment that could assist them to withstand communication, emotive reaction, contact, flexibility and assertiveness in thinking (Jasmina, 2009). Due to various reasons widespread philosophy and extra cautious tactics regarding treatment of children with ASD is aggravated (Jasmina, 2009). The main reason is the continuous rise in the number of children with ASD, increased number of new services and their efficacy. In addition, the requirement for education for ASD children in several environments, lack of resources in institutions including lessened coordination for diagnosis, detection and treatment as well as deficiency of professionals are some other reasons for this.

According to a study conducted in Macedonia, the majority of the parents, educators and rehabilitators believed that the treatments of children with autism should begin before the third year and it should continue lifelong. In that research, 90 percent of caregivers thought that the treatment should be given both at home and institutions. However, the greater proportion of parents thought that the treatments should be provided at institutions more willingly than at homes. Among the respondents, 1 percent of parents had concerns regarding higher number of children in groups, unsuitable core curriculum and maladapted environments and lack of other resources needed by children with ASD. Moreover, according to the study, in Macedonia a national strategy is needed to solve problem of people with ASD in order to provide effective education, their presence in the community and social care.

In Australia, various programs are available for ASD patients. For example, the government of Australia commenced a program called Helping Children, and created items in Autism Medicare Benefits Schedule (MBS), where Medicare items are available, for the early diagnosis and treatment. Through this, the patients are

provided with health insurance schemes, to aid in diagnosis and treatment of ASD patients (Australian Government, April 2014).

A report published on the condition of ASD in Somalia indicated that, several things are being done to help the ASD patients in diagnosing, treating, and helping. Even though Somalia is a poorly developed country, “Autism Spectrum Disorder Clinic “has been developed, which help the ASD patients under an insurance scheme (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). Also, using a comprehensive behavioral approach called “ Intensive Intervention Providers “, the outcomes for the ASD children are improving day by day (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). These interventions typically involve a full-time program of therapy individualized to your child’s needs either within your home or a specialized center (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). The social skills and social competence of ASD children are being developed and improved by Social Skills Groups formed in the Somalia (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). Often, these groups focus on recognizing common social indications and learning skills like holding a conversation, negotiating play with peers, handling difficult situations, and even more advanced adult skills like job interviews and dating (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). Many children receiving special education will attend a social skills group as part of their educational intervention plan at school (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). In addition to this, a government body of Somalia called, The Minnesota Department of Human Services offers many services such as Home and Community based services

(provides services and supports to maintain children in their own homes instead of an institution ), Personal Care Assistance ( provides services to children who need help with day to-day activities to allow them to be more independent in their own home ), Family Support Grant ( provides funding to prevent or delay the out-of-home placement of children with disabilities and promote family health and social well-being by facilitating access to family-centered services and supports ), etc. to help children with more severe disabilities. Moreover, there are many national resources available to help ASD children such as “Association of Maternal and Child Health Programs “for improving different programs held to help ASD patients (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013).

In a research study carried in Georgia stated that provocative and uncorroborated treatments are a waste of time, energy and moneys. Additionally, it stated that these programs have strategies that deliver inadequate services and treatments to the children with ASD and their families (Hess et al., 2008).

In many countries various laws and regulations are being enforced and implemented to help ASD patients. For example in United States of America ( USA ), under the U.S. federal law known as the Individuals with Disabilities Education Act (IDEA), children with disabilities, including those with autism spectrum disorders are eligible for a range of free or low-cost services (Helping Guide.org, n.d.). Under this, children and their families may receive medical evaluations, psychological services, speech therapy, physical therapy, parent counseling, and training, assisted technology devices, and many more (Helping Guide.org, n.d.). Also, in USA, infants and toddlers up to the age of two receive assistance through a program known as “Early Intervention Program “. (Helping Guide.org, n.d.). In USA, under the law of education for its citizens, the autism students are provided with autism special

education services (Autism Speaks. Org, n.d.). Under this, children over 3 years receive assistance through school based programs. Children with autism spectrum disorders are often placed with other developmentally-delayed kids in small groups where they can receive more individual attention and specialized instruction (Autism Speaks. org, n.d.). In some countries, special attention is giving to adult autism patients even. For example, in California of USA, special clinics have developed for adult autism patients (Autism Speaks. org, n.d.).

According to a report published by the Health Service Advisory Council of Australia, there are many different types of effective coverage parameters and interventions that reduce the symptoms of ASD (Ontario Ministry of Children and Youth Services, 2010). Since there is no cure for ASD at the moment, treatments are designed to decrease symptoms. Interventions can range from prescription drugs to address particular symptoms to allied health interventions (such as speech, occupational, and physical therapies) to improve delayed social, communication and physical skills (Ontario Ministry of Children and Youth Services, 2010). According to this report, different kinds of intensive behavioral and developmental interventions like Applied Behavioral Analysis, Naturalistic/developmental principles, Parent/family-based training etc. can be very effective for ASD patients (Ontario Ministry Children and Youth Services, 2010).

Researchers have examined a full range of interventions that have been studied to treat ASD or associated symptoms. Applied Behavioral Analysis, Parent training approaches, social skills training, play- and interaction-based interventions, cognitive behavioral therapy, Nero – feedback, sleep interventions, etc. (Health Services Advisory Council, 2013). Also, other health interventions include speech, occupational, movement and music therapies and animal-assisted interventions (such



as horseback riding therapy) (Health Services Council, 2013). Complementary and alternative medicine interventions include massage and acupuncture (Health Services Council, 2013).

There are many other various services provided in various forms in different parts of the world. For examples in some countries, support services in the form of advice, information, materials, consultation and training for families are provided. (Child Autism Parent Café, n.d.) Also, in the form of School Support Program children and youths are helped and guided by trained teachers (Child Autism Parent Café, n.d.). Through School Support Programs, they provide training and instructional workshops to principals, teachers, teaching assistants and other educational support staffs, consult with individual educator, provide in-school consultation, and identify other community supports available to teachers, students and families. Respite services are also practiced in some countries (Health Services Advisory Council, 2013). This involve, caring and providing families with temporary relief, in which these services allow children and youth to participate in meaningful activities that will help them learn new skills and build relationships (Health Services Advisory Council, 2013). Summer camps are also a form practiced in some countries, which help children and youth with autism to build new skills and have fun (Child Autism Parent Café, n.d.).

Many more services provided by the other countries for their autism patients include, diagnostic assessments, where detailed observations and interactions are made about the patients (Health Services Advisory Council, 2013). Functional assessments are practiced in some countries which involve providing an insight into the current level of performance of the child in various skill areas such as motor, speech, communication, imitation, cognition and activities of daily living (National Center for Autism, n.d.). Occupational and sensory assessment is also practiced in parts of the

world in which a detailed assessment is made based on a sensory profile questionnaire which addresses all the sensory systems in depth, and a comprehensive evaluation of the child is done using observation and feedback from parents (Health Services Advisory Council, 2013). Job training programs is a very effective service provided in many countries, in which young adults with autism are trained for various job skills depending on their preferential jobs (Health Services Advisory Council, 2013).

## **2.5 Situation of Maldives**

In Maldives, no research has been conducted to assess the prevalence and incidence of ASD, services available to children with ASD and other subjects related to ASD. Hence, I found it impossible to get an estimation of the number of children living with ASD in Male'. However, there are a few hundreds of children undergoing the intervention programs conducted at institutions in Male'. Also, the institutions that provide services to the children with ASD are few in number. The main institutions are Care Society of Maldives (CSM), Maldives Autism Association (MAA), SEN class at Imaaduddin School and recently opened Maldives Institute for Psychological Services, Training and Research (MIPSTAR). They work to improve the mental wellbeing of the individuals who seek help from them. Though the parents of the children with ASD are conscious about the problem, the government authorities seem not so concerned. This statement is obvious, since there has not been a study conducted at national level regarding autism. Additionally, most of the special need programs and educational curricula are established at private caregivers. The SEN class at Imaaduddin School is the only well-known education program conducted in a governmental body to help the children with ASD.

The studies conducted worldwide have shown the importance of early intervention programs and other essential services needed for the children with ASD. These

programs are carried out at different institutions to assist the children with ASD to develop their interaction level, communication and other behavioural actions. In addition, the parents are provided assistance to cope with stressful situations from the specialized institutions.

## **2.6 Conclusion**

In conclusion, this chapter has attempted to justify several research results, discussions and implications originated in the existing literature. Additionally, various ideas on services available to the children with ASD have provided a precise platform for my research study.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 Introduction**

This chapter describes the several tools and techniques used to carry out the research. The research design, study population and sample, instrumentation and framework of data analysis are the main elements discussed in this chapter.

#### **3.2 Research Design**

The institutions which provide services to people with disability are increasing yearly. They are the people who provide essential and special requirements to those who suffer with the disability. There is a need for these service providers to focus in delivering services regarding the needs of the clients or users, as well as to achieve a high level of satisfaction from them. In addition, due to the increased prevalence of autism in Maldives, trying to meet or exceed users' expectations in these institutions helps to maintain quality services and ensures the services are up to date. This is why I have chosen to focus my study on the services available to the autistic children and their families. As well, with the innovative technologies and modern challenges, the services need to be changed to offer quality services. It is important to ensure that the services that are offered match the needs of the autistic children and their families.

In relation to my study, I believe that there is a veracity that can be apprehended; autistic children and their families need services for the healthy development of the children as well as to help reduce stress and other mental disorders in their families.

This tilts my study in the direction of an objectivist way of viewing the social phenomena.

This study is a descriptive cross-sectional study which is based on the services available to the autistic children in Male' and the strategy used is quantitative in nature. I used this strategy because it is applicable to answer my research questions. This strategy permits to measure the variables derived more effectively and brings out the variations in people in terms of weighing their perceptions about the services available. This provides research findings with high validity and reliability. A descriptive cross-sectional study is considered as an inexpensive method and it takes less time to carry out the study. This type of study is very useful in informing the planning and allocation of health resources. The main strength of this study is that it can be applied to the whole study population at the time of the study or at a certain period of time. This type of research can be used to define characteristics that exist in a population and to collect preliminary data to help and support additional research and testing.

### **3.3 Population and Sample**

The study was conducted at the SEN (Special Education Needs) class at Imaaduddin School, Male', Maldives. There are 77 students studying at the SEN class. Even though the study population is the autistic children living in Male', the sample was taken from Imaaduddin School alone. Parents try to obtain each and every service available and try to provide their children with the services. They seek for the services available at every institution for the development of their children. As well, the parents in our society consider fulfilling the needs of autistic children as a high priority. Therefore, the needs and services available to autistic children and their families could be understood from a small sample. Hence, I have randomly selected

the participants and included a group of 30 parents of autistic children studying at SEN class, Imaaduddin School. The parents were selected as they would be the best people who could provide effective and sufficient information about their autistic children. In order to conduct the study each parent who participated in the study was given a questionnaire to complete. Besides, I have ensured that the questionnaire is completed by the parents in order to make findings fully dependent on them.

In addition to these questionnaires, 3 teachers at the SEN class were asked specific questions around parents' concerns and considerations to the future of their children and the specialized programs or services they receive. Likewise, I have asked specific questions as an interview to 2 specialists who influence or are a part of the treatment of children and adults with autism in Maldives.

### **3.4 Instrumentation**

The research instrument used in my study was a self-administered questionnaire. The questionnaire is attached with a letter which explains the purpose of the study. Additionally, the questionnaire is divided into two sections. The first part is designed to acquire the general knowledge of the parents regarding the services available to the autistic children. Similarly, the second part asks about the services available in Male' as well as the services they need the most. In both the sections, the majority of the questions are closed-ended questions. Therefore, the results of the questions are easy to relate, tabularize and evaluate. They offer efficiencies to the researchers and are fast to administer. However, there are questions that ask for parents' views and perceptions. Moreover, the last part of the questionnaire is intended for additional notes and comments of the parents.

Before the research was conducted, a pre-test was done using 5 questionnaires. The questionnaires were given to 5 parents of 5 autistic children. It was done to identify if the questionnaire was able to accumulate the required data as expected. Additionally, it was done to seek out if the questionnaire was easier to understand as well as to find out vague and confusing questions in it. The validity and reliability of the questionnaire was tested in the pre-test. After that, the questionnaire was used in the survey conducted at SEN class, Imaaduddin School. It was conducted on a week day. When the parents attended the school with their children, with the help of a teacher, the participants were randomly selected with their will.

### **3.5 Framework of Data Analysis**

In my study, both primary and secondary data sources have been used to answer the research questions. Primary data has been collected via the self-administered questionnaires and secondary sources like past studies and archives have been accessed from several databases like Doaj and PubMed. This was done to gather a number of reliable literature and empirical findings that can be applied in order to have a better understanding of the services.

Since the study was a quantitative research, quantitative analysis should be carried out using statistical tools. There are various software packages to analyze quantitative data and some are wide-ranging in scope and others are user friendly. As Microsoft Excel 2010 is user-friendly and easy to master, I have chosen it to analyze the results of my study.

### **3.6 Ethical Considerations**

I am going to treat any data I get from any individual confidentially without disclosing the participants identity. As well, I am going to be as open minded as

possible and express views as they are given. I will not alter any information and I am going to be very obliged of the literature that has contributed in any mode to my study.

### **3.7 Conclusion**

This chapter covers the methodology used in this research study. Information about research design and instrument and sampling of data collection has been explained. Lastly, I have discussed the ethical considerations.



## **CHAPTER 4**

### **DATA ANALYSIS AND RESULTS**

#### **4.1 Introduction**

This chapter presents the results and analysis derived from the survey carried out. The response rate was 100% since I received responses from the targeted 35 respondents including parents, lectures and specialists. In addition, the 30 parents who participated in this study completed the questionnaire by answering all the questions included in it. The responses gathered from the survey have been analyzed using Microsoft Excel 2010 software. This chapter merely focuses on presenting the gathered data meaningfully to facilitate the discussion, which will be presented in Chapter 5.

This chapter initially provides the background to the participants by evaluating their demographic information. This is followed by results and analysis of data, and the summary.

#### **4.2 Survey Results**

##### **4.2.1 Data Description**

The main objective of the analysis of primary data collected from survey as presented in the previous section is to answer my research questions which include finding out the services available to the autistic children and their families. This will support me to achieve the objectives of my study since primary data are more reliable.

#### 4.2.2 Background of the participants

Data analysis for this research was completed in two stages, the preliminary analysis and the key analysis using Microsoft Excel 2010. For preliminary analysis which consists of principally descriptive statistics to summarize data, the demographic features of the participants were defined to simplify the understanding of the data. The key analysis consisted of factor analysis whose determination to seek out if there are adequate services available in the institutions of Male’.

Characteristic		Percentage (%)
Gender	Male	26.67
	Female	73.33

Figure 4.1: Personal Profile of participants (30)

As shown in the above demographic profile of the participants, 26.67% of participants were males and 73.33% were females. The main reason behind this was that mostly the children with autism spend time with their mothers. In addition, the mothers go along with children to the institutions including SEN class at Imaaduddin School.

### 4.2.3 Diagnosis and Initial treatment

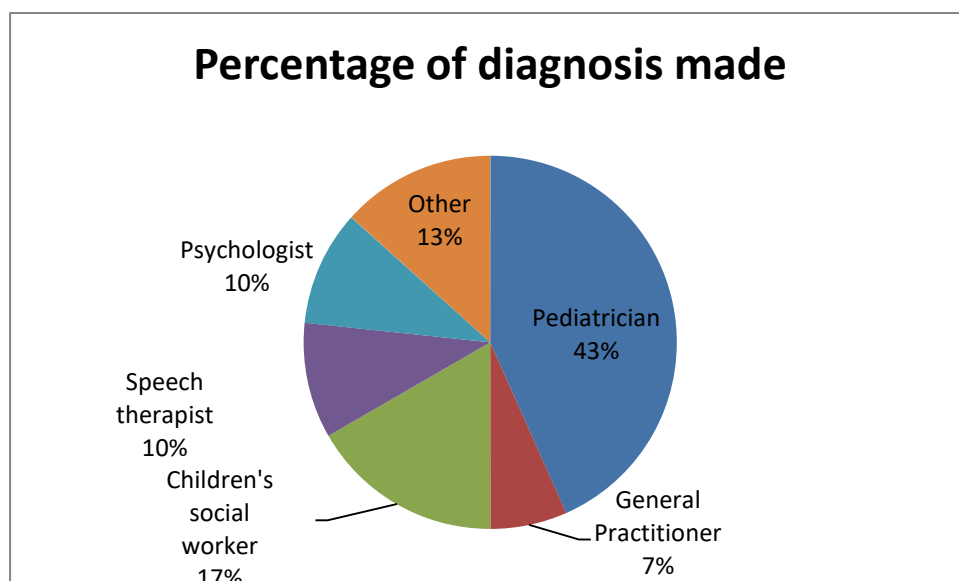


Figure 4.2: Percentage of diagnosis made by professionals

The above figure shows the professionals who have diagnosed the children as autistic as a percentage of the 30 respondents. It shows that the majority of the cases were diagnosed by a pediatrician and it covers 43%. Additionally, children's social workers have diagnosed 17% of the children as autistic children and 13% of the diagnosis were made by others and include the teachers or lecturers working at institutions assisting the children with autism. Similarly, 20% of the diagnosis was made by psychologists and speech therapists, which shares 10% for each professional. As well, 7% of the parents have said that their children were diagnosed by a general practitioner. This shows that the professionals at various institutions are aware of autism and its symptoms.

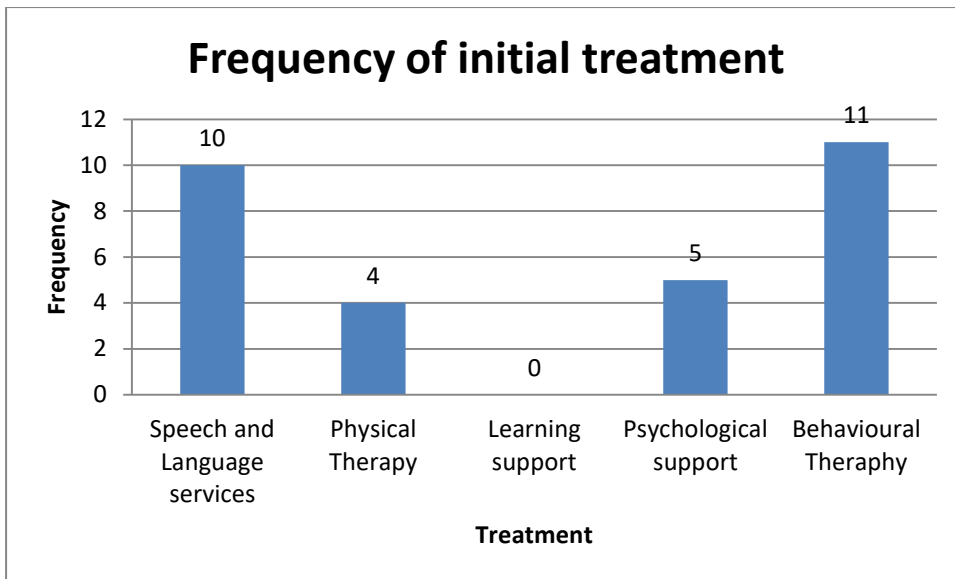


Figure 4.3: Frequency of initial treatment

The above graph shows the frequency of the initial treatment the parents provided to their children diagnosed with ASD. It shows that the majority of the parents have taken behavioural therapy and speech therapy as the foremost treatments as they count 11 and 10 among 30 respondents. In addition, 5 parents have gone through psychological support as initial treatment in order to reduce the stress in them. Additionally, some form of physical therapy has been utilized by 4 parents to minimize the physical weakness in their children.

#### 4.2.4 Services available

The services provided from various institutions in Male' differ slightly. The institutions lack resources including human resources, hence the services are limited. The below mentioned figure demonstrates the accessible services to the children with ASD. According to the parents who participated in this study, they have utilized the services available at every institution treating children with ASD in Male'.

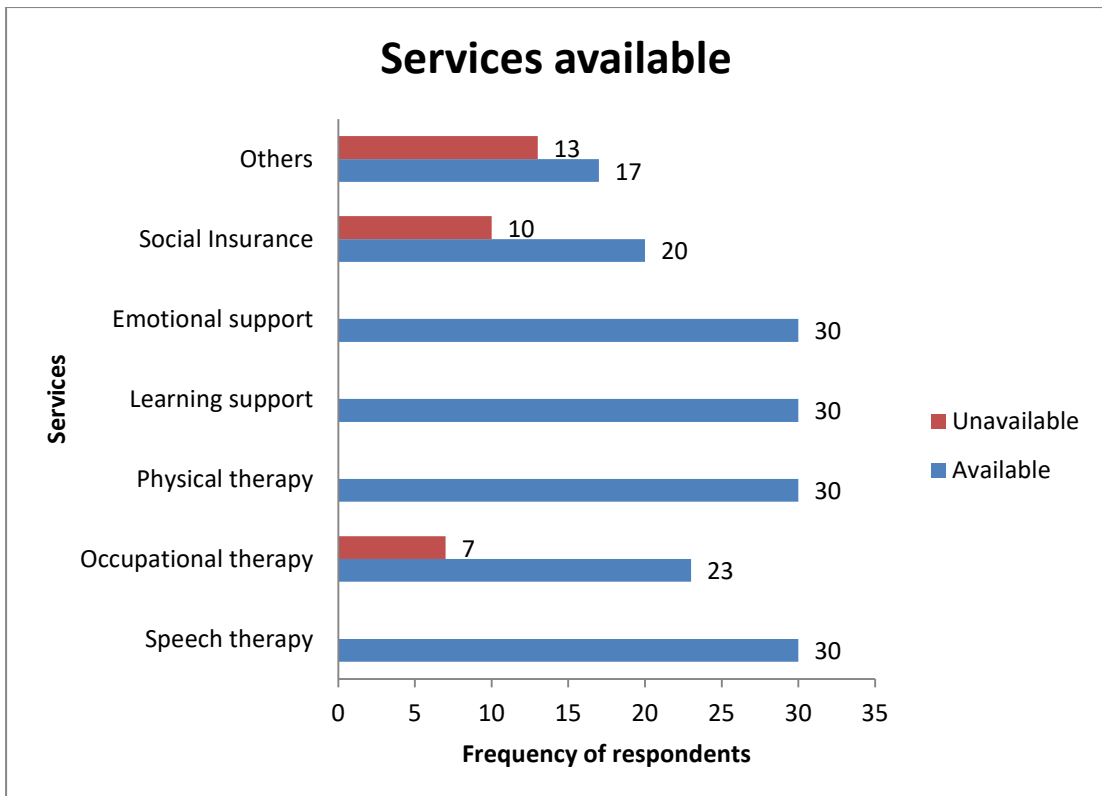


Figure 4.4: Services available at institutions in Male'

The 30 parents who participated in the study agreed that they receive speech therapy, physical therapy, learning support and psychological or emotional support from the service providers. However, according to the parents, educators and rehabilitators speech therapy is provided only by two speech therapists and one of them works at Indhira Gandhi Memorial Hospital (IGMH) and the other one works at MIPSTAR. Additionally, they mentioned that the therapy is ineffective and it consumes a lot of time to get an appointment. As the figure demonstrates, 23 parents agreed that occupational service is available in the institutions in Male', but 7 parents disagreed with it. On the other hand, 20 parents believed that they have a social insurance which helps them financially. However, 7 parents among the respondents said that they lack a social insurance policy which helps to treat specific disability in people. Moreover, 17 parents agreed that they receive other services like Islamic counseling from the

institutions. Meanwhile, they specified that MIPSTAR is an institution which provides Islamic counseling. Likewise, some institutions provide social interaction to the children and families by celebrating special days and events. These events are performed by them to provide social support to the children with ASD and to their families.

According to the parents, the government pays an allowance of MVR 2,000 per month which is given to each disabled person including the children and adults with ASD. As well, they have mentioned that they get wages from other private organizations and individuals when they find a way to gain specialized care from institutions abroad. Moreover, the National Social Protection Agency of Maldives offer special assistance financially when the parents are in need of it at the most. Furthermore, various organizations carry out fund raising programs and donate the funds to the institutions at national level, which indirectly help the individuals with ASD.

#### **4.2.5 Major challenges**

As said by the parents, the services they receive are paid. Maldives Autism Association collects a fee of MVR 500 for each child who obtains services there. In addition, MIPSTAR collects a charge ranging from MVR 300 to MVR 3,000 for the special therapies given there. A parent mentioned about an examination done for his child at one of the mentioned institutes. He said it has been a month since he has carried out the examination. However, to his notice the results are still in progress. Likewise, parents complained about the time they spend for the treatments.

When the parents seek for specialized care of the children with ASD, they have to sacrifice their vital time and sometimes end up not getting them when required. The

below mentioned figure illustrates the time they spend to get access to specialized care provided at Institutions established in Male’.

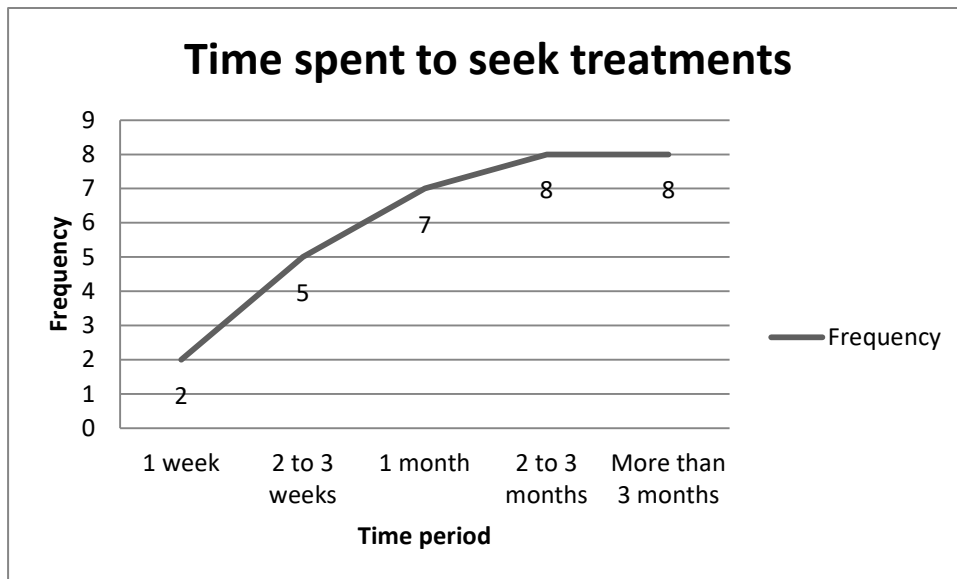


Figure 4.5: Frequency of time spent to seek treatments

The figure explains the time spent by the parents to seek specialized care or treatments needed by the children with ASD. According to 8 parents, they spend more than 3 months to get specialized care including speech therapy and behavioural therapy. Additionally, it takes 2 to 3 months for this purpose as said by 8 other respondents. A period of 1 month is spent for these services according to 7 parents among the 30. Also, 2 parents mentioned that they have to wait only a week to get those treatments and 5 parents said the time period they spent is 2 to 3 weeks. These results show the lack of human resources and unavailability of sufficient services and treatments for the increasing incidence of ASD in Maldives.

#### 4.2.6 Awareness and other supports

Since I have assessed the perceptions of the respondents in this study, they have identified what they deem as the most important services their children require. Some

of the parents said that they require specific services relating to the condition of the child and to the extent he or she is affected. Alternatively, others believe that the services provided from the institutions are helpful, but they need to be developed. In addition, majority of the parents are aware of the speech therapy, behavioural therapy, special education needs programs and psychological support. Also, they stated that these services are the most important for their children and for them as well. Besides, 60% of the parents agreed that they receive psychological support effectively from the service providers when required. The other 40% of the parents disagreed with the statement. Moreover, 50% of the respondents mentioned that the social support is increasing in the society as the individuals are more aware of ASD now and they agreed they get full support from the community. Respectively, 50% of the respondents believed that they do not receive adequate social support. The figure below illustrates the percentage of psychological and social supports the families of the children with ASD get.

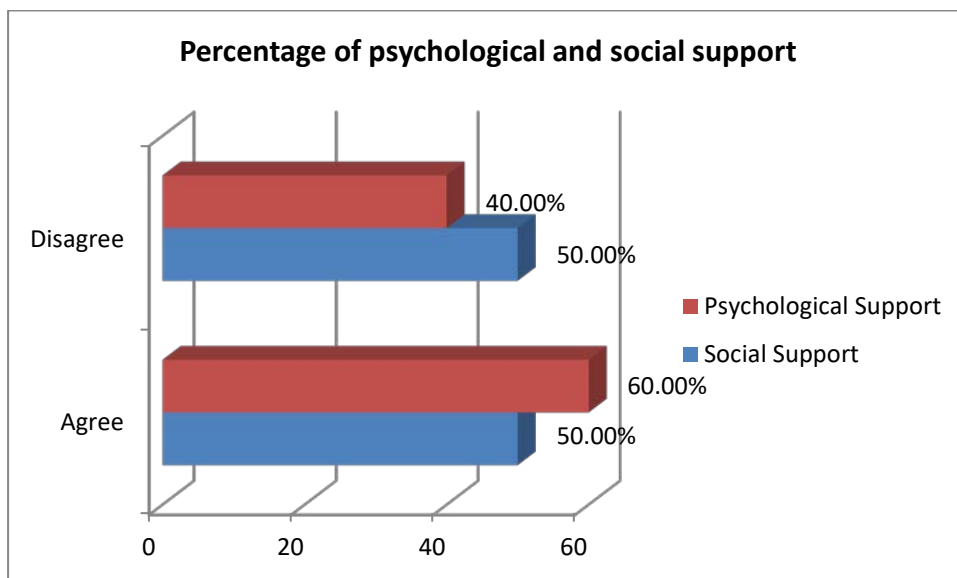


Figure 4.6: Percentage of psychological and social support received



#### **4.2.7 Educational Interventions**

When asked about the educational program conducted at SEN class, Imaaduddin School, 84% of the parents agreed that the curriculum is effective, while 16% of the parents strongly disagree with this. In their view, the effectiveness is measured by the presence of well trained teachers and other resources at the institutions. In Imaaduddin School, about 3 teachers are with experience and knowledge to teach the children with ASD. Some of the parents believe the classes conduct at SEN class, Imaaduddin is better than the previous education programs their children took part in. Similarly, the children are provided with tuition by the educators at their homes. Also, they collect a fee of MVR 500 for a tuition program conducted for 3 days a week as said by parents. At the same time, the parents mentioned that the effectiveness of tuition classes is greater if the classes are taken separately for each child.

#### **4.2.8 Follow-up care**

Over the past three months, most of the parents have gained assistance from the professionals. According to 15 parents, they have shown their children to a pediatrician. In addition, the speech therapy has been taken by 5 children of the respondents. Moreover, as said by 3 parents, they have visited a psychologist. Furthermore, 7 parents have taken their children to a social worker. These have been analyzed excluding the routine classes they visit to gain knowledge and skills.

#### **4.2.9 Perceptions of parents and professionals**

Many of the parents were concerned that there is no well-equipped institution to treat autism in Maldives including Male'. The specialized care is delivered ineffectively as a result of lack of human resources, infrastructure and other material resources. The teachers and specialists who participated in this study stated that they require the government support. As well, they mentioned about the lack of professionals in the

area of concern. Their programs are conducted by referring to the programs carried out worldwide. According to them, they have initiated the programs to assist the people with ASD in order to provide essential support and care.

### **4.3 Conclusion**

In conclusion, the chapter has presented various statistics and relevant analysis. In relation to my study, overall respondents were unhappy about the services they received from the service providers. In addition, their main concern was the lack of an infrastructure where each child of ASD can get the services regarding the needs of that child. Moreover, majority of the parents agreed that the money spent is not worth for the treatments that are existent in Maldives.

## **CHAPTER 5**

### **DISCUSSION AND CONCLUSION**

#### **5.1 Introduction**

This chapter presents a discussion based on the results and analysis conducted in the previous chapter of this study. Information on facts and figures as well as results will be discussed in this section. Additionally, this section will convey the cross-references to the relevant literature. At last, a conclusion will be defined.

#### **5.2 Discussion on parents' satisfaction**

I have studied the services available to autistic children and their families from the institutions located in Male'. I found that the respondents are aware of the services provided, but are not entirely satisfied with most of the services they receive. Looking at individual dimensions I realize that parents expect a lot from the service providers or institutions. The service providers need to pay a lot of attention to the variety of services they provide. With the increasing incidence of ASD in the country, the services provided by the service providers need to be broadened.

As said by law, everyone has equal rights and there should be no gap in seeking the services that are most needed for the specific group. From the results obtained in my research, I have found that the private sector is working extensively compared to the relevant authorities of the government. However, the government provides MVR

2,000 as an allowance which is a little amount when considering the current situation of the country. As well, the tertiary hospital of the government, IGMH provides a few specialized services to the children with ASD. The Helping Children program commenced in Australia aided the children with ASD by means of health insurance scheme by which overall expenses are provided to the parents in diagnosing and treating children (Australian Government, April 2014). In poorly developed Somalia, “Autism Spectrum Disorder Clinic “has been developed and it assists the children through an insurance scheme (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). In USA, under their federal law, children with disabilities including children with ASD are provided with free or low-cost services. Since the insurance scheme in Maldives does not definitely specify about disabled people including autism, it is vital to include a special scheme to help them. With such an approach, the burden faced by the parents could be solved since they state that the services are not financially worth it.

### **5.3 Discussion on specialized services available**

According to the results obtained in my study, the specialized care is mostly provided through private institutions and their competency is very high. In order to improve the quality and variety of services provided, the institutions could collaborate and develop the treatments they provide. The Minnesota Department of Human Services provides a wide range of home and institution based services to the children with ASD and they do this by means of a community approach (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). In Male’, previously the social support was lacking. However, as my study results explain, with the increase in awareness about ASD, people tend to give respect and assistance to the people affected, Therefore through a community approach and collaboration of

institutions, quality and easily accessible services could be provided to the people in need.

A survey conducted in Macedonia showed that majority of the parents, educators and rehabilitators believed the early intervention programs should be started before the third year of life of the children (Jasmina, 2009). According to the results obtained in my study, the children are diagnosed with ASD at early years of life and are referred to specialized care though they are limited. Therefore, I could say that the diagnostic measure is quite good in the institutions established in Male' and the services are accessible whenever required by the parents. However, it was found that parents have to spend a lot of time to seek specialized services of ASD after diagnosis. The main reason for this was the lack of resources both human and material. As a result of this the children are sometimes faced with unavailability of services when they require it the most.

Even in Male', a limited number of the services required by the children with ASD has been established as shown in the results. The Health Service Advisory Council of Australia mentioned in a report that there are many different types of effective coverage parameters and interventions that reduce the symptoms of ASD (Ontario Ministry of Children and Youth Services, 2010). Also, the services or programs range from prescription drugs to intervention programs designed to improve symptoms or disorders of ASD including poor social interaction, communication and physical skills (Ontario Ministry of Children and Youth Services, 2010). In Maldives, the institutions at Male' provide majority of the specialized services. They consist of behaviour therapy, speech therapy, relaxation techniques, religious counseling, parental counseling, special and remedial education programs, physiotherapy and occupational therapy. In addition, they provide intelligence and diagnostic testing, learning

disability assessment and psycho-educational testing. These services are provided by a limited number of staff in each institution and it is a big concern of the service providers. Even the caregivers are in need of specialized and trained staff in the area of ASD.

#### **5.4 Discussion on educational interventions**

The education programs conducted for the children with ASD should be in accordance to the needs of the children. Among the respondents who participated in a study carried out at Macedonia, 1 percent of parents had concerns regarding higher number of children in groups, unsuitable core curriculum and maladapted environments and lack of other resources needed by children with ASD. These are the main reasons for the failure of educational intervention programs for children with ASD. The Social Skill Groups play a key role in improving and developing social skills and competence of ASD children of Somalia (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). Usually, these groups concentrate on identifying common social indications and learning skills like holding a conversation, negotiating play with peers, handling difficult situations, and even more advanced adult skills like job interviews and dating (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). Most of the children receiving special education needs will attend a social skills group as part of their educational intervention plan at school (Minneapolis Somali Autism Spectrum Disorders Prevalence Project Community Report, 2013). In my results, it showed that most of the parents are satisfied with the SEN class, Imaaduddin School. In SEN class, the programs are designed in ways that interest the children towards communication and social interaction. However, according to a lecturer, they find difficulty in adapting some children to the environment. In addition, she mentioned

that teaching for a large group of children with ASD is a difficult task. Thus, the program should be developed in a more child-friendly way which makes the students feel more comfortable in that environment. The classes at Maldives Autism Association and Care Society of Maldives as well as MIPSTAR are described by some parents as very costly and unaffordable. However, all these places comprise a long waitlist of children wanting those services. Hence, this shows that parents are in need of such services but would appreciate lower costs. Alternatively, the government could help in it by offering donations or other financial support. A unique curriculum could be generated for all the institutions with the cooperation of related authorities. With a unique curriculum along with trained staff could bring up an effective educational intervention program for the children with ASD.

## **5.5 Conclusion**

This chapter discussed the results and analysis carried out previously. In summary, from the results obtained, it is seen that the parents' expectations are not reached by the service providers, though there are a number of services available. In this regard, parents are not fully satisfied with the services provided. Hence the service providers need to make improvements in the services, which would increase the effectiveness of the interventions and parents' satisfaction. Evidence from the study showed that services are available to the autistic children and their families at various institutions in Male'. Nonetheless, the services need to enhance these children's well-being and capacity to cope in different situations. Moreover, the satisfaction of the parents towards the services could be improved by collaboration, training and funds that would improve the quality of the services of ASD.

Furthermore, services needed to improve the mental health of the parents and other family members are lacking in the institutions. Since they are mentally affected, they

need psychological support and care. From my study, it demonstrates that services are solely based on treating the people with ASD, rather than treating their parents. As well, the parents are in need of social support that would enable their children to live peacefully in the community. In regard to my research study, the overall objectives of the study have been achieved which will help to understand the accessible services to children with ASD and their families.

## **5.6 Limitations**

There are a number of limitations related with this study that require to be discussed. At first, the results obtained from this study cannot be generalized to the islands other than Male' because the sample was only taken from the SEN class, Imaaduddin School in Male'. However, the methodology used in this study could be applied to similar situations or areas of concern. Also, due to absence of services in other islands, knowledge of these services in parents would be lacking, thus the perceptions could be questioned. Moreover, due to the little support from the government to carry out this study, the tasks carry out by the government has not been considered for this study.

However, the above limitations are less significant compared to the significance of carrying out this sort of study. Studies related to ASD should be conducted frequently in order to monitor the services available to children and parents as well as to improve the quality of services provided by the caregivers or service providers.

## **5.7 Recommendations**

### **5.7.1 Suggestions for Further Research**

There have been various limitations specified in this study including non-normal dispersal of data set. Hence, further research should be carried out in Male' as well as



in other areas to understand the quality of lives of children with ASD and hence to improve their quality.

### **5.7.2 Services**

The services provided from the institutions should provide better services for the healthy well-being of the children with ASD and their families.

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Helping Children with Autism

## APPENDICES

### **APPENDIX A: Cover Letter**

#### **Cover Letter**

Dear parent,

#### **Re: Services available to autistic children and their families – Research Project**

I am a student at Faculty of Health Sciences, Maldives National University. This is my final year and it is a requirement to do a dissertation (research) in order to complete my Bachelor of Primary Health Care course.

Therefore I would like to invite you to take part in a research project by filling in the enclosed questionnaire.

The study is intended to take part for the parents of autistic children at Imaaduddin School, Male', Maldives. By taking part you will inform service providers about the

services needed for your children. The aim of the research is to provide information that can help to improve services for autistic children and their families.

Thank you for your time.

Yours sincerely,

Ali Shafiu

(Bachelor of Primary Health Care/2<sup>nd</sup> batch)

## **APPENDIX B: Questionnaire**

### **Services available to autistic children and their families**

#### **Questionnaire for parents**

This questionnaire asks about the type of services your son/daughter and your family receives from the centers caring autistic children. The aim of the questionnaire is to give me an idea of how the services work for your family. It will take about 15 minutes to complete and mainly involves ticking boxes. There is also an opportunity to write additional comments if you would like to.

If you want to take part in this research but do not want to answer some of the questions, just leave them blank.

All information which is collected during the course of the research will be kept strictly confidential. Your name would not be asked to write on the questionnaire so that all the information is anonymous.

#### **Section A: (General knowledge)**

1. Please tick:  
Gender                      Female     Male
  
2. Which of the professionals has diagnosed your son/daughter as an autistic child?
  - a) Pediatrician
  - b) General Practitioner
  - c) Children's social worker
  - d) Language and Speech Therapist

- e) Psychologist
- f) other

If other, please specify\_\_\_\_\_

3. After diagnosis, what was the initial treatment given by the professional?

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4. Which of the following services do you get from the service facilities for autistic children?

- a) Speech and Language services
- b) Occupational therapy
- c) Physical Therapy
- d) Learning support
- e) Emotional support
- f) Financial support/Social Insurance
- g) Others

If others, please specify\_\_\_\_\_

**Section B: (Contact with the services)**

1. Does your child receive any financial support from the government/NGOs? Please specify

---

2. Do you have to pay any amount to see a speech therapist, behavioural therapist or any other professional related to autism?

- a) Yes
- b) No

If yes, please specify\_\_\_\_\_

3. How long do you have to wait to see a professional like speech therapist or social worker?

- a) One week
- b) Two to Three weeks
- c) One month
- d) Two to Three months
- e) More than Three months

4. In your opinion, what are the services needed by the autistic children the most?

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5. Do your family members receive any treatment (emotional and practical support) or social support from the service providers or any other NGO?

---

6. Do you get enough support from other family members and whole society?

a) Yes

b) No

7. Do you send your child to any other educational program conducted at another facility?

If yes, please

specify \_\_\_\_\_

8. The special education class for autistic children at Imaaduddin School is effective.

a) Strongly agree

b) Agree

c) Neutral

d) Disagree

e) Strongly disagree

9. In the past three months, has your child seen any of the professionals?

a) Hospital doctor

b) Children's social worker

c) Physiotherapist

d) Speech and language therapist

e) Psychologist

f) Pediatrician

g) Occupational therapist

10. Does your child get enough educational support or special education needs in Male'?

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11. Are you familiar with the services provided at Autism Association of Maldives and Care Society?

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12. In your opinion, are the educational programs conducted at autism support centers effective?

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13. Please note any specific comment on the services available or any improvements you would like to see.

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Thank you for taking the time to fill in this questionnaire!