



# **Diagnosing Autism in the United Arab Emirates**

**تشخيص التوحد في دولة الإمارات العربية المتحدة**

**By**

**Mahmoud Mohamed Abdulrahim Mahmoud**

**Student ID number: 2015101017**

**Dissertation Submitted in Partial Fulfillment of the  
Requirements of the Degree of  
Master of Education in Special and Inclusive Education  
at**

**The British University in Dubai**

**Dissertation Supervisor**

**Professor Eman Gaad**

**March 2017**

## DECLARATION

I warrant that the content of this research is the direct result of my own work and that any use made in it of published or unpublished copyright material falls within the limits permitted by international copyright conventions.

I understand that a copy of my research will be deposited in the University Library for permanent retention.

I hereby agree that the material mentioned above for which I am author and copyright holder may be copied and distributed by The British University in Dubai for the purposes of research, private study or education and that The British University in Dubai may recover from purchasers the costs incurred in such copying and distribution, where appropriate.

I understand that The British University in Dubai may make a digital copy available in the institutional repository.

I understand that I may apply to the University to retain the right to withhold or to restrict access to my thesis for a period which shall not normally exceed four calendar years from the congregation at which the degree is conferred, the length of the period to be specified in the application, together with the precise reasons for making that application.

---

Signature of the student

## **COPYRIGHT AND INFORMATION TO USERS**

The author whose copyright is declared on the title page of the work has granted to the British University in Dubai the right to lend his/her research work to users of its library and to make partial or single copies for educational and research use.

The author has also granted permission to the University to keep or make a digital copy for similar use and for the purpose of preservation of the work digitally.

Multiple copying of this work for scholarly purposes may be granted by either the author, the Registrar or the Dean of Education only.

Copying for financial gain shall only be allowed with the author's express permission.

Any use of this work in whole or in part shall respect the moral rights of the author to be acknowledged and to reflect in good faith and without detriment the meaning of the content, and the original authorship.

## **Abstract**

Early identification and accurate diagnosis of autism improve the likelihood of favorable outcomes for children with Autism Spectrum Disorder (ASD). Thus, early identification and diagnosis of autism are gaining global attention. There are needs to avoid the negative implications of lack of diagnosis, misdiagnosing or over-diagnosing children with autism. The study aspires to contribute in improving the services for children in the United Arab Emirates (UAE) by examining the current situation, parents' views, and other stakeholders' views. The objective is to provide information that will help design better procedures in the country. A combination of surveys, interviews, and focus groups are used as sources of data for the study. This provides a view of the missing components and the challenges that is faced in the process. It provides insights into the difficulties, struggles, and gaps in the current system that need to be addressed to improve the services in the future. The study of the literature, identifying gaps in the development of diagnostic processes, diagnostic criteria, training and educating professionals need to be addressed to develop the process. This research pointed out concerns related to certain aspects of the service in the UAE. Some recommendations are outlined in the study to better enhance the services and to provide effective services for children with autism.

## Arabic Abstract

لقد حازت خدمتي التشخيص الدقيق و الكشف المبكر عن التوحد على الإهتمام العالمي في محاولة لتجنب الآثار السلبية المترتبة على إهمال التشخيص أو سوء التشخيص أو على المبالغه في تشخيص الأطفال باضطراب التوحد ، فخدمتي الكشف المبكر والتشخيص الدقيق للتوحد يزيدا من إمكانية تحقيق النتائج المرجوه للأطفال المصابين باضطراب التوحد . ولهذا فإن هذه الدراسه تطمح لتحسين خدمتي الكشف المبكر والتشخيص في دولة الإمارات العربيه المتحده عن طريق فحص الوضع الحالي للخدمتين من وجهة نظر الآباء والمعنيين بالأمر. كما عنيت هذه الدراسه بجمع قدر كافي من المعلومات عن طريق الإستبيانات والمقابلات الشخصيه ومجموعات النقاش. تساهم هذه المعلومات في تبيان العمليه التشخيصيه في الدوله والصعوبات التي واجهها الآباء خلال محاوله الحصول على الخدمات لأبنائهم. كما تبحث عن التحديات والصعوبات والفجوات في عملية التشخيص بشكل كلي بغرض تحسينها في المستقبل . بينما يوضح هذا البحث الجوانب المختلفه في خدمه داخل الدوله فإن دراسة الأدب العالمي الخاص بالكشف المبكر عن التوحد وتشخيص التوحد يبين الفجوه في تطور العمليه التشخيصيه ومعايير التشخيص وكفاءة القائمين على الخدمه ويساهم في إبراز مجموعه من المقترحات والتوصيات التي من شأنها أن ترفع وتحسن مستوى الخدمات المقدمه لأطفال التوحد بداخل دولة الإمارات العربيه المتحده.

## **Dedication**

*“This work is dedicated to my beautiful beloved wife Safa for all the days and nights she spent without me and for her endless patience, understanding and support, Thanks for ensuring the right environment at home and thanks for being the way you are. This work is genuinely dedicated as well to my sweet little daughter Nada for making sure I’m on task, checking my progress every day and for that amount of patience she showed in such a young age, and for my brilliant son Tameem for every time he asked me to play with him and I couldn’t and never giving up on me”.*

*“Thank you, I Love you all”*

*Mahmoud Abdulrahim*

## **Acknowledgement**

I would like to thank my dissertation supervisor Prof. Eman Gaad the dean of the faculty of education at The British University in Dubai. The door to Prof. Gaad office was always open whenever I had a question and through all those moments of doubts about my research or writing. She consistently steered me in the right direction and added priceless knowledge to my experience as a practitioner throughout the entire Masters' courses..

I would also like to thank Dr. John McKenny and Dr. Sufian Forawi for offering collegial guidance and support they during the time of this Masters' degree and dissertation.

They say "Always keep notes of who supports you genuinely, those are the people you should always keep around" therefore I would like to acknowledge those friends for proofreading my work since the very beginning; "Sean, Jared, Tim, Rasha, Alan, Zachary, Megan, Nicole, Kasia and Flip". Without their passionate participation and input, the validation survey could not have been successfully conducted.

Finally, I must express my profound gratitude to my parents and my family for providing me with unfailing support and continuous encouragement throughout my years of study and through the process of researching and writing this dissertation. This accomplishment would not have been possible without them. Thank you.

Author

Mahmoud Abdulrahim

## Table of contents

1	Chapter one .....	9
	Introduction .....	9
1.1	Background .....	9
1.2	Purpose of the study .....	10
1.3	Research Question.....	11
1.4	Rationale and significance of the study.....	11
1.5	The UAE context.....	13
1.6	Early identification and diagnosis procedures in the UAE .....	14
1.7	Chapter organization .....	14
2	Chapter Two.....	16
	Methodology .....	16
2.1	Rationale .....	16
2.2	Theoretical Framework .....	17
2.3	Research Design.....	18
2.3.1	Quantitative Data .....	18
2.3.2	Qualitative Data .....	19
2.4	Participants.....	21
2.5	Assumptions and Limitations.....	22
2.6	Summary .....	23
3	Chapter Three.....	24
	Literature Review.....	24
3.1	Introduction .....	24
3.2	Diagnosing Autism: A Global Perspective .....	24
3.3	Diagnostic Instruments.....	28



3.4	Parent Satisfaction with Diagnostic Procedures.....	30
3.5	Diagnosing Autism in the UAE .....	33
3.6	Conclusion .....	35
4	Chapter Four .....	38
	Research findings and discussion.....	38
4.1	Introduction .....	38
4.2	Quantitative Survey Data .....	38
4.2.1	Part 1 - Questions about the system in the UAE .....	40
4.2.2	Part 1 Summary .....	46
4.2.3	Part 2 - Questions about individual parent experiences .....	47
4.2.4	Part 2 Summary .....	54
4.3	Qualitative Data .....	54
4.4	Summary .....	59
5	Chapter Five .....	60
	Conclusions and Recommendations .....	60
5.1	Conclusion .....	60
5.2	Recommendations .....	62
6	References .....	65
7	Appendices .....	70
A)	Parents Survey and Consent Form .....	70
B)	Focus Group Consent Form .....	73
C)	Interview Consent Form.....	74

# **1 Chapter one**

## **Introduction**

### **1.1 Background**

The number of children diagnosed with autism continues to grow. Although there is no cure for autism, children that receive early intervention have better outcomes in terms of functionality than those who do not. This makes it particularly important to diagnose the disorder as early as possible so that intervention can begin. The ability to detect and diagnose autism is improving on a global scale. Caregivers and professionals play a crucial role in the early identification and diagnostic process of the child.

Early diagnosis and intervention improve the quality of service delivered to children with autism and the likelihood of favorable outcomes. One of the problems faced by professionals is that as the number of children with autism increases, the children become vulnerable to misdiagnosis, overdiagnosis, or lack of diagnosis altogether (Waltz 2002). This issue has drawn the attention of the World Health Organization (WHO), which has indicated that there are many children with autism who remain unidentified or are mislabeled as having another disorder around the world (WHO 2014). This means that unidentified children are not receiving the early intervention that they need in timely manner.

The topic of early identification and autism diagnosis is gaining global attention. The instruments used for diagnosis are continually being revised and amended to ensure higher accuracy and reliability. Cundall (2002) mentioned that attention to the diagnosis procedures has resulted in significant progress. However, there are still needs to be met in the field of early detection and diagnosis of people with autism. Countries and concerned authorities around the world are working towards better diagnostic procedures in cooperation with the WHO. This organization focuses on sharing information and adopting better practices for the diagnosis of autism. In this

context, the UAE works towards improving the service in the country through the Ministry of Health in conjunction with the Ministries of Social Affairs and Education.

This study falls within the realm of both professional and personal interests. Several factors drive the curiosity to research this specific area about the UAE. This study is of a professional interest as the researcher is a current teacher in the field of teaching students with autism, serving over the last ten years in more than one school spread throughout multiple Emirates. During that time, it appeared that parents and teachers of students with autism lack access to essential information about the nature of autism diagnosis and early identification procedures, which causes delayed diagnosis for the affected students. Also, parents face a considerable amount of confusion and disappointment before, during, and after the process of diagnosing their children.

Moreover, regardless of the number of the centers that specialize in teaching students with autism, they do not all necessarily provide essential diagnostic services. The lack of diagnosis or misdiagnosis can negatively affect a student's placement, academic performance, and social life, in addition to the significant effects on their families and community both inside and outside the school system. Finally, the number of qualified professionals who have sufficient experience in diagnosing autism in the UAE is not adequate compared to the number of the children in need of appropriate diagnosis. Those reasons are the driving force for wanting to study the diagnosis of autism in the UAE.

## **1.2 Purpose of the study**

The number of people diagnosed with autism is increasing (WHO 2015). This rise in the incidence of the condition creates a responsibility to enhance the early identification and diagnosis procedures for autism to become faster, more affordable, more accurate and more reliable. This study aims to provide an in-depth look at the current status of diagnosis procedures for autism in UAE. It explores the process that parents follow to achieve a diagnosis, from early abnormalities to the final diagnosis from a professional.

The study focuses on parents' lived experiences about the difficulties they faced before and during the process of getting their children diagnosed. The study explores parents' level of satisfaction with the services in the three major cities of the UAE (Abu Dhabi, Dubai, and Sharjah). This study aims to bring attention to the deficits in the services and eventually will help decision makers to overcome those deficits and bridge the gap between the theory and practice in diagnosis. Additionally, the study strives to save children from being misdiagnosed, over diagnosed or remaining undiagnosed with autism due to its similarity in symptoms to other disabilities (Waltz 2002). The ultimate goal of this study is to support families and children with autism in getting appropriate and timely diagnostic service. This support will also help the children with autism to reach their maximum potential as independent and contributing members of the UAE through a research-based group of recommendations.

### **1.3 Research Question**

To serve the purpose of the study this research explores three main questions:

- What is the current status of autism early identification and diagnosis in the UAE?
- How do the parents perceive the process of diagnosing autism in the UAE?
- What are the recommendations to attenuate the deficits in the field of diagnosing autism to practice?

### **1.4 Rationale and significance of the study**

It is crucial for children to get an appropriate diagnosis at an early age. It is also crucial for parents to know what to do and where to go when they notice the first symptoms in their child. Cundall (2002) argued that early diagnosis and recognition of autism have substantial consequences for the ability to obtain appropriate health care, early intervention, and therapeutic services. This study portrays the researcher's personal experience as a teacher of children with autism for the last ten years a process of scientific inquiry. The last few years the researcher has witnessed

increased attention focused on this topic globally and locally. This attention stems from the growing need to avoid the negative implications of misdiagnosing children or over-diagnosing children with autism. Those implications can severely affect the children's progress and potential future. On the other hand, appropriate and accurate diagnosis and early identification lead to faster and more reliable inclusion for children with autism in mainstream school classrooms, as opposed to special classrooms for children with disabilities. Inclusion represents state of the art intervention on an increasingly global basis (Ruef 2003). The UAE works towards enhancing the diagnosis and early identification services for all children with autism. However, the services of early identification and diagnosis are in many cases not accessible, reliable, nor affordable for the parents.

The present study is important for professionals, caregivers, and decision makers as it contributes to improving the lives of children with autism in the UAE. It does this by first, exploring the different procedures for identification for potential children with autism and the diagnosis adopted in the two major cities of the UAE and by pointing out the issues and deficiencies related to those procedures. Second, it illustrates parental levels of satisfaction about different aspects of the process and the involved parties. Third, it aims to bridge the gap between the best global practice and the local practice by suggesting a group of recommendations for improving identification and diagnostic procedures.

Additionally, this study expands the researcher's personal and professional knowledge about the nature of autism diagnosis and best practices in the field globally and locally through exploring the status in different emirates. The study will also strengthen the researcher's academic research-based skills by applying mixed methodology research methods using the analysis of questionnaires, focus groups, interviews, and review of the current body of literature in the field of autism diagnosis. Finally, the lack of research in this area inside the UAE provides significant additional dimension to this study. The study explores the situation in the

field from different facets and will serve as an evaluation, baseline, and leading example for further studies in the future.

### **1.5 The UAE context**

The UAE is an Arabic country with a total area of 83,600 square kilometers. The country is located in the far eastern area of the Arabic world and is surrounded by the Arabian Gulf from the north, Oman from the east, the Kingdom of Saudi Arabia from the south and Qatar from the west. The country was founded by Sheikh Zayed Bin Sultan Al Nahyan on the 2nd of December of the year 1971. Sheikh Zayed gathered the seven Emirates (Abu Dhabi, Dubai, Sharjah, Om Al-Quin, Ras Al Khaimah, Ajman, and Fujairah) to form one country (Omar et al. 2005). The economy of the country is based on oil, which provides a stable economic foundation.

This powerful and steady economic status has allowed the population in the country to increase in the last four decades. Now there are more than 150 different nationalities who live in the UAE (Al-Raisi and Al-Khoury 2008). Professionals from various parts of the world have moved to the UAE to work and share their knowledge. This has provided significant enrichment in all types of occupational fields. The large variation in languages and cultures does not impede the progress of the country. On the contrary, significant progress has been accomplished in all fields as a result of the common use of English in communication between the UAE residents.

Federal law governs the country. The law number 29 of the year 2006 in respect of the rights of people with special needs in the UAE stresses in articles 10, 11, 13 and 14 the importance of establishing programs for early identification and diagnostic service for people with special needs. The articles highlight the importance of preparing national studies and developing competencies to support children with special needs (including autism) and their families regarding diagnosis, early detection, education, social, psychological, and medical aspects of the condition (MOE 2010).

### **1.6 Early identification and diagnosis procedures in the UAE**

Diagnosis and early detection of autism, in general, is progressing in the UAE. Many effective provisions were adopted in which put the UAE ahead of most of the other Arabic nations in this field (Nahad 2015). For a relatively new country to achieve such progress so quickly is impressive, but regardless of this, there are still more issues to be addressed in the development of the field. Those issues are related to the inconsistent procedures across the country in terms of early identification and diagnosis of autism, which causes confusion for the parents who get different and sometimes contradicting diagnostic results from professionals. Also, there are other issues related to the availability of information for parents, which results in disappointment and the feeling of being left alone in the struggle to try to understand what is wrong with their children.

Another issue stems from the affordability of the service that can cause frustration for parents who cannot afford the expenses of diagnostic tests, as medical insurance does not cover it. Also, the long waiting lists for diagnosis affects timely early intervention and eventually affects children's potentials regarding functional living skills and academics. Additionally, some issues related to the reliability and accuracy of diagnosis has prompted some parents to travel with their children abroad to get a more reliable diagnosis. Autism shares many symptoms with other disabilities (Robledo & Ham-Kucharski 2005), unqualified professionals may be prone to diagnosis issues. Those issues are the most urgent to be addressed to better enhance early identification and diagnosis of children with autism in need of services in the UAE.

### **1.7 Chapter organization**

This research paper consists of five chapters and appendices. This first chapter illustrates the background of the study and the purpose of the research. It also includes the main research questions and rationale behind the study and its significance. Chapter two highlights the research population, the researcher role, the

methodology for data collection, in addition to the research challenges and limitations of the study. Chapter three consists of a review of the related literature to focus the study on the definition of the key concepts and the history of early identification and diagnosis of autism. It also presents recent research in the field and other relevant topics. Chapter four outlines the findings from the interviews, surveys and focus groups and discusses those findings. Chapter five offers a conclusion of the findings and presents a group of recommendations for better practice and future research. The appendices consist of the different tools used in data collection and other related materials.



## **2 Chapter Two**

### **Methodology**

#### **2.1 Rationale**

The purpose of this research study is to examine methods to improve the processes of early identification and diagnosis of children with autism in the UAE. The objective is to provide information that will help to design better diagnostic procedures so that more children can achieve their maximum potential through early intervention. The research focuses on three research questions. The first question examines the current status of early identification and diagnosis of autism while the second relates to how parents perceive the diagnosis process and finally, the third examines deficits in the system and recommendations to improve them. Keeping these three research questions in mind, the study will use mixed methodology research. Mixed methodology research is appropriate when the questions are complex and cannot be answered using either a quantitative or qualitative methodology.

Choosing an appropriate research methodology is the most important component in the ability of the researcher to achieve their research objectives. In this study, the researcher intends to achieve a level of information that will allow recommendations to be made for the future. It is important to gather as much information from as many sources as possible to do this. In this study, the researcher will gain information from a number of different stakeholders with varying levels of expertise in the subject. The researcher will then triangulate these various sources of information to achieve a broad picture of the situation in the UAE regarding the diagnosis and detection of autism in early childhood.

To achieve these research objectives, the study needs to be both focused and broad at the same time. The topic is complex, and there are many different ways in

which the information could be gathered. Quantitative studies include both experimental designs and nonexperimental designs (Creswell 2011). An experimental design involves a certain treatment being applied to the sample population. A nonexperimental quantitative design involves gathering research that can be reduced to use a single data point that can be analyzed using statistics such as a survey (Creswell 2011). One of the main advantages of quantitative studies is that the researcher can quickly and easily analyze it. However, quantitative studies have the disadvantage that they do not allow collection of in-depth perspectives of the participants (Creswell 2011). Quantitative studies are easy to answer from the participant's perspective. This study will use surveys to collect information from a large sample of parents located in Abu Dhabi, Dubai, and Sharjah.

Even though quantitative studies are convenient and allow the researcher to collect large amounts of data quickly and easily, they do not provide in-depth information, or the ability to collect information that was not anticipated by the researcher (Creswell 2011). For this reason, qualitative data such as narratives, ethnographies, case studies, and grounded theory research provide more useful knowledge that can be applied to the real world (Creswell 2011). Mixed methods research is used when quantitative and qualitative data are collected concurrently, or when the study is transformative in nature (Creswell 2011). A transformative study uses a theoretical lens to gain an overall perspective on a set that includes both quantitative and qualitative data (Creswell 2011). A concurrent mixed methodology converges quantitative and qualitative data to provide a comprehensive overview of the research problem to be investigated. One data form is nested within the other when a concurrent mixed methodology is chosen (Creswell 2011). This study will use concurrent data that will be triangulated to provide an overarching perspective on the problem facing the diagnosis of autism in the UAE.

## **2.2 Theoretical Framework**

An examination of existing theories regarding the ability to diagnose autism in children at an early age yielded no relevant overarching theoretical framework. An examination of theories regarding disease diagnosis yielded the existence of numerous diagnostic tests and instruments for the diagnosis of autism, but no overarching theory regarding the development of these tests. A majority of the theories surrounding autism were concerned with educational theories as they applied to children with autism. The theories found were not relevant to the topic of the research or the stage in the diagnostic process of the child. The inability to find an appropriate theoretical framework for the study supports use of the concurrent mixed methodology research design.

## **2.3 Research Design**

The success of concurrent mixed methodology research lies in the ability to collect information from a number of different sources and to triangulate that information into a single set of conclusions. Concurrent mixed methodology research design dictates that a number of different methodologies and sources of information be considered (Creswell 2011). In this case, the researcher used a combination of surveys, interviews, and focus groups as sources of data for the study. This study will be divided into two sections. The first section will examine quantitative data collection methods and the second will examine the qualitative data collection methods that will be used in the study.

### **2.3.1 Quantitative Data**

The quantitative data collection process involved sending surveys to parents from three selected major cities, Abu Dhabi, Dubai, and Sharjah. These cities were chosen because they have high populations and were more likely to have a high concentration of study participants within the local area. Only three cities were chosen due to some research difficulties. Parents of children with autism were

recruited from Sharjah through a direct contact with the researcher, and through two autism centers located in Abu Dhabi and Dubai. The purpose of the study was explained, as well as how their participation would help to improve services for their children. The parents were mailed the survey with their children along with instructions to sign and return the consent forms and the surveys to the centers or the researcher directly.

The researcher sent out 180 surveys spread among parents of children with autism from the three cities that were selected for participation. The response rate was relatively low with 40 responses received from Abu Dhabi, 30 responses received from Dubai, and only 8 responses received from parents in Sharjah. This resulted in a total of 78 responses to the survey that were returned to be included in the research study. This data was analyzed, graphed and compared using Microsoft Office Excel to determine the frequency of each answer provided and then was divided into two groups based on the age of the children. One group included students aged from five to ten years old, the other group represented students whose ages are between eleven and sixteen years old. The purpose of the quantitative data was performed by specific information about the diagnostic procedures for children with autism from a parent's perspective.

### 2.3.2 Qualitative Data

Qualitative data for this study included interviews and focus groups. The purpose of the qualitative data was to provide in-depth exploration of the research topic. Three pediatricians were interviewed through phone calls, one from each of the cities under study. The interviews asked about screening procedures used by the pediatricians to indicate that the child needed to go for further screening and testing. The interviews examined the resources available to parents and pediatricians for further diagnosis if it was determined that the child was in need of this service. The interview examined differences in regulations in the three cities for the diagnosis and further screening of children with autism at various ages. These interviews from

pediatricians provided information on the overall diagnostic processes that are used throughout the UAE. It is felt that the procedures discovered during the interview process represent the processes used throughout major cities in the UAE, but may not represent those used in other emirates.

The research also involved the interview of one psychologist who is certified to diagnose autistic disorder in Dubai. This interview examined parental awareness and the age at which most children are referred for further testing for autism spectrum disorder. It also examined advances in the development of diagnostic centers and progress that has been made in the diagnosis of children with autism at early ages. The interview examined concerns over the diagnosis and less experienced professionals in the field. This interview adopted open-ended questions and allowed the interviewee to freely express her viewpoints during the interview process without further guidance from the researcher.

The interviews also included two interviews with the Director of the Speech and Language Services, the Chief Clinical Officer and Executive Director at one of the autism centers in Abu Dhabi. An open format was used for the interviews about how to improve services in the country and how to avoid parental concerns. Both interviewees in the autism center were allowed to express their views in unformatted manner using open ended question. These two interviews provided information on the overall system for identifying children with autism and getting them the services that they need. The interviews provided a different perspective than those of either parents or pediatricians of the children provided. It provided information on a different part of the diagnostic and treatment processes.

The qualitative portion of the study also included conducting two focus groups utilizing parents of with children of a different age. The first focus group consisted of four parents with children diagnosed with autism that were younger than six years old. The other group consisted of four parents whose children were older than thirteen years old. The focus groups were held in Abu Dhabi and used open-

ended questions regarding the affordability, speediness, and reliability of the services that they received. Using parents with different age children allowed the researcher to gain a perspective on how the services have changed over the past decade. It allowed the researcher to conduct a temporal comparison of the development of diagnostic and service development for children with autism. The focus groups provided the ability to determine which areas are still in need of further improvement.

The qualitative portions of the study allowed the researcher to gain many different perspectives from different stakeholder groups who were on various levels of the diagnostic and treatment system. When combined with the quantitative data from the parents, the researcher was able to gain an overarching view of not only the current state of the system but how it has developed over time too. The combination of quantitative and qualitative data allowed the researcher to fulfill purpose of the research study and to see the areas that need to be improved in the future.

## **2.4 Participants**

Sample participants in the study included three different geographic areas. The survey was sent to participants in 3 different cities, but the responses reflected a larger percentage from Abu Dhabi. The physicians were representative of all three cities. However, the focus groups were targeted on the city of Abu Dhabi. The psychologists interviewed were from Dubai. This provides the researcher with a variety of data from the various geographic regions that were targeted in the study.

The study participants included parents of children with autism, pediatricians, Speech and Language Services Director, Autism Center Chief Clinical Director, and a psychologist. This represents a variety of professional and personal opinions regarding the state of autism diagnosis in the UAE. This variety of opinions and research methods allowed the researcher to triangulate the viewpoints of the various study participants. In doing so, the researcher gained a broader vision of where the diagnosis and treatment process has come and where it needs to go in the future. The sample participants were from a number of different demographic groups including

males, females, and some different age groups. This makes the sample representative of the general population in the cities. It aids in the ability to reliably triangulate the results to make recommendations that will help the greatest number of children.

## **2.5 Assumptions and Limitations**

Every research study contains certain assumptions by the researcher that cannot be eliminated through an examination of the existing research. One of the assumptions of the researcher in this study is that the professionals who were interviewed and parents who participated in the focus groups are knowledgeable about autism and the various processes involved in diagnosis and intervention. However, no assessment was made of the actual knowledge level of the professionals or laypeople who participated in the study. The parents had children that already have been diagnosed with autism, which leads to the assumption that they have at least a certain minimal level of understanding about what this means for their children and themselves regarding future planning for their children. It is also assumed that the professionals have a certain level of knowledge about autism, as this was necessary for their licensing and professional practice.

One of the limitations of the study is that it only addressed the population of parents that had children with an autistic diagnosis between 5 and 16 years old. It was unable to address the population of children who might have autism but have not yet been diagnosed or older than 16 years old. Inadequate methods for diagnosis and identification of these children supports the need for this study but also presents many questions about how many undiagnosed children with autism remain. Additionally, this study does not promote one type of treatment intervention over another nor does it evaluate the efficiency of various types of diagnostic tests. More importantly, this study focuses on researching diagnosing autism in the UAE and does not research the diagnosis of other types of disabilities. Additionally, the sample of this study represents a specific age group between 5 years old and fifteen years old children.

The survey portion of the study had a low response rate from the parents. One of the reasons may be that social stigma attached to having a child with autism might have prevented them from participating in the study. Parents may have been reluctant to participate in the study for fear of others finding out that they had a child with autism. It may also be that they lack the resources in terms of time to fill out the survey and return it. It cannot be known for certain the reason for the low response rate, but because the most responses were received from Abu Dhabi and Dubai, the results of the study are more representative of these two cities than the others.

One of the factors that might affect the ability to apply the results of the study to other sample populations is that it took place in three large cities. The results achieved in this study may not be the same as one would expect if the same study were conducted among rural populations. The results of the study can only be applied to populations that are similar to those examined in the research study. This may represent sample bias towards urban populations. However, the recommendations that stem from the study will apply to improving diagnostic procedures among all populations. Rural populations may lack the resources of urban populations, which could affect the accuracy of diagnostic processes even further in these remote areas.

## **2.6 Summary**

This research methodology used a mixed methods approach to gaining an overall viewpoint of the diagnostic and service provision for children with autism spectrum disorder. It uses a combination of quantitative and qualitative data to provide perspective on the state of professional level knowledge and procedures about the research topic. It also examined the perspectives of parents, as well as the level of information that parents have about autism. This research method allowed the researcher to gain many different viewpoints regarding the conclusions that are drawn by this research study.



### **3 Chapter Three**

## **Literature Review**

### **3.1 Introduction**

This research explores the processes for diagnosing autism in the UAE in the cities of Abu Dhabi, Dubai and Sharjah as sources of information. The ability to diagnose autism early allows the child to receive early intervention, which provides a better chance for academic and life success. The research questions in the study examine the status of early diagnosis and intervention in the UAE, parents' perceptions of the diagnosis process, and will provide recommendations to help establish better standards for the future. To fulfill these requirements, the following literature review will examine the current status of autism diagnosis in the UAE and will compare them to standards in other countries to determine the best practice. This will allow us to identify components of the diagnosis process that may be beneficial to add to the current practice in the UAE.

### **3.2 Diagnosing Autism: A Global Perspective**

The term autism was first used in 1908 when Eugen Bleuler used it to describe the aloofness of patients with schizophrenia into their own fantasy life (Smith 2012). Later, in 1938, Hans Asperger uses the term to describe autistic psychopaths (Smith 2012). These early diagnostic terms associated autism with schizophrenia and considered them the same pathogenic family. Clinical work to clear up this misconception did not occur until 1978 with the work of Kanner and Asperger (Smith 2012). Currently, autism is no longer associated exclusively with schizophrenia and other psychotic disorders and is classified according to its pathology.

ICD-10, published in 1990, classifies autism under pervasive developmental disorders, rather than psychotic disorders. According to the ICD-10, autism is

characterized by difficulties in reciprocity in social interaction, unusual communication patterns, restricted communication, and repetitive interests and activities (Smith 2012; WHO 1990). Previously the DSM-IV listed several autism spectrum disorders under the same category. For instance, autism, Rett's disorder, Asperger's disorder, childhood disintegrative disorder, and other pervasive developmental disorders that are not otherwise specified all had the same diagnostic criteria (Smith 2012). The DSM-V was released in 2013 and now is the accepted standard for the definition of mental health and psychiatric disorders (American Psychological Association 2013). With the changes in the DSM-V, all of these disorders are categorized under one umbrella term: autism spectrum disorders. Each diagnosis falls along a formalized spectrum (Smith 2012). The DSM-V allows children and adults that display the classic symptoms to be more easily categorized in comparison to the older classification systems. However, some clinicians are concerned that this may cause further confusion in the diagnosis of Asperger's and that patients may lose their uniqueness in the spectrum (Kaufmann 2013).

For the most part, symptoms are apparent by 24 months of age, but not every child displays all of the characteristic symptoms of the disorder (Smith 2012). This can make diagnosis more difficult. Also, many statements used to describe children with ADHD are similar to ones used to describe children with an autism (Mitchell 2006). The similarities provide an even greater challenge in the diagnosis of autism.

Often, parents or a family doctor are the first to notice that something may be unusual with the child. This typically leads to a short screening by the physician to determine if they need to refer the child for further diagnosis (Health Council of the Netherlands 2009). Children that fall on the severe end of the autism spectrum are usually diagnosed by 24 months, but children with Asperger's and other milder forms may not be diagnosed until later on in life (Health Council of the Netherlands 2009). Milder cases are not diagnosed until it is discovered that the child has difficulty communicating, reading, and/or writing in school (McQuillan 2010). The goal of

early diagnosis is to detect autism spectrum disorders long before the child enters the school system.

Sometimes, the onset of autism spectrum disorders is marked by Childhood Disintegrative Disorder (CDD), where the child reaches a certain point in their development and then seems to regress to lower states of functioning from that point in time (Stockman 2011). When a child begins to regress, the parents will often become alarmed and seek help. Parents and caregivers often experience a variety of emotions while going through the diagnosis process. A study that examined the reactions of parents and adolescents upon hearing that they had been diagnosed with Asperger's syndrome differed significantly (Mannion & Leader 2014). Some were overwhelmed by the diagnosis and what it would mean for their lives. Others met the diagnosis with a sense of relief because they could finally put a name on the symptoms that they had been experiencing (Mannion & Leader 2014).

The diagnosis of autism can be complicated process. The International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) (2012) stated that:

*“Autism assessment is a complex task. A multi-professional approach to assessment needs to be resourced and supported for all patient age groups. A diagnosis of autism is usually regarded as life-long, although with early detection and intervention, more individuals are able to lead lives of independence and self-sufficiency as adults. Therefore, it is of equal importance that autism is diagnosed and, where appropriate, not diagnosed, accurately”.*

It has even been suggested that autism is not a specific disorder, but that it only exists as a set of disconnected symptoms (Rivera 2014). However, this viewpoint is not favored by many in the medical community, because it does not fit within the system of diagnosis and treatment protocols. With the current system, a disorder has to have a specific name and treatment associated with it. Recent studies indicate that early

autism diagnoses are stable over time and that the diagnosis remains after 48 months (Gationde 2008).

It is possible for the early signs of autism to be seen as early as six months, but reliable emergence of identifiable traits typically does not occur until 18 months (Ptak 2015). Autism represents a broad phenotype, which represents the challenge in diagnosis. Behavioral observation remains the standard for diagnosis (Ptak 2015). The difference in symptomology and patient creates the greatest challenge in developing diagnostic procedures that will be accurate for every child in every case. Currently, there is no pharmacological or medical test confirm and autism diagnosis.

One of the more concerning findings was that social, financial, and demographic factors seem to influence the age of diagnosis of autism. One study examined children in four different regions of the United States. It was found that when the child has an older sibling who has a developmental delay or has been diagnosed with autism, they are more likely to be diagnosed earlier than children that have typically developing older siblings (Adelman & Kubiszyn 2016). If the child had been diagnosed with another developmental disorder, then they had a better chance of being diagnosed with autism earlier (Adelman & Kubiszyn 2016). The type of first symptoms to appear and cause concern also affected the age of the child's diagnosis. Children that were referred to early childhood intervention often received an earlier diagnosis than those who were not (Adelman & Kubiszyn 2016). Whether the child switched pediatricians, pediatricians conducted regular screenings, and the reaction of the pediatrician to parental concerns also affected the age at which the autism diagnosis was achieved (Adelman & Kubiszyn 2016). Other factors including health insurance, annual household income, and the parent's level of education had an effect on the age at which diagnosis was achieved (Adelman & Kubiszyn 2016). These factors provide insight into external factors that may have an effect on the age at which diagnosis is achieved. Some of them represent pediatrician bias towards parents of lower education status, lower economic status, or who lack the ability to pay (Adelman & Kubiszyn 2016). It was also found that the age at which autism is

diagnosed is related to the severity of the symptoms, the level of caregiver's worry about the initial autism symptoms, and the attributions of the caregivers regarding the symptoms and social problems (Perryman et al. 2009). Caregivers along with a variety of other factors play a significant role in the diagnosis and the ability to receive early intervention.

There are many components to the diagnosis of autism. Currently, there are no definitive medical tests developed that can detect the disorder and provide a definitive diagnosis. Unlike other diseases, there is no known blood factor or physical symptoms that can be measured using diagnostic tests. The diagnosis of autism lies in the observation of behavioral and psychological manifestations that fall within a certain category. However, differences in the pervasiveness of the symptoms and how they manifest can hinder the ability to perform an accurate diagnosis. The World Health Organization agrees that more uniform standards need to be developed in the diagnosis of autism on a global basis (WHO 2014). In the following section, I will discuss some of the diagnostic tools that are currently used.

### **3.3 Diagnostic Instruments**

Numerous instruments exist for the detection and diagnosis of autism, however, there is little uniformity in the measures. Some of them may prove to be better than others. Some instruments and assessments based on behaviors have been developed, and these are used as the standard criterion for diagnosing the disorder (Ptak 2015). In a recent study, it was found that some instruments perform better than others when used to diagnose the same child. One study compared the Childhood Autism Rating Scale (CARS) and the Autism Diagnostic Observation Schedule (ADOS). CARS is an older diagnostic scale, and the ADOS is a newer one based on DSM-IV criteria (Mick 2005). The purpose of the research was to determine which of the diagnostic instruments were better at predicting whether the child would meet DSM criteria for autism. The study found that CARS was slightly more reliable than the ADOS at detecting autism and making a final diagnosis (Mick 2005). This suggests that

physicians need to be cautious about the instruments that they choose and how they use them in the diagnostic process. It also suggests that they should not rely on instruments alone in making the diagnosis, but must compare the results to other findings from behavioral observations and parent surveys. Diagnostic assessment tools should be a part of the diagnosis process, but they should not encompass the entirety of methods used for the diagnosis.

One of the challenges in autism diagnosis is differentiating children with ADHD from those on the autism spectrum. Many of the children on the autism spectrum also exhibit some of the hyperactivity and inattention issues that are seen in children with ADHD (Mannion & Leader 2014). The BASIC-2 is a comprehensive instrument that is used to assess child and adolescent behaviors to determine if they fall within clinically significant ranges (Mannion & Leader 2014). Using this instrument to examine children diagnosed with ADHD and those diagnosed with autism, it was found that use of this instrument had clinically significant differences in the results obtained between the two groups. The instrument indicated a higher level of maladaptive behavior in children with autism than in those with ADHD. It was also found that the instrument demonstrated gender and ethnic differences, as well as some differences in results that were due to culture (Mannion & Leader 2014). This suggests that the choice of instrument is imperative in the proper diagnosis, as choosing the wrong instrument can result in misleading information regarding the child.

Racial disparities also play a role in the diagnosis of children with autism. It was found that African-American children are less likely to be diagnosed with autism than white children (Stephenson 2016). Research also suggests that African-American children required three times as many physician visits as white children to be diagnosed with autism (Stephenson 2016). It was also found that children from higher socioeconomic status were less likely to be diagnosed with autism than those from lower socioeconomic statuses (Stephenson 2016). This demonstrates that cultural biases have an effect on the early diagnosis of autism.

Generally, there is agreement regarding the characteristics of autism. However, there is disagreement on how to determine when the child meets these criteria and displays these characteristics. Many different tools have been developed to aid physicians and other professionals in the diagnosis of autism. The question remains as to how accurate professionals are when diagnosing. A study looking at school psychologists found inconsistencies in diagnoses. These inconsistencies were found to be based on the experience, and training level of the psychologist. These findings suggest that training in autism and how to diagnose it are needed to improve the system (Baron-Cohen et al. 1996). This research could be extrapolated to include any professional who will be diagnosing children with autism. Training and experience could be predictive of their ability to make an accurate diagnosis. Now let us examine some of the perspectives of parents regarding their satisfaction with the diagnostic process.

### **3.4 Parent Satisfaction with Diagnostic Procedures**

Although diagnostic procedures for autism spectrum disorders have improved, parents still face many challenges in obtaining a proper diagnosis for their child. When a child is diagnosed with autism, it causes considerable stress in the parents (Gaitonde 2008). Studies indicate that it is the parents who are typically first to become concerned about their child (Gaitonde 2008). It was also found that parents who have younger children took half the time to seek help as those with older children (Gaitonde 2008). Studies conducted in 1994 found that parents had significant difficulty obtaining support and services after the initial diagnosis. They also felt that the description of the diagnosis they had been given was vague and unsatisfactory (Gaitonde 2008). A study conducted in 2002 reported that physicians felt many parents reacted with shock or denial. They also reported that this led parents to obtain a second opinion (Gaitonde 2008). Parents continue to report that they felt helpless and did not have sufficient support to cope with the diagnosis (Gaitonde 2008). When comparing the study conducted in 1994 in the one conducted

in 2002, it appears that parents continue to be dissatisfied with the support they receive following a diagnosis.

A study using mothers whose children were diagnosed with autism between 1974 in 2004 provides further insight on how diagnosis procedures and reactions to the diagnosis have changed. The study found that diagnosis of autism occurs later in children that also have a comorbid condition such as cerebral palsy or other disability such as Down syndrome (Hornstein 2015). It was found that when parents lack experience with children with autism, physicians will often take a wait-and-see approach with the parents. The study found that when the physician takes this approach, it creates considerable distress among the parents and that the stress is worse for mothers who are responsible for the care of the child (Hornstein 2015). This suggests that experience with the physician in the diagnosis of autism is associated with parental dissatisfaction with the diagnostic process.

Parents reported significant tension between themselves and the pediatricians and parents are often made to feel that they are “problem parents” by the physician (Hornstein 2015). When the physician is reluctant to order further diagnosis of the child, parents often become insistent that they take action. One of the key characteristics of this tension between physicians and parents occurs when mothers become defensive due to the physician’s insistence that they are being an overanxious parent (Hornstein 2015). Mothers report feeling that the position undermines her authority and abilities as a parent (Hornstein 2015). This sets up a confrontational context for further activities regarding the diagnosis of the child. It creates an adversarial position between the parent and the physician. Instead of working as a team for the benefit of the child, each becomes concerned with their reputation and feelings.

Parents are often the first line when it comes to identifying children that may be at risk for being diagnosed with autism. The question has been asked by researchers as how accurate these parental assessments are and how useful they may



be in achieving an official diagnosis of the disorder. It was found that in many cases, the parent was hesitant about mentioning the behaviors that they were seeing, hoping that their child would just grow out of it (Daniels 2002). Research also found that a lack of accurate screening tools for the early childhood setting was a factor in the ability to achieve early diagnosis (Daniels 2002). The Modified Checklist for Autism in Toddlers (M-CHAT), Screening Tool for Autism in Two-Year-Old (STAT), and the Pervasive Developmental Disorder Screening Test (PDDST) are instruments that were developed for using parental reports in the diagnosis of autism in their children. The M-CHAT reliably identified 10 out of 12 children who were later diagnosed with autism (Daniels 2002). The PDDST also performed well but had a false positive rate of .30 at the cutoff score of 10 (Daniels 2002). The STAT is a longer instrument and has only been tested on a small group of children, but these results also look promising (Daniels 2002).

Parents of children diagnosed with mild autism reported frustration with the system because they felt an overall lack of support from medical and educational professionals (Zwaigenbaum, Bryson & Garon 2013). One can see a pattern beginning to emerge in this portion of the literature review. Parents expressed frustration that physicians do not listen to them when they insist that their child may have a developmental delay such as autism. It was also found that due to cultural and social restrictions, parents are often hesitant to bring the topic up to their physician. This suggests that when they do bring it up, they are erring on the side of caution and are doing so after considerable observation and concern for their child. Research instruments developed to utilize parental observation were found to be quite accurate in diagnosing autism. This suggests that physicians may need to listen to parents more and consider their concerns a higher priority when making a diagnosis of autism. This literature suggests that parents are excellent observers of their child and know when something is wrong, but are frustrated because physicians do not take them seriously due to their lack of formal education. This is a gap that needs to be resolved for uniform diagnostic techniques can be developed in the UAE and around the globe.

### **3.5 Diagnosing Autism in the UAE**

Every 20 minutes a child is diagnosed with autism in the UAE (Edarabia 2012). One in every 88 children will be diagnosed with autism in the UAE (Gulf News Online 2017). When compared to other countries, such as the United States, the education, and diagnosis of autism is behind regarding research and practice in the UAE. Children with autism did not have a right to an education until 2006 (Farooq 2007). Provisions in mainstream schools for those with autism were found to be nonexistent as of 2007 (Farooq 2007). Top officials maintained opposing views regarding the education of special needs children in public schools (Farooq 2007). In the United States, it has been established for decades that children with special needs and autism have a right to access the same educational system as a general population. They have also established uniform laws regarding how that education should be carried out. The same cannot be said for the educational system in the UAE and schools have different methods for determining the child's strengths and weaknesses to devise an appropriate educational approach for the child (Farooq 2007).

These attitudes regarding the education of children with autism may have an effect on the priority that is assigned to diagnosing children with autism by physicians (Geranpayeh 2016). Many people in the UAE are still unaware that autism exists (Rai 2016). Asperger's was only recently recognized as a part of the autism spectrum in the UAE (American Center n.d). Once a child is diagnosed with autism, it may harm their ability to achieve an education. In the UAE, a diagnosis of autism may limit what they can achieve in life (Farooq 2007). Some physicians may be hesitant to label a child with autism, particularly if their symptoms are mild or if they are not certain of the diagnosis. Evidence exists that suggests many children and misdiagnosed with autism that have a different condition, including ADHD, behavioral, and emotional problems (Rizvi 2016). The consequences for the child and parents can be devastating. Physicians may not want to take on the responsibility that goes along with a diagnosis of autism in the UAE.

Genetic tests are available for screening infants whose siblings have autism, but these tests are often cost prohibitive (Rogers 2009). Tests are available in the United States that can use MRI to diagnose autism in infants whose siblings have autism, but this too is often cost prohibitive (Whyte 2009). Autism is now detectable in the brain a long time before symptoms appear, which lowers the age at which autism can be detected (Dajani & Uddin 2015).

These are not the same circumstances as in the United States, where a system exists that makes a diagnosis of autism to help parents and the child get the help that they need. Until social attitudes regarding the education and status of children with autism changes in the UAE, it is unlikely that physicians will develop better methods for diagnosis, even though they are needed. Future methods for the diagnosis of children with autism need to be based on evidence-based research, rather than social stereotypes and cultural biases. According to UNESCO, an education is an essential human right that is necessary for the enforcement and practice of all other human rights (Jubran 2015). Students were found to be an important resource for overcoming the technical, social, economic, and attitudes that create barriers to them achieving their human right to education (Jubran 2015).

Many of the problems faced by the UAE regarding the diagnosis and education of children with autism is similar throughout many Middle Eastern countries. A study in Jordan examined parental attitudes of children with autism aged 5-18 years old. Parents expressed an overall satisfaction the services that they received but they had issues regarding the cost of the services, issues working with professionals, and the overall quality of the services was viewed as low (Al Jabery et al. 2012). Parents indicate a need to improve the diagnosis and educational system for children with autism. Case studies support the concept that the Arab world views autism differently than Western society (Nahad 2015). For the most part, culturally negative feelings about people with handicaps exist, and when a parent's child is diagnosed with autism, many of them feel that they are on their own with little

support (Nahad 2015). These attitudes may hinder the development of better early diagnostic procedures in the UAE for children with autism.

This is one of the challenges that must be overcome not only in the UAE but on a global basis. Even in the United States, racial, cultural, economic, and social biases were found to hinder early diagnosis of autism (Stephenson 2016). Similar biases were also found in the UK for children that were of ethnic minority background, particularly those that did not speak English (Leather 2005). For children throughout the world, the diagnostic process for autism is a long and drawn out one involving many complicated issues (Rossi 2012). There is a need to streamline the process for all children around the world. While they are waiting for diagnosis, they are not receiving the intervention that they need.

### **3.6 Conclusion**

This literature review examined the ability to diagnose autism at an early age in the UAE and on a global basis. It first examined standards that are used to classify autism spectrum disorder. These included classifications such as the ICD-10 published by the World Health Organization, and the DSM-V, which is published by the American Psychological Association. These instruments were found to serve as the standard for determining when a child meets the criterion for being diagnosed with an autism spectrum disorder. However, it was found that in practice, the diagnosis process is not as clear. It is often difficult to determine when a child clearly falls within the spectrum. This was especially true with young children, with those that have comorbid conditions, with minorities, and with those who have milder symptoms. Children on the autism spectrum exhibit some different behaviors and not every child with autism exhibits all of the behaviors to the same degree. This was found to be the main challenge in developing standards for improving diagnostic procedures on a global basis.

This literature review found that parents are the first line in diagnosing children with autism. They are typically the first to report behaviors that they feel are

abnormal in their child to their physician. However, there was a gap in the diagnostic process because many times physicians do not consider the parents credible sources of information. Even though research indicates that often the parents are correct when they suspect their child has autism, physicians have a tendency to treat their concerns less seriously, unless the symptoms are serious. This is one of the gaps that needs to be examined to resolve the disconnect between parents and physicians.

It was found that diagnostic instruments exist, but that the results obtained by some instruments were found to have a problem with false positives, while others had difficulty discerning autism that was mild. This is another issue that needs to be resolved to improve the diagnostic process. It should be noted that no instruments have been designed to be used in the UAE. Most of the instruments found are designed for use in the United States and translated into Arabic. This is another gap in the diagnostic process that needs to be resolved by this and future research. Reliable instruments need to be designed that can detect autism, but which do not give false positives.

Compared to the United States, it was found that the ability to diagnose autism and the educational system for children with autism in the UAE was not far behind that in the United States. However, that does not mean that global problems are nonexistent. The problem of achieving an accurate diagnosis received attention from the WHO. They see the problem as a global one in the need for more consistent diagnostic criteria and the ability to diagnose autism at an earlier age (WHO 2014). The UAE is in need of improving the diagnostic processes for children with autism, but so does the rest of the world. The UAE needs to overcome cultural barriers that were discovered during the literature review regarding the social status of children with autism. This may prove to be the most difficult challenge facing the medical and educational system in the UAE.

This literature review identified gaps in the development of diagnostic processes, diagnostic criteria, training and education of professionals, parents and

professional relationships, and cultural barriers that need to be addressed to develop an improved process that will lead to the early diagnosis of children with autism. Further research will provide a multifaceted perspective that will aid in the development of recommendations to help the UAE move forward in its ability to diagnose children with autism at an early age and to help them receive the proper education and treatment that they need. This research represents the next step in meeting the recommendations set by the World Health Organization regarding improved diagnosis of those with autism spectrum disorder.

## **4 Chapter Four**

### **Research findings and discussion**

#### **4.1 Introduction**

This research examines methods for improving the identification and proper diagnosis of children on the autism spectrum in the UAE. The purpose of the research is to improve diagnostic methods so that these children can receive the early intervention and programs that they need to succeed in life. The study examines three research questions: First, it discussed the current status of early identification of children with autism in the UAE. Second, it examined parents' perceptions of the diagnostic process. Third, it examined the deficits in the system and recommendations to improve them based on both the quantitative and qualitative portions of this study. The study used mixed methodology research involving a survey questionnaire and interview with professionals in the area of autism diagnosis. This chapter will present the results of both the quantitative and qualitative portions of the study.

#### **4.2 Quantitative Survey Data**

The quantitative portion of the study directly relates to research question number two involving the experiences of parents with obtaining a proper diagnosis for their child. It provided many insights into the difficulties, struggles, and gaps in the current system that need to be addressed to improve the diagnosis of children with autism in the future.

The quantitative portion of the study involved conducting a survey for parents from three selected cities. The cities were Abu Dhabi, Dubai, and Sharjah. Two groups of parents were surveyed, the first group of parents has children between five and ten years old, and the second has children between 11 and 16 years old. The

parents were sent the survey and were instructed to return them to the researcher when completed. Parents were aware of the importance of the survey and how it would help their children and others like them in the future. 180 surveys were sent out to parents of children with autism from these three cities. Only 78 responses were received completed. Of these, 40 were from Abu Dhabi, 30 from Dubai, and only eight responses from Sharjah. 39 responses came from each of the groups. The reason for the low response rate is not known. It may be that parents felt they did not have time to complete the survey, considering their extra duties in caring for an autistic child. However, this is only speculation, and the real reason for the low response is not known. Due to the uneven distribution of the survey responses among the three cities, the results of the study will be more applicable to Abu Dhabi and Dubai than Sharjah and the other Emirates. One can say that the demographics in Abu Dhabi and Dubai are representative of the remainder of the population of the UAE. It is possible that the demographics of the two cities are unique, or perhaps they have a higher population of children with autism and parents who are involved. If the demographics of Abu Dhabi and Dubai regarding children with autism are different from the other emirates, then it will affect the ability to generalize the results of the study to the larger population. However, across tabulation of the results from the three cities indicated that the responses were consistent across all three major cities and across examined two age groups, the first aged between five and ten years old, and the second aged between 11 and 16 years old. Geography was not found to be a factor in differences in survey responses, unlike the factor of the age of the students in which showed slight different results between the two age groups, but consistent within each age group across the three major cities. This supports the reliability and validity of the survey as a representative sample of the remainder of the population in the UAE, particularly those in the major cities.

The purpose of the quantitative data was to learn about the diagnostic procedures and perceptions of the parents about them. The following responses are summarized, analyzed and compared along with a discussion of their implications for



the interpretation of the remainder of the research study. The survey was divided into two portions. The first part of the survey asks about the general conditions regarding the diagnosis of children with autism in the UAE. The second part of the study explored specific details about the experiences of the parents regarding their children. The following summary and discussion of the research questions will provide demonstration and insight into the experiences of parents in getting their children diagnosed and into the early intervention programs that they need.

#### 4.2.1 Part 1 - Questions about the system in the UAE

Question 1. How would you rate the importance of diagnosing children at early ages?

This question used to scale ranging from not important, indicated by 1, and extremely important indicated by 7. On this question, 94% of the parents of the examined two age groups responded that diagnosing

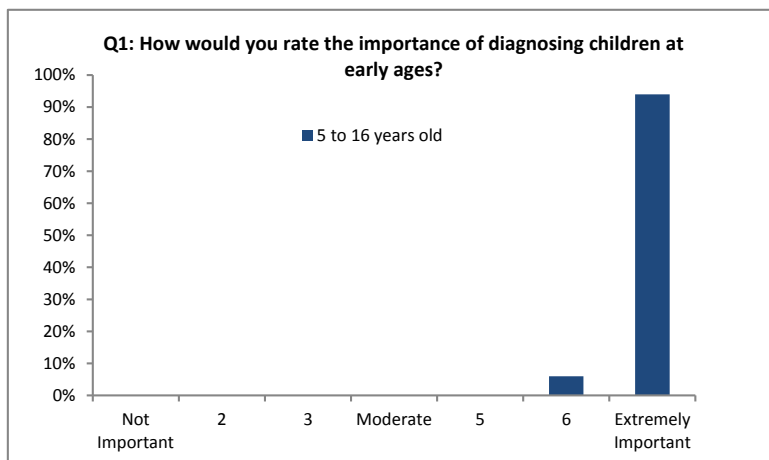


Figure 1

children at early ages was extremely important, indicated by a 7. Parents wanted to receive the diagnostic report to understand what was wrong with their children. This shows that they were aware something was wrong but did not know what it was.

Question 2. How easy was it for you to get information about a diagnostic center?

This question used a scale ranging from extremely easy, indicated by 1, and extremely hard, indicated by a 7. As shown in Figure 2, two age groups were

examined. Responses to this question from both groups were mixed. The responses from the older group came between 2 and 6 in which indicate that nearly half of the respondents felt obtaining information about a diagnostics center was at least moderately difficult.

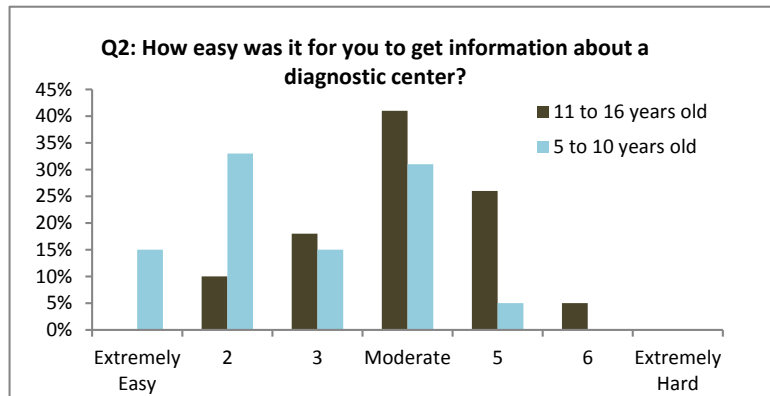


Figure 2

On the other hand, the responses from the younger group came between 1 and 5, in which indicate that the access to the information was slightly easier. It was easier to find information for younger students but more difficult for older ones. This indicates an improvement in the ability to obtain information about diagnostic centers. An overall look indicates a progress achieved in this area, however, there is a need for further guidance for the parents to make the process for finding a diagnostic centers easier.

Question 3. Describe the period of time you spent until you were able to get your child diagnosed.

This question used a scale where a 1 indicated a very short time in a 7 indicated an extremely long time. Responses from the older group indicated general dissatisfaction, 50% of the respondents

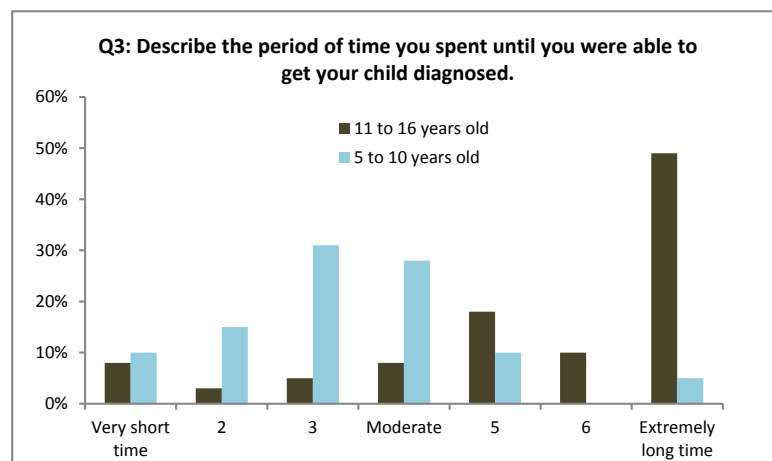


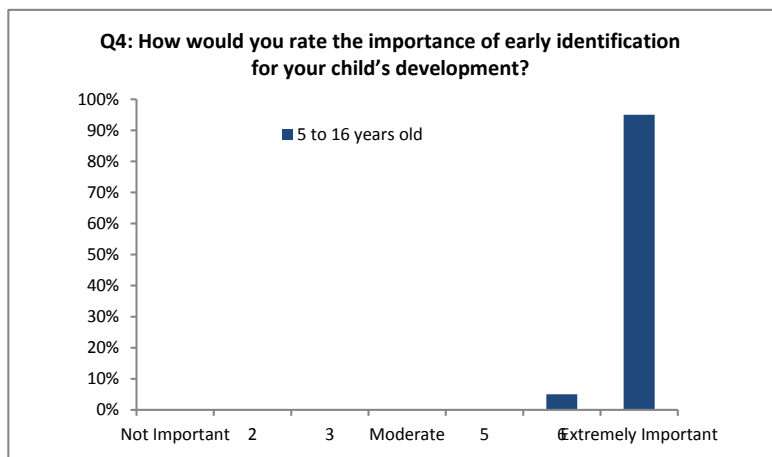
Figure 3

to this question from the older group were extremely dissatisfied with the amount of

time that it took to receive a diagnosis. Responses from the younger group varied along the scale, however, when compared with the older group, one can say that a significant progress has been accomplished in minimizing the long waiting lists for the children to get diagnosed. Data from the younger group show general moderate satisfaction. Some parents reported that it took up to eight months of time spent on waiting lists to get their child diagnosed. When one considers how rapidly children grow and change, eight months is a long time to go without diagnosis and intervention. One caution about this question is that it contains an element of subjectivity regarding how long the wait was and what the parents considered to be a long time. This question does not measure the amount of time, but rather the parent's perception of the length of time that it took. This question was supported in section two of the survey that measures the actual waiting time.

Question 4. How would you rate the importance of early identification for your child's development?

The rating scale for this question ranged from not important, indicated by 1, and extremely important indicated by 7. Responses were similar between the two age groups. Of those



surveyed, 94% indicated a 7, which means that they feel early identification is extremely important. Many of the parents commented that it would change the life of their child if they had known about the diagnosis earlier. It is worth to be mentioned that the majority of parents reported that their children did not receive any early identification procedures before the age of two years old.

Question 5. Rate your level of satisfaction about the clinician who ran the diagnostic test.

This question ranged from a 1, extremely unsatisfied, to a 7, extremely satisfied. Most of the answers to this question from both groups shows moderate satisfaction about the

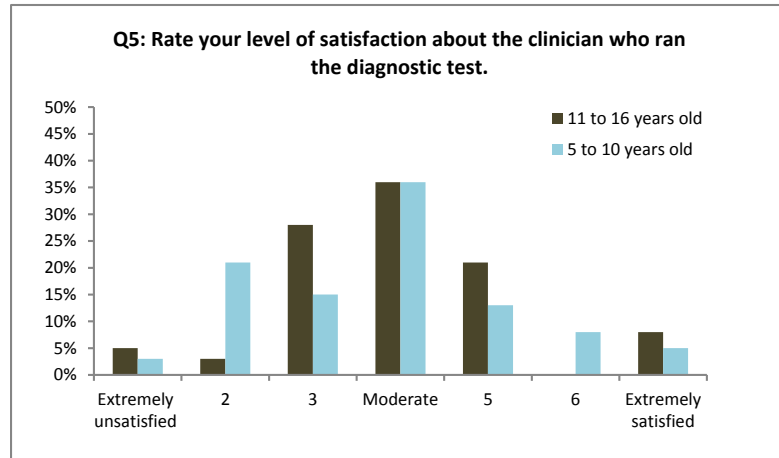


Figure 5

professional who conducted the diagnostic test, however, responses from the younger group indicate a slightly higher overall satisfaction than the older children group about the clinicians themselves and their ability to diagnose autism.

Question 6. Rate the affordability of the diagnostic test.

When asked to rate the affordability of the diagnostic test, a 1 indicated inexpensive, and a 7 indicated extremely expensive, the answers varied across the different categories,

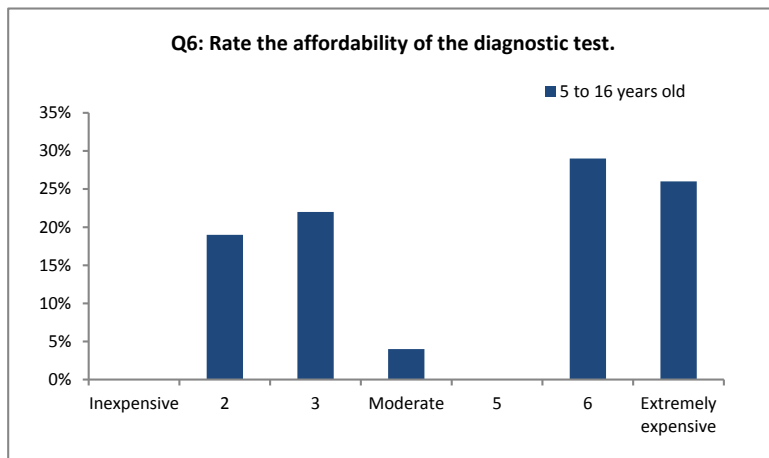


Figure 6

however, answers were closely similar between the two age groups. The two most frequent chosen categories were 2, 3, 6 and 7. There are many reasons for the variability of these replies. For instance, diagnosis services are not always covered by the medical insurance plans, especially for expats. Once again, this question measures

the perceptions of the respondents rather than the actual numerical impact on their financial situation. This question is supported in section two of the survey with a question that measures the actual numerical amount of money. It is not known the criteria that the respondents used to evaluate whether the test was expensive or inexpensive. It is more likely that those who felt it was extremely expensive were those who had to pay for the tests out-of-pocket.

Question 7. Rate your level of satisfaction about the diagnostic report of your child.

Regarding the quality of the diagnostic report, a 1 indicated extremely unsatisfied, and a 7 indicated extremely satisfied. Responses to this question as illustrated in figure 7 indicated that the responses from the

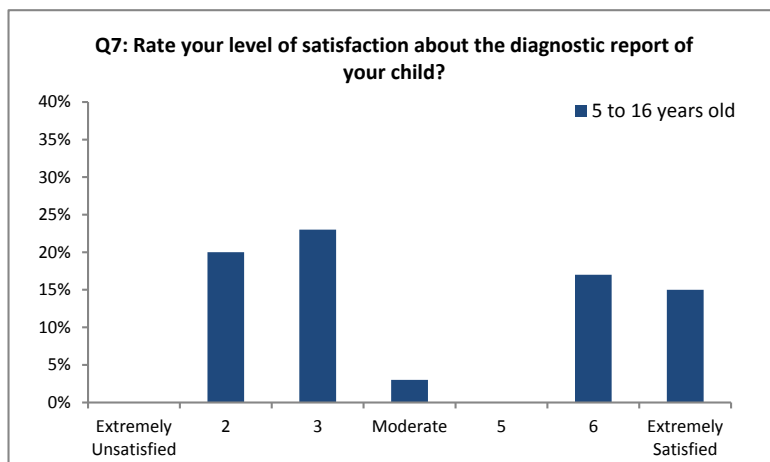


Figure 7

two age groups were similar in terms of levels of satisfaction. Nearly 50% of the responses fall within 6 and 7 categories indicating an extreme satisfactory with the quality of the report. An additional 50% indicated 2 and 3, which means that they were slightly dissatisfied. The respondents indicated various degrees of satisfaction with the report, and none indicated that they were extremely dissatisfied with the quality of the report. Many of the parents who marked dissatisfaction for this question reported taking their children to get diagnosed more than once and sometimes outside the country.

Question 8. How reliable is the diagnostic center you went to get your child diagnosed?

Question eight also used a scale where a 1 indicated extremely unreliable, and 7 indicated extremely reliable. This question measures the confidence of the parents in the diagnostic center. The

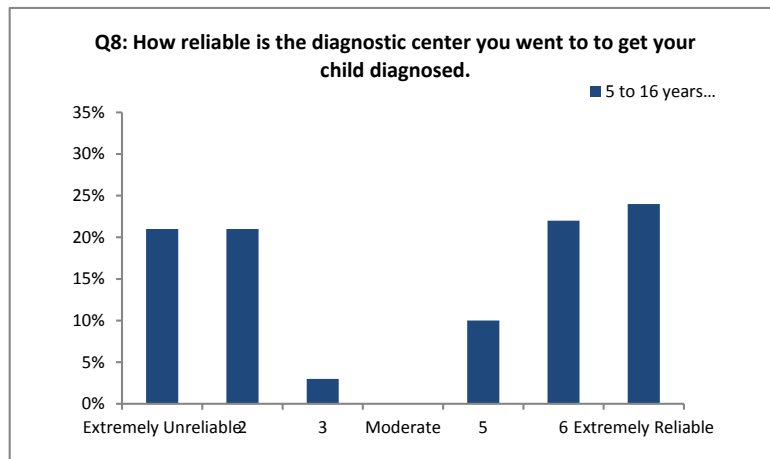


Figure 8

answers varied along the scale indicated different satisfactory levels. 50% of the answers indicated a 6, or 7, which indicates overall satisfaction about the diagnostic centers themselves. The second majority of the overall responses indicated dissatisfaction with the diagnostic centers. This coincides with the answers to question seven about the clinician and the report itself. All of these issues indicate disagreement between parents of children with autism on the clinicians, report, and the centers where the diagnosis took place. This disagreement may result from the variation of the age groups, diagnostic centers, processes of diagnosis and finally the clinicians themselves.

Question 9. How do you rate the help you received from the government to get your child diagnosed?

The scale for this question used a 1 to indicate extremely poor, and 7 to indicate excellent. A majority of the respondents indicated a 7, which is excellent. However, the

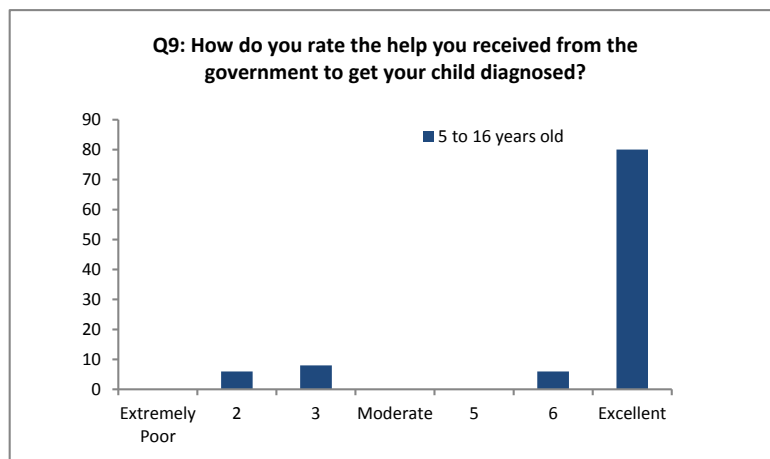


Figure 9

reliability of this question is of concern as the researcher used the term government instead of Ministry of Health or Education. The term government is too broad and is not directly related to the diagnosis of children with autism. Using a more precise term may have changed the answers provided. Even though the reliability of this question is of concern, it does not affect the ability of the study to draw conclusions overall. For other questions addressed satisfaction with various components of the diagnostic procedure. These questions provide sufficient information to determine the overall satisfaction of the parents without using question number 9 for the conclusion.

Question 10. How do you rate the overall service of diagnosing children in the UAE?

The final question in this portion of the study asked the parents to rate their overall satisfaction with the diagnosis of children in the UAE, which is similar to question number 9. For the purposes of analysis,

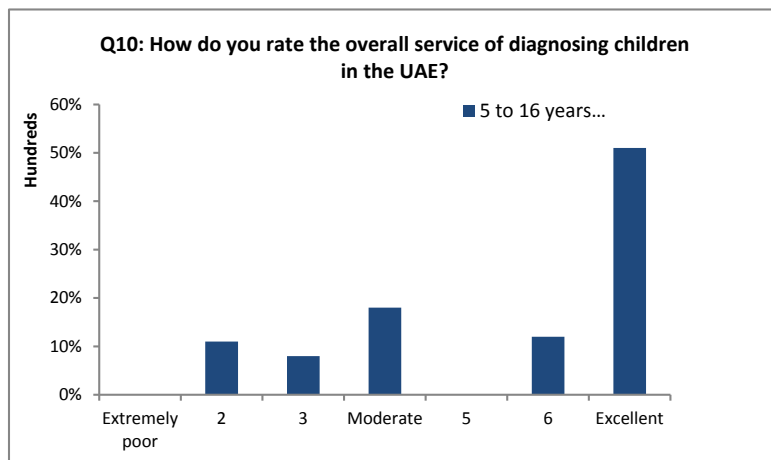


Figure 10

question 10 will be used to replace question 9. It encompasses satisfaction with the government and the ministries that are responsible for programs to diagnose children with autism at an early age. This question used a 1 to indicate poor, and 7 to indicate excellent. 50% of the respondents indicated a 7, indicating a high level of satisfaction overall services in the UAE, however, 40% of the respondents indicated moderate to low satisfaction about the overall service in the UAE.

#### 4.2.2 Part 1 Summary

Parents were generally divided in satisfaction based on multiple variables such as the age of their children, the service providers and the services provided, and the

location of the service provision. They indicated overall satisfaction on the system as a whole. The parts of the service that they were not satisfied with was the amount of time it took to wait for their child to be diagnosed and the costs of the service. Parents understand the importance of early diagnosis and feel that early diagnosis will have a significant positive impact on the life of their child. The responses to this portion of the study found two areas that need to be improved in the system. The number one concern was wait times because this has an impact on the outcome of the child. Finding ways to decrease wait times needs to be a priority as it will have a direct impact on the improvement of outcomes of children on the autism spectrum. Solutions to financing for parents that do not qualify for medical services are another priority issue that needs to be addressed in the future. Now let us examine part two of the study, which reflects the parent's individual experiences with their child through the journey of diagnosis and intervention services.

#### 4.2.3 Part 2 - Questions about individual parent experiences

The second portion of the study addressed factors and specific information about each child and their parents. In the analysis of the first portion of the questionnaire, these responses were used to provide insight into the categories chosen by a particular survey respondent. These results provide insight into the answers on the first portion of the survey.

Question 1. How old was your child when you first noticed any of the symptoms?

The age of diagnosis when parents first noticed symptoms that they felt indicated a problem with their child was early. The majority of the respondents felt that something was wrong with their children between the age of 2 to 3. The second majority noticed something was wrong between the ages of 1 year and to 2 years. Only few of the respondents felt that something was wrong between the ages of 3 and 4. This agrees with the information found in the literature review that indicates that parents are usually the first to notice something is wrong with their child (Health Council of the Netherlands 2009). It supports the ability of parents to recognize when



their child is not reaching milestones at an early age. As the literature review indicated, it is expected that children with milder symptoms may not be recognized until a later age. Children that are more severe in the presentation of their symptoms early on are likely to be the first to be noticed by their parents. The answers to this question suggest the need for further awareness of autism for the parents to be able to recognize early symptoms of autism as early as possible.

Question 2. Did your child get any early identification procedures before the age of 2 years?

Even though parents knew something was wrong with their child early on, the majority of the respondents indicated that they did not receive any official early identification procedures for their child below the age of two years old. The literature review indicates that it is possible to diagnose children as young as two years old accurately, but the responses to this question indicate that it is not being done. Only few of the parents were able to obtain an early identification before the age of two.

Question 3. Who did you first go to for consultation?

All of the respondents indicated that they first went to their pediatrician for a consultation about their child. The unified responses on this question increased the importance of interviewing pediatricians in which will be illustrated and discussed in another section.

Question 4. Who referred your child for diagnostic assessment?

All of the respondents also indicated that pediatricians were the first to confirm parents' suspicions and redirect parents to a specialized clinician for diagnosis. This demonstrates the importance of pediatricians in the early identification of children with autism. Parents visited their pediatrician's first, and the pediatrician administers preliminary tests in screening instruments. If the pediatrician feels that the child may have symptoms lying on the autistic spectrum, then they can send them to a specialty diagnostic center for further assessment and referral for

treatment. However, some parents reported that their pediatrician did not run any test and referred the parents to a specialist. Even though parents expressed disappointment in such cases in general, referring children to specialists for diagnosis is more ethical than labeling children with untrue labels. Pediatricians play one of the most important roles in connecting parents and their children to the system that can help them receive the diagnosis that they need for services. This highlights the importance of training and education for pediatricians in the ability to recognize the symptoms of autism at an early age.

Question 5. Why was it important for you to get your child diagnosed?

The answers in part one of the questionnaire indicated that parents felt it was extremely important to receive an early diagnosis for their child. This portion of the survey asked them why they felt it was important and probes a little more deeply into their knowledge about autism. The most frequent answers provided were because the parents wanted to know what was wrong with their child and to get them an appropriate treatment. They understood the importance of diagnosis in the ability for their child to receive the services and treatment that they need. Parents knew something was wrong, but they may not have known what was wrong with their child and were looking to pediatricians for answers.

Question 6. What was the diagnosis as written in the report?

This question asks what diagnosis was first written on the report by the psychologist. Even though the majority of the answers stated autism, some answers stated speech delay, ADHD, or mental retardation. It is important to remember that the survey respondents in the questionnaire now had a child who was definitively diagnosed with autism. This question is of concern because it indicates that psychologists may not have the tools, education, and experience that they need to make a proper diagnosis of autism in early childhood. This question indicates a need for more specific training for pediatricians and psychologists regarding the signs and symptoms of autism, particularly at an early age. This question is a serious concern

for the outcome of the study in the future of children with autism in the UAE. This question indicates that children diagnosed with autism received a misdiagnosis of another condition. This could have an impact on their ability to access programs specifically designed to address the needs of children with autism. They may have received the help that was not appropriate for their diagnosis, which may have done more harm than good.

Question 7. How long did it take between noticing the first symptoms and getting your child diagnosed?

Question seven asks how long the time was between when the parents first noticed the symptoms and the child's diagnosis. A majority of the respondents indicated that it took a very long time between the first symptoms and diagnosis. Those that were specific indicated that it could be as long as eight months. This means that children not only missed their opportunity for appropriate early diagnosis while waiting to meet the psychologist but will also then miss the opportunity for early intervention. It has been proven that early diagnosis and subsequent interventions for children with autism will help them achieve their maximum potential rather than waiting until they are older (waltz 2002).

Question 8. How long did it take between contacting the diagnosis center/clinician and the diagnostic assessment appointment?

The answers from parents varied showing a range of time between two weeks to eight months. This indicated that it took a very long time between contacting the diagnostic center and receiving the diagnostic assessment. When taken into consideration with the previous question, this represents an even longer time before the child receives a proper diagnosis and then can enroll in an early intervention program.

Question 9. How long did it take between getting your child diagnosed and providing him with specialized treatment?

This question supplements the previous two questions and those regarding the speed of the system in the first portion of the survey. Parents indicated that this portion of the diagnostic and treatment process also took a very long time. The major problem illuminated by these responses in the previous three questions of the survey is that there is an additive effect on the delay between when the symptoms first appear and when the child receives a diagnosis and the interventions that they need. In the first portion of the survey, parents indicated that they were unsatisfied with the time that they spent on waiting lists before their children could receive diagnosis and intervention. This is the most significant gap that was found in this study and shows that the expediency of this system is a priority issue that needs to be addressed. Taken in aggregate, the answers to these questions indicate the importance of meeting the needs of children on the autism spectrum regarding early diagnosis and intervention. This is the greatest challenge in improving services for children with autism.

Question 10. What was your child's age when he first got diagnosed?

This question is a repeat of question number two, which increases the reliability of the questionnaire to produce consistent answers. In this question, the majority of the answers indicated that their child was diagnosed at the age of three years old. The second largest group of responses showed that their child was first diagnosed at age two and one and half years. Some other answers indicated that their child was diagnosed as late as 3.5 years old. Only some of the answers showed that their child was not diagnosed until four years or older. The responses to this question mirror those found in question number two, which addressed the ability to diagnose children under the age of two. This indicates that until the child is two and one and half years, they are not likely to receive a diagnosis, and the literature supports that it was difficult to detect autism until approximately the age of two, especially in the case of children that do not have severe symptoms. However, more recent studies suggest the ability to diagnose autism as early as one year old, which suggests early diagnosis and interventions are possible which could make a big difference in the lives of children with autism (Kinard et al. 2016).

Question 11. Where was the diagnostic assessment conducted?

The majority of the respondents indicated that the diagnostics assistant met at private institutes, while only some responses said that diagnostics were performed at a government institute. This highlights the importance of private entities in the diagnostic process because they continue to play a role in the ability to assess children with autism and are the main support system for parents in obtaining a diagnosis and proceeding along the route to intervention.

Question 12. When did your child start to get any treatment?

This question is perhaps the most important one regarding assessing the effectiveness of the system for the diagnosis and treatment of children with autism in the UAE. Considering the importance of early intervention and treatment on outcomes for children with autism, this question shows a general inadequacy with the long length of time that it takes for children to enter intervention programs. Respondents indicated that the majority of the children did not receive any treatment until they were older than four years of age. The remaining responses indicated that children received treatment between the ages of three and four years. While this is better than receiving no treatment until they reach school, there is some room for improvement in reducing the time between when the parents first noticed the symptoms and when the treatment for the child begins. The key role in autism treatment is early intervention, and the earlier a child can receive access to early intervention, the better the outcomes behaviorally and socially.

Question 13. How many times did your child get diagnosed?

This question asks about the feeling towards the reliability of the system in the UAE. Almost half of the responses showed that children received a diagnosis one time only, while the other half of the responses indicated that children received two or more diagnoses. Also, many parents took their child for a second diagnosis in their homelands, Europe, or in the US, because they had a lack of trust of services in the

UAE. One factor that might have affected responses to this question is the ability of the parents to afford a second diagnosis. It may be that many of the parents wish to have a second diagnosis, but could not afford it. This is especially the case with a diagnosis involves taking the child to Europe or the US. Many parents may not have had the means to do so. It is worth mentioning that the need for a second diagnosis may also stem from the denial phase that parents usually experience when they first receive the news that their child has autism.

Furthermore, responses to the survey said that many children received a different diagnosis before the actual autism diagnosis. This may have an effect on the feeling of trust about the reliability of the diagnosis in the UAE. In the first portion of the survey, respondents said that they were not completely satisfied with the clinicians, report, and treatment centers in the UAE. However, the satisfaction may not have included trust in the system to make it a completely accurate assessment. When parents receive several different diagnoses regarding their child, it is natural that they would question the results of these assessments and therefore the reliability of the services in the UAE in general.

Question 14. How much did the service cost you?

Question six in part one of the questionnaire examined the cost of services. Many questions were raised as to the reasons for the answers that were received because they varied from costing nothing to extremely expensive. Question 14 in part two of the survey provided some answers and explanations for this variability in the replies. Many stated that the services cost them nothing because medical insurance covered them. Some of the survey respondents did not provide a numerical answer in regards to the cost. For those that did provide a monetary amount, a majority of the respondents said that process cost at least 6000 DHS up to 60,000 DHS in cases of needing to travel abroad. For many, this would represent a high cost from their budget. Cost may prevent some children from receiving the diagnostic and early intervention services that they need.

Question 15. What diagnostic evaluations were conducted?

The final question in the survey asks what diagnostic tests were used to determine the final diagnosis. Some of the more standard tests were listed as choices, and space was also included for tests that were not included on the list. Most parents could not recall the exact test that was used to diagnose their child.

#### 4.2.4 Part 2 Summary

Part two of the questionnaire provided deeper insight into the responses from part one of the survey. For the most part, the responses supported the reliability of the survey instrument. The answers contained in the second portion of the study corresponded to the answers received in the first part. The survey indicates that the greatest challenge to improving the system is reducing the wait time between when the symptoms first appear and a final diagnosis that allows interventions to begin. Pediatricians were found to be one of the most important links between the family and the interventions that they need. However, it was found that pediatricians often failed to diagnose the child properly and to place them into the proper system for children with autism. One of the most disturbing findings was that a considerable number of children received a misdiagnosis first, before finally being entered into the right system for their specific needs. This is concerning because this time lengthens the time between when first symptoms appear and intervention can begin. The cost was also found to be a significant challenge for parents in getting their child the treatment that they need. The next portion of Chapter 4 will examine the qualitative sections of the study and how they relate to the responses obtained through the survey questionnaire administered to the parents.

### 4.3 **Qualitative Data**

The qualitative portion of the study attempted to provide the perspective of professionals regarding the state of diagnosis and treatment of children with autism in the UAE. The purpose for collection of this data was to compare it to the answers that

were received in the survey of the parents and the two focus groups. This perspective will allow the researcher to triangulate these two pieces of data to see where the gap exists.

Pediatrician phone interviews were conducted, involving one pediatrician from each of the cities in which the study was conducted. The physicians in Abu Dhabi and Sharjah indicated that if the child is older than one year and six months they may be sent to a diagnostic center if they still do not produce any sounds. However, the first line of action is to determine if the child has any deficits in hearing, tongue, or mouth issues, rather than jumping to autism as the first diagnosis. Physicians want to rule out physical causes for the child's inability to speak first before referring them to diagnostic centers specific to autism. Even though these procedures seem enough for early identification of autism, it is not the most appropriate procedure for identifying autism. Many cases include students who can talk and maintain good eye contact but still have mild symptoms of autism.

However, the process for early identification was different in Dubai. The pediatrician from Dubai uses the Age and Stage Questionnaire Three (ASQ3) or the Modified Checklist for Autism in Toddlers (M-CHAT) with parents who have children as early as one year old. The ASQ3 was found to be a reliable early identification tool for autism at early ages (Hill 2014). It was argued that M-CHAT can improve the early identification for autism (Sunita & Bilszta 2012). Even though it is not known if all pediatricians in Dubai are consistent in using those tools, both tools provide pediatricians with the criteria that are standard. It also improve knowledge about what the early symptoms of autism and other developmental disorders can look like when they manifest and when to raise awareness that early intervention services may be necessary.

Notably, it is not known if the procedure in Dubai results in a higher number of children identified with autism at an early age than in other cities. Section 2 of the parent survey showed that some children were first diagnosed with a disorder other



than autism. This may be reflective of the inability of pediatricians to recognize the early symptoms of autism in some cities, especially, in case of children with autism who display mild symptoms.

An interview was conducted with Mrs. Maya Helou who is the manager for community service in one of the autism centers in Dubai. She discussed the importance of a diagnostic report in order for a student to get enrolled in the center. When asked about the speediness in the diagnostic service delivery in Dubai, she confirmed that there is a long waiting list for both diagnosis and students admission for centers in the city. She further added that the better the quality of the diagnosis service the higher the cost in Dubai. She also mentioned that due to the high cost of the service, parents prefer to pay the cost to receive therapeutic services even without proper diagnosis. When asked about the accuracy of the diagnosis and the reliability, Mrs. Helou pointed out that parents from Gulf countries come to Dubai to get their children diagnosed which shows that the service is better when compared to other Gulf countries, however, there is a room for improvement in Dubai as well. When asked about means of improvement she added that pediatricians can be one part of the problem. They are the first to recognize the first symptoms, however, in many cases, they delay redirecting children to other specialists because of the belief that the child does not have autism only because there was no manifestation of severe symptoms.

It is important to note here that autism does not come in a unified form or severity level, and that if a child can maintain eye contact and is capable of speaking, this does not eliminate the potential that the child has autism. She added that another part of the problem is that some psychologists are still in need of the awareness of the varied symptoms of autism, especially in mild cases. She gave an example of a case of a student with mild symptoms who got different diagnoses in three different times across three years until the child was properly diagnosed with autism at the age of four. This lack of ability to recognize autism at early ages has a negative impact on the child's progress and independence in the future. Mrs. Helou highlighted the importance of early identification and proper diagnosis as there are many cases with

mild autism that do not get diagnosed until the age of 7 or 8 when problem behaviors or attention deficits manifest as they grow up without suitable intervention. She added that those children in the primary stage at school may still be mislabeled with attention deficit disorders or speech delays rather than autism. She highlighted the need for further awareness for psychologists, parents, pediatricians, teachers at nurseries and all caregivers.

Further interviews were conducted with a school principal regarding the diagnosis of autism disorder and another interview was performed with a speech and language pathologist at an autism center in Abu Dhabi. The current director of this autism center detailed that there have been no significant changes over time in the paperwork processes for providing admission to children to the center. Parents must provide medical records confirming the diagnosis prior to admission. He explained that they refer children to some private and government facilities in the city for diagnosis. He felt that the time between the appearance of the symptoms and diagnosis in younger children had improved over the last ten years largely due to greater awareness about autism. He also felt that a greater availability of the people who could perform the diagnosis may have been a factor in these improvements. He agreed with the researcher that when parents go outside of the UAE for the second diagnosis, it may be because they do not have faith in the diagnostic abilities professionals in the UAE. He also added that it might be that they disagree with the diagnosis and want a second opinion for that reason.

The current director of this autism center shared that the reports did not always explicitly state the diagnosis. They use the language such as, “the child has characteristics of autism,” but that is not the same as a true diagnosis. Parents felt that the reports contain the diagnosis, which can create a misunderstanding regarding what the language in the report means and how the parents comprehend the diagnosis. He also confirmed the importance of educating doctors and pediatricians about the early warning signs of autism so that they can clarify their diagnoses to families.

Dr. Saleh Shaalan is the director of speech and language services at an autism center in Abu Dhabi. He responded to a question about the unqualified freelancers who provide the diagnostic services even though they are not associated with a diagnostic centers. He did not feel, however, that the problem was significant and that most students came to the center with a diagnosis from reliable private or government diagnostic centers prior to admission. Dr. Shaalan felt that a lack of certification and training was a problem leading to the misdiagnosis or uncertainty about the diagnosis that should be addressed across the country

Dr. Shaalan explained that there is no formal system for informing parents about the diagnosis centers, and instead information is primarily spread through word-of-mouth. This links back to question number two in part one of the survey in which parents in some cases found that finding the diagnostic centers was difficult or earlier in other cases depending on the age of their child. A lack of formal communication and information regarding knowledge about these diagnostic centers would help to explain the answers to the survey to these families in need. The doctor felt that an educational system for physicians about the symptoms of autism and what to look for before making an informed diagnosis would contribute to improving the overall performance of diagnosis and treatment in the UAE. Dr. Shaalan did not feel that significant improvements had been made in the overall system, except for an increase in the overall numbers of diagnostic centers.

The third portion of the qualitative section of the study involved conducting two focus groups. One group included parents of children younger than five years old, and the other one was with parents of children that are 13 years and older. The groups were asked open-ended questions about affordability, reliability, and speed of the services. The group involving parents of younger children provided more positive attitudes about the services than the parents of older children. This suggests that improvements in the system have had a real impact on the experiences of parents of children diagnosed with autism at a young age. The parents' responses from the two focus groups validate the collected data from the surveys. it also confirms the

concerns and difficulties parents of children with autism went through while trying to get a proper diagnosis for their children in terms of the waiting time, the contradicting diagnoses, the costly services, and the feeling of being left alone. Remarkably, one mother from the older group who took her son to get diagnosed in Germany stated that she was not only looking for a diagnosis but that she was looking for a medicine or a drug that could cure her son. This showcases the lack of awareness about the nature of autism among parents, especially parents of older children with autism, and that there is still an urgent need for the services, information, and communication regarding autism to be improved in the UAE

#### **4.4 Summary**

Chapter 4 presented the findings of the data collection methods used in this mixed methodology research. It provided several different perspectives on the state of the system in the UAE. Chapter 4 compared the results of the quantitative and qualitative portions of the study to achieve triangulation and the ability to draw conclusions based on it. The next chapter will present a conclusion of these results, their implications, and recommendations about the next steps that need to be taken to improve services for children with autism in the UAE.

## **5 Chapter Five**

### **Conclusions and Recommendations**

#### **5.1 Conclusion**

The results of the quantitative parent survey, the qualitative focus groups, and interviews agreed on several issues regarding the current system for early identification and diagnosing autism in the UAE. Both qualitative and quantitative data identified the accuracy of early diagnosis as well as the wait time between receiving a diagnosis and receiving treatment as being areas in need of improvement. The findings already discussed in this study indicate the greatest concern, and the most important challenge is that there seems to be a lack of uniform knowledge and education about the early symptoms of autism. This leads to a misdiagnosis or lack of a diagnosis in children and can prevent them from receiving services that they need quickly.

A comparison of the early identification criteria between the three cities in the study found that inconsistencies in the procedures exist that could explain the delay in diagnosis, misdiagnosis, or lack thereof. In Abu Dhabi and Sharjah, physicians only use language delay, inability to maintain proper eye contact, and also severe behavioral symptoms (self-injurious behavior, aggression, environmental destruction) as criteria. The criteria are inadequate to base a consistent and reliable method of early identification on. In Dubai, early identification tools such as the ASQ-3 or I-MATCH are administered to children under the age of two. These tools provide uniformed assessment criteria and increase awareness of predictable early childhood autism symptoms among physicians although it is unclear if all pediatricians across Dubai use the same tools. A consistent concern among participants was that lack of knowledge among healthcare professionals manifests in misdiagnosis of autism in young children. A standardized screening tool in the UAE would help to improve

accurate and early diagnoses. This would also enhance the confidence of physicians in determining a diagnosis of autism as well as providing parents with a greater feeling of trust in the system and its ability to properly identify their child at an early age.

Parents need to have a reliable system for the diagnosis of their children. Developing trust is a necessity of preserving the future ability to provide early intervention and the greatest opportunity for children to live fulfilling and successful lives. The second major issue, aside from uniformity in assessment criteria and education of physicians, was the wait time between when symptoms first appear and when intervention begins. Parents described lengthy wait times to even sit with specialist capable of giving a diagnosis. This delay in early intervention services can be detrimental to the overall potential treatment outcomes.

Both interviewees at the autism center in Abu Dhabi felt that although the number of diagnostic centers has increased parents still have some complaints about remaining on the waiting list for as long as eight months before an initial appointment. Professionals at the autism center in Abu Dhabi agreed that an increase in diagnostic centers and utilizing more practitioners in the diagnosis of early childhood autism symptoms would help improve the speed at which the child can begin receiving services.

Another factor affecting potential diagnosis appointments is money. It was found that the ability to pay for diagnostic assessments varied between the UAE cities and that the affordability varies between expatriates and Emirati locals based on whether health insurance covers the diagnosis service or not. This means that many children may not receive the help that they need because their parents cannot afford it. Financial assistance for those that do not qualify for insurance in the UAE is another issue that needs to be addressed but may lie beyond the scope of this study to resolve.

In summary, the findings of this research study indicate that even though the ability to diagnose autism and provide early intervention services has improved over the last decade, there is still much room for development. The main areas that need to be addressed include the development of a new more uniform system for screening, assessment, and intervention. Physicians and pediatricians need to have a more detailed understanding of autism and have a standardized screening tool that is consistently used across all areas of the UAE. Furthermore, an increase in the number of diagnostic centers and trained personnel to recognize the signs of autism would also help to alleviate current wait times.

## **5.2 Recommendations**

The findings from this research have provided insight into the procedures used in early identification and diagnosis of autism in the UAE. It was found that although great strides have been made in recent times to improve the services offered in the UAE, there are still many areas which could be addressed. The following recommendations work to address these areas and may help to improve the system to ensure that more children in the future get quick, affordable, accurate and reliable services.

A national early identification tool must be adopted as a requirement for the screening of autism in all children at an early age. This early age screening tool for autism should be evidence-based and could make benefit of such assessments as the ASQ3 or the M-CHAT while also considering the cultural and social aspects of the UAE. In addition to the use of standardized screening tools for the early diagnosis and assessment of autism, a national certification exam must be mandatory for all professionals who will provide the service of diagnosis ensuring procedural integrity. Standardized regulations and requirements regarding the education and training of people making the diagnosis of autism in children are a necessity to improving the integrity of the process in the future. This would help to prevent the occurrence of

misdiagnosis, the need for second opinions, and in most cases will make the service more affordable. Effective diagnosis in the beginning, decreases the time a child has to wait to receive the intervention.

A greater emphasis needs to be placed on knowledge of typical childhood development milestones in the early years. The need for this type of knowledge is essential to identify potential autism in children as early as possible. Another important element is to establish several national governmental centers for early identification and diagnosis in each emirate. Those centers can be the first place pediatricians refer children to once the first symptoms are identified by a standardized screening tool. In addition, more professionals qualified to assess and diagnose autism should be available at these centers. Spokespeople from these centers could then provide awareness of the importance of screenings at locations such as vaccinations clinics where parents are likely to bring their young children. A move towards an electronic database should also be considered for all potential and current children with autism could decrease waiting times by referring a potential child to another emirate with available diagnosticians instead of waiting longer periods in a busier Emirate.

More extensive trainings in the hallmarks of autism for pediatricians, paraprofessionals, and people involved in the care of children could be the start of a much needed national awareness campaign. Medical schools could also ensure that graduating students are made aware of standardized screening tools and the symptoms of autism prevalent in early years of development.

In summary, the recommendations suggested by this study included a standardized screening tool, increased standard of education for people involved in the assessment and diagnosis of autism, the development of awareness programs, increased availability to diagnostic centers and the professionals qualified to make the diagnoses. Implementing the recommendations made in this research study will have a significant long-term impact on outcomes for children with autism. The



recommendations, if implemented, help to bring the UAE closer to mobile standards when it comes to the early identification, diagnosis and treatment of children with autism.

## 6 References

Adelman, C.R. & Kubiszyn, T. (2016). Factors that affect age of identification of children with an autism spectrum disorder. *Journal of Early Intervention*, 22 November.

Al Jabery, M., Arabiat, D.H., AL Khamra, H.A., Betawi, I.A. & Abdel Jabbar, S.K. (2012). Parental perceptions of services provided for children with autism in Jordan. *Journal of Child and Family Studies* [online]. Vol. 23 (3), pp. 475–486. [Accessed 11 February 2017]. Available at: <http://dx.doi.org/10.1007/s10826-012-9703-0>

Al-Raisi, A.N. & Al-Khouri, A.M. (2008). Iris recognition and the challenge of homeland and border control security in UAE. *Telematics and Informatics*, vol. 25 (2), pp. 117–132.

American Center. (n.d.). *Asperger's disorder, Abu Dhabi* [online]. [Accessed 18 February 2017]. Available at: <http://www.americancenteruae.com/aspergers-disorder/>

American Psychiatry Association. (2013). *Diagnostic and statistical manual of mental disorders, 5th edition (DSM-5)*. 5th edn. Washington, DC, United States: American Psychiatric Publishing.

Baron-Cohen, S., Cox, A., Baird, G., Swettenham, J., Nightingale, N., Morgan, K., Drew, A. & Charman, T. (1996). Psychological markers in the detection of autism in infancy in a large population. *The British Journal of Psychiatry*, vol. 168 (2), pp. 158–163.

Creswell, J.W. (2011). *Research design: Qualitative, quantitative, and mixed methods approaches*. 3rd edn. New Delhi: SAGE South Asia.

Cundall, D. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Child: Care, Health and Development*, vol. 28 (5), pp. 431–431.

Dajani, D.R. & Uddin, L.Q. (2015). Local brain connectivity across development in autism spectrum disorder: A cross-sectional investigation. *Autism Research*, vol. 9 (1), pp. 43–54.

Daniels, S. (2002). Early screening: Can autism be identified in young children through parental report. *Humanities and Social Sciences* [online]. Vol. 63 (5A). Available at: [https://www.researchgate.net/publication/268132621\\_Factors\\_That\\_Influence\\_Age\\_of\\_Identification\\_of\\_Children\\_with\\_Autism\\_and\\_Pervasive\\_Developmental\\_Disorder-Not\\_Otherwise\\_Specified](https://www.researchgate.net/publication/268132621_Factors_That_Influence_Age_of_Identification_of_Children_with_Autism_and_Pervasive_Developmental_Disorder-Not_Otherwise_Specified) (Accessed: 16 February 2017a).

Edarabia. (2012). *Increasing number of autism cases in UAE demands more facilities* [online]. [Accessed 18 February 2017]. Available at: <http://www.edarabia.com/26308/increasing-number-of-autism-cases-in-uae-demands-more-facilities/>

Farooq, K. (2007). Current Status of Educating Emirati Children with Autism Spectrum Disorder in Dubai. *M.Ed. Dissertation. The British University in Dubai.*

Gaitonde, S. (2008). *A survey of parent satisfaction about services for children with pervasive developmental disorder*. ProQuest.

Geranpayeh, S. (2016). 'Reality of living with autism in UAE'. *Health,Society*, [online]. [Accessed 12 October 2016]. Available at: <http://gulfnews.com/news/uae/health/reality-of-living-with-autism-in-uae-1.1822477>

Gulf News Online. (2017). *UAE business: Managing autism in focus at UAE medical meet* [online]. [Accessed 18 November 2016]. Available at: <http://www.gdnonline.com/Details/61980/Managing-autism-in-focus-at-UAE-medical-meet>

Health Council of the Netherlands. (2009). *Autism spectrum disorders: A lifetime of difference* [online]. The Hague: Health Council of the Netherlands. [Accessed 18 February 2017]. Available at: <https://www.gezondheidsraad.nl/sites/default/files/200909E.pdf>

Hill, J. (2014). ASQ and ISPI: Mutual opportunities for influencing global performance. *Performance Improvement*, vol. 53 (6), pp. 6–14.

Hornstein, S. (2015). *Changes in mothers' experiences of receiving an autism diagnosis: A contextualized case study* [online]. PHD. Arizona State University. Available at: [https://repository.asu.edu/attachments/56797/content/Hornstein\\_asu\\_0010E\\_10390.pdf](https://repository.asu.edu/attachments/56797/content/Hornstein_asu_0010E_10390.pdf)

IACAPAP. (2012). *Declaration on autism spectrum disorders* [online]. [Accessed 21 January 2017]. Available at: [http://iacapap.org/wp-content/uploads/Autism\\_Declaration\\_2012.pdf](http://iacapap.org/wp-content/uploads/Autism_Declaration_2012.pdf)

Jubran, L.N. (2015). *Student voice for enhancing the quality of inclusive education* [online]. Master. The British University in Dubai. Available at: <http://bspace.buid.ac.ae/bitstream/1234/778/1/120043.pdf>

Kaufmann, W.E. (2012). DSM-5: The new diagnostic criteria for autism spectrum disorders. In *Research Symposium-Autism Consortium*. Department of Neurology, Harvard Medical School: Boston, MA.

Kinard, J.L., Sideris, J., Watson, L.R., Baranek, G.T., Crais, E.R., Wakeford, L. & Turner-Brown, L. (2016). Predictors of parent responsiveness to 1-Year-Olds at-risk for autism spectrum disorder. *Journal of Autism and Developmental Disorders*, vol. 47 (1), pp. 172–186.

Leather, S. (2005). *Towards equity in the process to a diagnosis: How children are given a diagnosis of an Autistic Spectrum Disorder or Autism in the London borough of Greenwich* [online]. Doctoral dissertation. University of London. Available at: <http://discovery.ucl.ac.uk/1444927/>

Mannion, A. & Leader, G. (2014). Attention-deficit/hyperactivity disorder (AD/HD) in autism spectrum disorder. *Research in Autism Spectrum Disorders*, vol. 8 (4), pp. 432–439.

McQuillan, M. (2010). *Guidelines for Identifying Children with Learning Disabilities*. Middletown, Connecticut: Connecticut State Department of Education.

Mick, K. (2005). *Diagnosing autism: Comparison of the childhood autism rating scale (CARS) and the autism diagnostic observation schedule (ADOS)* [online]. Doctoral dissertation. Wichita State University. [Accessed 5 January 2017]. Available at: <http://soar.wichita.edu/bitstream/handle/10057/439/d05001.pdf?sequence=3>

Mitchell, S. (2006). *The official autism 101 e-book: Autism today experts discover the awesome in autism! The official autism 101 e-book: Autism today* [online]. Alberta, Canada:Autism Today. [Accessed 18 February 2017]. Available at: <http://autismtoday.com/autism-101-ebook.pdf>

MOE. (2010). *General rules for the provision of special education programs and services (public & private schools)* [online]. UAE:The Ministry of education. [Accessed 15 November 2016]. Available at: <https://www.moe.gov.ae/English/SiteDocuments/Rules/SNrulesEn.pdf>

Nahad, A.L. (2015). One boy's journey: Living with autism in the UAE. *Journal of Psychology and Behavioral Science*, vol. 3 (2).

Omar, G., Ahmed, T., Tahir, A.-M., Rizvi, A. & Al-Gazali, L. (2005). *Genetic disorders in the Arab world: United Arab Emirates* [online]. [Accessed 6 November 2016]. Available at: <http://www.cags.org.ae/cbc03uae.pdf>

Pennington, B.F.F. & Denckla, M.B. (2009). *Diagnosing learning disorders: A neuropsychological framework*. New York:Guilford Publications.

Perryman, T.Y., Watson, L.R., Crais, E., Harrison, M., Reznick, S., Thomas, K. & Williams, S.W. (2009). *INVESTIGATING DISPARITIES IN THE AGE OF DIAGNOSIS OF AUTISM SPECTRUM DISORDERS* [online]. University of North Carolina. [Accessed 18 February 2017]. Available at:

<https://cdr.lib.unc.edu/indexablecontent/uuid:948e429c-efb7-43b2-8a62-70b52d4563ab>

Ptak, M. (2015). *A window into autism's early development: Features of behavioral data in a longitudinal multisystem evaluation in infants at high risk for autism* [online]. [Accessed 18 February 2017]. Available at: <https://open.bu.edu/handle/2144/16254>

Rai, B.S. (2016). Many UAE residents are still 'clueless' about autism. 15 January. [Accessed 18 September 2016]. Available at: <http://www.emirates247.com/lifestyle/many-uae-residents-are-still-clueless-about-autism-2012-04-08-1.452669>

Rivera, K., McDaniel & Bender, D. (2014). *Healing the symptoms known as autism*. 2nd edn. United States:Autismo2.

Rizvi, A. (2016). UAE children are being misdiagnosed with autism. 15 April. [Accessed 18 February 2017]. Available at: <http://www.thenational.ae/uae/health/uae-children-are-being-misdiagnosed-with-autism>

Robledo, J.S. & Ham-Kucharski, D. (2005). *The autism book: Answers to your most pressing questions*. New York:Avery Publishing Group Inc.,U.S.

Rogers, S.J. (2009). What are infant siblings teaching us about autism in infancy? *Autism Research*, vol. 2 (3), pp. 125–137.

Rossi, N.T. (2012). *The production of autism diagnoses within an institutional network: Towards a theory of diagnosis* [online]. [Accessed 20 September 2016]. Available at: <https://academiccommons.columbia.edu/catalog/ac%3A143070>

Ruef, M.B. (2003). Including students with disabilities: Let's move forward together. *Action in Teacher Education*, vol. 25 (1), pp. 1–4.

Smith, S. (2012). *Autism: Causes, symptoms, signs, diagnosis and treatments - everything you need to know about autism - revised edition -Illust*. United States:National Institute of Mental Health. <https://www.autism-watch.org/general/nimh.pdf>

Stephenson, R.W. (2016). *The Disparities in Autism Diagnosis of Children within the United States* [online]. PHD. WILMINGTON UNIVERSITY. Available at: <http://gradworks.umi.com/37/41/3741447.html>

Stockman, J.A. (2011). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Yearbook of Pediatrics*, vol. 2011, pp. 74–77.

Sunita & Bilszta, J.L. (2012). Early identification of autism: A comparison of the checklist for autism in toddlers and the modified checklist for autism in toddlers. *Journal of Paediatrics and Child Health*, vol. 49 (6), pp. 438–444.

Waltz, M. (2002). *Autistic spectrum disorders: Understanding the diagnosis and getting help*. 2nd edn. United States: O'Reilly Media, Inc, USA.

WHO. (1992). *The ICD-10 classification of mental and Behavioural disorders: Clinical description and diagnostic guidelines: Clinical description and diagnostic guidelines*. Geneva: World Health Organization.

WHO. (2014). *Autism spectrum disorders & other developmental disorders* [online]. [Accessed 18 August 2016]. Available at: [http://apps.who.int/iris/bitstream/10665/103312/1/9789241506618\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/103312/1/9789241506618_eng.pdf)

WHO. (2015). 'Sixty-seventh world health assembly'. *World Health Organization* [online]. [Accessed 1 October 2016]. Available at: <http://www.who.int/mediacentre/events/2014/wha67/en/>

Whyte, L. (2017). 'Scientists use MRI scan to diagnose autism in babies'. *Articles* [online]. [Accessed 18 February 2017]. Available at: <http://www.newsgrio.com/articles/446254-scientists-use-mri-scan-to-diagnose-autism-in-babies.html>

Zwaigenbaum, L., Bryson, S. & Garon, N. (2013). Early identification of autism spectrum disorders. *Behavioural Brain Research*, vol. 251, pp. 133–146

## 7 Appendices

### A) Parents Survey and Consent Form



#### Diagnosing Autism in the UAE Consent Form

Mahmoud Abdulrahim

Prof. Eman Gaad

The British University in Dubai

[2015101017@student.buid.ac.ae](mailto:2015101017@student.buid.ac.ae)

00971509890801

You are invited to take part in a research study about diagnosing autism in the UAE.

**What the study is about:** investigating the current status of diagnosing Autism in the UAE.

**What you will be asked to do:** answer the questions in the questionnaire based on your own experience. The estimated time for this questionnaire to be filled out is 20 minutes.

**Risks and benefits:** There are no anticipated risks in this study.

Your contributions to the research will greatly help in enhancing the early identification and diagnosis of autism in the UAE.

**Taking part is voluntary:** participating in this study is completely **voluntary**. If you choose to be in the study, you may withdraw at any time with no consequences of any kind. You may also choose to skip any question, participate in only some tasks.

**Your answers will be confidential:** The records of this study will be kept private, and all answers will be kept on a personal computer. Your name or any other information by which you could be identified will not be presented in public.

**If you have questions or want a copy or summary of the study results:** Contact the researcher at the email address or phone number above. You will be given a copy of this form to keep for your own personal records.

**Statement of Consent:** I have read the above information, and have received answers to any questions to which I consent to take part in the research study of diagnosing autism in the UAE.

How old is your child? \_\_\_\_\_

Participant's Signature

Date

**Parents Survey:** Please circle the answers based on your experience.

1- How would you rate the importance of diagnosing children at early ages?						
Not important						Extremely important
1	2	3	4	5	6	7
2- How easy was it for you to get information about a diagnostic center?						
Extremely easy						Extremely hard
1	2	3	4	5	6	7
3- Describe the period of time you spent until you were able to get your child diagnosed.						
Very short time						Extremely long time
1	2	3	4	5	6	7
4- How would you rate the importance of early identification for your child's development?						
Not important						Extremely important
1	2	3	4	5	6	7
5- Rate your level of satisfaction about the clinician who ran the diagnostic test.						
Extremely unsatisfied						Extremely satisfied
1	2	3	4	5	6	7
6- Rate the affordability of the diagnostic test.						
Inexpensive						Extremely expensive
1	2	3	4	5	6	7
7- Rate your level of satisfaction about the diagnostic report of your child?						
Extremely unsatisfied						Extremely satisfied
1	2	3	4	5	6	7
8- How reliable is the diagnostic center you went to in order to get your child diagnosed.						
Extremely unreliable						Extremely reliable
1	2	3	4	5	6	7
9- How do you rate the help you received from the government in order to get your child diagnosed?						
Extremely poor						Excellent
1	2	3	4	5	6	7
10- How do you rate the overall service of diagnosing children in the UAE?						
Extremely poor						Excellent
1	2	3	4	5	6	7

Please answer the following questions to the best of your ability:

- 1- How old was your child when you first noticed any of the symptoms?
  - .....
- 2- Did your child get any early identification procedures? If yes what was the procedure?
  - .....





3- Who did you first go to for consultation?

• .....

4- Who referred your child for diagnostic assessment?

• .....

5- Why was it important for you to get your child diagnosed?

• .....

6- What was the diagnosis as written in the report?

• .....

7- How long did it take between noticing the first symptoms and getting your child diagnosed?

• .....

8- How long did it take between contacting the diagnosis center/clinician and the diagnostic assessment appointment?

• .....

9- How long did it take between getting your child diagnosed and providing him with specialized treatment?

• .....

10- What was your child's age when he first got diagnosed?

• .....

11- Where was the diagnostic assessment conducted?

• .....

12- When did your child start to get any treatment?

• .....

13- How many times did your child get diagnosed?

• .....

14- How much did the service cost you?

• .....

15- What diagnostic evaluations were conducted? (Mark all that are applicable)

- ☐ Autism Diagnostic Observation Schedule (ADOS)
- ☐ Childhood Autism Rating Scale (CARS)
- ☐ Autism Diagnostic Interview- Revised (ADI-R)
- ☐ Mullen's scales of Early Development
- ☐ Gilliam Autism Rating Scale
- ☐ Asperger Syndrome Diagnostic Scale
- ☐ Adaptive behavior scale
- ☐ Any other. Explain:
- ☐ I don't know

Thank you for your participation

## B) Focus Group Consent Form



### Consent Form: Focus Groups

Age of your Child: \_\_\_\_\_

#### Purpose:

Under the supervision of the British University in Dubai and The New England Center for Children- Abu Dhabi, you are invited to participate in this focus group. The purpose of the study is to explore the process of diagnosing autism in the UAE. Specifically, we want to investigate the current status of the diagnostic service in the country. The information will help to come up with recommendations to overcome any obstacles and enhance the service of diagnosing children with autism.

#### Procedures:

If you participate in this study, you will be in a group of approximately 3 – 4 parents for one meeting that lasts for approximately two hours. There will be a researcher who will ask questions, facilitate the discussion, and write down the ideas expressed within the group. If you volunteer to participate in this focus group, you will be asked questions relating to your experience with getting your child diagnosed in Abu Dhabi. These questions will help us to understand the overall process better.

**Your participation is completely voluntary. You may withdraw from this study at any time without penalty.**

#### Benefits and Risks:

Your participation may benefit you and other parents by helping to improve the service in the country.

Everyone will be asked to respect the privacy of the other group members. All participants will be asked not to disclose anything said within the context of the discussion, but it is important to understand that other people in the group with you may not keep all information private and confidential.

#### Confidentiality:

Anonymous data from this study will be analyzed by the researcher. No individual participant will be identified or linked to the results. Study records, including this consent form signed by you, may be inspected by the administrators. The results of this study may be presented at meetings and poster sessions; however, your identity will not be disclosed. All information obtained in this study will be kept strictly **confidential**. All materials will be stored in a secure location within the British University of Dubai.

**By signing this consent form, you are indicating that you fully understand the above information and agree to participate in this focus group.**

Participant's name: \_\_\_\_\_

Participant's signature: \_\_\_\_\_

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

If you have any questions or concerns about this study, please contact:

+971509890801, 2015101017@student.buid.ac.ae

## C) Interview Consent Form



### Diagnosing autism in the UAE Consent Form

Mahmoud Abdulrahim  
 Prof. Eman Gaad  
 The British University in Dubai  
[2015101017@student.buid.ac.ae](mailto:2015101017@student.buid.ac.ae)  
 00971509890801

You are invited to take part in a research study about diagnosing autism in the UAE.

**What the study is about:** investigating the current status of diagnosing autism in the UAE.

**What you will be asked to do:** answer the questions in the interview based on your own experience. The estimated time for this interview is 30 minutes.

**Risks and benefits:** There are no anticipated risks in this study.

Your contributions to the research will greatly help in enhancing the early identification and diagnosis of autism in the UAE.

**Taking part is voluntary:** participating in this study is completely **voluntary**. If you choose to be in the study, you may withdraw at any time with no consequences of any kind. You may also choose to skip any question or participate in only some questions.

**Your answers will be confidential:** The records of this study will be kept private, and all answers will be kept on a personal computer. Your name or any other information by which you could be identified will not be presented in public without your permission.

**If you have questions or want a copy or summary of the study results:** Contact the researcher at the email address or phone number above. You will be given a copy of this form to keep for your own personal records.

Do you agree to use your name in this study? ...*Yes*..... (Yes/ No)

**Statement of Consent:** I have read the above information, and have received answers to any questions to which I consent to take part in the research study of diagnosing autism in the UAE.

Participant's name & signature

*Maya Helon*  
*Maya*

Date *27/2/2017*

**Diagnosing autism in the UAE Consent Form**

Mahmoud Abdulrahim

Prof. Eman Gaad

The British University in Dubai

[2015101017@student.buid.ac.ae](mailto:2015101017@student.buid.ac.ae)

00971509890801

You are invited to take part in a research study about diagnosing autism in the UAE.

**What the study is about:** investigating the current status of diagnosing autism in the UAE.

**What you will be asked to do:** answer the questions in the interview based on your own experience. The estimated time for this interview is 30 minutes.

**Risks and benefits:** There are no anticipated risks in this study.

Your contributions to the research will greatly help in enhancing the early identification and diagnosis of autism in the UAE.

**Taking part is voluntary:** participating in this study is completely **voluntary**. If you choose to be in the study, you may withdraw at any time with no consequences of any kind. You may also choose to skip any question or participate in only some questions.

**Your answers will be confidential:** The records of this study will be kept private, and all answers will be kept on a personal computer. Your name or any other information by which you could be identified will not be presented in public without your permission.

**If you have questions or want a copy or summary of the study results:** Contact the researcher at the email address or phone number above. You will be given a copy of this form to keep for your own personal records.

Do you agree to use your name in this study? ..... (Yes) No

**Statement of Consent:** I have read the above information, and have received answers to any questions to which I consent to take part in the research study of diagnosing autism in the UAE.

**Participant's name & signature**

Sabah Shaikh  
Saad

**Date**

30 Jan, 2017