

# Autism Speaks in Rabat and Casablanca



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Sponsored by Hafida Torres and Autism Speaks



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This is an Interactive Qualifying Project submitted to the faculty  
of Worcester Polytechnic Institute to fulfill a requirement  
for the degree of Bachelor of Science

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# Abstract

Autism Speaks has initiatives to better understand the challenges families of children with autism in Morocco face, with the goal of promoting solutions for their difficulties. My project assists with these initiatives. The project collected data on the issues and challenges caregivers of families of children with autism faced in Moroccan society. I interviewed families in Rabat and Casablanca. From the results a key finding was that a large percentage of interviewed families did not receive autism diagnosis for their children before the age of two, which is recommended by Autism Speaks. I sent the data collected to Autism Speaks and presented my findings from the results and offered recommendations to NGOs and Autism Speaks for policies they could implement to better service children with autism.

# Executive Summary

## *What is Autism Speaks?*

Autism Speaks is an international organization based in New York. The mission of Autism Speaks taken from their website is: “Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the lifespan, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of people with autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions” (Autism Speaks, 2017).

## *What is autism?*

Autism or autism spectrum disorder (ASD) is a mental disability that exists on a spectrum. The spectrum of autism encompasses many different levels of function capability. High functioning autism, otherwise known as Asperger’s Syndrome, of which the symptoms are communication deficiencies and repetitive behaviors, are only noticeable when the child does not receive support. Medium functioning autism symptoms are communication deficiencies and repetitive behaviors that are obvious to casual observers even when there is support for the child. In severe autism the person's communication deficiencies and repetitive behaviors are so great, that they make daily life very difficult for the person (Forman, 2018).

Autism disorder is potentially accompanied by a variety of other symptoms, such as Attention Deficit Hyperactivity Disorder (ADHD), gastrointestinal issues, anxiety, depression and so on. Autism Speaks recommends a diagnosis and intervention before the age of two, to maximize the progress the child is able to make and so that they do not adopt harmful habits early on (What is Autism, 2017).

## *Resources*

The project interviewed families from the Space for Brothers and Amal organizations. Space for Brothers is a public organization in Rabat that offers services to children with autism. Amal is a private organization in Casablanca that offers services to children with various mental disabilities including autism. The project obtained data from fifteen interviews, seven of the interviews were collected in a team setting, eight of the interviews were collected at the Amal

organization with a translator and an advisor watching over me. I collected data from interviews at the Space for Brothers organization, and eight interviews at the Amal organization.

### ***Purpose of the project***

Autism Speaks is conducting initiatives in Morocco to better understand the issues and challenges that families of children with autism face living in Moroccan society. The goal of this project was to aid in these initiatives by collecting and analyzing data regarding the current treatments and education available in Morocco to children with autism. To complete this goal, I had two objectives. The first was to assess and analyze resources and challenges for families of children with autism in the Rabat and Casablanca regions. My second objective was to identify new issues that families introduced when sharing personal stories. After completing these objectives, I gave recommendations for courses of action that could be taken to help benefit children with autism in Morocco.

### ***Methodology***

Autism Speaks provided the project with a specialized survey for data collection from caregivers. Autism Speaks also connected the project with the non-governmental organizations it would work with in Morocco. To accomplish my first objective from my goal, I worked with the team of students and a translator to hold in-person interviews at the Space for Brothers organization located in Rabat. I held in-person interviews with a translator and an advisor at the Amal organization for children with special needs located in Casablanca. During the interviews at both locations, the project gained data in the form of responses to multiple choice survey questions. I also gained data in the form of personal stories which caregivers told after questions.

I looked at the quantitative data which resulted from the survey questions, and the qualitative data which was in the form of the personal stories from the participants which I transcribed. This research compared and contrasted the quantitative data between both organizations where I collected results. Finally the project interpreted the personal stories, which required the use of coding to properly categorize and understand data from the transcripts of the interviews.

After the analysis of the unique aspects of each organization, the research analyzed the differences and similarities in the quantitative data from the Autism Speaks survey between the

Space for Brothers and Amal organizations. The project tied the quantitative and qualitative data together to help get a better understanding of the challenges families with children with autism face in Morocco.

### ***Results***

The following are the key findings in the result of the analysis of my data. These key finding encompass all the data collected between both organizations. The first thing that stood out during the interviews was the lack of diagnosis for many of these children. When asked about any documentation of official diagnosis, parents always explained that they did not and/or could not get one. Another parent explained that in Morocco there were no doctors qualified to give official diagnosis for autism in Morocco. Because of this, the main way that parents would find out their child was autistic was by taking him/her to a professional or organization to have a basic evaluation, then the doctor/person would say that the child likely had autism.

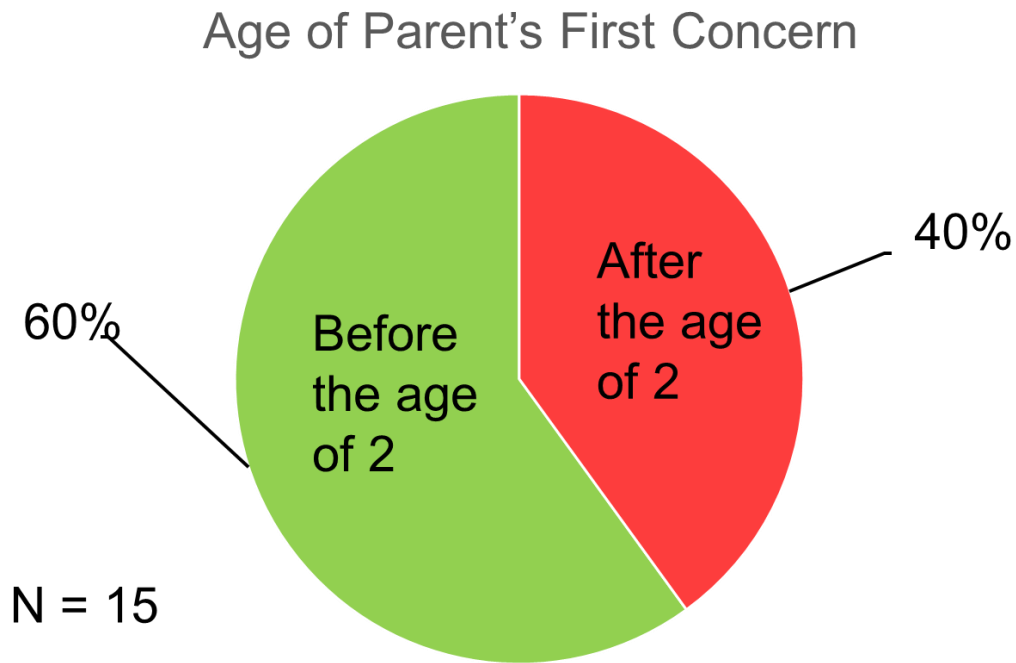
Families of children with autism face many challenges and struggle to receive treatment for their children with autism. The main struggle parents face when it comes to treatments and services is appropriate schooling opportunities for their autistic children. Traditional schools in Morocco do not offer any resources to help these children learn and progress academically. Parents who have resources send their kids to special schools where they do not receive a formal education.

Families complained that they did not know how organizations were treating their children. Based on the transcripts of the interviews, many parents could not name any of the specific treatments their children were getting. The information I obtained from the interviews with the families in these organizations indicate that the children were receiving many services and treatments. Based on this, one might infer that there is poor communication between families and the organizations.

Families talked about their experiences with rejection and social discrimination. There were two main challenges parents faced when it came to rejection and social discrimination. The families along with their child with autism would face discrimination from the rest of their family, or the parents would face scrutiny in the public because of their child.

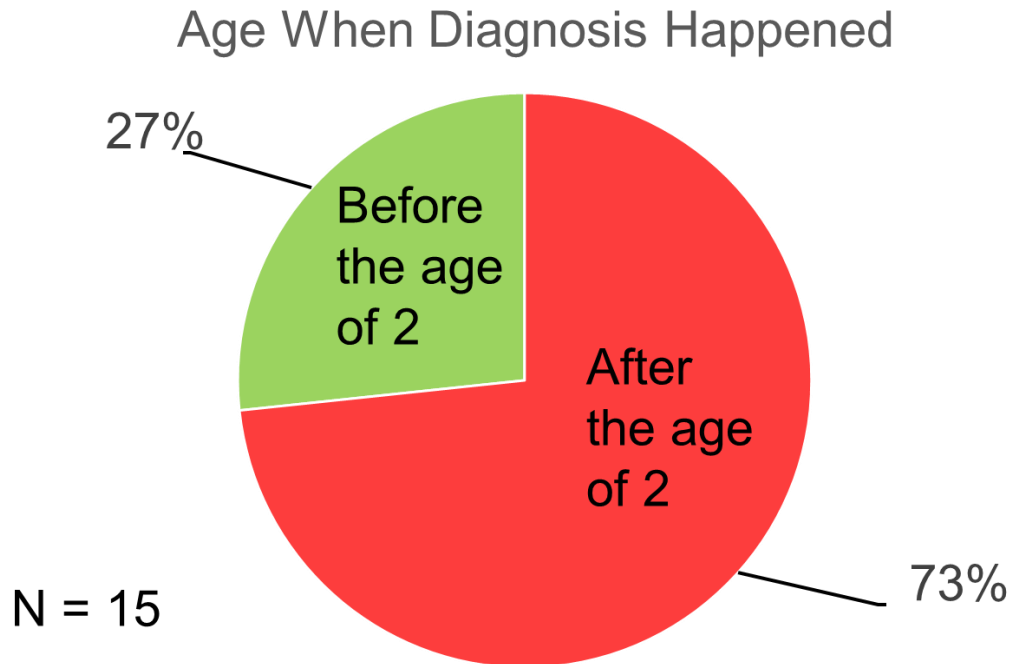
The final key finding was information regarding the age of autism diagnosis for children. Autism Speaks recommends on their website that children receive autism diagnosis and

treatment before the age of two. This is to avoid the development of harmful behaviors that characterizes autism. However, Figure 0.1 demonstrates that 40% of the interviewed families reported that they noticed abnormal behaviors before the age of two. Figure 0.1 represents fifteen families, seven from the Space for Brothers organization, and eight from the Amal organization.



**Figure 0.1** Amount of Parents Who Recognized Abnormalities in Children Before the Age of 2

The real issues began when diagnosis and treatment did not happen in a timely manner. Figure 0.2 illustrates that 73% of the 15 interviewed families claimed that they did not receive diagnosis for their children until after the age of two.



**Figure 0.2** Amount of Children Who Received Diagnosis Before the Age of Two

Unfortunately, the fact that this many children did not get their treatment in a timely manner means they may struggle with harmful behaviors and may require more intensive treatments.

### ***Recommendations***

This project yielded a few recommendations for NGOs which could apply to the NGOs and the Moroccan government. The project recommendations for the NGOs are:

- To introduce more routes of communication between parents and the autism organizations that serve their children so that parents can be aware of their children's situation.
- To offer new methods of communication for parents to talk to each other.
- To allow special schools for children with mental disabilities to give out standard education to children with special needs up to a certain point.
- For Autism Speaks to provide training for professionals to be able to perform diagnosis for autism in Morocco.



## *Conclusion*

Based on my analysis of the results of the data collected in Morocco, action needs to be taken to support legislation and awareness in the general population regarding autism. Parents struggle due to social rejection, lack of services, and lack of support. I hope the results, analysis and recommendations that I have provided to Autism Speaks will help bring change for these families who are suffering.

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- Forman, J. (2018). What are the 3 levels of autism? Retrieved from <https://www.verywell.com/what-are-the-three-levels-of-autism-260233>

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# Authorship

Around halfway through Tarek Safa’s work with Autism Speaks, Morocco Listens, circumstances arose, and we decided to work apart. Tarek worked on his own and they continued working with the Autism Speaks, Morocco Listens name. While Tarek refactored and made some edits across the whole project, they still deserve credit as the much of the work still came from them. Their team was composed of Tarek Safa, Edith Sawyer, Morgan Reisinger, and Angelica Pollard-Knight. The following are the Chapters/Sections that the other team-members were primary authors of.

Chapter/Section Title	Primary Author	Description
1.0 Introduction	Every team-member	Every team-member participated in this chapter and much of it was left unchanged, The parts almost completely unique to Tarek’s project are the last two paragraphs.
2.1 Autism Spectrum Disorder and its Complexity	Morgan Reisinger	
2.2 Social Implications of Autism in Morocco	Tarek Safa	
2.3 Advocacy in the Context of Site Specific Concerns: Rabat	Edith Sawyer	
2.4 Challenges in Receiving Support	Edith Sawyer and Angelica Pollard-Knight	
2.5 Stakeholders	Every team-member	Tarek made changes to this section.

2.6 Relevant Case Study	Edith Sawyer	
2.7 Summary	Morgan Reisinger	
3.0 Methodology	Every team-member	This chapter was heavily modified, and edited after Tarek left the team, he used sentences from the original adopted methodology, so credit is still due to the former teammates.
4.0 Results and Analysis	Tarek Safa	
5.0 Conclusion	Tarek Safa	
6.0 Appendices	Tarek Safa	The first seven transcripts in Appendix F were recorded by Morgan Reisinger, the rest were recorded by Tarek. The coding process was entirely Tarek's work.

# Disclaimer

The purpose of the project is the completion of the Interactive Qualifying Project (IQP) required for all WPI students. The goal of this project was to collect data for Autism Speaks to further their understanding of the issues facing families with children with autism in Morocco. I am not an expert or professional on Autism Spectrum Disorder. My opinions are my own and do not reflect those of Autism Speaks.

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# Chapter 1: Introduction

Autism Spectrum Disorder (ASD) is a neurological developmental disorder with symptoms typically observed between the ages of one and two years (Elder, 2012). In most cases, these symptoms are treatable but incurable, and they continue throughout an individual's lifetime. Patients diagnosed with ASD fall on a spectrum that people commonly identify under the umbrella term "autism." Commonly cited symptoms include difficulties with concentrating, adapting to traditional school settings, and controlling impulses. Repetitive behaviors are also a common symptom of ASD (What is Autism, 2017).

A small number of countries, including the United States, conduct most of the research on ASD. Other areas of the world, specifically Morocco, do not reflect these countries' efforts to understand and accommodate people with the disorder. As a result of a lack of support from the Moroccan government, parents and professionals affected by autism began establishing independent organizations. The goal of these organizations is to provide caregivers and teachers with the resources they need to effectively care for children with autism.

Families often utilize a variety of resources, such as the internet and word of mouth, to find support groups and non-governmental organizations (NGOs) in their regions. These organizations assist families by providing information and training that helps integrate their children into Moroccan society. Parents of children with autism frequently utilize resources provided by NGOs, since care is usually denied to them by hospitals and public schools. Parents have to enroll their child into facilities run by NGOs before they are eligible for additional state medical and educational assistance for their children (A. Mounir, personal communications, Jan. 21, 2018).

Together, Moroccan NGOs and Autism Speaks, launched an initiative in 2016 to gather data that represents the diversity of the population that suffers from autism. The purpose of this initiative is to gain an understanding of the current resources available for families affected by autism across the country. Two previous project teams from WPI worked to gather this information through surveys and interviews in predominantly rural areas throughout Morocco. This project has continued this effort by collecting data in urban areas within Morocco (Galindo, Grant, Languet, & Sirry, 2016; Hachim, Martin, Miner, & Rahman, 2016).

The goal of my project was to collect and analyze data regarding current resources and education for children with autism in the Rabat and Casablanca regions. My former three teammates and I worked with the Space for Brothers and Amal organizations to interview families of children with autism. The Space for Brothers organization in Rabat and the Amal organization in Casablanca provided the families that we interviewed. To accomplish my goal, I completed two essential objectives. First, the project assessed and analyzed resources and challenges for families of children with autism in the Rabat and Casablanca regions. Afterwards, the project identified new issues that families introduced while sharing their personal stories.

After data collection coding and then analysis of results, I identified problems based on the conflicts families I interviewed faced. The first result of my analysis of the data, was that parents tend to have difficulties receiving diagnosis for their children, they notice abnormalities but professionals they consult in Morocco are usually unable to tell what is wrong. My second result, was that parents had difficulties receiving treatments and services, mainly concerning services of traditional schools. These schools do not have any facilities to support children with autism, therefore these children are rejected and told to go elsewhere. Another result was that parents and children face rejection and discrimination in Moroccan society. Based on my transcripts, rejection and discrimination mainly came from within the families, and sometimes from the public. Finally, there is a deficit in communications between parents and organizations; parents were unaware of the treatments their children and any information sessions organizations were holding. I presented my results, data and recommendations to Autism Speaks to help support their initiatives and research in Morocco.

# Chapter 2: Literature Review

This chapter defines the complexities of Autism Spectrum Disorder (ASD); the aspects of the Moroccan culture that surround ASD; and it evaluates the social implications that people afflicted with autism face in Moroccan society. Additionally, it examines a cross cultural comparison of legislations pertaining to the rights and resources of the disabled and profiles this project's stakeholders.

## 2.1 Autism Spectrum Disorder and its Complexity

The term “autism” does not represent one disorder, but instead refers to a complex spectrum of conditions regarding personal strengths and weaknesses of the diagnosed. The areas in which individuals with autism are impaired include: difficulty with repetitive behavior, social interaction, and verbal and nonverbal communications, as mapped below in Figure 2.1 (What is Autism, 2012). A child diagnosed with Autism Spectrum Disorder (ASD), for example, may sway back and forth to soothe themselves, remain quiet while their peers are laughing, or not respond to their name.



**Figure 2.1** Aspects of Life Impacted by Autism

The diagram above represents the overlap potential of the areas of life affected by ASD. Children with ASD are likely to have impairments in one, two, or all three aspects in daily functioning. Additionally, the severity of each inhibition children with autism experience varies from child to child. Being that the disorder exists as a spectrum, children suffering from autism can have any combination of hindrances or abilities in their impaired areas of life (What is

Autism, 2012). The resultant variety in symptoms requires thoughtful individualization of care and treatments for each child.

As the severity of autistic behaviors and conditions increases in an individual, the impairment of their normal daily functioning increases as well. Similarly, autism research has linked intellectual disabilities to the disorder, existing in one third of all people living with ASD (What is Autism, 2012). Unfortunately, combinations of these same characteristics frequently leads to social isolation of people with autism. Research has linked this lack of proper understanding of the specifics and complexity of the disorder to stigmas around ASD.

### 2.1.1 Physical Ailments Associated with Autism

The quantitative data discussed here comes from a cumulative report by Autism Speaks detailing the complexities and treatments regarding the conditions most frequently compounded with Autism Spectrum Disorder. Sources providing similar specifics regarding the autistic condition in the United States are more prevalent and accessible than sources originating in other countries due to the involvement of government funding. In the United States, the Autism CARES Act of 2014 allocated \$1.7 billion for research aimed at understanding autism (What has Funding, 2014). Consequently, this database of statistical data regarding autism has served as the foundation of this project's research of the disorder.

Autism Spectrum Disorder commonly affects children with one or more additional physical or cognitive health conditions. Epilepsy, gastrointestinal disorders, disrupted sleep, eating and feeding issues, and Attention Deficit/Hyperactivity Disorder (ADHD) are among the most prevalent of these coinciding conditions. Understanding the variety of non-autistic ailments closely associated with ASD sheds light on the array of symptoms present in the autistic community. There is no singular "autism," but instead, an indefinite combination of circumstances and ailments experienced by those on the autistic spectrum. This section outlines several of the most common conditions experienced by individuals with autism.

#### *Autism and Epilepsy*

The most common condition seen in children with autism is epilepsy. Epilepsy affects one fifth to one third of the autistic population. Health experts characterize epilepsy by "unexplained staring spells, stiffening of muscles, involuntary limb-jerking, sleepiness, marked

or unexplained irritability or aggressiveness, and regression in normal development” (Autism and Health, 2017). Unfortunately, the severity of epilepsy can cause death in some cases. This condition is most prevalent during children’s preschool and adolescent stages of development. Caregivers consistently see epilepsy in tandem with regular sleep disturbances. Resultant sleep disturbances may lead to an increase in the prevalence of daytime behaviors such as repetitive actions and withdrawal from social interaction. Both autism and epilepsy, when occurring independently, have links to the same gene mutations.

#### *Autism and Gastrointestinal Issues*

According to a recent study, “autistic children are eight times more likely to suffer from gastrointestinal disorders than normally developing children” (Autism and Health, 2017). Additional scientific studies back this claim by showing that patients with ASD consistently test positive for impaired function of mitochondria in the mucus membranes of their gut (Rose, 2017). Scientists have found these imbalances to be unique and confined to children with ASD. This impaired gastrointestinal function can lead to conditions including: frequent abdominal pain, diarrhea, and constipation. Therefore, children who arch their back, grit their teeth, self-injure, and repeat self-soothing behavior show telltale signs of gastrointestinal disorder. The discomfort of gastrointestinal issues compounded with the inability to communicate emotions and stresses can lead to an increased severity of autistic mannerisms. Many facing this dilemma turn to self-soothing techniques to cope, such as spinning or repetitive behaviors. Affected individuals may also withdraw from society and become irritable.

#### *Autism and Eating/Feeding Issues*

United States government-funded research makes evident that “seventy percent of autistic children have feeding issues; thirty-six percent of these cases are severe” (Autism and Health, 2017). Health care professionals characterize feeding issues by pickiness in eating, insufficient consumption, and disruptive behavior while eating. Causes for these behaviors include sensory aversions, anxiety, and resistance to change. Behavioral medications which affect metabolism and appetite have links to chronic overeating; another problem commonly seen in the autistic community.

## 2.1.2 Cognitive Ailments Associated with Autism

Apart from physical ailments, there are many cognitive ailments that are common in children diagnosed with ASD. Cognitive ailments can be difficult to measure and identify; however, this section outlines three of the primary conditions that typically arise with ASD.

### *Autism and ADHD*

Recent studies show that between one third and two thirds of the autistic population also have ADHD, or Attention Deficit/Hyperactivity Disorder. Similar to autism, ADHD symptoms include difficulty focusing, listening, organizing, and remaining still. If a child receives diagnosis for ADHD or Autism, it could mask or delay the diagnosis of the other condition (Autism and Health, 2017).

### *Autism, Anxiety and Depression*

Social anxiety is very common in children with autism. This rises during adolescence and can remain high throughout the duration of a person's life. As many as 42% of children diagnosed with autism have anxiety. Comparatively, less than 10% of children diagnosed with autism have depression. Depression in a person with autism rises with age and intellect. Gastrointestinal issues and seizures may trigger this depression (Autism and Health, 2017).

## 2.2 Social Implications of Autism in Morocco

Children with autism typically exhibit multiple characteristics that set them distinctly apart from their peers. Consequently, a social stigma can often develop around individuals who exhibit these traits. When autistic individuals act in a manner considered inappropriate to the norms of Moroccan society, there is stigma due to the lack of proper awareness of mental disabilities. The stigma associated with children with autism is not exclusive to the educational setting; they also experience the stigma in daily activities, such as using public transportation. Various testimonies from current and past residents support this claim; many families struggle to raise children with these disabilities (Galindo, Grant, Languet, & Sirry, 2016; Hachim, Martin, Miner, & Rahman, 2016).

One testimony accounts how schoolmates labeled a child as “the funny kid” due to an unidentified mental illness. They made fun of, avoided, and criticized him. Another indication of

the harsh stigma in Morocco is the testimonial book described in Morocco World News: *My name is Momo. I am autistic*. This book explains the hardships of finding qualified personnel to help children with autism and the fight for rights of the autistic community (Morocco World News, 2016). Unfortunately, the stigma associated with autism in Morocco is undeniable and impedes the social development of the individuals it affects.

Moroccans tend to correlate autistic diagnosis alongside other mental illnesses. One consequence of this stigma is that Moroccans assume that autistic individuals are unfit to care and make decisions for themselves. This is due to the misunderstanding of social interactions associated with autism and mental disorders in Morocco. Families have protested for proper rights for children with autism in an attempt to combat these consequences of the autistic stigma. In these protests, families call for “the provision of social and psychological care for sick children, on a continuous and permanent basis,” (العربي الجديد, 2017; New Arab). They want the realities of the illness to be known to the public, just treatment from authorities, fair access to schooling, and accessible medical care. These protests occurred recently, in January of 2017, and might be an indication of a changing perception of autistic individuals in Moroccan society.

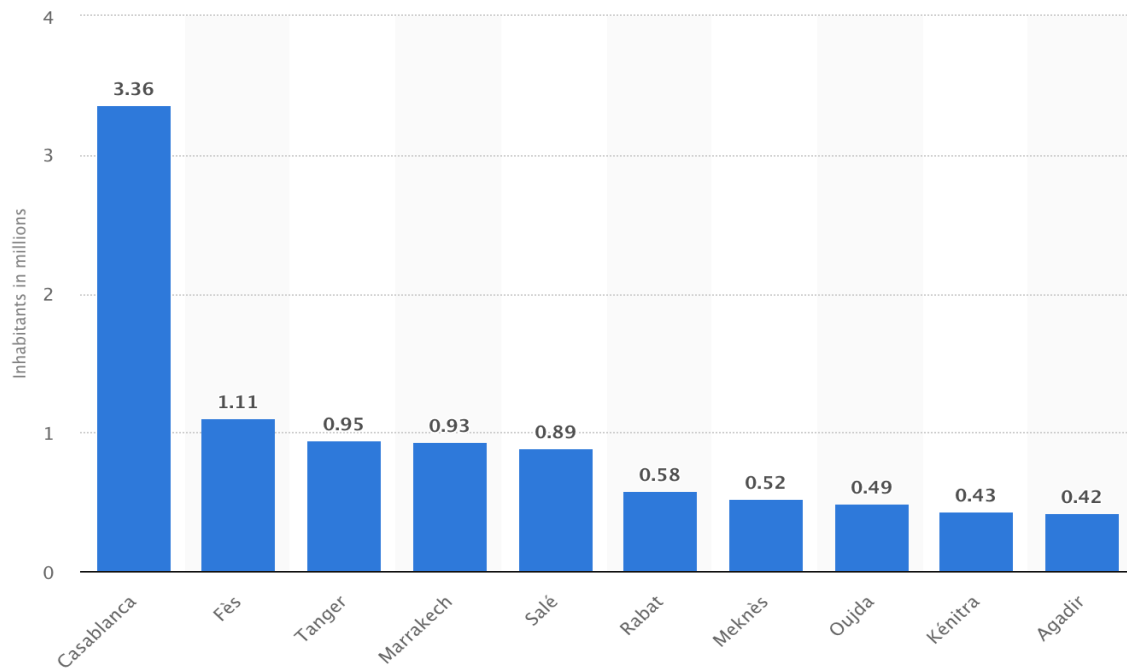
## 2.3 Advocacy in the Context of Site Specific Concerns: Rabat

Although advocacy and support groups raise awareness of ASD in Morocco, they have not yet caused a significant change in the policies toward and resources available to those with the disorder. Resources for families in the form of non-governmental organizations (NGOs) receive funding from the government to help treat children with autism. However, these organizations do not receive sufficient money to help families on a broader scale. Many other factors contribute to the lack of resources available to the population, and this section reviews these factors relative to the design and integrity of this investigation.

### 2.3.1 Trend Toward Urbanization

Morocco is a largely urbanized country. Since 2005, the urban proportion of the country has increased from 55% to 61.2% in 2015 (Urbanization, 2015; World Factbook, 2017). Much of the urban population resides in ten large cities across the country. Figure 2.2, shown below, provides a graphical representation of the population size for each of those ten cities gathered in 2014.





**Figure 2.2** Graph of Populations in Millions of Cities in Morocco (Morocco-Largest Cities, 2014)

The scope of my project focuses on the Rabat and Casablanca regions along the northwestern coast of Morocco. Casablanca, the most populated city of the two, is home to over 3 million people. Increased urban population in regions of Morocco, at a rate of 1.92% per year (World Factbook), makes availability of resources to these areas a rising concern. Rapidly increasing urban populations make access to basic resources, such as waste disposal, difficult. This lack of access is also evident when considering autism treatment resources (Francoise, 2003). Frequently, families seeking ASD treatment for their children must travel long distances for access to resources that have limited availability due to increasing demand. Rising urbanization suggests that this issue will continue until resources are readily available.

### 2.3.2 Literacy and Language

The overall literacy rate of Morocco is 68.5%, with a gender distribution of 78.6% for men and 58.8% for women (World Factbook). More specifically with regard to the Rabat region, literacy rates range from approximately 60% to 75% (Francoise, 2003). This may have caused barriers in the past concerning attempts to spread awareness among the Moroccan population.

For example, brochures and pamphlets may not have been equally accessible to every domain of Moroccan society. Advocates for autism understanding must share information in multiple languages for the Moroccan population to receive.

Moroccans speak many languages and the most prevalent languages vary between regions. The national language of Morocco is Arabic. However, those who live in the Rabat region most commonly speak the local Darija dialect. Additionally, Moroccans speak French as the language of diplomatic and government business (World Factbook). Darija and French are the two most widely spoken languages in Rabat and its surrounding cities. This data is important to consider while determining the way the project conducted interviews and how the interviewers prepare for interviewees from all backgrounds. These language and literacy statistics result in requirements that translators speak and read both the local Darija and French.

## 2.4 Challenges in Receiving Support

The Moroccan government has begun to develop and implement legislation to protect the rights of individuals with disabilities (Morocco: Flawed Draft, 2017). However, factors such as limited access to necessary resources and the stigmatization of mental disabilities hinder proactive legislation.

### 2.4.1 Recent Legislative Efforts

In October of 2015, the Moroccan parliament adopted an initiative to protect the rights of the disabled under the Draft Framework Law. Known as Draft Law 97.13, this law is the first law in Morocco to address the rights of people with disabilities. However, Morocco recently signed an International Human Rights Treaty that set the rights outlined in the Draft Framework Law below the international standard (Letter to Moroccan Parliament, 2015). Although Morocco was one of the first countries to adhere to the United Nations' Convention on the Rights of Persons with Disabilities, the Draft Framework Law does not follow the legislation of the international treaty (Letter to Moroccan Parliament, 2015).

Human Rights Watch, an international NGO that advocates for human rights, addressed the flaws presented in the Draft Framework Law in a letter to the Moroccan parliament. Flawed elements include the lack of an established right to education and a rights based approach to disability (Letter to Moroccan Parliament, 2015). The Draft Framework Law under article 24

states the right to education for the disabled. In their letter to parliament, the Human Rights Watch writes of the separation of special needs children from regular classrooms. This lack of proper accommodations for the disabled in an educational setting denies children with disabilities the right to education. (Letter to Moroccan Parliament, 2015). There are aspects of Moroccan legislation should change to better suit the needs of the disabled Moroccan population.

The Middle East and North Africa Director at Human Rights Watch, Eric Goldstein states, “people with disabilities in Morocco have been treated as objects of charity rather than as equal citizens, leading to stigma and discrimination” (Hicks,2005, p.1). Goldstein proposes that the Draft Disability Rights Law will help change the perception of disabilities in Morocco by giving official recognition to autistic individuals and treating them as proper citizens. However, Moroccans tend not to follow the Draft Framework Law due to lack of awareness.

#### 2.4.2 Regional Comparisons of Legislation for the Disabled

Morocco is relatively below its neighbors in effectively responding to disabled citizens. In contrast Saudi Arabia has exhibited a national commitment to protect the rights of the disabled under Article 27 of the Welfare Rights Act (The Saudi Network, n.d.). Changes to the Disability Rights Act encouraged an increase in resources for the disabled, including people with autism. Similarly, the Egyptian government has enacted legislation to provide more services for the disabled. Article 81 of the Egyptian Constitution supports this in its statement, “the state shall guarantee the health, economic, social, cultural, entertainment, sporting and education rights of people with disabilities. The state shall provide employment opportunities for such individuals and allocate a percentage of these opportunities to them” (New Legislation, 2016).

In addition to these accommodations, article 81 of the Egyptian constitution ensures that governmental officials adequately equip public facilities to serve the needs of the disabled. It further mentions, "the state guarantees their right to exercise their political rights” (New Legislation, 2016). Dedication to ameliorating the hardships of autistic communities is evident in the areas of North Africa and the Middle East. However, it is interesting to note that the dedication to accommodating the disabled through national legislation is not consistent across the Middle Eastern and North African region.

### 2.4.3 Education and Healthcare Limitations

In Morocco, hospitals, clinics, and schools which specialize in autism or other disabilities do not exist. These organizations will immediately turn families away and refer them to small NGOs which do specialize in autism and other disabilities. Families often receive diagnoses for their children at these organizations. The government provides funding for these NGOs because families are often unable to pay for their services. However, limited funding for the organizations prevents them from having the resources to service many families simultaneously. Hence, these organizations have very long wait lists that mean families do not have quick access to necessary services. Additionally, healthcare providers prioritize infants and younger children for admittance to their organizations, making it nearly impossible to find help for older children.

Once families and children have received specialized treatment from these organizations, they may return to hospitals to receive medical care and non-specialized treatment. Consequently, families are reliant on receiving treatment for their children with autism from these NGOs. However, the NGOs do not have adequate resources to help the many families who need help.

## 2.5 Stakeholders

The primary stakeholders for this project feature families and caregivers of children with autism, as well as members of NGOs in the Rabat and Casablanca regions. Over the duration of my project, these families were a primary source of statistical and qualitative information regarding experiences the autistic community encounters in the Rabat region. Professional caregivers, including doctors and teachers, provided technical insight to the current system of diagnosing and treating children with autism. The NGOs the project worked with facilitated interviews and contact with the families and professional caregivers affiliated with their organizations. Table 2.1 outlines the interests, perspectives, and assets of these key stakeholders.

<b>Stakeholders</b>	<b>Interests</b>	<b>Perspectives</b>	<b>Assets</b>
Families	<ul style="list-style-type: none"> <li>- Children’s well-being</li> <li>- Gaining resources and knowledge to help best care for their children</li> </ul>	<ul style="list-style-type: none"> <li>- Helping their children personally develop, thrive, and socially integrate</li> </ul>	<ul style="list-style-type: none"> <li>- Current knowledge of local resources</li> <li>- Experience with social implications associated with autism in Morocco</li> <li>- Knowledge of specific children’s difficulties</li> </ul>
Space for Brothers	<ul style="list-style-type: none"> <li>- Providing services for families of children with autism</li> </ul>	<ul style="list-style-type: none"> <li>- Treating autistic children</li> <li>- Spreading awareness of autistic information and resources</li> </ul>	<ul style="list-style-type: none"> <li>- Facilities for care of children with autism</li> <li>- Connections with families of children with autism</li> <li>- Caregivers trained to care for and treat children with autism</li> </ul>
Amal Association for Children with Special Needs	<ul style="list-style-type: none"> <li>- Providing services for families of children with autism</li> </ul>	<ul style="list-style-type: none"> <li>- Treating autistic children</li> <li>- Improving and increasing the services offered by their organization</li> <li>- support children's integration into society</li> </ul>	<ul style="list-style-type: none"> <li>- Facilities for care of children with autism</li> <li>- Connections with families of children with autism</li> <li>- Caregivers trained to care for and treat children with autism</li> </ul>

**Table 2.1:** Primary stakeholders involved in this project

What follows is details of the background of these organizations.

### 2.5.1 Non-Government Organizations

To compensate for limited governmental, medical, and educational efforts to improve the quality of life for the disabled in Morocco, NGOs have developed with the intention of providing awareness and resources for ASD. Families of children with autism and professionals who specialize in treatment of autism typically run these organizations.

#### *AMAL*

Founded in 2010, the AAEBMSM (Association AMAL Enfants Aux Besions Specifiques Mentaux) organization, otherwise known as AMAL, is a private organization that specializes in medical and psychological care of people with various levels of mental disabilities. Below is a picture of their logo (Figure 2.3).



**Figure 3.3** Official Logo of The AAEBMSM (AMAL) Organization

Their mission is to support the needs of families and children affected by Autism Spectrum Disorder. They accomplish this mission by educating parents on the needs of their child with special needs, as well as helping children flourish in modern society. They have a large facility that services over 300 children. Because of their large facility, they are able to which provides many services to children such as: speech therapy, motor skill therapies, psychologist services, psychiatric services, and behavioral intervention, modification (ABA), and many different physical activities such as basketball or soccer. Their goal for children includes providing proper education and support regarding social integration. Additionally, AMAL aims to alter public perception of mental disabilities to promote mutual respect and dignity for each member of society (AAEBMSM, 2017).

### *Space for Brothers*

An organization recently founded in September 2017, the Space for Brothers organization is a public organization with resources for children with autism located in Rabat.



**Figure 2.4** Official Logo of Espace Al Akhawayne (Space for Brothers)

Their mission is to prepare children with autism for academic and professional integration into Moroccan society. They provide many services for their clients, including: special education, speech therapy, psychomotor learning, psychological support, and swimming as a form of therapy (A. Attar, personal communication, Jan. 24, 2018). In order to maintain a holistic educational approach for development, this organization engages in both individualized training and group activities each day.

## 2.6 Relevant Case Study: Autism Assessment in Morocco, 2016

In my former team, we evaluated the methods a student team used in 2016 to conduct a project similar to this investigation. This case study depicts their interview methodologies as well as the obstacles they experienced throughout their project.

In the fall of 2016, two student teams from WPI partnered with Autism Speaks to collect and analyze data about the resources available to families of individuals with autism in Morocco. These teams gathered qualitative and quantitative data in Casablanca, Ouarzazate, Skoura, Tiznit, Agadir, Biougra, and Taroudant. Both project teams analyzed the data and suggested possible steps to increase understanding of autism in Morocco in the future. Throughout the project, the teams experienced roadblocks. One issue they faced included miscommunication between translators and sponsors. Miscommunications included translators altering their responses to the team and inadvertently misrepresenting the answers that stakeholders provided. Translators sometimes altered responses in small ways because they were unaware of the purpose of the interviews and wanted to give the team satisfying answers.

This case reveals the importance of scheduling and logistics. A local language school provided volunteer translators for the majority of the interviews the team conducted. During the time of the interviews, these volunteers could not work for the entirety of each workday or workweek. As a result, the teams emphasized the importance of establishing a clear relationship with translators, as well as paying for translation services.

The logistical planning and communication between participants and agencies faced challenges as well. This culminated into parents bringing their children to interview sites with the expectation of receiving a medical diagnosis. In another situation, the teams encountered sensitive survey questions in their questionnaires which produced difficulties collecting reliable data. Through their interviews with families, the team found that a few of the questions on the survey were culturally insensitive to the interviewed families. As a result, the team suggested avoiding asking questions related to religion and the stigma around autism. Additionally, they noted that language barriers led to inaccurate responses to survey questions by physicians and other professionals.



## 2.7 Summary

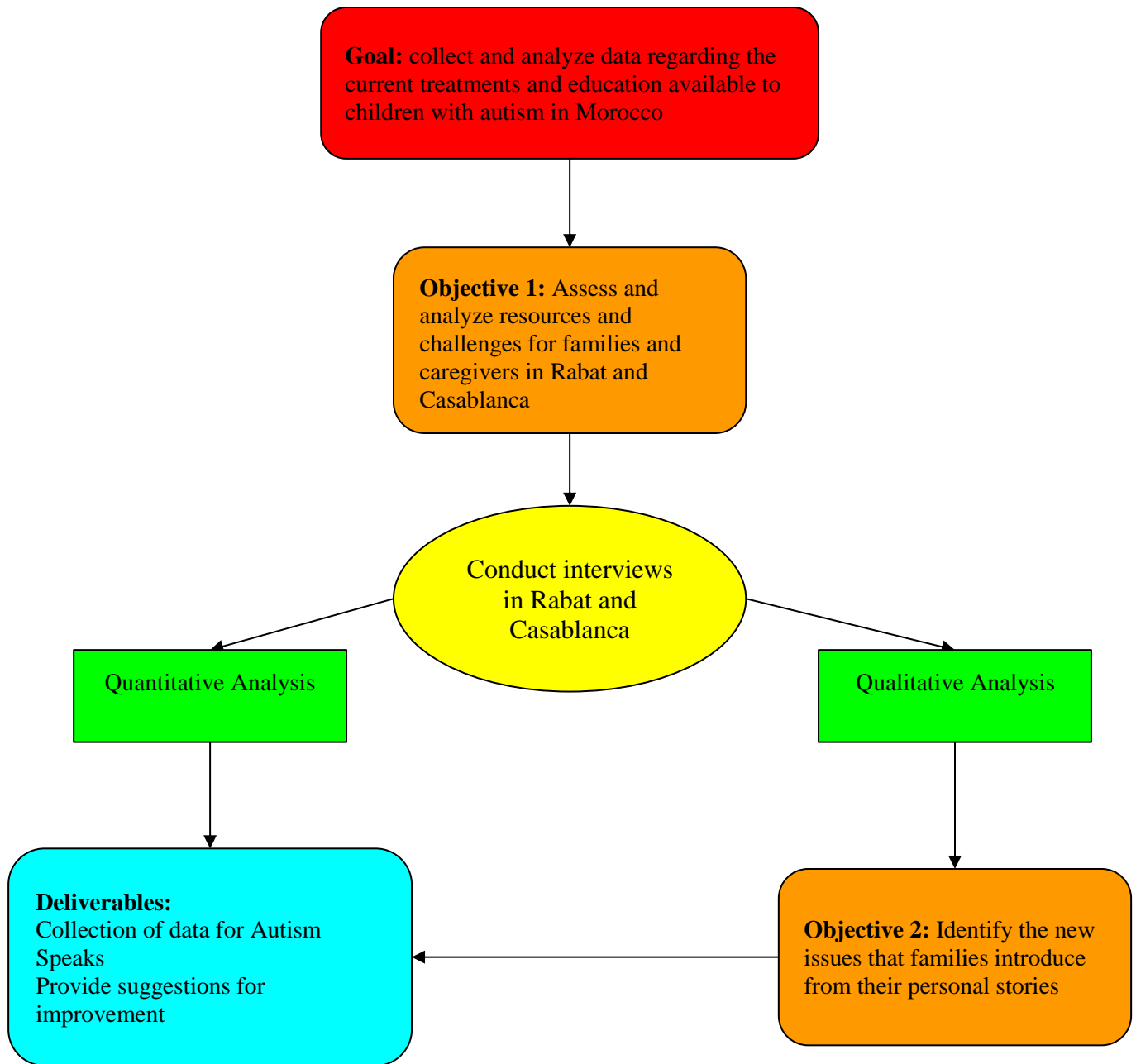
There is currently insufficient data to fully understand the resources available to children with autism in Morocco. The Moroccan government sees individuals with autism as unfit to care for themselves and the government does not guarantee the rights of these individuals. This makes being autistic in Moroccan society even harder. The Moroccan government has attempted to guarantee more rights for individuals with autism through recent legislative efforts. However, the Moroccan government did not properly enforce these legislative efforts which yielded little impact for individuals with autism. Additionally, families of children with autism struggle with limitations regarding accessing medical and educational services in their region. The methodology utilized to analyze and collect data on the current availability of resources and education for children with autism in Morocco is discussed in the next chapter.

# Chapter 3: Methodology

The goal of this project was to collect and analyze data regarding the current treatments and education available to children with autism in Morocco. The project completed the following two objectives while in Morocco in order to effectively reach this goal:

1. Assess and analyze resources and challenges for families of children with autism in the Rabat and Casablanca regions
2. Identify new issues that families introduce when sharing personal stories

Figure 3.1, shown below, represents the project flow. The project required the completion of two objectives which both followed separate methodologies. Described below is the method of implementation used for each of these methodologies.



**Figure 3.1** Flow Chart Depicting My Project Flow

## 3.1 Team Split

Due to certain circumstances, the three teammates I had been working with and I decided to work separately for the remainder of the autism research. This happened after the collection of data at Space for Brothers. Therefore, for the remainder of this paper, I refer to the actions I performed with the team of students by the phrase “my former team.”

## 3.2 Assess and analyze resources and challenges for families and caregivers in Rabat and Casablanca region

For my first objective there were two separate methods, one completed in a team based environment, and one completed individually. Using a survey tool that Autism Speaks created in 2016 that the team refined with the help of Jihan El Ouaragli, my former team conducted interviews with families at the *Espace Al Akhawayne* (Space for Brothers) organization in Rabat. I personally conducted interviews with eight families using the same survey tool accompanied by translator Mohammed Salhi and an advisor observing me in *Association AMAL Enfants Aux Besions Specifiques Mentaux* (Amal) located in Casablanca. To simplify the discussion of the interviews, this report will refer to the main caregivers of these children, whether they be immediate or extended family, friends, or other, as “family.”

Jihan El Ouaragli is the translator who Professor Tahar El-Korchi provided to conduct interviews at the Space for Brothers organization in a team setting. For the Amal interviews, Professor El-Korchi provided the translator Mohammed Salhi to assist in my interviews.

### 3.2.1 Refined Survey Tool

In 2016, two teams of WPI students collected a set of data regarding the current state of autism awareness and resource availability in Morocco (Galindo, Grant, Languet, & Sirry, 2016; Hachim, Martin, Miner, & Rahman, 2016). The teams used a survey that Autism Speaks provided to conduct in-person interviews of families and caregivers affected by autism. These interviews provided both qualitative and quantitative data to their team, and Autism Speaks.

Along with my former team’s translator, Jihan El Ouaragli, my former team looked at Autism Speaks’ surveys in both English and Arabic to assess the clarity of each question for

regular Moroccan families. We focused on phrasing questions in an unbiased and culturally appropriate manner by being considerate of the potential difficulties associated with having an autistic child. To communicate the questions effectively, my former team clarified the meaning of some questions and technical terms. We collaborated with Jihan to ensure clear phrasing of the questions. Our questions were simple and direct and our strategy was to avoid questions that contained two parts separated by a conjunction (Berg, 2012). We maintained a close correspondence with Dr. de Jonge while modifying these questions so that she could professionally approve them. As advised by Dr. Maretha de Jonge, my former team also asked families interviewed if they had answered the Autism Speaks survey conducted in 2016 and made note of their responses. Finally, the project team submitted the revised survey for approval to WPI's Institutional Review Board (IRB) prior to arriving in Rabat. The changes made were exclusive to the Arabic survey tool, which were primarily grammatical to help clarify questions to the interviewees. The IRB gave us approval for our interview process including the modified questions.

### 3.2.2 Space for Brothers Family Interviews

Following the team based methods, my former team conducted interviews at the Space for Brothers organization. This section discusses the preparations and methods applied to conduct our interviews.

#### *Space for Brothers Interview Preparations*

My former team practiced careful interview procedures to mitigate potential bias while conducting interviews. This was essential for obtaining the data required to complete this objective. My former team read through the questionnaire with Jihan in order to mitigate unintended biases during the interviews.

A calibration session in the form of a mock interview took place between the interviewers and Jihan to discuss specific wording for each question and unify conceptual understanding of each question. We conducted our mock interview with Amine, an Arabic and English speaker, whom we met through "Space for Brothers" (Ward, 2014).

These mock interviews served two purposes: they indicated that our interview questions were clear to hopefully prompt responses that accurately answered the question, and they helped

prepare my former team and Jihan for the reality of the interviews; they helped us practice avoiding multiple types of interview bias. My former team used a PowerPoint provided by Dr. Maretha de Jonge during our mock interview that contained information regarding how to avoid multiple forms of interview biases (De Jonge, 2018).

My former team worked with the “Space for Brothers” staff to stagger the arrival times for the family interviews. Staggered arrival times reduced the risk of families having to wait all day for their interview, a problem that occurred in 2016 when many families arrived simultaneously. Additionally, we collaborated with the organization to convey to families that they might need to wait and encouraged the families to bring any necessary accommodations.

To determine the families interviewed, the team used convenience sampling. The sample population consisted of the families that Space for Brothers were able to provide. Jihan organized and scheduled interview times for each family through this organization. The team conducted interviews one at a time. Due to the organization's time constraints and the limited availability of families, we completed one to four interviews per day. The project gained seven interviews worth of data from the Space for Brothers organization.

#### *Logistics of Interviews at Space for Brothers*

Each interview in Space for Brothers consisted of a respondent, translator, and four team members. In each interview, one team member read the survey questions aloud in English. Our translator then translated each question to the families and then translated their responses back to the team. A second team member recorded the responses of the participant with a laptop into an Autism Speaks database. While the respondent answered each question, a third team member was responsible for monitoring the physical demeanor, body language, and tone of the respondent(s). And the fourth team member electronically recorded these responses into a Word document.

The investigation utilized the online survey provided by Autism Speaks, however my former team presented it in the form of in-person interviews due to limitations with language compatibility, Internet access in Morocco, and literacy levels. Appendix B contains the survey we utilized to conduct interviews. Respondents received printed copies of a separate selection of the multiple-choice survey questions written in Arabic taken from the Arabic version of the Autism Speaks survey, due to difficulties with communicating them in an interview setting.

Appendix D contains the separate selection of Arabic multiple choice questions. Our translator was available to help explain certain questions if the caregivers did not understand a question. If the interviewees were not able to read, then our translator would guide them through each question. Our team recorded the respondents' answers through the electronic version of the survey.

My former team personally communicated the purpose of our interviews to the interviewees before each session began. Our translator Jihan El Ouaragli verbally expressed the statement of purpose and consent to families prior to beginning interviews; Appendix B contains the statement of purpose and consent. The statement of purpose and consent explained how we planned on conducting each interview, the usage of the data we were collecting, that the process would protect their identity and keep information confidential, and that the interview would take around thirty minutes to an hour to complete. This helped avoid miscommunications regarding the purpose of the study to the stakeholders.

Each interview at this location lasted between thirty minutes to an hour depending on translation requirements. My former team conducted the interviews over the course of two weeks at the Space for Brothers organization. Family interviews took place in the mornings and late afternoons.

### 3.2.3 Amal Family Interviews

I personally conducted a second set of similar interviews at the Amal organizations facilities from February 19th until February 20th. I conducted these interviews with a translator and an advisor observing the process. I used similar methods to conduct interviews in order to compare my former team's data with the new data.

#### *Amal Interview Preparations*

The interviews conducted at the Amal organization's facilities used the same survey that my former team modified. I conducted an interview preparation session with my translator Mohammed Salhi using the same PowerPoint provided by Dr. Maretha De Jonge. We prepared ourselves to avoid potential biases and improper techniques that may occur while delivering questions during the interviews with families. Anas Eddik contacted the Amal organization to organize staggered interview times for me.

The Amal organization manages a special needs school, so a majority of families would come at nine AM and drop off their children. They would then pick up their children and leave at four PM. With this being the case, the organization explained that the time window for interviewing families was within the hours of operation of the school. To determine the families interviewed, I used convenience sampling. The sample population consisted of families that Amal provided. Anas Eddik and I organized the interview times. I conducted interviews one at a time.

I presented physical copies of a separate set of lengthy multiple-choice questions for the families to fill out before the interviews started (Appendix D). These questions were difficult to communicate in an interview setting and were much more easily understood when read. To make the rest of the interviewing process easier, these time consuming questions were also the first questions that I with the help of the translator tackled during the interview if the parents could not complete them on their own beforehand. This process is different from the one my former team followed, since we presented the same separate set of questions while conducting our interviews.

#### *Logistics of Amal Interviews*

While collecting data in Amal, there were many events that I did not anticipate. On the first day I came to conduct interviews, no families were actually scheduled for interviews despite information I received that scheduled families were ready three days before. All the families scheduled for interviews arrived in the morning at nine, which was the time I arrived as well. At this point, the translator had not arrived, so I decided to give them all the separate set of survey questions meant for completion before the interviews started (Appendix D). This was meant to occupy their time until the translator arrived; the Amal staff also facilitated the process by reading out the questions to parents who could not read and explaining the questions to parents who did not understand them.

By the time the translator arrived at 9:30, the families explained to me that they needed to leave because of other responsibilities they had. This was also not anticipated as I assumed that they would wait for the completion of each interview based on my discussion with the Director of Amal, Mabrouk Touria. I offered full Arabic surveys (Appendix C) for people who could not



sit down for an interview and I tried to understand every parents schedule for the possibility of completing the interviews at later times in the day.

Three parents claimed that they could come back at one, and I explained to them that each individual interview would take around thirty minutes to an hour to complete; they told me they understood. I did manage to complete an unscheduled interview with an English speaker. At 1 PM when the parents came back, I discovered that two out of the three parents did not have autistic children. I decided against interviewing the families without autistic children and I only interviewed the parent with an autistic child.

I clarified to the director of Amal, Touria, that I needed the interviews staggered and scheduled properly the next day. The next day there were no issues regarding interview scheduling and timing. In total I acquired eight surveys worth of quantitative data from families in Amal. I only conducted interviews in Amal with parents of children with autism.

At the beginning of each interview, I read out the Statement of Purpose and Consent included in Appendix B in English, while the translator would translate for the families. I requested permission to record audio of the interview to accurately capture interview transcripts; if they rejected this, I instead recorded the extra information they provided by hand. Once the families responded with verbal acceptance to start, the interview would begin. I planned to conduct the interviews by asking the survey questions in English, and having the translator translate the questions into Darija for the families to understand. I conducted two of the interviews at the Amal organization in English since the interviewees could speak English. After receiving the family's answer back from the translator, I wrote down their answers on paper and paid close attention to any information following the answer to record personal stories of families, and changes in their body language.

Because I needed the best sample size I could manage, I made the choice to give families the opportunity to fill out printed copies of the survey if they could not stay for an interview. I allowed the Amal organization to give them out to families with the following guidelines: the families needed to be able to read, the organizational representative handing out the surveys should tell the families to expand on any of the survey questions they wanted to in the white space next to the question itself, and finally the families needed to have children with an autism diagnosis. I received two surveys from families of children with autism in this manner and I did not get any transcripts from them. I conducted six on site interviews with families at the Amal

organization. I collected eight surveys worth of data and six transcripts from the onsite interviews in total. Four surveys were from fathers, and four from mothers.

### 3.2.4 Analyze Collected Data

#### *Quantitative Analysis*

The Autism Speaks survey consists of multiple choice questions. This allows treatment of the results of each question to be quantitative. Once I finished tallying my results from the surveys, I began my quantitative analysis. I analyzed the results from Space for Brothers and the results from Amal separately to understand the differences between the two data sets. I then compared the similarities between the two organizations with the goal of providing an analysis of what most parents agreed on.

#### *Qualitative Analysis*

I analyzed the qualitative data from my interviews which were in the form of transcripts. The transcripts recorded elaborations families made from the questions prompted by the Autism Speaks survey. I used a combination of deductive open coding and inductive open coding. Deductive open coding involves tallying and tracking qualitative data by identifying commonalities with a group of pre-determined categories within a set of qualitative data. The predetermined category that I selected for my deductive open coding consisted of family challenges finding diagnosis for children with autism, and family challenges finding treatments and services for their children with autism (David R., 2006).

## 3.2 Identify the New Issues That Families Introduce from Their Personal Stories

While working in the two organizations, the staff explained that the main reason that parents wanted to participate in interviews was because they wanted someone to listen to their experiences. While I did use deductive open coding to analyze the transcripts, during the coding process, I noticed a few new trends in the transcripts of the interviews. After noticing these trends, I added five new categories for my coding process that would accompany them. These new categories were: rejection and social discrimination, autism family support groups, kids liking transportation, and lack of communication between parents and organizations. This involved performing inductive open coding, which includes tallying and tracking qualitative data by identifying commonalities within transcripts of information without a set of predetermined categories (David R., 2006). The categories arose as the coding process proceeded.

### 3.3 Timeline

Timeline	Week 0	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7
	1/8-1/14	1/15-1/21	1/22-1/28	1/29-2/4	2/5-2/11	2/12-2/18	2/19-2/25	2/26-3/2
Visit/ Meet Stakeholder Organizations								
Family and professional Interviews								
Analyze/ Compile New & Existing Data								
Accumulate Findings and Write Final Proposal								

**Table 3.2:** Timeline for the progression of my project

# Chapter 4: Results and Analysis

This chapter presents findings from my data analysis. The first section of this chapter discusses the data from the quantitative results gained in the Space for Brothers organization in Rabat.<sup>1</sup> The second section focuses on data collected from families in Casablanca in the Amal organization. The next section compares the results from the data collected at the two organizations. Finally, the last section displays the quantitative results gained from coding the transcripts of all interviews from Space for Brothers and Amal with correlations in the qualitative data.

## 4.1 Quantitative Analysis of Data from Space for Brothers

This section covers significant aspects of the results from the analysis of the data that my former team collected in the Space for Brothers Organization in Rabat. All the graphs and charts in this section are from the seven interviews conducted with my former team. The team could not interview some families from this organization due to difficulties they had reaching and staying for the interview process.

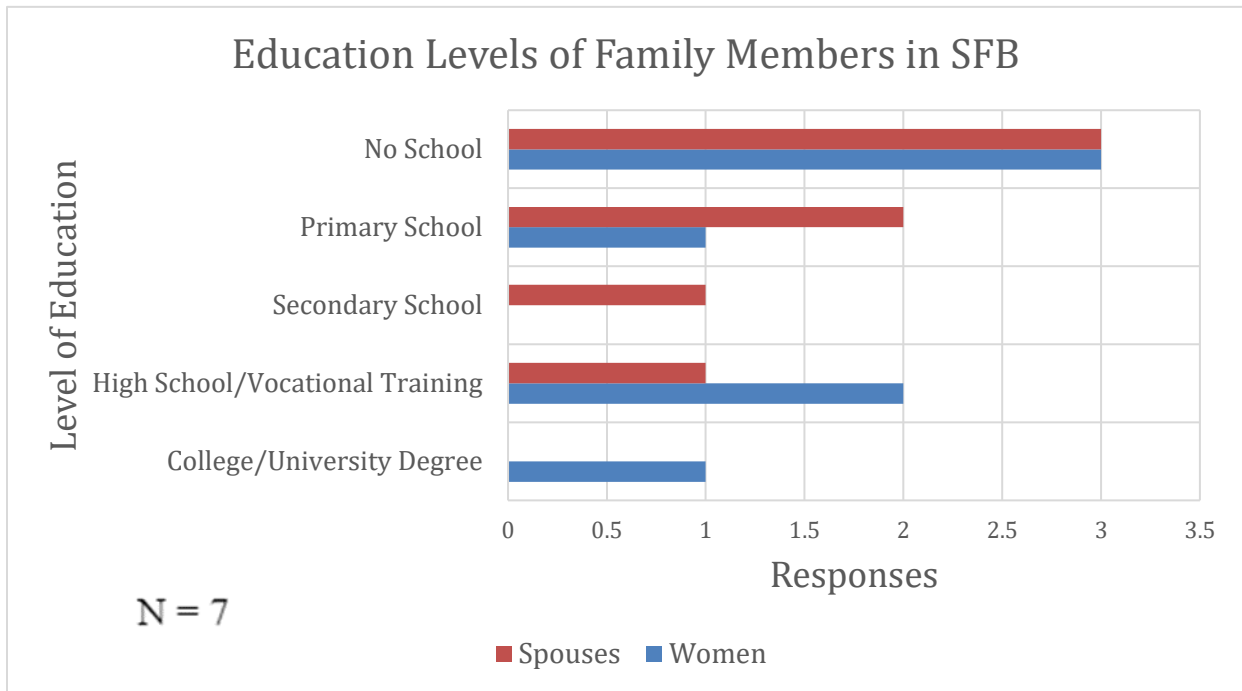
This section presents quantitative results based on the order of questions in the Autism Speaks survey (Appendix B). As the sections in the Autism Speaks survey consist of: Family Demographic Characteristics, Affected Child Characteristics, Service Encounters, and finally Parent/Caregiver perceptions. The presentation of project results follows an identical organization.

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<sup>1</sup> Angelica Pollard-Knight, Morgan Reisinger, Edith Sawyer worked with me to collect this information

### 4.1.1 Family Demographic Characteristics

My former team conducted interviews in the Space for Brothers (SFB) organization; we interviewed six mothers and one grandmother. Figure 4.1 represents the answers to questions 1.1 and 1.2 in the survey (Appendix B). Questions 1.1 and 1.2 ask about the level of education of the person interviewed, whom were all women, and their spouses. The women interviewed tended to have higher levels of education compared to their spouses, three of the families had a high-school education or higher. In comparison, only one of the fathers of children with autism had a high school education which was the highest level of education within the group of spouses.

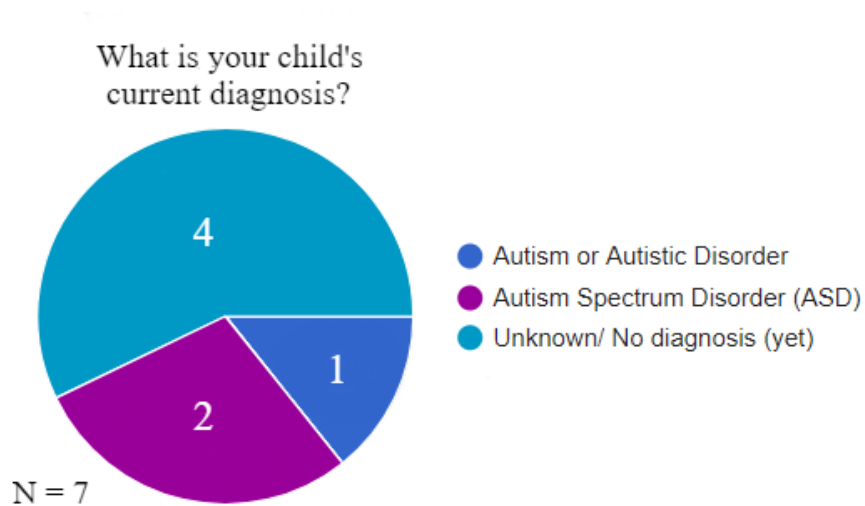


**Figure 4.1** Level of Education for Both Caregivers in Space for Brothers Interviews

### 4.1.2 Characteristics of Diagnosis

All the families interviewed noticed abnormalities in their child between the ages of 1 and 2.5 years old. As reported by the question 2.7 in the survey (Appendix B), the mother was always the first person to notice something amiss with their child. This includes the grandmother who said her daughter (the mother of the autistic child) was the first to notice there was an issue with her child. Figure 4.2 represents the data from question 2.1 from the survey, and it

demonstrates that more than half of the children never received diagnosis by any medical professional. According to our interview data, the families that did receive a diagnosis from a professional said the professional did not give a certain diagnosis but a most likely scenario of autism.



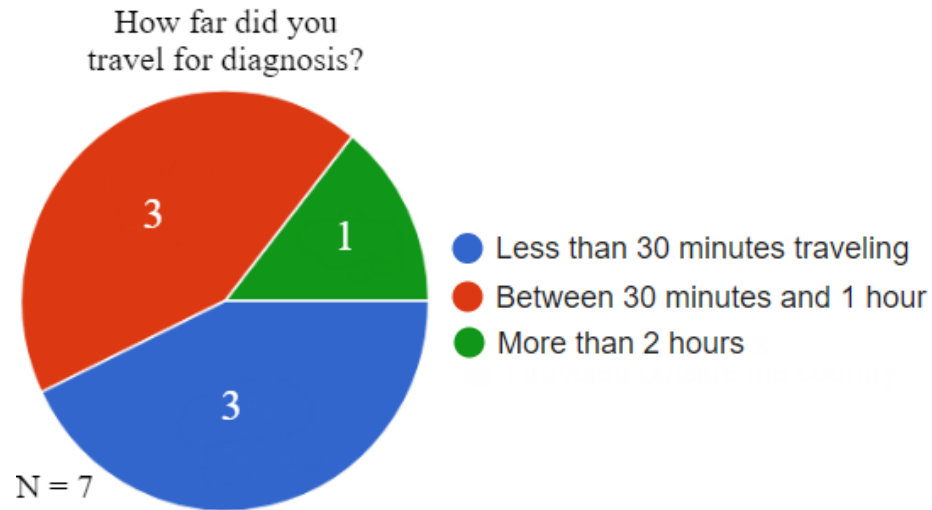
**Figure 4.2** Child's Current Diagnosis in Space for Brothers

While most families did not elaborate as to why they could not get diagnosis from professionals, a couple of families explained that there were no available doctors in Morocco who were qualified to give an official diagnosis to children with autism. Since the parents did not have an official diagnosis, they were uncertain about what to do to help their children. This led to late action and intervention in many cases according to the parent's accounts and responses to the survey.

The survey asked the families about eight different possible kinds of doctors who could provide diagnosis. The families indicated that only four out of the eight kinds of doctors provided by question 2.9 from the survey gave a diagnosis for their children. These doctors consisted of: pediatricians, neurologists, psychiatrists, and psychologists. From this data one could infer that families had different kinds of doctors diagnosing their children.

Figure 4.3 categorizes the distance parents had to travel to gain a diagnosis. Only 3 of the families had to travel less than 30 minutes to gain a diagnosis of their child's condition. Three of them needed to travel more than 30 minutes, and one of the families needed to travel more than 2

hours for a diagnosis. This suggests that professionals are not available in certain areas or that the caregivers lack information regarding access to professionals.

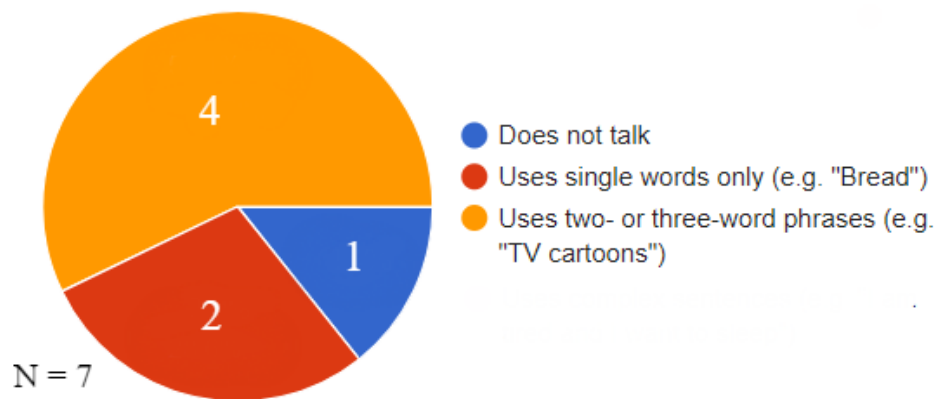


**Figure 4.3** Travel Time for Diagnosis in Space for Brothers

The last question pertaining to the category of Affected Child Characteristics in the Autism Speaks survey asks about the perceived verbal ability of the children. The largest population in the verbal ability category consisted of children who could only use two-word to three-word phrases (see Figure 4.4).



What is the perceived verbal ability of your child?



**Figure 4.4** Perceived Verbal Ability of Children in Space for Brothers

### 4.1.3 Services for Families and Their Children with Autism

#### *Education Services for Children with Autism*

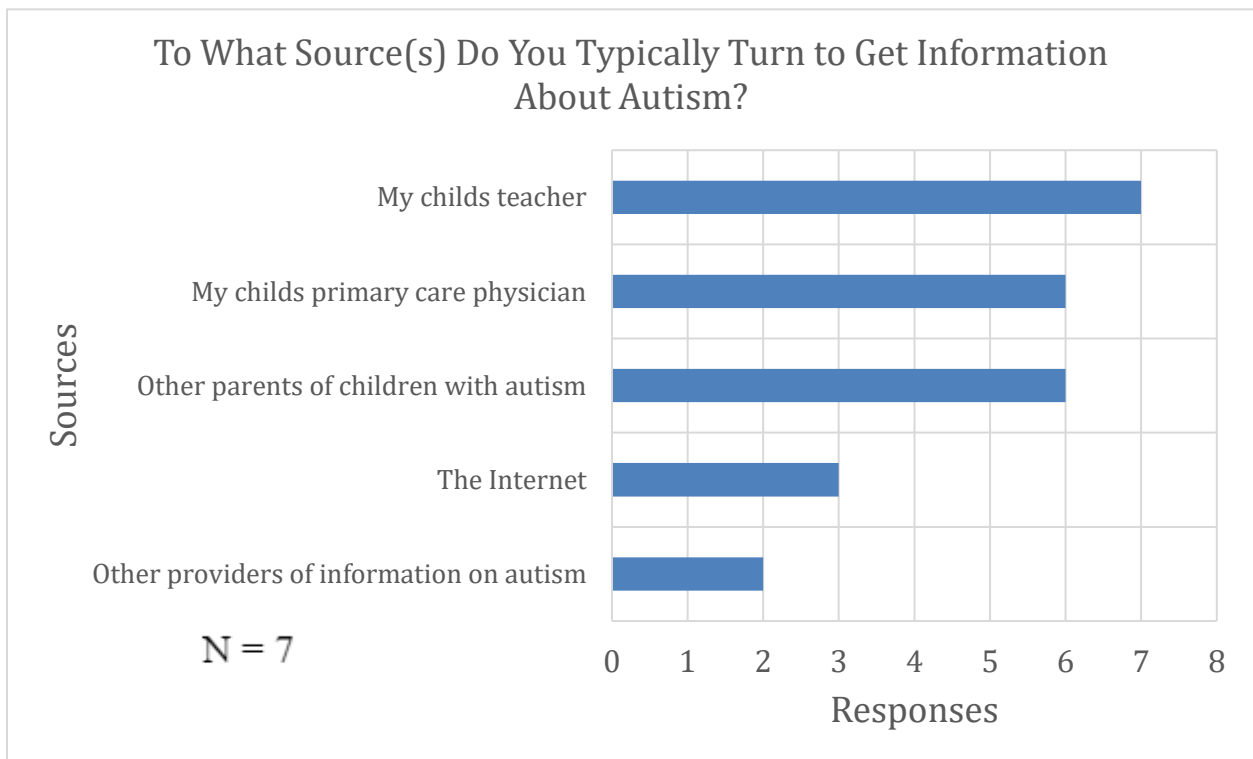
Every family interviewed in Space for Brothers explained that their autistic children attended special schools for children with disabilities. As stated by the parents, regular Moroccan schools do not have services for children with disabilities. Hence, many regular schools reject autistic children from the school program and the parents have no option but to send them to special schools.

Based on the families answer to question 3.8 from the survey (Appendix B), only one child had access to additional academic support because of his/her developmental needs, however the parent did not specify what kind of support the child received. Since only one family claimed that their child received additional academic support, it is possible that when my former team asked about additional academic support that their children received, the families may have interpreted the "additional academic support" to mean the special school their school attends. The intent of the "additional academic support" question was to determine if their child received any type of tutoring or support for academic progress. These misinterpretations may have affected the results.

*Other Services/Assistance*

None of the families interviewed received any special governmental assistance because of their child's autism. Question 3.10 from the survey (Appendix B) reports that, only two out of the seven parents received any type of training or help for managing or caring for their child.

Question 3.13 asked parents about the sources they turned to for information on autism and allowed parents to select every option for this question, or none at all. Figure 4.5 below reports the resources that parents turned to for information on autism. All the parents reached out to their child's teacher for information on autism, the teacher having the most accessible and valuable information readily available. Families indicated that having a good relationship with this children's teachers was very important.

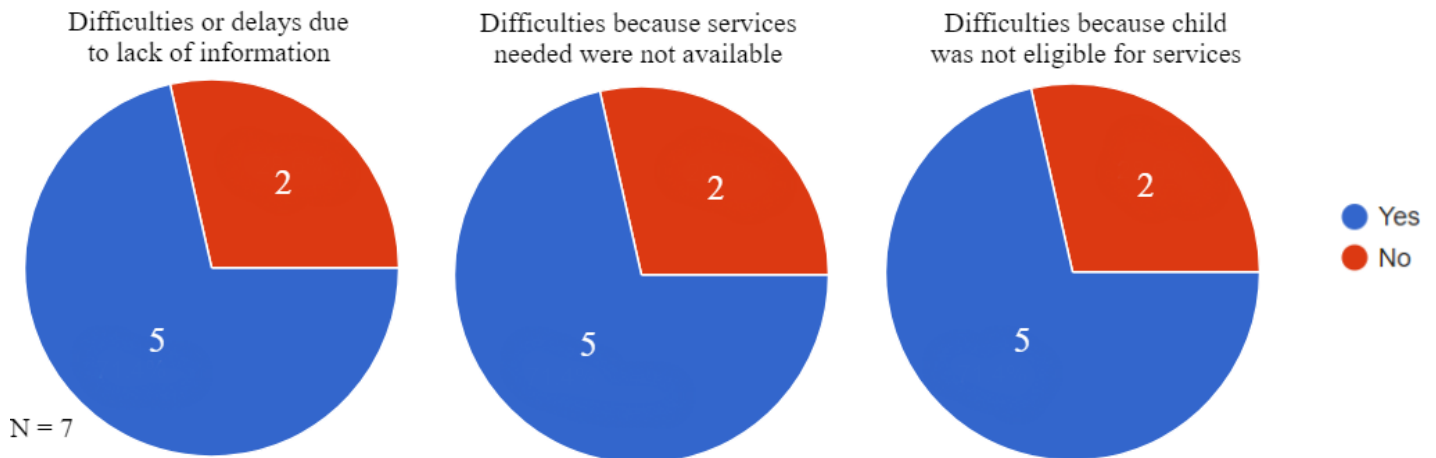


**Figure 4.5** Sources of Information on Autism for Families in Space for Brothers

#### 4.1.4 Parent/Caregiver Perceptions of Treatment/Services in Morocco

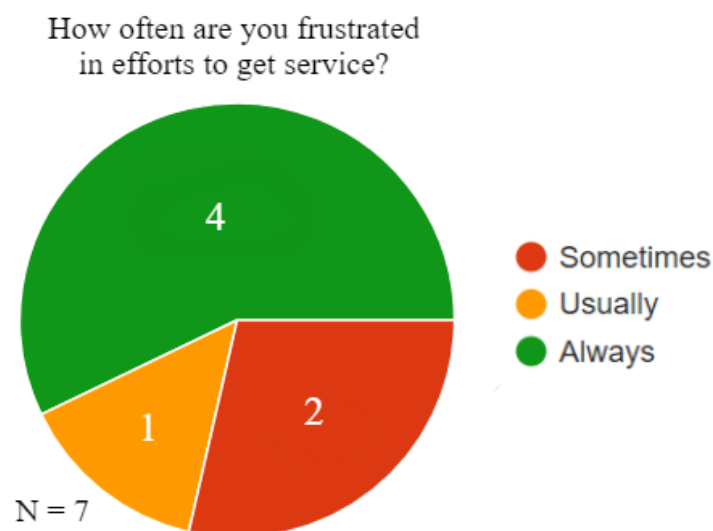
##### *Access & Unmet Needs of Children with Autism*

The questions in this section focus on difficulties families encountered during the last 12 months when attempting to provide the best care for their child with autism. A majority of the families experienced difficulties in several areas detailed in this section of the interview. Questions 4.1, 4.2 and 4.5 from the survey described in the figure below (Figure 4.6), all consistently had five out of seven families answering “Yes.” Families had difficulties getting services for their child because they lacked information about where to get services, they lacked services in their area, or the children were not eligible for them.



**Figure 4.6** Space for Brothers Families Difficulties

All seven families answered “Yes” to the following questions: Did you have difficulty or delays because there were waiting lists, backlogs, or other problems getting appointments?; Did you have difficulties or delays because of issues related to cost?; and Did you have difficulties or delays for any other reason? Only one out of the seven families said that they did not have financial difficulties due to their child's autism. Three out of seven families said that they had to stop working and/or cut down on the hours they work due to their child's autism. Figure 4.7 illustrates the answers to a question about parental frustrations, showing that every family experienced frustration in getting services at some point in the last 12 months.

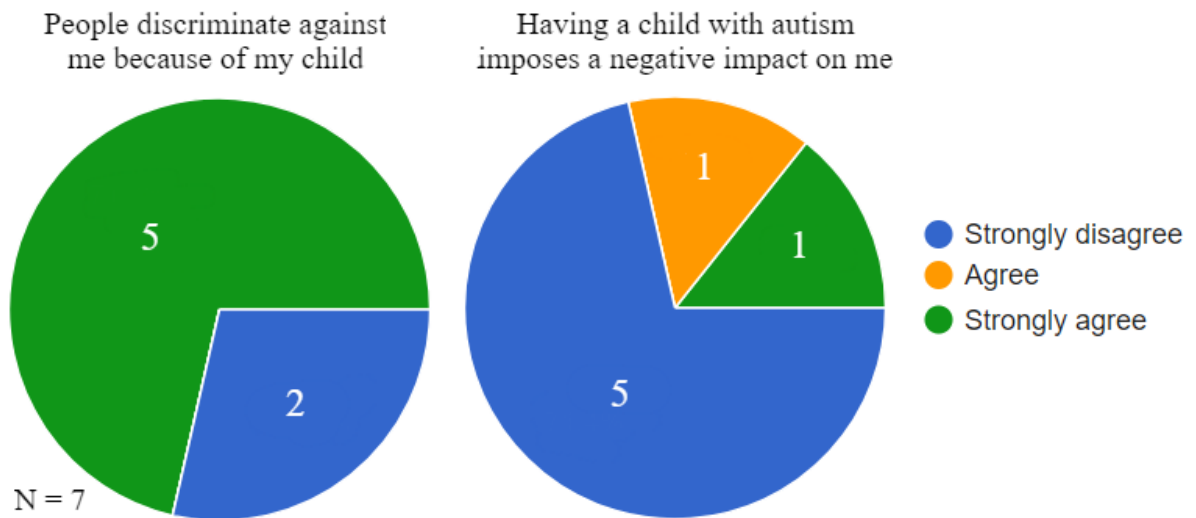


**Figure 4.7** Frustration in Getting Services in Space for Brothers

*Stigmas Against Autism*

In the survey questions about the stigma parents face due to having a child with autism, only one out of seven families agreed that having an autistic child made them feel helpless. Every family agreed that they were not worried that other people would find out that they have a child with autism.

Figure 4.8 which is based on questions 4.13 and 4.14 from the survey indicates that five out of seven parents feel that others would discriminate against them due to their child with autism. This is consistent with the transcripts of the interviews as many parents shared various stories of difficulties in their social lives, due to their child with autism. Figure 4.8 also shows that two out of seven parents agreed that having an autistic child had a negative impact on them.



**Figure 4.8** Challenges Parents Face Because of Their Child in Space for Brothers

*Quality of Life*

Questions in the “Quality of Life” section of the survey produced divided answers from parents, with most questions split halfway with negative and positive responses. However, the only two questions in the survey that all parents agreed were “Very Important” were the following: the importance of having a good relationship with the service providers who work with their children, and the importance of autistic children having support to make progress at home and in school. This implies that parents value productive relationships with the organizations that they have their kids attend, to help their children make progress for integration in society.

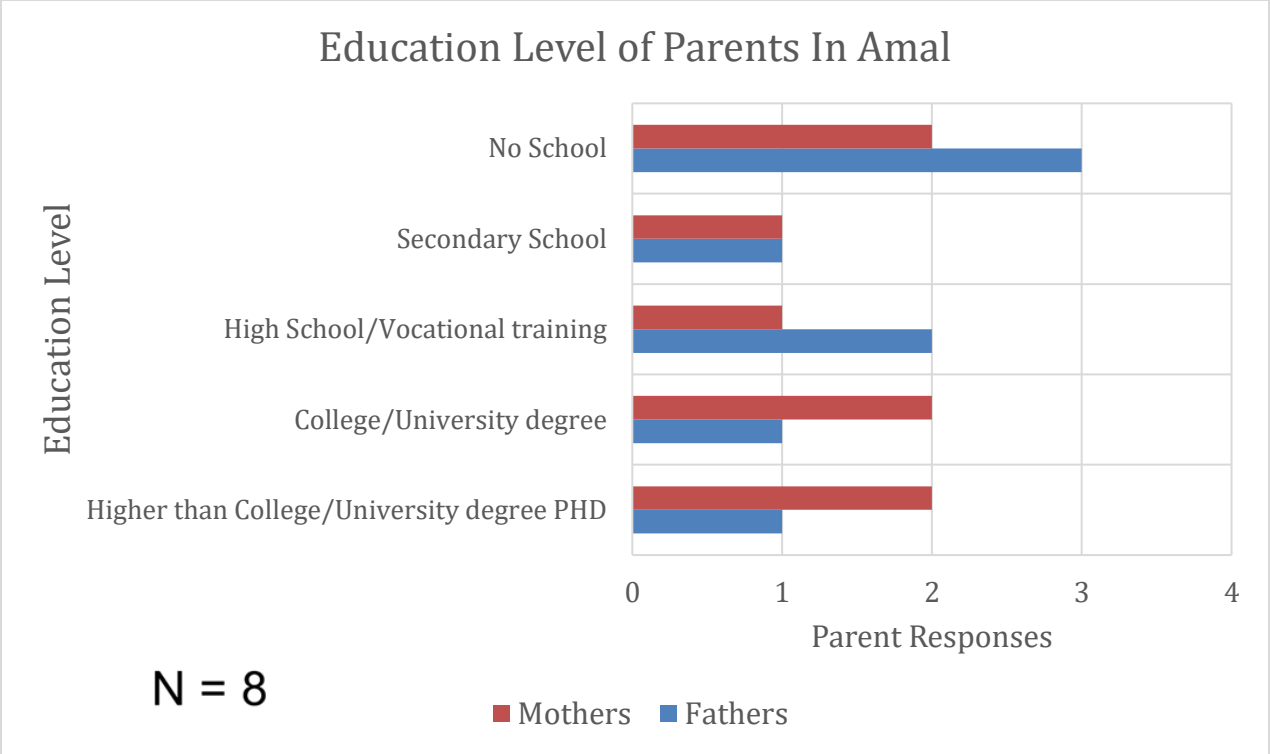
In addition, all seven families claimed satisfaction with the relationship between their children and the service providers that work with them based on question 4.22 in the survey (Appendix B). Four out of seven families reported that they were “Satisfied” with the support and therapies their children received in order to facilitate their home lives. Only two families were “Satisfied” with the support their children received towards establishing friendships. All seven families said that they were “Satisfied” with the relationship they had with the service providers in Space for Brothers. From this information, these families do not seem satisfied in all categories of the service Space for Brothers offers. However, the relationship families have with the professional caretakers seem to satisfy them.

## 4.2 Quantitative Analysis of Data from Amal

This section covers significant aspects of the results from the analysis of the data that I collected in the Amal Organization in Casablanca. All the graphs and charts in this section represent data from the eight interviews conducted. Some families from this organization were unavailable to be interviewed due to difficulties they had reaching and staying for the interview process.

### 4.2.1 Family Demographic Characteristics

In the family demographics section of the survey, two questions asked about both parents' education levels. Therefore, I collected information on the education of sixteen parents total based on eight interviews. Parents tended to have a high education in the Amal organization, with ten out of sixteen parents from Amal from the eight interviews completing a high school level education or higher. Something important to acknowledge about Amal is that it is a private organization; therefore, most, if not all, the parents subscribing to its services need to pay in full for them. This may have been possible since parents were more educated, which meant they were more likely working higher paying jobs, so they might have had more money available for a private education and were also willing to spend it to help their autistic children. Detailed below in Figure 4.9 are the specifics of schooling levels of Amal's parent caregivers.



**Figure 4.9** Education Level of Both Parents in Amal

Unlike the interviews in Space for Brothers, which included six mothers and one grandmother, at Amal I conducted four out of the eight with fathers of children with autism and conducted the other four with the mothers of children with autism.

**4.2.2 Characteristics of Diagnosis**

Autism diagnosis should happen early on in a child's development to minimize the harmful and repetitive habits that might develop with the child if left unattended. Autism Speaks recommends that intervention for children with autism begin before the age of two. Only half of the children with an autism diagnosis happened before the age of three in the Amal sample. Five out of eight families noticed abnormalities in their children after 30 months of age. In two cases in Amal, the first person to notice the abnormalities was someone other than the parents of the child with autism.

In Amal, the parents tended to be certain of their child's autism diagnosis. In seven out of eight Amal interviews, parents claimed that their children had autism with certainty. Six out of

the eight children were capable of producing sentences with two to three-word phrases or more complex sentences.

#### *Access to Autism Diagnosis*

A wide range of professionals diagnosed the children with autism in the Amal data set. Families at Amal indicated that six different types of doctors provided diagnoses for their children. These doctors consisted of: pediatricians, neurologists, psychiatrists, psychologists, a team of professionals, and a pediatric specialist.

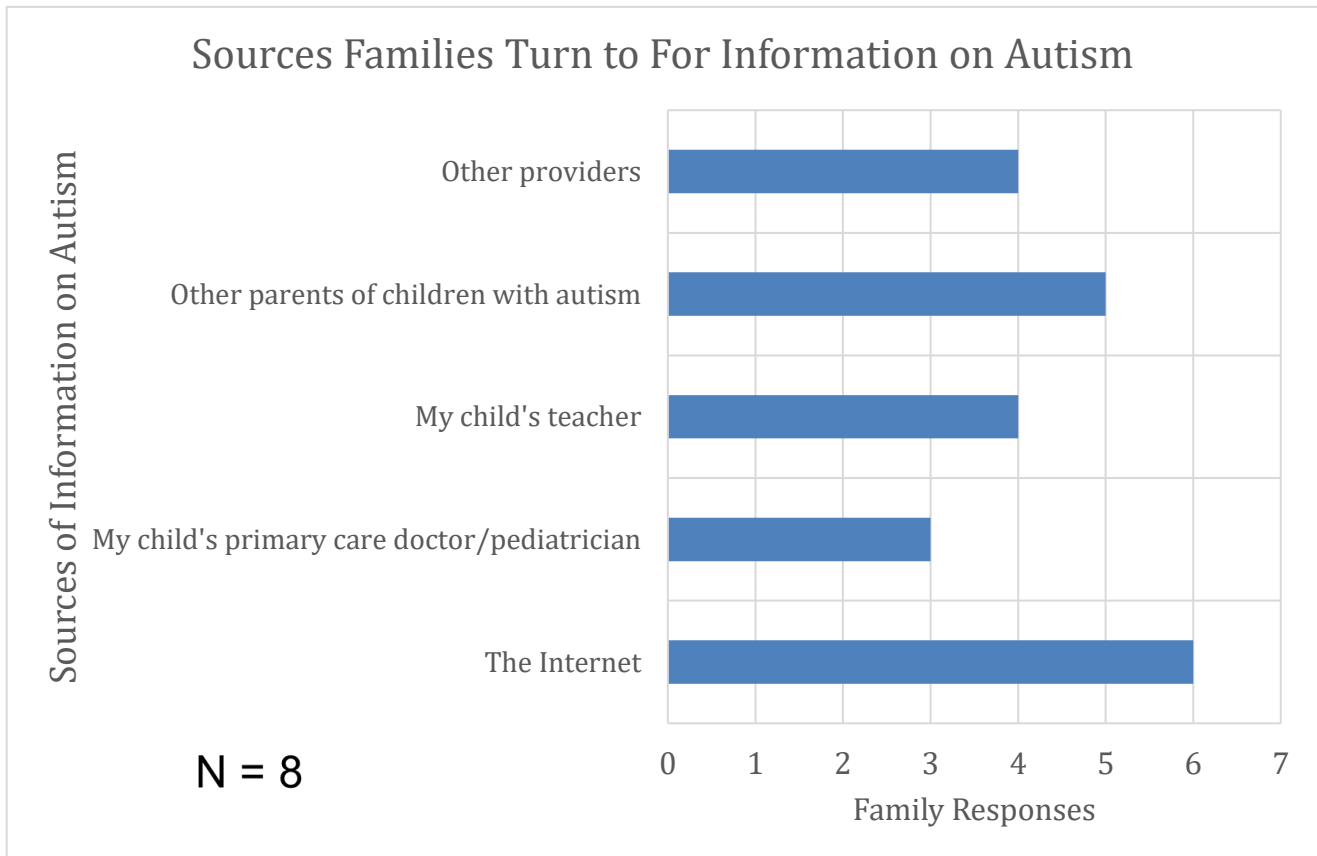
One parent claimed that they had to travel thirty minutes to an hour for diagnosis, however the rest of the parents only had to travel less than thirty minutes for a diagnosis. This may be due to the fact that there could be more professionals available to families in Casablanca. Another reason for this could be that families have more income which means that they own a car and can drive instead of having to rely on public transportation.

#### 4.2.3 Services

Two families explained that they received extra government assistance for their children in the Amal association. The first parent said that she was a teacher which made her eligible for the aid. The second parent claimed that because her husband who was a private architect died, she received a “RAMED” card, which she explained was a special card awarded to people who could not cover medical expenses. None of the other parents had access to this card. This implies that the families in Casablanca were more aware of services available to them either due to the higher overall education they had, or information Amal may have provided to them.

When asked about the parent’s primary source of information on autism, the most popular answer was the Internet, which included six out of the eight parents (see Figure 4.10). Only four out of the eight parents in Amal claimed that a source of their information was professional caregivers of their children.





**Figure 4.10** Parents Primary Sources of Information in Amal

This could mean that the parents with more schooling at Amal were proficient at researching their own information. In the personal stories families shared, parents from Amal expressed some difficulties and frustrations trying to receive information about the association from doctors themselves. Because of these issues, parents may have chosen to simply find other sources of information.

Six out of eight families in Amal reported that their child had received behavioral modification treatment at some point. In questions 3.15 to 3.17 of the Autism Speaks survey discussing the activity and participation levels of their children, across the board, parents in Amal described more active children. One possible interpretation of this is the possibility that children in Amal have received better treatment. Another possible interpretation is that outdoor activities in Amal make the children more active in general. This is due to the fact that Amal has a large facility and their staff informed me that they offer physical activities such as basketball and soccer.

#### 4.2.4 Family Perceptions of Treatment/Services in Morocco

##### *Access & Unmet Needs of Children with Autism*

The data in this section focuses on difficulties families encountered during the last 12 months when attempting to provide the best care for their child with autism. Six out of eight parents from Amal did not feel frustrations in getting treatments/services due to eligibility issues. Five out of eight parents from Amal did not feel frustrations in getting treatments/services due to availability in their area. Four out of eight parents from Amal did not feel frustrations in getting treatments/services due to availability lists or due to waiting lists/backlogs. Three out of eight parents from Amal did not feel frustrated in getting treatments/services due to costs. It is clear that while some Amal parents face the same problems that parents in Space for Brothers face, across the board parents from Amal face them to a lesser extent. In fact, three parents from Amal claimed to have never had frustrations in their efforts to get services for their children. This may be an indicator of higher standards that parents have in private organizations, since they are paying more they expect more results and impact.

##### *Stigmas Against Autism*

The questions regarding stigmas in autism also revealed some interesting details about the attitudes of families in Amal. Half of the parents agreed that having a child with autism made them feel helpless. Six out of the eight families in Amal were “Very satisfied” with their child’s ability to make friends, the remaining two families were “Neutral”. This may be due to the larger Amal facility, which may have given more opportunity for children to interact with one another.

## 4.3 Comparisons of the Quantitative Data from Space for Brothers and Amal

This section focuses on combinations and comparisons between the data collected in Space for Brothers and Amal organizations. The purpose of this section is to get a general consensus of what parents agreed or had conflicting opinions on in terms of the challenges families with children with autism face.

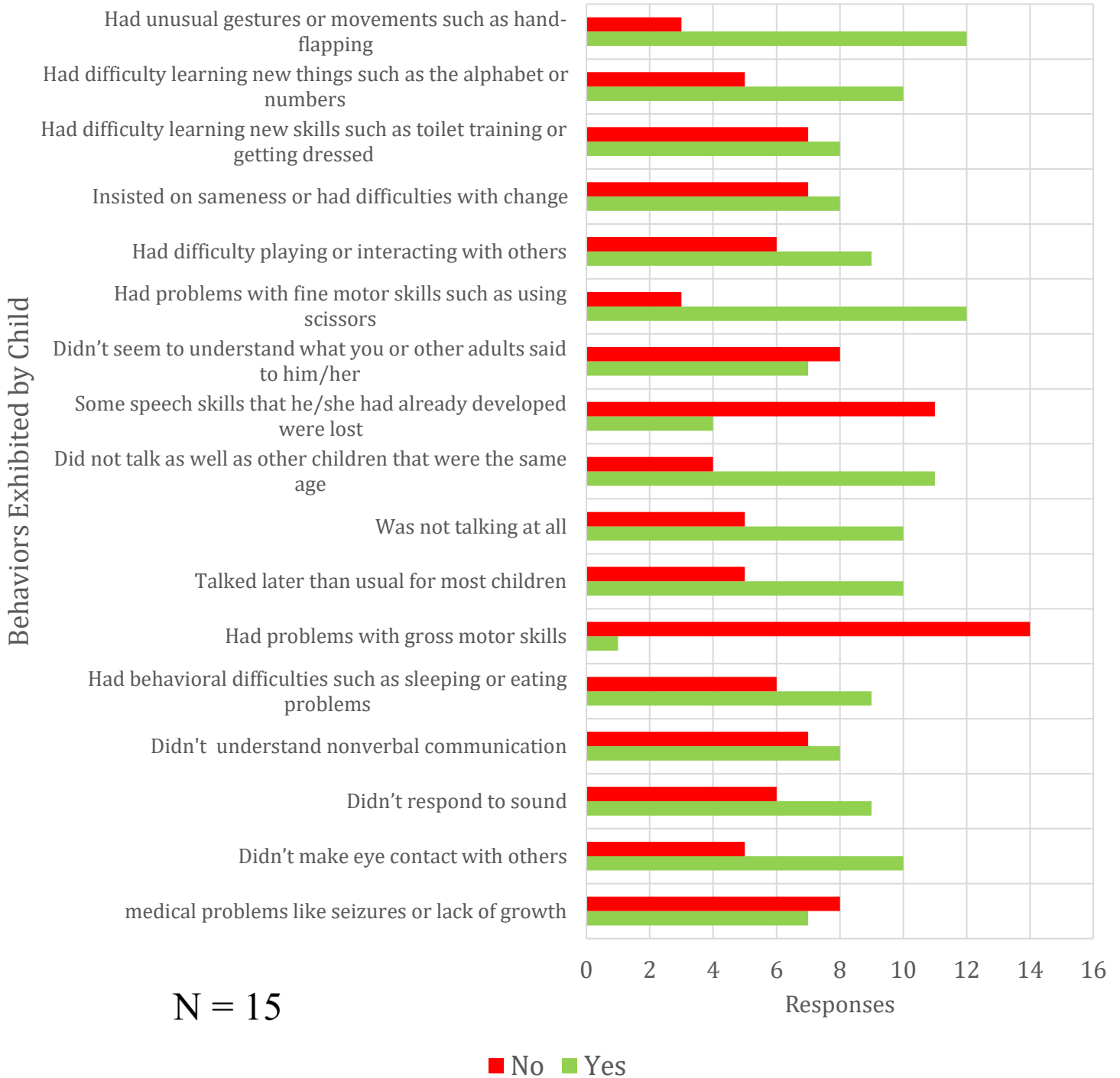
### 4.3.1 Differences in Family Demographic Characteristics

Parents in Amal had a higher education level overall in comparison to Space for Brothers, with ten out of sixteen parents from Amal from the eight interviews completing a high school level education or higher, while only four parents from Space for Brothers out of fourteen completed high school education or higher. The discrepancy in schooling between Space for Brothers and Amal indicated that children with autism in private schools tended to have parents who had more education. This may be due to the fact that since parents were more educated, they were more likely working higher paying jobs, so they were able to spend the extra money to send them to a private special school.

### 4.3.2 Characteristics of Diagnosis

There are many behaviors that could trigger a parent's concern in a child during early development before diagnosis. Based on question 2.6, the two most common causes for concern reported by parents was a tie between difficulties with fine motor skills such as scissor usage and the development of unusual movements such as hand-flapping. The next most commonly reported cause for concern was unusual behaviors. Figure 4.11 visualizes a combination of the Amal and Space for Brothers data from question 2.6 to clarify.

## Causes for Parental Concern During Early Child Development



**Figure 4.11** Causes for Concern During Early Child Development

Children with autism often develop unusual behaviors such as hand flapping, toe walking, and self-spinning (De Jonge, 2016). The cause for concern that was least reported from families was problems with coordination and gross motor skills similar to walking.

#### 4.3.3 Characteristics of Diagnosis

Most families noticed abnormalities in their children's development slightly later in the Amal organization than they did in Space for Brothers. Five out of eight Amal families noticed abnormalities in their children after 30 months of age, whereas every parent in Space for Brothers noticed abnormalities in their children's development before 30 months of age. The first person to notice the abnormalities also differs from Space for Brothers. In Space for Brothers, the parents were always the first people to notice abnormalities, however in two cases in Amal, someone aside from the parents noticed the children's abnormalities.

In Amal, the parents were more certain of their child's autism diagnosis in comparison to Space for Brothers. In seven out of eight Amal interviews, parents claimed that their children had autism with certainty, whereas four out of seven in Space for Brothers claimed to not have a diagnosis. Compared to Space for Brothers, the children who were the subject of my interviews at Amal had a higher perceived verbal functionality overall.

A much wider range of professionals diagnosed the children with autism in the Amal data set than in the Space for Brothers data set. Families at Space for Brothers named pediatricians, neurologists, psychiatrists, and psychologists as doctors who diagnosed their children. Families at Amal had all the same types of doctors provide diagnoses for their children, with the addition of a team of professionals and a pediatric specialist.

#### 4.3.4 Differences in Service

When I asked about the parent's primary source of information on autism, the most popular answer at Amal was the Internet, which included six out of the eight parents. This is different from Space for Brothers where every family interviewed claimed that professional caregivers of their children were their primary source of information. Only four out of the eight parents in Amal claimed that a source of their information was professional caregivers of their children. This could mean that the parents with more schooling at Amal were better at researching their own information than the parents at Space for Brothers. In the personal stories

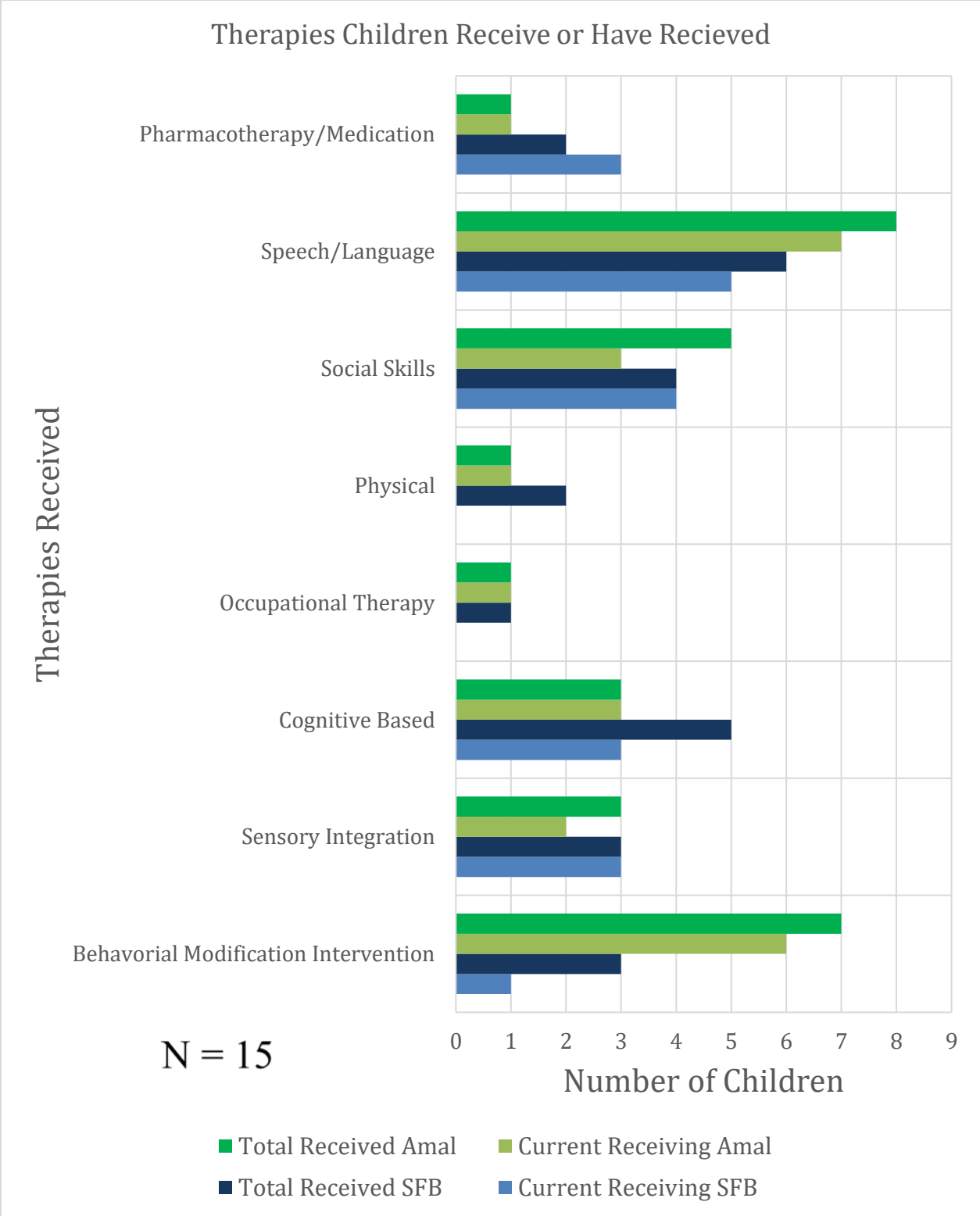
families shared, parents from Amal expressed some difficulties and frustrations trying to receive information about the association from doctors themselves. Because of these issues, parents may have chosen to simply find other sources of information.

In questions 3.15 to 3.17 of the Autism Speaks survey discussing the activity and participation levels of their children, parents in Amal described more active children than families in Space for Brothers. One possible interpretation of this is the possibility that children in Amal may have received treatment related to physical activity, this is likely due to the facilities Amal has access to. Another possible interpretation is that outdoor activities in Amal make the children more active.

When the survey asked parents about all the treatments that their child received at any point, answers were mostly comparable across the two organizations. There was only one area of difference between the Amal and Space for Brothers families. Six out of eight families in Amal reported that their child had received behavioral modification treatment at some point, while only one family in Amal claimed the same. This was in response to question 3.1 (Appendix B), which asked parents: “Has your child ever received any of the following services or treatments to meet his/her needs?”

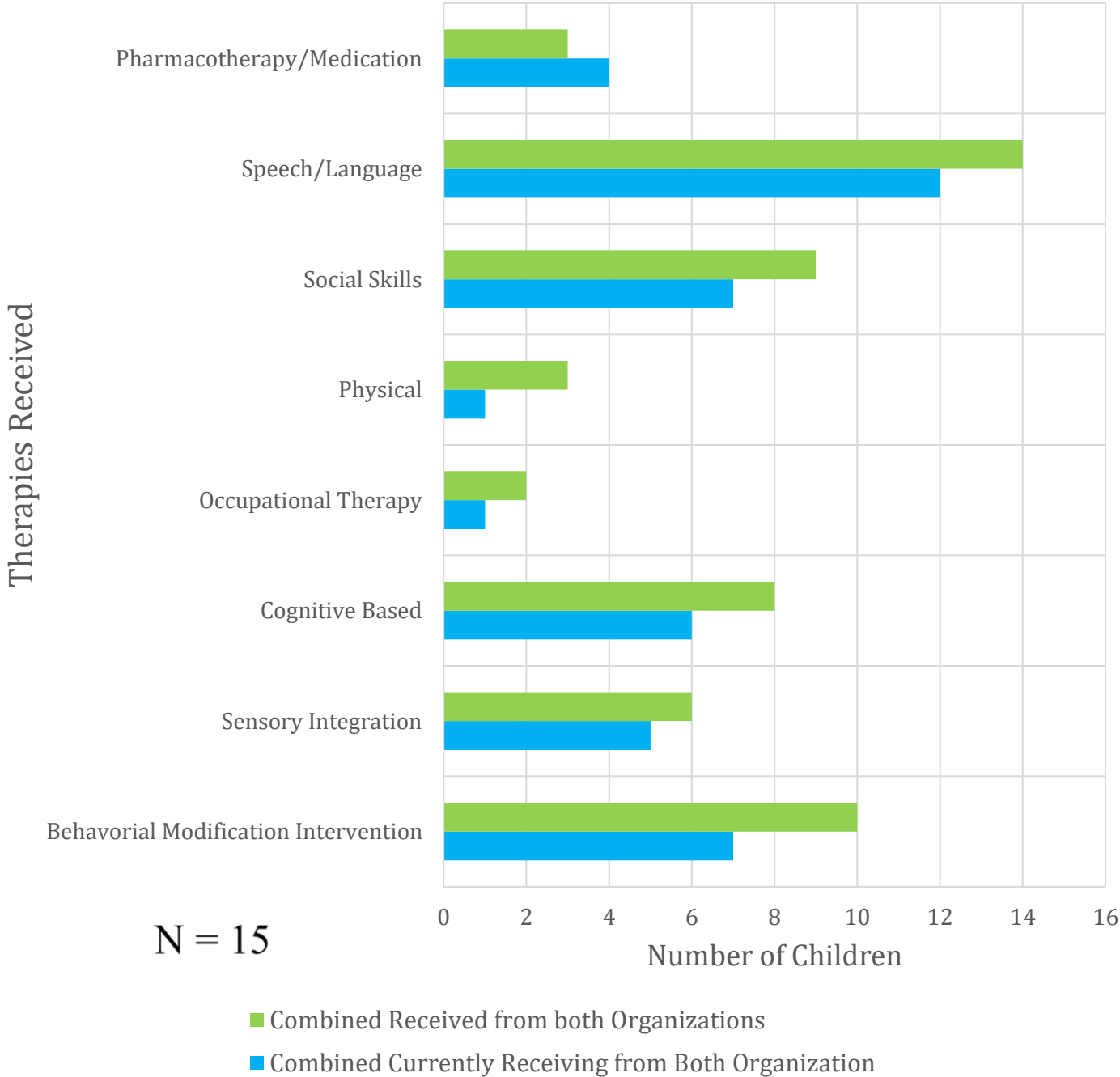
#### 4.3.5 Services Across the Board

Apart from this difference, most of the families’ answers in the services section of the survey were the same at both facilities. Figures 4.12 and 4.13 visualize a combination of the data from Amal and Space for Brothers. Based on these figures there was a net decrease in the services children received, to the treatments they currently received.



**Figure 4.12** Therapies Children Receive or Have Received in Amal and SFB

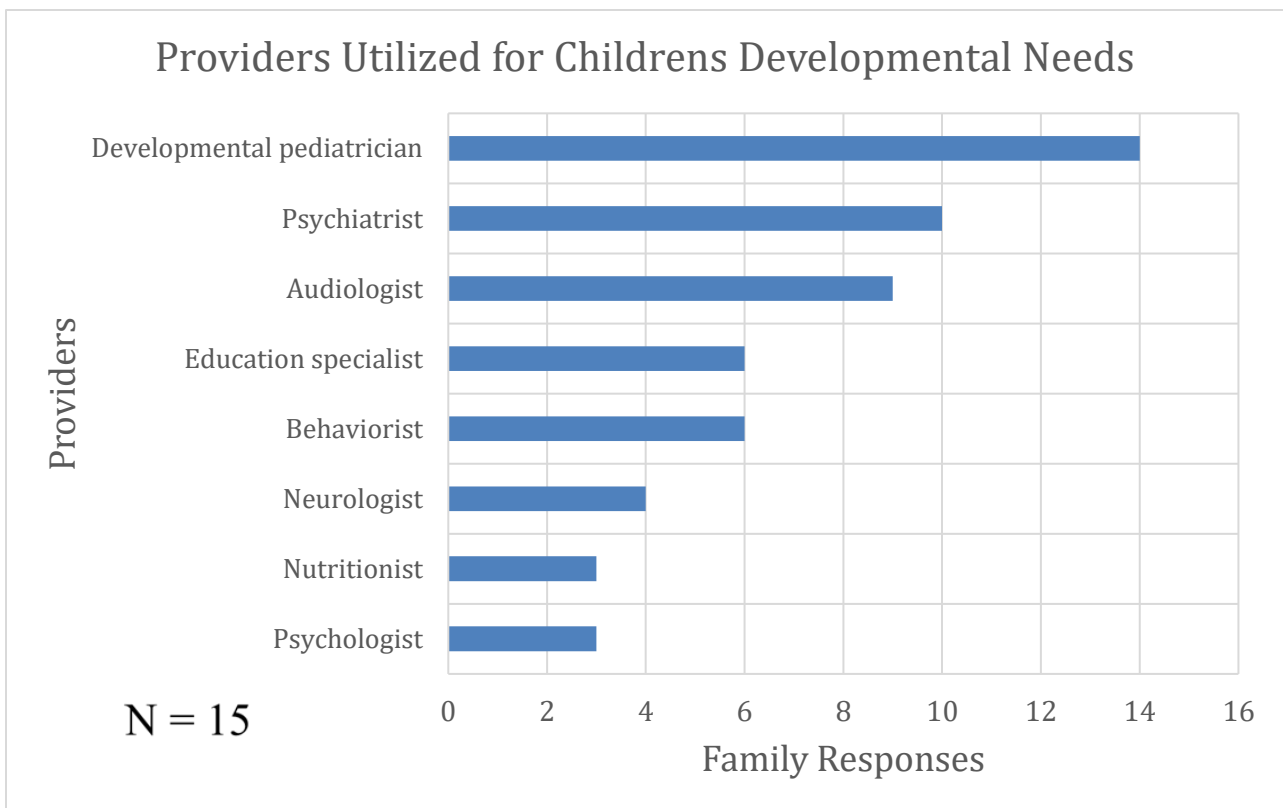
## Combined Number of Therapies Children Receive or Have Received



**Figure 4.13** Therapies Children Receive or Have Received in Both Amal and SFB Combined



Question 3.5 from the survey asks families about all the providers they have worked with to help with their children's developmental needs (Appendix B). Based on the results from question 3.5, the developmental educator was the most common service provider that parents worked with, with fourteen out of fifteen parents in total having worked with them at some point. A psychiatrist was the provider families utilized the second most, with ten out of fifteen families having utilized one in the past. Finally, the audiologist was the provider families interacted with the third most, with nine out of fifteen families having interacted with one. This data is outlined in Figure 4.14 below.



**Figure 4.14** Providers Families Worked With for Their Children

When asked about the providers their children received treatment from, the parents most common response yielded a three-way tie between behaviorist, developmental pediatrician, and a psychiatrist, with six out of fifteen children currently receiving treatment from each of them.

### *Education Services for Children with Autism*

No parent interviewed could send their children to regular Moroccan schools, so they had no option but to send them to special schools for children with disabilities such as Amal and Space for Brothers. Based on the answers to question 3.8 in the survey, 80% percent of families claimed to not receive academic support for their children. Despite this, twelve families also claimed in question 3.9 of the survey that their children received academic support in a special classroom for children with autism. It is possible that they may have misunderstood the question when asked. This suggests that the survey should be modified moving forward if Autism Speaks plans on using it again.

### *Other Services/Assistance*

When asked about training or assistance they received for their child's needs, only 33% of families agreed that they had received them. Most of the parents said that the training they received came through the association they had their children in. When asked for details on training sessions, the organizations said that they offered seasonal general information sessions for advice.

### 4.3.4 Parent/Caregiver Perceptions of Treatment/Services in Morocco

On the topic of access and unmet needs of children with autism, the answers from Space for Brothers and Amal were very different. While five out of seven parents from Space for Brothers felt frustrated in getting treatments/services due to eligibility issues, six out of eight parents from Amal did not. While five out of seven parents from Space for Brothers felt frustrated in getting treatments/services due to availability in their area, five out of eight parents from Amal did not. While every parent from Space for Brothers felt frustrated in getting treatments/services due to availability lists or due to waiting lists/backlogs, four out of eight parents from Amal did not. While every parent from Space for Brothers felt frustrated in getting treatments/services due to costs, three out of eight parents from Amal did not. It is clear that while some Amal parents face the same problems that parents in Space for Brothers face, across the board parents from Amal face them to a lesser extent. In fact, three parents from Amal claimed to have never had frustrations in their efforts to get services for their children while in Space for Brothers, every parent had some sort of frustrations with getting services for their

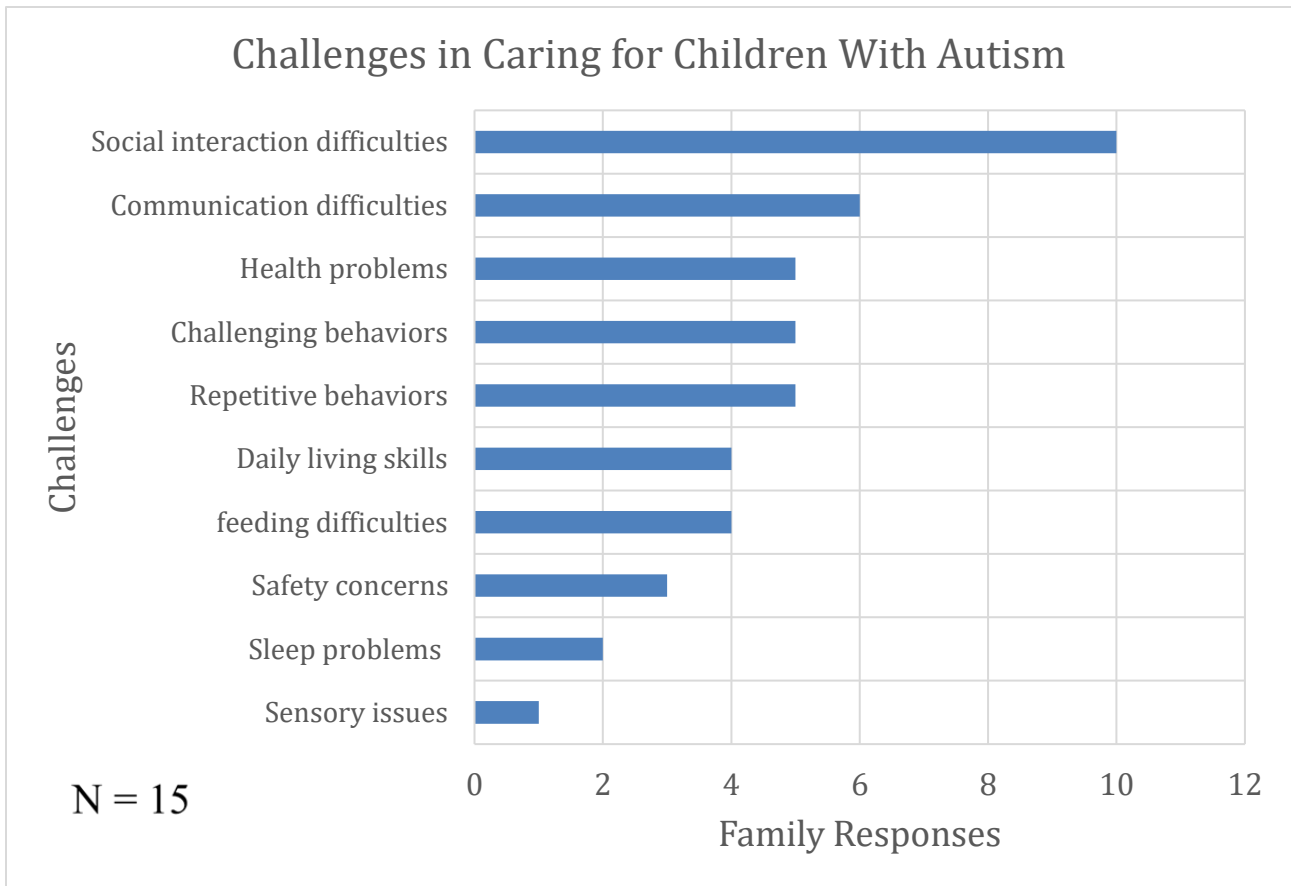
children. This may be an indicator of higher standards that parents have in private organizations, since they are paying more they expect more results and impact.

When it came to parent and caregiver perceptions of treatment and services in Morocco, most of the families had different opinions depending on the organization they enrolled their children into. However, there were some similarities between them. Eighty-seven percent of all families agreed that their child's autism caused financial problems for their families. Forty-seven percent of families needed at least one family member to stop working to care for their child with autism. Sixty percent of families needed at least one family member to cut down on the hours they worked to care for their child with autism.

Every family agreed that to have a good life together, their child needed support to make progress in school. Sixty percent of families were “Very Satisfied” with the support their children had to make progress in school. All but one family agreed that it was “Very Important” for a child to have support to make progress at home. Sixty-six percent families agreed that it was “Very Important” that their children had support to make friends. Every parent claimed to be “Very Satisfied” with the relationships they had with the service providers for their child despite many parents voicing various difficulties and hardships with treatments and services.

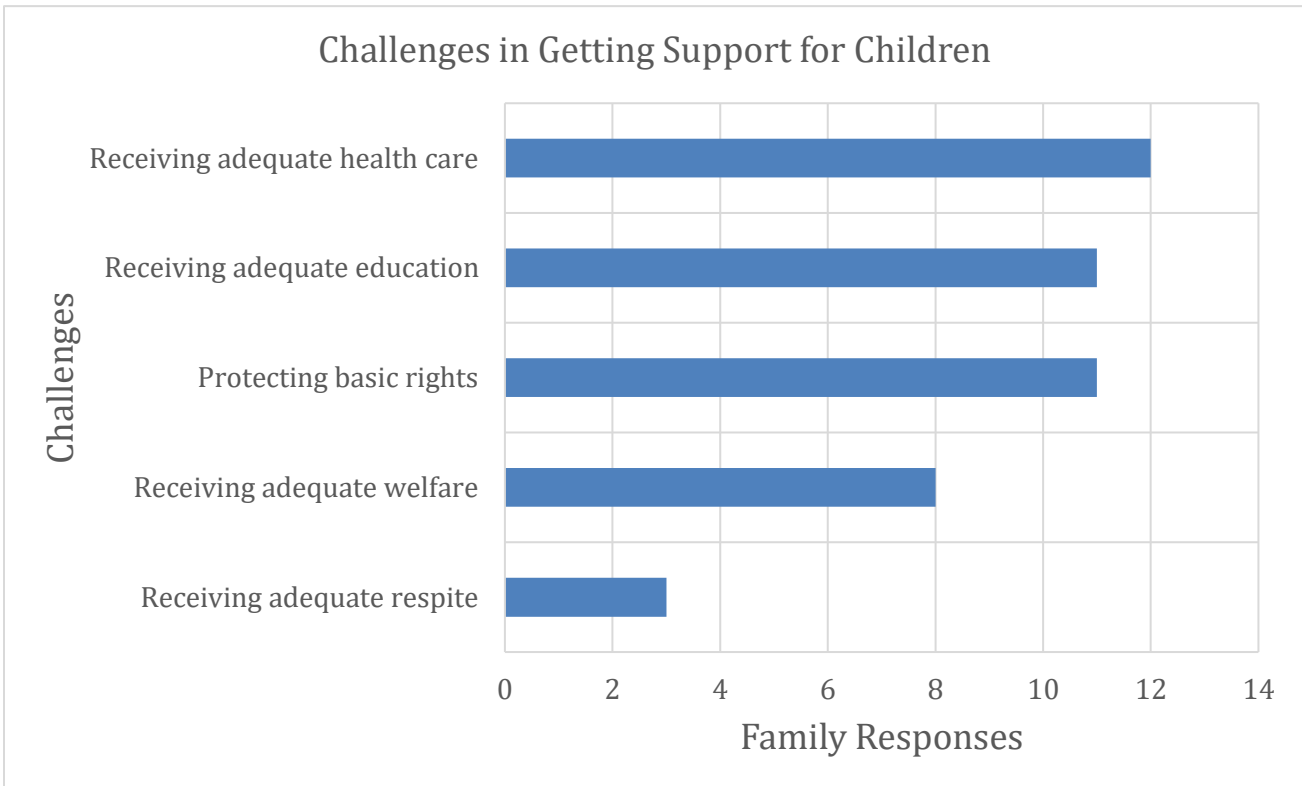
### *Challenges and Priorities*

The survey asked parents three questions about challenges and priorities they had regarding their children. Each question listed many options for the parents and asked them to choose what they felt were the three most important options out of all of them. The first question (Question 4.23) asked the parent what they felt were the greatest challenges to caring for a child with autism. The most selected answer was the social interaction difficulties they faced. The second most selected answer was communication difficulties (Appendix B). The data from this question is illustrated below in Figure 4.15.



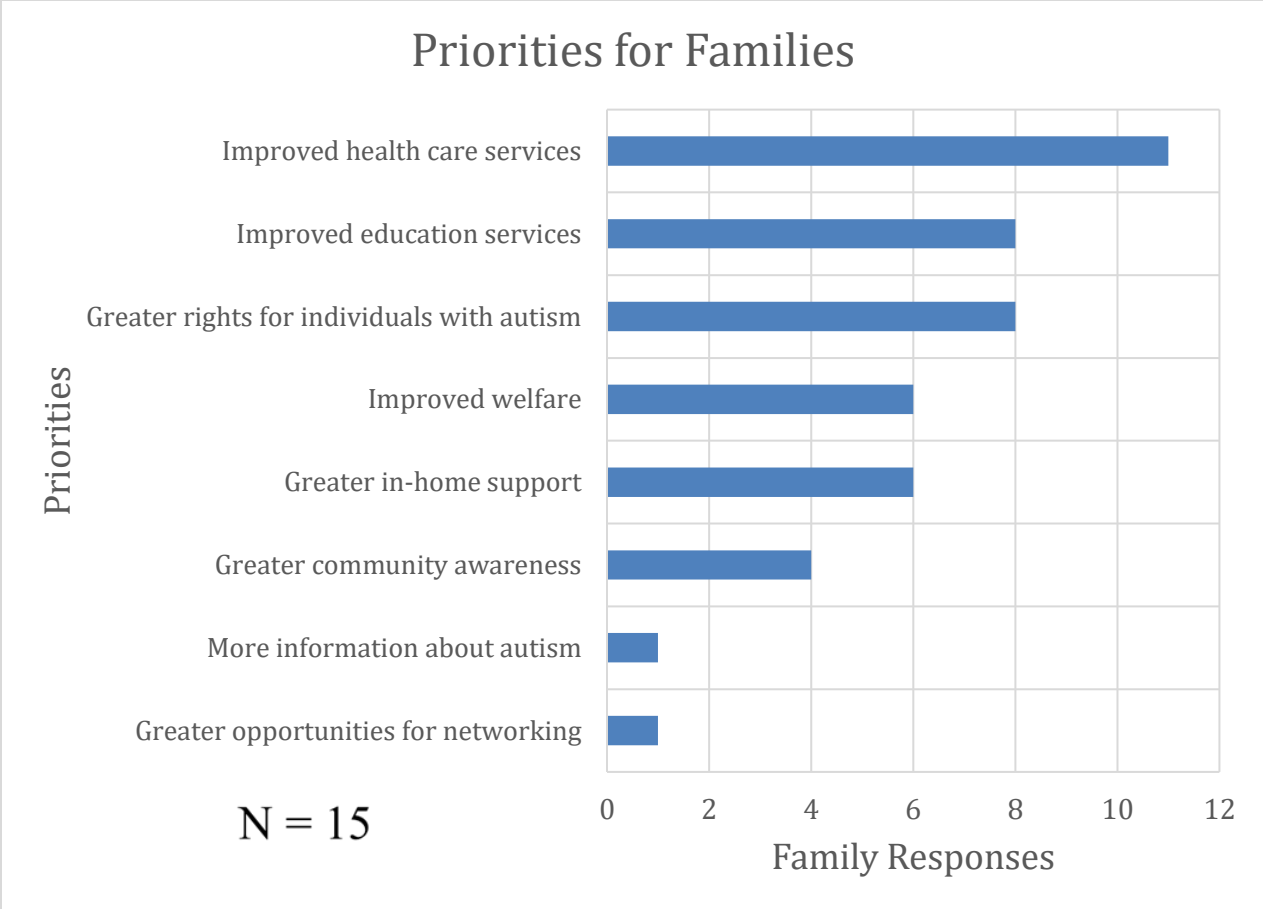
**Figure 4.15** Challenges in Caring for Children With Autism

The second question (Question 4.24) asked what parents felt were the greatest challenges they faced in getting support for their children (Appendix B). The most commonly reported challenge that parents claimed to face was making sure their children got adequate health care. The second most selected option was a tie between making sure their children receive adequate education and making sure their children's basic rights were protected. The data from this question is illustrated below in Figure 4.16.



**Figure 4.16** Challenges in Getting Support for Children

The third and last question (Question 4.25) asked parents what they felt to be the greatest priorities for families affected by autism in their country (Appendix B). The most selected option was improved health care services for children with autism. The second most selected question was a two-way tie between improved education services for their children and greater rights for individuals with autism. The data from this question is illustrated below in Figure 4.17.



**Figure 4.17** Priorities for Families

## 4.4 Qualitative Analysis of Interview Transcripts

This analysis section relates the stories and comments that parents discussed beyond the survey questions. My former team at Space for Brothers and I at the Amal association saved stories and comments in a script attributed to each interviewee, even though the team did not collect any personal information. To provide an insightful analysis, this section describes the qualitative data resulting from my coding process, with support from correlations in the quantitative data provided through the survey results presented earlier. This section discusses these results based on the categories that resulted from my inductive and deductive coding processes. The categories can be found in Appendix F.

### 4.4.1 Family Autism Support Communities

Three out of the seven of the mothers interviewed at Space for Brothers had difficulties reading and did not have formal educations. One correlation showed up between educated mothers and their involvement in support groups. Namely, three out of the four mothers that did have schooling also mentioned being in a community of families or getting advice from other families with children with autism. One of the mothers with schooling explicitly stated that she was part of a WhatsApp family support group where other parents of children with autism exchanged information and supported each other. Only one of the non-reading mothers mentioned wanting to get into contact with other mothers to gain advice on raising her child. Her reasoning for not making contact yet was that she was new to Space for Brothers and she was still adjusting to her environment. However, the other two mothers with no schooling did not mention any type of involvement with a community of parents.

From this information one might speculate that mothers who are literate are getting involved in online communities such as blogs and WhatsApp groups to share information. However, mothers who have difficulties reading may have a hard time getting involved in those groups. Another difficulty among Moroccan parents could be access to computers/smartphones. Based on question 4.8 from the survey (Appendix B), 86% of the families had financial difficulties due to caring for their children with autism. It is possible that some families did not have finances to keep up with the other parents technologically.

#### 4.4.2 Rejection and Social Discrimination

A recurring theme in most of the interviews was the difficulties families had in terms of social discrimination and rejection from acquaintances or even other family members. In one of the interviews, a mother indicated that her family avoided her. Two other mothers stated that their families stopped talking and acknowledging them altogether. One mother's husband left her due to having a child with autism because he was not proud of his child. Another mother explained that her family would bring presents for her child who was not autistic, however they wouldn't bring anything for her child with autism.

One mother did not feel discriminated against by her family. However, she did disclose an encounter in the bus with her child. She told my former team that a bus driver accused her of having a disabled child on purpose, so that she could use the disabled services in Morocco and avoid having to pay the bus fare. Another mother told us that when she would try to educate others on autism and why her child was different, people would usually respond telling her that her child was sick, and that she needed to keep her child away from the public. Based on the interview transcripts, fathers reported discrimination significantly less than the women interviewed. From these stories, one might infer that many Moroccan families face discrimination when they have a child with autism.

#### 4.4.3 Difficulties in Receiving Diagnosis

Throughout the interviewing process, parents described situations where they had difficulties getting an appropriate diagnosis for their children. In one mother's account, when her child was two months old she noticed something was wrong. She went to the doctor to address her concerns; however, the doctor did not provide any valuable information. When her child was nine months old she tried again, the second doctor she visited said that the child was too young for him to diagnose. It wasn't until the child was ten years old that a professional provided a diagnosis, thus delaying valuable intervention and treatment. These types of delays thwart the developmental process for the child.

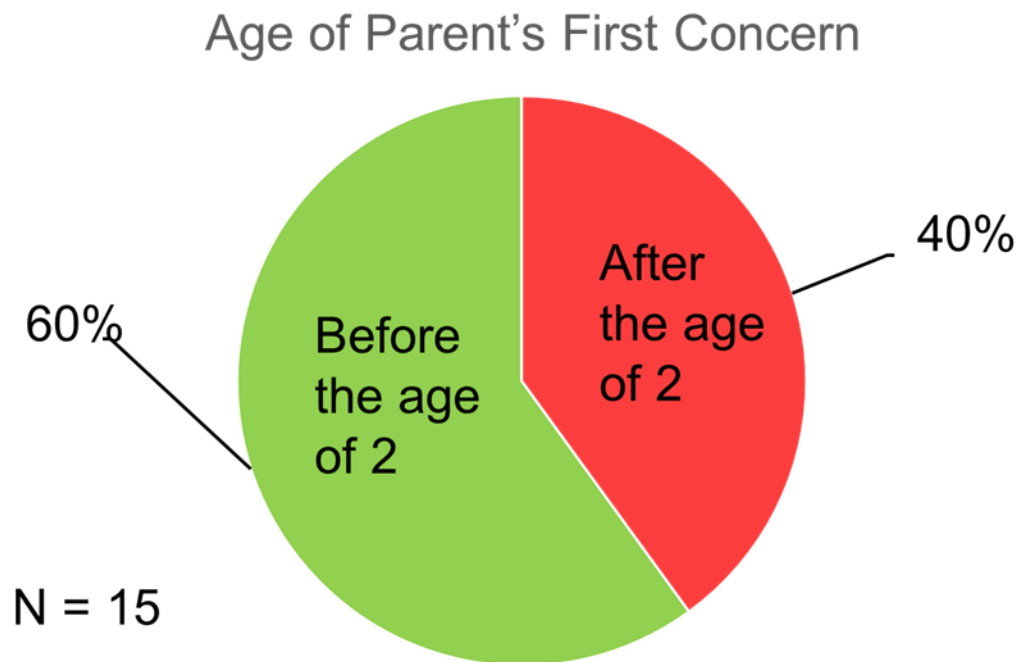
Five parents in total described difficulties in getting an official diagnosis from the doctors or getting any type of certificate which described their child's autism. Two of the parents outlined difficulties they had simply getting to a doctor to obtain a diagnosis; one parent's financial issues made it too difficult to seek treatment. Another parent simply did not have



enough time due to having to attend to her child in between other responsibilities. The last two families explained that the doctors would tell them that their children had autism, but they wouldn't give an official diagnosis.

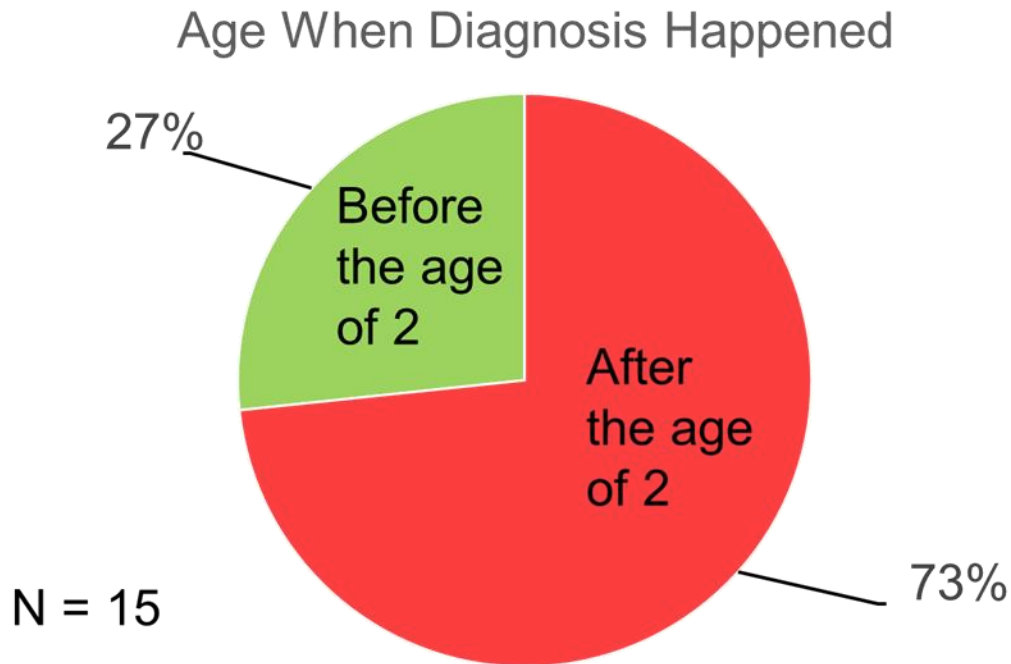
One parent recounted that he discovered that his child had autism when a retired doctor who was still active in the hospital took him into a room and googled his child's symptoms. The retired doctors then said that his child probably had autism and to not give him gluten because it was bad for him. The session lasted 15 minutes, and he had to pay 400 dirhams, which the parent explained was a lot of money for him.

In one parent's words, the reason for the lack of diagnosis is due to the fact that there is no official psychiatrist or hospital in Morocco for the diagnosis of autism. Parents difficulties in diagnosis intensified due to them being late in recognizing abnormal behaviors in their children before the age of two (see Figure 4.18).



**Figure 4.18** Parents Who Noticed Abnormalities in Their Children Before the Age of Two

This is a problem because Autism Speaks recommends children receive an autism diagnosis before the age of two. This led to many of the children as recorded by the survey receiving some type of diagnosis after the age of two (see Figure 4.19).



**Figure 4.19** Children Who Received Autism Diagnosis in Their Children Before The Age of 2

Our research learned from the parents over the course of these interviews that in Morocco there is difficulty getting an official diagnosis of autism.

#### 4.4.4 Difficulties in Receiving Treatment/Services

The most common theme in this project's interviews was difficulties in receiving treatment/services, with 26 different descriptions in nine out of fifteen interviews. There were many different reasons parents gave for difficulties in reaching treatment. Six parents explained that traditional schools rejected their children and forced them to attend special schools for their education until the children were capable of attending traditional school.

Two parents explained that if they wanted their child to stay in regular school, they needed to hire a special caretaker to stay with the child at all times which was not feasible due to it being very expensive. These comments indicate that it is likely that many schools do not have facilities to care for children with autism. The suggestion that formal schools do not have any facilities to support children with autism supports the fact that all the children of the parents interviewed have to attend a special school for children with autism.

One parent had a more in-depth explanation about the difficulties children with autism face when trying to attend school. He explained that in Morocco schools follow the francophone system, where a child's school day begins at eight AM and lasts until six PM. Sitting through almost 10 hours of school a day is a very long and difficult task for a child with autism. The parent explained that Morocco needs specialized schools where children with autism can complete the school curriculum at a slower pace or where teachers can employ different methods that are more suited to the children with autism.

Other reasons cited by parents that caused difficulties getting treatment were: financial difficulties, inability to find someone (a doctor) who cared about their child's situation, problems with waiting lists, and problems with transportation/mobility due to their child's hyperactivity and tantrums.

#### 4.4.5 Lack of Communication Between Parents and Organizations

While many of the interviewed families complained that they did not know how organizations were treating their child, a few claimed that they did know. Many parents also claimed to not have any training for dealing with their child, while some others did get training. The parents that did claim to have training for how to properly manage their child said that the organizations themselves offered the training to them. When asked about treatments offered to every child with autism, the organizations provided a full list that was not consistent with the answers parents gave to question 3.2 in the Autism Speaks survey. Question 3.2 asked parents what services/treatments their children were currently receiving. This is indicative of some level of miscommunication between the parents and the organizations.

### 4.5 Limitations in Study

Unfortunately, some external factors delayed my progress. After the creation of my team, I had a hard time setting up interviews with an organization for myself. This limited the amount of data I was able to collect. The biggest limitation was the time constraints on my project.

Translators Mohammed and Jihan both voiced concerns regarding the clarity of the questions. We tried to remedy this by taking steps described in the methodology to refine the survey. The fact that the survey questions might still be unclear, may have led to parents misunderstanding the intent of some of the questions and answering inaccurately.

## 4.6 Recommendations

The results from the interviews in this research indicate that organizations, treatments and services in Morocco need to improve since many of these families are in dire or very difficult situations. This section provides recommendations for organizations in Morocco, some of which might be easy to adopt, and some might be more difficult. One of Autism Speaks' methods for promoting solutions for people with autism is by advocating and pushing for legislation for the support of people with autism. Hence the proposed recommendations involve legislative action and action that Autism Speaks could take.

As described earlier, some mothers might get left out of WhatsApp or online blogs due to their low reading comprehension. One possible course of action would be for organizations to offer community updates. They could do this by possibly involving all the parents in advice sessions with professionals or perhaps sessions for parents to meet each other to offer each other advice and discuss issues. All these parents will have the fact that their children go to the same organization in common. Therefore, it would be easy for the parents to relate on some level, and it might be easy for them to talk and offer advice to each other.

With regard to the lack of communication between the organizations and the parents, I do not have any data that explains why the miscommunications happen. Based on my research results, I recommend that organizations take steps to clearly explain the treatments offered to the parent's children as well as communicating clearly when their organization holds information sessions. This could be accomplished by creating new information routes, such as blogs, WhatsApp groups, some form of weekly to monthly newsletter, or possibly some type of conferences with teachers.

Parents face many challenges after receiving diagnosis of autism for their children. The project interviews illustrate that the main reason for lack of diagnosis is a deficit of qualified professionals in Morocco qualified or authorized to give official diagnosis out for autism. One possible solution is for Autism Speaks to hold training seminars for professionals in Morocco to teach them proper methods in diagnosing autism.

Even if they received diagnosis, parents faced many difficulties in receiving treatments and services. However, the most difficult service for families to gain access to was attending school. Schools rejected the children if they could not conduct themselves in a manner they saw fit, which meant parents needed to find special schools to treat their children. To forward the

suggestion of another parent, I recommend that legislation or permission should come from the government, to allow for schools for children with mental disabilities to teach curriculum up to a certain grade level determined by the government. This would help prepare children with mental disabilities for school if they ever become able to attend regular school.

## Chapter 5: Conclusion

This project conducted research over the course of 14 weeks. My former team conducted seven interviews in the Space for Brothers organization in Rabat. I conducted eight interviews at the Amal organization in Casablanca. The goal of this project was to collect and analyze data regarding the current treatments and education available to children with autism in Morocco. After the collection and analyzation of data into results, these are the conclusions I have come to.

The dedicated parents I met and interviewed in Morocco constantly worked and desired for improvement of the status of their child. Every parent interviewed struggled providing for their children in some way or another, which shows that they are willing to strive to provide for their children. They struggled every day with very little respite since it is very difficult to receive support from the government, difficult to find a doctor who is capable of properly diagnosing and treating their child, and it is difficult for organizations to receive the funding they need to function at their best level. Even if the families manage to overcome all these obstacles, they still face the scorn of the masses and their families.

Based on my discussions with parents and research, progress has been made: the government has enacted legislation, and people are protesting the conditions of their autistic people in Morocco. However, based on my results these things are not happening fast enough. I hope that the data, results and recommendations I provide to Autism Speaks help make progress in relieving the struggles these families face on a daily basis.

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2017.المغرب: مرضى التوحد وأهاليهم يتظاهرون للمطالبة بحقوقهم - فيديو

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يتظاهرون-للمطالبة-بحقوقهم

# Chapter 6: Appendices

## 6.1 Appendix A: Family/ Caregiver Online Survey

My former teammates and I used the same Autism Speaks survey that the WPI Institutional Review Board (IRB) and World Health Organization (WHO) approved in 2016. The appendix includes a lengthy survey tool targeted toward families and caregivers of children with autism in Morocco. I have attached the link to the survey which the previous Autism Speaks teams from WPI used to collect data in 2016 which is in the format of a Google form. My former teammates and I also used this survey to collect data on families.

[https://docs.google.com/forms/d/1Rh\\_hpOOqPdMDlc1z9yedNBzQ-wrMXQVIV7vyKo1WBDU/edit](https://docs.google.com/forms/d/1Rh_hpOOqPdMDlc1z9yedNBzQ-wrMXQVIV7vyKo1WBDU/edit)

## 6.2 Appendix B: English Version of Autism Speaks Printed Survey

The English version of the Autism Speaks survey is located in the 2016 Autism Speaks teams IQP report at: <https://web.wpi.edu/Pubs/E-project/Available/E-project-101216-082715/>

## 6.3 Appendix C: Arabic Version of Autism Speaks Printed Survey

This is the modified version of the Arabic survey provided to my former team by Autism Speaks.

**Autism Speaks**

**Autism Speaks**

**Caregiver Needs Survey**

استقصاء لاحتياجات مقدمو الرعاية

**Developed by Amy Daniels**

تصميم ايمي دانيالز و شون

**& SEAN**

**National Coordinators**

المنظمون الوطنيون

**Kara A.Reagon**

كارا آرايغن

0-الباب الأول : البيانات الأساسية للإستقصاء

1- المنطقة (اسم الإقليم / المدينة / البلدة).

2- طريقة التسليم :

1- شخصيا (مسؤل الاستقصاء)

2- بشخصك

3- الهاتف

4- البريد الالكتروني

5- بطريقة أخرى (صف:).

3- صيغة التقديم:

1- ورقيا

2- الكترونيا

4- المنشأة:

1- المنزل

2- مؤسسة ، جمعية.

3- أخري (صف: )

5- اسم المنشأة (إدخال الاسم، إن كان مفعل).

1- \_\_\_\_\_ (غير مفعل)

2- \_\_\_\_\_.

6- تاريخ الإستكمال ( اكتب: اليوم / الشهر / السنة)

:الموافقة علي المشاركة

أعزائي الآباء/ مقدمو الرعاية

، \_\_\_\_\_ /اسم الجامعة/المؤسسة )

بشراكة مع جمعية ([www.autismspeaks.org](http://www.autismspeaks.org)) (Autism Speaks) ، سيتم إجراء استقصاء لفهم احتياجات الأطفال الذين يعانون من التوحد، والتحديات و الصعوبات التي يواجهونها هم وأسرهم في البحث عن المساعدة و تلقيها.. و بالرغم من أنكم لن تستفيدوا مباشرة بمشاركتكم، إلا أن نتائج هذه الدراسة سوف

تستخدم للبحث و التخطيط لاتخاذ معايير مناسبة لتحسين الرعاية والخدمات للأطفال المصابين بالتوحد وأسرهم. [نحن لا نتوقع أي مخاطر على مشاركتكم ما عدا تلك التي قد تواجهونها في الحياة اليومية .

إذا ما وافقت على المشاركة ، يتوقع أن تأخذ الدراسة الاستقصائية ما يقرب من 30 إلى 45 دقيقة للانجاز. يرجى قراءة الأسئلة و الأجوبة بعناية، و الإشارة بوضوح بعلامة X على الجواب الذي اخترته، و المرجو عدم ترك أي سؤال بدون إجابة، لان جميع المعلومات التي تقدمها مهمة جدا. المشاركة طوعية ، و الخاضع لهذه الدراسة الاستقصائية يبقى مجهول الهوية، و إذا كانت لديكم أي أسئلة ، فلا تترددوا في الاتصال:

الاسم [ \_\_\_\_\_ ] على [الهاتف \_\_\_\_\_ ]

أو [البريد الالكتروني \_\_\_\_\_ ] في أي وقت.

\*\*\*\*\*

لقد قرأت المعلومات الواردة أعلاه، و حصلت على الرد على كل الأسئلة التي سألت، و وافقت على المشاركة في الدراسة.

الأحرف الأولى من اسم المشارك]] \_\_\_\_\_

شكرا.

1.1- ما هو أعلى مستوى تعليمي لديك؟

- 1- \_\_\_\_ لم اذهب للمدرسة
  - 2- \_\_\_\_ المدرسة الابتدائية
  - 3- \_\_\_\_ المدرسة الإعدادية
  - 4- \_\_\_\_ المدرسة الثانوية / التكوين المهني
  - 5- \_\_\_\_ الكلية / الجامعة
  - 6- \_\_\_\_ الدراسات العليا / شهادة جامعية "الدكتوراه"
  - 7- \_\_\_\_ لا ينطبق
- بشهادة / بدون شهادة
- بشهادة / بدون شهادة
- بشهادة / بدون شهادة
- بشهادة / بدون شهادة

2.1- ما هو أعلى مستوى تعليمي لزوجك أو زوجتك؟

- 1- \_\_\_\_ لم تذهب للمدرسة
  - 2- \_\_\_\_ المدرسة الابتدائية
  - 3- \_\_\_\_ المدرسة الإعدادية
  - 4- \_\_\_\_ المدرسة الثانوية / التكوين المهني
  - 5- \_\_\_\_ الكلية / الجامعة
  - 6- \_\_\_\_ الدراسات العليا / شهادة جامعية "الدكتوراه"
  - 7- \_\_\_\_ لا ينطبق
- بشهادة / بدون شهادة
- بشهادة / بدون شهادة
- بشهادة / بدون شهادة
- بشهادة / بدون شهادة

3.2 ما هي علاقتك بالطفل؟

- 1- \_\_\_\_ الأم
- 2- \_\_\_\_ الأب
- 3- \_\_\_\_ الجد / الجدة
- 4- \_\_\_\_ أخرى ( حدد: \_\_\_\_\_ )

\*من الآن فصاعدا سيشار إلى الطفل في هذه الدراسة الاستقصائية (ب " طفلك "

## 2 – الباب الثالث : خصائص الطفل المعني :

هذه الأسئلة تعنى بطبيعة المخاوف الأولى التي كانت لديك على طفلك مع بداية تشخيصه بمرض التوحد وبعد تطور المرض.

### 2.1- ما هو تشخيص طفلك الحالي ؟

- 1- \_\_\_\_ التوحد أو اضطراب التوحد
- 2- \_\_\_\_ متلازمة اسبرجر
- 3- \_\_\_\_ اضطراب النمو المتقشي غير المحدد/اضطراب النمو الشامل غير المحدد (TED-NS)
- 4- \_\_\_\_ اضطراب النمو المتقشي/ اضطراب النمو الشامل (PDD/ TED)
- 5- \_\_\_\_ اضطراب طيف التوحد/ الاضطراب التوحدي (ASD/ TSA )
- 6- \_\_\_\_ أخرى (حدد : \_\_\_\_\_)
- 7- \_\_\_\_ غير معروف/ لم يتم تشخيص المرض (وضح \_\_\_\_\_)

### 2.2- ما هو جنس طفلك ؟

- 1- \_\_\_\_ ذكر
- 2- \_\_\_\_ أنثى

### 3.2- ما هو عمر طفلك الحالي ؟

\_\_\_\_ سنوات و \_\_\_\_ شهور

### 2.4- ما هي القدرات اللفظية لطفلك ؟



- 1- \_\_\_ لا يتحدث
- 2- \_\_\_ يستخدم كلمات مفردة مثل: "خبز"
- 3- \_\_\_ يستخدم عبارات مركبة مع كلمتين أو ثلاثة (مثل: "حذاء بابا")
- 4- \_\_\_ يستخدم جُمْل من أربعة كلمات أو أكثر ( مثل: " أريد المزيد من العصير")
- 5- \_\_\_ يستخدم الجمل المركبة (مثل: " أنا متعب وأريد أن أنام")

السؤال الهام الأول:

2.5- يرجى منكم شرح كيف و متى كانت أولى علامات تطور الحالة المرضية لطفلك؟ كم كان عمر طفلك عندما لاحظت تطور الحالة المرضية لديه؟

\_\_\_\_\_ أشهر

2.6- هناك أسباب كثيرة وراء كون أحد الوالدين قلقا بشأن نمو الطفل ، وفيما يلي قائمة من السلوكيات التي يمكن أن تسبب القلق لأحد الوالدين. فكر في أول المخاوف التي كانت لديك واختر كل ما ينطبق أدناه.

لا	نعم	المخاوف
		1 عانى من مشاكل طبية مثل النوبات المرضية ، انعدام النمو البدني، أو مشاكل في المعدة
		2 لا يقوم بالاتصال بالعين عند الحديث أو أثناء اللعب مع الآخر
		3 لا يستجيب عندما ينادى عليه أو لا يستجيب لأي صوت
		4 لا يبدو انه يفهم إشارات التواصل غير اللفظي
		5 كانت لديه صعوبات سلوكية مثل مستوى النشاط المرتفع ، شكل النوم والأكل ،
		6 لديه مشاكل في التنسيق أو المهارات الحركية مثل المشي
		7 يتحدث في وقت متأخر من المعتاد مقارنة مع معظم الأطفال
		8 لم يكن يتحدث على الإطلاق

9	بدأ في الحديث متأخرا بالمقارنة بالأطفال الآخرين الذين هم في نفس العمر
10	نسي بعض مهارات التعبير التي تعلمها مسبقا
11	لا يبدو انه/ها يفهم ما تقوله له/ها أو ما يقوله الكبار له/ها
12	واجه مشاكل مع المهارات الحركية الدقيقة مثل استخدام مقص أو الرسم بالأقلام
12	يجد صعوبة في اللعب أو التفاعل مع الآخرين أو اللعب وحده(ها) في عالمه(ها) الخاص
14	أصر على بقاء الأشياء كما هي أو واجه صعوبات في التغيير
15	وجد صعوبة في تعلم أشياء جديدة مثل التدريب على استعمال المراض أو ارتداء ملابسه
16	وجد صعوبة في تعلم أشياء جديدة مثل الأبجدية أو أرقام
17	كانت لديه إيماءات غير عادية أو حركات مثل خفقان اليد، المشي بأصابع الأقدام أو يدور حول نفسه

7.2- من كان أول الشخص لاحظ أن شيئاً لا يبدو صحيحاً مع نمو طفلك؟

- 1- \_\_\_\_ أنا
- 2- \_\_\_\_ زوجي أو زوجتي
- 3- \_\_\_\_ أحد أفراد الأسرة/ قريب
- 4- \_\_\_\_ طبيب أو غيره من مقدمي الرعاية الصحية
- 5- \_\_\_\_ المعلم
- 6- \_\_\_\_ أخرى (حدد: \_\_\_\_\_)

التشخيص :

8.2- كم كان عمر طفلك عندما تم تشخيصه بمرض التوحد لأول مرة؟

أشهر \_\_\_\_\_

9.2 من أعطى طفلك هذا التشخيص الأول؟

- 1- \_\_\_\_\_ طبيب الرعاية الأولية
- 2- \_\_\_\_\_ طبيب أطفال
- 3- \_\_\_\_\_ أخصائي في طب الأطفال ( طبيب أطفال مختص في تنمية الطفل )
- 4- \_\_\_\_\_ أخصائي نفسي
- 5- \_\_\_\_\_ طبيب نفسي
- 6- \_\_\_\_\_ أخصائي في أمراض الدماغ والجهاز العصبي
- 7- \_\_\_\_\_ ممرضة
- 8- \_\_\_\_\_ فريق من المختصين
- 9- \_\_\_\_\_ أخرى (حدد: \_\_\_\_\_)

10.2-كم من الوقت كان ينبغي عليك السفر من اجل الحصول على تشخيص لطفلك ؟

- 1- \_\_\_\_\_ أقل من ثلاثون دقيقة
- 2- \_\_\_\_\_ بين 30 دقيقة و ساعة
- 3- \_\_\_\_\_ بين ساعة إلى ساعتين
- 4- \_\_\_\_\_ أكثر من ساعتين (حدد : \_\_\_\_\_)
- 5- \_\_\_\_\_ سافرت خارج البلاد

### 3- الباب الرابع : الخدمات المقدمة :

هذه الأسئلة تتعلق بالصحة أو التعليم أو العلاجات أو خدمات أخرى التي قد تلقاها طفلك المصاب بالتوحد في الماضي أو يتلقاها حالياً لتلبية احتياجاته.

الخدمات الصحية:

1.3- هل سبق و تلقى طفلك أي من الخدمات أو العلاجات التالية لتلبية احتياجاته؟

اختر كل ما ينطبق:

لا	نعم	خدمات / علاجات	
		التدخل السلوكي أو تعديلات (مثال ABA)	1
		علاجات التكامل الحسي	2
		العلاج السلوكي المعرفي	3
		العلاج الوظيفي	4
		العلاج الفيزيائي	5
		التدريب على المهارات الاجتماعية	6
		العلاج اللغوي	7
		العلاج بالأدوية	8
		أخرى (حدد: _____)	9

4.3- هل عليك أن تدفع لقاء هذه الخدمة	3.3- كم عدد الساعات التي يتلقاها طفلك غالبا أسبوعيا؟	2.3- هل يتلقى طفلك حاليا أيا من الخدمات التالية لتلبية احتياجاته/ها؟	
1. نعم، تماما 2. نعم، جزئيا 3. لا		1. نعم، 2. لا	<b>1</b> التدخل السلوكي أو تعديلات (مثال ABA)
1. نعم، تماما 2. نعم، جزئيا 3. لا		1. نعم، 2. لا	<b>2</b> علاج التكامل الحسي
1. نعم، تماما 2. نعم، جزئيا 3. لا		1. نعم، 2. لا	<b>3</b> العلاج السلوكي المعرفي
1. نعم، تماما 2. نعم، جزئيا 3. لا		1. نعم، 2. لا	<b>4</b> العلاج الوظيفي
1. نعم، تماما 2. نعم، جزئيا 3. لا		1. نعم، 2. لا	<b>5</b> العلاج الفيزيائي

6	التدريب على المهارات الاجتماعية	1. _____ نعم، 2. _____ لا	1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا
7	العلاج اللغوي	1. _____ نعم، 2. _____ لا	1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا
8	العلاج بالأدوية	1. _____ نعم، 2. _____ لا	1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا
9	أخرى	1. _____ نعم، 2. _____ لا	1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا
10	لا اعرف		

5.3- هل سبق لطفلك أن عمل مع أحد من مقدمي الخدمات الصحية لتلبية احتياجاته/ها التنموية؟ اختر كل ما ينطبق:

	مقدم الخدمات	1. نعم	2. لا
1	إحصائي في أمراض السمع أو السمعيات		
2	مختص في السلوكيات		
3	إحصائي في طب الأطفال		

4	اخصائي التعليم	
5	اخصائي في الأمراض العصبية	
6	اخصائي التغذية	
7	طبيب نفسي	
8	اخصائي في علم النفس	
9	أخرى (حدد: _____)	

6.3- هل يعمل طفلك حاليا مع مقدمي الخدمات الصحية أسفله التالية لتلبية احتياجاته/ها التنموية؟ اختر كل ما ينطبق:

	المزود/مقدم الخدمات	1. نعم	2. لا
1	اخصائي في أمراض السمع أو السمعيات		
2	مختص في السلوكيات		
3	اخصائي في طب الأطفال		
4	اخصائي التعليم		
5	اخصائي في الأمراض العصبية		
6	اخصائي التغذية		
7	طبيب نفسي		
8	اخصائي في علم النفس		

## الخدمات التعليمية:

7.3- ما هو نوع المدرسة التي سجل فيها طفلك حالياً؟

1. \_\_\_\_\_ مرحلة ما قبل المدرسة (الحضانة)
2. \_\_\_\_\_ المدرسة الابتدائية العامة
3. \_\_\_\_\_ المدرسة الابتدائية الخصوصية
4. \_\_\_\_\_ مدرسة خاصة للأطفال ذوي الاحتياجات الخاصة
5. \_\_\_\_\_ الدراسة في المنزل
6. \_\_\_\_\_ غير ملتحق بالمدرسة

8.3- هل يتلقى طفلك أي دعم أكاديمي إضافي له/لها بسبب احتياجاته/ها التنموية؟

1. \_\_\_\_\_ نعم
2. \_\_\_\_\_ لا
3. \_\_\_\_\_ لا أعلم

9.3- ما نوع الدعم الأكاديمي الإضافي الذي يحصل عليه طفلك حالياً؟ أختار كل ما ينطبق:

	الدعم المدرسي	1. نعم	2. لا
1	فصول دراسية خاصة بالأطفال المصابين بالتوحد		



		فصول دراسية خاصة بالأطفال ذوي الاحتياجات الخاصة (clis)	2
		معلم في المدرسة	3
		مساعد في المدرسة	4
		معلم خارج المدرسة	5
		أخرى (حدد: _____)	6
		لا ينطبق	7

خدمات أخرى/المساعدة:

10.3- هل تتلقى حالياً أي تدريب أو مساعدة في إدارة أو معالجة احتياجات طفلك أو تنفيذ العلاجات لطفلك؟

1. نعم (حدد: \_\_\_\_\_)

2. لا

11.3- هل يحصل طفلك حالياً على أي مساعدة حكومية خاصة به/ها من أجل مرض التوحد؟

1. نعم (حدد: \_\_\_\_\_)

2. لا

12.3- هل أنت أو أي فرد من أفراد الأسرة يشارك حالياً في أي دعم للأسرة أو جماعة أو منظمة بسبب

الطفل المصاب بمرض التوحد؟

1. نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

13.3. - إلى أي مصدر تلجأ من أجل الحصول على معلومات عن مرض التوحد؟ اختر كل ما ينطبق

	2. لا	1. نعم	مصادر المعلومات
1			الإنترنت
2			طبيب أطفال
3			مُدرّس الطفل
4			آباء الأطفال الآخرين الذين يعانون من التوحد
5			غيرهم من مقدمي الخدمات (أي المتخصصين بالصحة، و المعالجين ) الذين يعملون مع طفلي
6			أخرى (حدد: _____)

14.3- اهم 3 تكوينات قد تلقيتها او تحتاج تلقيها كونك احد الوالدين (لمساعدة طفلك)

1-

2-

3-

15.3- هل طفلك يشارك حالياً في الأنشطة الأسرية اليومية داخل المنزل ( على سبيل المثال، غسل

الصحون، و إعداد مائدة الطعام)؟

1. نعم (حدد: \_\_\_\_\_)

2. لا \_\_\_\_\_

16.3- هل طفلك يشارك حاليا في الأنشطة العائلية خارج المنزل ( على سبيل المثال، النقل العام، و الصلاة في المسجد، زيارة العائلة/ الأصدقاء)؟

1. نعم (حدد: \_\_\_\_\_)

2. لا \_\_\_\_\_

17.3- هل طفلك يشارك حاليا في أنشطة اجتماعية (مثل دروس السباحة، الرياضة، أنشطة خاصة بالأطفال)

1. نعم (حدد: \_\_\_\_\_)

2. لا \_\_\_\_\_

#### 4-الباب الخامس:

إدراك الآباء/ الوالي: الاحتياجات الملابة و الغير ملابة:

هذه الأسئلة هي حول جميع أنواع الخدمات قد يحتاجها الأطفال، مثل الرعاية الطبية و العناية بالأسنان ، و العلاجات المتخصصة، و تقديم المشورة، و المعدات الطبية، و التعليم الخاص، و التدخل المبكر. و يمكن الحصول على هذه الخدمات في العيادات و المدارس و مراكز رعاية الأطفال، من خلال البرامج المجتمعية في المنزل، و غيرها من الأماكن.

1.4- خلال الـ12 شهرا الماضية، هل كانت لديك صعوبات أو تأخيرات في الحصول على خدمات لطفلك لانه/ أنها لم يكن مؤهلا للحصول على الخدمات؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

2.4- خلال الـ12 شهرا الماضية هل كانت لديك صعوبات أو تأخيرات بسبب الخدمات هو / هي في حاجة إليها و لم تكن متوفرة في منطقتك؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

3.4- خلال الـ12 شهرا الماضية، هل كان لديك أي صعوبات أو تأخيرات لأن هناك قوائم الانتظار أو مشاكل أخرى للحصول على موعد؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

4.4- خلال ال 12 شهرا الماضية، هل لديك أي صعوبات أو تأخيرات بسبب ارتفاع تكلفة العلاج؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

4.5- خلال ال 12 شهرا الماضية، هل لديك أي صعوبات أو تأخيرات بسبب صعوبات للحصول على المعلومات التي تحتاج؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

4.6- خلال ال 12 شهرا الماضية، هل لديك أي صعوبات أو تأخير لأي سبب آخر؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

7.4- خلال ال 12 شهرا الماضية، كم عدد المرات التي أحبطت فيها جهودكم للحصول على خدمات لطفلك؟

1. \_\_\_\_ أبدا

2. \_\_\_\_ في بعض الأحيان

3. \_\_\_\_ عادة

4. \_\_\_\_ دائما

5. \_\_\_\_ لا أعرف.

التأثير على الوالي/ العائلة:

هذه الأسئلة تتعلق بالتأثير الناتج عن إصابة طفلك بالتوحد، عليك و على الأفراد الآخرين في العائلة؟

8.4- هل تعاني أو عائلتك من مشاكل مالية بسبب توحد طفلك؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

9.4- هل توقفت أو أحد أفراد الأسرة الآخرين عن العمل بسبب مرض توحد طفلك؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

10.4- هل خفضت أو أحد افراد الأسرة الآخرين ساعات العمل بسبب مرض توحد طفلك؟

1. \_\_\_\_ نعم (حدد: \_\_\_\_\_)

2. \_\_\_\_ لا

3. \_\_\_\_ لا أعلم

التأثير النفسي:

المرجو الإشارة إلى ما مدى توافق بشدة، لا توافق أو لا توافق بشدة على الأسئلة التالية:

11.4- اشعر بالعجز بسبب وجود طفل مصاب بالتوحد

1. \_\_\_\_ لا أوافق بشدة

2. \_\_\_\_ لا أوافق

3. \_\_\_\_ أوافق

4. \_\_\_\_ أوافق بشدة

12.4- أقلق إذا كان الناس الآخرين يعرفون أن لدي طفل يعاني من مرض التوحد

1. \_\_\_\_ لا أوافق بشدة

2. \_\_\_\_ لا أوافق

3. \_\_\_\_ أوافق

4. \_\_\_\_ أوافق بشدة

13.4- هناك أشخاص آخرين قد يعاملونني باختلاف لأن لدي طفل يعاني من مرض التوحد:

1. \_\_\_\_ لا أوافق بشدة

2. \_\_\_\_ لا أوافق

3. \_\_\_\_ أوافق

4. \_\_\_\_ أوافق بشدة

14.4- إنجاب طفل يعاني من مرض التوحد يفرض تأثيرا سلبيا علي.

1. \_\_\_\_ لا أوافق بشدة

2. \_\_\_\_ لا أوافق

3. \_\_\_\_ أوافق

4. \_\_\_\_ أوافق بشدة

جودة الحياة:

لهذه الأسئلة التالية، نريد أن نتعلم كيف تشعر حيال جودة حياة عائلتك و الطفل.

15.4- لكي يكون ممكنا لأسرة الحصول على حياة جيدة، ما مدى أهمية دعم طفلي المصاب بالتوحد لإحراز

تقدم في المدرسة

1. \_\_\_\_ مهم قليلا

2. \_\_\_\_ هام



3. \_\_\_\_ مهم جدا

16.4- ما مدى رضاي أن طفلي الذي يعاني من مرض التوحد يحصل على دعم لإحراز تقدم في المدرسة؟

1. \_\_\_\_ غير راض(ية) تماما

2. \_\_\_\_ محايد(ة)

3. \_\_\_\_ راض(ية) جدا

17.4- لكي يكون ممكنا لأسرة الحصول على حياة جيدة معا، ما مدى أهمية دعم طفلي المصاب بالتوحد لإحراز تقدم في المنزل؟

1. \_\_\_\_ مهم قليلا

2. \_\_\_\_ هام

3. \_\_\_\_ مهم جدا

18.4- ما مدى رضاي عن دعم طفلي الذي يعاني من مرض التوحد لإحراز تقدم بالمنزل؟

1. \_\_\_\_ غير راض(ية) تماما

2. \_\_\_\_ محايد(ة)

3. \_\_\_\_ راض(ية) جدا

19.4- لكي يكون ممكنا لأسرة الحصول على حياة جيدة معا، ما مدى أهمية دعم طفلي المصاب بالتوحد لكسب الأصدقاء؟

1. \_\_\_ مهم قليلا

2. \_\_\_ هام

3. \_\_\_ مهم جدا

20.4- ما مدى رضاي عن دعم طفلي الذي يعاني من مرض التوحد لكسب الأصدقاء؟

1. \_\_\_ غير راض(ية) تماما

2. \_\_\_ محايد(ة)

3. \_\_\_ راض(ية) جدا

21.4- لكي يكون ممكنا لأسرة الحصول على حياة جيدة معا، ما مدى أهمية كون علاقة عائلتي جيدة مع مقدمي الخدمات الذين يعملون مع طفلي؟

1. \_\_\_ مهم قليلا

2. \_\_\_ هام

3. \_\_\_ مهم جدا

22.4- ما مدى رضاي عن علاقة عائلتي مع مقدمي الخدمات الذين يعملون مع طفلي

1. \_\_\_ غير راض(ية) تماما

2. \_\_\_ محايد(ة)

3. \_\_\_ راض(ية) جدا

## التحديات و الأولويات:

23.4- نحن الآن مهتمون بمعرفة ما تعتقد أنها أكبر تحديات لرعاية طفل يعاني من مرض التوحد يرجى اختيار أعلى ثلاثة تحديات من القائمة أدناه.

1. \_\_\_ سلوك التحدي (أي إيذاء الذات، و العدوان، نوبات الغضب)

2. \_\_\_ مهارات الحياة اليومية (أي المرحاض، التغذية الذاتية)

3. \_\_\_ مشاكل صحية (التي تحدث في نفس الوقت كالحالة البدنية / أو الصحة العقلية)

4. \_\_\_ مشاكل النوم (أي صعوبة في النوم، و صعوبة في البقاء نائما)

5. \_\_\_ صعوبات الحمية (الأكل/ التغذية)

6. \_\_\_ صعوبات التفاعل الاجتماعي

7. \_\_\_ السلوكيات المتكررة (السلوك المقيد / السلوك الشعائري)

8. \_\_\_ صعوبات في الاتصالات.

9. \_\_\_ المخاوف المتعلقة بالسلامة (اي التيه، و التسلق)

10. \_\_\_ المشاكل الحسية

11. \_\_\_ أخرى (حدد \_\_\_\_\_)

24.4- ما هي أكبر التحديات التي تواجهها في الحصول على دعم لطفلك، يرجى اختيار أعلى ثلاثة تحديات من القائمة أدناه.

1. \_\_\_ التأكد من تلقي الطفل رعاية صحية كافية

2. \_\_\_ التأكد من تلقي الطفل التعليم الكافي

3. \_\_\_\_ التأكد من تلقي الطفل رعاية / دعم اجتماعي كافي
4. \_\_\_\_ التأكد من أن حقوق طفلي الأساسية محمية
5. \_\_\_\_ التأكد من أنني و عائلتي نحصل على راحة كافية
6. \_\_\_\_ أخرى (حدد \_\_\_\_\_)

25.4- نحن أيضا مهتمون لمعرفة ما تعتقد أنها أكبر أولويات للأسرة التي لديها شخص مصاب بمرض التوحد في بلدك؟ يرجى اختيار أعلى 3 أولويات من القائمة أدناه.

1. \_\_\_\_ تحسين خدمات الرعاية الصحية
2. \_\_\_\_ تحسين خدمات التعليم
3. \_\_\_\_ تحسين الرعاية / الخدمات الاجتماعية
4. \_\_\_\_ مزيد من الحقوق للأفراد المصابين بالتوحد
5. \_\_\_\_ مزيد من المعلومات عن مرض التوحد
6. \_\_\_\_ دعم أكبر في المنزل
7. \_\_\_\_ زيادة في الوعي الاجتماعي
8. \_\_\_\_ زيادة فرص تفاعل الآباء / التعارف بينهم
9. \_\_\_\_ أخرى (حدد \_\_\_\_\_)

شكرا على مشاركتكم

## 6.4 Appendix D: Separate Set of Questions for Parents

These questions are part of the Arabic Autism Speaks survey created by me to be filled out before the survey started. If participants were unable to finish the set of questions, then we would complete them together with the translator before the interview started.

إذا لا تفهم معنى السؤال، لا تقلق، فقط تخطي إلى سؤال آخر و سنقوم بالرد معا

### 2.6

هناك أسباب كثيرة وراء كون أحد الوالدين قلقا بشأن نمو الطفل ، وفيما يلي قائمة من السلوكيات التي يمكن أن تسبب القلق لأحد الوالدين. فكر في أول المخاوف التي كانت لديك واختر كل ما ينطبق أدناه.

لا	نعم	المخاوف	
		عانى من مشاكل طبية مثل النوبات المرضية ، انعدام النمو البدني، أو مشاكل في المعدة	1
		لا يقوم بالاتصال بالعين عند الحديث أو أثناء اللعب مع الآخر	2
		لا يستجيب عندما ينادى عليه أو لا يستجيب لأي صوت	3
		لا يبدو انه يفهم إشارات التواصل غير اللفظي	4
		كانت لديه صعوبات سلوكية مثل مستوى النشاط المرتفع ، شكل النوم والأكل ،	5
		لديه مشاكل في التنسيق أو المهارات الحركية مثل المشي	6
		يتحدث في وقت متأخر من المعتاد مقارنة مع معظم الأطفال	7
		لم يكن يتحدث على الإطلاق	8
		بدأ في الحديث متأخرا بالمقارنة بالأطفال الآخرين الذين هم في نفس العمر	9
		نسي بعض مهارات التعبير التي تعلمها مسبقا	10

11	لا يبدو انه/ها يفهم ما تقوله له/ها أو ما يقوله الكبار له/ها
12	واجه مشاكل مع المهارات الحركية الدقيقة مثل استخدام مقص أو الرسم بالأقلام
12	يجد صعوبة في اللعب أو التفاعل مع الآخرين أو اللعب وحده(ها) في عالمه(ها) الخاص
14	أصر على بقاء الأشياء كما هي أو واجه صعوبات في التغيير
15	وجد صعوبة في تعلم أشياء جديدة مثل التدريب على استعمال المراض أو ارتداء ملابسه
16	وجد صعوبة في تعلم أشياء جديدة مثل الأبجدية أو أرقام
17	كانت لديه إيماءات غير عادية أو حركات مثل خفقان اليد، المشي بأصابع الأقدام أو يدور حول نفسه

### 3.1

هل سبق و تلقى طفلك أي من الخدمات أو العلاجات التالية لتلبية احتياجاته؟

اختر كل ما ينطبق:

لا	نعم	خدمات / علاجات	
		التدخل السلوكي أو تعديلات (مثال ABA)	1
		علاجات التكامل الحسي	2
		العلاج السلوكي المعرفي	3
		العلاج الوظيفي	4
		العلاج الفيزيائي	5

		التدريب على المهارات الاجتماعية	6
		العلاج اللغوي	7
		العلاج بالأدوية	8
		أخرى (حدد: _____)	9
		لا اعرف	10

### 3.2, 3.3, 3.4

4.3- هل عليك أن تدفع لقاء هذه الخدمة	3.3- كم عدد الساعات التي يتلقاها طفلك غالبا أسبوعيا؟	2.3- هل يتلقى طفلك حاليا أيًا من الخدمات التالية لتلبية احتياجاته/ها؟	
1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا		1. _____ نعم، 2. _____ لا	1 التدخل السلوكي أو تعديلات (مثل ABA)
1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا		1. _____ نعم، 2. _____ لا	2 علاج التكامل الحسي
1. _____ نعم، تماما 2. _____ نعم، جزئيا		1. _____ نعم، 2. _____ لا	3 العلاج السلوكي المعرفي

3. _____ لا				
1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا		1. _____ نعم، 2. _____ لا	العلاج الوظيفي	4
1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا		1. _____ نعم، 2. _____ لا	العلاج الفيزيائي	5
1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا		1. _____ نعم، 2. _____ لا	التدريب على المهارات الاجتماعية	6
1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا		1. _____ نعم، 2. _____ لا	العلاج اللغوي	7
1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا		1. _____ نعم، 2. _____ لا	العلاج بالأدوية	8
1. _____ نعم، تماما 2. _____ نعم، جزئيا 3. _____ لا		1. _____ نعم، 2. _____ لا	أخرى	9
			لا اعرف	10



### 3.5

هل سبق لطفلك أن عمل مع أحد من مقدمي الخدمات الصحية لتلبية احتياجاته/ها التنموية؟ اختر كل ما ينطبق:

	مقدم الخدمات	1. نعم	2. لا
1	اخصائي في أمراض السمع أو السمعيات		
2	مختص في السلوكيات		
3	اخصائي في طب الأطفال		
4	اخصائي التعليم		
5	اخصائي في الأمراض العصبية		
6	اخصائي التغذية		
7	طبيب نفسي		
8	اخصائي في علم النفس		
9	أخرى (حدد: _____)		

### 3.6

هل يعمل طفلك حالياً مع مقدمي الخدمات الصحية أسفله التالية لتلبية احتياجاته/ها التنموية؟ اختر كل ما ينطبق:

	المزود/مقدم الخدمات	1. نعم	2. لا
--	---------------------	--------	-------

1	إحصائي في أمراض السمع أو السمعيات	
2	مختص في السلوكيات	
3	إحصائي في طب الأطفال	
4	إحصائي التعليم	
5	إحصائي في الأمراض العصبية	
6	إحصائي التغذية	
7	طبيب نفسي	
8	إحصائي في علم النفس	
9	أخرى (حدد: _____)	

### 3.9

ما نوع الدعم الأكاديمي الإضافي الذي يحصل عليه طفلك حالياً؟ أختار كل ما ينطبق:

	الدعم المدرسي	1. نعم	2. لا
1	فصول دراسية خاصة بالأطفال المصابين بالتوحد		
2	فصول دراسية خاصة بالأطفال ذوي الاحتياجات الخاصة (clis)		
3	معلم في المدرسة		
4	مساعد في المدرسة		

5	معلم خارج المدرسة	
6	أخرى (حدد: _____)	
7	لا ينطبق	

### 3.13

إلى أي مصدر تلجأ من أجل الحصول على معلومات عن مرض التوحد؟ اختر كل ما ينطبق

	مصادر المعلومات	1. نعم	2. لا
1	الإنترنت		
2	طبيب أطفال		
3	مُدرّس الطفل		
4	آباء الأطفال الآخرين الذين يعانون من التوحد		
5	غيرهم من مقدمي الخدمات (أي المتخصصين بالصحة، و المعالجين) الذين يعملون مع طفلي		
6	أخرى (حدد: _____)		

### 4.23, 4.24, 4.25

نحن الآن مهتمون بمعرفة ما تعتقد أنها أكبر تحديات لرعاية طفل يعاني من مرض التوحد يرجى اختيار أعلى ثلاثة تحديات من القائمة أدناه.

1. \_\_\_ سلوك التحدي (أي إيذاء الذات، و العدوان، نوبات الغضب)

2. \_\_\_ مهارات الحياة اليومية (أي المرحاض، التغذية الذاتية)

3. \_\_\_ مشاكل صحية (التي تحدث في نفس الوقت كالحالة البدنية / أو الصحة العقلية)
4. \_\_\_ مشاكل النوم (أي صعوبة في النوم، و صعوبة في البقاء نائما)
5. \_\_\_ صعوبات الحمية (الأكل/ التغذية)
6. \_\_\_ صعوبات التفاعل الاجتماعي
7. \_\_\_ السلوكيات المتكررة (السلوك المقيد / السلوك الشعائري)
8. \_\_\_ صعوبات في الاتصالات.
9. \_\_\_ المخاوف المتعلقة بالسلامة (اي التيه، و التسلق)
10. \_\_\_ المشاكل الحسية
11. \_\_\_ أخرى (حدد \_\_\_\_\_)

ما هي أكبر التحديات التي تواجهها في الحصول على دعم لطفلك، يرجى اختيار أعلى ثلاثة تحديات من القائمة أدناه.

1. \_\_\_ التأكد من تلقي الطفل رعاية صحية كافية
2. \_\_\_ التأكد من تلقي الطفل التعليم الكافي
3. \_\_\_ التأكد من تلقي الطفل رعاية / دعم اجتماعي كافي
4. \_\_\_ التأكد من أن حقوق طفلي الأساسية محمية
5. \_\_\_ التأكد من أنني و عائلتي نحصل على راحة كافية
6. \_\_\_ أخرى (حدد \_\_\_\_\_)

نحن أيضا مهتمون لمعرفة ما تعتقد أنها أكبر أولويات للأسرة التي لديها شخص مصاب بمرض التوحد في بلدك؟  
يرجى اختيار أعلى 3 أولويات من القائمة أدناه.

1. \_\_\_ تحسين خدمات الرعاية الصحية

2. \_\_\_\_ تحسين خدمات التعليم
3. \_\_\_\_ تحسين الرعاية / الخدمات الاجتماعية
4. \_\_\_\_ مزيد من الحقوق للأفراد المصابين بالتوحد
5. \_\_\_\_ مزيد من المعلومات عن مرض التوحد
6. \_\_\_\_ دعم أكبر في المنزل
7. \_\_\_\_ زيادة في الوعي الاجتماعي
8. \_\_\_\_ زيادة فرص تفاعل الآباء / التعارف بينهم
9. \_\_\_\_ أخرى (حدد \_\_\_\_\_)

## 6.5 Appendix E: Statement of Purpose and Consent

“Hello, we are a team of university students from the United States. We would like to interview you because we want to understand the resources and educational opportunities that are available to your child. We are unable to diagnose or treat your child; however, the results of this survey will be used for research and planning appropriate measures to improve care and services for children affected by autism and their families. We would love to hear about you and your family’s experiences with your child’s condition. Taking part in this survey is voluntary and your information will be kept confidential and anonymous. You are free to stop the interview at any point if you have any concerns. If you have any questions before we begin, we will be glad to answer them.”

## 6.6 Appendix F: Coded Transcripts of the Interviews

Below are the raw transcripts of the interviews with the categories I used to code them. The transcripts are from the interviews performed at Space for Brothers with my former team and the interviews I performed at Amal. The highlighted phrases in the transcripts signify what I felt had attributes of the categories I determined. The numbers before each account from the parents signify the question numbers in the Autism Speaks survey that they decided to share this information.

Categories: difficulty in diagnosis, difficulties receiving treatment/services, rejection and social discrimination, autism family support groups, kids like transportation, lack of communication

### Interview 1:

1.1 Hard to understand because he has to repeat himself or use hand gestures to convey his thoughts

1.2 He was very calm; didn't say the word 'mom' until 4 years old; late development in walking and talking; started seeking treatment at 2 months' old

2.8 Doctor didn't say anything at 2 months, so she went to see another doctor with a great reputation (at 9 months); told doctor about how his development was late; doctor couldn't make any decisions/diagnoses because child was too young; didn't fully understand autism diagnosis until 10 years' old

2.9 didn't say autism directly; said he wasn't sick but has a 'little' autism/disability

3.15 Not really, sometimes

3.16 Really likes to take buses/public transportation

4.2 Everything is available

4.6 Related to social activities: ex. going to clubs

4.7 Many problems pertaining to waiting lists, transportation, finances

4.9 She stopped working

4.13 She is very proud of her child; one time a bus driver accused her as having had a disabled child on purpose so that she didn't have to pay for transportation (buses have disabled services)

## Interview 2:

They (parents of autistic children) really need help from people who care about their condition. She is the only one who understands her children. She has a son and a daughter with autism.

1.1 Really regrets not going to school, would be able to help children more if she did

2.1 Boy's autism much more aggressive than the girl's; they don't understand insults and can become very aggressive; girl understands most things, boy does not

2.5 Noticed they had difficulties speaking

3.5 She has only seen one doctor but would like to see others. She cannot because of financial problems. Her family gave up on her and offers her no assistance. They began neglecting her once she failed to show improvement in her circumstances (which she has no control over)

3.12 This is because she is new to the area and association. She would love to be more involved

3.16 They always ask to go outside; they really like the bus

4.2 Travels to Sale for treatments

4.16 Improvement in children came only after joining Espace organization

Notes: wants to be more involved but doesn't have any schooling, likely illiterate

So they joined an organization and things became better (again same theme of being connected and feeling like you are better off because you have info- let's keep this in mind to see if comes up again)

## Interview 3:

1.1 Didn't go to school because she lived in a rural area

2.5 When he was hungry, he didn't cry

4.8 Financial struggle not limited to medical treatment, couldn't afford things they needed or he wanted in everyday life

4.12 She is very proud because God wanted this for her.

4.13 Family stopped talking to her

4.14 She is making many efforts for a better life



#### **Interview 4:**

2.6 Child is learning a lot of daily activities very quickly because of involvement in Espace organization. Ex. going to bathroom, washing hands, cleaning, praying.

Scared of sharp things; likes to draw circles; is stressed out by noises. Independent: if he is thirsty he will go to the kitchen and drink. Knows that spoons go with soup, forks go with solid foods, etc.

Parents: father wanted to abort the child, didn't happen because of financial problems; father left before ever even seeing the child because he wasn't proud of a 'sick' child; mother and grandmother raised the child. Mother was 22 at birth of this child

2.1 She thinks he's normal, doctors say he has autism

2.5 Noticed he screamed inappropriately; didn't respond to noises

3.7 Rejected from public school for behavior (screaming)

3.16 He really likes cars

4.4 Mother works and doesn't have the time to seek treatment; Later had to stop working

4.13 People will push him away because they don't want to be near him. Child is locked in a room to minimize interaction between him and the outside world; don't bring him to events or gathering; grandmother spends all of her time with him

4.14 Father and other family members avoided and disapproved of the child's condition; other family members offered no help and didn't inquire about the condition

#### **Interview 5:**

2.1 Doctor says its ASD but they offered no certificate or authentication

3.14 Families offer a lot of advice and help

3.17 Thinking about future integration into social activities. Waiting until they are older than 8

4.2 Always

4.3 Bizzes (A lot)

4.9 Really sorry that she had to stop working because of her children's condition

*Note: Large difference between responses to section “Quality of Life” about satisfaction with resources and training (diff. Comparing education level of this respondent and the others)*

### **Interview 6:**

3.14 She’s received all of her training/knowledge about how to deal with her child from the internet. She tried to talk with other parents for advice. She didn’t have a lot of time to care for autistic child because she has another child. She learned: to be an educator outside and in the home; expose child to outside activities

4.1 A lot, it’s very difficult for her to get any services

### **Interview 7:**

Date: 29/1/18

3.7 Child was rejected from public school because of her condition

3.14 Share information between moms with similar children through WhatsApp

4.1 Young age made finding treatment hard

*Note: infants are prioritized in medical system, but many families can’t receive a diagnosis until they reach a certain age (2-3)*

*Notes:*

see if there is a correlation between families not involved in WhatsApp groups and literacy rate.  
How does it make you feel to be part of a group of families?

### **Interview 8:**

He went to a school called SOS autism that was the best school for autism in Morocco.  
Management changed and he kept asking questions about his child. About the services/treatments he was receiving but they would not tell him anything.

They refused to tell him and because of his constant questions one day they just stopped sending the bus to pick up his child. So the school kicked out the child

Autism treatment is like a mafia.

One organization gets all the government funding and all the others get very little.

School: They are always together and they know everything about each child.

And if you are not ok with this school let the school know about that and they follow up with your child.

I pay 3000 dirhams for my child, and he's ready to speak, at home he repeats everything, and he comes here to talk to the speech therapist and she says you need more classes for him and I always tell her to give him more hours, he's capable of speaking, but she says she does not have time for him.

My wife is a little sad, she doesn't accept the situation of her child being autistic, we all suffer: me, my wife, and my other son who is normal.

Last year he had to quit school they had to take him somewhere else and finally I brought him here

I have some people I know, they have autistic problems and they say that even here is not perfect

If you ask about the material and how they help, there are no answers

What is your child's current diagnosis: No diagnosis, just said he has a light autism? He can make eye contact, he can imitate, but does not speak. In Morocco there is no official psychiatrist or hospital for the diagnosis of autism.

I

discovered my child's autism when he was three years old. I went to many doctors who did not have knowledge of autism at the time. Then when he was 5 years old, I took him to the hospital and they said he is sick and has a mental problem, we can say autistic. Their suggestion was to take my son to a special school, speech therapy, and for psychomotor movement.

They offered(suggested) an expensive school, with no transportation to bring or take him, so I preferred to take him to SOST association (not sure).

He was one of the first classes in this new school. This was one of the newest center for children.

Gerome was the director at the time and he was doing a great job with the autistic children. After two years he left and they put another director that had no experience with disabilities. They mixed children with different disabilities and the school's level of education was not the same.

The hospital suggested that I take him to public school or private school. But there was no school for this kind of child. The school they suggested was not good and far from where I live and there was no transport.

So I ended up taking him to the SOST and I pay 3000 Durham for the whole day with transportation.

When he was at home, he was beating his head and biting himself. But now he changed, there is no crisis, he is good and we can accept his situation. He is good.

He used to run when he found the door open, but no more

When they get older they get more mature

2.4 Single words, he understands everything, he sits at the table, he eats. He needs someone to help him. But here I don't know what they do. They take him at 9 and return him at 4.

What services does he receive: speech therapy, ibex, educational psychotherapy, and physical therapy (but he does not need physical therapy)

How many hours for each service: I don't know anything about hours? I spoke to the speech therapist and she comes 2 days a week and she gives classes to all the children at the same time. If I ask to speak with the speech therapist they say: you have to wait until they finish, they say she is not here, she will come the next day. Etc.

When did you know your child had autism? He was 3 or 2 when I noticed autism. I noticed he had no speech until 3 years old. I had some knowledge from another colleague whose daughter had autism and he talked a lot about it, so I knew the signs

Did he have Medical problems: no

Eye contact when he was younger: no, but I fixed the problem by putting his head in front of my eyes and practiced looking into each other's eye.

Did he understand nonverbal communication: His problem is he is not understood, he wanted to say things but he couldn't. When my son wants something he goes straight to it and takes it, he takes the tomatoes and pasta and we understand that he wants us to cook pasta. If he wants to eat he opens the refrigerator

Sometimes he gets very angry and cry. He needs help with speech therapy. And he will be good. He can write his name, draw shapes and circles and follow things. That is what he learned from the French guy (Gerome), he was good with him, everyone knows him here in Morocco, he is a reference. I think he opened a center somewhere, but I don't know where.

Does he have behavioral problems: He is hyperactive and he can stay awake all the night, but now he's better. He sleeps with his mom. We turn off the lights he screams a little and then he

sleeps. We don't give him any medicine right now. I am thinking of giving him medicine to help with the hyperactivity because he may slow down and do more activities and learn more if he takes medicine. **But now he does nothing, he needs to speak and be understood. And he wants to go out and there is no place for him.** Once I took him to some big markets. He wants to get everything, to touch everything. When he comes back from school the bus drops him near the market and he forces his mom to go to the market to buy Pepsi. If he doesn't get his Pepsi, he starts to scream and throw himself on the floor.

Did he have problem with fine motor skill: no, he's good, he likes to climb and stay high, he has skills, he is athletic

Did he interact with others: Before, but now he plays with his brother?

Did he have difficulties changing routines: he makes art, he takes soap and sticks things on it like leaves and he likes to rearrange the house

Difficulties with new skills like toilet training or getting dressed: no, he can dress himself

Difficulty with learning new things: yes of course. Now he says all the alphabet. He can repeat that, but he can't make a sentence. He can't make even a word. He can say mama papa, the easy words for him

Who gave your child the diagnosis: **I had gone to a different physician and said I am concerned my child had autism, they didn't even know what that was. So they sent me to Hajj Khaliah. She was recommended to us because she was the pediatric professor for pediatrics. We went to a private hospital to see her and she listened to us, but she didn't know a lot and was not very knowledgeable. She just googled and repeated what she read. She said your son shouldn't eat wheat because it contains gluten. I paid 400 dirhams for 15 min. Then I went to the public hospital two times and one year before getting an appointment to see a psychiatrist. The doctor saw my son and said, don't say autism. He has a mental sickness but not autism. She recommended that I take him to a special school and that he do physical therapy and speech therapy. She said to bring him to her after I did that, if not don't come back. The school was very expensive, 6000 dirhams, and we could not afford that. So I had some friends that helped get my son into the school he is now**

I want him to go to a regular school, but if you do that, you have to pay someone to go with him (shadow teacher). It's expensive for me, I can't do that, maybe the in the future.

Can you tell me about the first three training needs: I went to some seminar and they said we could change his diet to help him and right now at home we (prevent) him to eat so much sugar. But he eats very little food, so we have problems.

3.16 Every Sunday his grandma takes him to their house where they have an enclosed garden and lots of children go there to play. We lost him many times, he would just run away. But at his grandmother he is safe and they are diligent of him, it's the only place he can go that I feel safe to send him.

4.1 He's not accepted in public school, I took him once and they said to take him to a specialty school. No one can help me to take him because he's getting older his mom can't handle him he's strong, she can't go with him in the streets

In the past 12 month did you have difficulties with services because not available: it's hard because he enjoys playing. But If he has a cut it's hard to take a stitch, I need 4-5 people around him to hold him down. It is hard to give him with the medicine because he doesn't like medicine. He's very smart and he doesn't like medicine. This is a problem that we face.

Did you have difficulties making attempts: Once I want him to go to a place where are toys. There is an Ikea with a playground, I wanted to take him there and he can't wait. There was a big line to get in. So he hit his head and I told them (the employees) that he is sick and needs to be first. The responsible people(workers) said no he has to wait. They said, he can take the line. I said no he needs to be first, so they called a supervisor and they allowed him to go first.

Any difficulties because you did not have the information you needed: The only thing we have is to get him into the public hospital, but now I heard there are good services there for children with autism. They make it hard for me, because his case is not hard so you need specialists to look closely into this case.

Delays for any reason: sometimes. **In general, when they see my child they don't delay. They understand and any frustration: there are some mentalities that are negative,** even here at the school sometimes I'd say: I don't have money I'll pay later. They say, no you have to pay now.

Anyone stopped working: my wife can't work; she has lots of things to do because of him. She can't get help in the house, they stay for a week and leave. **Even our family does not come to see us frequently, because my son disturbs them**

Cut down on work: I have to cut down on work when I have to take him from school, I have to take permission all the time.

**I want the quality of the center to be good**

Comment: Constantly complaining about services

**Interview 10:**

Could not answer 4.16

**Interview 11:**

**His child came here when he was 4, when he was 2 years he was in a normal school. When he went to the normal school, everything was normal. He extremely active/hyper. When he was in the school for babies, it was fine, but to get in the actual school there were conditions he had to meet such as being able to sit at a table, which he couldn't do.**

He had a delay to speech.

**When he went to school, because of his extreme activity, they did not want to keep him there unless the parent hired a special caretaker to stay with the child in school to take care of him. However, this costs a lot of money. At this time, he was in financial trouble so he couldn't do it.**



He stopped working for 3 months and so looked for a school for his child. He found this association, when the school told him to take out the child, he went with his child to the hospital every day to diagnose his child. The hospital says that his child was not an autistic. Just that he had some sort of mental delay, but it was not a case of autism. After one month at the hospital he brought his child to this association. At this association they have all types of professionals that could help his child. He has seen progress since he came to Amal.

Amal you have to pay.

The Moroccan government does not offer any type of support so everything has to come from the parent.

For his son Yuns, he does not have a bad case of autism. At home he is fine, the problem is in the school system.

Moroccan government copies Francophone system not Anglo Saxon system. In Scandinavia the system is different. In general children in primary school play and have fun at their own pace. In the French system that Morocco follows, they have 8-hour school days, they start from 8 until half past 5. After they get out of school they have a lot of homework from Monday to Friday. For the week they also have homework. For autistic individuals it is impossible for them to function in these intense school situations.

In Amal they prepare children to enter normal school, his child is making a lot of progress for that. He is learning how to write correctly and write entire words and such. And he can read French and little English. His child plays video games really well.

He figures out how technology works and downloads games and can figure out things on his own. He also has precision for using computers and figuring out things for himself.

He can remember games he has played before, he has played the same games again on different platforms, cut the rope.

In association there is a lot of effort for treatment, but if his child got more attention and concentration. He thinks that his son will be able to accelerate his progress and make it into school very soon.

For him if there was a partnership between the government and association, there should be a way to make a primary school/middle school for the children with special needs that they can graduate. It is best for his child to stay in the association until he is 14-15 years to start in normal middle school.

When he saw the experience of his 2 other children, he knows that his child cannot go through the same system, the best thing, is if there is an association for children with autism so that they can graduate primary school so that he is prepared for middle school. So that he can have more time to adapt to the normal education system.

He is fine with being in his car. When he sees something new, he gets excited. They go two to three times per week in the bus around the city, however he wants to go every day. After seeing people on the bus he wants to go with everyone else instead of going with his father in his car. He loves to play with the dashboard of the car.

Electronics can be bad for children, because they stay closed in their own world.

Doctors say that he should not use electronics, but he is afraid that his child would be ignorant of the world if he didn't know how to use them

He does not have time to get involved with other families to share information about caring for children with autism,

He wants to create an association for children more than 12 years old. He does this because he is friends with a Belgian person who is connecting him with plenty of people that can help with the process.

After the autistic person turns 18 associations say that they cannot help them anymore and turn them away.

## Interview 12:

3.16 She cannot sit still; she loves taking transportation but she does not want to sit while doing it

4.12

She wants people to ask about her daughter to raise awareness about the issues of autism

4.16

Some great things about the association, some bad things in the association

There are some beautiful things in this association, some things not so much

Any elaborations or anything you want to express?

The problem is that when someone sees my child, they tend to say something along the lines “your child is sick”, when she told them about the autism, they told them to take her child away and keep her away from other people. So she finds a lot of problem with people around her.

Not the neighbors because they know the situation, outside the area people don't know what it means to be autism

Even her family she faces a lot of problems with them as well. games, for family, they bring games for the normal child and not for the autistic child. People differentiate between the normal and autistic people.

She says she has suffered a lot.

Her daughter cannot differentiate between people, she might walk off with anyone, her mother is like anyone else to the autistic child. Her daughter doesn't treat her like a mother, she knows that she is her mother but she is like any other person. She can call for her mother over and over and then she might forget that she exists.

The daughter loves puzzle with letters and colors.

It's so expensive to treat her child. It is 300 dirhams for one session which is a lot for Moroccans. And her daughter needs many doctors for her daughter's treatment.

The daughter does not know how to eat with her hands.

### **Interview 13:**

Interview 13

2.1 Mental delay with autism. He keeps his hand closed so she opened them. I don't know which type. If there is a lot of people he can't speak, only if there is one person

2.2 Male

2.5 4 years old. When he went to preschool I remarked that he didn't speak with other children and I noticed he was different.

2.7 In the nursery a specialist/teacher told me she should get my son tested and evaluated

3.8 I have the proof from the government that I have no money to pay for the school and my son can study for free. (because my husband died, he was a private architect, so I have no support after his death.)

3.10 Yes, they have train 3 trainings per year for the parents in this association.

3.11 In Morocco the government gives a lot of benefits for people that are poor. They give you an ID from the government so you don't pay for the hospital. So I have assistance, but not direct

3.14 They train me how to treat her child. The trainings are not specialized, but is one training many times (the same type of training) I can't give a specific type, the doctors come and they teach them how to treat their children

3.15 He can take the dishes from the table, put pajamas on

3.16 No he can't go out alone, never. He has no problem when he is with her. He can visit the family, but he doesn't speak with them. When there is only one person he can talk, but when there is a lot of people he stays quiet

3.17 Yes. In this association they have art, sports, and music.

4.4 Yes. He wants to travel to Turkey, because of the influence of Turkish soap operas. But he can't travel there it's expensive. He loves soccer and would love to go to real Madrid

My child is extremely calm. When he came to this association, he learned so much and I learned so much. He became a bit more active.

Notes: this woman talked about the government offering services to people that are poor, but everyone else has said that the government does not support them. I think the case here is that since her husband was in the workforce in a good paying job, and since he died suddenly, her family might be a special exception in terms of support.